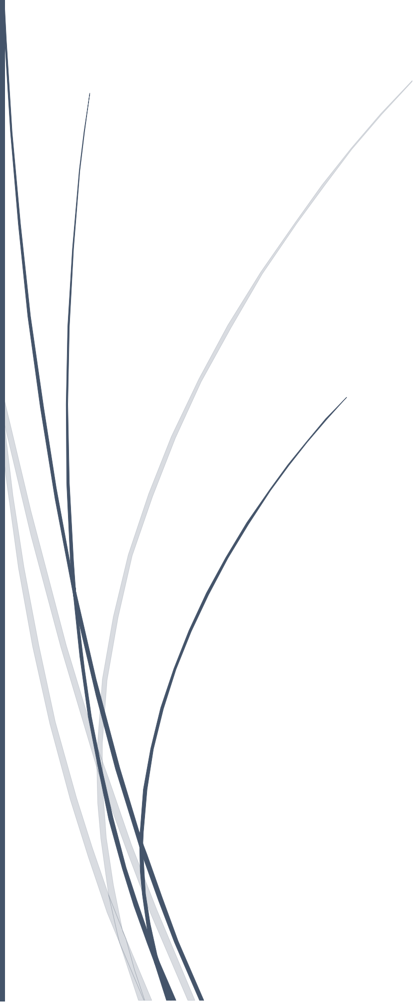
A Situational Analysis of Community Physical Activity Participation by Children and Young People with Neurodisability

A PhD Thesis



Karen S. Visser
CARDIFF UNIVERSITY
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Dedication and Acknowledgements

I dedicate this work to children and young people with neurodisability and their families.

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Summary Abstract

Physical activity (PA) brings health benefits. Children and young people (C&YP) with neurodisability face challenges to PA, participate less than typically developing peers, and have fewer community opportunities and choices. I examined the situation using interview data involving families and community PA providers and applying situational analysis (SA). Cardiff University ethically approved the study.

Participants included C&YP with neurodisability (4-17 years), parents, and service providers supporting community PA participation. All participants gave informed consent/assent for participation.

SA of participants' interview data answered three research questions:

1. What community PA participation opportunities are available and where do C&YP participate?
2. What are the barriers/facilitators to participation?
3. What are key action areas to increase participation?

SA findings showed C&YP participated in informal play and sport within families, school, and community neighbourhoods/groups. They participated in therapeutic exercise with healthcare professionals and in formal sport in community groups/sport programmes. Most community opportunities were sport, supported by charities and volunteers.

Barriers and facilitators fitted into eight situational categories: people, organisations, resources, information, organisational/institutional, discursive, environmental, and temporal. Barriers and facilitators connected and interacted in a complex network of relations that enabled or hindered participation. Thus, presence of facilitators did not guarantee participation. Overall, a fragmented situation made navigating participation difficult for families and providers. Influential disability discourses could hinder participation, while C&YP's participation altered over time.

SA identified three areas for future action:

1. Develop participation-focused healthcare education.

2. Co-ordinate situation elements e.g., people, information and resources.
3. Assist families and providers navigate participation.

Glossary of Abbreviations

Abbreviations:	**Terms:**
ADHD	Attention Deficit Hyperactivity Disorder
AIM	Activity Inclusion Model
ALN	Additional Learning Need
ALNCo	Additional Learning Need Co-ordinator
ANT	Actor-Network Theory
ASD	Autistic Spectrum Disorder
C&YP	Children and Young People
Covid-19	Corona Virus Disease 2019
Covid	Corona Virus Disease 2019
CP	Cerebral Palsy
DLA	Disability Living Allowance
DSDO	Disability Sport Development Officer
fPRC	Family of Participation Related Constructs
GAPPA	Global Action Plan on Physical Activity
GMFCS	Gross Motor Function Classification System
GMFCS-E&R	Gross Motor Function Classification System-Expanded & Revised
GT	Grounded Theory
HEPA	Health-Enhancing Physical Activity
ICF	International Classification of Functioning Disability and Health
ICF-CY	International Classification of Functioning, Children and Youth Version
InSport	Inclusive Sport
MAPi	Method for using Audit and feedback for Participation implementation
MET	Metabolic Equivalent of Task
MVPA	Moderate to Vigorous Intensity Physical Activity
NDSO	National Disability Sport Organisation
NHS	National Health Service
NSO	National Sport Organisation
OECD	Office of Economic Co-operation and Development
OT	Occupational Therapist
PA	Physical Activity
PE	Physical Education
PMLD	Profound Multiple Learning Disabilities
QoL	Quality of Life
RCT	Randomised Controlled Trial
SA	Situational Analysis
SI	Symbolic Interactionism
STS	Socio-Technical Systems
TDFQ	Theoretical Domains Framework Questionnaire
UNCRC	United Nations Convention on the Rights of the Child
UNCRDP	United Nations Convention on the Rights of Disabled People
UK	United Kingdom
WHO	World Health Organisation

Chapter 1. Introduction and Background

1.1. Personal Contextualisation

Involving children and young people (C&YP) in physical activity (PA), games and sport has always been of interest to me. I've always gravitated towards playing physical games with C&YP in family and community gatherings and completed a level 2 tennis coaching course to increase C&YP's PA participation; subsequently delivering weekly tennis lessons to C&YP aged 5-7, and 8-11 years. I enjoy PA and sport and know participation brings health benefits. Involving as many C&YP as possible in PA, to enhance their health and wellbeing, is a primary goal of this thesis.

Clinically, my pathway into paediatric clinical practice was initiated with an 8-month rotation at a large children's hospital managing a broad caseload, including rehabilitation following multi-level surgery (for C&YP with Cerebral Palsy [CP]), rehabilitation during leg lengthening procedures, and following traumatic injuries, as well as following cardiac surgery. Additionally, I managed caseloads involving C&YP with cystic fibrosis, worked on intensive care neonatal units, and within oncology - managing young people before and after bone marrow transplants. I liked the variety I found within paediatric practice and the rewards I found working with C&YP and families. I found it rewarding making therapy accessible to C&YP through appropriate communication and play and seeing C&YP and families supported to overcome challenges. Simultaneously, I enjoyed rotations working in adult Musculo-skeletal outpatients. Subsequently, I took a promotion specialising in adult Musculo-skeletal out-patient work but continued working weekends and on-call for the large children's hospital. After several years following this pathway, I decided to specialise in paediatrics and took a clinical position in community paediatrics.

Within my community paediatric practice, I managed Musculo-skeletal conditions in out-patient clinics and visited families in their homes to provide therapeutic management for conditions such as CP, genetic disorders, developmental delay, talipes equinovarus (club foot), and birth injuries/complications such as obstetric brachial palsy and torticollis (wry neck). Additionally, I worked within a special school two mornings per week providing therapy and support to C&YP, parents and school staff. Furthermore, I regularly visited mainstream schools to review C&YP special educational needs, completing the necessary assessments, treatments, and reports to support C&YP (mainly C&YP with CP) within mainstream education, including involvement in physical education (PE). I also began supervising physiotherapy students on paediatric placements and eventually enrolled in an MSc programme, with the aim of becoming a teacher/lecturer in physiotherapy.

When working as a community paediatric physiotherapist, I experienced several moments of discomfort/disquiet within my practice. I was uncomfortable when becoming aware of views that C&YP with CP needed to be “fixed” - as if there was something wrong with them. I often found myself saying – “But they are not medically ill, why are we treating them as if they are”. I had experienced medically ill C&YP when working at the children’s hospital. In my opinion, C&YP with CP seen within the community were not medically ill but going about every-day life; potentially needing support to enjoy a full life but being constrained by medical views of them. I also thought that the organisation of community paediatric practice supported these medical views because paediatric treatments seemed ongoing, for years, rather than being organised into a specific, goal-oriented framework. There did not seem to be an existing framework for when C&YP would need ongoing treatment/management, focused intervention, or intermittent review. These organisational practices sent tacit messages saying C&YP were ill because they needed ongoing treatment and management for years; until turning 18, when they transitioned into adult services and were suddenly discharged from care. I felt uncomfortable with these organisational practices and messages. I wanted to find ways to support C&YP and parents become autonomous and actively involved in taking care of themselves, long-term; able to enjoy life, be physically active, and throw off medical constraints. Whilst simultaneously receiving targeted interventions, when and where appropriate, to support their needs.

When enrolled on an MSc in Physiotherapy, I became more aware of my discomfort when completing a research dissertation which examined the effects of a functional strengthening home exercise programme for C&YP with CP. Parents involved in the study reported they were unsure regarding suitable exercises/PA for their child. One parent reported not allowing her child to go on a trampoline as she had been told previously by a therapist that this would increase her child’s spasticity. I felt indignant that a child had been denied a fun opportunity to enjoy “a normal life”, due to being medicalised by advice from a therapist - advice with no supportive evidence. The situation brought clearly into focus a gap between evidence and practice.

On becoming a Physiotherapy Lecturer, I started exploring research evidence and practice more specifically. One of the first funded research projects I conducted was a mixed methods study examining dynamic adapted cycling participation for C&YP with CP. At the time, there was little evidence available on cycling as a community-based participation intervention for C&YP with CP. I led the quantitative aspects of the study whilst a colleague led the qualitative aspects. Reflecting on this previous research and my clinical practice at the start of my PhD, I realised I held a very quantitative positivist position, which was reflected in my initial PhD research aims. These aims were to produce something with a measure of objectivity to it, which physiotherapists could use in clinical practice to examine and facilitate C&YP's participation in community-based PA. I was unsure of what this product would be or look like, although I considered some type of shared decision-making aid that had quantitative participation markers, which would help physiotherapists collaborate with families to increase C&YP's PA. I did not realise at the time that I had a narrow view of the situation, not considering the complexities involved, and over-simplifying the matter by seeing a single profession, physiotherapists, as the solution to the problem. Working through my thoughts, in collaboration with PhD supervisors, I realised that I did not actually know much about the situation of community PA participation for families or providers. I questioned whether there was a system in place, what its operational parts were, and its strengths and weaknesses. Thus, I decided I would examine the situation with the aim of identifying ways to increase C&YP's participation. I decided to include C&YP with cognitive and physical impairments because I reasoned providers would need to be able to include C&YP with different attention, cognitive, and physical abilities. During clinical practice, I, myself, had struggled to make therapy and PA accessible to C&YP with attention and cognitive impairments when compared to C&YP with physical impairments. I decided to focus on school-aged C&YP as I reasoned they would more likely be involved and attending community-based PA opportunities than pre-school C&YP. Furthermore, I wanted to constrain and define the boundaries of the situation in a way that a single researcher could manage.

1.2. Literature Review Contextualisation

At the start of the PhD journey (when I first determined that I wished to create a clinical shared decision-making aid to support C&YP's community PA participation) I decided that conducting a systematic review of community PA participation interventions would form the basis of my literature review, to inform my research goals. A systematic review of community PA participation interventions would help determine if, how and where PA was being used as a community participation intervention for C&YP with neurodisability, identify the outcome measures that were being employed, and the effectiveness of the interventions. On first scoping the literature to inform such a systematic review, I found a wide range of evidence examining PA. Often, however, it was difficult to ascertain from the evidence what domain within the International Classification of Functioning, Disability and Health (ICF) (World Health Organisation [WHO] 2001) the intervention was aimed at. Whether PA was being provided as a body structure and function physical performance intervention, activity intervention, or participation intervention. Additionally, I discovered many types of PA interventions/programmes without any synthesis of these different types/forms of PA. For example, interventions included ice-skating, hippotherapy, football, swimming, table tennis, cardiovascular-respiratory (CVR) fitness exercise programmes, muscle strength exercise programmes, online physical gaming and other types of physical games and exercise programmes. Much of this literature seemed to have poor scientific rigor containing much selection, allocation, assessment, performance, and reporting biases (Higgins et al. 2011). The literature was also often in the form of opinion pieces and reports and most of the empirical studies that I found were case studies, with no control comparisons, reducing their scientific rigor. Often, authors did not report sufficient detail about their interventions, which made it difficult to determine if participation was the intervention or the outcome of interest. Some papers detailed an interest in participation but then measured outcomes on the body structure and function or activity domain of the ICF. I therefore moved to examining literature on the participation construct more specifically to be able to define more clearly what it was that I was investigating. This literature helped me define participation and make sense of community PA from a participation viewpoint. Furthermore, the evidence confirmed the resistance I had experienced in some physiotherapy forums when disseminating findings from my research involving adapted dynamic cycling by C&YP with CP, where some physiotherapists asserted that being involved in participation contexts was not the role of a physiotherapist.

Exploring literature on the participation construct helped me refine my inclusion criteria for my planned systematic review, e.g. defining PA participation as taking place outside of medicalised settings (hospitals), not aimed at fixing body structures and functions, and including communal involvement, such as having peer interaction. I also determined to only include randomised controlled trials (RCTs) within the systematic review to ensure some measure of scientific rigor. I presented the systematic review protocol at a Health-Enhancing PA (HEPA) Europe conference, at the same time as the WHO (2018) published their global action plan on PA (GAPPA). GAPPA (WHO 2018) aimed to increase PA in population groups globally and highlighted that PA participation was a systems construct involving multiple sectors and stakeholders. In conversations with my PhD supervisors, I had also realised that it would be difficult to create a shared decision-making aid without knowing much about community situations, and their different component parts of community PA, such as the different sectors and stakeholders involved. GAPPA (WHO 2018) had introduced me to policy and policy actions aimed at increasing PA that showed me there was a wide variety of components within a situation of community PA participation. I therefore started examining policy more broadly to include these different component parts e.g., active travel and play sufficiency and started examining research methods that took a systems approach. Simultaneously, I had determined 10 papers for inclusion in my systematic review but had grown discontent with conducting a systematic review due to my changing PhD focus to examining the broad situation and taking a systems approach, and due to being a single researcher. Systematic reviews require more than one reviewer (i.e., need a primary and secondary reviewer) to be of good quality (Porritt et al. 2014).

My thesis introduction and literature review chapters reflect this PhD journey. I start by providing a background to the problem being investigated, define the concepts involved in the thesis and discuss related policy. I continue by considering the problem of defining participation and community PA participation, and the difficulties faced to increasing participation, which leads me to considering barriers and facilitators to participation. I introduced a literature search on barriers and facilitators to participation late in the PhD journey, following most of my data analysis. At that stage of the PhD, I considered barriers and facilitators as constituent parts of the system/situation, which partially reflected some of its strengths and limitations but did not show the whole picture. It was encouraging to note that my thesis findings confirmed existing literature on barriers and facilitators whilst also adding to the literature by showing how barriers/facilitators could connect and interact to provide a unique situation for individual families and providers. Furthermore, that the multiple socio-ecological levels involved, all needed to be considered for each individual and in the broader situation when aiming to support and increase community PA participation.

I eventually decided not to present my planned systematic review within my background and literature review chapters. I made this decision due to the quality limitations of being a single reviewer and due to the PhD journey that I finally took. However, I have added and threaded findings from the systematic review searches into the literature review (chapter 2) when discussing evidence on PA participation interventions, which is why those specific papers are discussed. The literature discussed within the thesis are papers found from the database search strategies described and listed at the start of chapter 2.

1.3. Community Physical Activity

This thesis examines the participation of C&YP with neurodisability in community PA. Community-based PA and community PA are interchangeable terms within this thesis meaning the same thing i.e., participation in PA within communities/community settings, such as within the home, school, community groups and surrounding neighbourhood environments rather than participation within medicalised settings. This definition of community settings is provided based on my own thoughts and experiences of working in community settings as a community paediatric physiotherapist and in alignment with U.K. National Health Service (NHS) (NHS England 2019) community health policy drivers. These community health drivers describe the need to include consideration of social and environmental factors affecting health when providing services, and require consideration of communal involvement i.e., the need for individuals and groups within communities to play an active part in supporting C&YP’s health. Consideration of the setting and people involved are not the only part of my definition of community PA participation, but its rationale is also considered within my definition. Community PA participation contrasts to PA participation of a medical nature which is aimed at addressing a medical condition, instead community PA is social in nature, and not focused on fixing a medical problem. Examples of community PA include informal or formal sport and recreation physical activities within community groups/clubs, and informal physical play e.g., rolling, crawling, running, hopping, skipping, climbing, kicking, throwing, and catching physical activities performed purely for fun and enjoyment. Literature supporting this definition of community PA participation that includes communal involvement and participation for recreation, fun, and enjoyment, predominantly references PA in the forms of social physical recreational activities or leisure/leisure-time activities and sport (Bult et al. 2011; Carlon et al. 2013; Shikako-Thomas et al. 2014; Jaarsma et al. 2015; Martin Ginis et al. 2016; Ross et al. 2016). This is the type of PA participation examined in this thesis to determine what the situation of participation is like for C&YP, families and providers.

PA is important for health (World Health Organisation ([WHO] 2007a; WHO 2020) and community PA can provide and increase opportunities and choices available for PA participation, but C&YP with neurodisability can struggle to participate in community PA (Rimmer and Rowland 2008; Carlon et al. 2013; Ross et al. 2016; Shields and Synott 2016; Martin Ginis et al. 2016). Researchers investigating barriers to community PA by C&YP with neurodisability describe this population group as having less opportunity to participate in organised sport and physical recreation activities (Murphy and Carbon 2008; Rimmer and Rowland 2008; Shields and Synott 2016) and being more inactive than their typically developing peers (Shields and Synott 2016). There is growing interest and focus on participation yet a dearth of data on community PA participation frequencies, intensities, PA total volume, communal involvement and related participation outcomes for this population group, which highlights the need to consider their situation of community participation.

1.4. Neurodisability and Community Physical Activity

Neurodisability causes a range of problems - physical and sensory impairments, learning, behavioural, and communication difficulties, and health problems such as epilepsy (Morris et al. 2013) - that can reduce PA. However, considering these body structure and function impairments and activity limitations as the sole reason for reduced PA participation, affirms a medical model of disability, that sees disability resulting from the characteristics of the individual child/young person. The use of a medical model reduces focus on the role and influence of social and environmental elements that can restrict C&YP's participation. Whilst a medical model dominates the discourse, societies' rationale for taking responsibility to provide PA inclusion for C&YP with neurodisability, is reduced, because limits to inclusion are seen as inherent in the child/young person and not inherent in the social and environmental worlds surrounding them. Furthermore, while healthcare therapists focus predominantly on body structure and function impairments and activity limitations, they will, possibly unknowingly, be supporting this medical position that disadvantages C&YP. Social and environmental barriers to PA exist within community settings such as schools, neighbourhood environments and community groups/clubs. Social and environmental barriers can include inaccessible environments that reduce active travel (Anaby et al. 2013), socio-economic barriers such as reduced family resources (Arakelyan et al. 2019), and negative attitudes towards disability that can limit inclusion in community PA opportunities (Shields et al. 2012; Reid 2016; Shields and Synnott 2016). Additionally, while C&YP may need extra help to participate in PA, this may not be readily available (Colver et al. 2011).

High levels of physical inactivity in childhood can cause a range of health problems (Tasdemir et al. 2001; Ekelund et al. 2019; Hanssen et al. 2021; Gesek et al. 2023) with these C&YP at higher risk. They participate in less PA than typically developing peers (Carlon et al. 2013; Shields and Synnott 2016), have fewer PA opportunities and choices (Bult et al. 2011; Masse et al. 2012; Bult et al. 2014), and have higher levels of physical inactivity and sedentary behaviour (Eriksson et al. 2007; Carlon et al. 2013; Ekelund et al. 2019). Having high levels of physical inactivity increases cardiometabolic health risk factors (Gesek et al. 2023), whilst being physically active aids development of bone mineral density, muscle strength and mental health during childhood (Elhakeem et al. 2020; Hulst et al. 2023).

All C&YP can have problems accessing PA and health-enhancing PA (HEPA). HEPA is any PA that benefits health and functional capacity without any undue harm or risk (WHO 2007a p6). To address the problem of insufficient HEPA in all C&YP governments and policy makers have sought to increase C&YP's PA through policy and legislation (WHO 2007a; WHO 2018; GOV.UK 2019; Welsh Government 2022).

However, despite policy and legislation being put in place, reports show funding for PA programmes, provision of PA programmes, and uptake in PA programmes for disabled C&YP remains poor (Reid 2016). Healthcare professionals have tried to help by providing interventions for C&YP with neurodisability. However, healthcare interventions typically focus on changing body structures and functions, physical performance, and functional activity, and may not result in desired changes to community participation (Palisano et al. 2012; Ross et al. 2016; Novak et al. 2020). Community participation is important to support healthy childhood development (McConchie et al. 2006; Palisano et al. 2012; Imms et al. 2017), often reported as an ultimate goal of rehabilitation (Adair et al. 2015) and viewed as primarily important by parents and C&P with neurodisability (Vargus-Adams and Martin 2011). A diverse range of organisations from different social sectors (e.g., education, sport and local government) have tried to address the issue of increasing community PA participation by C&YP (Martin Ginis et al. 2016; Reid 2016; GOV.UK 2019), but C&YP's PA levels remain low (WHO 2020; WHO 2022). Organisations often work with different aims and objectives, do not collaborate, and do not always have C&YP with neurodisability as their primary focus (Reid 2016; WHO 2018). Overall, no established, co-ordinated approach exists and there is a need to examine the multiple influences involved to determine best ways forward.

One way to examine a complex problem is to use systems thinking and socio-ecological theories (Bronfenbrenner 1979). These examine the whole (everything and everybody involved), rather than individual parts, and examine relationships between individual parts, to make sense of the whole. Bronfenbrenner (1979) used systems thinking in his socio-ecological theory on child development showing multiple individual, organisational, environmental, and societal structures and actions interacting to influence C&YP: at any given moment, and over time. Community PA is a complex system, comprising many socio-ecological influences, particularly when involving C&YP with complex needs (Martin Ginis et al. 2016). The WHO (2018) global action plan on PA (GAPPA) recognises the multifaceted nature of community PA participation and advocates a systems-based approach to increasing participation, globally. Yet, despite these acknowledged drivers advocating the need for sectors to work together to increase PA participation, organisations, institutions and professions still tend to work separately, focusing on their specific area of expertise and missing opportunity to share expertise and resources to address the problem (Martin Ginis et al. 2016; WHO 2018). Socio-ecological theory involving systems thinking (Bronfenbrenner 1979) has helped researchers develop methodologies and methods to examine complex situations. Situational Analysis (SA) is such a research methodology and methods package having a socio-ecological approach (Clarke 2005; Clarke et al. 2018). Therefore, I chose SA to examine this topic. There is a gap in evidence examining community PA participation by C&YP with neurodisability using a socio-ecological approach. This thesis therefore contributes to addressing this knowledge gap and moves evidence forward in this area.

C&YP with neurodisability have an ethical and legal right to participate in PA, to improve their health. These rights are evident in the United Nations (UN) Convention of the Rights of the Child (UNCRC) (UN 1989) and the UN (2006) Convention on the Rights of Disabled People (UNCRDP). Additionally, the Equality Act (2010) provides legislation to ensure disabled individuals have equal access and opportunity to participate within society. GAPPA (WHO 2018) highlights these rights when advocating a principle of universal proportionality. Universal proportionality posits that most resources for community PA should be provided to those most disadvantaged. Clarke (2005; et al. 2018) assert SA effectively explores situations containing disadvantage. Researchers (Anderson and Whitefield 2011; Uri 2015; Martin et al. 2016; Spyropoulos et al. 2022) have justified SA as a novel and robust way to research disadvantaged population groups, affirming my choice to use SA in this thesis.

I used SA to address three research questions:

1. What community PA opportunities are available and where do C&YP participate?
2. What are the facilitators and barriers to participation?
3. What areas need further action to increase participation and support for participation?

The research questions mapped onto two study aims:

1. To understand the system of community PA participation in operation
2. To identify key action areas for promoting increased participation.

To answer the research questions, I set five objectives:

1. To explore C&YP and their parents' experiences of community PA, using family interviews.
2. To identify service providers supporting C&YP's PA from family interview data.
3. To explore service provider and their organisations' support for participation using service provider interviews.
4. To identify facilitators and barriers to participation using all participant interview data.
5. To make recommendations aimed at increasing C&YP's participation using SA of family and provider interview findings.

The thesis comprises eight chapters. In chapter one, I provide an introduction, overview of the problem, definitions for key concepts, and discuss related policy. In chapter two, I discuss research evidence related to the research problem. I examine evidence on the participation construct, participation focused healthcare, and PA participation interventions for C&YP with neurodisability. In chapter three, I discuss SA as a research methodology and methods package and show it appropriate for use in this thesis. In chapter 4, I present the research questions, aims and objectives, research design, and detail research ethical approval and ethical considerations. I detail study methods including the systematic processes I used for data generation and analysis. Additionally, I discuss steps taken to ensure study trustworthiness. In chapter 5, I present each family situation, the types of PA and places C&YP participated, and facilitators and barriers. In chapter 6, I present where and how providers supported participation, and facilitators and barriers to their support. In both chapters 5 and 6, I include participant quotes to show thesis data supported study findings. In chapter 7, I synthesise family and provider findings to demonstrate answers to the three research questions, showing the socio-ecological system in action, and my application of SA' methodological theory. Thereby, I identify key areas for future action. In chapter 8, I provide recommendations within the action areas. I discuss these in relation to theory and research evidence within the field, and show my contribution to the evidence. Additionally, I discuss strengths and limitations of the thesis. Finally, I discuss my planned future actions, in alignment with thesis recommendations.

1.5. Definitions of Key Concepts

I begin by introducing the key concepts deployed in the thesis: neurodisability, participation, PA, exercise, physical fitness, sport, HEPA and PA intensities, sedentary behaviour and physical inactivity.

Neurodisability

Neurodisability, neurodevelopmental disorders, and neurological disorders are terms used interchangeably by clinicians and researchers (Morris et al. 2013). The chosen term used in this research is neurodisability, defined as "C&YP having congenital or acquired long-term conditions due to impairment of the brain and/or neuro-muscular system, resulting in a variety of functional limitations, which can alter over time". (Morris et al. 2013 p1103). Before choosing this term and definition for the thesis sample population, I also considered using the term neurodevelopmental disorders or neurological disorders.

Neurological disorders in C&YP are regarded as an umbrella term including a variety of congenital and acquired, rare and more common conditions that affect the central nervous system (CNS) and peripheral nervous system (PNS), having varied presentations that can alter as C&YP develop (WHO 2006; Welsh Government 2017p18). Neurological disorders in C&YP thus includes conditions such as, paediatric stroke, epilepsy, CP, Autistic Spectrum Disorder (ASD), Learning Disabilities (LD)/Intellectual Disabilities (ID), Minor Neurological Deficit (MND), and Profound Multiple Learning Disabilities (PMLD). Childhood neurological disorders also include genetic conditions where the source of the condition is genetic, but the condition has muscular and neurologic effects, such as neuromuscular disorders like Duchenne Muscular Dystrophy (DMD) (Kroger and Blake 2000; Verghese 2021). Childhood neurological disorders can additionally include developmental conditions that have neurologic effects such as Attention-Deficit Hyperactivity Disorder (ADHD) and Developmental Co-ordination Disorder (DCD) (WHO 2006). Thus, the term is an umbrella term including a variety of conditions having varying complexity and severity (Welsh Government 2017p18). The problem with using the term neurological disorders is the potential creation of a medical lens that views C&YP as having an inherent neurological condition/disorder that causes their disability. Furthermore, the term neurological disorders can apply to adults and thus includes potential to dilute focus on C&YP and ignore childhood factors/influences.

The term neurological disorders, neurodevelopmental disorders and neurodisability are however often used interchangeably in paediatrics. Morris et al. (2013p1103) argue the term neurodisability is a predominantly UK-specific term whereas neurodevelopmental disorders is a term more commonly used in the wider English-speaking world. Farmer and Deidrick (2006) define neurodevelopmental disorders as disorders where CNS impairments affect motor, cognition, behaviour, and language functioning, which results in numerous challenges with ambulation, information processing, self-regulation and communication. A potential problem with the label neurodevelopmental is the implication that the neurological pathology is developing when it is static/unchanging, such as happens in CP (Rosenbaum et al. 2007). The original neurological insult does however place limitations on the function of the nervous system which interacts with changing bone and muscle structure with growth, to cause additional problems such as reduced muscle length, strength, physical skill performance, function and physical mobility (Poutney 2007). Secondary problems/impairments can then be seen as part of the child’s disorder/condition and their development, which potentially places C&YP in a position of being viewed as needing to be fixed.

Similarly problematic, the term neurodisability includes the word “disability”, which can imply disability is an inherent characteristic of C&YP, reinforcing a view of C&YP needing to be fixed. This lens aligns with the medical model of disability, which situates disability as an inherent characteristic of an individual due to their impairments/ability limitations. Contrastingly, the social model of disability distinguishes between impairments and disability, and views disability caused by society, resulting from an interaction of the person with sociological and environmental factors (Oliver 2013; European Parliament 2021). Alternatively, to the medical and social models, the affirmation model of disability reasons body structure and function limitations are differences that can be both positive and beneficial for C&YP and adults (Swain and French 2000). An affirmation disability model accepts difference and does not seek to fix or normalise C&YP. Thus, having potential to liberate professionals, C&YP and families from expectations regarding how C&YP can participate in community PA, and/or have meaningful life experiences. None of the three terms considered for defining the population sample in this thesis seemed to include an affirmation disability model view or seemed ideal for use.

In support of the term neurodisability, Morris et al. (2013) argue that including the word disability does not label C&YP as having inherent characteristics of disability; Disability remains an interaction of individuals with a variety of factors, including environmental factors and C&YP should therefore be referred to as “disabled children” and not C&YP having disabilities. Both the definitions of Morris et al. (2013) (neurodisability) and Farmer and Deidrick (2006) (neurodevelopmental) reference body structure and function, and activity domains of the ICF (WHO, 2001) potentially reaffirming a medical view of C&YP. The definition for neurodevelopmental disorders is also limited to referencing CNS impairments, whereas neurodisability includes reference to functional limitations resulting from impairments of the CNS and/or neuro-muscular system; thereby, by definition, being more expansive and inclusive of a wider population.

In efforts to be as inclusive as possible within the thesis, covering a wide range of conditions, and keeping disability as a separate construct from C&YP, I first determined to use the term neurological disorders when defining the sample population. On reflection, using the term childhood neurological conditions/disorders may have been more appropriate to provide greater inclusivity and remove the term disability. The term neurological disorders would describe a wide variety of congenital and acquired, rare and more common conditions, and conditions that affect any part of the nervous system, including developmental neurological problems. Furthermore, include conditions of genetic origin that have neurologic and neuromuscular effects. I wanted to include a wide range of childhood neurological disorders to enable consideration of C&YP’s community-based PA participation comprehensively. Comprehensively, because it would include C&YP having varied physical and cognitive functional presentations who therefore might require different/varied support structures within communities; especially as evidence suggests C&YP’s age and functionality are significant predictors of meeting PA guidelines, rather than diagnosis type alone (Case et al. 2020). C&YP with different social, behavioural, emotional, cognitive and physical abilities may additionally require that providers adapt in numerous, different ways to enable PA participation, which would be important to capture for analysing the situation comprehensively (Pushkarenko et al. 2023). Additionally, including a diverse population of C&YP having varying needs and presentations, addresses the fact that PA participation is a human right for all C&YP (United Nations [UN] 1989), and all disabled people (UN 2006) whatever their physical, social, emotional, behavioural, and communication functions.

Using the term neurological disorders caused me some consternation, however, as the term is also applicable to adults, and I wanted to make sure I included terms and definitions that were specific for C&YP. Finally, I decided to compromise and use the term neurodisability, although I felt some discomfort using the word disability. However, disability is a term that many providers in a non-medical field would likely be able to relate to - making it an accessible term to others in the field of community PA Participation. Similarly, disability is a term included in equality law (Equality Act 2010) and a term widely used within childhood' clinical and research networks/forums e.g., the European Academy of Childhood Disability (EACD) and British Academy of Childhood Disability (BACD) - making disability a universal construct - albeit having different frameworks of understanding.

Participation

Participation and community participation are key concepts in this thesis. Participation has received increased attention in clinical practice and research since the introduction of the International Classification of Functioning Disability and Health (ICF) (WHO 2001). The ICF identified and described participation as a constituent domain of disability and health. The ICF (WHO 2001) has 5 domains influencing health, which are i) body structures and functions ii) activity, iii) participation, iv) environmental factors, and v) personal factors; showing a multi-faceted bio-psychosocial approach to health. The ICF (WHO 2001) defines participation as involvement in a meaningful life experience, which provides a very broad and person-centred definition. This could include involvement in meaningful life experiences within community participation.

Following initial introduction of the ICF (WHO 2001) the WHO (2007b) went on to consider the ICF more specifically for C&YP and provided an ICF for children and youth (ICF-CY). The ICF-CY adds consideration of childhood factors e.g., social and environmental factors that include family contexts, developing body structures and functions, and increasing independence as C&YP age and develop. Rosenbaum and Gorter (2012) developed the concept of the ICF-CY even further by labelling its domains with F words related to childhood development. These F words are - function, fitness, family, fun, friends and the future. The participation domain they labelled “friends”, providing an evolved description of participation as - involvement in meaningful life situations interacting with friends/peers. The paper by Rosenbaum and Gorter (2012) is an opinion piece which the authors state aims to encourage clinicians to incorporate childhood considerations into the ICF, and into clinical services, research and disability advocacy. The popularity of the ideas in this paper is evidenced by its publisher listing 419 citations to date (Wiley 2024). This is encouraging, as it reflects an uptake in consideration of childhood factors within the ICF (WHO 2001; WHO 2007) and suggests there is increasing support for focusing on participation in child health. However, the ideas put forth in the paper are not supported with empirical evidence, nor do the authors provide concrete ways forward to address disability inclusion within the ICF participation domain. Additionally, the authors suggest the need to focus on participation because such an approach could potentially lead to improvements in a child’s functional activities and/or result in changes to their body structures and functions. I have seen evidence of this effect when conducting an adapted cycling participation intervention for C&YP with CP that resulted in increases in muscle strength i.e., improvements at the body structure and function level of the ICF (Visser et al. 2012; Visser et al. 2014). However, I found that taking measurements at the body structure and function level was invasive and could negatively alter C&YP’s participation experiences. Furthermore, by focusing on the need to obtain empirical evidence at a body structure and function level (muscle strength and length, and heart rate) the cycling participation intervention was medicalised to some extent, which created tensions in providing a social participation experience. Taking measurements at the body structure and function level of the ICF does not measure participation elements, such as social friendship formations, growing independence, participation activity competence, self-efficacy, enjoyment, and satisfaction. Furthermore, taking body structure and function measures can maintain a medical lens that views C&YP as needing to be fixed, because the underpinning rationale seeks to see if there are changes in body structures and functions, even when focusing on participation.

Imms et al. (2016 p18) provide a further definition of participation for C&YP, which is attendance and involvement. These researchers defined attendance as “being there” and involvement using several intrinsic person-related factors, namely - "engagement, motivation, persistence, social connection and level of affect" (mood, feelings and emotions). This definition acknowledges social elements within the concept of participation instead of utilising a medical model involving body structure and function elements alone. Imms et al (2016) examined participation language in published evidence to provide their definition of participation. Ross et al. (2016p8) combined the constructs of participation and PA to provide a definition for PA participation, which is: "experiences in physically demanding movement, sport, game, or recreational play that results in energy expenditure and perceptions of communal involvement". This definition provides a description of participation elements that include physical exertion, recreation, games and sports, as well as social elements of communal involvement. Finding ways to measure all these elements reliably, non-invasively and in a valid way would provide a comprehensive assessment of community PA participation to inform practice and health outcomes for C&YP. Furthermore, raise awareness of the need to address participation as a multi-faceted health construct. My definition for participation in this thesis includes an understanding of all these elements and these published definitions of participation- (WHO 2001; WHO 2007; Rosenbaum and Gorter 2012; Imms et al. 2016; Ross et al. 2016) but in relation to PA within community settings. I define community settings as settings outside of a medical hospital setting, within private and public community environments, such as at home, in school, within community neighbourhoods/environments, and participating within community groups and organisations.

Physical Activity (PA)

Caspersen et al. (1985) defined PA as any bodily movement performed by skeletal muscles, which results in energy expenditure. Policy makers and researchers use this definition in their PA policy recommendations (WHO 2007a, WHO 2010; WHO 2019; WHO 2020). PA is a broad term and can happen at rest, in leisure and daily functional activities. PA includes subsets of exercise, physical fitness and sport (Caspersen et al. 1985). Exercise is - planned and structured repetitive bodily movement. Usually done with the aim of improving an element of physical fitness. Physical fitness has several attributes related to PA performance. These are cardiorespiratory endurance, muscle endurance, muscle strength, body composition and flexibility (Caspersen et al. 1985 p128). Paediatric physiotherapists often focus interventions on these dimensions of PA (i.e., performance) with some evidence of increases in functional PA (Novak et al. 2013; Novak et al. 2020) and less evidence of increases in leisure/recreation community PA participation (Ross et al. 2016; Reedman et al. 2017; Novak et al. 2020).

Play and sport are forms of leisure PA for C&YP (Ross et al. 2016). Play is defined as the active engagement in leisure recreation activities for fun and enjoyment (Oxford Dictionary 2023). Sport is a competitive form of leisure PA, divided into subsets of informal, formal, and performance sport. Informal sport is unorganised participation where the rules may not be followed exactly, there is informal play, and the participation is unstructured (King et al. 2003). C&YP can play informal sport with friends and family in and outside the home e.g., in school and neighbourhood environments. Formal sport is organised, structured participation, which can happen in school and with community groups where the sport activities follow the rules and there is a designated leader/coach involved (WHO 2007b; King et al. 2003). Performance sport involves elite levels of participation e.g., competing with national teams in international competition (Disability Sport Wales 2024a). Sport also has terms related to disability inclusion using the activity inclusion model (AIM) (Scottish Disability Sport nd). AIM defines four ways of participating in sport for disability inclusion: open, modified, parallel and specific. All people participate without modifications or adaptions in the same sport activity, in open sport. People do the same activity but in different ways in modified participation. Parallel activities are sport activities organised into ability groups. In specific sport activity, people take part in a unique activity specific to that sport e.g., wheelchair rugby.

Evidence shows some disabled C&YP can access open sport i.e., unmodified mainstream PA opportunities (Bevan Foundation 2011; Hodge and Runswick Cole 2013). However, evidence also shows that disability participation is often limited to specific organised sports, (Shikako-Thomas and Law 2015) and that in the UK, access and inclusion is often, only if a parent remains present with their disabled child (Hodge and Runswick Cole 2013; National Assembly for Wales 2019). Overall, most disabled C&YP appear to attend segregated PA opportunities - where segregated attendance is dependent on having a particular diagnosis, which categorises and segregates C&YP from the normative population, and allows them entrance into the defined, segregated group (Hodge and Runswick Cole 2013; National Assembly for Wales 2019). A call for more disability inclusion in all sport (Council of the European Union 2019; Tow et al. 2020) and for reverse integration in sport is happening but there are still limitations to provision of disability inclusion and reverse integration. For example, reverse integration is not recognised within elite competitive sport (Ramsden et al. 2023). Reverse integration involves inclusion of able-bodied and disabled individuals playing with and alongside each other, in the same team, which reduces ableism and provides more opportunities and choices for sport participation (Ramsden et al. 2023). There are few studies examining this situation. I found one example in my systematic review searches. Ozer et al. (2012) deployed a Special Olympics Unified Soccer Programme intervention that included typically developing C&YP and C&YP with cognitive impairment playing soccer together. Results showed positive outcomes in typically developing C&YP's attitudes towards their peers with cognitive impairment, and significant improvements in social competence ($p=0.04$) and friendship formations ($p=0.03$) for C&YP with intellectual impairment. It may be difficult to provide reverse integration in a sports environment due to its competitive nature, which is probably why reverse integration is not recognized in elite sport. There could be ways of increasing reverse integration such as supporting inclusion within mainstream PE. By providing more opportunities for inclusion of disabled C&YP alongside typically developing peers, there is the possibility of inclusion becoming legitimised as mainstream, thereby widening access for all.

Health-Enhancing PA (HEPA)

HEPA is a term used in PA policy and research referring to PA that benefits health and functional capacity (WHO 2007a, 2010, 2018, 2019; GOV.UK 2019; WHO 2020). Volume (intensity, frequency and duration) of PA participation influences the amount of energy expenditure during PA and the health gains acquired from PA. Therefore, PA volume is important to consider when evaluating the health benefits accrued from taking part in PA. Frequency and diversity of PA participation can be measured by counting attendance at PA opportunities and the diverse range of PA opportunities attended. Examples of such measurements are found in outcome measures like diaries and surveys/questionnaires that measure activity frequency and diversity e.g., the Children's Assessment of Participation and Enjoyment (CAPE) that includes measures of attendance and diversity of participation (King et al. 2006; Adair et al. 2018). These outcome measures involve measures of participation but may not necessarily be of PA participation. Measuring attendance also only provides information on whether C&YP attended i.e., their frequency of attendance and what they attended (diversity). This outcome does not measure physical exertion i.e. energy expenditure during PA. Therefore, the outcome provides no direct data on physical health benefits accrued from taking part in PA. Measuring how many minutes C&YP spend physically taking part in a specific PA provides some measure of their involvement, but that involvement could have varied intensities of energy expenditure at any given moment during a single participation event, making consistency and agreement in measurement (reliability) more difficult, especially if measured by different people.

There are several ways to measure energy expenditure during PA, but measurement may not always be feasible in a community setting (i.e., outside the hospital and a laboratory environment) and measuring energy expenditure could alter how C&YP take part, thereby influencing the outcome measured. For example, measuring the maximal rate of oxygen consumption (VO2max) during progressively demanding exercise, such as increasing rates of cycling or running, is a recognised way of determining an individual’s energy expenditure during exercise and helps in determining individuals’ aerobic capacity (Ndahimana and Kim 2017). However, this measurement (indirect calorimetry) requires an individual to have the motor ability to participate in a standardised progressively demanding exercise and requires laboratory testing, as the test involves wearing an oxygen mask to measure the volume of oxygen breathed in and the volume of carbon-dioxide breathed out during exercise. An individual’s metabolic rate can also be calculated using indirect calorimetry, by additionally including measurement of body mass and the use of heart rate monitoring (Ndahimana and Kim 2017). All these measurement procedures can be problematic when involving C&YP as the measurement processes are invasive and demanding due to the need to apply oxygen masks and heart rate monitoring equipment and engage in progressively demanding exercise.

The use of heart rate monitoring equipment alone - as an estimate of energy expenditure during PA - is a recognised measurement method and there is an increase in child-friendly wearable heart rate monitoring devices in recent years, providing the potential to make heart rate monitoring in C&YP, less invasive (Ndahimana and Kim 2017). However, evidence indicates that there are reliability issues due to discrepancies in measurement accuracy between different wearable devices, as well as noise/artefact interferences; and the way in which devices are worn, and their length of application can also influence measurements (Behere and Janson 2023). Thus, standardisation and reliability of measurement between individual C&YP and groups of C&YP, can be difficult to achieve. Measuring heart rate during PA provides an estimate of energy expenditure due to the correlation between heart rate, oxygen consumption and PA intensity i.e., the heart needs to work harder to deliver oxygen to body systems during higher PA intensities. This correlation is low however for sedentary and light PA, which may be the type of PA more likely to happen in disabled population groups. Furthermore, there are numerous other variables that can affect the correlation e.g., muscle mass, body mass, physical fitness, and types of activities/exercise that further reduces scientific rigor in measurement (Ndahimana and Kim 2017).

Another way to estimate energy expenditure during PA is by using the concept of metabolic equivalent of task (MET). The MET concept expresses PA energy consumption as a multiple of the resting metabolic rate, where one MET is the amount of oxygen consumed when sitting at rest (Jette et al. 1990). One MET is thus an individual’s resting energy expenditure; therefore, PA costing five METS would be an energy expenditure 5 x the amount of energy spent at rest. The WHO (2020) defines low intensity PA in C&YP as equivalent to 1.5 - 4 METS, which is energy expenditure of 1.5 - 4 times energy spent at rest for that child/young person. Moderate PA intensity is defined as PA costing 4 - 7 times energy expenditure at rest, and vigorous PA is energy expenditure > 7METS. MVPA (moderate to vigorous PA) is PA that gets C&YP hot and breathless, and HEPA when performed for 60 minutes daily, across a week (WHO 2020). Observation of C&YP i.e., monitoring and measuring how long in seconds/minutes C&YP are hot (look red/flushed) and out of breath during PA, provides an estimation of MVPA. There is however a dearth of validated and reliable measurement tools for the measurement of energy expenditure via observation of C&YP, and when observing disabled C&YP specifically. It may be that research examining observation methods could lead to validated and reliable observation measurement tools. Estimating METS from observation of PA involvement is complicated further by resting metabolic rate being variable between C&YP - dependant on their body mass, body compositions, age, sex and pubertal status (Ridley and Olds 2008). Compendia of MET values for specific PA have been produced for adults but there is little data available for C&YP and methods for adopting/adapting adult values to C&YP are unclear because C&YP usually have higher resting metabolic rates than adults (Ridley and Olds 2008).

C&YP with neurodisability, especially those with more severe and complex disability, struggle to achieve MVPA intensities, reducing their potential to accumulate health benefits from PA (Palisano et al. 2011; Reedman et al. 2017; Reedman et al. 2019). Additionally, they may need high levels of physical and behavioural support to participate in PA, and providers and carers may have concerns regarding adverse incidents and risk, which could reduce C&YP's ability to gain MVPA (Palisano et al. 2011; Cleary et al. 2017; Reedman et al. 2017). MVPA is challenging PA and participation in challenging PA is an important part of child development (King et al. 2003). Besides struggling to achieve MVPA, C&YP with neuro-disability also spend more time in sedentary behaviour, which limits their HEPA (Eriksson et al. 2007; Ross et al. 2016; Ekelund et al. 2019). Sedentary behaviour is any waking behaviour costing 1.5 METS or lower, which is usually sitting, reclining or lying down, including in wheelchair use, and doing activities such as working at a computer, reading, watching television and other screen time activities (WHO 2020). C&YP with neurodisability are known to spend more time in sedentary activity than typically developing peers and have high levels of physical inactivity (Eriksson et al. 2007; Ross et al. 2016; Ekelund et al. 2019). Physical inactivity is an insufficient level of PA to meet the established recommendations for health (WHO 2020).

1.6. Policy Overview

There are many policies supporting PA participation, both for health in general and specifically for C&YP. Firstly, I discuss policy recommendations for PA and health, including for disabled C&YP. My aim is to show the relevance of PA for health, and to show the recommendations on the amount of PA necessary for health. Secondly, I integrate policy with data on the status of C&YP's PA, both typically developing and disabled C&YP. I discuss this evidence to show the state of PA participation for disabled C&YP, which adds to the argument for this thesis. Thirdly, I consider relevant social care policy and social care support for disabled C&YP, which is part of families’ situations.

Policy and Health Promotion

PA was first recognised and acknowledged internationally as important for health with the Ottawa Charter (WHO 1986) followed by the WHO (2007a) PA-specific framework for health. The WHO (2007a) framework highlighted the growing problem of physical inactivity in childhood due to increased vehicular transport, large built-up urban areas without safe infrastructure for walking and cycling, increased sedentary time in school and in screen leisure activities, which were rapidly overtaking physically active leisure activities. These barriers reduced C&YP’s physically active play, their physically active leisure activities, and active transport in walking and cycling; reductions in PA that C&YP with neurodisability already faced (King et al. 2003). The PA framework (WHO 2007a) moved the health promotion agenda forward. It recognised the influence of multiple organisations and sectors - such as health, transport, urban planning and housing environments, schools and nurseries, workplaces and leisure/sport sectors - on PA participation. Additionally, it recommended integration and collaboration between different sectors to increase PA participation. The WHO (2007a) PA-framework also made recommendations on PA intensities for health (HEPA) in C&YP; C&YP should have at least 60 minutes of moderate intensity PA across a week. In 2010, the WHO changed the recommendation to 60 minutes per day across the week. Guidance was for C&YP aged 5-18 years. In 2019, the WHO introduced guidance for C&YP under the age of 5 years. There were no specifications or considerations for disability within any of the recommendations provided, leaving families and other people in different sectors working with disabled C&YP, without any guidance. In 2020 for the first time the WHO included PA intensity guidelines for disabled C&YP. Within their 2020 guidelines, the WHO recommended the same intensities for disabled C&YP as typically developing C&YP and suggested there were no major risks for disabled C&YP to engage in PA, if the PA was appropriate to their current activity levels, physical function, and health status, and PA health benefits outweighed any accumulated risks. Recommendations stated all C&YP, typically developing and disabled C&YP, should start PA participation doing small amounts, and gradually increase frequency, intensity and duration over time. In comparison to typically developing C&YP, the WHO (2020) suggested disabled C&YP might need to consult a healthcare practitioner/disability specialist to help determine the type and amount of PA suitable for them.

Along with stating C&YP need to meet PA recommendations daily, WHO (2019; 2020) state C&YP also need to meet all recommendations on physical inactivity, sedentary behaviours and sleep, within a daily, 24-hour period. The United Kingdom (UK) provided PA guidance for disabled C&YP for the first time in 2022 (GOV.UK 2022; Welsh Government 2022). UK guidance recommends disabled C&YP to spread moderate intensity PA out over the week, at 120-160 minutes per week, which is 260-300 minutes per week less than the WHO (2020) recommendations, and the UK, provides no recommendation for daily PA participation. The UK recommendations assert disabled C&YP can accrue health benefits when engaging in lower intensities and frequencies of PA over a week (GOV.UK 2022). However, the guidance acknowledges that evidence used to make recommendations for disabled C&YP is sparse and lacks methodological rigor (WHO 2020; GOV.UK 2022). Both WHO (2020) and UK (GOV.UK 2022) recommendations state that more PA is better for all C&YP, and to break up sedentary periods of inactivity regularly, preferably spreading PA throughout the day.

Due to the global prevalence of physical inactivity in adults and C&YP, the WHO provided an action plan on childhood obesity in 2017 and a Global Action Plan for PA (GAPPA) in 2018. GAPPA aims to have 100 million more people physically active by 2030 (in comparison to 2016 baseline data collated across multiple countries). GAPPA objectives include a 10% increase in physically active people by 2025, and 15% increase on the baseline data by 2030; GAPPA aims to achieve this by ensuring that all individuals and communities have access to safe and enabling environments for PA participation, and access to diverse PA opportunities. Lack of environmental access and limited opportunities and choice for PA are strong barriers to participation by C&YP with neurodisability (King et al. 2003; Shikako-Thomas et al. 2014; Shields and Synott 2016).

To achieve its aims, GAPPA has four key policy action areas with 20 policy action plans, across the four areas. GAPPA deploys a whole-systems approach to increasing PA participation that advocates multiple cross-sector collaborations within and across its four action areas. The first action area aims to make societies more active by increasing everyone's knowledge of the benefits of PA. The second area aims to create more opportunities and choices for participation e.g., by providing programmes across sectors and community settings. The third area aims to make more accessible, safe environments for participation e.g., by providing safe walking and cycling areas. The fourth area aims to enhance PA systems by strengthening policy and developing research, leadership, governance, advocacy, innovative finance mechanisms, and providing better data integration systems. The four areas have related policy action plans to provide focus for researchers, healthcare professionals and all members of society regarding actions required to increase community PA participation. Unfortunately, the plan does not highlight disability needs and since GAPPA launch (and start of this thesis), a Coronavirus global pandemic (Covid-19) created widespread quarantine, social distancing and closure of recreational facilities and travel (Coronavirus Act 2020). Many families with neurodisability rely on services having specialist equipment such as hoists and modified and specific targeted activities to access PA, thus, Covid-19 exacerbated the barriers these families already faced (Cadwagan et al. 2022). The WHO (2022) asserts that since the Covid-19 pandemic there is now even greater need to provide systems-based support to increase PA participation, globally.

Policy and PA Data Integration

Reports on national (Reid 2016; Guthold et al. 2022) and international data (Guthold et al. 2022) on disabled C&YP's PA participation status is poor. In 2022, the WHO published the first global status report on PA, assessed against the four key GAPPA policy actions areas, using pre-pandemic data (2016 - 2020 data). The global status report does not include data on disabled C&YP as a specific category, illustrating a further lag in consideration of disabled C&YP. The report showed slow and uneven progress to reaching PA targets for 2030, with populations' most socio-economically disadvantaged making the slowest progress. Only two of GAPPA's 20 policy action plans from over three quarters of its 194 member countries showed implementation i.e., i) national, road safety, design standards for safe crossings for pedestrians and cyclists; and ii) national PA surveillance data for adults and C&YP. However, the surveillance data does not include a subcategory for disabled C&YP. Guthold et al. (2022) provided a review of the surveillance data to inform the global status report and showed no available data on disabled C&YP's PA participation, globally. C&YP surveillance data came from questionnaires, mostly completed in mainstream school settings without differentiation for disabled C&YP. Disabled C&YP may be present in the data, potentially skewing the data, or not represented in the data at all. Thus, despite policy and policy actions being provided, these still neglect to recognise and prioritise population groups legally recognised as disabled, i.e., individuals who have the protected characteristic of disability (Equality Act 2010) because disabled individuals are not recognised/legitimised in data collection and analysis processes.

The measurement of global PA status in C&YP uses a report card system informed by questionnaires (Hewitt et al. 2019; Richards et al. 2022). The report card system reports on 10 PA indicators using national surveillance data and indicator related benchmarks, which relate to meeting global PA recommendations (Hewitt et al. 2019; Richards et al. 2022). Each report card indicator has one or more benchmark statements for grades ranging from A (excellent; 94-100% of C&YP met the criteria) to F (failing; <20% met the criteria) (Ward et al. 2018). The report card status for C&YP in Wales showed a decline in overall PA from 2016 to 2021 (Richards et al. 2022) with only 14% of C&YP in Wales participating in the recommended 60 minutes moderate to vigorous intensity PA (MVPA) daily, on 7 days per week. Results also showed more boys engaged in PA (18%) than girls (10%). Younger C&YP, 11 years, reported higher levels of MVPA participation (20%) compared to older C&YP, 16-year-olds, (10%). Regarding socio-economic status, 12% of C&YP from less affluent families met the PA recommendations compared to 17% from families that were more affluent. There was no report on disabled C&YP as a subcategory. Thus, GAPPA's (WHO 2018) push for universal proportionality includes consideration of family status and socio-economic status but does not include consideration of disability or highlight the intersectionality of disability with socio-economic factors and family status.

The Netherlands, Finland, Hong Kong, China, and the United States are the only countries who have previously reported, specifically, on disabled C&YP's PA status within their PA report cards (Ng et al. 2023). Ng et al. (2023) have worked recently to provide para-report cards for disabled C&YP using the same matrices developed for typically developing C&YP. However, modifying certain terminology to be specific to disability; and including the addition of a specific environmental context benchmark.

The researchers included an environmental context benchmark because previous evidence shows lack of environmental access, accessible facilities, and adaptive equipment are barriers to PA participation for disabled C&YP (Shields and Synott 2016). Twelve countries' government policy reports and data from disability studies and surveys across 14 countries, informed development of the para-report cards. Para-report card indicators reported data for overall PA, organised sport, active transport, active play, sedentary behaviours, family and peers (involvement/influence), physical fitness, school, community and environment. The multiple areas measured indicate multiple influences on C&YP's PA within communities, and a socio-ecological system in action (Bronfenbrenner 1979). Results for para-report card grading, in the 14 countries that use para-report cards, were lower than the grade results for the 57 countries reporting data involving typically developing C&YP i.e., reported in the global matrix (Silva et al. 2022). This evidence confirms lower levels of PA in disabled C&YP compared to typically developing peers but still provides sparse data evidence because 45% of para-report card assessments were inconclusive, due to lack of available data (Ng et al. 2023). The para-report card results showed Finland with best overall PA, achieving Grade C+, whilst the remaining 13 countries using the para report cards showed 7 countries achieved F grade results, and 6 achieved D/D- grades. Use of global reports cards and para-report cards has limitations as approaches to their application, data collection and data analysis, appears to differ slightly across regions/countries. Introduction of para-report cards does however raise awareness of the need to collect data specific to disabled C&YP, and provides a means to collect that data, and compare data globally, regarding the PA status of disabled C&YP.

It is disappointing to note a lack of UK involvement in the evidence on development and use of para-report cards. Reid (2016) notes there is a lack of data on the PA and level of fitness in disabled C&YP in Wales. Asserting, often organisations' PA programmes, and funding for their PA programmes, do not capture specific data on disabled C&YP and their experiences. Additionally, there is a lack of disability specific measurement and evaluation, which makes it difficult to know where to focus attention and funding to increase participation. Schools are where most data sources come from but do not always include disability as a representative category. Further, although there is policy and legislation in place there is currently no guarantee of PA integration in practice for disabled C&YP in schools. For example, there is some data evidence that indicates disabled C&YP often excluded from physical education (PE) sessions in school and doing separate therapeutic exercise rather than participating in PE with typically developing peers (Reid 2016).

Policy and Play

Another form of PA is informal play. C&YP can participate in informal play at home, in schools, informally in community groups, and within environmental spaces e.g., parks. The play sufficiency duty (GOV.UK 2012) is a legal duty Welsh government local authorities must meet, to ensure assessment and provision of opportunities for C&YP to play. Survey assessment of play sufficiency occurs every 3 years. Play Wales assessed the state of play for disabled C&YP in 2022 and reported disabled C&YP have fewer opportunities to access outdoor play areas than typically developing peers. Additionally, they reported some disabled C&YP expressed isolation, loneliness and exclusion. Potentially, due to poorly designed environments, C&YP's disability impairments that limited their participation, and community attitudes that reinforced difference. Reasons for lack of accessible community play environments, reported in the survey, included lack of disability awareness and no legislative requirements for disability inclusion when designing and providing play areas, due to large numbers of play areas established prior to the Disability Discrimination Act (1995). The survey reported aged facilities also made disability inclusive play facilities difficult to adapt to provide inclusion, and community councils had limited financial resources to provide play equipment that allowed wheelchair access. In some areas, there was also a transfer of responsibility for play areas to transient community councils, which potentially reduced long-term planning and governance. Overall, disabled C&YP face disadvantage in outdoor play within communities, which is evidenced as a national (Play Wales 2022) and international (van-Engelen et al. 2021) situation for C&YP with neurodisability. Outdoor play is not only reliant on accessible physical environments but also accessible social environments where families, carers and providers can facilitate social and communal involvement of C&YP with other C&YP, through physical play. Evidence shows this type of inclusion can be hindered by community attitudes that focus on C&YP's differences rather than focusing on facilitating inclusivity and on C&YP's

strengths (Campbell 2008; Campbell 2009; Hodge and Runswick-Cole 2013; Verscheuren et al. 2012; Shields and Synott 2016; Play Wales 2022).

Policy and Social Care

Social Care Policy is there to support people in need. The Children Act (1989) considers disabled C&YP as individuals in need. Evidence shows families with disabled C&YP face additional time and financial costs within daily life; increasing their need. Scope (2023) estimates families with disabled C&YP faced additional costs of £581 per month in 2019 and £975 per month in 2023. The Covid-19 pandemic, cost of living crisis, and increased inflation has increased financial difficulties for families involving C&YP with neurodisability (Cadwagan et al. 2022). The role of the Children's Commissioner for Wales (2024) is to ensure the wellbeing of all C&YP in Wales and reports 30% of all C&YP in Wales, are living in poverty. The Wellbeing of Wales report (Welsh Government 2023a) shows 56% of single parent households are, materially deprived. Thus, the inter-section of being a single parent and having a disabled child has a high chance of material deprivation. A systematic review of family factors affecting community participation by disabled C&YP showed consistent association between reduced leisure activity participation and lower socio-economic family status and living in a single parent household (Arakelyan et al. 2019).

There are UK social care benefits to support families in material deprivation. The Disability Living Allowance (DLA) is available for all disabled C&YP and adults to support their care and mobility assistance needs and reduce the burden of these costs on families. To gain DLA families need to show that a disabled child/young person's care and mobility assistance needs are substantially higher than for other C&YP at their age (Tidswell 2006a; Tidswell 2006b). Furthermore, to receive the additional support of Carers Allowance, in the DLA care component, the carer must meet a threshold number of hours per week caring for a disabled child/young person, earn less money than a specific threshold amount, and be over 16 years. When considering poverty and child health, the Welsh Parliament (2023a) states there is a lack of ambition to set targets to tackle child poverty, and lack of coordination and cohesion in systems to improve the situation for families. The likelihood of families involving C&YP with neurodisability facing increased need is great and there is a lack of coordinated support to improve the health and wellbeing of C&YP with neurodisability, who may face additional socio-economic disadvantage to participating in PA (WHO 2018).

The Social Services and Well-being (Wales) Act (2014) provides a structure for families in Wales to gain financial support (direct payments) so that disabled C&YP and their carers can participate within society e.g., attend community PA opportunities. The Social Services and Well-being (Wales) Act (2014) required the Welsh Assembly Government to set regulations regarding eligibility criteria against which Social Services could assess C&YP and their families/carers, to provide them with the necessary support. The Act details assessment eligibility criteria, including assessment of physical, social, emotional, and financial support needs. Families who want help from Social Services need an assessment, otherwise families must pay themselves, for services used to meet their support needs. Families are free to choose not to have an assessment for support. Assessments work out how much money government local authority councils provide via direct payments to families (Carers Wales 2022), who can then use the direct payments to pay for the support services they choose to use e.g., attending a community PA opportunity/programme. The Social Services and Well-being (Wales) Act (2014) also makes it a legal requirement for government councils to make information available within communities regarding what services and opportunities are available within communities e.g., services and charities providing community PA opportunities to disabled C&YP.

Policy and the School System

The school system is important to consider as part of the socio-ecological system of community PA participation. C&YP spend much time in school, including in PA and sedentary time. In Wales, local authorities oversee the school system and there are 22 local authorities across Wales (Local Government (Wales) Act 1994). The local authority governs C&YP’s allocation to public schools and funds and maintains public schools, and the provisions to meet disabled C&YP’s support needs within these schools (Office of Economic Co-operation and Development [OECD] 2018). The local authority has less governance and provides less support to independent schools. The Welsh Government (2018) has a strategy for most disabled C&YP, termed C&YP with additional learning needs (ALN), to attend and access education in mainstream schools i.e., schools with typically developing peers. Mainstream schools may include a specialist disability unit however not all mainstream schools do. Where a mainstream school or mainstream school with disability unit cannot meet C&YP needs, C&YP attend a special school (OECD 2018). Families including C&YP with neurodisability may need to travel some distance for school, dependent on location of schools having disability provisions to suit their child. Every public school governed by the local authority must have an ALN co-ordinator (ALNCo) to help co-ordinate support for disabled C&YP's needs in school (Special Education Needs and Disability Act 2001; Welsh Government 2018).

The Special Educational Needs and Disability Act (2001) makes it a legal requirement that disabled C&YP are not discriminated against within schools, whatever model of school they attend, and that schools take reasonable steps to overcome any disadvantage that disabled C&YP may face within school e.g., to PA participation, and to accessing the curriculum. The Welsh school curriculum has undergone change since start of this thesis, with a new curriculum implemented in all year groups and schools from, September 2023 (Welsh Government 2023b). The new curriculum aims to give schools more ownership of how they facilitate education including PE, and the health and wellbeing of C&YP within schools. Another aim of the new curriculum is to promote the health and wellbeing of C&YP into adulthood. The Well-being of Future Generations (Wales) Act (2015) also focuses on C&YP's future. This Act states all public bodies, including schools, health boards, local government authorities, community organisations, must work together to secure the present and future well-being and health of C&YP in Wales. These policies provide support mechanisms for inclusion of disabled C&YP in community settings but rely on people and organisations' knowledge, work, and collaboration to support C&YP and their families effectively.

1.7. Summary

In Chapter 1, I have introduced the problem at the centre of this thesis, limited community PA by C&YP with neurodisability, and the need to address the problem. I have shown that many sectors and socio-ecological levels (Bronfenbrenner 1979; WHO 2018) are involved in the situation and that these sectors and different levels can positively or negatively influence the situation. I have introduced legislation and policy drivers aimed at increasing PA participation and policy advocating that all sectors need to work together to increase PA participation (WHO 2018). Yet, despite this policy and the presence of legislation supporting disability inclusion, evidence and policy shows C&YP’s PA participation remains low. Low levels of PA participation are common across typically developing C&YP and C&YP with neurodisability, but the situation appears worse for C&YP who face social and environmental barriers to participation, like C&YP with neurodisability. The disparity in PA participation is also confirmed by data from para report cards, albeit sparse data (Ng et al. 2023). The healthcare sector is part of the situation, and I have shown how therapeutic healthcare has often medicalised C&YP by focusing on attempting to fix C&YP using interventions aimed at altering body structure, body functions, and activities. However, evidence on healthcare interventions focusing on these ICF levels do not conclusively show causal links to increasing community recreation and leisure PA, and/or sport participation. Neither does it appear that this focus improves the situation of participation long-term i.e., as C&YP move into adulthood. In this introduction, I have thus shown that limited community PA participation by C&YP with neurodisability is a problem and set out why I want to address the problem. I have set out my aims and objectives in addressing the problem and provided relevant research questions. Furthermore, I have introduced key concepts within the thesis and provided definitions for these. I have discussed policy related to PA participation and health and shown many policy directives, both nationally and internationally, involved in PA participation - which highlights the relevance and importance of the topic area. I have also shown that despite policy and legislation, disability inclusion remains problematic, and there is a lag in data and policy provisions for disabled C&YP compared to their typically developing peers. I have integrated data on PA to show the PA status of C&YP and the gap in evidence for C&YP with neurodisability. The gap in data collection, analysis and management for disabled population groups (like C&YP with neurodisability) highlights the difficulties in comprehensively assessing the situation, which makes it difficult to direct resources and research to where it is most needed. I have discussed policy on play and on social care support for families, including within schools. I have shown the relevance of this policy and the subsequent support that must be made available to facilitate C&YP’s play participation and inclusion. All these discussions show the many aspects and influences on families and C&YP’s community PA participation. In Chapter 2, I will increase demonstration of the complexity of the situation by discussing in greater depth research evidence on the participation construct, influences on community PA participation, and community PA participation interventions for C&YP with neurodisability.

Chapter 2. Literature Review

In chapter 2, I discuss research evidence on the concept of participation and its component parts. Thereby, I gain a deeper understanding of the participation construct. In gaining a deeper understanding of the participation construct I develop my understanding of community PA participation, its potential influences, and the complexities involved. I also consider evidence from database searches seeking evidence on whether PA is being implemented as an intervention at the ICF (WHO 2001) participation level. Additionally, I consider participation-focused healthcare, to determine the state of the evidence regarding providing a participation focus when managing C&YP with neurodisability within paediatric healthcare. I do not focus in depth on quantitative evidence of physical exertion/energy expenditure, although I have introduced these concepts and some related evidence in Chapter 1. The aim of the literature review in chapter 2 is to examine the participation construct and participation from a sociological and situational perspective, due to the thesis being a SA of community PA participation. I acknowledge, it would have been beneficial to include greater examination of evidence regarding energy expenditure and the difficulties involved in increasing PA energy expenditure within community settings, particularly for those C&YP with greater physical limitations e.g., Gross Motor Function Classification System (GMFCS) levels IV and V (Palisano et al. 2007). However, this thesis does not specifically focus on the topic of energy expenditure because it is a SA involving qualitative interviews. Qualitative interviews do not provide quantitative data of PA exertion/energy expenditure. Thus, the literature review does not have this specific focus. I acknowledge it would have been beneficial to explore such evidence alongside evidence on participation outcome measures and their validity, reliability and feasibility in relation to community PA participation and its measurement. Especially in relation to taking a participation-focused approach within healthcare management of C&YP with neurodisability. This thesis did not aim however to have a specific healthcare focus, due to healthcare being only one of many elements/sectors within the situation, and the research focus being the situation. Despite this reasoning and justification, I acknowledge that not including discussion of evidence involving these different aspects of community PA participation, does limit the literature reviewed.

2.1. Searching for Evidence

I used a range of strategies to identify relevant research and scholarship. I searched for grey literature via online searches scoping web sites of known organisations working in the field. I searched for peer reviewed journal articles via database searches. I conducted backward citation searches from articles read to obtain further relevant articles. I also searched for articles published by known authors I identified in the field. This approach did unfortunately lead to some publication selection bias because authors that I knew to have published on the participation construct were from a specific collaboration, and backward and forward citation searches of their work lead to further articles by the same group of researchers, or their affiliated collaborators in the field.

Databases searched included: Allied and Complimentary Medicine (AMED), MEDLINE, MEDLINE in process, Cumulative Index to Nursing and Allied Health Literature (CINAHL), PEDro, Scopus and Excerpta Medica database (EMBASE). Initial searches near the start of the thesis, October 2018, were from January 2001 - October 2018. I used a 2001 start date because the WHO publication of the ICF in 2001 introduced the participation domain as an important construct in health and disability. This is a common approach quoted in the literature that investigates participation i.e. searching for evidence on participation from a 2001 start date due to the introduction of the ICF in 2001 (WHO 2001). This approach to setting database search dates could bias literature search results if all researchers examining participation are using the same search dates, i.e., this could result in unknowingly missing older relevant publications. In November 2023, I updated searches adding further keywords and keyword combinations, searching from October 2018 - November 2023. All searches were restricted to English language only. I produced keywords for all searches from the three key concepts - C&YP, neurodisability, and PA. I developed keywords closely assisted by Ovid MEDLINE Medical Subject Headings (MeSH). I illustrate the keywords I used in initial database searches in Table 1. I have placed the additional keywords for latter searches into the same table using italics. Latter searches included searching AMED, CINAHL, and MEDLINE databases.

Population:	**Intervention:**	**Outcome:**
Child* Adolescent Youth Young People Young Person Teenage* Neurodisability Neurodevelopmental Disorders Developmental Disabilities Cerebral Palsy Movement Disorder Nervous System Disease Genetic Disorder Psychomotor Disorder	Physical Activit* Recreational Activit* Leisure Activit* Sports Recreation Exercise Exercise Therapy Participation [Keywords for Latter searches: *Barriers* *Facilitators*]	Physical Activit* Recreational Activit* Leisure Activit* Sports Recreation Exercise Exercise Therapy Participation

Table 1: Keywords Generated for Database Searches

I conducted searches using various combinations of these keywords via Boolean operators “OR” and “AND” in a systematic manner. I list the keywords and their combinations for initial searches and a latter search, in Figure 1 (p36).

I screened the titles and abstract results from searches to determine article relevance. I determined relevance looking for discussion of: neurodisability and participation, PA participation interventions, and barriers and facilitators to PA participation. I had three aims in reading the research evidence:

1. To understand the concept of participation and influences on participation for C&YP with neurodisability.
2. To understand approaches to increasing participation and community PA participation specifically, in C&YP with neurodisability.
3. To understand the state of the evidence regarding community PA participation interventions and outcomes for this group of C&YP.

1. Exercise/
2. Exercise therapy/
3. Leisure activities/
4. Sports/
5. Recreation/
6. Recreation therapy/
7. Recreational activit*.mp
8. Physical activit*.mp
9. 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8
10. Neurodisability.mp
11. Neurodevelopmental disorders/
12. Developmental disabilities/
13. Cerebral palsy/
14. “Movement disorder”.mp
15. “Nervous system disease”.p
16. “Genetic disorder”.mp
17. “Psychomotor disorder”.mp
18. 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17
19. 9 AND 18
20. Child/
21. Adolescent/
22. Child*.mp
23. Youth.mp
24. “Young people”.mp
25. “Young person”.mp
26. Teenage*.mp
27. 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26
28. 19 AND 27
29. Limit 28 to year=”2001-Current” (October 2018)
30. 21-28 limited to year 2018 (October) - Current (November 2023)

Figure 1: Keyword Combinations for Database Searches

I added Barriers AND/OR Facilitators to these keyword combinations for latter searches (example: numbered 30 in Figure 1).

In the next section, I discuss the research evidence considering the participation construct, influences on participation, participation focused healthcare practices and PA participation interventions for C&YP with neurodisability.

2.1.1. The Participation Construct

There are several challenges in addressing the topic of community PA participation. One major challenge arises from a lack of consensus and specificity in the definition of the participation construct. The ICF (WHO 2001) defines participation as a meaningful life experience, but what is meaningful for one individual and/or family, may not be meaningful for another. Furthermore, what is meaningful for one family could be related to either social, emotional, psychological or physical elements of participation, or a combination of these elements. This multi-faceted nature of participation makes it a complex construct, causing challenges for clinicians and researchers grappling with defining and studying individual or overlapping participation elements. Challenges also arise when searching for evidence, due to a range of different interventions and outcomes emerging e.g., social, emotional, cognitive, developmental, and/or physical, with many not specific to community PA participation. I therefore started my literature review by first considering evidence regarding the definition of the participation construct, and its definition in relation to childhood development. Thereby, I aimed to understand and clarify the many elements involved, to be able to distinguish more clearly and coherently those aspects that influence participation in community PA, and influence C&YP’s participation.

Several researchers and scholars have examined the participation construct and the importance of participation for childhood development with some focusing on participation in general (McConchie et al. 2006; Palisano et al. 2012; Imms et al. 2016; Imms et al. 2017), or participation in leisure activities - but these not being specific to PA leisure/recreation activities alone (Shakiko-Thomas et al. 2013), and some focusing specifically on PA leisure/recreation activities (King et al. 2003; Ross et al. 2016; Reedman et al. 2019). King et al. (2003) were some of the first researchers to conduct a literature review to provide a conceptual framework of the influences on recreational and leisure community PA participation by disabled C&YP. Their evidence showed participation influences being the child/young person, the family, and the environment. Their literature review found family influencing factors were family activity preferences/orientation, family socio-economic status and parental educational levels which positively predicted participation. Other environmental influences they found were the presence or absence of supportive relationships from others towards parents and C&YP, and the presence or absence of physical and institutional barriers. The intrinsic child/young person influencing factors determined were C&YP's perceptions of their athletic competence, their activity preferences, and their physical, cognitive, communication, emotional, behavioural and social function. These child/young person function influences give credence to taking a medical-model lens as they confirm body structure and body function elements (e.g., of cognition and physical function) are influential on participation, which is further confirmed by later evidence (Shakiko-Thomas et al. 2014). However, King et al. (2003) and Shakiko-Thomas et al. (2014) also identify socio-ecological influencing factors within their review of the evidence. Socio-ecological factors included the family and school environment. Despite evidence of these wide-ranging influences on participation, and thus community PA participation, it appears healthcare clinicians are still choosing to take a medical approach, focusing on ICF activity levels (e.g., mobility) and body structures and function (e.g., strength) to improve participation (Novak et al. 2020). This may be due to a lack of training, skill, confidence, and knowledge in management of social, psychological or ecological influencing factors. For example, socio-ecological factors have not traditionally been a focus within the physiotherapy curriculum and the current physiotherapy framework predominantly defines physiotherapists as having and applying practical motor skills to improve individuals' health and wellbeing (Chartered Society of Physiotherapy 2020).

A common theme across the evidence examining participation is acknowledgement of a growing shift towards participation within healthcare practice and research, and the use of the ICF as a guide for defining and evaluating participation (Ross et al. 2016), as well as an increasing consideration of childhood factors within the participation construct. For example, in referencing the production of the ICF-CY (WHO 2007b), and referencing Rosenbaum and Gorter (2012) position paper on childhood disability that labels the participation domain of the ICF-CY (WHO 2007b) with the F word, "Friends" and the personal factors domain with the F word, "Fun". The increasing focus on participation within paediatric clinical practice and research has demonstrated the need for informed use of participation outcome measures (Adair et al. 2015) and the importance of examining participation as an intervention, and as an outcome within clinical practice and research (Adair et al. 2018;

Kolehmainen et al. 2020). However, evidence shows there has been a lack of consensus in definitions for participation, for its measurement, and its use as an intervention, or intervention outcome (Adair et al. 2015; Imms et al. 2016; Ross et al. 2016). Additionally, evidence shows there is a lack of participation-focused healthcare and translation of participation evidence into clinical practice (Anaby et al. 2015; Kolehmainen et al. 2020). Furthermore, a recent systematic review of systematic reviews has highlighted that participation in community PA/HEPA by C&YP with neurodisability is complex, difficult to provide as an intervention, and difficult to measure as an outcome (Novak et al. 2020).

Ross et al. (2016) conducted a systematic review of evidence (2000-2016) to provide a conceptualisation of community PA participation and its measurement for clinical practice and research. Seventeen articles were reviewed with the majority (n=11) published 2014-2016; illustrating a shift towards focusing on participation over the latter review period. The systematic review showed that researchers did not commonly provide an operational definition for PA participation. Eight of the seventeen studies operationalised PA and participation as separate constructs. This operationalisation is further evidenced when examining literature I found using the search strategies previously presented (Chapter 2, Figure 1 and Table 1). The evidence found showed therapeutic interventions often delivered in the form of exercise performance programmes that measured outcomes in body structure and function and activity ICF domains (Ozmen et al. 2007; Scholtes et al. 2010; Tsai 2009; Memarmoghaddam et al. 2016; Cleary et al. 2017) rather than participation interventions e.g., recreation/leisure PA participation programmes that measure participation as an outcome (Reedman et al. 2019). Ross et al.’s (2016) review of participation evidence showed PA was often measured by frequencies, intensities and duration i.e., PA volume, while participation was measured with perceptions of involvement, inclusion and/or enjoyment. The separation of these two elements within the participation construct, as it relates to PA participation, does aid measurement and evaluation of each of these PA participation domains, but does not evaluate participation in its totality. Furthermore, there is a lack of evidence examining whether these two domains influence each other, and if so – how, and whether this influence is important to know about when aiming to increase participation and participation related health outcomes. Ross et al. (2016) further reported that the descriptive nature of the research reviewed (i.e., describing where PA occurred, what it looked like, with whom it occurred, how frequently, and what it meant to disabled C&YP), lacked translation onto a scale for health. Therefore, it was difficult to establish PA participation as a health index. A possible index for physical health was identified via measures of PA frequency and intensity, and an index for psychosocial health level via measures of social experiences, perceptions of inclusion/engagement, and enjoyment. Drawing on this evidence, Ross et al. (2016p8) provided a definition for PA participation as “experiences in physically demanding movement, sport, game, or recreational play that results in energy expenditure and perceptions of communal involvement”. They qualified the definition in three ways. Firstly, by level of PA participation i.e., frequency of attendance and intensity of physical exertion. Secondly, by quality of experience i.e., self-perceived feelings of social inclusion, enjoyment, self-efficacy, and satisfaction. Thirdly, by overall profile i.e., the extent to which the level of participation matched the expectation for a quality experience. Finding ways to measure and evaluate these three different levels/domains at the same time would be beneficial for providing a more comprehensive view and evaluation of community PA participation by C&YP with neurodisability. Ross et al (2016) state that most of the research they reviewed to provide their qualified definition of PA Participation used self-report measures of participation, which did not measure all three of their PA participation qualifiers. To distinguish the qualifiers of PA participation more specifically, Ross et al. (2016) suggested dividing PA participation into two parts: PA engagement and PA participation. They proposed PA engagement be a term used for describing PA levels i.e., frequency of attendance, and physiological measures of energy expenditure/intensity/volume of PA. They proposed PA participation be a term used for the broader concept of health experience i.e., feelings and perceptions of social inclusion, self-efficacy, satisfaction and enjoyment.

It is unclear from reading the evidence which elements of PA participation are likely to sustain or increase C&YP’s PA participation in the short, intermediate and long-term. Considering the multiple parts of the participation construct, and that of community PA participation specifically, several elements for sustaining participation spring to mind, namely, enjoyment, confidence, competence, understanding and knowledge of PA, social support (involvement of family and friends), C&YP and parental expectations, and levels of satisfaction. What is not contained in the definition and conceptual models provided are other environmental influences such as availability of PA opportunities and the choices available (i.e., availability and diversity of programmes), or the influence of service providers' knowledge, skill and ability to support participation. This appears to be a gap in the evidence regarding socio-ecological factors within conceptual models and the evidence discussed regarding the participation construct.

Due to a lack of consensus in the definition of participation, Imms et al. (2016) conducted a systematic review of participation intervention research to examine how researchers defined participation and the language they used. The systematic review suggested the need for researchers to define the participation construct carefully and to use appropriate participation measurement choices. Like Ross et al. (2016), Imms et al. (2016) also used the term involvement in their definition of participation. From their systematic review involving review of participation language, Imms et al. (2016) provided a definition of participation, which was attendance and involvement. They defined involvement as the time that C&YP spent engaging and interacting socially, physically and contextually in the situation - with the environment and the activity. Contrastingly, Ross et al. (2016) used the word involvement when referring to perceptions of communal involvement, however, used the word engagement when referring to levels of physical exertion, which Imms et al (2017) define as physical involvement. Following, their systematic review, Imms et al. (2017) went on to collate various themes they identified inherent in the participation construct into a family of Participation Related Constructs (fPRC) (Imms et al. 2017).

The fPRC includes extrinsic environment and context themes, and numerous intrinsic themes such as C&YP's preferences, sense of self and self-regulation. Additionally, the fPRC includes a theme of skills and abilities that relate to elements of activity competence, capability, capacity and performance. Engagement also plays a role in linking the individual, related constructs within participation. Imms et al. (2017) assert all these elements are part of the participation construct, influencing each other and participation. This evidence has developed a deeper understanding of the complexity of the participation construct, and its complexity for complex C&YP, such as those with neurodisability. Imms et al. (2017) place activity competence, capacity, and performance into the fPRC (Imms et al. 2017), which are concepts that also relate to motor competence and physical performance, which can affect the ability to physically participate in PA (Caspersen et al. 1985; Cairney et al. 2019). However, Imms et al. (2016) definition of participation and the elements of the fPRC (Imms et al. 2017) are not specific to PA participation alone and using similar terms to Ross et al.'s (2016) definition for PA participation, while having slightly different associated meanings, could cause confusion for clinicians and researchers.

Overall, Imms et al. (2017 p18) define participation as attendance and involvement, and attendance as “being there”. This provides a definition that aids in determining appropriate measures for participation but needs to be combined with Ross et al. (2016) definition to provide specificity to community PA participation. Based on Imms et al. (2017) and Ross et al. (2016) definitions, measures of PA participation could include measuring attendance at community PA opportunities, frequency of attendance, and the range and diversity of PA opportunities/choices a child/young person attended. Attendance does not however provide a full assessment of participation, as C&YP could attend a number and variety of PA opportunities and not be involved in them. However, attending would be a requirement for involvement (Imms et al. 2017; Adair et al. 2018). To provide a full measure of participation the intensity of physical involvement needs to be additionally measured e.g., energy expenditure during PA, which is defined as physical involvement by Imms et al. (2016) and engagement by Ross et al. (2016). Imms et al. (2017) describe involvement as time that C&YP spend engaging and interacting socially, physically and contextually in the situation - with the environment and the activity. Ridley et al. (2000), initial researchers examining children's engagement (in childcare environments), described engagement as the amount of time children spent interacting with their environment in a contextually meaningful way. Imms et al. (2017p18) describes involvement including the concepts of engagement, but additionally concepts of motivation, persistence, social connection and level of effect. These can only happen during attendance. Thus, involvement and attendance are inter-twined. Adair et al. (2018) who conducted a systematic review of interventions aimed at improving participation outcomes assert the inter-twined concepts of attendance and involvement decreases standardisation in measuring these participation variables (Adair et al. 2018).

Challenges in measuring participation are further increased by the fact that involvement could be different at different times of an activity and when engaging within different contexts of the activity. Further, involvement could also vary between C&YP who are attending the same activity. Furthermore, measurement of involvement could differ depending on who is measuring involvement e.g., self-report (C&YP), parent report, and/or researcher report (proxy reports) (Imms et al. 2016). Thus, measuring participation is complex and can lack consistency within research evidence (Imms et al. 2016; Imms et al. 2017; Adair et al. 2018). Additionally, evidence shows it is currently not usual practice to measure participation within paediatric clinical practice, and there is clinician behavioural, and organisational/institutional barriers to participation-focused therapy that targets participation interventions and outcomes (Shikako-Thomas et al. 2014; Anaby et al. 2015; Adair et al. 2018; Kolehmainen et al. 2020).

In summary, participation is a complex construct defined as attendance and involvement but includes the process of engagement that links involvement and attendance, and other inter-related family of constructs, which are influential on participation (Imms et al. 2016; Imms et al. 2017). Influential participation related constructs include motivation, persistence, social connection/relatedness and level of effect e.g., mood and emotion regulation. These elements are likely to affect community PA participation as well, which additionally includes engagement in physically demanding movement. Participation additionally includes contextual physical and social environmental influences (WHO 2001; Rosenbaum and Gorter 2012; Imms et al. 2017) that are likely to affect the ability to access physically demanding movement, especially in the presence of physical and activity competence restrictions. Levels of physically demanding movement are also likely to vary at different stages of PA participation and with different types of PA participation, which affects the levels of energy expenditure, which can also be influenced by activity competence, capacity and performance (Ross et al. 2016; Imms et al. 2017; Cairney et al 2019). Considering these different aspects of the participation construct and PA participation, shows both constructs have the same influencing features, but that PA participation has additional specificity related to energy expenditure that can be influenced by activity type, activity competence, physical capacity and performance. Furthermore, the evidence shows the various features and elements of participation interact and influence each other, and it is difficult to determine which are most influential and have priority for providing effective interventions. It may be that an individualised approach including examination of all these elements to determine which factors apply most to each child/young person and family, is the way forward. Therefore, if wishing to design and provide a shared decision-making aid to facilitate participation, it would need to contain consideration of these different elements and be used collaboratively with C&YP and families, and involve consideration of other community stakeholders e.g., providers, to effectively help increase C&YP's participation. I consider the influences on participation in more detail in the following sub-section.

2.1.2. Barriers and Facilitators to Participation

Several researchers have examined the factors that influence participation for disabled C&YP (King et al. 2003; Lawlor et al. 2006; Anaby et al. 2013; Hodge and Runswick Cole 2013; Shikako-Thomas et al. 2013; Martin Ginis et al. 2016; Shields and Synott 2016). As previously highlighted, King et al. (2003) were some of the first researchers to provide a conceptual model of influences which listed influential factors as the child/young person, the family, and the environment, after conducting a review of four bodies of literature. The literature evidence included rehabilitation literature on participation by C&YP and adults, psychological literature on risk and resilience in C&YP facing adversity, recreation literature on determinants of recreation and leisure activities, and general literature on factors influencing PA and exercise. Review of the literature showed family influences included: i) Absence of financial and time constraints of caring for a disabled child ii) better family socio-economic situation iii) supportive home environment, and iv) strong family interest in recreational/leisure activities. Environmental influences included: i) absence/presence of physical and institutional environmental barriers, ii) absence/presence of supportive relationships for the child/young person, iii) absence/presence of supportive relationships for the parents. The model linked all these factors to show that an absence of cost/financial restrictions, no physical environmental restrictions, conveniently located accessible facilities, alongside positive community (institutional) attitudes towards inclusion, increased participation in community recreation and leisure activities. Furthermore, supportive relationships between C&YP and parents, friends, classmates and other adults, provided an environment conducive to participation. Parents' perceptions of support (either informal or formal support) and parents having supportive relationships, additionally facilitated C&YP's participation. The model additionally showed that greater participation (intensity/frequency) was associated with more supportive physical and institutional environments.

Subsequent studies lend support for the family influential factors in this model when showing that families can face large financial burdens and extra time constraints in caring for a disabled child, which makes participation in PA recreation and leisure activities difficult (Tidswell 2006a; Tidswell 2006b; Winckler 2009; Colver et al 2011). Shikako-Thomas et al. (2008) who conducted a systematic review on determinants of participation in leisure activities by C&YP with Cerebral Palsy (CP) also determined intrinsic C&YP factors, family factors, and extrinsic environmental factors as influential. Following this systematic review, these researchers estimated the potential of the identified factors to influence participation and proposed a conceptual model of determinants (Shikako-Thomas et al. 2013). A strength of the research was the large sample of C&YP with CP (n=187) who completed a range of valid and reliable standardised assessments and questionnaires on participation, along with their parents as proxies, where necessary. Results identified child/young person intrinsic factors, and family and environmental extrinsic factors as influential. Intrinsic C&YP' characteristics influencing participation were the same as those proposed by King et al. (2003), confirming the evidence, but there was an additional influential intrinsic characteristic identified. This was persistence, and pleasure in persisting to master challenging activities. Majnemer et al. (2008) have also shown that mastery motivation (persistence in problem solving) is associated with more participation, and increased pleasure in participation, in C&YP with neurodisability. Shakiko-Thomas et al. (2013) also showed family preference for PA participation was associated with C&YP's intensity (frequency) of PA participation. Thus, C&YP who participated in their preferred PA and the preferred PA of their family had high attendance. However, results showed that many C&YP did not have opportunity to participate in their preferred PA.

In contrast to the findings of King et al. (2003), Shikako-Thomas et al. (2013) found no relationship between the number of physical environmental barriers and the amount of participation in leisure activities. However, several other researchers have shown evidence that physical environmental barriers are strong hindrances to community participation for disabled C&YP (Colver et al. 2011; Anaby et al 2013; Hodge and Runswick Cole 2013; Shields and Synott 2014; Reid 2016, Shields and Synott 2016). Environmental influences on participation include the physical environment e.g., stairs, and the social environment e.g., attitudes, rules, and regulations.

The ICF (WHO 2001) environmental domain has five components: Natural Environment (e.g., landforms); Products and Technology (e.g., building accessibility); Support and Relationships (e.g., parental support); Attitudes (e.g., perceptions of disability); and Services, Systems and Policies (e.g., community programmes). Shields and Synnott (2016) demonstrated environmental, exclusionary attitudes towards disabled C&YP within communities, including from providers and families involving typically developing C&YP, were strong barriers to participation, while typically developing peer involvement and acceptance were strong motivators of community PA participation. Ableism is a form of social prejudice that sees disabled C&YP as different and not able to fit into what is “normal”, usual, “mainstream” participation (Campbell 2008; 2009; Hodge and Runswick-Cole 2013). Verscheuren et al. (2012) showed C&YP, and parents encountered negative attitudes towards disability inclusion within community environments, low expectations of C&YP’s abilities, and providers were unable to accommodate sport/PA to C&YP’s abilities. These findings indicate a potential lack of provider attunement to C&YP and insufficient disability inclusion knowledge and skill. Lack of attunement is present when providers expect C&YP/families to fit into services rather than providers actively seeking to match their services to what is possible and meaningful for C&YP/families, and/or where providers fail to recognise the legitimacy of C&YP and families’ voices (Carnevale 2009; Carnevale et al. 2017; Carnevale et al. 2020).

Besides social attitudinal environmental barriers, physical environmental barriers also play a major role in hindering C&YP’s participation. Anaby et al. (2013) did a scoping review on the effect of the environment on disabled C&YP’s participation and presented their review findings organised into the five ICF environmental components. Their evidence showed the most common environmental barrier to participation for disabled C&YP was the physical environment, particularly for C&YP with physical disabilities. Physical environmental barriers included lack of access to buildings, building structures, lack of ramps, lifts, lack of accessible parking spaces for wheelchairs, and lack of accessible public transport. Physical environmental barriers negatively correlated with participation in after-school activities for disabled C&YP.

Colver et al. (2011) were some of the first researchers to examine and compare environmental access for C&YP with neurodisability (CP) across Europe. They compared provisions across eight European regions - Denmark, France, Germany, Ireland, Italy, Sweden and UK (England and Northern Ireland) via work of the SPARCLE group. Researchers in the SPARCLE project (Colver and SPARCLE Group 2006) visited 818 C&YP with CP, randomly selected from population registers, and administered the European Child Environment Questionnaire (ECEQ). The ECEQ measures parents' perceptions of availability of the required environment including the physical, social and attitudinal environment in home, school and other wider community settings (Colver et al. 2006; Dickinson and Colver 2011). Study results showed C&YP with less walking ability had less access to the environments they needed, including physical, transport and social support. They also faced increased attitudinal barriers from family and friends. There was significant difference in access ($p \leq 0,0001$) between European regions. Families in Denmark reported having most required environmental access needs met and best Quality of Life (QoL). The differences for Denmark compared to the other European countries were Denmark's public school system of after school clubs, which are attended by most C&YP up to the age of 12 years, whether disabled or not. Additionally, Denmark has provision of an established adapted vehicle transport system to take C&YP to after school clubs and other social activities. This evidence suggests having adapted vehicle transport providing access to participation programmes reduces environmental barriers and increases participation and QoL.

During the SPARCLE project, Tidswell (2006a; 2006b) collated evidence on environmental contexts affecting the lives of C&YP for seven of the nations involved in the SPARCLE research project. The UK information includes Northern Ireland and England but not Scotland or Wales. Tidswell (2006b) reported that in the UK the relative poverty of disabled families and the extra costs of disability, makes accessing leisure and recreation activities difficult, particularly if living in rural areas. Additionally, there is a lack of access to clubs and sports activities, more so for those

C&YP with mobility impairments and self-care impairments, due to lack of suitably adapted facilities. Colver et al (2011), Hodge and Runswick Cole (2013), Reid (2016), and the National Assembly for Wales (2019) have reported on the state of PA access for disabled C&YP in the UK. Access is often only possible if a parent remains present with their disabled child in a PA opportunity/programme. Disabled C&YP can also experience removal from PE in mainstream schools, having specific PA participation (usually exercises) separate from typically developing peers; particularly those C&YP with physical disabilities.

The family is part of the child/young person’s environment and influential on their participation (King et al. 2003; McConchie et al. 2006; Rosenbaum and Gorter 2012; Shikako-Thomas et al. 2013). Families influence the lives of C&YP and their participation; and C&YP influence the lives of family members and families’ participation (Simeonsson et al. 2003; McConchie et al. 2006; Rosenbaum and Gorter 2012). Rosenbaum and Gorter (2012) support this position of the family as environment, when labelling the ICF-CY (WHO 2007a) environment domain with the F word, “Family”. The fPRC (Imms et al. 2017) shows families as influential on participation, thus important to consider when focusing on community PA participation for C&YP with neurodisability.

Imms et al. (2017) have moved the evidence forward by providing the fPRC showing multiple influences on participation. However, the fPRC does not provide any indication of weighting for these different inter-related and overlapping constructs identified within it, or weighting relevant to different community contexts, which limits use by researchers and clinicians to determine priorities to focus on when attempting to increase participation. The fPRC includes consideration of how current and past participation influences child/young person intrinsic factors, which in-turn influences their future participation. Thus, showing participation is not a one-off event, but a series of events that build on each other, and connect to each other. Each participation event is influential, making the need to prevent negative participation experiences for C&YP and families important, to ensure future/continued participation.

Combining the evidence reviewed, suggests that absence of financial restrictions, no physical environmental restrictions, and conveniently located accessible facilities/opportunities; as well as positive community attitudes towards inclusion, and supportive relationships for C&YP and parents, will increase support for participation and enable C&YP's participation. Healthcare professionals could play a role in providing supportive relationships to parents and C&YP as the evidence suggest this is beneficial to increasing participation. Support could assist families' persistence in PA, C&YP's activity competence, signpost to suitable community PA opportunities and choices, provide information to community PA providers that could assist C&YP's inclusion, and aid in addressing environmental adaptations to increase and sustain community PA participation. However, this would require healthcare professionals including a participation focus within their clinical practice, integrating their clinical practices with community PA participation, and with the different elements/domains involved, acknowledging the importance of doing this, and acknowledging the important role they can play. Providing these types of supportive relationships has potential to increase C&YP's attendance, frequency/intensity and diversity in participation (especially if C&YP participate in their preferred PA) which could additionally facilitate C&YP to achieve health recommended MVPA intensities i.e., HEPA.

2.1.3. Increasing Participation

Several researchers have conducted literature reviews and systematic reviews of evidence to examine evidence on participation and healthcare approaches to increasing community participation (Palisano et al. 2012; Shikako-Thomas et al. 2014; Adair et al. 2015; Reedman et al. 2017; Reedman et al. 2019). These studies synthesise evidence regarding effectiveness at improving participation outcomes and some propose steps to increasing participation, which usually start with setting participation goals collaboratively with C&YP and parents. Collaborative goal setting is asserted as important to ascertain C&YP and families preferred choices for participation, which involves identifying C&YP and families' interests and preferences, to provide family centred care (Kuo et al. 2011), and to increase C&YP and parents' motivation for participation, their self-determination, and enable their autonomous participation in their preferred activities.

The process of achieving autonomy in PA is part of the process of attaining physical literacy. A concept defined as valuing and taking responsibility for PA participation to improve/maintain health, which involves knowing, understanding and valuing the importance of PA participation for health (Whitehead 2010, 2019; Liu and Chen 2020; Pushkarenko et al. 2021a; Pushkarenko et al. 2021b; Pushkarenko et al. 2023). Physical literacy also involves having the physical competence, confidence and motivation to take responsibility for PA participation (Whitehead 2010; Whitehead 2019). Working through a process of determining C&YP's preferred PA and their goals for PA can be a starting point towards achieving physical literacy (Paponetti et al. 2023). Brown et al. (2020) in a nine-year longitudinal study showed that high levels of physical literacy in C&YP is associated with increased PA participation and influences C&YP's PA participation trajectories from a young age. Starting PA participation at a young age and sustaining it into adulthood is recommended to gain health benefits from PA (WHO 2007b; WHO 2020).

Healthcare research has not traditionally examined collaborative goal setting combined with C&YP achieving physical literacy. C&YP with neurodisability can have reduced physical literacy, i.e., reduced autonomy in PA participation, and their potential reduction in motor competence and activity limitations predict lower PA participation levels and less ability to participate in their preferred PA (Bult et al. 2011; Bult et al. 2014). Suboptimal motor functions also correlate with decreased frequency and diversity of PA participation (Kanagasabai et al. 2014). Motor competence is therefore important to consider and is part of the physical literacy construct (Cairney et al. 2019) and part of different conceptual models of participation (King et al. 2003; Shikako et al. 2013; Imms et al. 2016; Imms et al. 2017). Motor competence is something healthcare professionals focus on in their interventions however without demonstrating significant increases in community PA participation (Adair et al. 2015; Reedman et al. 2017). Probably, due to PA participation and physical literacy being multi-factorial constructs requiring consideration of multiple components, not just motor competence. Therefore, participation-focused approaches to increasing PA participation advocate consideration of multiple influences on PA participation, and not only motor competence and physical performance (Murphy and Carbone 2008; Palisano et al. 2012; Shikako-Thomas et al. 2014; Reedman et al. 2019; Paponetti et al. 2023).

Sport and education professionals more often than healthcare professionals use enhancement of physical literacy to increase community PA participation (Paponetti et al. 2023). Paponetti et al. (2023) showed physiotherapists working with obese

C&YP did however consider physical literacy when attempting to increase C&YP's PA participation. The physical literacy enhancement steps these physiotherapists employed involved asking C&YP about their PA goals, motivators and interests, asking C&YP about their current and past PA experiences, any associated feelings, and their perceived barriers to participation. Their physical literacy enhancement processes also involved agreeing collaborative PA goals and assisting and promoting autonomy in achieving the goals. Additionally, they included providing assistive resources to aid autonomous PA participation, as well as advice on the benefits of regular PA participation, and advising on opportunities available within communities to meet C&YP's preferred PA choices. The evidence suggests using a physical literacy approach increases confidence in physiotherapists and better equips them to address barriers and enable PA participation by C&YP.

Reedman et al. (2019) conducted a randomised controlled trial (RCT) to test the efficacy of a community-based participation-focused PA intervention aimed at increasing community PA in C&YP with CP, which included determining C&YP's preferred PA and mirrored steps involved when using a physical literacy approach (Cairney et al. 2019; Paponetti et al. 2023). The participation-focused therapy involved collaborative goal setting, was family centred, context specific to the child/young person and individualised i.e., tailored for the child/young person and included modifying intrinsic and extrinsic participation factors, as appropriate to the child. The intervention aimed to strengthen intrinsic influences on participation and reduce environmental, contextual and PA skills barriers to participation. Reedman et al. (2019) are the first researchers who have provided such a comprehensive PA participation intervention within community settings that includes reducing environmental barriers to participation, skills practice in real life community settings and increasing C&YP/families' empowerment and autonomy in PA participation. Reedman et al. (2019) employed a range of valid and reliable outcome measures to assess multiple participation related constructs (Imms et al. 2017). Results, after the 8 weeks intervention, demonstrated that the intervention group had significantly greater improvements than the control group on perceived performance of PA goals ($p<0.001$), satisfaction ($p=0.014$) and confidence ($p<0.001$), which was retained at 16 weeks (8-week follow up period). There was however no significant difference in habitual MVPA participation at 8 weeks ($p=0.874$), light PA ($p=0.523$), and sedentary time (p=0.626), with similar results at 16 weeks. However, the study was powered to measure goal performance changes and not habitual PA participation changes. Additionally, there was missing accelerometry data, which was the outcome used to measure habitual MVPA participation. As this study is, the first study of its kind, there remains a gap in the evidence regarding increasing community PA participation (including in MVPA) by using a participation-focused community PA intervention that is individualised, goal directed, collaborative, context specific, and includes modifying environmental barriers.

The participation evidence reviewed demonstrates there is a lack of knowledge, theory application, and practical skill and consistency in practice regarding setting collaborative goals with C&YP and families to increase their community PA participation (Darrah et al. 2012; Nijhuis et al. 2012; Pritchard-Wiart and Phelan 2018). Pritchard-Wiart and Phelan (2018) scoped the literature regarding goal setting in paediatric practice and found the role of C&YP in the process not well described and C&YP often left out of the goal setting process. Additionally, there was a lack of reference by researchers and clinicians to theoretical frameworks for goal setting and lack of use of behaviour change models when performing participation goal setting with C&YP having motor disabilities. Using theory in practice and translating theory into practice is difficult and sparsely evidenced when aiming to facilitate participation-focused therapy, and increased community PA participation. Anaby et al. (2015) examined 14 clinicians’ participation-focused practices and influences on their practice, using six participation-focused practice, learning sessions. These clinicians reported barriers to participation-focused practice were organisational values/cultures, every-day practice structures, knowledge requirements e.g., behavioural change knowledge requirements, insufficient time, resources, and funding. Anaby et al. (2015) demonstrated that six participation-focused, knowledge translation, learning sessions, had a positive influence on clinicians’ knowledge for practice, their reflective practice, and their readiness to integrate a participation-focused approach into their clinical practice. However, long-term uptake of a participation-focused approach remained uncertain, particularly in the presence of participants’ identified barriers.

The conceptual models put forward regarding the participation construct and its influences do not include consideration of the need to support clinicians and community service providers in their support of C&YP and families, which is a gap in the models and discussion of their influencing constructs. Support for clinicians appears to include the need for knowledge, training, reflective practice skills, behavioural supports, time, institutional/organisational management and leadership support, and funding (Anaby et al. 2015; Kolehmainen et al. 2020). Palisano et al. (2012) following review of participation evidence to determine a model for increasing participation, suggested healthcare therapists get out into real life participation situations. Thereby, to aid collaborative goal setting with families, find solutions to participation challenges, aid C&YP's practice of PA skills within real life situations, support C&YP in learning new activities, developing skills, and empowering families to be advocates for disability inclusion. Performing PA with C&YP and families in real life situations can be difficult however for healthcare therapists working in the National Health Service (NHS) due to numerous resource and organisational barriers (Anaby et al. 2015; Kolehmainen et al. 2020).

Kolehmainen et al. (2020) audited participation-focused therapeutic healthcare practices and services using an audit tool, the Method for using Audit and feedback for Participation implementation (MAPi). MAPi provided an audit template to audit 25 clinicians' (occupational therapists, physiotherapists, and speech and language therapists) case notes regarding their participation-focused service behaviours, when managing parents and C&YP with neurodisability. MAPi captured three participation-focused behaviours i) Targeting participation outcomes through interventions ii) Collaborative identification and decision-making regarding participation outcomes (collaboration with C&YP and/or parents), iii) Measurement of participation outcomes. The researchers used the Theoretical Domains Framework Questionnaire (TDFQ) to identify barriers to clinicians' participation-focused service behaviours. The barriers identified were clinician's lack of skills in practical application of participation-focused services, low positive social influences on participation-focused behaviours (e.g., organisational/institutional influences), and limited behavioural regulation to achieve the behaviours. Audit results showed only 30.3% of 122 clinicians' targeted participation within their practice/services, 13.1% involved the child/parent, and 19.7% measured participation outcomes/progress. Findings confirm a lack of participation collaborative goal setting with C&YP and families, interventions targeting participation outcomes, and participation measurement and evaluation.

Another way to approach increasing community PA participation is via signposting community opportunities and connecting C&YP/families to community opportunities (Chin and Reid 2015; Paponetti et al. 2023), which is part of social prescribing (Husk et al. 2019). Social prescribing involves connecting people to community services, groups and opportunities to support their health and wellbeing, and is a recognised part of expanding healthcare practitioners' options to provide individualised care (Husk et al. 2019). Murphy and Carbon (2008) however assert healthcare providers need to ensure that the community PA participation options they connect disabled C&YP to are appropriate for them, and take into account potential influences of pathology, thereby to ensure safe and appropriate signposting/social prescribing. Jaarsma et al. (2015) have shown that integrating C&YP into community sports opportunities via healthcare practice has its difficulties, as perceptions of barriers differ between C&YP, parents and healthcare professionals. Furthermore, there is a lack of evidence on effectiveness of social prescribing for health promotion (Husk et al. 2019) but there are high expectations for its effectiveness (Welsh Government 2023c).

2.1.4. Physical Activity Participation Interventions

As detailed in my introduction, when I started my PhD journey, I aimed to conduct a systematic review examining community PA participation interventions that included peer interaction (peer communal involvement) and involved C&YP with neurodisability. The aim was to find out whether community PA participation was being used as an intervention or health outcome, and whether it included consideration of childhood factors such as fun/enjoyment and friendships. I aimed to examine RCT's, due to RCT's being a rigorous form of evidence. Ultimately, I did not include the systematic review in the thesis as systematic reviews involve following specific steps that require more than one research reviewer to be considered high quality, and I did not have the additional resources for several researchers to review literature. However, in the process of searching the literature for RCT's by following the review search strategy (Table 1, Figure 1) and its inclusion criteria of participation involving communal involvement (peer interaction), I found 10 studies that met review inclusion criteria. Interventions across the ten studies included hippotherapy (Bass et al. 2009), soccer (Ozer et al. 2012), swimming (Declerck et al. 2016), table tennis (Tsai 2009), and group exercise programmes aimed at improving strength (Scholtes et al. 2010) and aerobic fitness (Ozmen et al. 2007; Hoza et al. 2015; Bustamante et al. 2016; Memarmoghaddam et al. 2016; Cleary et al. 2017). Stakeholders delivering the interventions included researchers, PE specialist teachers, healthcare professionals, sport coaches, and healthcare and sport science students. Most interventions were delivered in schools, a mixture of special and mainstream schools, with the remainder delivered within community groups and one in a university hall. The diversity of the interventions, contexts and stakeholders demonstrated the numerous sectors, individuals and contexts involved in community PA participation, highlighting the possibility of a disparate situation with conflicting priorities and approaches to supporting and/or increasing community PA participation. Only 2 of the 10 studies reported that peer interaction/communal involvement, was the primary goal of their intervention (Ozer et al. 2012; Bass et al. 2009). All studies lacked comprehensive and specific details regarding how interventions were applied/delivered, which reduced studies' repeatability, transparency, confirmability and trustworthiness.

Considering the evidence found in these database searches, I found no studies that showed an overt understanding of the multi-faceted nature of the participation construct or detailed specifically which aspects of the participation construct the intervention was addressing (e.g., intensity of physical exertion, levels of communal involvement, participants' expectations, and/or the quality of the experience). This lack of clarity could indicate that researchers are not considering the multi-faceted nature of the participation construct when attempting to improve PA participation. Overall, I found the evidence lacked detail and specificity regarding interventions' content and how the content was delivered. The lack of detail made it difficult to draw conclusions regarding what the active ingredients of the PA participation interventions were that made a difference to specific participation outcomes. With further literature searching, I did find one RCT that did provide specific details on the contextual nature of their community PA participation intervention - a RCT by Reedman et al. (2019), which I have previously discussed. There are high risks of bias in RCT's for this topic area, as the intervention cannot be blinded to participants, which creates performance bias, and the heterogeneous nature of neurodisability makes controlling random sampling allocation to achieve similar groups at baseline, difficult (Higgins et al. 2011). However, RCT's are high-level research evidence

(Higgins et al. 2011). I, therefore, searched for RCT’s, especially for ones involving community PA interventions involving typically developing peer social interactions. Evidence shows C&YP with neurodisability have fewer opportunities for friendship formations with typically developing peers in community participation settings (Kang et al. 2010). As already detailed, I found one study (Ozer et al. 2012) that explored friendship formations as part of a community PA intervention which showed positive effect (previously reported p19). The sample only included male participants, which suggests a potential male gender bias in some community sport participation.

Systematic reviews can provide high-level evidence on participation interventions. A systematic review of systematic reviews by Novak et al. (2013) and updated by Novak et al. (2020), examined the state of evidence for C&YP with CP. These systematic reviews used Grading of Recommendations, Assessment, Development and Evaluation ([GRADE] 2004) and an Evidence Alert Traffic Light System (Novak and McIntyre 2010) to evaluate the state of the evidence for C&YP with CP. The reviews showed that most interventions for CP continue to use performance interventions and outcomes with a limited focus on participation interventions and outcomes. However, the updated review by Novak et al. (2020) did show a shift towards interventions targeting participation outcomes, and/or targeting barriers to participation. The research cited to demonstrate a shift towards participation focus was the work of Palisano et al. (2012) and Reedman et al. (2017). Novak et al. (2020) did note a change in their updated evidence from the expectation that interventions not focused on the participation level would result in changes to participation. However, there was no mention of evidence using a reversal approach, i.e., focusing on participation with the possibility of gaining improvements in activity and body structure and function, and activity.

Palisano et al. (2012) highlights the possibility of improving body structures and functions, and activity, by focusing on participation. In a previous research project, there was evidence of this reversal effect in C&YP with CP when these C&YP participated in a six-week community adapted cycling programme (Visser et al. 2012; Visser et al. 2014; Pickering et al. 2015). Participation resulted in significant quadriceps strength changes within the cycling group (Right: p=0.018; Left: p=0.021) while the non-cycling control group had a small decrease in strength (not significant) over the same period (Visser et al. 2012; Visser et al. 2014). Strength increases in the cycling group were not significant compared to the control group. However, trends in strength increases indicated this possibility with a larger sample size and longer intervention duration.

Novak et al. (2020) review of reviews for PA interventions showed only Reedman et al. (2017) reported on participation outcomes. Reedman et al. (2017) reviewed evidence on the effectiveness of therapy and behaviour change interventions at increasing leisure time (community) PA participation. The evidence reviewed showed interventions for increasing PA were usually not goal-directed or participation focused. Additionally, skills-based interventions that focused on activity limitations and body structures and functions alone, were not able to increase habitual PA participation. Designing PA interventions that result in increases in regular, habitual PA, and regular MVPA is complex; especially for C&YP with complex needs, and especially for those C&YP with complex needs who have severe mobility limitations (Reedman et al. 2017; Novak et al. 2020). C&YP with CP at levels III - V on the Gross Motor Function Classification Scale (GMFCS) fit this description (Palisano et al. 1997). Palisano et al. (2011) have shown that C&YP with CP at GMFCS levels III - V participate in less PA than those C&YP at GMFCS Levels I and II and have less participation in moderate and vigorous intensity PA. Indicating a need to find ways to enable HEPA specifically for this population group to target C&YP in most need.

The barriers and facilitators to community PA participation for C&YP with neurodisability and their families have been studied (Hemmingson and Borrell 2002; King et al. 2003; Rimmer et al. 2004; Shields et al. 2012; Verscheuren et al. 2012; Shikako-Thomas et al. 2013; Jaarsma et al. 2015; Shields and Synott 2016; van Engelen et al. 2021). There is consistency in the evidence findings however barriers remain consistently most discussed compared to facilitators. Barriers usually fall into three categories, namely - C&YP intrinsic factors, family environmental factors, and other extrinsic environmental factors. There appears to be an interaction/inter-play of the barriers and facilitators that is socio-ecological in nature, which is not analysed or discussed within the literature. While consistent focus on the barriers hinders building on strengths (facilitators) and evidence tends to list barriers and facilitators without testing solutions (Martin Ginis et al. 2016). Martin Ginis et al. (2016) proposes that rather than producing more evidence on barriers and facilitators researchers should use the evidence to select, design, test and implement strategies to increase community PA, using a socio-ecological approach. They report a lack of synthesis of the information in a way that is useful to do this and propose using a socio-ecological approach to do so, because behaviour results from multiple influences on the personal, social and environmental levels. Martin Ginis et al. (2016) therefore provided synthesis of the evidence into five socio-ecological levels, namely - intrapersonal, interpersonal, institutional, community and policy. They propose strategies should focus on multiple levels and include collaboration across levels. At the intrapersonal level, they suggest strategies should focus on reducing negative emotions and perceptions. At the interpersonal, institutional and community levels, focus should be on improving negative societal attitudes, enhancing practitioner knowledge, increasing collaboration to provide information and other supports. At the institutional, community and policy levels, interventions should reduce transportation and financial cost barriers. These researchers appear the first to propose such a way forward with Anaby et al. (2018) and Reedman et al. (2019) proposing a similar way forward by establishing that modifying environmental barriers (ecological influences) can increase PA participation.

GAPPA (WHO 2018) has provided four key action areas using a socio-ecological framework to increase community PA participation. Policy action points include promotion of the benefits of PA, and provision of information and publicity. Additionally, provision of programmes across multiple settings, especially programmes for the least active and within schools for C&YP. Furthermore, policy actions include integration of PA into healthcare services, and increase of advocacy, data integration, financial mechanisms, and improved environmental access. There is lack of evidence integration on interventions for C&YP with neurodisability within these policy action areas, using a socio-ecological approach. Reedman et al. (2019) is the first study providing a participation intervention integrating multiple socio-ecological levels in an individualised, collaborative, contextual way. Anaby et al (2018) have also recently proposed an ecological approach for C&YP with neurodisability, i.e., modifying elements of the environment (e.g., social, attitudinal, access to resources/information) to improve activity performance (not necessarily however in PA).

Another way forward recently proposed within literature evidence is the use of mentorship for C&YP in community PA participation. Shields et al. (2019) have recently explored using a community mentorship programme that provides mentors to exercise with disabled C&YP in community gyms. These researchers tested feasibility of such an approach and found it feasible (Shields et al. 2019). Following this, they tested up-scale of the approach to more community settings and found this possible (Shields et al. 2021). The programme (FitSkills) paired a disabled young person with a physiotherapy student and the pair exercised together in a local community gym. The programme required risk analysis for C&YP's participation and supports for the mentor, as well as additional screening for more complex disabled C&YP. Additional screening involved communication with medical professionals and parents to attain additional information. There was some difficulty in upscaling FitSkills in some community places/spaces with difficulties in gaining access to new sites. There is lack of discussion on the role of the community gym providers and personnel within this evidence, and discussions on access challenges involving community providers. This is a common gap in evidence involving community PA participation with disabled C&YP (Jaarsma et al. 2015; Martin Ginis et al. 2016). FitSkills however showed positive benefits in increasing social connectedness in disabled C&YP and normalising disability (reducing ableism) in mentors (Shields et al. 2021; Shields et al. 2024). Several families reported ongoing autonomous participation, but these reports also included evidence of the need for ongoing professional support for modifications to participation, and some families employing mentors following participation in the research. Not all families will have such resources and the evidence of taking these steps provides inconclusive evidence on the mentorship programme achieving physical literacy in families (Cairney et al. 2019).

2.2. Summary

There are challenges in focusing on participation as an intervention and/or outcome for C&YP with complex needs. Community PA participation is a complex construct having social, physical, psychological and environmental components. This can cause challenges in determining whether a child/young person is participating (e.g., their involvement), and the extent to which they are participating (e.g., their physical exertion). There is growing understanding regarding the participation construct and its component parts, however, little of the evidence underpinning this growing understanding directs healthcare workers to specific priorities for increasing participation. Based on the evidence reviewed, it is likely that an individualised approach is needed to determine which aspects of the participation construct, and specifically which elements in relation to PA participation, need to be addressed to support and increase participation by C&YP with neurodisability. Key factors that appear important from the evidence reviewed include supporting C&YP and families to persist in PA participation and addressing environmental barriers – both physical and social. The role of service providers, including healthcare service providers, is overlooked in the evidence examining participation and the evidence providing underpinning conceptual models for participation. This neglect of the role of providers within communities continues a situation where it is difficult to integrate providers from different sectors to facilitate disability inclusion and it is difficult to make community PA participation a priority within healthcare. There is little evidence regarding how providers can be integrated with community PA participation to support C&YP's participation, or how providers can be integrated with each other to support each other in their facilitation of C&YP's participation. Yet policy and policy actions call for a co-ordinated approach (WHO 2018). The policy and evidence reviewed highlights a need to address the problem of decreased community PA participation by C&YP with neurodisability. There is evidence on facilitators and barriers to participation with greater focus on barriers than on facilitators. Evidence on effective ways to strengthen facilitators and reduce barriers to increase support and community PA participation are only just emerging, with sparse evidence available on suitable ways forward. Often C&YP and families are the focus, which is appropriate, however the socio-ecological complexity of the situation, and complexity of C&YP and families' situations, suggest the need to include wider considerations, and address the multiple socio-ecological levels involved, to improve support for participation, and increase community PA participation. This thesis therefore aims to provide a SA of community PA participation to gain in-depth understanding of the situation and identify appropriate ways forward to increase support for participation. Thereby, to increase community PA participation by C&YP with neurodisability.

Chapter 3. Methodology and Methods

The policy and literature reviewed indicates community PA participation by C&YP with neurodisability is complex, involving many socio-ecological influences (Martin Ginis et al. 2016). I therefore examined a variety of research methodologies and research methods having a systems-based ecological approach before deciding on using SA (Clarke 2005; Clarke et al. 2018) and interviews. In this chapter, I examine SA and its foundations. I show its strengths and weaknesses, and appropriateness, for examining the situation central to this thesis.

3.1. Situational Analysis

SA uses a grounded theory (GT) framework (Glaser and Strauss 1967) for data generation and analysis. There are debates and lack of consensus within GT however regarding application of its framework, especially in relation to the role of the researcher in generating and analysing data. Debates involve the potential of the researcher to reduce study quality when generating and analysing data and introduce bias into study findings. I discuss these tensions later in this chapter (p65). SA includes three ecological analytic cartographic/mapping tools as part of its methods. The analytic mapping tools include mapping all elements within situations using situational mapping and exploring their relations, using relational analysis. Additionally, cartography includes mapping social worlds and arenas, and mapping positions on matters of concern. Thereby, Clarke et al. (2018) assert SA provides thick situational analytics to clearly, map the landscape of social situations, including multiple perspectives and consideration of complexity.

SA draws on numerous social theories and philosophies to provide justification as a combined methodology and method. The theories include symbolic interactionism (SI) theory (Blumer 1969), social worlds/arenas theories (Strauss et al. 1964; Strauss 1978), influences of discourses (Foucault 1972), and post-modern actor-network theory (ANT) (Latour 1987; 2005). The inclusion of numerous theories provides opportunity to examine a situation from multiple perspectives, showing its complexity, but can simultaneously hinder focus and create confusion for researchers not familiar with the different theories. Clarke (2005) and Clarke et al. (2018) assert SA does however allow consideration of complexity, is an evolution of

GT, and pushes GT further into post-modernity because SA includes an interpretive epistemology. Researchers have referred to SA as situational GT (Denzin 2010; Uri 2015).

SA, like GT, can include numerous data sources in data generation e.g., documents, interviews, participant observation. Therefore, SA takes the GT position that everything has the possibility for being data (Glaser and Strauss 1967). Allen (2010) like Clarke (2005) reports SA is a combined methodology and method, and describes SA as a hybrid methodology and methods approach, following in the GT tradition. However, Allen (2010) also describes SA as a whole, new, methodology and methods approach.

SA involves cartography that has roots in social worlds/arenas theory (Strauss et al. 1964; Strauss 1978), draws on Strauss and Corbin (1990; 1998) conditional matrix, and includes context as situated. Additionally, includes consideration of positions and power as seen in analysis of discursive influences (Foucault 1972). Clarke et al. (2018) assert discourses influence elements within situation, conditioning knowledge, and thereby what action is possible within situations. Furthermore, SA includes relational analysis within its cartographic mapping tools that enable consideration of the influence of human and non-human actors/actants on each other and the action under investigation, as seen in ANT (Latour 1987; 2005). Thereby, SA enables thorough mapping of the landscape of a situation in all its complexity (Uri 2015). SA also acknowledges the role of the researcher in data generation and analysis, thus, includes an interpretive epistemology as seen in SI theory (Blumer 1969) and social constructionism (Berger and Luckmann 1991).

Before deciding to use SA and interviews to examine the situation of community PA by C&YP with neurodisablity, I considered other methodologies and methods and the generation of both quantitative and qualitative data. Including both quantitative and qualitative data could provide data triangulation and thereby increase study rigour (Bryman 2012). I considered using accelerometry measurement of PA intensities and frequencies, combined with diaries to collect data on frequency of attendance at community PA opportunities. Accelerometry provides quantitative data on PA at specific time points (Gorter et al. 2012), which could address a PA data gap for C&YP with neurodisability (WHO 2022), but there is some debate on C&YP's

concordance wearing activity monitors (McAnn et al. 2016) and questions on their accuracy (Gao et al. 2021). Additionally, I did not have funding to provide sufficient activity monitors for a robust study. Thus, I decided against accelerometry, particularly when considering the need to gain an in-depth understanding of a complex socio-ecological system.

Next, I considered qualitative data generation via interviews that explored all stakeholders (families and providers) experiences of community PA. Qualitative data is an appropriate data source when attempting to gain insight into people's experiences, their views on their experiences, and potential reasons for their experiences (Bryman 2012). I therefore decided to take a qualitative approach involving as many of the numerous, and varied stakeholders, and PA community settings, as possible. Another key factor supporting this choice was the desire to ensure research findings were practically useful therefore involved the people for whom the findings were relevant (Mohrman et al. 2001). Therefore, I determined I needed to interview families, C&YP, and those service providers who offered support and/or provided community PA opportunities to C&YP.

Initially, I considered using stakeholder analysis as a chosen research method (Schmeer 1999) because stakeholder analysis involves identifying stakeholders who implement policies and programmes, then explores stakeholders' characteristics, interests, and actions, and how these influence policy/programme implementations. I reasoned stakeholder analysis could help me identify all stakeholders relevant to community PA participation policy, analyse policy implementation, and identify and examine any gaps between PA policy and its implementation. Stakeholder analysis, however, focuses on a specific policy; therefore, seemed too narrow because literature findings and personal experience showed community PA participation by C&YP with neurodisability contained multiple influences, including several policies and programmes across numerous settings e.g., sport, school, and community environments.

Another research approach I considered was Translational Mobilisation Theory (TMT) (Allen 2018). TMT is an ecological approach and sociological theory that aims to understand work processes, how work is organised, and how collective action emerges, particularly within institutional contexts (Allen 2018). TMT enables consideration of action e.g., community PA participation, and how PA participation is organised and processes from the collaborative work, action and interaction of people and material elements. TMT however appeared primarily focused on institutional work contexts. I reasoned community PA participation by C&YP with neurodisability would involve many contexts, and not only institutional work contexts. Therefore, I determined SA (Clarke 2005) more appropriate as SA included consideration of diverse and numerous contexts, involved all socio-ecological levels (Bronfenbrenner 1979), and included consideration of numerous human and non-human elements, their relationships, and influences on each other, and on the action under investigation. Furthermore, researchers have used SA in public health, and applied health research studies, to explore socio-ecological influences on health behaviours, including PA (Anderson and Whitefield 2011). Thus, evidence indicated SA being an appropriate ecological approach to consider the PA health behaviours of C&YP with neurodisability. Previous applied health studies using SA include Anderson and Whitefield (2011), Martin et al. (2016), and Spyropulos et al. (2016). However, SA has previously, not been used to examine C&YP with neurodisability community PA participation, therefore, providing a gap in the research evidence that I could address.

Anderson and Whitefield (2011) used SA to examine barriers and facilitators to stroke survivors' everyday activity choices. Study findings showed multiple interactions between individuals and numerous environmental factors influenced stroke survivors' participation. SA findings suggested interventions that co-ordinate multiple socio-ecological levels i.e., policy, community environments, friends and family can promote activity in disabled people. Other researchers, Martin et al. (2016), have used SA to explore public health programme implementations and reported SA enabled examination of often overlooked and presumed structures and conditions within health systems that negatively affected disadvantaged individuals. Martin et al. (2016) asserted SA was a method that could strengthen public health systems and move public health research forward. Similarly, Spyropoulos et al. (2022) described SA as a valuable and novel methodology for complex systems research thinking and evaluation. Spyropoulos et al. (2022) used SA to explore system effects on peoples with multiple needs and disadvantage e.g., homelessness, substance misuse, mental ill health, and offending.

Denzin (2010) and Allen (2010) describe SA as a methodology and method that can explore complex systems that potentially contain disadvantage and inequality. Therefore, I determined SA could be a suitable way to explore families' situations due to the existing gap between equality legislation (Equality Act 210) and the number of community PA participation opportunities and choices available for disabled C&YP (Bevan Foundation 2011; Ross et al. 2016; Shields and Synnott 2016; Martin Ginis et al. 2016). This discrepancy suggests the possible presence of inequality and/or disadvantage in the system of community PA participation. However, I realised investigation needed an open mind, with reflective research practice, being aware of potential bias in entering research with the idea of disadvantage already present. SA does however include extensive reflective memo writing, to aid researchers increase their awareness of their own perspectives and influence on data generation and analysis. Additionally, SA provides iterative analytic tools that consider numerous positions and perspectives. These processes facilitate researcher awareness and the potential to limit researcher influence on data generation and analysis (Clarke et al. 2018).

3.1.1. Strengths and Limitations

In deciding to use SA (Clarke 2005; Clarke et al. 2018), I considered its strengths and weaknesses as a methodology and methods approach. Allen (2010) criticises SA for making assumptions regarding equity, equality, and power relations within situations. Allen (2010) suggests that in comparison to traditional GT (Glaser and Strauss 1967; Glaser 1992), SA has potential to stop data findings emerging, due to having underlying assumptions, which a researcher could place onto the data. Underlying assumptions include the presence of conflict, negotiations, partialities, power and positionalities, which SA data analytic mapping processes consciously seek. Clarke et al. (2018) however assert that the researcher does not place these assumptions onto the data, especially if using regular reflective memo writing. Regular reflective memo writing however, does not automatically ensure that a researcher will not make assumptions in data generation and analysis. Researcher reflection is however a recognised way to limit researcher influence on data generation and analysis (Bryman 2012). Clarke (2005) and Clarke et al. (2018) assert that in addition to reflective memo writing, SA' iterative, cartographic, data analytic tools further enable the researcher to examine the situation, considering positions and power, without making assumptions. Consciously seeking positions, power influences, and silent implications within data is however a potentially biased approach to researching a situation. Therefore, a challenge in using SA is in minimising the influence and assumptions of the researcher during data generation and analysis. To mitigate my potential for making assumptions, I determined to conduct extensive reflective memo writing, gain regular feedback on data generation and analysis from two research supervisors/moderators, and build on SA' strengths. Despite, SA' limitations, Allen (2010) still argues in favour of SA, describing it as a rigorous and comprehensive methodology and methods package. Denzin (2010) also supports SA as an appropriate and rigorous way of considering situations, and potential conflict and positionality within situations; stating SA offers a situational, cartographic analysis of social structure, infrastructure, and social action, which can address equity and social justice.

Another consideration when using SA is its potential for messiness during data generation and analysis (Maher 2008). SA includes multiple social theories that leads to a hybrid approach including multiple perspectives, elements, relations, social worlds/arenas, discourses and positionalities (Clarke 2005; Clarke et al. 2018). This hybrid inclusive approach aids in recognising the messiness and complexity of situations, as the research approach intends but, simultaneously, can lead to what Maher (2008) titles, making a mess with SA. Maher (2008) posits that making a mess with SA can occur in two areas, namely in defining situation, and when performing relational analysis. SA' definition of situation includes everything, as everything is considered, situated. However, Maher (2008) describes a social science understanding and definition of situation as a confined temporal and spatial unit. With this social science definition, situation has confined and definite boundaries, however the boundaries of situation within SA, are difficult to concretely define. Maher (2008) suggests SA definition of situation is rather a definition of the field of study. Thus, with the scope and boundaries of a project difficult to define, and the study of situation potentially being a study of the field, Maher (2008) argues there is the opportunity to miss in-depth examination of specific situations within the field. In other words, by examining the big picture the researcher misses examination of small pictures within that larger picture/field. Furthermore, Maher (2008) asserts Clarke (2005) is contradictory when criticising classic GT for over-simplifying and not including complexity or considering partialities, inconsistencies, and heterogeneity. When Clarke (2005) similarly, oversimplifies when using relational analysis within SA. Maher (2008) asserts this is because SA uses relational analysis to examine relations between elements within a situation but does not examine the elements themselves, e.g., their production, existence, or reduction within the field. Thereby, according to Maher (2008), SA has potential to miss in-depth study of elements within defined situations, and within a larger field of study.

Using a hybrid approach with a broad definition of situation could limit the ability to distil data findings from specific, defined units, within a larger field of study/broad situation. By including examination of everything in a situation, as Clarke (2005) and Clarke et al. (2018) defines situation, a specific focus may be hindered, and make a study unmanageable, particularly for new researchers. SA' three cartographic analytic mapping processes however allow examination of individual elements and their relations, i.e., smaller pictures within situation, whilst simultaneously facilitating examination of complexity and the broader situation. Clarke (2005) and Clarke et al. (2018) also states study findings should be practically useful and that this should be the guiding principle for decisions on final analytics and study outputs. Furthermore, Clarke et al. (2018) assert it is ultimately up to the researcher to decide which salient features are most practically useful and beneficial to write up in final study reports. SA' data analytic mapping tools are also purported to be just that - tools for analysing the situation and recognising situation complexity, and not an end in themselves. Therefore, I decided to let participants data, answers to the research questions, and SA' theory guide final output and presentation of the study findings.

A final critical consideration in determining use of SA relates to its GT traditions (Glaser and Strauss 1967) and whether SA truly follows GT traditions, is a form of GT, or not, and what final outputs will result e.g., production of substantive theory or not. Clarke (2005) and Clarke et al. (2018) asserts SA has a GT framework and positions SA in the interactionist GT tradition (Strauss and Corbin 1990; 1998) but states SA' final outputs do not need to be substantive theory. Despite this difference, Denzin (2010) still calls SA a form of GT, describing SA as situational GT. Other researchers have also described SA as situational GT (Uri 2015), while Clarke et al. (2018) describes SA as an evolution of GT.

SA uses GT data generation and analysis processes, such as overlapping data generation and analysis, data coding and abstract conceptualisations, constant comparison of cases, elements of theoretical sampling, and general, provisional theorising. However, Clarke et al. (2018) states there is no need to generate substantive theory using SA, which is in opposition to the aim of GT (Glaser and Strauss 1967; Charmaz 2006). In fact, Clarke et al. (2018) favours thick situational analytics and/or provisional theorising over production of substantive theory. This position could be criticised as using GT vocabulary, yet not following all GT processes, which Glaser (2009) describes as jargonising GT i.e., applying GT vocabulary without applying GT associated meanings. However, SA does include GT data generation and analysis processes with their associated reasoning and meanings, as foundations to data generation and analysis (Clarke et al. 2018). For example, when data coding and performing abstract conceptualisations. Therefore, a researcher can follow GT data generation and analysis processes to provide thick situational analytics without producing substantive theory. Other researchers have therefore described SA as a form of GT and an evolution of GT (Denzin 2010; Allen 2010; Uri 2015). However, SA includes consideration of other theories in its methodology and methods (Blumer 1969; Foucault 1972; Latour 1987). To manage this complexity of multiple theoretical influences within my chosen research approach, I determined to keep accurate records of data generation, cartographic analysis, reflective memos, and explicitly show emergence of study findings, while acknowledging complexity.

In conjunction with decisions on what ecological methodological approach to take, I needed to make decisions on what forms of qualitative data to generate. Like GT, Clarke et al. (2018) describes using elements of theoretical sampling to inform developing ideas and new and varied data sources to seek. SA therefore has potential to source any types of new data once a study has begun. Although this is a strength when exploring a situation, providing data triangulation (Bryman 2012) and thorough exploration of situation (Clarke et al. 2018), there are potential limitations. For example, ethical approval decisions on the types of data for collection in research studies (e.g., documents, interviews, focus groups etc.) usually occur before data gathering and analysis starts. Thus, ethical approvals can place constraints on the types of new and relevant data sources a researcher is able to include at later stages/work-streams in the study, thereby constraining theoretical sampling. SA however proposes using elements of theoretical sampling, or purposive theoretical sampling, to ensure thorough analysis and inclusion of numerous perspectives on a situation. Therefore, unless including all possible sources and types of data for sampling in ethical applications, at study outset, a study will likely require regular amendments to ethics applications to pursue theoretical sampling adequately, which could be time-consuming and not feasible for some research study timelines.

Having considered all these aspects, I considered including interviews, focus groups, documents and participant observation as qualitative data sources, but decided including numerous data sources was not practically feasible with the time available to me, and with the research resources I had available. Additionally, evidence shows researchers using single data sources e.g., interviews only, can explore situations appropriately and adequately, using SA (Anderson and Whitefield 2011; Uri 2015; Martin et al. 2016; Spyropoulos et al. 2022). Therefore, I determined interviews appropriate to use with SA, having considered other qualitative data sources as well.

3.1.2. Using Interviews

Before confirming a decision to use interviews for data generation, I also considered participant observation (ethnography) and document analysis. I reasoned studying documents would enable me to analyse discourse about community PA participation and uncover the lenses (Goffman 1974) under which different stakeholders framed, viewed, included/excluded, promoted or discussed community PA participation by C&YP with neurodisability. However, in considerations, I realised this approach would narrow exploration of the topic to published work, social media, and other online platforms where documents were available. I reasoned it possible to explore these sources as an adjunct to a more in-depth approach exploring people’s experiences, rather than limiting data to document sources alone. Therefore, I turned to consider ethnography and interviews.

Ethnography would enable me to immerse myself in community settings where C&YP participated; enable me to observe first-hand C&YP experiences, organisations’ working practices, allow me to ask questions of people involved in observations, and take field notes (Bryman 2012). Ethnography has a rigorous, logical and transparent approach that can produce large amounts of data while staying close to the situation investigated (Jones and Smith 2017). However, my literature reviews and scoping of several participation settings informed me C&YP were likely to participate in several different community settings with numerous different providers. Therefore, I reasoned it would not be feasible for one researcher (myself) to observe all community PA participation settings. Additionally, there were potential logistical problems in being able to gain access to all environments for the length of time needed.

I therefore determined interviews preferable as interviews would enable me to generate data from numerous participant sources - service providers and families, therefore allow me to involve all relevant people (stakeholders). Additionally, I would be able to ask questions about participation in the numerous, varied, community settings. In-depth interviews would also enable me to gain knowledge on participants’ experiences and their viewpoints of their experiences (Bryman 2012). I realised that interviewing C&YP can be difficult and that I might not gain C&YP’s views, especially when not having research experience interviewing C&YP, or technology available to me to reduce potential social and environmental communication barriers. I understood I would be able to interview parents as proxies for C&YP where necessary, however gaining proxy views is not ideal, because they do not provide C&YP’s individual viewpoints. Interviews would however enable me to question families (C&YP and parents) to gain knowledge of their experiences and views, and question providers from numerous and varied organisations - regarding their working practices and their support of PA, their difficulties and/or successes. Thus, I decided to generate data using interviews and SA. Before presenting how I did this, I present a critical discussion on the many theoretical and philosophical foundations of SA, as these foundations influence data generation, analytic processes, and how I present thesis findings.

3.1.3. Theoretical Foundations

SA has GT (Glaser and Strauss 1967) foundations but places itself into the Strauss and Corbin (1990; 1998) GT tradition, which includes interpretation and interactionist epistemologies. SA therefore additionally places itself in favour of symbolic interactionism (SI) theory (Blumer 1969) as SI considers interpretations and re-interpretations central to social interactions. SA additionally has foundations in a social worlds and arenas perspective (Strauss 1978) and has evolved Strauss and Corbin (1990) ecological conditional matrix, to provide the situational matrix. The situational matrix illustrates conceptual categories found within situations that can influence action within situations. SA additionally includes consideration of discourses (Foucault 1972) and the relationships of discourse, knowledge and power within situations (Foucault 1976; 1977; 1978). Finally, SA includes post human theories in its foundations, such as ANT (Latour 1987; 2005). ANT is a post human theory giving equal credence to non-human material elements and their ability to influence action within situation, through a network of relations. I now discuss each of these foundations to SA, starting with GT.

A Grounded Theory Foundation

Clarke (2005) and Clarke et al. (2018) positions SA in the GT tradition because SA data generation and analysis contains classical/foundational GT roots (Glaser and Strauss 1967). However, Clarke et al. (2018) claims SA follows the Strauss and Corbin (1990) interactionist GT approach. Simultaneously, however, Clarke (2005; Clarke et al. 2018) states SA expands Strauss and Corbin (1990) version of GT to push GT further into post-modernity and interpretation.

GT has multiple versions based upon different epistemological stances (Denzin 2010). The different versions of GT include positivist objectivist GT (classic GT) (Glaser and Strauss 1967; Glaser 1992), systematic and procedural, interactionist GT (Strauss and Corbin 1990; Strauss and Corbin 1998), constructivist GT (Charmaz 2006), and situational GT (Clarke 2005). Glaser and Strauss (1967) originally developed GT as a way to systematically generate and analyse qualitative data, at a time when qualitative social science research was criticised for being too subjective. Classic GT (Glaser and Strauss 1967) therefore sought to introduce a systematic, positivistic approach to qualitative data generation and analysis.

GT is a method of inductive analysis, which involves constant comparison of data cases to generate an abstract theory on a social matter or problem. Thereby, theory derives inductively from the data rather than data deductively testing a theory. Atkinson et al. (2003) describe GT as a way of generating ideas based in empirical research. GT proceeds by moving back and forth between the empirical data and abstract conceptualisations of the data, to provide a deeper, overall abstract conception of the data, which then has practical applications (Dey 2004; Richardson and Kramer, 2006; Clarke 2007; Charmaz and Thornberg 2021). The importance given to the practical usefulness of abstract conceptualisations and generated theory demonstrates an underlying pragmatic philosophy to GT (Bignall et al. 2014).

Following introduction of GT, Glaser and Strauss parted ways regarding how to generate theory. Subsequently, different researchers have placed themselves into different epistemological stances regarding GT. Either following Glaser (1992) positivistic approach, Strauss and Corbin (1990) systematic procedural, interactionist approach, Charmaz (2006) constructivist approach, or Clarke (2005; Clarke et al. 2018) situational approach. Tracing the history and use of GT shows GT's turn from positivism towards interactionism, interpretation, and constructivism. Today, traditional (classic) GT (Glaser and Strauss 1967) is often criticised for being unrealistically positivistic (Clarke 2005; Denzin and Lincoln 2005; Charmaz 2006; Clarke 2007; Clarke et al. 2018). I have chosen to acknowledge the important role of interpretation by taking a situational GT approach (Clarke et al. 2018).

A central conflict in the different approaches to GT relates to the role of interpretation and influence of the researcher and its relationship to research credibility and trustworthiness (Bryman 2012). Debates on the role of the researcher include differing viewpoints on whether data findings truly emerge during GT or whether researchers place findings onto the data, or construct findings collaboratively with the data (Bryman 2012; Charmaz 2006). Glaser (1992; 2002) argues for classic, positivistic GT, stating GT theoretical sampling and abstract conceptualisations objectivise findings. For Clarke (2005; Clarke et al. 2018), this disregards consideration of the researcher's influence on data collection and analysis. Clarke et al. (2018) assert that ignoring the researcher role and perspective in data gathering and analysis is irresponsible, unrealistic, and conceptually and practically impossible. Clarke (2005; Clarke et al. 2018) acknowledges the need for researcher reflexivity to limit researcher influence on data gathering and analysis. However, also argues that the researcher perspective is just another perspective on the data that is useful to consider. Clarke et al. (2018) link the process of considering multiple perspectives, including the researchers, to doing provisional open coding during initial GT and SA data analytic steps, where initial open coding considers numerous and provisional perspectives on the data. Thus, SA encourages repeated iterative situational data analytic coding and mapping processes, which involve GT open coding, selective coding and abstract conceptualisations, as well as repeated reflective memo writing, to become aware of, and consider numerous perspectives on the data, including that of the researcher.

SA therefore holds to a GT framework (Glaser and Strauss 1967), by using numerous GT analytic processes. However, SA has many differences to GT, including the use of extensive analytic cartography, the inclusion of considerations of partialities, positions on power, consideration of knowledge and discourse (Foucault 1972), and consideration of relationships i.e., network relational influences, as seen in ANT (Latour 1987; 2005). Furthermore, SA aims to provide thick situational analytics with an option not to generate substantive theory, which is in contrast to the aims of GT that seeks to generate theory. Regarding theory generation, Clarke et al. (2018) argue no need for substantive theory production, based on an underpinning position in favour of SI theory (Blumer 1969). The presence or absence of SI theory within GT roots is another area of debate and division that occurred between different proponents of the varied forms of GT.

SI theory (Blumer 1969) holds that social reality (society) can change dependent on individuals and groups' interpretations and re-interpretations. Therefore, Clarke et al. (2018) argue that substantive theory is unlikely to remain substantive for long, particularly in areas not well investigated. For this reason, Clarke et al. (2018) propose general, provisional theorising and/or production of thick situational analytics rather than substantive theory, using SA. Considering the complexity of participation for C&YP with neurodisability, I have chosen SA for data generation, analysis and presentation of research findings. SA rejects structural and universal claims on reality found in a positivistic epistemological stance (e.g., in Classic GT), but instead favours an interpretive epistemology that acknowledges complexity, and inclusion of varied perspectives, including the researcher's perspective. This approach has roots in Chicago School SI Theory (Blumer 1969), which is another theoretical foundation SA draws on.

Symbolic Interactionism Theory

SI theory is a micro-level theory derived from several Chicago school sociologists with Blumer (1969) being the first to coin the term SI. Blumer (1969) set out several premises within SI theory that support interactionist, and constructivist GT premises and provides foundational reasoning for Clarke (2005; Clarke et al. 2018) definition of situation. I define and discuss situation later in this chapter, but first examine SI premises, and show how they relate to SA.

SI theory (Blumer 1969) holds that people act towards symbols (e.g., individuals, groups, words, language, ideas, objects) according to the meaning they attach to the symbol. Furthermore, the meanings people attach to symbols occurs through their interaction with others. Meaning creation is therefore not passive but individuals actively create meaning through processes of interaction and interpretation (Blumer 1969). Different individuals could therefore have different meanings/perspectives attached to the same symbol dependent on their interpretations. An example of this can be found in an interaction between a mother and a horse-riding provider, reported by a thesis participant (mother), and the meaning the mother attached to a letter (a symbol). The mother interprets the request for a letter by the provider, and the letter, as evidence of the provider's lack of confidence and ability to include her child, which stops the mother from letting her child participate.

> *I enquired about horse riding years ago and they wanted a [GP] letter to say Sian was okay to go on and I was like, well you can see she's okay to go on! I just tend to think then, oh well, whatever then, you know, if you want that type of thing then you're obviously not confident to be working with somebody who might need something slightly different (Participant Mother)*

As the provider is not a thesis participant, we do not have their interpretation of the interaction and their reasons for the request of a general practitioner (GP) letter and are reliant on the mother's interpretations.

SI theory allows for several interpretations of interactions, which include an individual's interpretation of others' interpretations of them and their actions, such as seen in the mother's interpretation of the provider's actions in their request for a letter. Additionally, SI theory allows for an individual's own interpretation of self (I and me). Mead (1967) defined interpretation of "I" as an individual's own interpretation of themselves and their actions, and the interpretation of "me", as an individual's interpretation of how others see them and their actions. Thereby, SI theory holds individuals can enter the perspectives of others and the interpretations that others have on them and their actions (Cooley 1922; Blumer 1969). Several examples were provided by parents within thesis data showing their attempts to interpret providers' behaviours, words and actions. Majority parents' interpretations were of providers being fearful of including disabled C&YP in community PA participation opportunities.

> *I don't know whether it's just the fact that they're frightened (Participant Mother)*

> *I say, can you cater for her? Because there's that fear for people as well, I think… But it just doesn't happen* (Participant Mother)

These interpretations are potentially fallible i.e., an individual's interpretations of others' perspectives of them and their actions could be accurate, or inaccurate. Providers in the thesis did however confess to being fearful of risk when including disabled C&YP and viewing/interpreting inclusion of disabled C&YP (a symbol) as risky e.g., inclusion in physical education (PE), confirming parents' interpretations.

> *We've got to be really careful about what we're doing, because if we push them and tell them to do something… and something's happened. We're liable (Participant, PE Specialist)*

SI theory (Blumer 1969) additionally holds that individuals are capable of reflection, therefore can modify, and change their actions, dependent on their interpretations and re-interpretations. Blumer (1969) asserted symbolic interactive interpretations, and re-interpretations, were the basis for individual, and group behaviour. Namely, individual and group interpretations determined the action/s that individuals/groups took. SI theory (Blumer 1969) also proposes that individuals and groups in society will adapt to each other, and accommodate each other, based on their interpretations and re-interpretations. Thereby, constructivism occurs i.e., people construct social reality based on their interpretations and re-interpretations during social interactions (Berger and Luckmann 1991). Therefore, social reality does not exist objectively and externally to people's interpretations. Following this reasoning, social reality can alter by influencing individuals and groups' interactions, interpretations, and re-interpretations. Thus, using SA, allows researchers to actively seek interpretations of discursive interactions within situations, to understand their influence on action e.g., community PA participation.

The first researchers using SI theory were Chicago School ethnographers studying urban ecology and criminology in Chicago (Jaynes et al. 2009). These researchers used analytic cartography (mapping processes) to analyse situations, to determine findings, and to present their findings cartographically. These early SI Chicago School, ethnographic studies, described the concept of a social world, a concept that Clarke (2005) includes within SA, along with cartographic mapping of social worlds. Strauss (1978) drew on early Chicago School ethnographic studies and their consideration of social worlds to provide a social worlds perspective that includes social world mapping. Clarke (2005; Clarke et al. 2018) draws on all these foundations to include examination of social worlds and arenas, using social worlds/arenas data analytic mapping, within SA.

A Social Worlds and Arenas Perspective

SA includes a social worlds/arenas perspective (Strauss et al. 1964; Strauss 1978). It uses social worlds/arenas analytic cartography to consider the role of social worlds within situations - their aims, actions and influences. Social worlds are social groups (e.g., families, schools), organisations (e.g., sport organisations), and institutions (e.g., government institutions). Kling and Gerson (1978 p26) provide a general definition of a social world consisting of *“a set of common or joint activities or concerns, bound together by a network of communication”.* Descriptions of social worlds include descriptions on how some groups develop and advance, whilst others do not - usually due to inequalities, force, coercion or persuasion (Fisher and Strauss 1978; Thomas 1907). Fisher and Strauss (1978) state early ethnographic studies that explored social worlds, did so, to address inequalities, and to bring about social change and progress. Therefore, these studies examined and described the workings of social worlds, their conflicts, arrangements and functions, due to the desire to see social reform (Fisher and Strauss 1978).

Strauss et al. (1964) and Strauss (1978) assert that a social worlds/arenas perspective is necessary to understand social structural processes, how people shaped society, society shaped people, and society changed. When Strauss et al. (1964) and Strauss (1978) discussed a social worlds’ perspective they included the Mead (1967) concept of social group fluidity i.e., social groups/worlds have boundaries that can evolve, subdivide, or disappear. They argued that group fluidity be considered alongside the interactionist view of social construction when studying social change, rather than focusing on micro, meso and macro socio-ecological levels (Bronfenbrenner 1979; Schensul 2009). Clarke et al (2018) also draws away from overt consideration of socio-ecological levels to, rather consider, elements within situations and their relations, social worlds in situations and their relations, and positional relations within situation i.e., regarding discourses and contention. Clarke et al. (2018) argue these considerations will naturally include all socio-ecological levels but provide a more nuanced and comprehensive consideration of situation complexity.

Clarke (2005) suggests studying social worlds and arenas is important in situation to understand negotiated order. Negotiated order is a branch of SI developed to express the dynamic relationships between interaction processes and social orders. Strauss et al. (1964) and Corbin and Strauss (1993) discuss negotiated order as a constituent part of social world/arenas' theory, asserting social worlds negotiate actions and change - within organisations, between organisations, and in the advancement of social world agendas. Furthermore, Strauss et al. (1964) suggested social worlds negotiate within shared arenas, to enhance their positions in relation to other social worlds. Strauss et al. (1964 p377) defined arenas as - *"In arenas, all the social worlds that focus on a given issue and are prepared to act in some way come together".* Arenas are therefore areas of mutual concern for numerous and varied social worlds and where numerous, varied, social worlds can be studied (Clarke 2005; Clarke et al. 2018). An example of numerous social worlds coming together in a mutual arena of concern is illustrated in disability sport where numerous social worlds e.g., funders, sport governing bodies and sports organisations partner together to develop and support disability inclusion in sport (i.e., in the InSport programme). A thesis participant, an executive of the National Disability Sport Organisation (NDSO), describes the InSport programme and this arena of mutual concern that various social worlds are involved in.

> *…we now have 26 national governing bodies working with us. We've got about 500 clubs. We've got all 22 local authorities and about six third sector partners like the Outdoor Partnership, some of the big kind of football club trusts. So yeah it's a successful programme which is working well to make changes (NDSO Executive)*

Strauss (1982; 1984) asserted that studying social worlds and their divisions, subdivisions, and contested issues, raised questions regarding social world's authenticity and legitimacy. Strauss (1982) argued that considering social groups' authenticity and legitimisation when doing research, provided sensitising concepts to analyse social world function, structural processes, and discourses. Strauss (1982;

1984) proposed several processes necessary for a social world to gain legitimacy. First, the social world needed a belief and claim to worthiness. Second, the social world needed distance from other groups e.g., through different activities. Third, the social world needed an ideological base from which to claim worthiness, defend itself, legitimise its activities, and aid in its negotiations. Fourth, all groups (social worlds) needed set standards for performance, product etc. and ways of judging those standards. Considering these sensitising concepts during social worlds/arenas cartography will aid me in my analysis of the situation and provision of thick situational analytics (Clarke et al. 2018). An example of a social world gaining legitimisation, is the social world of disability sport, which has needed to gain legitimacy amongst able-bodied sport social worlds (subworlds). This can be seen in the thesis data when being described by a NDSO executive.

> *…we [NDSO] shouldn't have to do that, make people a part of the sporting community or physical activity community. So that's primarily how we're working is to change approaches and embed inclusion of disabled people at the heart of everything that partners are delivering within physical activity and sport… what we found about 10 years ago was that whenever a query came in to the sport development team that had the word disability associated with it…it would go to the Disability Sport development officer. So… what we were actually doing was starting a process of segregation - so it was absolutely necessary at the time because it did start to embed a programme, it started providing opportunity, but what it didn't do was encourage other people to take responsibility for their sport and the communities that fit within it (NDSO Executive)*

The NDSO executive quote shows that for disability inclusion in sport to gain legitimacy, different sports and organisations involved in different sports need to take responsibility for legitimising disability inclusion, but not all sports and organisations have fully embraced that disability inclusion is their responsibility.

Clarke et al. (2018) claims SA use of social world analytic mapping facilitates consideration of social world function, authenticity, legitimacy, negotiations, discourse and power, and provides thick analytics of social worlds structural processes, collective actions, discourses, and negotiations. Thereby, Clarke et al. (2018) engages meso level analytics, whilst simultaneously considering discourses, power, and negotiation within situation. An example of meso-level analysis is shown in Chapter 4 (p111) where I illustrate a messy sport social worlds/arenas map showing the different sport social worlds and subworlds of which disability sport is a part, striving to gain legitimacy and recognition in all sports and all community contexts. Clarke et al. (2018 p151) argues such social worlds/arenas mapping locates a research project in its broader situation, and aids analysis of organisational/institutional collective actors and their agency within situations. The concept of agency additionally links to ANT (Latour 1987; 2005) and to consideration of discourses, which are also foundational to SA.

Discourses

Foucault (1972) is the main influence within SA when considering discourse. Foucault (1972) fundamentally felt discourse was about power and power's relationship with knowledge; arguing discourse, power, and knowledge inextricably linked. Foucault (1972) felt discourse linked with power and knowledge because discourse shaped how people thought about an issue, therefore shaped what was known (knowledge), which then influenced what people were able, or not able, to do. Thus, discourse had power. Foucault (1972) also stated power relations within different historical eras influenced the systems of thought available (knowledge) at those historical time-periods. Therefore, Foucault (1972) saw knowledge and power as historically contingent.

The position Foucault (1972) takes suggests knowledge, logic, and reasoning do not stand objectively on their own, but are contingent on a system of thought available at any given time-period. This position additionally suggests that the systems of thought/knowledge available at any given time, will exert power over individuals' thoughts, therefore, can determine what new knowledge can or cannot emerge. Such a position provides understanding for why the medical model of disability has dominated thought systems in health and social care practices over a long time and provides support for the slow emergence of the bio-psychosocial model of disability (WHO 2001) and affirmation model of disability (Swain and French 2000); which views impairments positively. Further, for the slow move from a body structure and function, and activity focus, to a more participation-focus within healthcare clinical practice (Anaby et al. 2015; Kolehmainen et al. 2020). An example of the power of discourse, and the historical influence of discourse, can be seen in the slow emergence of new knowledge regarding participation-focused healthcare, and the slow involvement of physiotherapists in participation contexts. This can be seen in the discourse of a physiotherapy thesis participant when they discuss the concept of participation and a physiotherapist's role in participation.

> *I think we have got to be careful, if it is just a group practicing football skills, from a participation point of view, then I don't think that is necessary the role of therapists, that's the role of…of the local sports club (Participant, Physiotherapist)*

Foucault (1972) was a critic of systems of thought and their exertion of power over individuals' ability to have agency, and self-empowerment, and a critic of how systems of thought coerced individuals to behave in certain ways in different historical eras (Gutting 2019). Foucault (1972) did not see discursive knowledge-power relations within these contexts in a hierarchical, top-down, or centralised manner. However, saw power-relation influences diffused throughout society in the way language was used, and institutions were organised e.g., prisons, schools, hospitals (Foucault 1972; 1976; 1977; 1978). Therefore, Foucault (1972) argued language and systems of social practices and thought, limited an individual's knowledge and power regarding their own identity, and coerced individuals to fit into the social structures and thought processes of their given era. Foucault's (1972) position on language, discourse, power and social practices, binds discourses, language, knowledge and power, to social practices, therefore, to the social construction of reality (Berger and Luckman 1991) and to SI theory (Blumer 1969). SA (Clarke et al. 2018) thus includes consideration of discourse in analysing how language and power influences are evident, or silently at work, within situations. Positional situational analytic mapping aids these considerations and analysis (Clarke 2005; Clarke et al. 2018).

Discourses are part of social worlds' theory. Strauss et al. (1964) described discourses as the basis of social worlds' functioning, asserting social order occurs via social worlds negotiating with other social worlds, within arenas. For example, social worlds negotiate regarding meaning (using SI interpretations), resources, and action. Strauss et al. (1964) defined arenas for these negotiations as organised locations that included different ideologies and mind-sets (systems of thought) expressed through varied discourses. Strauss et al. (1964) argued these discourses were the basis for social worlds' negotiation and power relations, which therefore influenced social world action and practice. An example of the influence of social world’s mind-sets (discourses) can be seen in the slow emergence and acceptance of disability sport within the sport sector, and the different sport sub worlds e.g., different sports. A thesis participant, a National Disability Sport Organisation (NDSO) executive, illustrates these social world discourse influences and the slow legitimisation of inclusion of disabled individuals in the sport sector.

> *[NDSO] vision was always slightly different to that of the sport sector because the sector vision was never explicitly [disability] inclusive so previously, we’ve had to translate the vision for sports into one which was accessible to disabled people (Participant, NDSO Executive)*

Clarke (2005) and Clarke et al. (2018) argues SA’ social world analytic mapping aids consideration of social worlds’ negotiations and discursive power influences within social worlds’ processes and actions. Further, positional analytic mapping aids consideration of different discursive positions. SA additionally includes consideration of the influences of non-human material elements within social world practices, and their discursive influences on action. Foucault (1972) linked non-human objects to discourse stating an object’s meaning comes from views on the use of the object, not from the object itself, which is a very symbolic interactionist approach to objects. Foucault (1972) additionally argued time and history influenced the meaning given to an object therefore situated non-human objects historically. An example of the historical situatedness of objects can be seen in the limitations that a product designer (thesis participant) encountered when attempting to design new objects to facilitate disability inclusion.

> *Where the trouble lies, most of the products that we are asked to do, we are asked to do because there isn’t something existing, therefore there isn’t a British Safety Standard to test it against (Participant, Product Designer)*

This quote illustrates the historical nature of objects and the power of discourse i.e., knowledge and understanding related to objects that influences the design, safety testing and use of objects. This interconnection of human knowledge and understanding and non-human objects, also illustrates a network of relationships/connections between human and non-human actors as seen in actor-network theory (ANT), another theory found in SA.

Actor Network Theory and the Non-Human

SA includes overt consideration of non-human elements within situation and their ability to condition action. SA goes back as far as SI theory to examine how an individual experiences self in relation to physical objects (Mead 1967). Additionally, SA draws on Foucault (1972) ideas regarding non-human objects. Other ideas and theories regarding the non-human within SA include post human theories, which posit non-human objects have agency (Latour 1987; 2005). Having agency gives a non-human element the ability to act and influence. SA draws on post human theories such as ANT that gives non-human elements equal agency to the agency that human elements have (Latour 1987; 2005). An example of the agency of non-human objects is seen in the quote of a participant mother where she calls her son's wheelchair his legs, thereby showing the agency of this non-human object.

> *...for him the chair has been his legs (Participant Mother)*

This mother also described the use of assistive technology allowing her son, who had no physical speech i.e. was a non-verbal communicator, to make a speech in school. This example shows the agency of non-human objects, and their equal agency, as the speech facilitated the young man to be voted into the role of Deputy Head Boy, similar to the processes usually followed by the mainstream majority i.e., verbal communicators.

> *He's quite a popular student. He was voted in as Deputy Head Boy. Yeah, he had to give a speech. So, he put a speech together on his computer and then they put a voice to it and so he had this little speech, and they voted him in (Participant Mother)*

Contrastingly, the equal agency of the wheelchair as this young person's legs, can be questioned, as the wheelchair is not able to negotiate all terrains, whereas legs possibly could.

> *...with his new wheelchair wheels, it would be very difficult to take him onto the sand [beach] (Participant Mother)*

Other parents in the thesis sample raised similar concerns.

> *...all kids love going in the sand, it's just, it's tricky then to be thinking of dragging wheelchairs across sand (Participant Mother)*

ANT is a theoretical, analytic approach and constructionist viewpoint that emerged from social science and technology studies however has since been included in different social science fields (Johannesson and Baerenholdt 2009). ANT's link with technology can be seen in another example of the agency of non-human objects, where a physiotherapist thesis participant asserts that non-human objects i.e., technology/equipment, can make a big difference to enabling participation, especially for C&YP classified at GMFCS levels IV and V (Palisano et al. 2009).

> *…the IV's and V's and even the III's, it is more difficult to find something they can actively do independently… but technology helps. Yes, technology helps (Physiotherapist)*

The physiotherapy participant went on to provide an example.

> *One of the little girls I was working with had never played a board game before and it didn't take a huge amount of adaptation. We had a switch activated dice and we had the board on an easel, so it was visually accessible, and magnetic pieces, so she didn't have to cradle over to see. But even things like that, children don't get access to* (Physiotherapist)

A product designer, thesis participant, gave another example of the agency of non-human technology and objects when describing a product, he had designed for a young person without arms to control the release of a ball, to shoot the ball at a target.

> *We've made this controller as an, anything they can move on their body, controller, but there's no reason why it can't be head switches, it could be an iPad, an iPhone, anything that's got left, right and shoot written on it, and they can move that [with any part of their body under their movement control], and then it shoots, and this little lever comes down and releases the ball. So, you've got all that extra involvement themselves* (Product *Designer)*

SA, like ANT, includes analysis of relationships between human and non-human elements to understand how they influence each other, and how resultant action consequently emerges. Therefore, SA includes relational analysis within analytic mapping processes. An example of these relations found in the thesis data, is expressed by a physiotherapy participant who described equipment as an extension of what she did, and that without her connection/relationship to equipment, equipment could lack agency.

> *I'd already seen that equipment could also be left very easily and it's very easy to say just use this piece of equipment and everything will be fine and that's just not how it works. Equipment is just there as an extension of what we do (Physiotherapist)*

The product designer previously introduced (thesis participant), similarly spoke of unused equipment. His descriptions reveal the importance of communication, connections/relationships between humans, and between humans and non-human objects, to facilitate participation.

> *We could send a product out, and frequently do, and never hear from the parent again. No - it's arrived but it's the wrong size – they just stick it in the corner and don't use it and then we call them a year later and say, "you know that thing – did it work? How did you get on with it?" - "Oh, it didn't fit, so we just stuck it in the loft." That is demoralising (Product Designer)*

ANT views all actors as having the ability to influence each other via a network of relationships (Latour 1987; 2005). Clarke (2005) and Clarke et al. (2018) therefore move away from socio-ecological levels being close or far removed from different situational elements within situation and move to a position where all socio-ecological levels are present within situation via connections/networks of relationships. For example, Clarke (2011) in a lecture on SA provides an example of globalisation, a macro level element (Bronfenbrenner 1979), connected to micro-level human and non-human elements within situation, via the labelling of an individual's clothes. Clarke (2005), Clarke (2011) and Clarke et al. (2018) assert that using SA analytic mapping and reflective memo writing aids researcher analysis and understanding of the relationships between elements, and their influences within a given situation of inquiry.

Clarke et al. (2018) references her own social science and technology research that examines the complexities of Socio-Technical Systems (STS) when discussing ANT. STS research examines systems of inter-relations between an organisation, such as a healthcare organisation, and its technical systems e.g. information technology (IT) systems, and its social dimensions e.g., stakeholder relationships, attitudes, knowledge and understanding (Cresswell et al. 2010). Cresswell et al. (2010) asserts the way in which these elements inter-relate, fit with each other, and/or detract from each other, or complement each other, are important in determining how the system will function. Cresswell et al. (2010) provides examples of how IT systems used to convey information across healthcare teams to deliver safe, effective patient care, inter-relate with social elements e.g., attitudes and stakeholder relationships, to influence emerging healthcare processes in a way that was not necessarily intended. Cresswell et al. (2010) state the components of STS and their different relationships tend to become more obvious when things go wrong, in comparison to when things go smoothly. Asserting, when things are apparently going smoothly the inter-connections between all elements can remain hidden. Cresswell et al. (2010) links these dimensions clearly to ANT. Clarke et al. (2018) assert SA aids the researcher to find these relations, whether they are overt, silent, or hidden within situations, and to analyse their influences on action. Stating SA’ analytic mapping processes and reflective memo writing enable the researcher to do this. Considering these theories during analytic mapping can aid the researcher in their analysis and synthesis to determine research findings.

Latour (1987; 2005) asserts inter-relations and networks between elements/actors are not static but are also emerging and can change. For example, the removal or addition of an actor can change a network’s stability, as can a new human interpretation or viewpoint on how to use a material/non-human actor. ANT central premise requires identification and examination of the relationships between actors, how they come into being, disappear, influence, shift, and change the activity of other actors within the network (Latour 2005). Additionally, how forming new relationships can grow a network and/or reduce other network connections. SA does not examine how elements/actors within situation come into being (Maher 2008) but does examine their relations, interactions, and how these influence action.

ANT is a useful sensitising concept within SA and used via relational analysis within SA analytic mapping, to consider relationships and their influences (Clarke et al. 2018). Inclusion of ANT within SA enables me (the researcher) appreciate complexity and fluidity in the situation and enables me to examine relations, including power relations, and if/how relations shift, and influence the existence, and/or emergence of community PA participation by C&YP with neurodisability.

3.2. Analysing Situations

Clarke et al. (2018) aims to capture the complexity of social situations with her SA methodology and methods package. Capturing complexity occurs by using multiple social theories, which enables consideration of the situation using different theoretical frameworks, and by having three iterative analytic mapping processes for data analysis, supported with reflective memo writing. Following, I discuss each analytic mapping process and summarise its aims, objectives and theoretical foundations, as these relate to analysing situations.

3.2.1. Situational Maps

The GT framework included in SA provides systematic and rigorous processes for data generation and analysis, despite SA not necessarily generating theory. Similar to GT, SA follows processes of coding data, line-by-line, identifying elements/codes relevant to the situation researched, however, the identified codes/situational elements are then placed into analytic maps. First, these are placed into messy situational maps and relationships between elements examined, using relational analysis. Relational analysis involves drawing relational lines between the elements within messy maps and writing reflective memos on the relationships. Examining relationships enables groupings of related elements into conceptualised categories. Thereby, inductively generating situational categorical concepts. Following, the researcher places these into organised situational maps. Reflective memo writing supports these processes. Inductive reasoning aids generation of abstract situational conceptual categories from the coded data excerpts and relational analysis. While abductive reasoning confirms abstract concepts match data excerpts when moving repeatedly between abstract situational conceptual categories and data excerpts. Clarke et al (2018) provides a framework of situational conceptual categories, which she suggests are possible within situations, drawn from Strauss and Corbin (1990) conditional matrix. Strauss and Corbin (1990) mapped contexts that condition social processes and action, thereby introducing the conditional matrix into GT (Figure 2 p88).

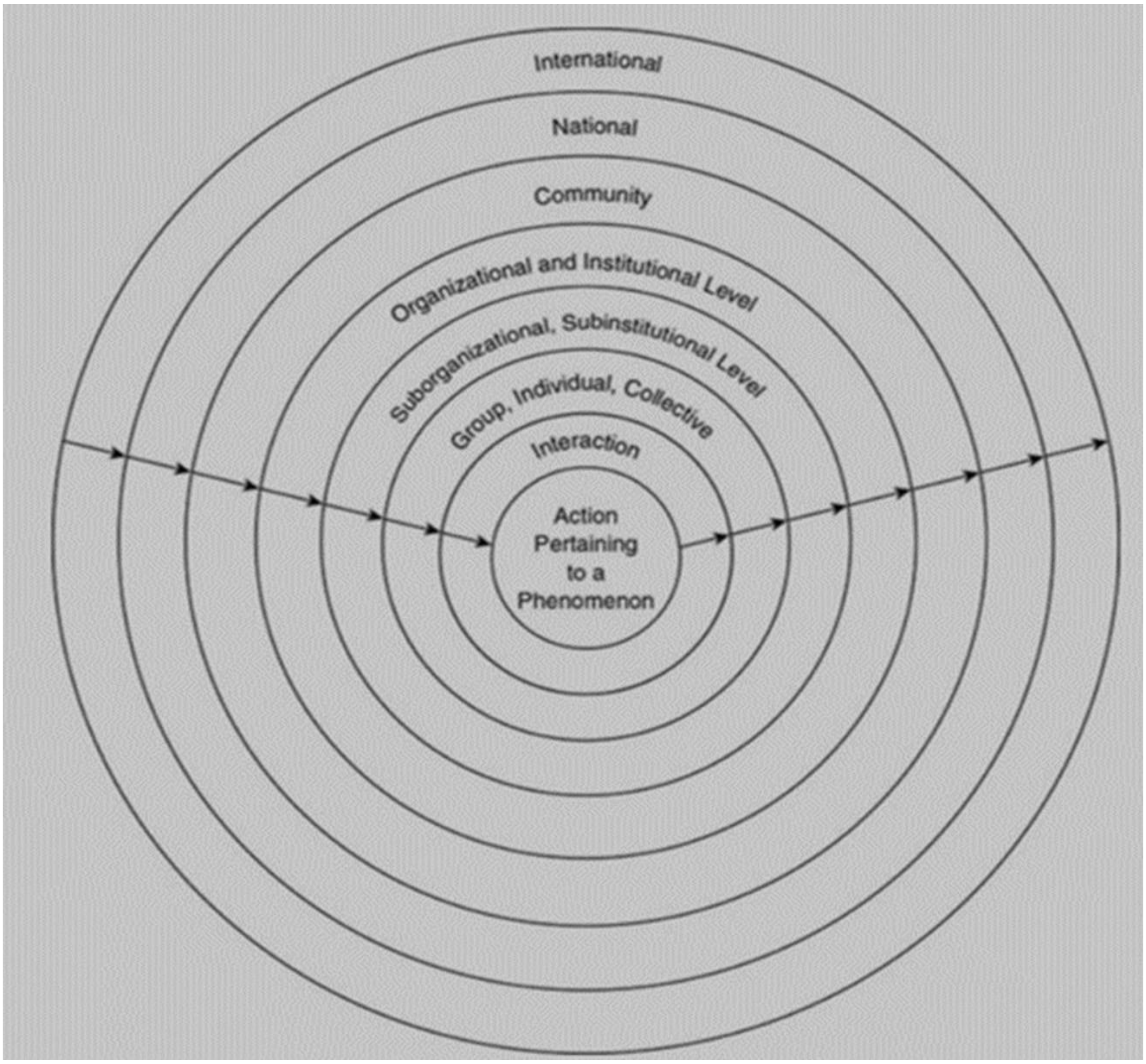


Figure 2: The Conditional Matrix (Strauss and Corbin 1990 p163)

The conditional matrix brought context overtly into GT, by considering numerous contexts to be surrounding and conditioning action. The inclusion of context provided another divisive debate between the Glaser style classic GT (Glaser and Strauss 1967) and Strauss style GT (Strauss and Corbin 1990). Glaser (1992) argues against context as relevant and important unless context emerges from the data via GT theoretical sampling and abstract conceptualisations.

Clarke (2005) and Clarke et al. (2018) expanded and revised the conditional matrix to produce the situational matrix; arguing the conditional matrix did not go far enough in considering context and limited situations to context, when context was only part of situations. The situational matrix includes conceptual categories that involve context but is not limited to context. Therefore, the situational matrix does not show different contexts surrounding action, as shown in the conditional matrix. Instead, there is no illustration of distance between elements, but everything is situated. I illustrate the situational matrix in Figure 3.

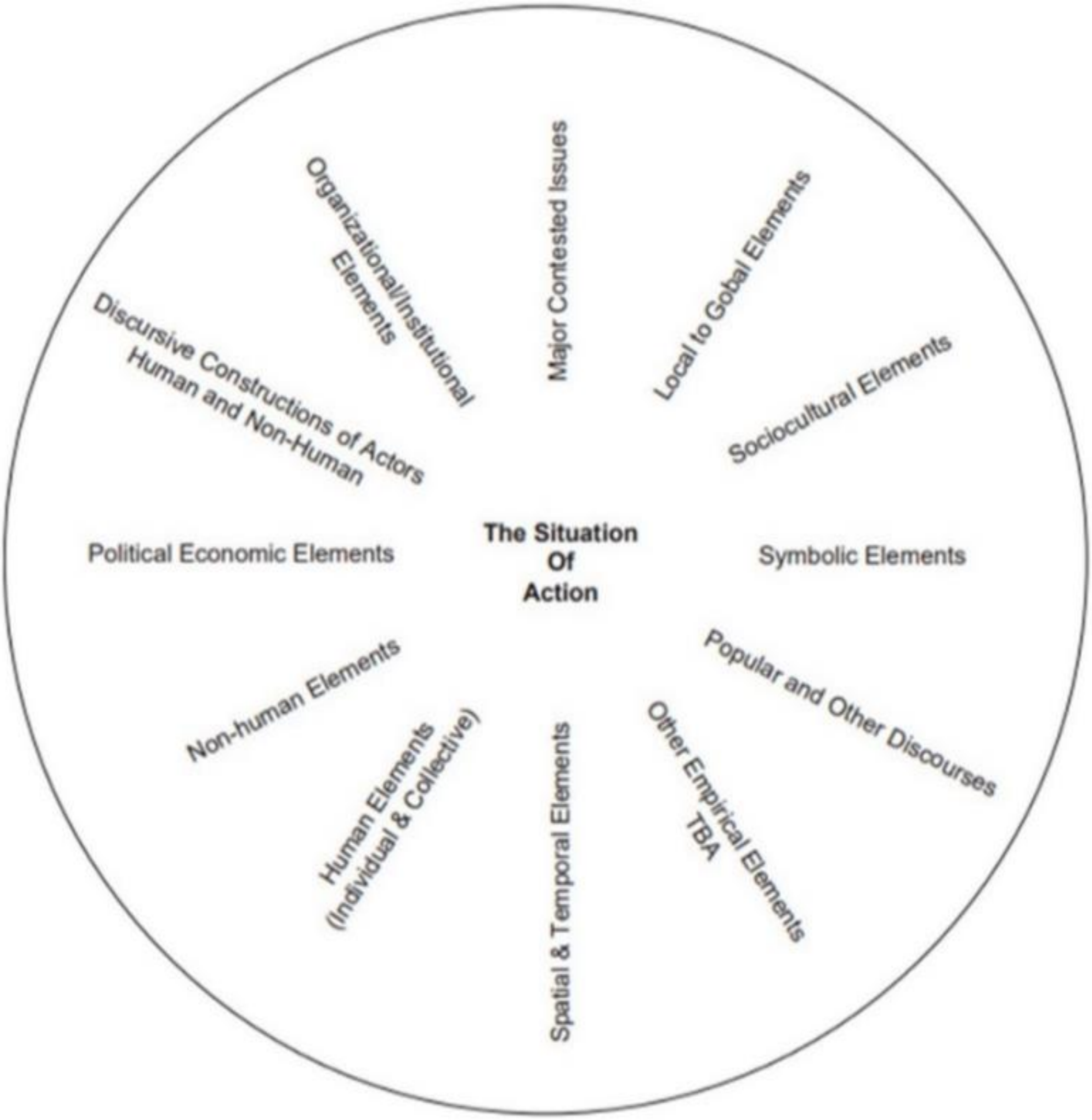


Figure 3: The Situational Matrix (Clarke et. al. 2018 p45)

Clarke (2005) and Clarke et al. (2018) in expanding and revising the conditional matrix argued context did not surround action or stand apart from action but was constituent of action. The situational matrix therefore shows context neither surrounding action, nor near, nor far from action, as in ecological theories, which contain micro, meso, and macro levels (Bronfenbrenner 1979; Schensul 2009). In contrast, context is part of situation. Ultimately, Clarke et al. (2018) asserts all knowledge, all process, all context, all action - is situated.

The situational matrix shows action within situation. It shows situation containing numerous conceptual categories, which are within and part of situation and therefore able to influence action. Clarke et al. (2018) asserts these conceptual categories are part of situations, and it is up to researchers to analyse situations to find which abstract/conceptual categories are present, and how they are influencing situated actions. Therefore, situational mapping organises related situational elements into related conceptual categories within organised situational maps. Clarke et al. (2018) suggests not all situational matrix conceptual categories are necessarily present within a specific situation. Some categories not illustrated within the situational matrix, could also be present. It is up to the researcher to identify these during situational mapping and relational analysis.

3.2.2. Social Worlds/Arenas Maps

The second data analytic cartographic tool within SA is social worlds/arenas mapping. Social worlds/arenas mapping facilitates examination of the work of organisations and their associated social worlds and arenas, their influences on each other, and the action under investigation. By examining arenas, the social worlds involved, and their negotiations and relationships, the researcher can examine action at an organisational and group level. Additionally, negotiations and discourses between social worlds, and any contentious issues between social worlds, can be analysed. Relational analysis of social worlds/arenas analytic maps is an important part of considering how social worlds/groups relate and influence each other. In Figure 4 (p91), I provide an example of an abstract social world/arena analytic map.

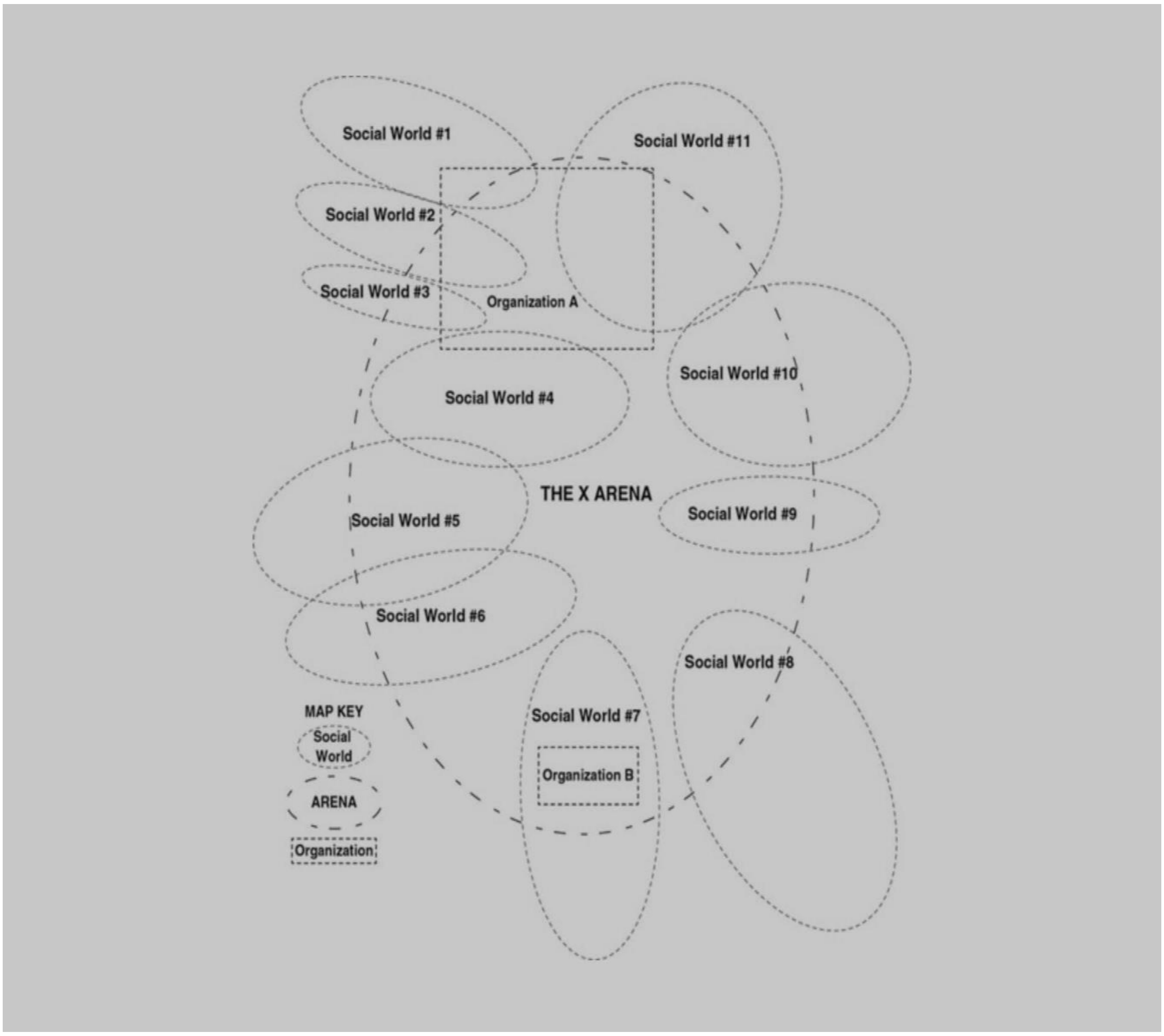


Figure 4: Abstract Social World/Arena Map (Clarke et al. 2018 p152)

The abstract social world/arena map (Figure 4) shows numerous social worlds present within the abstract situation of inquiry. Some social worlds overlap - illustrating close working, collaboration, and/or mutual commitments. Some social worlds stand separately - showing distancing (difference) from other social worlds. The boundaries of illustrated social worlds are not solid but porous, having dotted lines, showing accessibility. Figure 4 also illustrates two organisations. One organisation is present within several social worlds, crossing all these social world boundaries, therefore involved in all these social worlds. The second organisation is within only one, separate social world, showing involvement in only that one social world.

The role of discourses is an additional important consideration when analysing social worlds' relationships and actions (Strauss et al. 1964; Strauss 1978). Consideration and analysis of discourse enables the researcher to identify and analyse discursive influences on the different actors (human and non-human) within social worlds, and the influences of collective actors' (i.e., organisations) discourses, regarding matters of concern. Thereby, SA can identify and analyse power relations within and between social worlds, aided by the third cartographic analytic mapping tool, positional mapping.

3.2.3. Positional Maps

Positional mapping is another data analytic mapping tool used in SA. Positional analytic mapping allows consideration of numerous positions on a matter within a situation. For example, positional mapping can illustrate issues of contention, and/or major discourses within the situation, and varied positions taken up in the data on the matters involved (Clarke et al. 2018). Positional mapping can also democratise positions as individuals and/or organisations are not named in maps. Rather, the researcher names the positions within the maps, and the positions become what is analysed, rather than people and/or organisations (Clarke et al. 2018). Positional mapping can illustrate all possible positions on a matter found in the data and show what positions are missing from the data. Reflective memo writing aids consideration of all positions, including silent influences i.e., positions implied and/or not found in the data. Therefore, positional mapping can make silent influences and implicated influences overt within situations. Clarke (2005; Clarke et al. 2018) suggests using positional mapping iteratively and only once researchers know the data extensively i.e., as a final analytic mapping tool within data analysis processes.

When performing positional analytic mapping, the researcher chooses two different axes against which to map positions on an issue. Clarke et al. (2018) encourages repeated positional mapping to confirm the axes that are most appropriate to show all possible positions on a contentious matter. However, also encourages using reflective memo writing to consider absent positions and enable silences to be articulated. Silences may also trigger further theoretical sampling for data sources to inform articulation. Clarke et al. (2018) asserts positional mapping is very important, as social science research, including GT, have traditionally sought similarities, homogeneity and deleted heterogeneity and differences i.e., different positions on a matter. Positional mapping however consciously seeks different positions and makes them known. In Figure 5 below, I provide an example of an abstract positional map.

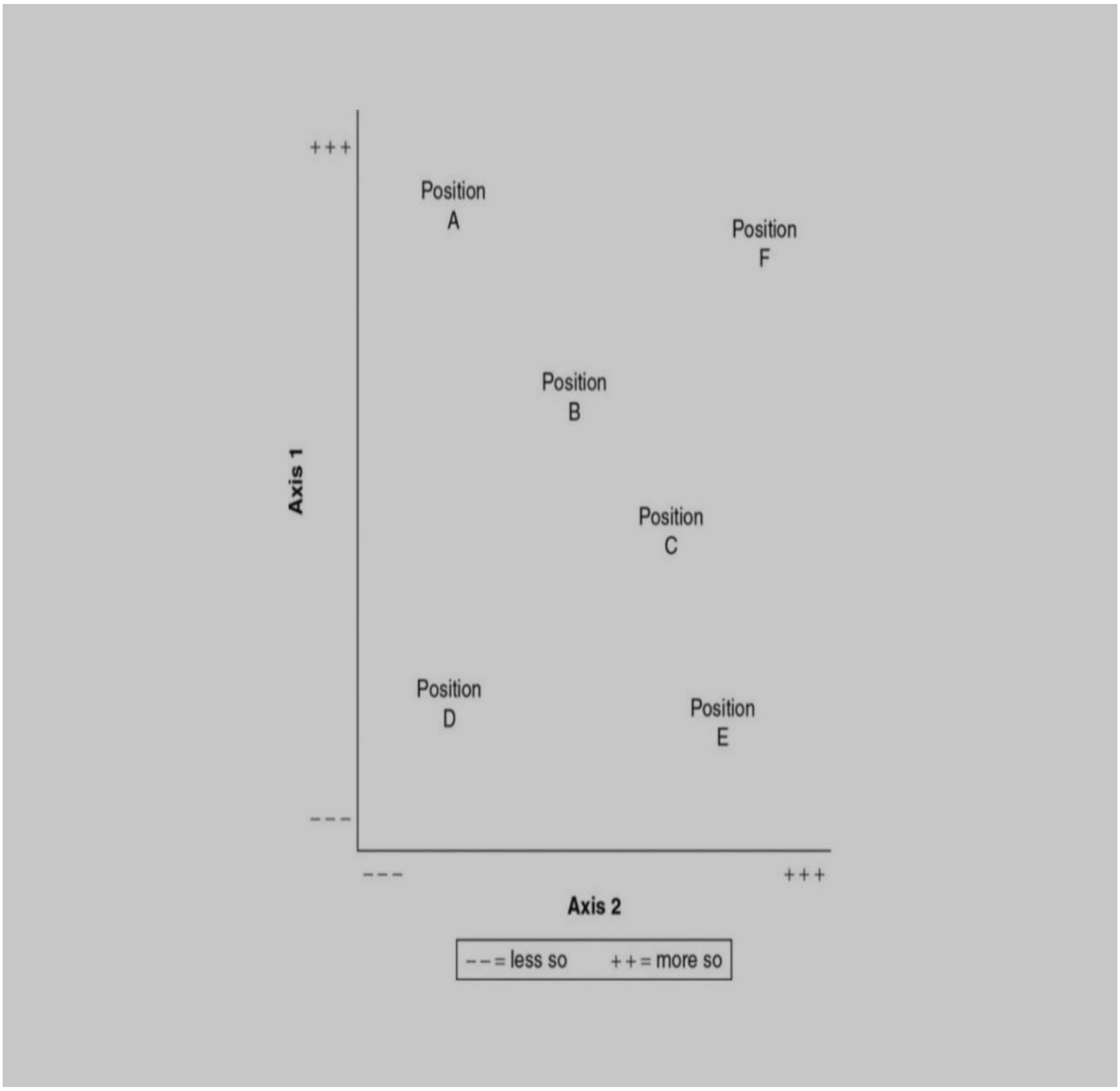


Figure 5: Abstract Positional Map (Clarke et al. 2018 p167)

3.3. Summary

Clarke (2005) and Clarke et al. (2018) situates everything using SA - e.g., social worlds/arenas, human and non-human elements, relations and influences, power and knowledge, and discourse - asserting all are part of situation, therefore, all can influence situated action. The concept of situation is central and foundational to SA. Clarke et al. (2018 p46) assert - *"the conditions of the situation are in the situation. The conditional elements need to be specified in analysing the situation, and the situation itself is conceptualised and analysed ecologically (Star 1995; Clarke and Star 2008)".* When defining situation, Clarke et al. (2018) references interpretation and perspective, as assumed within SI theory (Blumer 1969; Mead 1967) and Thomas's (1928) theorem. Thomas's theorem (1928 p572) states: *"Situations defined as real are real in their consequences".* Thus, positing symbolic interactionist interpretations by individuals and groups (organisations) within a situation will have real consequences. I provide an example of Thomas' theorem in action when synthesising family and providers findings in Chapter 7 (p225). Clarke et al. (2018) also references other sources when defining situation, namely Mill's (1940) writing on situated actions, Denzin's (1989) ideas on situated interpretation, and Haraway's (1988) work on situated knowledge. When claiming actions, interpretations and knowledge are situated, this locates action, interpretation, and knowledge in time, space, history, and context. Thereby, SA provides a "big picture" view of investigated social problems that additionally enables focus on smaller (micro level) elements within that "big picture" (Clarke et al. 2018 p117). Clarke et al (2018) argues the need for this approach to enable pragmatic thick situational analytics. Furthermore, Clarke et al. (2018) state that qualitative inquiry and GT have traditionally ignored action and interaction as situated, and historically situated, thereby missing an opportunity to gain specific, deeper understanding of a social problem.

One of the tensions I found when applying SA was in its definition of situation. Clarke et al. (2018) assert researchers should start with the situation vaguely defined and then grow understanding of the situation by considering everything as situated, i.e., examining everything to determine its relevance to the situation. I found this approach provided me with a tendency towards messiness and confusion. Maher (2008) provides this same critique of SA. This all-inclusive approach to situation can be a strength by ensuring researchers do not miss anything influential in the situation and are able to show a situation's complexity. Maher (2008) acknowledges this, but simultaneously criticises SA's all-inclusive approach asserting it hinders closer examination of individual situations within the larger situation. Contrastingly, I found that I did consider individual families and providers situations during my SA to determine final study findings (examples provided in chapters 5 and 6). Furthermore, I think I will be able to present individual situations in later work, should I choose to do so, to show these individual situations in more detail.

Another tension I found in SA was in determining final study findings. Like GT, SA determines final research findings by using constant comparison of individual cases to draw out similarities across cases. Yet, simultaneously, SA speaks to difference and asks researchers to include differences (e.g., differences in families and/or providers stories) and to consider silent influences within the situation. This approach can cause tensions in making it difficult to decide which study findings are most relevant and most practically useful to answer the research questions, and achieve the research aims. For example, it can be difficult deciding whether individual details and/or differences in providers and families' stories are most relevant to the situation, or whether the similarities across all participants' stories are the most relevant. This situation mirrors clinical practice and research challenges where individuals can be managed as population groups yet have individual differences. These tensions also fed into my positivist position and tendency to seek numerical solutions when analysing data e.g., the tendency to base study findings and study solutions on the greatest number of commonalities across the most participants. This approach can lead to researchers missing important differences that are individual in nature and influential within the situation (Clarke et al. 2018). Furthermore, the dichotomy of determining findings from commonalities or differences across participants, speaks to the tension of achieving data saturation – e.g., are individual differences truly individual or because of too small a sample and thus lack of data saturation. This reflects debates within qualitative research regarding whether saturation is feasible and appropriate to consider when examining social situations and reflects debates on the transferability of qualitative research findings (Denzin and Lincoln 2005). Clarke et al. (2018) potentially found a solution to these problems by asserting SA makes researchers consider and include differences and silences to reflect the complexity of situations and that differences and silences are important to consider within situations.

Having considered SA as a methodology-methods research package, its strengths and weaknesses, I concluded SA was an appropriate way to gain a thorough understanding of the situation of inquiry. However, I was aware of the need to use

SA reflectively during data generation and analysis, due to the possibilities of making assumptions (Allen 2010). Additionally, as I was restricting data generation to interviews, I acknowledged a possible limit in theoretical sampling and how much data I could generate to fully, illustrate all the complexities of the situation. I also acknowledged the potential for messiness and difficulty in distilling the most relevant findings when taking an all-inclusive approach to situation (Maher 2008). Therefore, I determined to use my research questions, aims and objectives as guidelines in all processes of data generation, analysis, and synthesis. Further, to apply the theoretical principles involved in SA data generation and analysis throughout, including when presenting study findings.

Chapter 4. Methods

In this chapter, I present the research study questions, aims, objectives and research design. I consider ethical matters and steps taken to ensure an ethical study. I describe sample inclusion/exclusion criteria, recruitment processes, interview format, and an outline for interview questions. I describe the systematic data generation and analysis steps I took. Furthermore, when describing the data analytic processes, I provide examples of data analysis to show research transparency. Additionally, I explain steps taken to manage influence of the Covid-19 pandemic, which occurred during data generation and analysis. Finally, I present study quality assurance processes and the steps I took to ensure research credibility and trustworthiness.

4.1. Research Questions

Three main research questions underpinned the study:

i. What community PA opportunities are available for C&YP with neurodisability and where do they participate?
ii. What are facilitators and barriers to participation?
iii. What key areas need further action to increase participation and support for participation?

I defined community PA participation by its context and its form, as highlighted in research evidence. For example, Carlon et al (2013) define habitual PA as the accumulation of PA across a day from daily occupations, plus physically active play and participating in organised sports and physical recreation activities. Daily occupations are an important part of daily PA and a way of increasing PA participation i.e. by reducing sedentary behaviours during usual daily life. However, this thesis does not examine sedentary behaviours and usual activities of daily living (ADL), rather this thesis examines PA within the ICF participation domain (WHO 2001). Therefore, I chose not to include usual daily occupations as part of the definition of community PA participation. Instead, I followed the other aspects of PA that Carlon et al. (2013) examined, namely physically active play and participating in organised sport and recreational activities, as well as following Ross et al.’s (2016) definition of PA participation. This definition requires that PA involves physical exertion and communal involvement; at the same time understanding that I would not be able to measure the amount of physical exertion expended using a qualitative approach (interviews). However, I would be able to get PA descriptions from interview participants regarding their physical involvement in community PA and their physical exertion, which was a pragmatic compromise. I also followed Imms et al. (2016) definition for participation that requires involvement i.e., physical involvement in PA participation, and requires attendance i.e. attending a participation opportunity. I did not only consider attendance at PA opportunities however but also included physical play and informal, spontaneous sport and recreational physical activity participation that can happen when not attending a PA opportunity.

The aim of this thesis is to find ways to increase C&YP’s PA participation over and above usual daily living occupations in a participation context. Therefore, I chose to include PA outside of a daily occupations and hospital clinical settings as already detailed, and defined community participation contexts as participation within schools, community groups/clubs, families’ homes and/or surrounding neighbourhood environments e.g., in parks, on cycle paths. I defined community participation within these contexts in three-ways - i) physical play, ii) informal, unorganised, unstructured physical recreation/leisure activities and sport iii) formal, organised, structured physical recreation/leisure activities and sport. Physical play is an important part of childhood and provides opportunity to increase physical exertion. Therefore, I sought to include it as a form of PA participation. I defined physical play as being actively involved in physical movement with others e.g., parents or friends and participating in PA informally for fun and enjoyment (Oxford Dictionary 2023; Shakiko-Thomas et al. 2014). Examples of physical play include running, rolling, climbing, hopping, skipping and jumping in games and/or informal sport, and playing in this way with others. I defined play being with others to follow the communal involvement component of Ross et al.’s (2016) definition of PA participation. I defined informal, unorganised recreation/leisure and sport activities according to the definition provided by King et al. (2003) - participation in physical recreation/leisure activities and sport that have recognised rules, but these are not followed exactly, i.e., there is informal play with others, and the participation is unstructured. Similarly, according to King et al. (2003) and WHO (2007b) I defined formal, organised sport and recreation/leisure activities as structured participation with others where rules are followed and there is a designated leader/coach involved. The difference between recreation/leisure activities and sport activities (whether formal or informal) is that sport always involves an element of competition, whereas recreation/leisure PA may not.

4.2. Research Aims and Objectives

The research study had two aims:

i. To identify and understand the system of community PA participation in operation for C&YP with neurodisability.
ii. To identify key action areas to increase support for their participation and increase their participation.

I set five research objectives:

i. Explore C&YP with neurodisability and their parents' experiences of community PA participation using family interviews.
ii. From family interview data, identify service providers and service provider organisations supporting community PA participation.
iii. Explore service provider and service provider' organisation provision and support of community PA participation, using service provider interviews.
iv. Identify facilitators/enablers and barriers/hindrances to participation using SA of all participant interview data (families and providers).
v. Make recommendations to increase participation and support for participation using SA.

4.3. Research Design

The research design was a SA, using interview data, a qualitative, interpretive epistemology, and inductive and abductive reasoning.

A Qualitative Interpretive Approach

I determined a qualitative interpretive approach most appropriate to answer the research questions, because qualitative research methods find out about social matters and gain participants' views on how issues affect their lives (Bryman 2012). I deemed interviews appropriate, as interviews facilitate sharing and discussion regarding social situations, and allow participants to explain and clarify their experiences, and their views on their experiences (Barbour, 2008). I chose semi-structured interviews because semi-structured interviews provide participants with freedom to express themselves and discuss their experiences and views, whilst still allowing the interviewer to keep interview conversations focussed on the research aims and objectives (Silverman 2017). Further, semi-structured interviews allowed me to follow SA methods of starting with the situation broadly conceived and growing knowledge of the situation with data generation. Semi-structured interviews gave me a broadly conceived situation to explore and flexibility to follow where interview content led, to determine the situation in more detail. I understood however that using interviews had limitations. For example, interviews would not provide observable data regarding participation i.e., could not give me directly observable information on C&YP's physical exertion, attendance and communal involvement – which are the component parts of the PA participation and participation definitions (Imms et al. 2016; Ross et al. 2016). Ethnography alongside the use of interviews would provide more details regarding these aspects of participation because C&YP, families and providers could be directly observed and interviewed regarding their participation, and regarding what researchers observed. However, it was likely that a large team of researchers would be needed to observe numerous and diverse participation contexts/settings, families and providers, and determining which contexts/settings and individual stakeholders' situations to choose for observation brought challenges, due to the dearth of evidence directly examining community PA participation that could inform such an approach.

SA develops knowledge of a situation using overlapping data generation and analysis due to following a GT theoretical sampling tradition (Glaser and Strauss 1967). Thus, SA supported my approach to using two overlapping, cyclical interview work-streams, which informed each other, thereby using a form of purposive theoretical sampling. GT introduced the concept of theoretical sampling to purposively sample, with the aim of producing and refining an emergent theory (Glaser and Strauss 1967). However, theoretical sampling is now also a recognised term used in qualitative research that does not claim to be GT. Where the term indicates purposive sampling informed by developing ideas from analysis of previously generated data (Bryman 2012).

An interpretive approach (Blumer 1969) facilitated my interpretation of numerous perspectives on the interview data, including my own perspective. I saw this as beneficial because I reasoned exploring numerous perspectives, including my own, would allow thorough analysis and increase critical awareness of my influence on data generation and analysis. SA' multiple data analytic mapping processes, and extensive reflective memo writing, provided me with another opportunity to increase my critical awareness of different perspectives. For example, reflective memo writing alongside repeated analytical cartography helped me become aware of my own thought processes, interpretations, and their influences on data generation and analysis. I provide an example of some reflective memo excerpts in Appendix 1. To further, increase my own critical awareness, as I was the data generation and analysis instrument (Bryman 2012), I asked for regular feedback from PhD supervisors during data generation and analysis. By involving two external feedback sources in this way, I had two experienced research moderators of my thought processes during data generation and analysis.

Logic and Reasoning

SA uses both inductive and abductive logic and reasoning. I used inductive reasoning when making generalisations from specific data findings. For example, I developed generalisations inductively by comparing a growing number of similar observations from a growing number of specific interview cases. Similar observations from more and more cases revealed regularities within and across the data, from which I could then draw general conclusions i.e., generalise, perform provisional general theorising (Clarke et al. 2018). I then confirmed generalisations by moving from the generalisation back to examine the specifics within interview data. If I encountered irregularities or differences between cases, I sought more information by reading published documents, making enquiries e.g., emailing participants to clarify their data, making telephone calls to information sources e.g., insurance providers to find answers to insurance questions raised in the data, and seeking participants who could speak to the irregularities and differences found. I also investigated web site sources of information e.g., organisations' web sites. To stay true to the SA approach, I did not exclude difference and irregularity from final data findings and final study findings but saw these as part of the situation (Clarke et al. 2018). During data analysis, I used abductive reasoning when comparing the generalisations I generated against specific details within the empirical interview data. I also moved back and forth between the generalisation and data specifics, to confirm findings and to synthesise final study findings.

4.4. Ethical Considerations

The study received ethical approval from Cardiff University (CU), School of Healthcare Sciences, Research Ethics Committee, in September 2019 (Appendix 2). I conducted study interviews over a 20-month period, November 2019 - June 2021.

Ethical issues included consideration of involving C&YP in research, participant recruitment processes, access to C&YP, consent and assent processes, risk management and safeguarding of C&YP. Additionally, participants' expenses and remuneration, maintenance of participants' anonymity and confidentiality, and ensuring secure and appropriate data management, and data dissemination. I present consideration of these ethical matters starting with involvement of C&YP in research.

Involving C&YP in Research

Article 31 of the UN convention on the rights of the child (UNCRC) states that C&YP have a right to play and participate in recreation activities e.g., sport and PA (UN 1989). Thus, the UNCRC (1989) provides an ethical framework for exploring community PA participation by C&YP with neurodisability. Furthermore, equality legislation (Equality Act 2010) recognises individuals with disability have an equal right to access community participation, and to have equality and equity in provision of opportunities and choices. Similarly, article 30 of the UN convention on the rights of persons with disability (UNCRPD) (UN 2006) recognises disabled persons equal right to participate in community recreation and leisure activities. Therefore, the thesis has strong ethical foundations.

By involving C&YP in research, I aimed to find out C&YP's views and their perspectives on their life conditions, activities, and experiences (Fleming and Boeck 2012) - as these related to community PA participation. I viewed C&YP as social actors able to express their views, who had agency and ability to shape and influence the situation of inquiry (Alanen 2001 p12). When involving C&YP with neurodisability, I realised physiological and developmental impairments could potentially hinder their ability to express their views and perspectives. Therefore, I sought to meet them with suitable linguistics within interviews, to use adjuvants such as toys, drawing, play, and parents' support - to gain access to C&YP's views and perspectives. To aid this process, I additionally sought to meet C&YP in their own home environment with a known adult, i.e., parent, present. However, I also sought to limit parental influence within interviews to ensure I gained access to C&YP's views and experiences. I did this by clarifying with parents, prior to interview, my aim to facilitate C&YP to express their own and not others e.g., parent viewpoints and perspectives. Additionally, I provided parents with a separate interview opportunity, to express their own views without their child present in case parents wanted to discuss challenges and difficulties they faced, uninhibited, i.e., without their child present. Hoping this would also limit parents' need to express themselves within their child's interview.

As C&YP were not adults, a parent with parental rights needed to provide consent for their participation, I only accessed C&YP through parents, who therefore acted as gatekeepers for their child. Thus, I involved parents throughout the research process. For example, in asking parents to share study information with their child, discuss participation with their child, in planning interview times with parents, having a parent present when interviewing C&YP, and in asking parents to share final study findings with their child.

Recruitment Processes and Access to C&YP

Recruitment of C&YP occurred via gatekeepers therefore I had no direct access to C&YP. Gatekeepers included parents, professionals and service providers within varied organisations. I approached providers I knew in charity, healthcare (outside the NHS), and education organisations and networks. I gave providers information on the study via a study advert (Appendix 3), which providers could share with families. The study advert contained my contact details therefore families interested in participating could contact me to find out more about participating. I therefore did not contact any families directly. I also asked the providers who shared the advert with families whether they wanted to participate. I gave these providers additional information on the study via an adult/provider participant information sheet (PIS) (Appendix 4). Providers could then contact me to find out more about the study and ascertain whether they wished to participate or not, and whether they wished to share the study details with families within their organisations and/or organisation networks.

Consent and Assent Processes

All consent and assent processes were completed prior to all participants' participation. All adult participants provided written informed consent for their own participation. All parents provided written informed consent for their child's participation. All C&YP provided written informed assent for their own participation. The requirement that C&YP provide written informed assent meets the ethical expectations required for ethical approval of the study but is a limitation of the study. An institution requiring written informed assent from C&YP within their ethical approval processes is an example of institutional ableism. Some C&YP with neurodisability are not physically able to write and may not have assistive technology to be able to write. The need to provide written informed assent thus excludes these C&YP. This exclusion does not meet the ethical principle of providing equal opportunity for any child/young person with neurodisability to participate in the study. To gain consent and assent, I prepared several PIS, consent forms, and assent forms for different age groups. The different PIS and consent/assent forms contained age-appropriate information on the study, detailed what would happen if participating, and what happened to participants' data. I emailed all the different PIS with related consent/assent forms to potential participants at least two weeks before completing consent/assent processes. Thereby, all participants had opportunity to read the PIS, or have the PIS read to them by parents at least two weeks prior to participation. All potential participants then had opportunity to ask any questions, and have their questions answered - in person, via telephone, and/or via online platforms - before completing consent/assent processes.

I conducted consent/assent processes in person, for face-to-face interviews, and made sure to have all PIS versions (adult and child/young person versions) available in hard copy with me, when conducting face-to-face consent/assent processes. Thereby, I could make sure all participants had read the PIS, previously sent to them, and that they understood what participating involved. Participants had time to ask questions, have these answered, before signing and dating consent/assent forms, with myself as witness. During Covid-19 social restrictions, I completed consent/assent processes with C&YP, parents and providers using an online platform e.g., Zoom or Microsoft Teams. When consenting and/or assenting online, participants used an electronic signature or the draw feature in Microsoft Word to provide draw/sign consent/assent. Furthermore, families and providers completed consent/assent processes visible and audible to me, via the online platform, enabling me to witness the process. Parents and providers then sent the consent/assent forms via their personal or organisation email to my secure CU email address. I ensured receipt of fully completed consent and assent forms, for all participants, before involving adults and C&YP in interviews.

To gain written informed assent from C&YP, I provided two, different age-appropriate PIS i.e., one for C&YP aged 4-11 years (Appendix 5) and one for C&YP aged 12-17 years (Appendix 6). I encouraged parents to read the PIS with their child and discuss the study with their child - to see whether their child wanted to participate. As previously reported, I provided the PIS again when meeting parents and C&YP, to discuss study participation and complete consent/assent processes. Prior to consent/assent meetings, I additionally discussed all study information, interview formats/processes with parents, what I hoped to find out in interviews, and answered parents' questions - usually via telephone, or sometimes using an online platform. Conversations with parents additionally enabled discussion on a suitable interview format, time, and place for a family interview. Moreover, I discussed with parents how I hoped to gain C&YP's own views and experiences within interviews.

Following all these processes, if C&YP were happy to proceed, they were required to sign/initial/mark the relevant areas of an age-related assent form in the presence of their parent and myself, as witnesses. I used two age-appropriate assent forms - one for C&YP aged 4-11 years (Appendix 7) and one for C&YP aged 12-17 years (Appendix 8). Parent consent for their child's participation followed the same process, however, involved a parent for child PIS (Appendix 9) and parent for child consent form (Appendix 10). If parents were willing to additionally, participate themselves, I also provided them with the adult PIS previously described (Appendix 4) and an adult consent form (Appendix 11), which they signed prior to participation. I also clarified with parents their child's CP Gross Motor Function Classification Scale (GMFCS) (Palisano et al. 1997) and GMFCS-Expanded/Revised version (GMFCS-E&R) (Palisano et al. 2008) levels for C&YP who had CP, using language descriptors (Appendix 12). Service providers received an adult PIS (Appendix 4) and adult consent form to sign (Appendix 11) and followed the same consent processes as followed by parents for their own participation.

All PIS provided to families and service providers detailed what the study involved, that participants had the right to withdraw at any stage without providing a reason, and the right to withdraw their data up to the point of thesis submission. Furthermore, that I would use anonymised quotes within the thesis and other dissemination and education formats. PIS additionally detailed how I would maintain participants' confidentiality and anonymity and manage and store data securely and confidentially. PIS also detailed study risks, how I would manage study risks, and how participants could make a complaint if necessary. I presented details on risk, liability and safeguarding to all participants, including in a child-friendly format to C&YP (within their age-appropriate PIS).

Risk Management and Safeguarding

Prior to study commencement, I conducted a study risk assessment. I used a CU study risk calculator to calculate study risk (CU 2019a). I calculated the study risk as low (Appendix 13) therefore no ameliorating actions were necessary. Study risks involved potential emotional distress to participants when discussing potentially emotive topics. I detailed study risks were low in the PIS and discussed risks with all participants prior to their participation, as part of consent/assent processes. To reduce emotional risk to participants I advised participants they could refrain from discussing anything if they wanted to, and could withdraw from the study at any stage, without providing a reason. Furthermore, I advised participants they could stop the interview, and the recording device, at any time. In the interviews, I was sensitive to linguistics and body language, pausing as necessary to provide participants time and space to deal with any emotions raised by the topics discussed. Therefore, I paused and gave time to participants, if they got emotional, and clarified with participants whether they were happy to continue. Two parents cried in their interviews and one young person got upset when describing their difficulties with walking. In these instances, I paused the interview and recording device and gave participants sufficient time to deal with their emotions. Furthermore, I ensured they recovered emotionally within the interview, and were happy to continue the interview, before continuing. I also clarified no adverse effects at conclusion of the interview. Following all interviews, I contacted all parents and adult participants within a week, via telephone and with a follow-up email, thanking them for their participation, and enquiring regarding any potential adverse effects following participation. Additionally, I gave opportunity for the parent/adult participant and C&YP participants to meet with me again to debrief following study participation, should they wish to do so. No participants reported requiring such measures. Additionally, I advised all parents to contact their general practitioner (GP) services should they feel the need for emotional and mental health assistance, for themselves, or their child. No participants communicated this necessary.

Regarding safeguarding, I made all participants aware that I would need to contact their local authority social services should I encounter any safeguarding issues whilst conducting the study. This information was provided in writing in all the PIS and discussed with parents prior to their child's participation. I noted no safeguarding concerns whilst conducting the study. To safeguard myself, I followed CU guidance provisions on lone working (Health and Safety Executive 2020). Following this guidance, I ensured I left my contact details with a work colleague, including the location of an interview, before attending interviews on my own. I conducted most interviews during working hours, Monday to Friday. However, one family interview occurred on a weekday evening, and two occurred on a weekend. When interviews moved online during Covid-19 restrictions, following lone working guidance was not necessary, as all processes and interviews moved online. However, I ensured no personal details/effects were visible during online meetings and interviews to maintain confidentiality of personal information.

Remuneration

I made all participants aware, before participation, in writing (in PIS) and verbally, that participation was voluntary and that there were no payments or rewards for participation. Furthermore, that the study had no funding to provide payment or remuneration, however, I told participants that I would reimburse any travel expenses encountered to travel for interviews. I endeavoured to meet participants in their home or at their place of work so that they did not need to travel, and that location of interview was convenient for them. However, I was ready to reimburse any parents or providers for any travel expenses encountered, from my own personal funds. No participants reported accruing any travel expenses. However, I accrued travel expenses, which I paid from my own, personal funds.

Personally, I wanted to thank families for their time therefore self-funded £10 book vouchers, pizza eatery vouchers, and online store vouchers for families to choose from, as a thank you for their participation. I only notified parents of these voucher choices and availability following families' participation, i.e., via follow up telephone and email communication following their participation. Thereby, avoiding any possible bribery or coercion concerns. I then sent the voucher to families via postal mail, with a thank you card, thanking families for their participation. I checked receipt of the voucher and card one week later, via email or telephone. I encountered no problems following these processes.

Data Management

I securely stored and managed all data according to General Data Protection Regulation (GDPR) principles, the Data Protection Act (2018), and CU (2019b) Information Security Classification and Handling Policy. All participants contact details (names, email, postal address, telephone number) were stored on my CU password protected hard drive (One-Drive) and deleted following completion of the study and dissemination of findings to all participants. All paper consent forms were stored in a locked drawer in my locked CU office, in Ty Dewi Sant CU building. All, electronic, digitally photographed, and scanned copies of electronically completed consent forms were stored on my CU password protected One-Drive. I submitted all paper copies and electronic/digitally photographed/scanned copies of consent forms to CU on completion of study for CU to keep for 5 years, in alignment with the CU (2023) Data Retention Policy. I then deleted all copies from my CU One-Drive.

All Dictaphone interview audio recordings, I downloaded onto my CU password protected One-Drive, then, deleted the audio files from the Dictaphone. All online interview audio recordings were download into a file, on my CU password protected One-Drive. Once I had transcribed the interviews, I deleted the audio recordings from One-Drive and ensured they were no longer located on the online platform. I anonymised all identifying names of people and organisations in transcripts by using pseudonyms or general descriptions, and deleted actual names of people, organisations, and places. When using a transcription service, I uploaded audio files to the transcription service, using their secure encrypted processes. The professional transcription service guaranteed data security and deletion of audio recordings once I downloaded completed transcripts from their secure service platform.

I kept all transcripts in a file on my password protected CU One-Drive to which only I have access. I shared some of the transcripts with PhD supervisors as part of quality assurance processes when coding and analysing data. I shared transcripts with PhD supervisors via CU secure email and/or in face-to-face meetings via my One-Drive. Following thesis submission, I will keep the transcripts securely on my CU password protected One-Drive, for five years, according to CU (2023) Data Retention Policy. Similarly, CU will keep securely for five years the transcripts and consent forms handed to them on completion of the study, before destroying/deleting the data, according to their Data Retention Policy (CU 2023).

Anonymity and Confidentiality

To ensure all participants anonymity and confidentiality, all participants chose a pseudonym, or I gave them a pseudonym if they failed to choose one. I then anonymised all participants within transcripts and reflective memos, using their pseudonym. I stored all transcripts and reflective memos under participants' pseudonym with no identifying features such as participants' names and contact details alongside transcripts and interview reflections. Thereby, I kept data and participant identifiable details, separate. Furthermore, I reassured all participants of these anonymising processes in writing (in the PIS) and verbally before, during and after completion of consent/assent processes and their interview. Participants agreed to these processes when signing the assent/consent forms. I anonymised service providers' organisations and locations by giving organisations and locations descriptions/descriptive abbreviations, and did not specifically name any organisation, or its location. Thereby, I protected organisations' anonymity and confidentiality. I reassured all participants, service providers and provider organisations of their anonymity and confidentiality, i.e. within data generation, analysis, PhD thesis, and any research dissemination outputs. Additionally, I reassured all participants that I would not inform anyone of their participation, unless a safeguarding matter arose. I informed all participants of the need for me to break anonymity and confidentiality processes if a safeguarding matter arose and that I would contact their local authority social services department in such instances.

To generate interview data, I employed two overlapping, cyclical interview work-streams. Work-stream-one involved interviews with families and work-stream two involved interviews with service providers. First, I present details regarding family interview data generation followed by service providers.

4.5. Family Interviews

Family interviews involved C&YP with neurodisability and their parents. Where C&YP did not have verbal communication and/or did not wish to participate, I interviewed their parents as proxies. There are limitations in understanding a situation when using proxy views gained from parents because parents are insiders in managing their child and regarding their child. Thus, parents may inadvertently express views of themselves instead of their child or express their own views as representing their child’s views. Interview data could therefore be generated in a biased way that does not represent C&YP’s experiences or viewpoints i.e., proxy interviews do not provide first person accounts from C&YP about their experiences and viewpoints. First, I describe family interview inclusion and exclusion criteria, followed by sample recruitment processes, interview format, and interview quality assurance processes. I also detail how I managed the impact of Covid-19 social restrictions following the first Coronavirus Act (2020).

Inclusion and Exclusion Criteria

Family interview inclusion criteria were families involving a child or young person with a confirmed diagnosis of neurodisability e.g., Cerebral Palsy (CP), Autistic Spectrum Disorder (ASD), Profound Multiple Learning Disability (PMLD), Attention-Deficit Hyperactivity Disorder (ADHD). Inclusion criteria aligned with conditions commonly seen in paediatric physiotherapy clinical practice, and matched published definitions of neurodisability (Poutney 2007; Rosenbaum and Gorter 2012; Morris et al. 2013). A physician needed to have previously confirmed diagnosis with the family. The aim of asking parents whether their child had an official diagnosis and clarifying this diagnosis with parents before including C&YP in the study, was to ensure sample participants fitted the population defined to be the target population of the research study. However, requiring clarification of a diagnosis prior to inclusion, could have excluded those families who did not have an official diagnosis, or were unaware of one. Thereby reducing equal opportunity for participation. The study recruitment materials did not however state that a diagnosis was required, therefore anyone wanting to participate was able to contact the researcher to explore participation because the study advert did not advertise the inclusion criteria.

Furthermore, all those parents who contacted me to enquire about their child/family’s participation provided an official diagnosis. Therefore no one who enquired about participation was excluded based on this inclusion criterion. However, reflecting on the use of this inclusion criterion has highlighted an unintentional medical lens/bias in the study inclusion criteria.

C&YP needed to be school aged i.e., 4-17 years. I reasoned school-aged C&YP necessary as they are eligible to participate in PA within school and other, wider ranging, community settings, rather than just eligible for pre-school playgroups (such as C&YP aged 2-4 years) (Welsh Government 2023d). I determined an upper age limit based on the UN (1989) definition of a child i.e., anyone under 18 years. Families needed to live in a specific geographic region covering four specific local authorities - including three large cities, numerous towns and villages, and rural, coastal, and inland areas. This situated the inquiry geographically to include a variety of community settings and local authorities. The reasoning for location criteria were to include a variety of environmental factors that could influence the situation, whilst keeping the project manageable by one researcher. Parents included, needed to have parental responsibility for their child and provide consent for their child, and their own participation.

Exclusion criteria were C&YP without a confirmed diagnosis of a neurodisability, who lived beyond the study geographic boundaries, who were under 4 years of age, or ≥ 18 years of age. I also excluded C&YP who were unable to provide written informed assent for participation, and those C&YP whose parent/s did not provide written informed consent for their participation.

Recruitment

Overall, I recruited 12 families involving 13 C&YP. One family included two C&YP (siblings) diagnosed with a neurodisability. All participants were volunteer participants recruited via purposive sampling. I recruited participants as detailed previously when presenting ethical considerations. The study advert and various PIS I created and shared for study recruitment and consent/assent processes, described my interest in exploring games, sport and PA participation. Therefore, those families already participating in PA, and who had an interest in PA participation, may have been more likely to respond to the study advert and PIS. Thus, potentially biasing recruitment and study sample towards more, physically active C&YP/families. I attempted to limit this bias by informing providers of my desire to include non-active C&YP, and families not engaged in community PA.

In addition to purposive sampling, I used snowball sampling (Silverman 2017). I asked participant families and providers whom else they thought should be involved. If families and providers identified other potential participants and offered to share the PIS and advert with them, I provided families and providers with additional study adverts and/or PIS to share. Snowball sampling is powerful in showing networks of relationships but is unlikely to be representative of the wider population of C&YP with neurodisability therefore does have limitations (Bryman 2012). Data analysis of family interviews additionally grew sampling, by identifying organisations involved in family situations, whose contact details I then scoped online. I then sent the study advert, and PIS to these providers, asking providers to consider participation and/or to consider sharing of study information within their family networks. At no point did I use bribery or coercion within recruitment processes, and I abstained from any further contacts when receiving negative or no responses following initial, and one further follow-up, contact. I did not recruit via the NHS, or use NHS contacts, as this involves additional ethical approval requirements, which would have increased the time needed to start and complete the study. I had planned to obtain NHS ethical approval in 2020 for recruitment through the NHS, to spread a wider net for greater recruitment and more, varied recruitment. However, Covid-19 stopped this plan and process due to the unprecedented pressures the NHS faced in 2020 from the Covid-19 pandemic (Coronavirus Act 2020).

Interview Format and Quality Assurance

Family interviews were semi-structured. Therefore, I had some pre-planned questions to ensure I addressed the primary research questions, aims and objectives. However, simultaneously the semi-structured format allowed flexibility to follow participants’ interview conversations wherever they led (Bryman 2012). My aim was to facilitate participants to tell their own story/stories and follow where they lead when they recounted their experiences. Simultaneously, I aimed to ensure I addressed the research questions, aims and objectives.

I offered face-to-face, telephone and online interviews. The aim of offering a variety of interview formats was to ensure interview choices for families. I offered interview time and place to be whatever was convenient for participants e.g., at their home, at any time of day suiting families. By providing flexibility to suit families, I additionally hoped to ensure families would be comfortable, at ease, and freely able to talk. A parent accompanied C&YP during interview, which may have limited C&YP's ability to talk openly. However, reflections on the interviews did not evidence parents limiting C&YP's conversations. Additionally, I informed parents prior to participation that I wanted to gain C&YP's own opinions, experiences, and viewpoints; therefore, I asked parents to let C&YP talk without interruption wherever possible. Furthermore, I offered all parents the opportunity to talk with me, without their child present. Thereby, providing parents with an opportunity to talk uninhibited regarding their experiences and viewpoints, and any challenges or difficulties they may have faced. I reasoned providing this opportunity could potentially limit parent influence on C&YP as well, during interviews with C&YP, as parents would have their own opportunity to speak.

I broadly conceived the situation of community PA participation, therefore, did not want to lead or limit interview conversation so that I could gain a more detailed and accurate view of the situation, from participants' perspectives. I provided guidance regarding interview format and questions to parents prior to interview, so that parents were informed and could inform their child regarding interview participation. The information I provided detailed interview process and likely interview questions. I provide an example of questions in Appendix 14. Before, during and after participation I made sure all participants were aware they had the opportunity (at any stage), to clarify anything, refrain from answering any questions, and to withdraw from the study without consequences, or needing to provide any reasons. No families withdrew from the study, or withdrew their data from the study, during or following participation.

I started interviews with icebreaker questions getting to know C&YP, building rapport, finding out what C&YP were interested in, if they had siblings, siblings' ages, and what C&YP liked to do. In face-to-face interviews I made sure I was sat at the same level as C&YP e.g., sitting on the floor, I made sure, I was clearly visible and audible, and that C&YP were clearly visible, audible, and looked comfortable to participate. I aimed to establish rapport with C&YP from the outset; to ensure C&YP felt valued, respected, relaxed and were aware that I was not a threat to them, in any way. I wanted C&YP to feel in control of the interview, and to be relaxed and happy to chat to me and tell me their views and experiences.

Therefore, I used age appropriate cognitive, linguistic, social, and developmentally appropriate interpersonal communication (Morison et al. 2000). Having worked clinically as a paediatric physiotherapist for many years, volunteered with C&YP in several different community contexts, and having two children of my own, I drew on my experiences with C&YP and my established skills in healthcare communication with C&YP and families, to manage interview conversations. I encouraged C&YP to tell me if they had experiences of PA or not, if so, what they were, if not, why? I aimed to let C&YP lead me in conversation directions appropriate for them, whilst attempting some underlying guidance - i.e. light-touch management in keeping conversation topics relevant to the situation of inquiry. I was ready to involve parents (present in interviews) or not, dependent on whether parents appeared as facilitators or inhibitors of C&YP’s conversations. I followed Morison et al. (2000) conceptual model for interviewing C&YP, which involves gaining background information on C&YP from parents prior to the interview. Establishing with parents, prior to interview, parents’ willingness for me to interview their child, and willingness for their child to speak for themselves. Additionally, establishing with parents, the most suitable time and place to interview their child.

Following Morison et al. (2000) conceptual model for interviewing C&YP, I established rapport with C&YP at the beginning of the interview. I explained the aims of the interview in a child-friendly way, gave guidance on how long the interview would likely take, and reassured all participants that they did not have to answer any questions, if they did not want to. Furthermore, I informed C&YP and parents they could stop the interview at any time, and/or stop the interview audio recording device, at any time. I made sure C&YP were aware of the audio recording device, in both online and face-to-face interviews. Furthermore, had handled the Dictaphone (in face-to-face interviews), and were able to switch it off and on, before starting interviews. During online interviews, I used the online platform audio recording device and checked regularly through interview that participants were happy for me to continue the interview and continue recording the interview.

Throughout every family interview, I made sure, I was aware of C&YP’s emotions, and responses, to ensure their comfort and my response to C&YP’s conversations and needs in an appropriate and timely manner (Morison et al. 2000). I used paraphrasing, prompts and empathetic, encouraging, age-appropriate linguistics and body language, to aid participants conversation. At the end of interviews, following Morison et al. (2000) guidance, I summed up how helpful participants had been, what the next steps were regarding their interview data, next steps regarding the conduct of the research, and included the intent to provide interview transcripts to parents and C&YP. I made sure participants were aware they could check transcript content on receipt of the transcript, further clarify content, redact content, or add content should they wish to do so. I shared my intent to provide feedback to participants regarding study findings, on completion of the study. I also checked with C&YP, and parents, no adverse effects during and on conclusion of interviews. Parents had my contact details and were able to contact me at any stage before, during and following participation, to clarify anything, or to raise any concerns, or questions. I encouraged parents to do so if they wished. Additionally, I contacted all adult participants one week following interview to provide a debrief meeting and check no adverse effects following participation. No participants reported any adverse effects or required a de-brief meeting.

Audio recording interviews ensured no data generated was lost. I transcribed all interview audio recordings verbatim, which allowed me to immerse myself in the data, and become familiar with the data (Braun and Clarke 2006). As the research timeline progressed, I was able to secure funding for a transcription service to aid completion of interview transcriptions in a timely manner. I checked all interview transcripts for accuracy, both those I transcribed and those the transcription service transcribed. I checked transcripts accuracy by listening to the interview audio recordings and reading the transcripts simultaneously. Once satisfied transcriptions were accurate, I sent a transcript copy to parents to read, and to share with their child. On sending transcripts to participants, I additionally encouraged all participants/families to check transcript content for accuracy, and to clarify, add or redact anything if they wished to do so. No families reported any problems with the transcripts or wished to add or redact anything. No families withdrew from the study or withdrew their data from the study at any stage.

Covid-19 Considerations

With Covid-19 social restrictions, all study interviews and study processes e.g., gaining consent moved online (previously detailed). Six family interviews involving four families occurred face-to-face in family homes (prior to Covid-19), and 10 family interviews involving eight families occurred online (during Covid-19 and easing of Covid-19 restrictions). Following introduction of Covid-19 social restrictions, I used the same semi-structured interview guide as used prior to Covid-19 to explore participation prior to Covid-19. However, I then added questions regarding community PA participation during Covid-19 restrictions, during easing of restrictions, and any aspirations or concerns for future participation following Covid-19 restrictions.

Prior to Covid-19 restrictions, all C&YP were involved in interviews, along with their parents. However, with enforcement of Covid-19 restrictions, C&YP's participation dropped, and families became more difficult to recruit. Some parents described their child not wanting to participate in an online interview or not having the communication ability. For example, three sample C&YP (from three different families) were non-verbal communicators therefore I interviewed their parents online, as proxies and family representatives. Overall, I felt, Covid-19 had a negative impact on interviews, hindering my ability to work face-to-face with C&YP and include C&YP with communication difficulties in online interviews. Additionally, Covid-19 stopped face-to-face interaction with providers, therefore hindered family recruitment via service provider gatekeepers.

Summary

Overall, I conducted 16 family interviews. Seven interviews with C&YP (parent/s present) and nine interviews with parents alone. I conducted six in person interviews, face-to-face, in family homes. Four with C&YP and parent present, and two parent only interviews. I conducted ten online interviews - three involving C&YP with parent present, and seven parent only interviews. The total interview time for 16 interviews, was, 14 hours and 23.43 minutes.

I summarise family interview participants, interview format, and total interview time for all family interviews, in Table 2 (p117).

Family No:	**Interview with C&YP - parent present:**	**Interview with Parent alone:**	**No. of Interviews**	**Interview Format:**	**Total Interview Time in hours and minutes (min.):**
1	Yes	No	1	In person Face-to-Face	47.39 min.
2	Yes	No	1	In person Face-to-Face	38.53 min.
3	Yes	Yes	2	In person Face-to-Face	2 hours plus 42.54 min.
4	Yes	Yes	2	In person Face-to-Face	1 hour plus 6 min.
5	No	Yes	1	Online	51.56 min.
6	No	Yes	1	Online	55.56 min.
7	No	Yes	1	Online	1 hour plus 5.13 min.
8	No	Yes	1	Online	1 hour plus 23.16 min.
9	Yes	No	1	Online	1 hour plus 3 min.
10	No	Yes	1	Online	45.51 min.
11	Yes	Yes	3 (2 C&YP, 1 Parent)	Online	1 hour plus 28.51 min.
12	No	Yes	1	Online	1 hour plus 6.17 min.

Table 2: Summary of Family Interviews

The sample of C&YP included nine males and four females. The sample therefore has a male gender bias. I attempted to include more females by asking gatekeepers if they could provide information again, specifically, to families involving female C&YP. However, as I did not approach families directly but waited for families to contact me following their receipt of study information from the gatekeepers/providers, I could not control female recruitment numbers. Additionally, as participants were volunteers, I was unable to target female recruitment more specifically. Predominance of male participants may be due to chance or could be due to more males than females being physically active within the study community area, and/or more males being interested in discussing PA participation, and/or participating in community PA participation. Chapter 1 shows evidence of more males participating in community PA than females (Reid 2016; Ward et al. 2018; Richards et al. 2021). I am however unable to draw any conclusion on this matter.

4.6. Service Provider Interviews

Participants for work-stream-two interviews were service providers from different professions/disciplines who supported families and C&YP with neurodisability in communities, and/or who worked or volunteered for varied organisations supporting families, and/or C&YP's community PA participation. There are tensions in interviewing service providers as they may respond as individuals or as representatives of their organisation or be comfortable speaking for themselves and their organisation. If responding for themselves, there is the potential to share positive and negative experiences/viewpoints (warts and all). If responding on behalf of an organisation, there is the danger of reporting the viewpoints that the organisation wants to project to the public, i.e., the organisations' collective persona, and interviewees therefore glossing over contentious issues or challenges. This tension reflects the situational matrix categories already highlighted in chapter 3, where organisations are viewed as collective humans rather than individual humans or as non-human entities. An example of this tension was encountered when generating data. The example involved an additional learning education needs co-ordinator (ALNCo) I encountered within an education forum. This ALNCo was anxious about participation in the study due to concerns about whether her school head teacher would be happy with her participation. Despite reassuring the ALNCo that her and the school would be anonymised within the data and their confidentiality protected and offering to speak personally about any concerns together with her and/or the head teacher, the ALNCo eventually refused participation. To address this tension when recruiting providers, I did reassure providers that their individual and organisation's anonymity and confidentiality would be protected, I reassured providers they did not have to answer any questions they did not want to and clarified during interviews any uncertainty regarding expressed viewpoints. I also made these ethical elements clear to organisations when approaching them for potential participants, both verbally and in writing with study participant information sheets.

Inclusion and Exclusion Criteria

Inclusion criteria for work-stream-two interviews were individuals and individuals representing groups (i.e., organisation representatives) actively supporting families having C&YP with neurodisability, and/or actively supporting community PA participation by C&YP. Active support could be paid support (employer/employee) or voluntary support (volunteer). The individuals and organisation representatives needed to be active within the geographic boundaries set for the situation of inquiry, which were the same geographic boundaries detailed for family interview inclusion criteria. Exclusion criteria were service providers not located within the study geographic area and providers who did not provide written informed consent for participation. I spoke with several organisation representatives whilst conducting the study, who willingly engaged in conversations regarding the situation, but were unwilling to consent for study participation. Therefore, I excluded these conversations from data analysis and study findings. However, conversations informed knowledge of the situation, and further purposive sampling, including data sources to gain a better understanding of the situation e.g., organisation web site information on their goals and objectives.

Recruitment

I recruited all provider interview participants via purposive volunteer sampling. I sought participants via numerous methods including online searching of service provider' organisations contact details, after identifying organisations as part of the situation from family interviews. When contacting service providers, and service provider, organisation representatives, I introduced myself and shared the study information verbally, and in writing, e.g., emailing the PIS. Those providers interested in participating then contacted me to ask questions, have their questions answered, and set up a time to go through consent processes. Additionally, to set up an interview date and time for interview participation. Some service providers responded positively during initial conversations but then failed to communicate further to set up consent processes and an interview. Additionally, not all service providers responded to my contacts. For example, using purposive theoretical sampling, I deliberately tried to recruit government, law, and insurance representatives, to answer gaps in knowledge identified from family interviews. However, although providers from these social worlds/sectors informally talked with me, they did not consent for study participation. Overall, communication with, and recruitment of providers became increasingly difficult during Covid-19 restrictions. Additionally, even as restrictions eased, I found service providers' responsiveness to communication decreased. My inability to visit providers' organisation work sites and communicate with providers face-to-face, due to Covid-19 restrictions, additionally hindered recruitment. I followed up all initial contacts with a further reminder contact, e.g., via email and/or telephone, before refraining from further contact.

Interview Format and Quality Assurance

The service provider interviews followed a semi-structured format, containing questions informed by research study questions, aims and objectives and previous interviews (e.g. family and other service provider previous interviews). Service provider interview format had slightly more structure than family interviews due to wanting to know about providers' organisation working practices and organisations' aims and objectives. However, interviews still contained flexibility, with open-ended questions that allowed participants to lead conversations. I provide examples of provider questions in Appendix 15. I used the questions along with prompts, active listening skills, empathic paraphrasing, clarification, and summarising to ensure sufficient conversation depth and detail to answer the research questions, aims and objectives (Bryman 2012). I also asked questions raised by family interview data and previous provider interviews.

Every adult service provider gave written informed consent for participation (see ethical considerations). I ensured time, and place of interview, was at a place and time convenient for the participant. I informed participants, prior to the interview, regarding potential questions and topics of discussion. I gave participants the opportunity to ask questions and clarify anything before, during and after participation. Additionally, I reassured participants of their ability to add, redact or redirect conversation within interviews and to redact or add anything to the interview transcripts.

Philipps and Mrowczynski (2021) suggest open, unstructured interviews are best to provide opportunity for participants to express their experiences and perspectives.

However, social constructivism implies interviewee, and interviewer will simultaneously co-construct meaning within interview discussions (Charmaz 2006). Therefore, I provided only light-touch guidance throughout the interview to ensure participants could tell their own stories, share their own views and experiences, whilst still ensuring I addressed the research questions adequately. I ensured I co-constructed accurate meaning with interviewees, listening for participant phrases within interviews that indicated the need for further clarification and detail from participants. Thereby, I hoped to ensure I did not make assumptions. Additionally, I used reflection in action (Schon 1983) during interviews to ensure accurate meaning co-constructions within conversations - reflecting back to the interviewee, wherever possible, my understanding of their meanings to clarify and confirm meaning constructions (Roulston 2010; Philipps and Mrowczynski 2021). Thus, I used the interview guide and prompts intelligently, reflectively, and sensitively. Furthermore, I reassured participants that they did not have to answer any questions they did not wish to, and could stop the interview, and/or the audio recording device at any time.

I audio recorded all interviews to ensure no data was lost and to ensure accuracy of data transcripts, following the same processes as detailed for family interviews. I reassured participants of confidentiality and anonymity in their participation, for them and for their organisation. I offered providers a chance to give pseudonyms for themselves and their organisations and chose pseudonyms where providers did not offer any. At the end of the interview I detailed, again, use of the data, and the ability to check transcripts following transcription processes. Additionally, I detailed that I would share study findings with participants, on study conclusion. I checked no adverse effects following interviews. All participants had my contact details and were able to contact me at any stage before, during and following participation, to clarify anything or raise any concerns. I provided interview transcripts to participants following interviews for them to check content for accuracy and to add or redact anything, should they wish to. Three participants returned their transcripts with added information relevant to the research topic. No participants redacted information or withdrew their data from the study.

Covid-19 Considerations

Covid-19 social restrictions meant all recruitment, consent and interview processes moved online, as already detailed. During Covid-19 restrictions, and easing of restrictions, I focused interview questions on the period before Covid-19 restrictions, then the period during Covid-19 restrictions, easing of restrictions, and aspirations and concerns for the period following Covid-19 restrictions. Overall, service providers' communication and response to my communication became more inconsistent and reduced during Covid-19 social restrictions. During Covid-19 restrictions routine services supporting vulnerable C&YP and families stopped. Placing increased pressure on service providers and unprecedented changes regarding how to organise and manage their services (British Medical Association 2022), which may have influenced provider reduction in communication and recruitment.

Summary

In total, I recruited 11 service providers covering school, sport, healthcare and charity sectors/social worlds. Most participants were involved with charities. For example, some sports organisations were registered companies but also registered charities. High representation of charity organisations within the sample could be due to chance or recruitment processes. Family data informed provider sampling and family data analysis shows that charities, schools and sports organisations were the main service providers that families were involved with and many of the sports organisations involved, were registered charities.

Service providers' professional backgrounds included two physiotherapists, one occupational therapist, one Educational Psychologist, two school PE teachers, one sport company executive, one sport coach, one charity family officer, one physiotherapy student, and one product designer/manufacturer. All providers worked or volunteered in the study designated geographic region and all participated in only one interview.

Total time for 11 service provider interviews was 11 hours and 13 minutes. Seven providers participated in face-to-face, in person, interviews. Four providers participated in online interviews. Providers thus initially responded well to recruitment processes in the overlapping, cyclical interview work-streams. However, with Covid-19 restrictions, service providers became increasingly difficult to recruit. I summarise service provider interviews in Table 9 (p123 &124).

Provider:	Role/Profession:	Organisation:	Format:	Time:
1	Physiotherapist	Independent community volunteer	In Person Face-to-face	43.56 minutes
2	Educational Psychologist	Healthcare Organisation Registered Charity Government School	In Person Face-to-face	56.27 minutes
3	Occupational Therapist	Government School Private Agency Healthcare Organisation Registered Charity	In Person Face-to-face	1 hour plus 44.26 minutes
4	Healthcare Student (physiotherapy)	Community Group, Registered Charity, Volunteer	In Person Face-to-face	45.03 minutes
5	Product Designer	Registered Charity Company Limited by Guarantee	In Person Face-to-face	49.22 minutes
6	Physiotherapist	Healthcare Charity	In Person Face-to-face	46.51 minutes
7	Family Officer	Healthcare Charity	In Person Face-to-face	50.34 minutes
8	Manager	Sport Company Limited by Guarantee Registered Charity	Online	1 hour plus 50.55 minutes
9	Teacher - Physical Education Specialist	Mainstream Primary School with Special Needs Disability Unit attached	Online	53.14 minutes
10	Teacher - Physical Education Teacher	Mainstream Senior School	Online	1 hour plus 5.56 minutes

11	Sport Coach	Sport Company Limited by Guarantee Registered Charity	Online	43.20 minutes

Table 3: Summary of Service Provider Interviews

4.7. Data Generation and Analysis

Initially, I immersed myself in the data by transcribing the data myself. However, I did use a transcription service as the research progressed. I immersed myself in interview data by reading and re-reading the transcripts and listening to the interview audio recordings simultaneously. Thereby, I also checked transcripts for accuracy. The process of listening to audio recordings, reading the transcripts, and reflecting on interview content, allowed me to reflect on the conduct of each interview and consider improvements for future interviews. For example, what additional questions to ask and/or in what ways to find out information. I shared some of the transcripts and my reflections with my PhD research supervisors, which also allowed me to gain more perspectives on the content.

When reading transcripts, I interrogated the data with the research questions in mind. I also used SA sensitising questions (Clarke et al. 2018; Uri 2015), namely - Who and what are in this situation? Who and what makes a difference to this situation? What elements make a difference to this situation? What patterns of collective commitment are present? What are the salient social worlds operating? What are the basic issues and contentions present? What are the different positions on these issues? I open coded the transcripts, line by line, with the research questions and SA' sensitising questions in mind. I placed open, provisional codes in the margins of the transcript. I repeated this process several times with each transcript providing several versions.

Following this process, I started cartographic analysis with the first mapping process - situational analytic mapping. I first created messy situational maps. To do this, I wrote the open codes onto a large piece of flip chart paper. I also found writing the codes onto post-it notes and pasting them onto a blank wall and/or the flip chart paper another useful process to visually, create messy situational maps I provide some examples in Appendix 16. I also used Microsoft Word to create messy situational maps. I performed many iterations of messy situational maps for all interview transcripts. I took photos of many of the maps to keep records of map creations. I created many messy maps before performing relational analysis on the messy maps. During relational analysis, I considered the numerous open coded situational elements in the maps and looked for relationships between them. I then drew relational lines between the coded elements. I created many relational analytic maps and wrote reflective memos on relationships. I provide an example in Appendix 17.

Relational analysis allowed me to organise related, coded elements into conceptualised categories, and fit them into organised situational maps. I provide an example of an organised situational map in Appendix 18. Organised situational maps contained conceptual categories, many matching Clarke (2005; et al. 2018) situational matrix, however, I was open to other categories presenting themselves. In the organised situational maps, I collected different organisations into categories to identify social worlds involved in the situation. Relational analysis of messy maps and organisation of conceptual categories into organised maps also identified social worlds involved. I explored organisations and their social worlds' workings and relations and interactions using social world/arenas mapping; the second data analytic mapping process. Social worlds/arenas analytic mapping grew my understanding of the work of different social worlds and their organisations within the situation. I could also triangulate data from families' experiences of these organisations and social worlds against service providers' experiences. I created numerous iterations of social worlds/arenas maps. In figure 9 (p126), I provide an example of one provisional, social worlds/arenas map. The various lines in the map indicate relationships. Solid lines indicate strong relationships and dotted lines weaker relationships. I analysed strength of relationships and types of relationships when performing repeated cartography and using reflective memo writing.

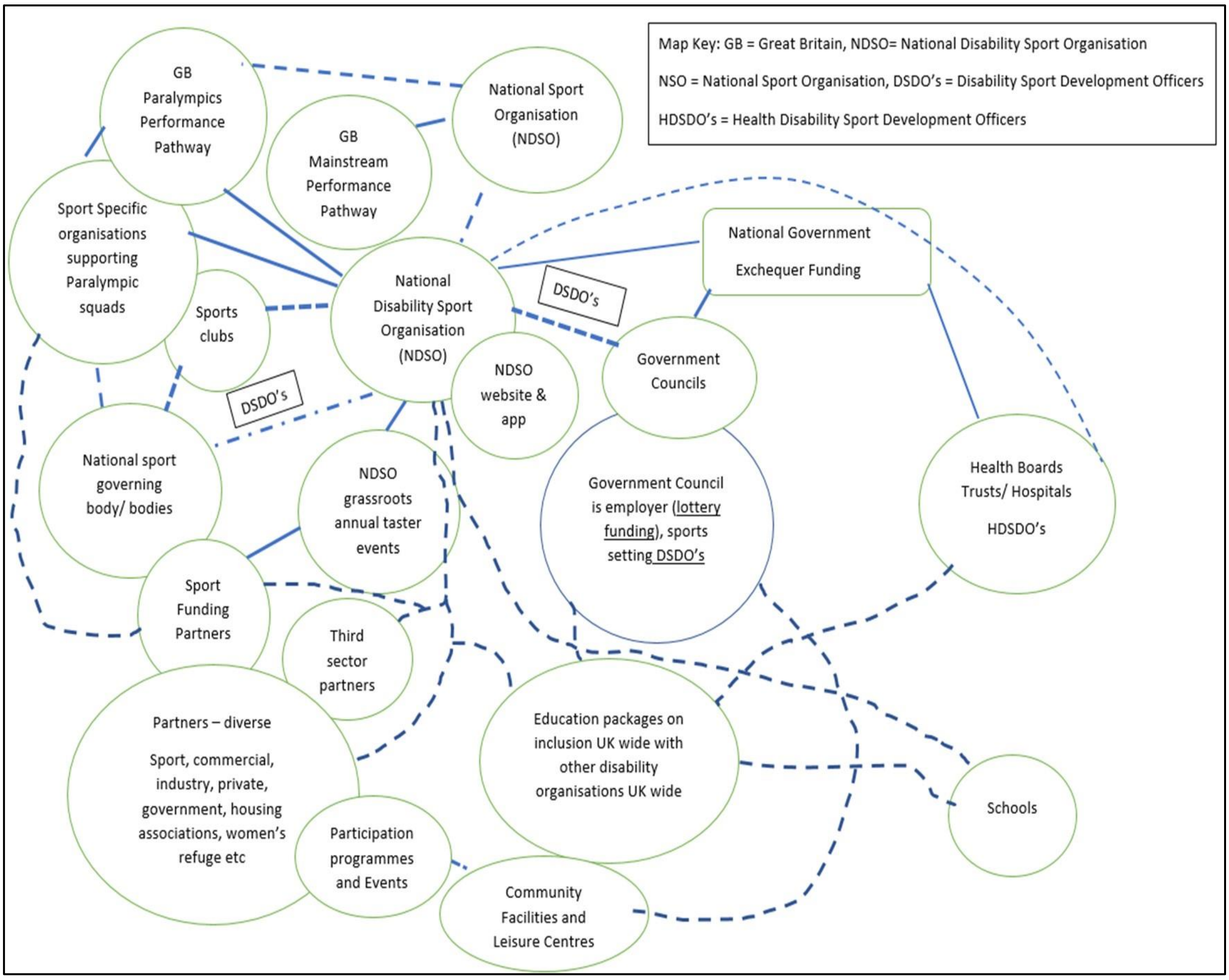


Figure 6: Provisional Sport Social Worlds/Arena Analytic Map Including Relational Analysis

I compared all the social worlds/arenas maps I created for all participants to ensure inclusion of all relevant organisations and their social worlds. Iterative, analytic mapping and comparison of cases helped me identify the most common issues and discourses in the situation. Considering issues and discourses led to the third analytic mapping process, positional mapping.

In creation of positional maps, I firstly determined two different, specifically named, axes on which to map a matter of concern. I drew the axes dimensionally, using an x and y-axes. I positioned different viewpoints/discourses on an issue, at varying points along both axes showing more or less of a position on an issue. I created many positional maps and wrote reflective memos regarding different positions. Positional mapping allowed me to consider numerous perspectives freely without constraint of representing families or service providers (Clarke et al. 2018). Positional mapping also allowed me to use abductive reasoning, moving from conceptual positions in positional maps to discursive empirical data excerpts. I used inductive reasoning to move from discursive empirical data excerpts to map positions. I provide an example of one provisional, positional map in Figure 7 below.

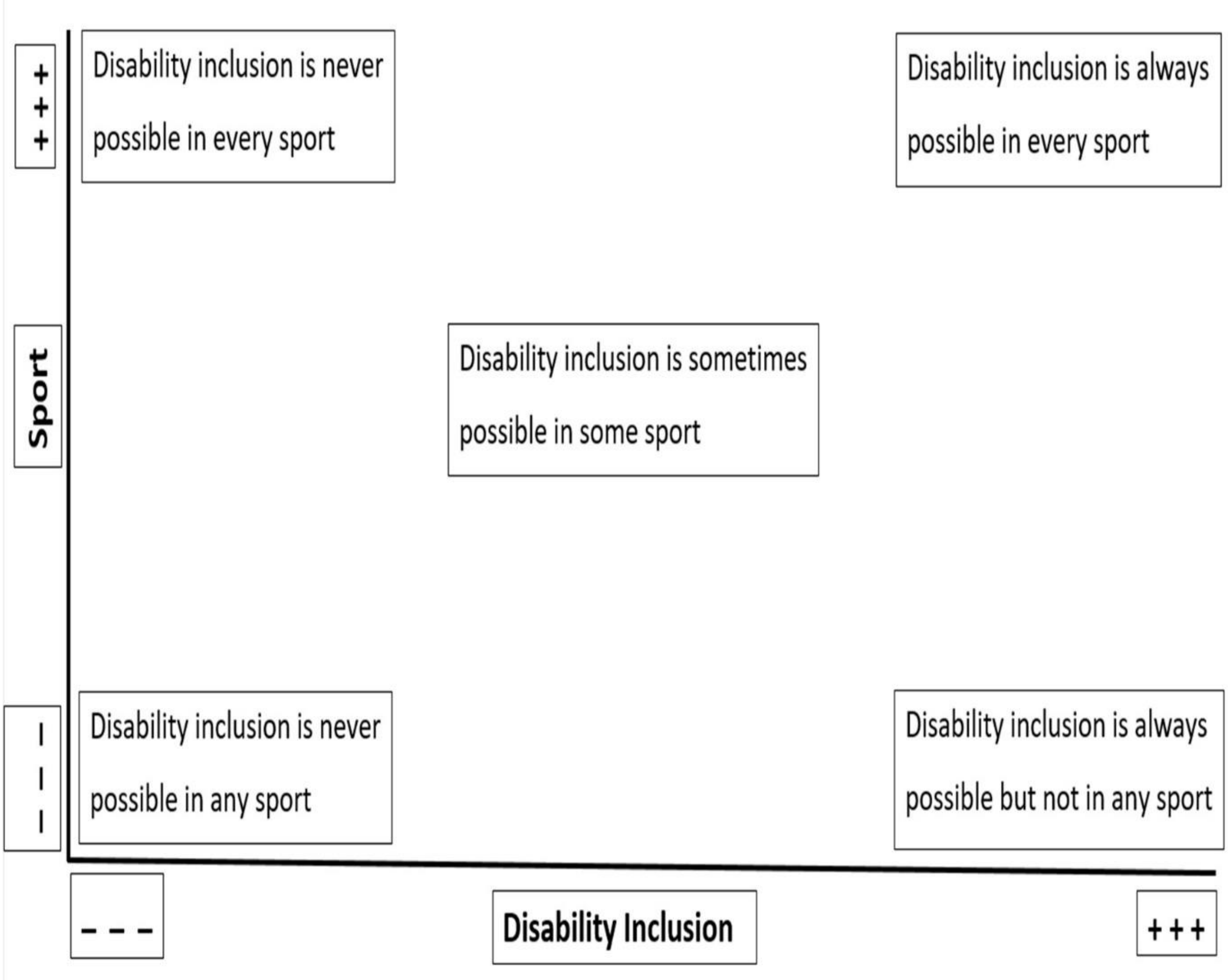


Figure 7: Example of a Positional Analytic Map Map Key: ++++ = more so - - - - = less so

After completion of all three SA' cartographic analytic processes, with many iterations, and much reflective writing, I then decided which findings to present in the thesis findings. Clarke (2005; et al. 2018) asserts the researcher ultimately decides the salient features of the situation to present and how to present the final study findings e.g., whether to illustrate findings with a synthesised, final map or not. The research questions, aims and objectives should guide researchers' decisions. I decided which findings to present using my final synthesised analytic maps and the theory that underpins SA (SI [Blumer 1969]; social worlds theory [Strauss et al. 1964; Strauss 1978], considerations of discourses [Foucault 1972] and ANT [Latour 1987;

2005]); guided by thesis aims and research questions. I also let the pragmatic needs of C&YP, families and service providers guide my decisions by asking myself repeatedly: “So what does this mean for C&YP?”; “So what does this mean for families?”; “So what does this mean for providers?”

4.8. Trustworthiness

I ensured thesis trustworthiness by considering four aspects of qualitative research, credibility, dependability, transferability and confirmability (Denzin and Lincoln 2005). To ensure credibility I knew I needed to link the study findings very clearly to the real world I was exploring, to demonstrate the truth of study findings. I used several processes to achieve this. First, I increased research credibility by using member checking and triangulation (Dey 2005). Member checking involved giving the transcripts back to participants and asking them to check the transcripts accuracy i.e. I asked participants whether the transcript represented their actual experiences and views and if it was an accurate representation of their recollection of our interview conversation. I supported member checking by recording all interviews, and transcribing them verbatim, then listening to the recordings several times whilst reading the transcripts, to check transcript accuracy. I then shared transcripts with all adult participants and asked them to check the transcripts for accuracy. I additionally asked parents to read transcripts to/with their child, so they and their child, together, could check them and determine if they were happy with the transcript accuracy. I asked all participants to complete member checking i.e., provide assurance that their transcript was an accurate record of their interview and their viewpoints, as they recalled them (Dey 2005). I completed an audit of this process using an excel spreadsheet. Additionally, I used a form of triangulation to improve study credibility, namely, analyst triangulation and data source triangulation (Silverman 2017). Analyst triangulation included using two additional researchers (PhD supervisors) to moderate some of the data generation and interpretation processes, particularly at the start of the study. Moderation occurred by sharing transcripts, my reflections, and interpretations. I met with supervisors regularly and discussed data generation, and excerpts of the transcripts and my interpretations, as part of this moderation process.

Besides using a form of analyst triangulation, other forms of triangulation I used included triangulation of data sources, to increase research credibility. I used data source triangulation by including service users (families) and service providers;

additionally, providers from different organisations and different social worlds. In this way, numerous data sources were able to share their perspectives as part of data generation and analysis, thereby increasing research credibility. Additionally, I was able to compare and contrast viewpoints, experiences, and information from numerous participant sources when doing analytic cartography. I did not perform respondent validation to increase research credibility. Respondent validation involves taking the study findings back to the participants for their confirmation. I viewed respondent validation as another means of potentially producing new data rather than validating the thesis findings (Hannigan and Allen 2006). Therefore, did not include respondent validation.

I ensured research dependability by fully recording the iterative process of sample recruitment, data generation and data analysis, and by using regular reflexivity (Silverman 2017). I wrote many reflective memos during data generation and my interpretation processes. Clarke (2005) and Clarke et al. (2018) describes this reflective practice as a helpful way of recording reasoning for interpretations and a way of recognising and limiting the researcher's influence on data generation and interpretation. Furthermore, reflexivity and record keeping ensured dependability by creating an accurate audit trail of data generation and analysis.

Transferability is often a limitation in qualitative research that explores social worlds of individuals and small groups (Mills et al. 2010). The situational nature of my research does limit its transferability to wider population groups and other geographic locations. However, comparing findings from families and providers does give more than one perspective and perspectives from more than one social world. Thereby, providing a wider perspective than just one individual or one social group (Dey 2005). Similarly, comparing and contrasting thesis findings to wider national and international policy and research provides a measure of national and international transferability.

It is important to make sure my personal biases and positions on matters have not influenced thesis findings to ensure research confirmability (Dey 2005). Therefore, transparency in research data generation, interpretation and analysis is important. I consistently used reflexivity, writing reflective memos, to reflect on my role, thoughts, feelings and positions during data generation and analysis to limit my influence on data generation, analysis and findings. I regularly consulted two additional researchers (PhD supervisors) on the steps I took during data generation and analysis. As part of reflexivity, I continually reflected on whether my predispositions were influencing data generation and study findings. Furthermore, I regularly sought contradictions to my own predispositions. The fact that participants generated further participants for study inclusion, enabled me to situate the research within participants' real worlds, and arguably, therefore, provided an additional form of participatory confirmability (Bryman 2012).

Chapter 5. Family Findings

In chapter 5, I present family interview findings. Firstly, I present descriptive details of the sample including C&YP's functional mobility. Secondly, I present facilitators and barriers to PA participation.

5.1. Interview Sample

I deployed volunteer, purposive, and snowball sampling to recruit twelve families that included thirteen C&YP and their parents. One family included two siblings with neurodisability. I recruited nine males and four females. Ages ranged from 5-17 years and the mean age was 10.7 years. In Table 4, I present C&YP pseudonyms, gender, ages, diagnoses, and the GMFCS-E&R levels (Palisano et al. 2008) for C&YP with CP.

Case No. & Pseudonym	Gender	Diagnosis & GMFCS-E&R (CP)	Age
Case 1: Dwayne	Male	CP, Diplegia, GMFCS-E&R II	11
Case 2: Donny	Male	CP, Hemiplegia, GMFCS-E&R II	12
Case 3: Buster Snare	Male	CP, Diplegia, GMFCS-E&R II	7
Case 4: Molly	Female	CP, Hemiplegia, GMFCS-E&R II	8
Case 5: Trevor	Male	CP, Hemiplegia, GMFCS-E&R II	14
Case 6: Mark	Male	CP, Quadriplegia, GMFCS-E&R IV	10
Case 7: Catherine	Female	Angelman's Syndrome	14
Case 8: Bethany	Female	CP, Quadriplegia, GMFCS-E&R IV	11
Case 9: C-Jay	Male	CP, Diplegia, GMFCS-E&R II	12
Case 10: Phillip	Male	CP, Quadriplegia, GMFCS-E&R V	17
Case 11: Sian	Female	CP, Diplegia, GMFCS-E&R III	8
Case 12: Alex	Male	ASD & ADHD	10
Case 13: Jack	Male	CP, Hemiplegia, GMFCS-E&R II	5

Table 4: Children and Young People Demographic Details

Eleven C&YP had CP, one had ASD and ADHD (Alex), and one had a genetic syndrome causing PMLD (Catherine). CP is the predominant diagnosis within the sample and the study is therefore limited in representing the diversity of neurodisability and achieving the aim of considering the situation of community PA participation for C&YP with a range of abilities and neurodisability diagnoses. C&YP with CP can however present in a variety of ways and have wide and varied abilities thus having a mainly CP sample population still provides opportunity to explore the situation of community PA participation by C&YP with neurodisability comprehensively. Especially as evidence suggests C&YP's age and functionality are significant predictors of meeting PA guidelines, rather than diagnosis type alone (Case et al. 2020). CP typography showed four C&YP with hemiplegia (Donny, Molly, Trevor, and Jack), four with diplegia (Dwayne, Buster-Snare, C-Jay, and Sian), and three with quadriplegia (Mark, Bethany, and Phillip). Most C&YP with CP were classified on the GMFCS-E&R at level II (n=7), one at level III, two at level IV, and one at level V. Thus, the sample includes predominantly independently mobile C&YP with CP.

Family Cases

There were twelve families and thirteen cases. I have numbered families numerically and labelled individual C&YP as cases. Two C&YP (cases 11 and 12) were siblings from the same family (Family 11). Regarding overall physical mobility, eight C&YP were independently mobile but with varying difficulties. One young person (Sian, 7 years) walked with a Kaye-walker and used a manual wheelchair (mostly pushed). One young person (Catherine, 14 years) walked minimally with a walker and significant additional support, walking short distances and mostly pushed in a wheelchair. She was unable to mobilise herself in a wheelchair. Two young people could not walk and did not walk with aids but mobilised themselves independently using a powered wheelchair (Mark 12 years and Bethany 11 years). One young person had very little movement control and was unable to walk or mobilise in any way (Phillip, 17 years). In the following section, I present a synopsis of each case and family. This synopsis provides an overview of family status (e.g., single parent household or not, siblings or not), school status (e.g., mainstream or special school attendance) and activity restrictions. Activity restrictions were ascertained via discussions with families when determining GMFCS classifications for C&YP with CP and in discussions with parents and C&YP when asking them to describe their participation and any difficulties. On reflection, providing a synopsis as I have done below, does view C&YP with a medical lens; facilitated by using a classification system like the GMFCS and asking parents and C&YP what difficulties they had. Contrastingly, the benefit of using GMFCS descriptor levels and sharing pictures defining these, was that it facilitated parents to share with me their child's physical mobility strengths and limitations. For families involving C&YP that did not have a CP diagnosis, I similarly asked what physical activities C&YP enjoyed and if they had any difficulties or challenges in taking part, which enabled parents and C&YP to share with me anything they felt pertinent to these questions. For example, Donny (in Family 2) told me he had difficulties straightening his arm and stepping sideways without me prompting that type of information.

Observing movement and participation to provide descriptions of how C&YP participated, if they had activity restrictions that affected participation, and what they struggled with during participation, would have provided a more appropriate biopsychosocial view of C&YP's situations. However, I was unable to observe participation (especially during covid-19 restrictions) therefore questioned families regarding GMFCS levels and asked parents and C&YP if they had any difficulties during PA participation and daily mobility.

Family One - Case 1

Dwayne is an 11-year-old male with CP diplegia, GMFCS-E&R Level II. Dwayne is able to mobilise independently without mobility aids but has balance difficulties when negotiating uneven ground, crowded spaces and stairs. I interviewed Dwayne with his mother present, Sarah (pseudonym). Dwayne attended a mainstream high school. Dwayne had an able-bodied twin brother and a sister 18.5 months older. They all lived with Sarah, their mother, in a single parent family. The family lived in a town 31 miles from the nearest large city (CITY1).

Family Two - Case 2

Donny is a 12-year-old male with CP left-sided hemiplegia, GMFCS-E&R Level II. Donny mobilises independently without mobility aids but has some balance difficulties and difficulties with left upper limb (UL) and left lower limb (LL) function. Donny described having difficulties getting his left foot flat on the ground and having balance and agility difficulties, particularly when sidestepping. Donny reported some difficulties with grasping and releasing objects using his left hand, and difficulties in relaxing and straightening his left arm. Donny lived with his father, Carl (pseudonym), mother, Poppy (pseudonym) and younger sister in CITY1 and attended his local mainstream high school.

Family Three - Case 3

Buster-Snare is a 7-year-old male with CP Diplegia, GMFCS- E&R Level II. Buster-Snare can mobilise independently without mobility aids but has balance difficulties, especially negotiating uneven ground, stairs, and in crowded spaces, some difficulties with sitting balance and bilateral UL fine motor control difficulties. I interviewed Buster-Snare with his father, Martin (pseudonym) present. Buster-Snare attended his local mainstream primary school, had a younger sister, and lived with his mother, Sally (pseudonym), father (Martin), and sister in a town 24 miles outside CITY1.

Family Four - Case 4

Molly is an 8-year-old female with CP right-sided hemiplegia, GMFCS-E&R Level II. Molly mobilised independently without mobility aids but had balance difficulties negotiating stairs (needing a handrail), crowded spaces, and uneven ground. Molly additionally had difficulties with right UL function i.e., grasping/releasing, and manipulating, objects. Molly tired quickly, reported by her mother, Sophie (pseudonym), and sometimes mobilised (pushed) in a wheelchair. I interviewed Sophie separately, and Molly with Sophie present. Sophie reported that Molly additionally had visual and memory disturbances, and speech and learning delay. Molly was under investigation for these and a possible additional diagnosis of ASD. Molly attended a mainstream primary school and had three siblings. They all lived with Sophie in a single parent household. The family lived in a town 24 miles outside the second largest city in the study geographic area, CITY2; and 24 miles from CITY1.

Family Five - Case 5

Trevor is a 14-year-old male with CP right hemiplegia and hemianopia, GMFCS-E&R Level II. Trevor is independently mobile, without any mobility aids, but has balance difficulties e.g., negotiating crowded spaces. I interviewed Trevor’s mother, Sandra, as his proxy. Sandra reported Trevor to be independent with PA, but sometimes needing additional support e.g., equipment to keep his right hand on the handlebars when cycling, and to keep his right foot on the cycle pedal. Trevor had a brother 18 months older and a sister 4 years younger. Trevor attended his local mainstream high school and lived with both his parents and siblings in CITY1.

Family Six - Case 6

Mark is a 10-year-old male with CP quadriplegia, GMFCS-E&R Level IV. Mark is able to sit on his own but does not stand or walk without significant support. Mark is reliant on a powered wheelchair for mobility. I interviewed Mark’s mother, Harriet (pseudonym) as Mark’s proxy. Harriet reported that even with trunk support, Mark had reduced UL function, particularly on the right, with extreme limitations in his ability to grasp, release and manipulate objects. Harriet additionally reported that Mark had speech and language difficulties and epilepsy. Mark attended a special school for disabled C&YP. Mark had no siblings and lived with his mother, in a single parent household. They lived in a town approximately 10 miles from CITY1.

Family Seven - Case 7

Catherine is a 14-year-old female with a genetic disorder and PMLD. Catherine is unable to mobilise independently. She is unable to walk independently or independently power herself using a manual or powered wheelchair. Catherine is also unable to perform daily tasks without supervision or a great deal of assistance. Catherine is therefore completely dependent on others for her mobility, and all her care needs. Catherine has ataxic, uncontrolled movements, is a non-verbal communicator, and has epilepsy. I interviewed Catherine’s mother, Mandy (pseudonym) as Catherine’s proxy. Mandy described great difficulty in motivating Catherine to move. Catherine could stand, transfer and mobilise very short distances with significant support. The family and special school Catherine attended therefore regularly used additional equipment, including hoists, for mobility purposes. Catherine lived with her mother, Mandy, her father and her older brother. The family lived in CITY1.

Family Eight - Case 8

Bethany is an 11-year-old female with CP quadriplegia, GMFCS-E&R Level IV. Bethany is reliant on a wheelchair for mobility and needs significant support to stand or walk. I interviewed Bethany’s father, Frank (pseudonym) as Bethany’s proxy. Frank reported Bethany previously walked with a walking aid but no longer walked and was reliant on a powered wheelchair for mobility. Frank reported Bethany had spinal (scoliosis) and hip deformities and needed seating equipment to provide trunk support, and enable upright positioning, comfort, and UL functions. Bethany was often mobilised with a hoist between positions but could transfer, standing, over short distances with significant support. Bethany was cognitively age appropriate and attended a mainstream school. Bethany had no siblings and lived with her mother and father in CITY1.

Family Nine - Case 9

C-Jay is a 12-year-old male with CP diplegia, GMFCS-E&R Level II. C-Jay can mobilise independently without aids; however, he has balance difficulties, particularly negotiating steps/stairs, over uneven ground and in crowded spaces. C-Jay uses a manual wheelchair at times, when covering long distances, due to fatigue and balance difficulties. C-Jay is a verbal communicator but has dysarthria. C-Jay attended a mainstream school. I interviewed C-Jay with his father, Raymond (pseudonym) present. C-Jay has no siblings and lives with his father in a single parent household in CITY1. The family lived in local authority supported housing.

Family Ten - Case 10

Phillip is a 17-year-old, male, with CP quadriplegia; GMFCS-E&R Level V. Phillip is unable to sit on his own, has difficulty controlling his head and body in most positions, and has difficulty achieving any voluntary movement control. Phillip needs a specially adapted seating, and special equipment e.g., hoists to move. Phillip is a non-verbal communicator who uses assistive technology to communicate. Phillip additionally has epilepsy. I interviewed Phillip’s mother, Pauline (pseudonym) as his proxy. Phillip attended a special school and had an older brother. Phillip lived with his mother, father and older brother in a town 28 miles from CITY2, and 70 miles from CITY1.

Family Eleven - Case 11 and Case 12

Family 11 included two children, case 11 and 12. Both C&YP lived with their mother, Sierra (pseudonym) in a single parent household with no other siblings. The family lived in a town 12 miles from CITY2, and 58 miles from CITY1.

Case 11

Alex is 11 years old, male, with ASD and ADHD. Alex can mobilise independently. I interviewed Alex with his mother, Sierra present. Additionally, I interviewed Sierra on her own regarding Alex. Sierra reported that Alex had social and emotional developmental delay, and behavioural issues such as constant hyperactivity, inattention, and anxiety. When anxious Alex exhibited behaviours such as uncontrollable screeching and pulling his hair out. Sierra described Alex as having a hidden disability, as his disabilities were not immediately apparent for an onlooker or someone who did not understand ADHD, and ASD. Sierra reported Alex was on medication to help control ADHD behaviours. Alex is a verbal communicator who attended a mainstream school.

Case 12

Sian is 8 years old, female, with CP diplegia, GMFCS-E&R Level III. Sian walks with an aid, a Kaye walker. She has difficulty climbing steps and negotiating uneven ground and needs additional support for all these activities. I interviewed Sian with her mother, Sierra present. I also interviewed Sierra on her own, regarding Sian. Sierra and Sian reported the main physical problem being poor leg function and the inability to walk. The family often used a manual wheelchair when travelling over longer distances and in crowds, which Sierra tended to push. Sian is a verbal communicator (without delay), cognitively age-appropriate, and attended a mainstream primary school with one-to-one assistance.

Family Twelve - Case 13

Jack is a 5-year-old male with CP right hemiplegia, GMFCS-E&R Level II. Jack walks independently and unaided but often finds it difficult negotiating steps, walking on slopes, over uneven ground or in crowded spaces. I interviewed Jack’s mother Tessa (pseudonym) as Jack’s proxy. Tessa described Jack as having a weak right leg, very stiff right foot, and a slumped gait. Tessa reported Jack’s right UL and hand most severely affected, with very limited mobility, e.g., difficulty opening, grasping, releasing and manipulating objects. Other difficulties Tessa described were slow eating and drooling, speech and language delay and some speech articulation difficulties. Jack also had epilepsy. Jack has a younger sister (3 years old). Jack lived with his mother, Tessa (pseudonym), father, and younger sister in CITY1.

Family PA Participation - Summary

C&YP and families participated in PA in several places and in several ways. Informal play happened in the home and community environments e.g., park/playground. Younger C&YP participated in informal play and informal sport in school and in the home (e.g., cases 3, 4, and 11) usually with friends and family. Older C&YP who were independently mobile (e.g., cases 1, 2, and 12) participated in informal play, often in the form of informal sport, in outdoor areas like parks with friends and/or siblings. C&YP who were less physically mobile and older, thus potentially outgrowing developmental stages of play as reported by the mother of Phillip (case 10, aged 17 years), did not report participating in play in the home or in parks and neighbourhood environments.

Families all needed to travel, using their own car/van, to accessible outdoor environments to participate in outdoor walking and cycling. C&YP participated in formal, organised PA, mostly sport, in school PE sessions and within community sport and charity groups.

5.2. Facilitators of Community Physical Activity Participation

I organised the common facilitators across all families into three common situational matrix categories. These were **Human Elements** (individual and collective people [organisations]), **Non-Human Elements** (information and resources) and **Environmental Elements** (environmental access). Within these situational categories were sub-categories (related elements). It was very difficult to label categories and subcategories because of their overlapping elements and network of relations. I therefore chose to use SA’s situational matrix categories and subcategories as sensitising labels when mapping situational elements, which made mapping elements, codes, categories and subcategories easier. However, SA refers to organisations as collective human elements, therefore categorising organisations as a human element when organisations could be viewed as non-human, created some tensions. For example, organisations provide programmes that need information, resources, and working practices to run, all non-human elements. However, organisations and their programmes are also made up of collective people who deliver programmes and the work of the organisation. Thus, within the situation, the collective human elements are closely linked to, and overlapping with, non-human elements, as asserted in one of the underpinning theories of SA, ANT (Latour 2005). I resolved these tensions by adhering to the situational matrix categories, i.e., naming organisations as collective human elements just as SA's situational matrix names them. I further adhered to the situational matrix in my categorisations as it does not delineate categories as separate entities apart from each other i.e., there are no boundaries between them (as seen in Figure 3) - they are all found within situation (Clarke et al. 2018). This made it possible for me to provide a situational category of collective humans (organisations) having sub-categories of non-human elements within it. This process did however provide a tendency to make presentation of my findings messy. I felt justified in this tension and messiness because it adhered to the methodology I was following and illustrated the network of relations within the situation, as well as its complexity – which is a unique contribution of SA.

In the following sub-sections, I present each situational matrix category and its related sub-categories, showing their situational elements and relations that enabled participation. I support findings with participant quotes.

5.2.1. Human Elements

Individual People

Individual people supported PA participation and were predominantly parents. Other family members e.g., siblings, and other people e.g., friends, teachers, sport coaches, personal assistants, and healthcare professionals also played a role. People supported participation in three main ways, through their i) Beliefs in the benefits of PA, ii) PA role modelling behaviours, iii) Attitudes of persistence and problem solving.

- **People's Beliefs in the Benefits of PA**

Beliefs in the benefits of PA, particularly parents' beliefs, supported participation. I have selected 5 quotes because they each illustrate a different belief that parents had regarding community PA participation, its benefits and its influences, which shows the wide variety of beliefs that parents had. These PA beliefs included physical benefits (e.g., mobility improvements), social skills benefits (e.g., gaining teamwork skills), and wellbeing benefits (e.g., improving happiness, friendships, and self-worth). The 5 examples illustrate a wide variety of parental beliefs. For example, Sophie believed community PA participation brought improved mobility, Tessa believed including variety in PA brought physical benefits, Pauline believed involvement brought happiness, Raymond believed participation brought friendship and camaraderie, Sandra believed it brought independence and self-worth.

Tapping into the belief systems of parents and families could be a way to facilitate participation but would require providers taking time to find out parental and families' beliefs. Providers may not always have the time to do this or may not see this approach as effective in facilitating participation.

> *100%, I passionately believe that physical activity helps with Molly's mobility over the course of the week (Sophie, Molly's Mother)*

> *I wanted him to join up to gymnastics, something that would get him on the ground tumbling, using his hands, his feet, everything, which would probably involve activities of benefit (Tessa, Jack's Mother)*

> *It's really, really important for him, for his happiness. By involving him in as many things as he could do, has helped that (Pauline, Phillip's Mother)*

> *I signed him up to rugby when he was 6 [...] it's the social aspect and friendships, camaraderie. It's all about that you can get on and be part of the team (Raymond, C-Jay's Father)*

> *You've gotta think what's the overall benefit and gain for the self-worth of the child (Sandra, Trevor's Mother)*

C&YP also reported PA beliefs. I have selected 5 quotes to illustrate the wide variety of beliefs C&YP had about PA which I interpreted from how C&YP described their PA participation i.e., they described PA as providing fun, friendships and the chance to win in sport (social benefits), and that participating in PA made them faster and stronger (performance benefits).

> *When you have fun and you're with your friends and you're socialising, I feel like, that lightens everyone, it just brightens up their day (Dwayne, 11 years)*

> *I like swimming. Because it's fun and we get soaked and we feel warm inside (Sian, 8 years)*

> *I just think it's a really fun sport that anyone can get involved in and it's really good 'cause if you keep at it then you'll get a lot, lot better and you'll start winning things (Donny, 12 years)*

> *I'm getting better at the sport as well now. I'm getting faster and getting stronger. I feel like now I joined the rugby, I've gone faster, I've gone stronger. Just everything about me has grown (Dwayne, 11 years)*

> *I really like playing against my friends because they're really strong, I'm really strong (Buster-Snare, 7 years)*

- **People's Role Modelling Behaviours**

Parents and siblings motivated and supported participation via PA role modelling behaviours. Other family members e.g., cousins and friends supported this role as well.

> *Whatever his brother did, he did (Sandra, Trevor's Mother)*

> *Often, me and my sister do the bikes and then, Daddy and Mummy – they like run after us (Buster-Snare, 7 years)*

> *I always wanted to play rugby. Because my father used to play for Wales and that pushed me, and my brother as well, my cousins, they all pushed me to play rugby (Dwayne, 11 years)*

> *My partner is a cyclist and he always wanted our children to be on bikes, so, we've really tried to push bike work with Jack (Tessa, Jack's Mother)*

> *Phillip has always had kids or cousins of the same age round him who involved him in games and playing (Pauline, Phillip's Mother)*

Several C&YP reported participating in specific sports because their friends participated.

> *I quite like rugby because my friends like it and they always want me to play with them (Buster-Snare, 7 years)*

> *I play games with my friend in school, running down hills (Molly, 8 years)*

> *Yesterday, with my friend, we were in the yard with the football. At break we were out and went out into the yard and just kicked the ball around (C-Jay, 12 years)*

> *If I go out, I'll play, I'll play whatever sport with my friends. Wherever, whatever sport we feel like playing, just play (Dwayne, 11 years)*

Some families reported teachers and sport coaches were role models too.

> *His coach, he's very inspirational, he's a young lad that's Para Athlete himself (Sandra, Trevor's Mother)*

> *The coach, he's really good, he's a PE teacher and a maths teacher in Dwayne's school (Sarah, Dwayne's Mother)*

One child had a personal assistant who participated in much PA and had regular access to a leisure centre, which enabled the child’s participation. When this individual was no longer the child’s personal assistant, the PA stopped.

> *She took me to soft play, I went swimming, I went to the library, to gymnastics. She used to always take me rock climbing (Molly, 8 years)*

> *She was a lifeguard. So, she could take you down the leisure centre and you could go on all of the things, the rock climbing and then she’d take you to the gymnastics, and she was the teacher in gymnastics as well (Sophie, Molly’s Mother)*

Other C&YP had personal assistants in school to ensure safe access to the school environment, to daily tasks in school and the PE curriculum. However, these C&YP did not have a personal assistant outside of school as Molly (reported above). Personal assistants in schools provided supervision for safety, did physical tasks for C&YP, or helped them do physical tasks.

> *Jack has a key worker at school who's there to help him with his development and help him physically because you know, there's various things he can't do. He can't undo his sandwich and his crisp packets. He can't open his lunch box. If he’s outside in the playground and he's trying to climb, she just needs to be there to watch that he doesn't fall (Tessa, Jack’s Mother)*

> *In school, if they’re playing rounders or something like that, Bethany would try and bat and the one to one, so she’s got a full time one to one, would help her (Frank, Bethany’s Father)*

> *There’s somebody there with her all the time to help her really, because going to the toilet and things like that are difficult, and on the yard she’d get easily knocked over (Sierra, Sian’s Mother)*

These parent narratives show an opportunity for personal assistants to provide PA role modelling behaviours through their close and regular interaction with C&YP, daily, in schools, but PA role modelling behaviours are not overtly present in the actions and behaviours described. There are tensions in focusing on personal assistants’ role modelling behaviours to increase C&YP’s participation as role modelling is likely dependent on and specific to the types of PA that assistants take part in and the types of PA that C&YP prefer, as well as the personal characteristics of personal assistants – as seen in Molly’s situation with her personal assistant (quoted above). Molly’s example does illustrate the potential to increase PA participation via personal assistants. There is potential for healthcare integration and collaboration at this level to support personal assistants' and their PA role modelling behaviours, and their support for C&YP's participation. However, evidence is sparse investigating such an approach.

- **People's Attitudes of Persistence/Persistent Problem Solving**

Persistence, problem solving, and persistence in problem solving were attitudes that supported participation and were required to overcome difficulties and challenges. Families without these qualities often stopped participating when encountering difficulties (reported in barriers). Martin, Buster Snare's father, described persistent problem solving required for Buster-Snare to participate in cycling.

> *It was clear from a few months of trying that he could not, on multiple levels make the bike move [...] so we tried some straps and we realised that was going to help but then the bike was still too heavy [...] then I somehow heard about very light framed bikes for kids. I stuck some straps on his feet – and you, actually sort of moved it. So, we thought well, we'd give it a go. So we bought it, and we got stabilisers put on it and lo and behold he was able to ride it then, so that was when we started doing our sort of bike trips (Martin, Buster-Snare's Father)*

Tessa, Jack's mother also described working to find cycling solutions.

> *He's had a balance bike, which he started on and did very well on and now we've just taken pedals off a bigger bike now for him. So, we just turned a normal bike into another balance bike, and he goes out also on the tag along and my partner's trying to get him to get used to pushing pedals on the tag along bike (Tessa, Jack's Mother)*

Sandra, Trevor's mother reported persistence and a "can-do" attitude necessary to support participation.

> *There's no stopping us. There's always a way isn't there but, from a very young age, he was stuck on a bike or strapped onto something and just cracked on with it [...] I think that's the massive difference. The can- do attitude (Sandra, Trevor's Mother)*

C&YP also reported needing persistence for participation.

> *In rugby, I very often fall over but then I just get back up (Buster-Snare, 7 years)*

> *I keep on going (Molly, 8 years)*

> *Well, I just think that you just need to keep on trying really. You will improve; you'll definitely improve and just keep at it (Donny, 12 years)*

Collective People - Organisations

Organisations (collective people) provided PA programmes and events that supported participation opportunity and choice. Organisations included schools, and a variety of community sports and charity organisations. Key organisations, mentioned repeatedly across numerous families, were the national disability sport organisation (NDSO), a disability swimming charity, a cycling charity, and schools. Organisations' programmes facilitated participation if they provided, i) Fun Inclusive Opportunity and Choices, ii) Financial subsidy, iii) Accessibility, and iv) Time.

Organisations' Programmes

- **Fun Inclusive Opportunity and Choice**

The NDSO provided an event, two or three times a year, that involved various sport clubs/groups coming together in a large sports centre to provide opportunity for families to try out a variety of sport choices that were disability inclusive. Families reported the event positively due to its inclusivity, and the provision of choice and fun.

> *It's showcasing what's available and sibling inclusive. So, you bring your brothers and sisters, Mums and Dads and everybody, just come along. It's a fun day for people to experience what's available and to show that everybody can be involved (Sandra, Trevor's Mother)*

> *There's lots of different activities that your child can do; and that's what I really love. I just love the day itself. But you can take what you want from it. It's up to you how much you take from it. So, [named cycling charity] is there, there's a gymnastics club, a dance club, quite a few different things, and you just go and take advice, you know, take as much as you want from it (Tessa, Jack's Mother)*

> *There are kids with all different abilities there. It's fantastic for the kids, it's great for their confidence, it's all sorts of levels of abilities. And, they've got all sorts, archery, shooting, badminton, running, tennis, football, squash. It's a real opportunity if you wanted to see what was out there really and have a go (Poppy, Donny's Mother)*

NDSO collaborated with numerous sports clubs/organisations to provide the opportunity and the sport participation choices at the event. Therefore, collaboration between organisations enabled provision of PA choice at the event.

- **Financial Subsidy**

Financially subsidised programmes also facilitated participation. For example, a swimming charity provided a disability specific swimming programme free of charge, or financially subsided, to families, which facilitated participation and offered swimming opportunity.

> *They are a charity that help finance one to one swimming lessons with children with a physical disability, absolutely fantastic charity. They'll provide up to, and sometimes more, than a year's worth of one to one weekly swimming lessons (Sophie, Molly's Mother)*

> *They have been wonderful. They funded individual lessons and the idea is they do it up until he's at a level where he can join in with regular mainstream classes (Martin, Buster-Snare's Father)*

Martin however reported that despite Buster-Snare improving, he was continuing with the charity individual lessons, due to swimming benefits and enjoyment gained. However, lessons were no longer free at this stage yet still subsidised.

> *He definitely could go into group lessons now, but we just think it's a really nice thing for him and he looks forward to it and the teacher loves doing it as well. So, they are still funding a portion but now not the full amount which we're more than happy with and we would probably carry on even if they weren't funding it, which again, we're lucky enough we can do (Martin, Buster-Snare's Father)*

Unlike Martin's reports, Sophie reported she was unable to afford swimming lessons for Molly and needed the financial subsidy.

> *I wouldn't access swimming if it wasn't free, if I'm honest, as much as I know it's a need for Molly, if they completely stopped the funding, would I go? I'm not sure I'd be able to commit to it; it is quite expensive (Sophie, Molly's Mother)*

Collaboration between the charity and local government council leisure centres provided the opportunity for Molly and Buster-Snare by providing a swimming pool that the charity could use to provide lessons to families.

- **Access**

Organisations provided access to PA. For example, a cycling organisation provided accessible areas (long, flat, wide areas for cycling), adaptive equipment (e.g., trikes with adaptations), and staff/people to support and facilitate participation.

> *There's a disability place, which are fantastic, and Donny had only about four lessons with the Children's Officer and then one night he just took his hand off and Donny carried on riding (Carl, Donny's Father)*

> *There was a chap down there who was very nice and he gave you a little sort of assessment and stuck him on an adapted trike, which had a bit of a backrest thing, seatbelt, strap the feet in, he was able to switch it to – something to do with the modes where it was like free-wheeling, so it was very low geared, so it was easier. And there was this wonderful moment, you know, he takes off on this bike and it was one of the most wonderful things (Martin, Buster-Snare's Father)*

> *He's almost certainly going to be too big for that bike this year [...] I'm anticipating we'll be going back to [named cycling charity] and maybe moving back into the range of trikes or something like that because my guess would be he won't have the core and the balance for a normal bike (Martin, Buster-Snare's Father)*

> *We're looking at trying one of the trikes they've got [...] and see if that's easier for her to get in and out of now she's grown (Frank, Bethany's Father)*

Special schools provided regular access to PA programmes for C&YP attending special schools. Access provision occurred via people e.g., physiotherapists providing therapeutic exercise, accessible facilities and specialist equipment.

> *They do hydro, he has physio in school. I mean, he follows the general school pattern, with lots of fun (Pauline, Phillip's Mother)*

> *I know he does get an awful lot of input in school because he's now in [Named] Special School, where they've got their own OTs and physiotherapists and he's also got access to the hydro pool in school (Harriet, Mark's Mother)*

> *I think in the school environment, because Catherine's in a special school, so their physios are there all the time [...] there's a trampoline in school [...] the pool in the school is used a lot (Mandy, Catherine's Mother)*

- **Time**

Families reported schools, both mainstream and special schools, enabled PA via provision of time within school programme sessions.

> *They do daily miles so the children run for a mile every day or walk for a mile every day just round the playground [...] some days they have a whole day where they'll do no classroom work whatsoever and just do whole days of activity which is absolutely fantastic (Sophie, Molly's Mother)*

Molly is in a primary school. Families within the sample having C&YP in secondary school did not report whole days of PA. C&YP reported time for PA during organised PE lessons and informal play with peers at school break times.

> *Every break time in school I play rugby [...] In PE we get to do dodgeball and we can do Taekwondo and we got to, like, we had these balls and then we could throw hoops and then we had to try and get the hoops onto the ball (Buster-Snare, 7 years)*

> *PE is like a rotation. So, my group started off with basketball and last term we did rugby and now I believe we're on football. It's a rotation and with PE last term we did swimming one week and one week of fitness (C-Jay, 12 years)*

Donny's mainstream school also supported his performance sport (table tennis) by allowing him time out of school for training. Donny was the only family participant who reported extra time provided by school for PA, which suggests social-cultural prioritisation of time for performance sport over informal and formal sport.

> *Donny got involved in the Paralympic side of things. He was invited to join the Great Britain Future Squad. So, once every six weeks he does that training session on a Thursday and all day Friday. Obviously, he has to have time off school and they've been very supportive. He even has a trainer in school now. Once a week, the [National] Coach goes to the school, 1:30 'til 3. He loves coming out of his lesson to do that and all his friends are gutted! (Carl, Donny's Father)*

5.2.2. Non-Human Elements

Information and resources were non-human elements that facilitated participation. These subcategories have previously been presented as part of the human category i.e., in the collective human (organisations) subcategory. This overlapping and linking of human and non-human elements/categories creates tension and possibly, confusion (as previously highlighted) but illustrates the messiness and complexities of the situation. For example, organisations are made of collective humans (human elements) but also non-human elements like information and resources, which humans inside and outside the organisation rely on. Information and resources are non-human elements that also stand apart from organisations to facilitate participation e.g., individuals outside an organisation access information to find out about the organisation's PA opportunities. Information is therefore also a resource. However, unlike other resources such as time and money, information is non-depletable i.e., it can be shared and reused without depleting, therefore it is distinguishable from other resources. Thus, I have given information its own subcategory amongst the non-human elements identified as facilitating participation.

Information

Information on community PA programmes provided knowledge on what was available, thereby, facilitating programme attendance. Parents obtained information online and from people (word of mouth and signposting). Parents reported searching for information via web sites, social media, and Google searches. Additionally, via online registration with organisations (e.g., government councils and the NDSO), to receive their emails and newsletters.

> *I did a Google online to see what local disability sports were available [...] I phoned the leisure centre and they said, yeah, they did the trampolining (Harriet, Mark's Mother)*

> *I knew about the [NDSO] so I went onto their website and had a look and saw what was available. There's obviously social media. There's a lot of things that aren't put onto Facebook, but you can search things out on Facebook and see if it's appropriate [...] So there's websites, there's the county websites, word of mouth, Facebook, I think that's probably where I've looked. Just online, you can have a little Google of what's on in the area (Mandy, Catherine's Mother)*

> *We're registered with them, [NDSO], so they send out emails (Carl, Donny's Father)*

Families also reported obtaining information via word of mouth and signposting from others. For example, Donny started regular attendance at a table tennis club, and Trevor started regular attendance at an athletics club, due to signposting by sport coaches at the NDSO annual, event.

> *At the event, I met this guy [...] he plays for Wales and he's in the Para as well (Donny, 12 years)*

> *He gave us the number of the club where we could enquire. It was within a couple of days actually. So, within a week Donny was in the Table Tennis Club. Just starting off and it's just progressed from there (Carl, Donny's Father)*

> *We attended that event and within 10 minutes, this guy in a wheelchair came up to Trevor and said 'do you fancy doing some athletics?' and we've been going three times a week ever since (Sandra, Trevor's Mother)*

Sandra also reported signposting to the NDSO event from a community, swimming provider.

> *We attended swimming lessons and the lady that ran the swimming lessons, her son was a Para Athletic champion, so she spotted Trevor and recognised him as being hemiplegic and I spoke to her at length and she mentioned there's a yearly event that is held at the Athletics Centre, which celebrates all the different disciplines available for children with disabilities (Sandra, Trevor's Mother)*

Mandy, Catherine's mother, reported two teachers at Catherine's special school signposted her to community dance opportunities.

> *The school has got two staff members that encourage parents to come in for different coffee mornings. They were the ones that encouraged me to go to some of the classes with a dance studio and that's why I found out about different classes (Mandy, Catherine's Mother)*

Overall, however, families reported needing to work hard to find information on opportunities (reported in barriers section).

Resources

Family resources such as money, transport, and time helped facilitate participation. Families' finances bought or hired equipment to support participation.

> *We've hired the race runner for a while and we've also hired the hippocamp as well, if we want to go out (Raymond, C-Jay's Father)*

> *I've got one of these machines that shakes you [...] I get him to stand and sit on that, to try and get his legs as straight as possible. I use an i-Joy, it's a mechanical horse, to try and get him to use his core as much as possible [...] I've got weights to put on his legs to try and get him to hit my hands with his knees [...] I've bought all of that myself. I do buy it off eBay – I don't buy it brand-new – but yeah, I've bought it all myself (Harriet, Mark's Mother)*

> *He uses a handy hand thing to strap him on to the handlebars, because his right arm would just bounce off, so we've got this, active hands. We've bought that privately. This active hands piece of Velcro costs £60/£70, so not all families would have that money to go buy stuff and, his leg as well is a little bit weaker, so you need the clip on shoes to clip him on, and then*

> *we've got a tandem, so he goes on a tandem as well (Sandra, Trevor's Mother)*

> *The light framed bikes, they're not cheap, but for children in his situation with a mild to moderate cerebral palsy, it was just lovely (Martin, Buster-Snare's Father)*

Family resources included transport. All families used a family car or van for transport to attend PA programmes and travel to accessible outdoor environments. Sophie reported that transport was essential with a child with a disability, especially if living in rural locations.

> *So, you really have to have a car to get anywhere. When you've got a child with an additional need, whether they're in a wheelchair or not, public transport can be very difficult for the child, whether it's a physical illness or their mental understanding of everything (Sophie, Molly's Mother)*

Pauline described finances and travelling large distances, and extensive time required, to facilitate Phillip in surfing with a disability specific surfing programme.

> *I think it's about 40 - 50 pounds a session [...] and it takes an hour to get there, at least an hour. So, it's about a two-and-a-half-hour round trip. So, it's a full day out really (Pauline, Phillip's Mother)*

5.2.3. Environmental Elements

Accessible environments facilitated PA such as outdoor walking and cycling. Families used equipment to access outdoor walking and cycling and required transport to travel to accessible spaces for this type of PA. Frank reported Bethany used an adapted trike to cycle outdoors in a flat, wide space. However, Frank needed to transport the trike in a van to reach accessible spaces.

> *What we do is put the trike in the van and come down to the park or down to the bay. So anywhere that's more flat, more accessible (Frank, Bethany's Father)*

Martin, Buster-Snare's father, also reported using accessible environments for cycling participation.

> *We go where there's some converted railway tracks, there's a long flat section to go on, because he struggles with anything uneven or hilly, so we found two good places and one has a very long flat path which is excellent for him. And the other place we go is a converted railway line, behind the shops (Martin, Buster-Snare's Father)*

I have previously reported several organisations provided programmes supported by accessible environments and equipment. For example, the cycling charity and swimming charity, previously reported. Families also provided examples of accessible indoor environments in special schools such as hydrotherapy pools and rebound trampolines.

> *They do hydro, he has physio in school (Pauline, Phillip's Mother)*
>
> *[Named] Special School, they've got their own OTs and physiotherapists and he's also got access to the hydro pool in school (Harriet, Mark's Mother)*
>
> *Catherine's in a special school, so their physios are there all the time [...] there's a trampoline in school [...] the pool in the school is used a lot (Mandy, Catherine's Mother)*

The indoor facilities reported connected to people in the school with training and experience in using the facilities to support C&YP's participation e.g., physiotherapists and Occupational Therapists (OT). Thus, people, equipment and accessible environments were closely related, and interacted to facilitate participation.

5.3. Summary of Facilitators

Facilitators of community PA participation were people, both individual and collective (organisations). People included family members, friends, sport coaches, teachers, personal assistants and healthcare professionals. Parents were key people who created and provided opportunity for participation via their support for participation. Parents' beliefs in the benefits of PA, their role modelling PA behaviours, and their problem solving and persistence when facing challenges and difficulties facilitated their support for participation. C&YP also needed these personal characteristics to participate. Thus, focusing on identifying and addressing family, parental, and C&YP's beliefs about PA could be a way of increasing participation. As could increasing PA role modelling behaviours in those supporting C&YP e.g., parents and personal assistants.

Organisations provided participation programmes. Key organisations were NDSO, a cycling charity, swimming charity and schools. Inclusive and fun, financially subsidised and accessible programmes facilitated families' access and attendance. Collaboration between organisations provided more programme opportunities and choices for families. Collaboration may also be a way of increasing resource and information sharing. Information provided knowledge of programmes and choices available thereby supporting attendance. Families obtained information via online sources, organisations' email lists, and via signposting from other people. Families' resources of finance, equipment, transport and time helped them attend programmes and participate in PA at home and in surrounding environments. Accessible environments facilitated active travel (walking and cycling). Environments that provided flat, wide spaces for using large equipment such as walkers and trikes were accessible. Families transport (car or van) was necessary to travel to accessible spaces. Organisation programmes also provided accessible environments to participate and equipment to aid access to environments and PA.

I summarise facilitators in Table 5 (p152 & p153). Whilst the facilitators are presented in table format, the reality of inclusion in PA for C&YP with neurodisability is a complex picture, with factors being interrelated and individual circumstances giving different weighting to certain aspects of facilitation to participation.

Situational Matrix Category:	**Sub-Category:**	**Elements/Relations:**
Human Elements:	Individual People:	Beliefs, Behaviours, Attitudes
	Collective People - Organisations:	Programmes: Fun inclusive choices Financial subsidy Accessible Time provisions [Collaboration]
Non-Human Elements:	Information and Knowledge:	Online Searching & Signposting
	Resources:	Money Time Transport Equipment

Environmental Elements:	Access	Flat & wide accessible spaces/places Transport Individual people with knowledge Organisations with programmes and human and non-human resources

Table 5: Facilitators of Participation - Family Findings

5.4. Barriers to Community Physical Activity Participation

I organised the common barriers across all families into five situational matrix categories (Clarke et al. 2018). These were **Discourses, Environmental Elements, Non-Human Elements, Political-Economic Elements, and Temporal Elements**. Within these situational categories were sub-categories (further related elements). I summarise these findings briefly before presenting the situational elements and relations within categories and sub-categories, showing how they created situations hindering participation.

Discourses: Three dominant discourses hindered participation, namely discursive constructions of disability, disability participation and disability inclusion.

Environment: Environmental barriers included the geographic location of programmes/opportunities. Most disability specific programmes were in large cities far located for some families. Family also forms part of C&YP's environment. Family factors such as juggling family commitments, child-care and time reduced attendance, particularly at far located opportunities. There was also limited access to flat, wide environments for PA such as walking and cycling with large assistive equipment.

Non-human: Non-human elements involved information and fragmented information systems that meant families did not know what programmes were available and where to find information on opportunities and choices.

Political-Economic: Political-economic elements related to school funding barriers (real and perceived) and onerous, stigmatised processes for obtaining social care funding, which included elements of lack of trust (a problem for three single parent families).

Temporal: Temporal barriers related to time. C&YP with more severe physical impairments became difficult to mobilise as they grew with age, and equipment needs additionally changed. Covid-19 was an additional time contingent barrier that temporarily decreased opportunity and choice, and access to environments for PA. Covid-19 restrictions also reduced motivation for PA in some families.

In the following section, I present barriers showing how they relate and interact to hinder participation. I support findings with participant quotes.

5.4.1. Disability Discourses

Disability discourses viewed/constructed disability as a high risk, and therefore C&YP were unable to participate or prevented from participation. This created negative experiences for families, which caused some families to stop further attempts at participation. In the following section, I shall consider discursive constructions of disability, participation and inclusion.

- **Disability**

Several families had experiences with providers where families perceived providers viewed disability as high risk and C&YP unable to participate. Families reported providers expressed caution and exclusion (unwelcoming language) rather than inclusion (welcoming language). Sierra, Sian's mother, reported explaining Sian's disability and promoting Sian's ability, but Sian being excluded by providers. Sierra reported providers expressed caution and fear towards disability, which had the additional exclusionary effects of stopping Sierra making further attempts at participation.

> *I've been in contact with the leisure centres, like dance, Sian loves trying to dance in her own way, the dance schools down here, gymnastics. Her friend goes to gymnastics. I say, can you cater for her? Because there's that fear for people as well, I think. I've said she's fine, mentally cognitive or whatever you want to call it, it's just her legs, you know, she's just like any other child. But it just doesn't happen, the gymnastics basically said "no", and the dance said "oh well yeah, that's fine but maybe you could come with Sian", which I would've anyway, but then they said, "actually it's up some steps". I was thinking, yeah well that's fine, but now are you trying to put me off? (Sierra, Sian's mother)*

Sierra did not attempt participation again. In a similar way to Sierra, Harriet gave up making further attempts at participation when encountering provider caution.

> *I don't know whether it's just the fact that they're frightened [...] They wanted to know exactly what his illnesses were, so once I'd listed them, they were like, 'Oh, are you definitely sure?' as if to say, 'Is he up to it?' [...] I just said, 'Oh, that's fine.' (Harriet, Mark's Mother)*

Sophie, Molly's mother, also reported exclusion where providers' language and action suggested Molly was a risk for participation. Sophie reported providers therefore needed her to stay with Molly (like Sierra's previous reports), which was not always possible because Sophie had three other children and was a single parent with no available child-care. Sophie felt providers did not want to be responsible for disabled C&YP therefore needed her to stay in sessions.

> *With a child with a disability, whether it's insurance purposes or people just don't want to have any comeback on them, they say, "oh no someone has to be with them" or "you can't leave them, we're not responsible". When really an accident could happen to even an able-bodied child [...] it is something that hinders what we do then (Sophie, Molly's Mother)*

Families also suggested that providers lacked confidence dealing with disability and managing disabled C&YP. For example, Sierra reported she encountered provider caution that suggested the provider lacked confidence with disability.

> *I enquired about horse riding years ago and they wanted a letter to say Sian was okay to go on and I was like, well you can see she's okay to go on! I just tend to think then, oh well, whatever then, you know, if you want that type of thing then you're obviously not confident to be working with somebody who might need something slightly different (Sierra, Sian's Mother)*

Sierra did not attempt horse riding with Sian again. Sophie, Molly's mother, also surmised that the providers' exclusionary discourse could be due to providers' lack of confidence, which made them cautious of responsibility.

> *They run summer holiday clubs for free in the council for children eight to eleven, but again, if you've got an additional need you can't go because they're saying - "we don't want to be responsible for this, or that and the other". Or if you write on a form, cerebral palsy, then they look at these things and on paper it's like, well, "we can't be responsible for that" [...] and then they say, "sorry, your other daughter can come but actually this daughter can't come" (Sophie, Molly's Mother)*

Sophie compared how providers' managed Molly and how providers managed Molly's sister, Molly's sister being typically developing and only one year older. Sophie reported several incidences where providers excluded Molly but included her typically developing sister. Sierra similarly described a difference in how providers managed her two children, Alex and Sian. Alex did not have a physical disability but ADHD and ASD, therefore, appeared more able to access mainstream opportunities, due to having a "hidden disability", while providers excluded Sian who had a visible physical disability.

> *I couldn't send Sian to the holiday club [...] They'd take Alex but they wouldn't take Sian because of her disabilities (Sierra, Sian and Alex Mother)*

Family one, Dwayne and Sarah, (Dwayne's Mother) also reported an incident of exclusion by a provider. The family reported that a provider excluded Dwayne due to a claim that there was no insurance to include him. However, the provider included typically developing peers.

> *My brother was allowed to play but I was not because of my leg (Dwayne)*

> *She [Coach] told Dwayne, in front of everybody that he was not allowed to play rugby because he is not insured (Sarah, Dwayne's Mother)*

Sarah, therefore, sought information and advice from the NDSO regarding disability, rugby participation, and insurance.

> *We got in contact with [NDSO], who got in contact with the National Rugby Union, who said of course there's no such thing as not being insured. They got in contact with [named professional rugby club] who then phoned the rugby club to offer to train the coaches, but they refused [...] I had to go down to see her because Dwayne was so upset and I just thought, please don't do that to any other child [...] I knew that it's discriminating. But she couldn't see [...] she slammed the door in my face (Sarah, Dwayne's Mother)*

The providers actions regarding additional insurance, suggests the provider associated disability with increased vulnerability and risk. I confirmed, via telephone conversation with a sport club insurance provider that insurance providers do not differentiate between disabled C&YP and typically developing C&YP, when providing liability insurance to sports clubs. The insurance provider stated -

> *"We are not allowed to discriminate." (Unnamed Insurance Provider)*

Families reported provider exclusionary language increased in the presence of disability labels, which suggests disability labels facilitate negative constructions of C&YP's ability to participate.

> *Quite often, they're very funny: if it's anything to do with the brain, they're very - 'Oh, are you sure that you want him to be doing this type of thing?' (Harriet, Mark's Mother)*

Sandra, Trevor's mother, similarly reported providers cautious towards inclusion when faced with a disability label such as brain injury e.g., CP. Therefore, Sandra worked at gaining inclusion by not using disability labels and strongly promoting Trevor's abilities.

> *I was probably very careful with my choice of words as to how I would describe Trevor's disability. I sound as if I wasn't telling the truth at the time! Very often, I wouldn't say that he has cerebral palsy because people will jump to all kinds of conclusions. I would say something like 'Trevor's had a stroke so he can't use his right arm, but he's able to use his legs and he's able to follow instructions'. People are quick to judge. So, when you use a term such as cerebral palsy, then they would probably think 'oh no, we can't have them in our lesson. We don't accommodate kids with disabilities, sorry'. So, it was always a bit about how you would sell something to somebody. How you would explain things to people (Sandra, Trevor's Mother)*

The families' narratives suggest that parents need to work to overcome providers' cautious, exclusionary discursive constructions of disability, to gain C&YPs inclusion.

- **Participation**

Discursive constructions of participation for disabled C&YP also hindered participation. For example, providers labelled/categorised disability for participation, organising participation according to knowledge interpretations of disability categories and types. The organisational practice of labelling/categorising disability participation reduced the number of opportunities and participation choices available as not all C&YP fitted the organised labels/categories. The practice also placed responsibility on C&YP to fit with a specific participation programme label/category rather than programmes adapting to fit any child/young person. Disability discourses thus intersected with provider organisational practices to create a barrier. Such organisational practices enabled participation in formal sport and performance sport for two C&YP but could hinder participation in formal sport for several other C&YP. For Donny, table tennis participation categorisation (classification) enabled his participation and ensured fairness during performance table tennis competitions.

> *I've been put in class 7 for tournaments, but I won't get officially classified until I go abroad for a competition. I know 6 is the lowest for standers and then it goes down 1 to 5 for people in wheelchairs. I've been put in class 7 temporarily, all it means is how your disability affects the way you play (Donny, 12 years)*

Donny and his parents were, however, the only family who did not report barriers to participation due to disability participation constructions. Sarah and Dwayne, described problems, due to Dwayne not matching the rugby categories available to him.

> *This is what we find difficult, is finding a sport for Dwayne. For example, with the rugby, the [NDSO] do wheelchair rugby. Dwayne doesn't want to do wheelchair rugby (Sarah, Dwayne's Mother)*

> *I don't want to be stuck in a wheelchair (Dwayne, 11 years)*

Dwayne is not a wheelchair user therefore does not want to play rugby in a wheelchair. However, initially, there did not appear to be a discursive construction or organisation of rugby participation that matched his dis/abilities. The family also reported lack of other sport opportunities.

> *There doesn't seem to be any clubs, around here that Dwayne can play a sport against his own ability (Sarah, Dwayne's Mother)*

Perceptions of disability and participation and expectations and preferences for participation therefore hindered participation in this family example.

Frank, Bethany's father, also reported disability participation categories hindered Bethany's participation because Bethany did not match the categories available.

> *Bethany's in this grey area she doesn't really fit into anything (Frank, Bethany's Father)*

Sarah additionally described disability categories hindered Dwayne's participation because most disability specific opportunities were for C&YP having cognitive/learning disabilities and Dwayne did not have a learning disability.

> *A lot of the activities are for people with learning disabilities and I don't know, with Dwayne, I don't think he would [pause] want to compete against children with learning disabilities? (Sarah, Dwayne's Mother)*

C&YPs self-concept and identity linked to their preferences for participation e.g., Dwayne did not want to play wheelchair rugby, as he was not a wheelchair user. He also had a mainstream role model in his father and siblings who played mainstream rugby. Parents' perceptions of their child's identity also influenced parents' preferences for their child's participation e.g., Sarah did not think Dwayne would want to play in a team with C&YP having learning disabilities but had not asked him. Frank also reported Bethany did not fit into mainstream participation (example reported above).

Harriet provides another example of disability labelling/categorisation linked to identity. Harriet reported participation opportunities in her local leisure centre were primarily for C&YP with cognitive disabilities, namely, autism, which limited Mark's ability to attend.

> *I phoned the leisure centre and they said, yeah, they did the trampolining, but I think it's more for autistic children (Harriet, Mark's Mother)*

Martin, Buster-Snare's father, similarly reported local disability PA opportunities limited to C&YP with autism.

> *Most of it, again, if I'm being honest, most of it seems to be autism-related, it doesn't ever seem to be that much, that's sort of saying, come along and try this or what have you (Martin, Buster-Snare's Father)*

Martin reported a lack of invitations to opportunities for anyone, with any kind of disability, and/or calls for participation for any type of disability.

Participation additionally had sub-category labelling, e.g., sub-categories in learning disabilities. Disability labelling also categorised providers' training and their availability to support C&YP's participation e.g., in schools.

> *You only have so many members of staff trained to do rebound therapy with children. The rebound trampoline isn't used much because the staff aren't qualified or the staff that are qualified are working in an autism class, but actually they then have to be taken out of the autism class to go and work with a PMLD child, and often that causes friction because there's no coherence. It's almost like in the school there's a 'them' and 'us' policy, you're either in profound and multiple or you're the autistic spectrum classes, and never the twain shall meet. I find that really frustrating that they don't mix (Mandy, Catherine's Mother)*

C&YP with different neurodisabilities do not appear to mix in participation programmes and people do not provide support in different disability categories, which appears to link to staff, people provision, their training and availability (time). Overall, discursive constructions of disability and participation resulted in limited PA opportunities, choices, and limited people available to support participation.

- **Inclusion**

Discourses are about knowledge and systems of thought that govern practices (Foucault 1972). Family narratives illustrated a lack of inclusion knowledge governing community practices, particularly in mainstream participation settings.

Several families reported providers lacked ability to differentiate for C&YP or provide reasonable adjustments to provide inclusion within mainstream settings.

Sierra described an incident where a mainstream provider did not provide reasonable adjustments that led to Sian and Alex's exclusion.

> *There was a huge barrier for me because, with Covid, they wanted the children at the door in their swimwear with a onesie over them, and then we had to pick them up from the door, we weren't allowed in. I did try a couple of times, but oh my god, like Sian coming out with no shoes on, with her walker [...] so then I was trying to carry her, and everything was blocked off because of Covid, to keep people away. So, I was parking as close as I could and it was raining [...] and I asked them, "look, can I use the changing rooms?" I was a paying member there at the time as well, I could have been going in, but they were sort of "oh well, if they do it for me, you know, they'll have to do it for others" and I'm thinking - yes, it's a bit different though, can you not, see? In the end, it was just easier to give up then really (Sierra, Alex and Sian's Mother)*

In this example, the family reports the provider communicates they want to treat all families the same - equality. However, treating everybody equally did not provide reasonable adjustments to give equitable access for Alex and Sian, who have neurodisability. The service provider's Covid-19 management strategies increased the exclusionary barrier the family faced, and the family gave up attendance.

Frank, father of Bethany, similarly reported giving up attendance when a provider did not provide reasonable adjustments for inclusion. Frank's report of the provider's communication suggests the provider lacked disability awareness and inclusion knowledge as the provider states they are inclusive but then does not provide reasonable adjustments and seems unaware of this need.

> *Another prime example is just across the road from us is a dance group and my wife phoned up, and I said "don't do it". Bethany likes dancing and singing, they put on shows and the woman said, "yeah, yeah that's no problem, we do that, we do inclusive, bring Bethany over". I took Bethany there twice and all the children went up on the stage, but there was no facility for Bethany to get up on the stage in a wheelchair and Bethany sat below the stage and the kids sang and danced and Bethany just sat there. I said: "I'm not having that, and Bethany won't be coming again", and they said "why", and I said: "because I'm not having her just sit there and feel awful" (Frank, Bethany's Father)*

Frank’s descriptions show communication between the provider and the family did not provide mutual understanding regarding what inclusion entailed. Frank highlights the experience as negative because Bethany was not included and felt awful. Frank’s narrative also shows him warning his partner against attempting access; previous negative experiences have reduced Frank’s will for more attempts at community participation. Dwayne also reported feeling awful following exclusion from rugby and not wanting to attempt participation again.

> *For the remainder of the training session, I just went over and sat on a bench and cried [...] When that incident happened, I didn’t feel like doing anything [...] I didn’t feel like doing much then, like going out and socialising with anyone (Dwayne, 11 years)*

The negative incident caused Dwayne to, initially, stop further attempts at community sports participation. This is similar to other reports, where parents gave up continuing attempts at participation following negative exclusionary experiences.

Sierra, reported a mainstream swimming provider (previous provider to the one reported above) was unable to differentiate for Alex in swimming sessions, limiting his inclusion and performance improvements. Sierra felt she should not need to access a disability specific swimming provider for Alex.

> *Alex always has a bugbear, because he was in the same class for a year and they weren’t moving him on. He was literally, in the end, standing there in the pool and I thought, crikey! [...] some of these instructors, they know their job as in to teach children to swim, but then there’s initial tuning-in I suppose to different children, they’re not all the same [...] and I thought that he shouldn’t have to go through a special place to teach kids to swim (Sierra, Alex’ Mother)*

> *I’m always there with the younger ones. I didn’t like it. I was with the younger ones. I was only on stage one. It’s just my friend was on stage number two or three (Alex, 10 years)*

Tessa, similarly, reported a gymnastics mainstream provider lacked disability inclusion knowledge, as well as time to facilitate Jack’s successful inclusion in gymnastics.

> *When I took Jack to this gymnastics group down the road, resource wise he could use all the equipment there, but the trouble was that he needed extra time to use it, and they didn't have that extra time, and they didn't have the knowledge of how to help him on the equipment. [...] So, I suppose, it's the resources and the knowledge and training that goes with it, and the time.*

> *You need time to help a child that's disabled and maybe they don't have that time when they are teaching a group of able-bodied children. Because disabled children need just a little bit more time to do things. So, yes there's a bit of a battle there really, isn't there. Knowing how to overcome something like that. It kind of makes you think, well, maybe disabled children are just better off going to a group that is primarily for disabled children, because they will always have the resources and the time, and the knowledge. But then it's accessing these things and where can you find these groups? Are they in all our areas? I don't know (Tessa, Jack's Mother)*

Tessa, in contrast to Sierra, suggests the potential need to access disability specific providers, rather than mainstream providers. Tessa ponders this need, suggesting providers offering programmes/events solely for disabled C&YP, will likely give disabled C&YP appropriate support and sufficient time to participate. However, Tessa is not sure where to find disability specific gymnastics providers, and if any are locally available. The location of community PA opportunities was a common barrier across families.

5.4.2. Environmental Elements

Several environmental elements worked to hinder participation such as the geographic location of PA opportunities and the lack of physical access to opportunities. Additionally, like previous tensions highlighted, the linking and overlapping of category elements made the situation complex when considering the environmental influences. For example, non-human elements such as resources of time, transport and social elements - like family commitments - overlapped and connected to environmental location, to cause barriers and hinder participation. I also consider this complexity within the environmental element subcategory.

- **Geographic Location**

Several families reported location of opportunities hindered participation. For example, disability specific PA opportunities were all located in CITY1, which was too far for some families to travel.

> *[NDSO] have a lot of things, but they're all in [CITY1], which is a long way to go for us, it's a long drive. And then, with being a single parent, you've got one that's got netball, you've got the other one that's got something else and it's hard (Sarah, Dwayne's Mother)*

Far located opportunities increased time costs, which were difficult to manage when families were juggling a variety of priorities.

> *But again the vast majority of stuff in our area seems to be [CITY1] way which is just a bit too far I think, when we're trying to, you know what it's like when you've got young children and work and whatnot. I don't know, you just feel like doing that, just there and back is probably going to be the best part of an hour and a half sometimes, depending on the times. I mean we are a bit in the middle of nowhere, I can accept, but it does all feel very weighted in that direction (Martin, Buster-Snare's Father)*

Martin reported the swimming charity Buster-Snare attended just happened to be in their local community leisure centre. However, the charity did not provide swimming sessions in all local authority, leisure centres. For example, another family at the sessions travelled a long distance to attend.

> *[Named swimming charity] has been wonderful and that is in our local pool, but we know there's another boy there who comes all the way from [far named town] because [named local pool] is the nearest one that accommodates that charity (Martin, Buster-Snare's Father)*

Sierra also described location as a barrier. For example, Alex and Sian had once attended a cycling charity and enjoyed the adapted cycles. However, the family had not continued attendance as the opportunity was not local.

> *[...] they've got all these different types of bikes, some you use your hands, feet, and I thought, oh they were loving it, but there's nothing like that around here (Sierra, Alex and Sian's Mother)*

- **Intersection of Physical and Social Environmental Elements**

Location environmental elements interacted with family elements to hinder participation. Sierra described attempting horse riding for Sian but location and timing of the opportunity, alongside juggling work, travel time and sibling commitments was difficult and created too much stress. Therefore, Sian stopped attending horse riding.

> *Sian was, once a week doing disability horse riding. I think she's had two sessions. But it was on a Wednesday morning, she was having to miss school, I work, her father works, and we're not together anymore [...] trying to manoeuvre all that, plus the fact we had to travel [...] it was a good 45-mile round trip and I was feeling torn all the time trying to get it sorted, and it was so, so stressful. The way I perceive it is unless I'm living somewhere like [CITY1] there just isn't anything, it's all travelling, it's all*

> *time and it's all effort, it's all organising and then for me that's becoming an issue then because I think it becomes stressful (Sierra, Sian's Mother)*

Sophie, Molly's mother, reported that the combination of location with limited family time, juggling many family commitments and lack of sibling child-care presented the greatest barriers to participation.

> *The biggest limitations I think is never Molly's ability as funny as that sounds, I think it's the other factors that stop us from accessing the sports or the activities. Because there's several factors to that. One is location, so a lot of the sports that are specifically designed for children with disability are all in like the main cities, so like [CITY1], and transport links aren't great. So, you really have to have a car to get anywhere. Then, additionally, you've got other children. I've been a single parent now for six years and all my family live in England so it's not like I can drop my children off at parents or siblings and say, can you have them while I take Molly to this activity. Then, a lot of the activities, as much as they will try and organise them, you are responsible one on one with looking after your child in that activity. So, bless them, my older children are always being dragged along but then they're not allowed to take part either (Sophie, Molly's Mother)*

Sophie's narrative illustrates a lack of consideration of family factors when providing community PA opportunities. Sophie went on to give a specific example of Molly stopping attendance at a frame/race-running group due to these combined barriers.

> *Molly's tried race running but the barriers for us were it's in [CITY1], it's on a Friday evening, rush hour traffic, 5 o'clock in the evening, for two hours, so getting into [CITY1] is just impossible at that time. And then you've got the children, it's straight after school, they're hungry and then they're told to just sit and watch [...] and I have to run alongside the bike with Molly for safety reasons and to help steer it, she can't steer because she doesn't use one of her hands. So then I'm having to leave my older children to their own devices a bit. So that's just one example but there are many examples like that (Sophie, Molly's Mother)*

- **Access**

Inaccessible environments were a hindrance to participation. Raymond, C-Jay's father, described a lack of accessible flat, wide spaces for cycling and frame running. Raymond also described busy local traffic where the family lived making it unsafe. Covid-19 social restrictions at time of interview increased access barriers to community environments.

> *There's a pub near us and they've got a large car park. When Covid-19 first started, I went up there to see if I could speak to somebody about using the car park but there was a huge sign at the front of the car park saying "Pub closed, car park not to be used". We used to go on the frame runner around the park but got a bit anxious with the fact that it is not even, and C-Jay has fallen off the frame runner and it's near water. So, we stopped that. But you really need a flat surface, you can't be doing kerbs and other stuff. Where we live, it's all roads. It's not really safe to go out on the roads, we live in a really busy area, so, it's pretty tough (Raymond, C-Jay's Father)*

Sierra similarly reported lack of flat wide spaces close to home hindered outdoor walking with Sian. Sian used a walker but additionally Sierra needed to take the wheelchair along as well - because Sian could not walk long distances.

> *Even for walks, it's constantly thinking accessibility for Sian because of the wheelchair, or if she wants to have a walk herself with her walker [...] to even go for a walk with her, say to post a letter, the pavement, getting up, you just can't (Sierra, Sian's Mother)*

Some families needed to have wheelchairs, walkers and/or trikes on family outings to access outdoor PA. Difficulties managing all these large material elements, increased over uneven ground, in narrow spaces, and spaces containing large crowds or rushing/racing cyclists.

> *It's very difficult to have a wheelchair, a walking frame and the two of us. We do take up quite a lot of space so you need to have a flattened area so it's accessible. Her trike, I can get that down onto [named] Trail and that's not a problem. I think the only problem there is the fact there's a lot of traffic on the Trail these days with bicycles and a lot of people. I do feel that the bicycles should slow down in these areas, that's something the council should insist that bicycles are not in packs racing, because it's very frustrating if you're pushing a buggy or you're pushing Catherine on her trike, or I'm not pushing her, she's cycling it, but I have to run with her, and you've got a stream of fast bicycles going past. There should be some kind of slow down signage up for cyclists. But I do think that the paths should be made flatter, and certainly less bumpy in places around some of the parks and the green spaces, there should be at least an area that you can walk round quite nicely (Mandy, Catherine's Mother)*

Sierra similarly described difficulty managing crowds and many cyclists, particularly when simultaneously managing two children with disabilities, a wheelchair, walker, and a dog. The effort involved stopped Sierra from attempting to take Sian and Alex on walks.

> *...there was loads of people round, trying to manage that kind of thing, and bikes everywhere, and then she was using the walker, going from this side, that side, then the dog, and then Alex's squawking, because he does loads of high-pitched noises at times and I just think, oh my god! [laughs] You know, it should have been such a nice walk and I almost said, "why do I bloody bother?" That's how I feel a lot of the time and I just think I've learnt over the years that it's easier not to bother (Sierra, Alex and Sian's Mother)*

Families also reported poor maintenance of spaces e.g., debris on cycle tracks and lack of signage increased difficulties and reduced the desire to use outdoor environments.

> *I don't like it [the cycle path]. I always hurt myself. I fall over because of all the branches on the floor. Once I fell over and you could see my bone. I'm never going down there again (Molly, 8 years)*

> *I think you could have more, accessible places, as in flat areas. For example, for somebody who's either a wheelchair user or somebody that uses walking frames. Because for us to take Catherine where I live locally, I can't really take her in her walking frame because the paths, you've got all the dips and the bumps and everything and it's not very good for her walker (Mandy, Catherine's Mother)*

Some outdoor spaces were particularly difficult for families to access when using wheelchairs and walkers e.g., the beach.

> *With his new wheelchair wheels, it would be very difficult to take him onto the sand (Pauline, Phillip's Mother)*

> *I couldn't take her down the beach [...] I did take her once, my aunty came with me to help and two of the boys from work carried the wheelchair. But it's things like that you sort of take for granted. She didn't go down the water because I couldn't have carried her down. So I think accessibility as well in those ways, I mean all kids love going in the sand, it's just, it's tricky then to be thinking of dragging wheelchairs across sand (Sierra, Sian and Alex' Mother)*

Two parents reported environmental access concerns regarding toileting hindered physical play with friends after school.

> *People are almost a little bit afraid to have her down their house just to play. And she's fine! [laughs] But with toileting and that accessibility, the parents are a bit nervous because they're not friends of mine, it's just the children are friends in school. So everything tends to be based around the house which is, not ideal really (Sierra, Sian's Mother)*

> *I always remember the social worker who said, "isn't Bethany invited round to other people's houses" and I said, you're missing the point here again, Bethany needs one to one assistance and I don't want to go into things with parents like have they got a downstairs loo, how do they manage for the toilet? They couldn't grasp that aspect, it was just a question of - well, Bethany goes to mainstream school can't she interact with children outside as well, but the restraints on it, they just don't understand, people don't understand (Frank, Bethany's Father)*

Concerns with toilet accessibility therefore hindered informal play and friendships for some C&YP with physical mobility limitations.

5.4.2.1. Information

A lack of information, signposting, and fragmented PA information systems hindered participation. For example, Catherine's mother, Mandy, described a lack of information available and a desire for signposting.

> *If you've got a disabled child nobody gives you a handbook and says, look, these things might be useful to you. Nobody's ever done that [...] I think the physiotherapists and the occupational therapists need to have an idea of what activities are available, what sporting activities are available to children with disabilities (Mandy, Catherine's Mother)*

Sandra reported not having experienced any signposting from any healthcare professionals, and the desire for healthcare professionals to educate parents on the benefits of PA.

> *I can't say that I had any drive or enthusiasm from any healthcare disciplines in terms of promoting sport for Trevor. I think as healthcare professionals, they can promote it and probably provide the information because, not everybody would be motivated to look what's out there for their children [...] I can't honestly say that any of my therapists directed me towards any sport, but, once you tell them how much physical activity Trevor does, then they will all praise you for that, and say that he is doing so well because of the physical activity that he does. But, I can't recall anybody encouraging Trevor to participate (Sandra, Trevor's Mother)*

Martin, Buster-Snare's father, described difficulties finding information on PA opportunities. He suggested these difficulties were potentially due to disabled C&YP living widely dispersed; therefore, only few disabled C&YP attending individual mainstream schools, and information thus fragmented and difficult to connect.

> *I don't see things talking about [named disability swimming charity]. Because it is a UK thing, but still applies on a local level [...] It's difficult*

> *to think of one area which would mean that everybody with an affected child would have information, maybe in schools, but then I'm conscious that most schools are only going to have one or two affected children, so then that feels a bit overkill. [NDSO] would be good one to link with other third parties like [disability swimming charity], but then you've still got the problem that people need to know about [NDSO]. So it's joining the dots, it's trying to raise the profile of things [...] the idea that there'd be parents who wouldn't know [disability swimming charity] exists, would be very sad to me, because it's certainly been wonderful for him (Martin, Buster-Snare's Father)*

Indeed, Tessa, Jack's mother, did report she was looking for a suitable swimming opportunity for Jack to learn to swim and had not found one. On questioning, Tessa did not know about the disability swimming charity Martin named in his interview. I was therefore able to provide Tessa with this information at the end of her interview.

5.4.3. Political-Economic Elements

Political-economic elements were influential on participation, often silently, therefore making them difficult to examine. Additionally, they were difficult to examine without all the relevant stakeholders being interviewed e.g., political stakeholder participants were not part of the sample population. Challenges also existed because families and providers often referred to political-economic elements indirectly e.g., by expressing the need to have more support workers within school classrooms to facilitate participation. Thus, participants did not always overtly discuss political-economic elements. SA aided identifying silent political-economic influences within the situation using positional mapping and relational analysis within situational and social worlds/arenas cartography. I divided political-economic elements into two subcategories - school education and social care provisions. These two subcategories could overlap and interconnect within individual family situations further raising complexity within the situation.

- **School Education Provisions**

Local authorities make decisions on C&YP's school allocations, and the funding allocated to support their inclusion in school (OECD 2018). Sophie reported Molly was unable to go to the independent faith school her siblings attended due to the need for local authority funding, and accountability of funding, to give Molly access to education and PA in school.

> *My other children go to a different school. They go to a faith school but when Molly started going there the building wasn't equipped for Molly and because it's a faith school they're not accountable to the council, so their funding can be spent wherever, so the ability to support Molly was lacking, I suppose. Molly was signposted to go to this school because it's got a special needs department, it's a newer building, it's got a lift in and it seemed on the surface to be better equipped for Molly, but my other children, they're in a different school (Sophie, Molly's Mother)*

Frank (Bethany's father) felt Bethany's mainstream school allocation inappropriate due to lack of sufficient disability inclusion. Frank felt this was due to insufficient local authority funding. Frank also reported perceptions of too much difference between Bethany and her typically developing peers, with Bethany not fitting into the mainstream school.

> *I think they try and make it inclusive but it's not and it can't be, it can't be inclusive unless it's specifically providing for disabled children [...] You can't make do from one area to another. It's either very specific or it's not and I understand you know, it's all funding (Frank, Bethany's Father)*

Frank reported asking the local government authority to allow Bethany to have a mainstream and special school combination approach to school allocation and funding support. However, Frank reported denial to this request.

> *I think Bethany has fallen in the gap because they keep telling us all the time about this grey area and she doesn't really meet any criteria [...] So, what we've tried to ask them is can we have some parts of the special school side and some parts of the mainstream school side, and over time what we've been told is, "no" (Frank, Bethany's Father)*

Sophie, mother of Molly reported insufficient personal assistant hours funded in Molly's mainstream school. Further, the requirement of a specific disability label to gain more funded hours. Sophie reported the school suggesting some disability labels gained funding easier than other labels.

> *I think to have a personal assistant or a one to one in school is needed for parts of the day. But for them to provide it or recognise it, they're saying, well, we can get it easier if we have an autistic diagnosis and I'm like why is cerebral palsy not enough of a diagnosis that you think that she needs that (Sophie, Molly's Mother)*

Management of personal assistance provisions may also be problematic. Dwayne reported having funding for a personal assistant in primary school but not having one provided. The family were not sure why.

> *For my primary school, they said I was having my one-to-one but I wasn't. Yes, I think it was being paid for, that, but it wasn't happening (Dwayne, 11 years)*

- **Social Care Provisions**

Political-economic support is available to families to support PA outside of school if families are eligible for economic support, choose to apply for support (direct payments) and use direct payments for that purpose. Sophie and Molly, Family 4, were the only family using the social care support benefit for PA participation. Sophie described the application processes involved and reported them difficult, and reported difficulty in getting the hours paid for.

> *Within social care, they have the normal social workers and then they have a disability team and they can provide home adaptations, they can provide personal assistant support, so it's called direct payment. So, what the council will do is they assess the need of the child and the family and then they will potentially provide so many hours a week for a personal assistant to come and assist the child in an activity, or provide respite care, those types of things. It's very, very hard to get any hours [...] the social worker said to me, quietly on the side, the only reason Molly got the hours is because I'm a single parent and I haven't got a partner to take responsibility for the children (Sophie, Molly's Mother)*

At the time of interview, Sophie was struggling to find a suitable personal assistant available at the time required, to support Molly in weekly swimming participation.

Harriet reported Mark was not eligible for a social worker and was therefore not eligible for social care funding for adaptions in the home to support Mark's daily PA. Harriet reported the family required the financial support and Mark required the adaptions.

> *We were told we couldn't have a social worker because I wasn't at risk. They said, 'Because you work and you're fully-functioning, you don't need one (Harriet, Mark's Mother)*

Harriet also reported the family was not eligible for government funding despite a previous assessment stating eligibility.

> *Even when we had a social worker previously, she said, 'Oh, you need this, this, this,' and she made a huge lists of the things that we need, and she said, 'We'll get it all funded for you.' So we went back to the council and the council said, 'Oh, we don't fund any of those things.' (Harriet, Mark's Mother)*

Harriet reported a lack of trust in government institutions to help provide funding to support Mark.

> *I just think they don't generally care about disabled people. I think there's not a concern there for them. I get a feeling, because they're not affected by it, it's. 'Oh, well', and it's just a pot of money that they don't feel as if they should be parting with (Harriet, Mark's Mother)*

Due to the situation continuing for some time without resolution, Harriet had started legal processes against her local authority.

> *I am trying to take [Named] Council to court due to the fact that I've been in this house since 2016 and Mark still hasn't got a toilet that he can access safely (Harriet, Mark's Mother)*

Raymond also reported not having much faith in their local authority to provide resources to support them.

> *They don't go out of their way for you. I'm sure the Council could help, it's just getting somebody to listen to you and take it on board and then realise what you need and then get them to help you. But I don't have a lot of faith in Councils (Raymond, C-Jay's Father)*

Sophie felt that the difficult processes involved in gaining direct payment, and the stigma involved in needing to have a social worker assessment, hindered families applying for funding support.

> *I know friends - they have severely disabled children and they should have been accessing this service. But, they say, "oh, we don't want a social worker" (Sophie, Molly's Mother)*

Sophie described the stigma attached to having a social worker acted as a barrier to applying for direct payment, as well as the onerous and invasive processes involved. Therefore, Sophie reported, many times, thinking of giving up on renewing applications for direct payment.

> *I won't outwardly say, "Molly's social worker's coming today" because immediately, they're like, "oh yes, what are you doing?" Even in school sometimes – they'll say, "the social worker phoned today", and I'll say, "No, it's the disability team" [...] but you have to jump through so many hoops to get it as well. You have to have about six different meetings with them and they go into every area of your life. They speak to your other children to see how they feel about having a sibling with a disability, it is really invasive. They come and speak to me, they have an appointment where they speak to Molly and sometimes Molly on her own, sometimes my*

> *other children on their own. You feel like you're being ridiculed almost. I suppose the services are so under pressure that they have to give the absolute needy these things, so unless you tick every box and say, "yes, we need it" you're not going to get it. There has been two occasions since having the direct payment where I have said to the social worker, I would rather not. Because, you just do, you feel like you've done something wrong I suppose (Sophie, Molly's Mother)*

Raymond and C-Jay were additionally reliant on the local authority for housing. The family reported their local authority wanted them to move and was not considering their needs for storage space for a large, adapted trike, frame-runner, wheelchair, and seating equipment.

> *The Council have been on about, we're going to move, and I'm trying to explain to them, we can't just move into a two-bedroom flat. We need storage, we need space. We need space for his chair, and they're like, 'oh, so are you refusing to take a flat?', and I'm saying, 'I'm not refusing, I'm just telling you it's not good for us'. That's ongoing (Raymond, C-Jay's Father)*

5.4.4. Temporal Elements

Temporal elements relate to history and the passing of time which presented in the data as influences related to age and stage of development and the Covid-19 pandemic, present at the time of data generation and analysis.

- **Age**

Age related changes with growth made C&YP taller and heavier over time, and therefore, more difficult to mobilise and support - particularly severely physically disabled C&YP. Thus, over time, families with severe physically disabled C&YP became more dependent on equipment (e.g., hoists) to access PA participation; however, this equipment was not always available. Furthermore, developmental aging reduced some C&YP interests in physically active play and sports.

Pauline reported that developmental aging changed Phillip's PA interests away from physically active play.

> *When he was smaller, we used to go to the park the whole time because he's relatively small built. I was able to put him on my lap and we used to swing, but I think that would be not cool for Phillip now. He's grown out of that, and it's kind of "ugh" (Pauline, Phillip's Mother)*

Pauline also reported Phillip used to surf with his father. However, Phillip was now too large and heavy to lift and hold on a surfboard. Additionally, Pauline reported no longer being physically able to take Phillip swimming due to his growth.

> *When he was smaller, he used to surf with his Father. His father used to put him on the board, and ride the wave in together [...] There's one thing that I physically can't do any longer because he's grown, I couldn't take him swimming any longer. I think it would be quite difficult for us now to take him to the local swimming pool (Pauline, Phillip's Mother)*

Frank similarly reported Bethany had stopped a range of PA e.g. frame running, walking, and horse riding since growth increased her physical limitations and made moving and handling difficult.

> *What we found was over a period of years that slowly the CP seems to have kicked in more and it's reducing her mobility and strength. So we've had to stop a lot of activities [...] with horse riding because of her hip displacement, she was always leaning quite badly to one side, which meant you had to try and pull her over to the other side. Then, to get Bethany on the horse, because she had to be manually lifted and put on, it would send her into overdrive, she just couldn't cope with that [...] between that and the position on the saddle - they said it wasn't beneficial to her (Frank, Bethany's Father)*

Similarly, Mandy reported difficulty, lifting Catherine onto a horse since growth and a lack of adapted supportive seating hindering horse riding.

> *Horse riding she used to do quite a lot of, but because she's got bigger it's much harder to get Catherine on a horse when you don't have any real support to get her on, because obviously there's all the manual handling when it comes to getting on a horse. She absolutely loved horse riding, but now she's bigger it's really hard for me to get her up on a horse now. And the saddles aren't brilliant, they've just got mainstream saddles, and I think you do need more of a supportive saddle to go horse riding, particularly with those children that don't have the physicality to sit properly (Mandy, Catherine's Mother)*

Frank reported increasing CP impairments with growth had also limited Bethany's ability to keep up with disabled peers, in formal disability specific sports. Therefore, Bethany had stopped attending specific disability sports.

> *Wheelchair basketball she liked that, but we found, she could move herself in the manual wheelchair but not quickly enough. She didn't have the stamina or the strength to keep up with the other kids. So when they moved her into the powered wheelchair it didn't make that any better, because she*

> *was having less exercise with the wheelchair, so we stopped that [...] we found with race running Bethany liked that and she was quite good actually. But we found as she was growing and getting heavier her tone became so tight at the tops of her legs that saddle wise, she couldn't tolerate that either, and that's even stopped her with the walking frame as well, so she doesn't use that either (Frank, Bethany's Father)*

- **Covid-19**

PA opportunities provided by schools and community groups stopped during the Covid-19 social restrictions, which also increased isolation and decreased some families' motivation for PA participation.

C-Jay and Raymond described a dip in motivation for PA during Covid-19 due to social restrictions and lack of participation opportunities.

> *It's having a lack of motivation, and we've got to get that motivation back (C-Jay, 12 years)*

> *It's trying to get things done as easy as possible, and not having a lull. Getting him motivated to do it (Raymond, C-Jay's Father)*

Sierra reported Alex lacked motivation for PA participation and motivation was key to his participation. However, the lack of interaction with his friends in and after school due to Covid-19 had decreased his motivation further.

> *He's missing his friends, he wants to go out to play, he wants to be able to take the dog down to the park and see the boys, his motivation levels are very poor, it's easier a lot of the time not to bother (Sierra, Alex and Sian's Mother)*

Besides reducing motivation for PA, Covid-19 stopped participation programmes, which exacerbated barriers for families who already lacked opportunities, and who needed specialist assistance for participation. Pauline, Phillip's mother, described the inability to take Phillip to a disability surfing group as a result.

> *Last summer, we tried to get into [named disability surfing charity] but they closed, they closed 'cause of Covid and hopefully they'll open up a bit this summer, maybe, I don't know (Pauline, Phillip's Mother)*

5.5. Summary of Barriers

I summarise barriers to PA participation in Table 6 (p176). Disability discourses created unwelcoming, exclusionary experiences that reduced families' attendance and hindered creation of mutual understanding/interpretations between families and providers within participation situations, as described by SI theory - where meaning is created through interactions and interpretations of these interactions (Blumer 1969). Environmental elements reduced attendance when environments were not physically accessible, and environments and opportunities for participation were located far from families' homes. Furthermore, when competing family commitments overlapped/interacted with these environmental barriers. Fragmented information systems reduced knowledge on opportunity and choice which affected ability to attend. Political economic systems involved lack of resources and trust that hindered collaborative support for participation. Temporal elements involved change, uncertainty, and transition regarding age related changes (physical and social) that reduced participation over time, as did temporal Covid-19 restrictions that were present at the time of data generation and analysis.

Situational Matrix Category:	**Sub-Category:**	**Elements/Relations:**
Discourses:	Disability	Fearful, lacking confidence, not responsible, labelling, C&YP at high risk, incapable
	Participation	Labelling/Categories, C&YP's identity, preferences Providers: Lack training, availability
	Inclusion	Lack of reasonable adjustments, legislation, knowledge, time
Environmental:	Location:	Distance, Time
	Family:	Juggling commitments, time, siblings, fatigue
	Access:	No. of Spaces, Traffic, Maintenance, Changing/Toilet spaces
Non-Human:	Information	Fragmented
Political-Economic:	School	School Allocation, Funding, Disability, Labelling/Categories
	Social-Care	Stigmatised, Onerous Processes
Temporal:	Age	Changing - Interests, Impairments, Manual Handling, Equipment Needs
	Covid-19	Reduced - Access, Support, Opportunity, Motivation

Table 6: Barriers to Participation - Family Findings

5.6. Summary Conclusion

SA of the family interviews revealed a nuanced landscape of factors influencing the community PA participation experiences of C&YP and their families. Use of SA revealed a complex interplay between the many different elements, facilitators and barriers, within the situation, with varying degrees of importance for different elements, facilitators and barriers, dependant on individual family and child/young person circumstances. Given this complexity, determining and providing effective practice recommendations is likely to require a tailored approach that considers all the diverse influences within the situation, and the diverse needs of C&YP and their families. It looks like recommendations will therefore require flexibility and adaptability to ensure they can address the unique challenges for each individual child/young person and their family, and leverage C&YP's and families' specific strengths, whilst also considering the overall, larger situation.

It appears from family findings that to take an individual approach, individual family and child/young person need to identify their beliefs about PA and be educated and encouraged in beliefs that support PA participation, and support PA participation through childhood transitioning phases. This approach aids families' physical literacy i.e., their autonomy and responsibility for taking part in PA. Providers could assist families in obtaining physical literacy e.g., healthcare providers could assist in identifying families and child/young person beliefs and provide education to support beliefs that promote PA engagement. Furthermore, healthcare providers could help families navigate community PA opportunities and resources that support C&YP's attendance and inclusion. This could be a way of integrating healthcare and providing a participation-focus within healthcare to facilitate C&YP's community PA participation.

Chapter 6. Service Provider Findings

I present provider interview findings showing the interview sample demographic details and facilitators and barriers to providers' support for C&YP's participation.

6.1. Service Provider Sample

I recruited 11 service providers using purposive, volunteer sampling. The sample represents charity, sport, healthcare and education social worlds. I report all details on providers using their pseudonyms.

Eight providers supported community PA participation through employment or volunteering with registered charity organisations (Kelly, Debbie, Hermione, Harry, Gerry, Saul, Vicky, Twinkle-Toes). Saul was a Paralympian, who worked and volunteered as a coach for a table tennis club. The club was a registered charity, but also a limited company. Vicky and Twinkle-Toes worked for a healthcare therapy centre that was a registered charity and a limited company. Vicky as a physiotherapist, Twinkle-Toes was a family officer. Twinkle-Toes was also a parent of an adult child with CP. Harry was a product designer who worked for a children's brain injury charity that was also a limited company. Gerry was a manager who worked for NDSO. NDSO is a registered charity and limited company that additionally receives exchequer funding. NDSO is an organisation that is in the sport and charity social worlds with links to government/political social worlds and commercial social worlds.

Kelly was an educational psychologist employed in healthcare, and working in healthcare and schools. Kelly also volunteered at a support group for families and C&YP with neurodisability. Debbie was an OT employed in healthcare and working in schools and in private practice. Debbie was also a volunteer manager of a support group for families and C&YP with neurodisability. Hermione was a healthcare student who volunteered for a disability ski, charity group involving C&YP with ASD and their families. Evelyn was a physiotherapist working in healthcare who volunteered in support of community PA participation, independent of any company or registered charity.

These providers represent an overlap and intersection of several social worlds. Predominantly charity and sport, but also an intersection with healthcare, education, political/government and product design and manufacture. Several charities were also limited companies, which represents an overlap and intersection of charity and sport social worlds with the commercial social world. I discuss these overlaps and intersections in more detail in chapter 7.

Two providers were PE schoolteachers (Zoe and Mario) who worked in mainstream government schools. Zoe worked as a PE Specialist Teacher in a primary school having a specialist disability unit. Mario worked as a PE Specialist Teacher in a secondary comprehensive, middle school i.e., having both primary and secondary school pupils. Mario worked predominantly with C&YP aged 11 - 18 years. I present a summary of providers in Table 7 (p179 &180).

Provider:	**Pseudonym:**	**Profession/Role:**	**Organisation/Group:**
1:	Evelyn	Physiotherapist	No organisation affiliation, is an independent volunteer managing a C&YP's frame running group (no affiliation)
2:	Vicky	Physiotherapist	Physiotherapist at a therapy charity and employed by the charity
3:	Twinkle-toes	Family Support Officer Mother of an adult child with CP	Family support officer for a therapy charity and employed by the charity
4:	Saul	Sport coach & paralympian [table tennis]	Coach at a city1 table tennis club, employed and volunteer at club
5:	Harry	Product designer	Children's charity product designer and manufacturer, employed by the charity
6:	Kelly	Educational Psychologist	Employed in healthcare and education Volunteer for a charity support group for C&YP with neurodisabilities

7:	Debbie	Occupational Therapist	Employed in healthcare and education, and self-employed in private practice Volunteer for a charity support group for C&YP with neurodisabilities
8:	Hermione	Physiotherapy Student	Full time physiotherapy student Volunteer with a disability ski charity
9:	Gerry	Manager Chief Executive	National Disability Sport Organisation representative, employed
10:	Zoe	Physical education (PE) Specialist teacher	Primary school PE specialist, employed in government school
11:	Mario	PE Specialist teacher	Middle school PE specialist, employed in government school

Table 7: Service Provider Demographic Details

6.2. Facilitators of Community Physical Activity Participation

I organised the facilitators across all providers into three situational matrix categories - **Human Elements, Economic Elements** and **Non-Human Elements.** However, the different categories, and their related sub-categories, elements and relations overlapped and intersected that meant constraining them all neatly to one category is not always possible within the situation. The overlapping and inter-related nature of the different elements made them difficult to group into specific situational matrix categories, which meant that a more descriptive approach apart from situational matrix labelling may have worked better. I considered using descriptive labels and resolved tensions in using situational matrix category labels by identifying and using relevant descriptive labels within the different situational matrix categories. I briefly summarise the categories before presenting them with their related sub-categories and elements.

The human category I organised into subcategories of individual people and collective people - organisations. Organisations provided PA programmes, which relied on collaboration between people, and relied on non-human elements of funding, information, education/training (knowledge), and equipment to support C&YP's participation.

The Economic category had sub-categories of grant funding and fund-raising events. These linked to elements of time, inclusion training, and access, which provided participation opportunity and choice.

The Non-human category had sub-categories of equipment and education/training. These elements related to human elements (people and organisations) and their knowledge, skill and experience. Human and non-human elements therefore linked to provide participation opportunity and choice.

6.2.1. Human Elements

Collective People - Organisations

Organisations were key collective people facilitating participation. Key organisations were NDSO, the National Sport Organisation (NSO) and the CITY1Sport organisation (all pseudonyms). These key organisations are sport organisations, which illustrates a predominance of sport opportunities as the main form of community PA participation available to C&YP.

- **Organisations' PA Programmes**

Providers delivered community PA programmes that facilitated C&YP's participation (confirming family findings). PA programmes required collaboration between providers, funding, people with inclusion knowledge/skill, and the sharing of information between providers, and between providers and families. I present each sub-category of PA programmes, and their related elements supported with participant quotes.

- **Collaboration**

Community sport opportunities existed via programmes supported and delivered through collaboration between sport organisations e.g., NDSO, NSO, CITY1Sport, and a variety of sport clubs. Zoe, a PE specialist in a primary school, described these collaborative programmes/opportunities.

> *[CITY1]Sport have something called the [CITY1]Games, it's lots of different activities children can do, physical activities from climbing, canoeing then you've got your football and netball, all of those things. So, we participate in that and we are a very active school within that [...] There's the same thing for the special needs as well so they have a range of activities [...] CITY1Sport are based at [named University] so we use a lot of students as well, operating there [...] CITY1football, they do a lot of*

> *things in collaboration with CITY1Sport so it's an opportunity for the children to try things (Zoe, PE Specialist)*

Zoe's descriptions show collaboration between numerous sport organisations and sport clubs offer participation opportunities and choices. Additionally, the programmes provide facilities (University premises) and staffing/people (University students) in support. Zoe also reported collaboration from her school necessary to support C&YP's participation in the programmes.

> *Our head is very good, she's really positive, because we take them out of school [...] we enter everything, absolutely everything (Zoe, PE Specialist)*

Zoe's narrative suggests C&YP's attendance reliant on schools' collaborative involvement in the community programmes.

Gerry, an employee of NDSO spoke of the collaborative work of NDSO with other sport organisations to provide community programmes, which offered opportunity and choice.

> *Our aim is to ensure that there is good access to good quality opportunity with real choice for disabled children, young people [...] We work with any partner who wants to be a partner. We've got the traditional partners - health boards, sport national governing bodies, sport focused or activity focused organisations - from local clubs to the national governing bodies, parks, local tracks, venues, leisure trusts, certain commercial partners [...] our partners are very wide ranging, multiple partners, who have an interest in activity and or disabled people (Gerry, NDSO)*

Saul, a table tennis coach at a CITY1 table tennis club, collaborated with NDSO to provide table tennis at disability inclusive sport events/programmes, InSport events (similarly reported in family findings). Collaboration meant Saul and his table tennis club could offer disability inclusive table tennis to C&YP attending these events and signpost them to community clubs for ongoing participation.

> *We've worked with [NDSO] or Sport [CITY1] when they have the Insport days. They're really good. But obviously, I think they get hundreds of kids [...] bus them in and they can try all different sports, so those sessions are really good (Saul, Table Tennis Coach)*

Saul reported NDSO InSport grant funding provided the bus transport for families, described in his quote above.

- **Funding**

Programmes required financial resources for delivery, and provision of transport, and/or subsidised or free sessions. Hermione, a healthcare student volunteering at a skiing charity for C&YP with ASD reported a parent of a young person with ASD raised funds and collaborated with a ski-slope centre, who were willing to share their resources at a subsidised rate, to provide subsidised skiing for C&YP with ASD.

> *The lady who runs it, her day job is working with kids with autism, and one of her children also has autism [...] she does some fundraising [...] and the other professionals are ski instructors who she has co-ordinated with to set this up. [...] They hire the whole ski slope and those guys, run it [...] the kids are getting outside to do a sport that would be really hard for them to access, cos, it's a very expensive sport and, here you are able to do it with closer tuition, otherwise they would probably need one on one and it would probably be just priced out (Hermione, Healthcare Student)*

Hermione's narrative additionally suggests that disabled C&YP likely need individual support that is costly to provide, especially in expensive sports.

Debbie (OT) reported collaboration with the community NDSO officer (Sam - pseudonym) which gave access to funding and subsidised community PA programmes. Debbie also reported collaborating with other community PA providers e.g., a rebound company, for subsidised trampoline sessions.

> *Because we haven't got a huge amount of money, we did a deal with Sam, who is the [NDSO] disability development officer. Sam said to me "look, I've got a pot of money I can pull in for that, if I can do this, this and this", and that's what we did. We do a lot of negotiating with people. So with Rebounders we did a deal, we often do a deal with people (Debbie, OT)*

Zoe also described collaborating with community sport providers for them to provide sport taster sessions in her school; however, only when these opportunities were free.

> *"Basically, if anybody sends anything to our school that is "oh we're offering this, it's free", I always get them in" (Zoe, PE Specialist).*

Saul also reported reduced costs for sessions supported participation. For example, he reported that families were more likely to attend sessions if they were free. Grant funding enabled Saul's table tennis club to provide free sessions to families in financial need.

> *Yes, when the sessions are free it's easier to attract people. We have a grant that provides free sessions for people who meet criteria showing they cannot afford them (Saul, Table Tennis Coach)*

Gerry reported the NDSO received lottery funding to provide disability sport development officers (DSDOs) within the 22 local authority regions. (Debbie's previous narrative showed collaboration with Sam, her local DSDO). Gerry reported DSDO provision was partly funded by local authorities and lottery funding. Local authorities could decide whether or not to increase DSDO provisions or not, meaning some local authority regions had more provision than other regions (family findings confirm location as a barrier to participation).

> *The most well established partnership programme is the community programme, which is 22 local authority Disability Sport Development Officers, which is probably the contact that children, young people and their families have [...] We receive funding from the lottery to put funding into the local authorities, so the local authorities are the employer, but we put funding in for a part time post. Some of the authorities top that up to a full-time post. Some of the authorities balance the part time Disability Sport Development Officers' role against another sport focused or equality focused role so a lot of them are full time but not necessarily around disability sport work (Gerry, NDSO)*

Gerry reported that DSDOs also provided inclusion training for individual people and organisations to facilitate disability inclusion in communities. Inclusion knowledge and skill was another requirement for community PA programmes.

- **Inclusion Knowledge and Skill**

Gerry reported NDSO provided disability inclusion training to organisations. The training was also available to support InSport programmes (programmes that provided disability inclusive sport opportunities). The InSport programme also accredited sports clubs/organisations in disability inclusion. InSport had four standards of accreditation - ribbon, bronze, silver, and gold. Ribbon was the first, basic level. Gold was the highest level of accreditation, which indicated established inclusive programmes from grass roots level participation (community sport club formal participation) to Great Britain (GB) Paralympic participation levels (performance level formal participation).

> *We now have a programme called InSport, which is a hybrid word, inclusion and sport [...] it's an inclusive cultural change model. At ribbon the organisation would be committing to the principle of inclusion and that*

> *they want to be an inclusive organisation that deliver to disabled people. By the time they get to gold, they're actually doing that, and the sector can have confidence that they know what the pathway looks like. That they've got a well-furnished pathway, that they know how to support right through from initial engagement to just sub-elite performance, taking through up to performance programmes in the case of InSport and GB (Gerry, NDSO)*

Family findings showed families enjoyed attendance at NDSO InSport events due to its inclusivity and choice (chapter 5). Furthermore, family findings showed signposting at these InSport events facilitated continued participation for some C&YP e.g., Donny's table tennis (Family 2) and Trevor's athletics participation (Family 5).

Inclusion knowledge was additionally available in schools via PE specialists/teachers training and their collaboration with additional learning needs co-ordinator teachers (ALNCo) within schools. Zoe described communication between her and the special needs teacher/ALNCo aided her inclusion of disabled C&YP in the school PE sessions.

> *The special needs teacher, we're communicating all the time. If it doesn't work she wants to know, she wants to know why, she wants to know if we can adapt it. So, we're just communicating all the time (Zoe, PE Specialist)*

Kelly, an educational psychologist working in healthcare and schools, spoke of the need for communication between PE teachers and ALNCo's to ensure inclusion.

> *I think whoever is running the PE lessons they need to work with the ALNCo to make sure that the child can be catered for within that environment (Kelly, Educational Psychologist)*

- **Information**

Several providers reported collaborative sharing of information aided their signposting of opportunities to families. For example, as previously reported, the NDSO development officer (Sam) provided information on community opportunities e.g., football, to Debbie (OT) who then provided signposting to families.

> *We've been able to link up with the national disability sport team [...] so Sam, he did our tennis session and he is very good at sending us links. For example, to one of the disability football teams (Debbie, OT)*

Twinkle-toes, a charity family support officer, reported being on the NDSO mailing list, which gave her access to information on programmes/events, which she shared with families on her mailing list.

> *I have regular information sent through to me from NDSO and their open days throughout the year that they do with different activities. Whenever I get new information from them, I email that to our families so they get that and a lot of families take that up. Over the years' lots of our families have gone to that, and siblings, they'll get in a wheelchair and they'll have a try at a sport or things. I always say to the family, those days will introduce them, show them, and talk to them about sports that may not be on their radar (Twinkle-Toes, Family Support Officer)*

Family findings (chapter 5) confirm families who attended the NDSO events, enjoyed the choice available and the family inclusivity, as Twinkle-Toes describes. Twinkle-toes additionally reported gleaning information from families regarding their own PA participation, to obtain information on opportunities that she could then share with other families.

> *There are families out there who have found their own way into sports and found out locally what's available, or found sports that their kids are really enjoying. Then they come in and tell me about that and I can pass it on (Twinkle-Toes, Family Support Officer)*

Individual People

Alongside organisations, individual people played a role in facilitating participation. Providers reported a wide range of individuals supported participation e.g., coaches, teachers, instructors, parents, carers, helpers and peers. People with specific knowledge and skills in disability inclusion enabled participation, as well as helpers (paid or volunteering), family members and peers.

Hermione (healthcare student) described a ski instructor with disability inclusion knowledge, skill and experience that was very good at facilitating participation.

> *I just think he's brilliant in how he deals with absolutely everybody and all the situations [...] He knows when to let them be for a minute. Knows when to let them ski down the mountain. Knows when to say - you've got no gloves, you're not coming up, don't care if there's a temper tantrum. Don't care, those are the safety rules - and sort of manages all the staff as well. He is very good with the kids. I feel like he can read them quite well (Hermione, Healthcare Student)*

Helpers and assistants provided individual time and support to C&YP, which enabled participation in large groups of C&YP with mixed abilities. Mario (PE Specialist Teacher) gave such an example.

> *What works is, if you're able to give a little bit of individual attention – so, having a teaching assistant in there to help them - not having to rely on one of us to turn up and concentrate on that one pupil while the other 29 are doing something else (Mario, PE Specialist)*

Similarly, Debbie described needing additional helpers, numerous volunteer assistants, to provide individual supervision and attention to C&YP during group work.

> *What I found is, we have a heavy ratio of volunteers to children [...] whilst we're in a group, we're almost doing individual work within a group context (Debbie, OT)*

Vicky gave another example of helpers needed to support individual C&YP, and many helpers needed, particularly if C&YP had complex needs.

> *Manpower is a big issue and I don't know what the answer is to that. All these things take money, which of course is short, but I think often, people will need people to help make it possible and the ratios that you need are huge when you think about complex kids. Like the group we ran, we had lots of participation in it but we had more than one-to-one. Yeah, so we had sort of two to one for each child and floating people and expense-wise, it's huge (Vicky, Physiotherapist)*

Vicky's narrative makes the link between funding and the ability to provide people. Vicky reported two supervisors needed for each child, and extra people necessary in sessions with C&YP having complex needs. Harry similarly described surfing participation for C&YP with complex disabilities needing increased supervision and helpers, due to C&YP strapped into surfboard, which thus increased risks of drowning should the board overturn.

> *There's no point giving this surfboard to just a family, you need too many people to operate it. You need at least one competent surfing instructor surfing it. I think we recommend at least another 5 people in the water, because when you are walking the board out, you need at least two or three to support it as it goes up and over waves. Then when the board turns round and comes back towards the beach, we recommend that you have people, staggered along the route so that if they turn over, you've got people instantly there to get the kid out (Harry, Product Designer)*

Hermione also described numerous helpers necessary within group sessions, due to behavioural issues providing challenges to participation.

> *There are some, who are sometimes quite challenging, behaviourally. So, there will be a few tantrums, throwing things down, refusing to do it, tears*

> *and running off, which is why it is probably good to have extra volunteers (Hermione, Healthcare Student)*

Providers reported family members were key helpers (family findings showed parents supported sessions but not all parents were able to do so).

> *I've volunteered within disability sport for a long time, coached at a club for a good number of years and the guys who used to come down - it was for children, young people and adults with intellect impairment - so it was a range of people being supported by either their parents or their family or a personal assistant (Gerry, NDSO)*

Providers also reported peers could act as facilitators e.g., in PE when adult helpers/assistants were not available.

> *Sometimes with the special needs children [...] they come and join the lessons so sometimes they have a helper and that's great, an adult helper so that means that adult helper can literally just say what I'm saying to the child and adapt accordingly. If they don't have a helper then that's where sometimes I use peers so they're going to help each other, making sure it's not the same peer all the time (Zoe, PE Specialist)*

Mario also described using school peers as helpers when adult assistants were not available.

> *Now and again, what you have to do, is put one pupil to do a different activity with that pupil (Mario, PE Specialist)*

6.2.2. Economic Elements

Funding supported participation, either grant funding and/or fund-raising events.

- **Grant Funding**

Providers reported that grant funding provided finances for staff time and training, information provision, accessible facilities, and adaptable equipment. All of which supported PA programmes. Providers followed formal processes when applying for grants; however, these took time and effort. Saul reported obtaining grant funding to provide table tennis opportunities but sourcing, applying and obtaining funding was difficult (reported in barriers section).

> *We apply for any grants that we can to put on sessions [...] it's tricky but I think we're trying to get better at applying for grants and then delivering the project and satisfying all the needs. We've got a funded project as well that's ongoing and anyone with a disability comes under that (Saul, Table Tennis Coach)*

Gerry reported that the NDSO collaborated with charity organisations (e.g., lottery), government organisations (e.g., local authorities), and commercial organisations (e.g., supermarkets and banks) to obtain funding.

> *We have a proportion of lottery funding, which goes to community and performance and we have exchequer funding which goes to community and performance [...] We also do some work around Play Together which is an education and training resource aimed at children, 7 to 11 year olds, where they're playing together. It's basically disability inclusion training for children (Gerry, NDSO)*

In Gerry's narrative, community provision refers to grass roots sport clubs, while performance refers to Paralympic teams and pathways supporting performance teams. Gerry reported funders could place restrictions on funding use, which limited flexibility regarding support provisions (see more detail in barriers section).

> *We have some commercial funding. They are restricted pots, so we have very stringent parameters about what we can do with that money. But then, we have some unrestricted pots that come in through commercial partnership, so we do some work around the InSport series events with that (Gerry, NDSO)*

Kelly (an Educational Psychologist) reported grant funding supported the charity group she provided.

> *We get grants. We get our funding through grants. We've been very fortunate that [named children's charity] have funded us on an annual basis (Kelly, Educational Psychologist)*

Harry was a product designer working for a brain injury charity. He designed and manufactured products for C&YP with brain injuries. Many products Harry designed enabled access to PA. The charity raised money for the work via funding raising events such as a weekly lottery, grants from companies, and relied on funding left in wills and trusts. Harry reported the charity did a lot of searching for funding sources to raise funds for its work.

> *So, a lot of the funding is through, they have a call centre. They do a lottery scheme and then there's other fund-raisers that specifically search for grants from companies, funding bodies, and, wills and trusts and things like that. But, yeah, there's no government funding, or anything like that (Harry, Product Designer)*

- **Fund Raising Events**

Harry has described a range of fund-raising activities (above) alongside grant funding resources. Fund raising was an additional source of funds that other providers also reported. For example, Kelly reported doing regular fund-raising events in addition to grant funding applications.

> *We do fund raising events but we do also get grants (Kelly, Educational Psychologist)*

Evelyn reported doing a large annual event to raise funds for the frame running group she managed. Most of the money raised went on insurance costs.

> *For insurance, we do fund-raising. Our insurance is £600 that is our biggest expense, we do this fund-raising event once a year, which raises our profile, which raises expectations and everybody enjoys doing it (Evelyn, Physiotherapist)*

6.2.3. Non-Human Elements

I organised non-human elements into two main subcategories of equipment and education and training although both these subcategories involved and needed links to humans to be effective in supporting participation.

- **Equipment**

Equipment was another common support for PA across providers. Equipment was essential for some sports e.g., skiing, and for some severely disabled C&YP e.g., supplying hoists for access. Providers also reported people’s knowledge and experience with equipment was essential to facilitate access.

Evelyn described the essential connection between human characteristics and non-human equipment, to support participation.

> *I’d already seen that equipment could also be left very easily and it’s very easy to say - just use this piece of equipment and everything will be fine - and that’s not how it works. Equipment is just there as an extension of what we do with people (Evelyn, Physiotherapist)*

Evelyn reports that equipment cannot fulfil its purpose if people do not use it in an informed way. Evelyn went on to describe this human-non-human connection in more detail.

> *You need people who understand what difficulties you can expect so that you can react quickly and not spend hours trying to amend something or*

> *adapt something, which then doesn't work out, and you've got to find a good solution. So, you've got to either be prepared or you've got to have an amount of equipment which can easily adapt to all needs (Evelyn, Physiotherapist)*

Saul reported using his knowledge and skill in adapting a range of equipment to support table tennis participation by disabled C&YP.

> *We can make adaptions if they need it. We can use larger balls, different colour balls and adjust the game, we can take away the net completely, put sides on the table and make it a little more like the air hockey game [...] We're quite creative - use balloons, or use anything (Saul, Table Tennis Coach)*

Zoe also described her knowledge in adapting activities and use of equipment to modify activity enabled her support of participation.

> *We've got adaptors - so we've got balls with bells in [...] I try to get a whole range of equipment so like tactile master. The special needs unit will use a lot of that stuff. I just adapt the activities give them different equipment, brighter equipment maybe they can feel, they can touch and it's just making the activities simple for them (Zoe, PE Specialist)*

Zoe included in her adaptions the need to make PA simpler to facilitate C&YP's access.

Hermione also described a range of adaptable equipment necessary to facilitate skiing participation, especially for a range of different types of disabilities.

> *We had a couple of days where they showed us adaptive skiing and working with people with modified equipment and sit skis and blind people and children with autism and I really enjoyed it. I enjoyed thinking about how can you adapt equipment or adapt sessions (Hermione, Healthcare Student)*

Hermione's narrative shows the link between people, their knowledge and skill, and the use of equipment to support participation. Hermione's narrative suggests people may also need knowledge and skill in the specific sport they are facilitating.

Harry reported designing and manufacturing a range of products/equipment specific to families' needs and desires for participation (bespoke provision). Harry gave examples of products for C&YP with physical impairments that enabled surfing, sledging, crawling, boating, playing the game of Botcha, horse riding, and throwing a ball for a dog.

> *We designed this adaptable surfboard, we've made bespoke horse riding helmets. This "scoot-seat", it basically allows kids that can use their legs but maybe don't have the strength to stand and walk themselves, they can sit on that and sort of crawl along. We made that running chair and the front wheel drops out and it fits onto the back of the bike. Specifically, for sport, we've made sledges, we've made boats, that funny device we made for kids to play a sport called Botcha. This GoTO seat, it allows you to get out-and-about, and do stuff. That blue thing over there is a ball shooter for a lad with an assistance dog. The only thing that the child could give back to the dog is being able to throw a ball for him, but his arms didn't work, so he couldn't throw a ball. So, we robotised a tennis ball shooter, with a big handle. They're as varied as from a horse riding helmet to that ball shooter, to a sledge, to a surfboard. It depends on what the child wants to do. But there will usually be a physical impairment involved (Harry, Product Designer)*

Gerry reported a range of sport wheelchairs and sport equipment available via InSport community programmes.

> *There's wheelchairs all across the country which would be good enough for initial engagement in community participation. In the InSport series events, the local clubs have access to some good equipment, which the young people use (Gerry, NDSO)*

- **Education and Training**

I identified education and training as a common category across all providers' situations that enabled providers to support participation. Education and training could be formal training sessions, or informal education via on-the-job experience.

Gerry reported the NDSO, and NDSO partnership programmes provided a range of free, formal training sessions, in disability and disability inclusion. Providers from different sectors accessed the training.

> *We have disability inclusion training, where we create training for transient workforce - so whether that's teachers, whether that's coaches, whether that's leaders. We offer weekend or evening disability inclusion, training for coaches and volunteers. We do board training for governing bodies [...] we provide a raft of free disability inclusion training and some inclusion around InSport and what that is. So we work with delivery partners, we don't deliver all of that, but we fund those courses so that people can get free access to it if they're involved with an InSport club, to develop their provision (Gerry, NDSO)*

Gerry's narrative additionally shows that links to her organisation facilitated funding for other organisations to deliver disability inclusion training to a wide range of community providers. Other providers also reported disability awareness and disability inclusion knowledge necessary for the staff within their organisations/groups to support C&YP's inclusion in PA. For example, Debbie described providing a training package for volunteers.

> *We have had a series of volunteers, we advertise every year, so we'll have a trickle through. This year we had about five or six go through the training, because we put a training package together (Debbie, OT)*

Hermione described the skiing charity where she volunteered providing her with free (funded) training in autism and skiing instruction.

> *They gave us an option to start getting a qualification so we could help more and it helps the organisation because they pay the instructors. So, if you volunteer and then get qualified to teach you can do that. So, we started doing a qualification as well to teach skiing. It just helps to give the kids a bit of a better experience as well [...] they're organising some dates for autism training as well [...] how to interact with the children and that sort of thing (Hermione, Healthcare Student)*

Hermione's narrative reveals the ski charity potentially facing financial pressures that additional staff training could alleviate. Hermione reported her physiotherapy student training helped her support participation, due to physiotherapy education including training on disability, communication, and task analysis.

> *You also work with learning disabilities as a physiotherapist. So, you're thinking about how to engage them, how to get them to do the movement, so doing something where it is fun. Where they can see - oh, I've got to get down here. But also thinking about how you explain those movements and you deal with fear that comes with it as well. Looking at their movement patterns in this sport, see how they are doing it, and why they might not be doing something, and relating it to the psychology behind the disorder, and the actual sport itself, and the equipment, and the conditions on the slope on that day (Hermione, Healthcare Student)*

Hermione describes several participation elements that training supports e.g., enabling physical movement skills, understanding disability, and applying those skills and understanding to the specific sport itself.

Mario reported being exposed to disability management in his teaching and pre-training. However, he felt that experience was his main source of knowledge and skill enabling him to support disabled C&YP's participation.

> *When you start doing your teaching practice you would get some training, but most of it's on the job training. The majority of it – how you adapt it to different requirements of the pupil in class is up to you individually as a teacher (Mario, PE Specialist)*

Zoe also reported practical experience being her main teacher. However, she additionally reported attending continuous professional development (CPD) opportunities.

> *I trained as a class teacher and in my training, I did PGCE, we had two weeks of PE and that was it. You were the PE specialist because you chose to do PE in those two weeks. So, for a primary school teacher unless you've got a passion - you've got to have a real passion for it - then you go and do your own training so I went and got other qualifications [...] but I guess it's just learning as you go and I've never seen special needs children as different to other children. You have an abled-bodied child if you like that struggles with certain things, so it's just adapting along the way, which you're taught that in teaching anyway, to adapt your lessons (Zoe, PE Specialist)*

Zoe, like Mario, described her initial PE teacher training was limited to two weeks. In contrast to Mario however, Zoe described additional experience with a special needs teacher. Zoe reported this additional, specialist experience increased her confidence and problem-solving abilities in disability inclusion.

> *I'll tell you one person who did really help was when I was initially training, I went to a special needs school. I was with a teacher, I was helping her so she opened my eyes to that side of things and she was very helpful (Zoe, PE Specialist)*

6.3. Summary of Facilitators

Providers supported and delivered community PA programmes that gave C&YP opportunities and choices for participation. These programmes relied on collaboration between organisations. Most of organisations involved in programme provisions were sport and charity organisations who delivered a variety of inclusive or disability specific sports programmes. Schools and community groups engaged with the programmes, which facilitated C&YP's attendance, as did information sharing between organisations and signposting. Funding (via grants or fund raising) supported programmes and people in organisations who delivered the programmes. People in organisations with inclusion knowledge, training and skill, enabled participation of C&YP.

A wide range of people supported this participation, individually or as part of an organisation, and supported delivery of PA programmes. Individual people included parents, other family members, carers, helpers, personal assistants and peers. Organisations provided people with inclusion knowledge, skill and experience to facilitate participation. Sufficient numbers of people enabled individual attention to C&YP in large groups, which enabled safe access and inclusion. People with knowledge and skill in adapting PA and use of equipment facilitated participation. Equipment and people thus linked to facilitate participation. Inclusion training, knowledge and experience additionally facilitated these processes. I summarise provider facilitators for their support of C&YP's community PA participation in Table 8 (p195).

Situational Matrix Category:	**Sub-Category:**	**Elements/Relations:**
Human:	Individual People	Inclusion Knowledge/skill Sufficient No./Ratios
	Organisations	Collaboration Funding Inclusion Knowledge/Skill Information
Economic:	Grant Funding, Fund Raising Events	Time Inclusion Training Access
Non-Human:	Equipment	People with Knowledge/Skill & Experience, Adaptability, Funding
	Education/ Training	Inclusion Training People with Knowledge/Skill & Experience, Adaptability, Funding

Table 8: Facilitators of Participation - Provider Findings

The categories, sub-categories and related elements do not stand alone, or act only in rows or columns as in the diagrammatic representation within figure 8. However, elements interact within and across categories, and sub-categories (these numerous rows and columns represented), to facilitate participation.

6.4. Barriers to Community Physical Activity Participation

I organised the common barriers across all providers into seven situational matrix categories - **Historical Influences**, **Organisational/Institutional Elements**, **Human Elements**, **Contested Issues**, **Economic Elements**, **Environmental Elements**, and **Temporal Elements**. Each category had related sub-categories that contained related elements. These elements had relationships with each other and interacted to create an overarching situation of limited opportunities and choices for participation. I present these barriers supported by participant quotes, starting with historical influences.

6.4.1. Historical Influences

Historical influences continued influencing the present-day situation and involved limited responsibility for inclusion across sectors/social worlds, limited organisational inclusion practices, and limited inclusion governance.

- **Limited Responsibility**

A position of historical social exclusion of disability (Disability Discrimination Act 1995) and only more recent protection of disability to enable social inclusion (Equality Act 2010) was present within the situation. Inclusion was happening but providers reported people and organisations were slow to take responsibility for inclusion. Gerry described this historical situation in sport.

> *What we've found about 10 years ago was that whenever a query came in to the sport development team that had the word disability associated with it, it would go to the Disability Sport Development Officer. So, what we were doing in terms of embedding inclusion, was actually starting a process of segregation. So, it was absolutely necessary at that time because it did start to embed a programme, it started providing opportunity, but what it didn't do was encourage other people to take responsibility for their sport and the communities that fit within it (Gerry, NDSO)*

Gerry's narrative reveals a debate within the sport sector between different sport organisations regarding taking responsibility for disability inclusion.

> *NDSO vision was always slightly different to that of the sport sector because the sector vision was never explicitly inclusive so previously, we've had to translate the vision for sports into one which was accessible to disabled people (Gerry, NDSO)*

Within healthcare, similar historical debates exist regarding taking responsibility for participation.

> *I think there are many physiotherapists who will think about participation but many physiotherapists don't. One of the things that I don't want to see happen - that I've seen pockets of, is people, just seeing participation, and thinking that the intervention is participation. I think, there, as a therapist, you are missing that your strength is that task analysis, so how can I help that participation. Participation is what you want, but if what you need to do, to make it happen, is in body structure and function, then that is what you do [...] because I think we have got to be careful, if it is just a group practicing football skills, from a participation point of view, then again I don't think that is necessary the role of therapists, that's the role of [NDSO] or the local sports club (Vicky, Physiotherapist)*

Vicky describes the goal of physiotherapy being participation but the need to work to physiotherapy strengths by focusing on ICF (WHO 2001) body function and structure, and activity domains, to achieve participation. Vicky also describes a difference in the roles and responsibilities of physiotherapists and sports providers; asserting physiotherapists need to be absent from community sport situations for the situation to be classified as participation. Contrastingly, Evelyn, also a physiotherapist, felt physiotherapists needed to be part of community PA participation situations.

> *As physio's I felt we were in a good position to do participation because we know how difficult it is, from a physical point of view, how much they struggle, and we also know that we want them to do more exercise [...] physios, I think, can help by going out and seeing what's going on, and where do people stop? Why can't they get at something, and not accept that you can't do something (Evelyn, Physiotherapist)*

Evelyn felt physiotherapists needed to be involved in participation situations to help address barriers and motivate and support families in PA/exercise. Evelyn felt families were more likely to exercise in participation situations. Evelyn relates this position to her experiences of supporting families in a community cycling programme and working in healthcare settings.

> *I saw all those families with cycling, who loved the cycling, and I'd been told by my colleagues, when I said they were the same families as the ones we see in the NHS, I was told - "No, they couldn't be. They must be different families" and I said, "No, they are the same families" and they said, "But they're so motivated" and I said, "The only reason they're so motivated is because they're doing something they love, that they enjoy and*

> *they can see their children being happy". Cycling is something that most families want to do, they just enjoy going out as a family (Evelyn, Physiotherapist)*

Evelyn, additionally asserted physiotherapists needed to be part of participation situations to ascertain whether opportunities were accessible and provided good experiences.

> *I think we've got a big role to play in finding out if the access is good. We shouldn't send people to places where we know it's bad because that means a bad experience for that family. So, I think, instead of recommending anything, or people who tell us to recommend something, we shouldn't rely on that (Evelyn, Physiotherapist)*

The historical debate on roles and responsibilities for supporting or not supporting disability PA participation were also apparent in school situations. Mario reported recent changes in law meant all teachers now had to take responsibility for disability inclusion, suggesting within his narrative that this had not always been the case.

> *With the changes in the laws now, everybody has to have the same access, it's us as individual teachers that have to make sure that the lessons are accessible – I think that's the term that they use – they're accessible to all the pupils within the class. So if somebody is there with special educational needs, that it's accessible to them as well, that they have the opportunity to succeed and develop as well (Mario, PE Secialist)*

- **Limited Organisational Inclusion Practices**

Gerry reported organisations recognised disability inclusion as important but lacked well-established social, cultural, philosophical and practical inclusion practices.

> *Some of it is not there yet because philosophically and culturally the organisations aren't there yet. They recognise, everybody recognises inclusion and equality and diversity are important. Embedding those principles is what's just starting to happen, and is better for some organisations than for others, and that's not because there's a greater intent on their part. It's just that they've probably been thinking about it a little bit more, maybe got a little bit more resource or maybe got better connections with people who can tell them - if you do this, this would be better (Gerry, NDSO)*

Gerry reports disability inclusion knowledge is needed to embed disability inclusion practices. Evelyn described similar requirements.

> *A lot of people will want to change their access and make it better, but they don't realise that they need some advice from people who've got a bit more*

> *experience to say what is going to be a good solution (Evelyn, Physiotherapist)*

In addition to legislative changes, Mario mentioned recent political drivers changing the national school curriculum to establish health promotion practices within schools.

> *You've got the new curriculum and you've also got the new law coming in to make sure everybody's got access, they inter-twine together. As a school, we have to make sure that they intertwine, that everybody has access to the same curriculum, the same chances to succeed [...] In the past it's been more the old fashioned games orientated activities – your rugby, football, hockey, netball, gymnastics, athletics but with the introduction of the new curriculum - it's more geared for a healthy future and enjoyment and giving them the core skills to be able to participate in physical activities when they're older (Mario, PE Specialist)*

Vicky also described socio-cultural changes needed within sport; to focus sport participation on health and wellbeing rather than performance. However, she felt the priority focus on performance continued, with most community PA opportunities being sport.

> *The emphasis can be too much on elite sport and even in the typically developing population, we've moved towards participation more than just having to be good at something, to do it. It's not all about Paralympian's and people being the best at it. You also need all the also runs and people who just do it as a lifestyle participation choice, which will also help their health and wellbeing [...] But it's mostly sport. I don't think there is someone who is going to say: "Oh, well, there's this group and there's that group" and to me it feels like a gap (Vicky, Physiotherapist)*

Similarly, Evelyn described traditional social expectations regarding PA hindered participation. For example, Evelyn shared her perception that parents and providers had low expectations of disabled C&YP, which needed to change to increase their participation.

> *The other thing is under-expectation that we as physios have, we don't expect as much, parents don't expect as much from their children and that in itself is a sort of attitude which we need to change (Evelyn, Physiotherapist)*

- **Limited Inclusion Governance**

Harry, a product designer, reported an historical lack of product design safety-testing standards for the manufacture of equipment for disabled individuals; and the lack of governance in the production of equipment serving disabled peoples' needs.

> *Where the trouble lies, most of the products that we are asked to do, we are asked to do because there isn't something existing, therefore there isn't a British Safety Standard to test it against [...] But then the other thing that we also find is that most parents are at their absolute wits end. They haven't been able to find something (Harry, Product Designer)*

Products could not officially be safety tested. Therefore, products were termed prototypes, which limited the insurance possible for their use and the amount of production numbers possible.

> *We have product liability insurance and public liability insurance but only for it being a prototype. So, we can't go and manufacture something on that insurance [...] So, the max, the most we've ever done is batches of 10, 15, 20 or so [...] But because we're still making them in-house, by hand, they're still classed as prototypes (Harry, Product Designer)*

Kelly described a lack of historically established support systems for PA participation due to charities (third sector) historically carrying responsibility for community PA participation. Kelly argued that whilst charities were important to support participation, they lacked established organisational-institutional governance structures to support participation.

> *What worries me about third sector organisations, and I am saying this as someone who runs one, is a lack of governance. So, if I refer a child from us to another local group, unless I go there and ask to see their safeguarding documents and their risk assessments, I have no way of knowing that those things exist. I think third sector have a huge role to play but it does worry me that we are entrusting some of our most vulnerable children to third sector [...] So that is my only hesitation with third sector, where is the governance around it? (Kelly, Educational Psychologist)*

6.4.1. Organisational/Institutional Elements

Organisational institutional elements involved limited adaptability, inclusion knowledge and opportunities and choices for inclusion and participation.

- **Limited Adaptability**

The providers reported that the need to adapt was essential to aid inclusion and participation. However, this adaption of PA and participation practices was difficult to achieve. Evelyn and Hermione summarised the problem.

> *It's so easy to pretend it's a one-size fits all, because it's not, that is the problem, it's not (Evelyn, Physiotherapist)*

> *Well, I think I'm learning that you can't use one style really. Like with a lot of kids you can go in with - "oh, come on, let's do this, it's going to be fun. It's going to be great. Don't worry, I'll be with you". That might not necessarily work here (Hermione, Healthcare Student)*

Disability differences between C&YP meant providers needed adaptability of activities to fit them with C&YP's abilities, which providers reported was difficult to achieve when managing large groups of C&YP.

> *We had a pupil one year that was in a wheelchair. We tried to include him as much as possible, but the activity of the whole class would have to be changed to cater for that one pupil (Mario, PE Specialist)*

Saul (Table Tennis Coach) described a similar situation to Mario where he felt inclusion of disabled C&YP came at the expense of not including typically developing C&YP because disabled C&YP needed more time and attention. There was a lack of adaptability in terms of activity (as reported with Mario above) and time when working in groups including typically developing and disabled C&YP.

> *For example, if you've got someone with a disability who comes into the standard group session, a lot of the time, they'll need a lot more attention. So, then by being inclusive, you're excluding the people that don't need the extra help. So, it's such a fine balance, because that's really, really, tricky [...] say there could be 12 people, with two disabled players, how do you split the time and how do you make it fit? It's really tricky. What I find is sometimes you end up not being inclusive because you're trying to be inclusive to the people with actual needs. It's very tricky (Saul, Table-Tennis Coach)*

Saul described difficulty making the time and activity fit with all C&YP and their different abilities. Lack of fit, was a common subcategory of adaptability and inclusion where providers struggled to achieve appropriate activities with C&YP. Debbie (OT) reported families had perceptions of not fitting in, which hindered their inclusion.

> *They've gone and they [C&YP] perceive they don't fit in, or they've gone and the parents perceive they don't fit in (Debbie, OT)*

Rather than C&YP needing to "fit in", Kelly reported providers' needed to adapt their provision for C&YP, to ensure their inclusion. However, Kelly felt mainstream providers lacked this ability (as previously evidenced by Mario and Saul above).

> *What they [C&YP] have told me is when they've joined mainstream clubs, whether that be football club or it be whatever, they don't feel that the people that are running it understand their disability and they feel they are not differentiated for (Kelly, Educational Psychologist)*

Kelly additionally reported some providers were trained to manage inclusion for some disability types, but not others e.g., hidden versus visible disabilities.

> *[C&YP] have hidden disabilities, so, disability sports groups often don't understand the hidden disabilities. That isn't necessarily their area of expertise (Kelly, Educational Psychologist)*

Family reports (chapter 5) fitted with the viewpoints Kelly described.

Debbie described the range of disabilities in communities hindered C&YP "fitting in" with different community providers' groups and programmes.

> *Some of our children go to a charity group that offers leisure facilities for children and young people with a disability or developmental disorder. Some of our children would not go there because they wouldn't perceive themselves to be that disabled [...] so they don't quite fit in with those disabled children [...] but they also don't fit in with mainstream (Debbie, OT)*

Saul reported programme attendance was low when providing specific disability table tennis sessions because disabled C&YP did not fit neatly into a specific disability category.

> *We have tried to do different specific disability sessions but it's quite hard, the uptake from them, I think because there's such a wide range of disabilities it's hard. Just because you have a disability you don't just fit nicely into that box anyway, so it's never really worked that well (Saul, Table-Tennis Coach)*

- **Limited Inclusion Knowledge**

The historical lack of established practices in disability inclusion and slow change across multiple social worlds towards this revealed a situation of limited inclusion knowledge and understanding, within and across social worlds. Gerry provided a definition of inclusion to aid understanding -

> *We talk about inclusion as being the provision of meaningful opportunity where meaningful means that it's the right thing at the right time for that individual (Gerry, NDSO)*

Gerry felt the biggest barrier to participation was providers' lack of knowledge and understanding in how to apply disability inclusion. Gerry described providers/organisations often not understanding the concepts of equality and equity, which were fundamental to inclusion.

> *One of the attitudinal barriers that comes in is a misunderstanding of what equality is, or the correct understanding of equality but applying it the wrong way, applying it where equity should be the focus. So, an assumption that you have to treat everybody the same, if you don't treat everyone the same you're discriminating. Actually, it's about treating people differently to get the same outcome. So, we have a sport governing body as an example, they were determined to treat everybody the same. So, a non-disabled person within sport would behave in this way and do this and be allowed that, so therefore that's the same for the disabled participants and actually that causes the big problems, because that then meant that they were discriminating, through an attempt to be equitable but applying the wrong approach. So I think attitudinal I think is probably the biggest barrier (Gerry, NDSO)*

Gerry gave several examples of lack of inclusion practice amongst providers based on her work within NDSO. Gerry reported many providers, ultimately, matched participation to what providers felt they could or could not do, rather than providing a meaningful opportunity that matched PA to individual C&YP.

> *It could be that the child goes to a disability, focused, session, wheelchair basketball is an example. But the reason that they're there is not because of inclusion - they're there because the coach has gone - "look we can't coach you, you need to go to wheelchair basketball" rather than - okay it's a wheelchair, have you ever played in a chair, do you need to use a chair daily?"[...] It's about making sure it is the right thing for the individual, that it's not just the right thing for the coach because that's the thing that they feel most comfortable with, I can't do this - therefore do that (Gerry, NDSO)*

The wheelchair basketball example Gerry provides mirrors what Dwayne (Family 1) reported regarding limited rugby participation possibilities i.e., the only option for rugby participation appeared to be wheelchair rugby but Dwayne was not a wheelchair user. Saul also reported exclusion from rugby as a child, similar to Dwayne. Saul reported exclusion due to providers not knowing any other forms of participation appropriate for him. He described the hope that such practices were no longer happening in practice. However, family findings (chapter 5) suggest such occurrences still occur in family situations and in social worlds such as school and sport.

> *I wasn't allowed to do rugby, so in school I had to do the bits that I could do, the non-contact stuff and then when they were playing the matches they said 'Right, you sit out' and you had to stand in the rain while they were playing. So, from that point of view, they didn't know what to do, they were like - 'Okay, just sit over there.' [laughs]. Hopefully, it wouldn't happen now (Saul, Table-Tennis Coach)*

Family findings show some C&YP still encounter exclusion. However. C-Jay (family 9) had found an alternative in rugby, participating as linesman.

Gerry reported families continued to share negative, exclusionary participation experiences with her.

> *Unfortunately, we still do hear - we hear it around teaching staff, we hear it around coaches, we hear about leisure facility staff, who are the first person that those disabled people meet. Their first contact with physical activity, physical educational support, and if it is negative in any way - "you can't do; you can't come; you can't engage" then that, in any way shape or form, it destroys the person's capacity to be the person they could be, if only that one point of contact was different (Gerry, NDSO)*

Family findings (chapter 5) show such experiences reduced C&YP and families' persistence in community PA participation.

Vicky also reported experiencing C&YP being excluded from participation e.g., from school PE, because the PE teacher did not know how to organise, modify/adapt participation for inclusion.

> *I think, in many schools there is room for improvement within PE, to be more inclusive. Particularly, in mainstream schools where sometimes children are taken out of PE because no-one has worked out how to modify it, or there's been discussion about how you can't possibly have that bit of equipment (Vicky, Physiotherapist)*

Vicky reported a lack of knowledge existed in communities regarding how to adapt participation and what the possibilities for participation were, especially for C&YP with more complex difficulties.

> *I think the thing that the children miss and the thing that they seem to really love in the sessions, was actually doing it themselves. Because, the thing that they're actually missing, is the doing it themselves, particularly the more complex kids - it is more difficult to find something they can actively*

> *do independently. I think there should be more specialist groups for things like that, that's got the access, and I think you need physios and OT's and people, and speech and language therapists, to be able to see how you can make it possible (Vicky, Physiotherapist)*

Vicky's narrative shows a range of humans necessary to determine PA possibilities, and to make available more community opportunities and choices for families.

- **Limited Opportunity and Choice**

Lack of adaptability and the inability to fit activities to C&YP, along with disability labelling limited C&YP's opportunities and choices for participation. This was especially apparent when C&YP did not feel like they fitted in, and/or parents perceived this. Twinkle-toes reported it appeared that there were many opportunities and choices, but when considering disability labelling there was a lack of opportunity and choice.

> *I think sometimes it can sound or look as if there's a lot on offer. But then you think 'oh no that's for that group of children' and it might be say for learning disability group of children as opposed to a group with a physical disability (Twinkle-toes, Family Officer)*

Kelly similarly reported limited opportunities and choices.

> *I'm not aware of many physical activity groups for children with ASD for example. I am not aware of any. I can't think of any actually (Kelly, Educational Psychologist)*

Vicky described a gap in the provision of opportunities for different types of disability presentations.

> *I don't think there is someone who is going to say: "Oh, well, there's this group and there's that group" and to me it feels like a gap (Vicky, Physiotherapist)*

The provision of PA opportunity and choice for C&YP was hindered by the organisational/institutional labelling of disability and the corresponding lack of adaptability.

6.4.2. Human Elements

Insufficient numbers of people and/or people lacking inclusion knowledge and experience hindered participation. Further, people lacking disability inclusion confidence hindered participation. Providers also reported limited funding to provide sufficient people to supervise and facilitate participation and access participation.

Mario reported the lack of helpers in sessions to support individual C&YP, when managing large groups of C&YP could hinder participation.

> *Usually I don't get much assistance, I get basically nothing. We're teaching in a class of over 30, so again, coming back to a budget, so that we're able to get somebody in that helps them, you know a teaching assistant in there to help them, and help facilitate (Mario, PE Specialist)*

Kelly reported people could lack disability inclusion knowledge to facilitate different forms of participation to suit C&YP's abilities and lack understanding of the need to provide sufficient time to C&YP for their inclusion.

> *I think the people that are running the physical activity groups, I think if they better understood that actually some children need longer to process information, some children have a significant motor difficulty, it doesn't mean that they can't participate; it might be that their participation is different (Kelly, Educational Psychologist)*

Gerry also reported that peoples' lack of confidence in disability inclusion hindered participation (which echoed the family findings). For example, Gerry reported paediatric physiotherapists lacked confidence to signpost and facilitate participation. Furthermore, Gerry reported paediatric physiotherapists' confidence was dependent on whether physiotherapists were involved in sport activities themselves.

> *We were noticing that the paediatric physios were being asked by the PE teachers, or the teachers if they were in primary school, for support around inclusion for PE. So, we did an education focused disability inclusion training for the physio's so the physio's had a greater level of confidence in giving some advice to the teachers. They obviously know physicality, they know movement, they know functional ability but they didn't necessarily know sport and how to match the two up [...] physios had to have strong confidence around being physically active and to a certain extent sport, but it depended really if they were sporty themselves (Gerry, NDSO)*

Gerry's narrative showed a lack of relevant healthcare professionals' supporting PE participation in schools, which echoed Mario's experiences.

> *Basically, for pupils that are in mainstream education we get, I'll be honest, majority of them, we don't get any guidance – medical guidance (Mario, PE Specialist)*

Gerry also described people lacked confidence to support PA and sport e.g., carers and personal assistants.

> *I think a big population of people that we haven't quite got to yet and who make a real difference in terms of disabled people's physical activity and sport engagement are carers and personal assistants [...] often the disabled person who employs those care support services do the things that their personal assistant is interested in. So, they go to the cinema to see the movie [...] we definitely see it in sport, if a personal assistant isn't necessarily interested in sport they may not look for sport as an option for the person that they're supporting (Gerry, NDSO)*

Gerry's narrative regarding the personal characteristics of carers and personal assistants is similar to Evelyn and Vicky's reports regarding these matters. For example, Vicky reported experiences of helpers/assistants who were not physically active, and were therefore, unlikely to support PA participation.

> *Sometimes, you'll find things like you'll get the child's One-to-One that isn't a very physically active person, or physically able person, so therefore the child gets less physical activity because the One-to-One can't get on the floor [...] those things have to be considered when recruiting as well. If it's going to impact on what the child can do, then you need to get someone who can fulfil the job description (Vicky, Physiotherapist)*

Evelyn also described a lack of PA role models. For example, when parents appointed personal assistants via direct payment these were often physically inactive.

> *You need interested people who themselves enjoy sport or who enjoy being out, because if you're just happy to sit, and you don't do physical activity yourself, you're not going to be motivated to try and make that accessible for somebody who can't access it themselves [...] Parents have got more control over who they pay to support their children now with direct payment; they have now got the right and the possibility to check - are you interested in helping my child to go skiing or cycling or horse-riding (Evelyn, Physiotherapist)*

Sarah and Molly (Family 4) described Molly participating in much PA when she had a physically active personal assistant (funded via direct payment). However, Sarah reported funding for personal assistants was difficult to access. Twinkle-Toes similarly reported funding appeared to be less in recent years.

> *Children might have access to direct payment money but it depends how the family and parents choose to use that. I think things have changed again with that in the last few years. I don't think families are getting that as easily as they were a few years ago [...] I don't think the funding is as easily available now for short term things like two hours to go to a youth club (Twinkle-Toes, Family Support Officer)*

Twinkle-toes' narrative also shows families may not choose to use direct payment to support community PA participation. Twinkle-Toes reported that not all families wanted to engage a personal assistant for their child.

> *But also that doesn't always sit well with some parents, they don't want to handover to other carers [...] There's two sides to it, it's getting the funding and then it's the parents allowing other people to take and be responsible for their child (Twinkle-toes, Family Support Officer)*

There appeared to be a lack of people, a lack of confident people, a lack of funding for people, and reduced numbers of PA role models that supported participation, which hindered C&YP's access to participation. Vicky reported the lack of people as a major barrier to participation.

> *I think manpower is a big issue and I don't know what the answer is to that. All these things take money, which of course is all short. But I think often, people will need people to help make it possible and the ratios that you need are huge when you think about complex kids (Vicky, Physiotherapist)*

Vicky also raised the issue that much of the support was provided by adult helpers. Therefore, C&YP had limited meaningful interaction with peers during community PA participation.

> *I think, even in school, often the interaction with a person is with an adult, or the helper, and not so much with peers. I think, particularly around teenagers, that's not what teenagers do, is it? Particularly teenage girls, they spend a lot of time talking to each other or messaging. It's a lot about relationships. I think that part of participation is also missing. Yes, because it is not just about sport, it's about relationships (Vicky, Physiotherapist)*

Family findings showed that social interaction and friendships were strong facilitators of community PA participation. Therefore, a lack of this provision could hinder participation.

6.4.3. Economic Elements

Economic elements included funding constraints that limited opportunity and time available for PA programmes and there was limited time to source, acquire and manage funding requirements.

- **Funding Constraints**

Funding constraints were another barrier reported by providers. Funding applications were onerous and time consuming and provided transient and restricted pots of money. Ongoing costs such as equipment maintenance or the influence of family factors on C&YP's attendance were not always considered.

Gerry reported funders placed restrictions on funding usage, which could hinder participation.

> *We have some commercial funding. They are restricted pots so we have very stringent parameters about what we can do with that money (Gerry, NDSO)*

Evelyn reported funders' restrictive requirements limited the financial provision to meet participation needs. For example, Evelyn described the need for funding to provide training in the use of equipment e.g., hoists, and the need for funding to maintain equipment such as hoists. However, Evelyn felt funders were either not aware of, or did not wish to pay for these needs.

> *We need to offer more training to people. Not that they can do the hoisting themselves, but that they are trained to help somebody with a hoist and understand that it has to be inspected and the money has to be available. When you get a hoist, it's not just the hoist money, you need £70 twice a year just to have it inspected, and that's very difficult to get that money. You can't fund-raise, can I have fund-raising for inspections? Nobody will give you that money [...] and if my hoist is not inspected I cannot use that hoist, I would be in breach of my contract if I use it. And that's an extra burden, if you want to provide an accessible service, and people don't think about those costs (Evelyn, Physiotherapist)*

Evelyn also reported that when making awards, funders were probably unaware of family factors affecting C&YP attending. I have already shown a range of family factors hindering families' regular attendance (Chapter 5).

> *When you apply for funding and you say I want to offer opportunities, that doesn't count. It only counts if you have a club and you come every week. Well, a lot of people with disabilities, they can't come every week, they depend on somebody else taking them and they have more illness, they have more appointments, they have siblings who are already missing out and who need their parents as well. There are so many reasons why they can't come every week (Evelyn, Physiotherapist)*

Zoe also expressed this general lack of knowledge and awareness regarding family factors, which could affect funders and other provider provisions. If C&YP were not attending, funders might think there was no need for opportunities, when this is not the situation.

> *Our special needs class come from all over [CITY1] so sadly I don't think it's the same for them [...] they seemed to find it difficult to take their children to these activities, and again - I don't know why? Whether it's because they're working, or whatever, I don't know. Definitely, our special needs class doesn't do as many things outside of school as our able bodied classes (Zoe, PE Specialist)*

Zoe hints at location being a possible hindrance i.e., C&YP with special needs who attended her school came from all over CITY1, whereas typically developing C&YP attending her school lived local to the school. The family findings (chapter 5) showed location of opportunities were a hindrance to some families' participation

Kelly reported that location hindered participation, when describing funding arrangements for schools, where it was assessed according to location.

> *Schools sit in clusters, so the school doesn't have a budget the cluster has a budget and the challenge with that is [...] in the same cluster, you might get a school that is in a particularly affluent area, which is not many in [CITY3], but there are a couple, and then the other schools are in really deprived areas, and then it's a battle between those schools as to how the money is then allocated (Kelly, Educational Psychologist)*

Evelyn described the need for funders to reconsider requirements when considering access needs.

> *This idea that you can go every week because that's what a club should expect, is not realistic. I think funders have got a real issue with that, and we can never comply with what funders want because they give us those lists - how often do they come, and the group is never going to be big enough [...] So, there's something missing, the way that we calculate what is worth doing [...] and access, we go to the beach because it's nice weather. We don't go because we have to fill in a box and get funding for that. And, that's still something that people don't accept. You can't measure access in the way that you measure other things [...] Access has got to be part of day-to-day (Evelyn, Physiotherapist)*

The decision on what PA to fund appeared to change over time. For example, Saul reported decreased funding in recent years for sport clubs and coaches to engage with C&YP in schools.

> *...when I first started, [CITY1]Sport had loads of funding. We were in about 15 schools a week, all getting paid for, and then those sessions slowly cut down. They would operate with like a couple of thousand pounds a year for each school and they operate on a zero budget now. So, we're in schools a lot less (Saul, Table Tennis Coach)*

- **Insufficient Time**

Many providers linked a lack of time and a lack of funding when recounting difficulties supporting C&YP's participation. For example, Mario described needing more time in sessions, as well as time to prepare and plan for inclusion, and that funding for this was not available.

> *I need time to provide more individual attention, so you can just spend that little bit extra time with different pupils [...] Before a lesson when you're preparing as well, to give extra time off to prepare before the next lesson comes in - and time is money [...] I have got to have time to sit down and say - 'right how can I facilitate and change things so that your lot is more inclusive without having to change the lesson completely" (Mario, PE Specialist)*

Saul also described a lack of time to provide attention to individuals within sessions, particularly when including disabled C&YP in groups with able-bodied C&YP.

> *If you've got someone with a disability who comes into the standard group session, a lot of the time, they'll need a lot more attention (Saul, Table tennis Coach)*

The family findings show a lack of time within participation sessions hindered participation. For example, Tessa (Family 12) described a mainstream gymnastics provider was not able to include Jack because the provider did not provide time to facilitate inclusion.

Both Saul and Mario linked time with money. For example, Saul reported that acquiring grant funding to provide sessions, took time. Additionally, where granted, funds were strictly time limited, hindering sustained participation.

> *It's tricky but I think we're trying to get better at applying for grants and then delivering the project and satisfying all the needs [...] It's hard, if we do get funding, it's usually for a set period of time [...] and at the end of the day, we're still a charity and we've got to make the business work. I've only recently taken a wage after all this time, like a part time wage (Saul, Table Tennis Coach)*

Saul's narrative suggests transient grant funding hinders salary provisions for staffing to support participation. Therefore, this also limited time available to support participation.

6.4.4. Discourses and Contested Issues

Risk management and inclusion was a common contested issue with related discursive positions that hindered participation.

- **Risk and Inclusion**

Providers expressed concern about risk and inclusion, which increased in the absence of disability knowledge and lack of information from parents and healthcare professionals. Although not an overt contested issue, it remained silently present between families and providers, without parents and providers overtly and collaboratively discussing or addressing the issue.

Mario listed information from healthcare professionals as first on his list of requirements to facilitate participation and lack of information resulting in lack of inclusion and/or exclusion of C&YP due to risks.

> *I need information from the consultant or physio, saying what they can do, what they can't do. But basically, for pupils that are in mainstream education we get, I'll be honest, majority of them, we don't get any guidance – medical guidance [...] for example: we've had one girl with really poor eyesight, and we asked them: 'can you give any guidance?' We basically got nothing back [...] usually it's us as a profession having to almost Google it to see (Mario, PE Specialist)*

Mario reported not receiving information from parents either, especially as C&YP aged, which hindered what he could provide for C&YP.

> *You get some parents who are extremely keen for their kids to participate – will go out of their way and say: 'right this is what he enjoyed; this is what he can do; this is what he struggles with'. What I find, there's a lot of them once they've left primary school, it's - "ah, it's okay, just don't worry about it". [...] We really don't know the boundaries of what we can and can't do (Mario, PE Specialist)*

Gerry reported sport coaches were concerned with the potential need to provide care within sessions, which they were not qualified to do.

> *One of the things that we note within the coaching and leaders networks is that often there is a real concern that the coaches are going to be the ones that need to provide care support to children within a sports setting and obviously they're not qualified to do that. They're qualified to provide coaching for sports and that should be the same regardless of whether the child or young person is disabled or non-disabled. What they're not qualified to do is provide any kind of personal or intimate care support. So*

> *if those kind of needs are required by the child or young person then there is going to be a need for a third person to be around the person who is that individual's trusted carer or provider of care support (Gerry, NDSO)*

There were unclear boundaries on the roles and responsibilities for providers and parents/carers regarding inclusion and participation, which was influenced by individual's discursive interpretations of disability inclusion and participation, and individuals' interpretations of each other's language, behaviour and action (as seen in SI theory [Blumer 1969]). These tensions are reflected in my personal clinical experiences and previous research experiences when disseminating cycling participation research findings (reflections in chapter 1). However, these tensions are not overtly reflected in the published literature reviewed (chapter 2). Families reported the need to stay in sessions due to providers cautious approach to risk and responsibility (Chapter 5), which some families found difficult e.g., when lacking sibling child-care. Families' interpretations thus appear confirmed by providers' narratives shown in chapter 6. For example, Mario reported the need to exclude C&YP in the absence of information regarding C&YP's abilities, due to fears of injury to C&YP and associated risk of his potential liability (a reason, families surmised for providers' cautious/ exclusionary discourse).

> *We've got to be really careful about what we're doing, because if we push them and tell them to do something – then they say 'we can't do it, and something's happened.' We're liable – by now it's come to the point where I'm thinking 'okay if they say they don't do it, okay fine, I'm not going to question you'. If you can't do it, you can't do it and I'll just put a note in the contact book asking the parents 'can you tell me what they can and can't do and if they don't come back to us, that's it (Mario, PE Specialist)*

Some providers showed uncertainty and fear about being out of their depth and doing the wrong thing, echoed in family findings.

6.4.5. Environmental Elements

Challenges to providing physical access was a common barrier to participation.

- Physical Access

Providers commonly reported environmental access barriers due to the lack of specialist equipment, suitable changing places and the lack of information about access.

Twinkle-toes described many families she worked with reported limited access to community environments e.g., parks. Twinkle-toes linked the lack of specialist equipment in parks to provide access, to lack of funding.

> *I think a lot of families they don't even go to the park. They might go for a walk, but they don't go for a swing. I think, it's difficult because more specialist equipment would be lovely to see in general parks but then to some degree you have the issue of vandalism and the stuff costs so much (Twinkle-toes, Family Officer)*

Vicky reported that families told her they did not go to community spaces due to the lack of accessible changing spaces and toilet facilities.

> *I think there is still a lot around accessibility that needs to be addressed, for example, changing places. When we talked to groups of parents - one of the biggest things they said is - "we don't go out, or not very far, because we need to know where we are going to change the child, and I'm not changing my child on the floor in the disabled toilet, or they are too big to do that". There are so few changing places. Some of the more complex children need hoisting and changing tables and stuff, so, I think that is a big issue, and it's Government taking responsibility for that and mandating more of those things (Vicky, Physiotherapist)*

Evelyn provided families with all-terrain wheelchairs to access the sea during summer holidays and similarly described families reported the need for accessible changing facilities, to access outdoor areas such as the beach.

> *If the children go in the water, they need somewhere to change afterwards, because it's quite cold afterwards. You've been in the water and then you get back in your wheelchair but then where do you go? Do you lift somebody down on the sand to change them? Do you change them in the wheelchair? We do need somewhere they can go with the wheelchair, hoist them onto a bed, and perhaps even have a shower so that they can warm up, and have a proper accessible changing room (Evelyn, Physiotherapist)*

Twinkle-toes described access that was not necessarily the same in every locality.

> *I don't know exactly how many accessible individual sports clubs and places there are. There must be places around now that people are accessing some stuff. But it doesn't mean it's the same everywhere, it doesn't mean you'll have the same choice in every* area *(Twinkle-toes, Family Officer)*

Gerry linked environmental barriers to information barriers when discussing access e.g., the need for organisations to provide access information. However, Gerry felt organisations were not culturally or philosophically in that position yet.

> *I think, when a disabled person thinks - "I fancy going for a walk but I don't actually know where I could go because I'm a wheelchair user and stiles are going to be a challenge for me, or gates are going to be a challenge - where's an accessible place for me to go with my family, or with my dog?" When the Ramblers Association or when the local authority who might produce walking maps produce those with wheelchair users in mind, or frame users in mind, or with people who have different levels of function and movement restriction - that's when we start building a really good picture of what is available. So, some of it is not there yet because philosophically the organisations, culturally the organisations aren't there yet (Gerry, NDSO)*

The providers' narratives show an historical and current lack of cohesion, or cohesive governance regarding planning and provision of access, something families also reported (chapter 5).

6.4.6. Temporal Elements

Temporal elements included C&YP's changing age and stage of development and temporal COVID-19 barriers to participation at the time of data generation and analysis that exacerbated existing barriers.

- **Age and Stage of Development**

Access to PA and participation in PA could be temporal, resulting in a reduction of PA with time as C&YP aged and developed. With growth, the more severely disabled C&YP required additional manual handling. Manual handling equipment to access PA and/or the ability to move C&YP without equipment was not always possible, as C&YP became bigger and heavier. For example, Zoe could get a young, primary school aged child in a wheelchair onto the floor for PE. However, Mario doing PE with a secondary school aged pupil could not.

> *We've got a little boy in a wheelchair who's profoundly deaf and blind he's Year 3 now. He comes out of his wheelchair with his helpers. He loves the sound of the children, he loves to be involved, so if we can literally put him in the middle of whatever (Zoe, PE Specialist)*

> *We had a pupil one year that was in a wheelchair [...] By the time, he was in year nine he wasn't comfortable, and he would be doing PE with another*

> *pupil that wasn't able to, things like bowls and things like that (Mario, PE Specialist)*

Age also related to fundamental movement skills taught in school, which enabled access to the PA curriculum. Some C&YP who did not have the required fundamental movement skills struggled to participate in the PE curriculum.

Zoe described fundamental movement skills taught in school PE in early years, as C&YP developed PE progressed into specific sport skills.

> *Basically there's progressive skills, it's something called fundamental movement skills, which is worldwide. Basically your fundamental skills are the skills you need to be able to play any sport, to take part in any activit. Like your balance, your coordination, your body coordination, body awareness all those different things. They are progressive and we do them in a progressive order. By the time you get to Year 5 and 6 they do look like structured netball, hockey things like that (Zoe, PE Specialist)*

Mario reported C&YP who lacked fundamental movement skills struggled to participate in the secondary school PE curriculum.

> *How do you get a pupil to come through with the core skills of catching, kicking, running by the time they're twelve? If they're not doing it by the time they're twelve, there's a lot of catching up to do and then if they haven't got it, and they're not used to going out and kicking, catching, throwing with mum and dad, when they're young - they're not going to be doing it when they're thirteen, fourteen. So, when they come to us, they've already mentally attuned to 'I don't do PE' (Mario, PE Specialist)*

Social factors also related to age and development. Zoe reported C&YP became more self-aware regarding appearance and abilities as they aged, which hindered participation in certain forms of PA e.g., swimming. Therefore, the school had changed swimming scheduling to when C&YP were younger.

> *We also changed our swimming because we used to do swimming in Year 6 and one of the reasons for not doing it in Year 6 was the body image. As you know, a lot of them have got body issues and it's a massive thing for them then to go swimming. So we do it in Year 4 now because of the body conscious and body awareness (Zoe, PE Specialist)*

Zoe also described the need to focus away from competitive sport within the PE curriculum, due to C&YP's increasing self-awareness with development. However, she admitted that she was not always able to follow this approach.

> *All children are aware as they get older that - oh I'm not very good at this - and that's the thing that I try to change maybe. In the past few years, I've started to be less competitive with the children and less structured games as in netball, hockey things like that because I don't want them to be put off sport. I think the worst thing I could hear was - "oh god it's PE" - that, to me, would be I've done something wrong. So, they're the children that I try to engage all the time, and it means sometimes that it is less competitive. Sometimes I haven't been. I've been guilty of not providing that option for them [...] I do try to include them so they don't become self-conscious (Zoe, PE Specialist)*

Kelly reported C&YP shared with her that they had high levels of anxiety and low self-worth, which led to them opting out of mainstream school PE.

> *The things that young people share with me are lack of confidence, high levels of anxiety, high levels of low self-worth, high levels of depression [...] and they are opting out of physical activity. So, for me, it is absolutely critical that we get this right because these are children that are already at a disadvantage, and by allowing them to opt out [...] I'm not saying that we shouldn't allow them to opt out, because clearly that is their right, but we need to find another way than simply opting out (Kelly, Educational Psychologist)*

- **Covid-19**

Covid-19 was a barrier across some providers at the time of their interviews. Covid-19 limited providers' ability to provide opportunities and limited PA input to C&YP, due to C&YP having a limited time in school. Additionally, PA appeared to have less priority in schools than other subjects when time was limited.

> *My main concern is, with time being limited, how much time are they actually going to be spending in school? If it's two days a week then are they going to decide to concentrate on a core curriculum of Maths, Welsh, English, Science and the rest you do from home? So, with PE maybe then we just give them exercises to do at home and they come back and say 'right we've done them'. But is it going to happen? It's only going to happen with pupils who are already active; whose parents are keen for them to be active. If their parents aren't supportive, it doesn't matter what we give them, they've not got a hope (Mario, PE Specialist)*

Mario's narrative illustrates that barriers already existed in schools regarding prioritisation of subjects over PA/ PE participation, prior to Covid-19. These were exacerbated by Covid-19. Further, Mario indicates his position that unless C&YP have supportive parents then C&YP will not participate in PA at home.

Zoe similarly described limited time for PA existed in schools prior to Covid-19 restrictions.

> *I still think there's too much emphasis on sitting down, reading, writing. The school, they are in so much pressure to get kids to a certain standard by the time they reach the end of Year 2 and the end of Year 6. I'm not allowed to take our Year 6's out, it's really sad. So, in Year 5 they do everything. Then, by the time they get to Year 6, I'm not allowed to actually take them out, because they have to achieve certain standards. So it's really sad because they're 10, 11 years old (Zoe, PE Specialist)*

Zoe's narrative shows a decreasing priority for PA in schools as C&YP aged. Zoe additionally stated that due to Covid-19 restrictions all PE activities/education had stopped within school.

> *Obviously, we had to stop everything (Zoe, PE Specialist)*

Mario expressed concern at the amount of time lost from PA due to Covid-19 restrictions and the potential effects that could have on C&YP's PA participation, long-term.

> *A lot of the pupils, kids' exercise, is playing football and rugby and that's been taken away from them. I am glad I won't be there ten, fifteen years to teach them, when everybody comes through from primary school by then! Listening to the news everybody was talking about how to get professional football restarted, I'm thinking, it's not - how are we going to get professional football going but how are we going to get kids back playing? (Mario, PE Specialist)*

I did not investigate whether C&YP returned to community PA following Covid-19 due to thesis aims and objectives set prior to Covid-19, and thesis time constraints.

6.5. Summary of Barriers

The lack of disability inclusion has created a situation of limited inclusion practices and inclusion governance. Additionally, there has been a limited number of people and organisations taking responsibility for disability inclusion and participation. Thus, there are limited organisational/institutional adaption for inclusion and inclusion practices, which limits participation opportunity and choice. People have insufficient inclusion knowledge, practice and skill, and there are insufficient numbers of people for the supervision and support ratios required. There are also insufficient PA role models across all roles, in all social worlds.

Funding processes are time consuming and onerous, provide transient support and have constraints limiting the widening of opportunity and choice, as well as limiting sustained opportunity and choice. Inaccessible indoor and outdoor environments hinder participation, as does lack of equipment to enable access and lack of information on environmental access. Risk and inclusion is a contested issue confounded by lack of information, communication and collaboration between providers. C&YP can have limited opportunities to participate, related to increasing age and stage of development. This makes PA participation susceptible to time and a temporal phenomenon. Covid-19 was a further temporal restriction on participation that increased existing barriers to providers' support for C&YP's PA participation. I summarise barriers in Table 9.

Situational Matrix Category:	**Subcategory:**	**Elements/Relations:**
Historical Elements:	Limited Inclusion	Not Taking Responsibility, Limited Practices & Governance
Organisational/ Institutional Elements:	Limited Adaptability. Limited Inclusion Knowledge	Limited Opportunities & Choices
Human Elements:	People	Insufficient Numbers, Limited Inclusion Knowledge, Limited PA Role Models
Contested Issues:	Risk & Inclusion Responsibility	Limited Information, Lack of collaboration
Economic Elements:	Funding Constraints Funding Time	Funding Constraints Insufficient Time Time Constraints
Environmental Elements:	Inaccessible Environments,	Equipment, Access Changing Places
Temporal Elements:	Age & Stage of Development Covid-19	Fundamental Movement Skills, Self-Awareness, Interests Time available for PE & PA in School

Table 9: Barriers to Participation - Provider Findings

6.6. Summary Conclusion

Like family findings, provider results show barriers and facilitators overlap and inter-relate within the situation. Dealing with complex findings where multiple factors are inter-related makes it challenging to focus and prioritise recommendations for practice. Since providers' knowledge and skills frequently emerge as influential on participation, it is likely beneficial to focus on providers knowledge and skills within policy and practice recommendations; including those of healthcare providers who could support families and providers in community PA participation. Funding, information and resources also frequently emerged as influential within the situation. Discovering ways to co-ordinate these different resources is therefore likely to be beneficial. Provider findings confirm family interpretations (revealed in family interviews - chapter 5); findings that positioned some providers as lacking confidence and being risk averse, which hindered C&YP's participation and inclusion. Increasing providers knowledge and skill in risk management is thus crucial. Appropriate risk management strategies would need to include families' input i.e., families and providers would need to work together to create safe environments for C&YP's participation, where problems hindering inclusion could be resolved. SA shows that such a situation will likely require sufficient and appropriate information and resources to successfully facilitate participation.

Chapter 7. Synthesis of Family and Provider Findings

In chapters 5 and 6, I presented influences on community PA participation for families and providers by grouping related situational elements into situational matrix categories e.g., human, non-human, environmental (Clarke et al. 2018). I showed how the related elements and their interactions influenced community PA participation. In chapters 5 and 6 I illustrated individual family and provider stories, their similarities and differences, and how facilitators and barriers were determined within the situation. These chapters are limited however in presenting a SA because they do not show a synthesis of family and provider findings within the social worlds involved in the situation. I have presented the study findings in this way however as it shows a layered analysis and transparency in how findings were determined. Additionally, the presentation overtly answers the second research question regarding barriers and facilitators to participation. This approach also provides transparency in consideration of similarities and differences in barriers/facilitators between individual stakeholder participants, and across all participants within the situation. Thereby, also providing smaller pictures (individual situations) within the larger picture (the situation). This presentation does however reflect the tensions in SA when defining situation (as previously discussed). I have resolved these tensions due to my presentation of the findings following SA's proposed order of cartographic analytic mapping, which starts with situational mapping - organising the different elements into categories and showing their relations. Clarke et al. (2018) then propose researchers move on to consider social worlds/arenas mapping and end with positional analytic mapping when researchers have extensive knowledge of the data generated, due to previous repeated iterative analysis using situational and social worlds/arenas mapping.

I now move on to synthesise participants findings within the different social worlds within the situation to provide a comprehensive SA, showing strengths and weaknesses/limitations in the situation, which enabled identification of key action areas. SA has not previously examined community PA participation by C&YP with neurodisability in this way. Thus, I provide a unique contribution to the evidence that enables greater understanding of the situation and provides recommendations for new ways forward.

In chapter 7, when synthesising family and provider findings using social world analytic mapping and positional analytic mapping (Clarke et al. 2018), I show the different social worlds within the situation and their influences on community PA participation and bring these worlds together in the arena of community PA participation. In presenting this synthesis, I show each social world and its influences on community PA participation, as well as how the relations and interactions of social worlds influence each other and participation. Exploring relations between actors and actants (human and non-human) within different social worlds shows the theoretical actor-network (Latour 2005) roots of SA, while considering discourses and discursive influences on participation, demonstrates another theoretical root (Foucoult 1972).

7.1. A Social World Perspective

The study findings showed the key social worlds involved in the situation were family, school, sport, charity, healthcare, politics and commercial. Clarke et al. (2018) assert social world cartography aids analysis of organisations and social groups. Families are a social group therefore represented as a social world. Arenas are areas where social worlds intersect, negotiate, interact and can be seen negotiating over matters of concern e.g. resources (Strauss et al. 1964; Clarke et al. 2018). In figure 8, I present the arena of community PA participation with its associated social worlds, including some of the organisations and resources found in the situation. The figure shows porous boundaries (dotted lines) surrounding accessible social worlds, and solid boundaries (solid lines) surrounding social worlds not so easily accessible to families and all providers. Social worlds overlap each other where there is interaction between them and/or where organisations work in more than one social world e.g., NDSO is visible in the sport and charity social world.

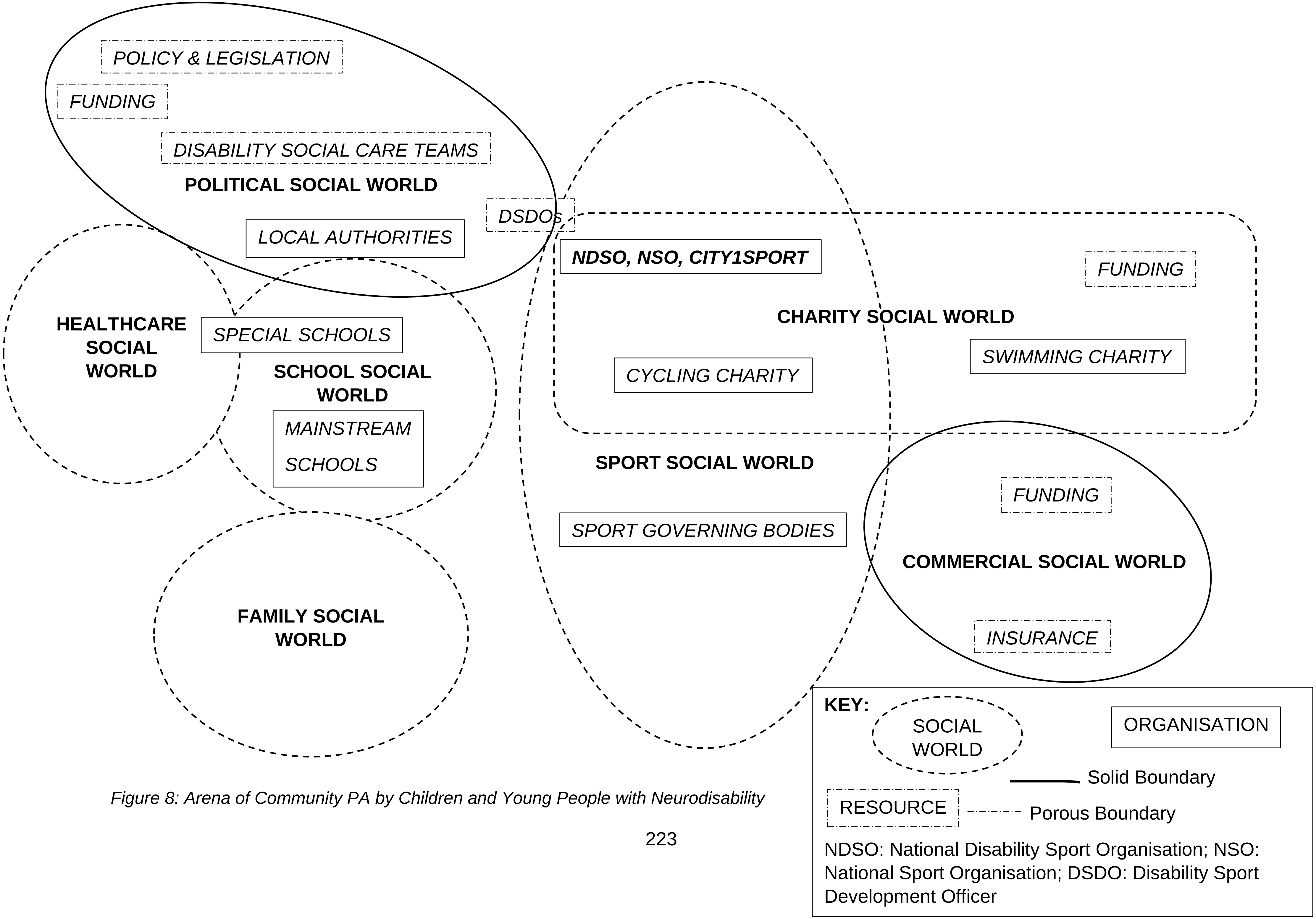


Figure 8: Arena of Community PA by Children and Young People with Neurodisability

Following, I discuss each of the social worlds, how they functioned and interacted with other social worlds, thereby showing situations that enabled or hindered community PA participation. In presenting and describing each social world, I show a separate portion of the arena, which allows an examination of smaller pictures within the larger picture i.e., the situation (Clarke et al. 2018). There are tensions in using the word “situation” as I have described it in the paragraph above i.e. I have described the larger picture as the “situation” whilst simultaneously stating that there are “situations” hindering or enabling participation within the “situation”. This descriptive rhetoric demonstrates the complexities of SA and the challenges of defining "the situation" within a broad arena of social worlds, which is a published criticism of SA regarding its definition of situation (Maher 2008). My presentation approach in the following sections does however confirm and demonstrate the intricate, multi-layered, and interconnected nature of social situations and arenas of social worlds - as these relate to the situation of community PA participation.

By focusing on the different individual social worlds and their associated social worlds in the presentation following, I reveal the overlapping and interconnected aspects of the situation. Simultaneously, I want to acknowledge that the full picture might not be entirely captured by my thick descriptions. There may be other social worlds within the arena that I have not identified. In defence of what I have identified and present within the study findings, I can claim to have involved multiple stakeholders, i.e., service users and service providers. I have represented their social worlds and the social worlds they spoke of in their interviews - even if my sample did not include participants from those social worlds e.g., political and commercial social worlds, whilst acknowledging limitations in not having primary participants from those worlds. I have used participants descriptions, views and experiences to describe the different social worlds and used iterative processes to analyse the study data and uncover details about the social worlds. On reflection, a better presentation would have been to incorporate the findings of barriers and facilitators from families and providers (chapter 5 and 6) into a synthesis with social worlds, using participant quotes and social worlds cartography. Such an approach would have shown greater synthesis of families and providers within and across social worlds and had greater potential to reveal situation complexity through that synthesis and thicker descriptions. However, by presenting the findings separately I have shown layering of findings and transparency in determining research findings, as well as shown individual situations within the larger situation. I have used reflexivity within analytic processes and endeavoured to provide thick descriptions to ensure research integrity. Alongside this, SA cartographic mapping and the different theories foundational to SA allowed me to explore the situation from different perspectives. My analysis shows the different aspects/layers of the situation and how these layers/aspects interact and influence each other and how they influence the action of interest – community PA Participation. There are limitations in my findings and how I present them due to not synthesising family and provider quotes into the social worlds' presentations in this chapter (chapter 7), meaning readers need to cross-reference descriptions of findings in chapter 7 with evidence from chapters 5 and 6. Being a new qualitative researcher wishing to be overtly transparent with findings has led to such an approach. Other limitations in my findings are the limited number of sample participants, data being generated purely from interviews and no other data sources as well, and sampling methods producing a sample skew that is evidenced in the family sample involving mainly C&YP with CP classified at GMFCS level II.

7.1.1. The Family

The family social world is central and key to participation. C&YP in the sample who participated in PA usually did so with their family, or the support of their family. The type of PA families participated in together was usually informal, unstructured and often followed parents' own PA interests. The most common PA that families engaged in was cycling and swimming. Achieving the ability to cycle and swim were often, viewed as PA childhood milestones. Families additionally participated in informal play together, however, only when C&YP were young (≤8 years). Families having older C&YP did not describe informal play together as part of their PA participation. Older C&YP did less PA with family members and spent more time participating in PA in other social worlds e.g., in school and with sport groups, predominantly if they were independently mobile. Thus, some C&YP in the study demonstrated they were able to grow independent of families in PA as they aged. C&YP with less physical mobility had less independence, which made participating in PA with friends in their homes, and in surrounding neighbourhoods, difficult. These C&YP therefore tended to be limited to PA/play in the family home, which was reliant on siblings and parents' engagement. Age, physical mobility, and ability to become independent were influential on PA participation, as were extrinsic family factors and other environmental factors, which could increase parental work to support PA participation.

PA participation was not the central work of the family social world, and there were competing family priorities. Competing priorities included parents’ commitments (e.g., work, childcare, household tasks), sibling commitments (e.g., sport, school), healthcare commitments (e.g., C&YP’s healthcare appointments) and commitments to maintaining the home (e.g., financial). Parents’ work was to manage C&YP and the many family commitments, which made engaging in PA inside and outside the home environment more difficult for families with more demands and fewer resources. Examples of more demands and fewer resources included - single parent families, families with more than one child, families with no financial income, and families needing to travel long distances to participate in community PA opportunities, usually rural living families. Most families attempted PA participation but did not always know what PA was appropriate or where to find PA opportunities. Additionally, families could not always easily include PA participation into their daily life or sustain participation. Those parents with more resources were more likely to sustain participation (e.g., dual income, dual parent households). Especially if having existing PA interests, beliefs in the benefits of PA, problem-solving skills, access to neighbourhood environments, and easy access to community opportunities (e.g., living in CITY1). Such families were also more likely to successfully overcome difficulties and challenges to participation, such as being able to adapt PA and equipment for participation, gain access to community environments, gain inclusion in community PA groups, find opportunities for participation, manage transport and travel time, manage C&YP’s fatigue and sibling childcare, and their financial resources.

Parents were strong role models and motivators of PA participation especially when having strong beliefs in the benefits of PA, being physically active themselves and having problem solving skills and persistent attitudes. Parents and C&YP needed these beliefs, skills and attitudes to overcome difficulties and challenges to participation. These intrinsic family supports were not always sufficient to facilitate PA especially if much effort and cost was involved. Effort and cost increased when opportunities were located far from the family home or delivered at times that increased travel time and conflicted with C&YP's increased fatigue levels, and other family commitments. This was exacerbated when PA opportunities were not sibling inclusive, especially for families with no sibling childcare. It was more difficult if providers did not make reasonable adjustments for inclusion and families perceived providers as unable to support inclusion, or unwelcoming of inclusion. In these circumstances, families required strong PA beliefs and attitudes of persistence to gain inclusion and/or attend opportunities, or they gave up attendance. Families with fewer resources were more likely to stop attendance/participation. Thus, presence/absence of intrinsic family supports inter-related with provider factors, and community programme factors, to either support or hinder participation.

Providers in the school social world most immediately interacted with the family social world and provided regular opportunities for participation. However, the connection between families and school was not the same in all family social worlds. For example, in the absence of connection, school providers could lack knowledge on how to include C&YP in PA/PE, or how to support C&YP's PA participation in school, and within community' PA programmes. In these instances, C&YP were sometimes, excluded. Another social world for C&YP's PA that intersected with the family social world, indirectly, was the healthcare social world. Indirect connection to families was via school where healthcare professionals provided therapeutic exercise to C&YP in special schools. Most families had previously seen allied healthcare professionals independent of schools, but this decreased as C&YP aged, and if they were independently mobile.

PA also happened in community environments; however, families reported needing to travel to get to physically accessible environments. Families thus needed their own transport and associated finances to access outdoor walking and cycling. The sample does not contain a family who reported they did not have these resources. This lack of representation is a silence within the data, which echoes a wider silence and gap regarding the intersection of socio-economic factors (e.g., no car) and the ability to participate in outdoor PA. Families 4, 9 and 11 described often giving up on outdoor walking and cycling because the time and travel involved became too much effort. These three families were single parent families with more than one sibling, one family involved two C&YP with neurodisability, and one family lived in local authority housing in an area with much traffic. Thus, environmental factors interacted with family factors to hinder PA participation within community environments, but these barriers increased for those families with fewer resources.

In figure 9, I present a portion of the arena of community PA participation illustrating the family social world and its immediate intersection with community neighbourhoods, and school and healthcare social worlds. I also illustrate some of the types of PA that C&YP participated in, within these associated social worlds.

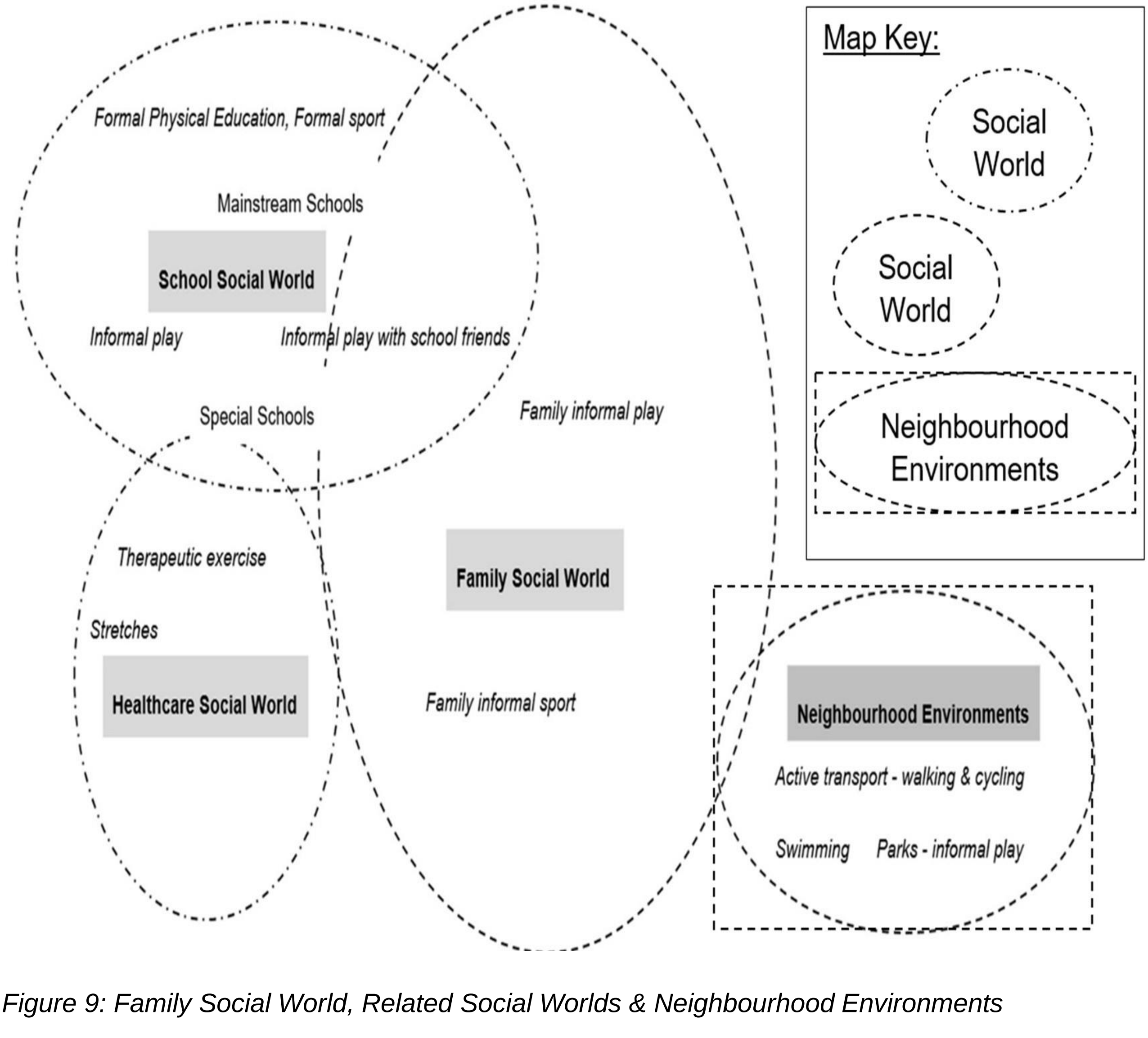


Figure 9: Family Social World, Related Social Worlds & Neighbourhood Environments

7.1.2. Schools

The school social world immediately intersected with the family social world and schools played an important role in facilitating PA participation. C&YP in schools had peers to interact with in unstructured informal play, informal sport and structured formal PE lessons that included physical exercise and formal sport. Schools provided resources for PA such as equipment, facilities, outdoor areas and programmes of PA. However, schools relied on funding, predominantly political-economic funding, to provide these opportunities and supports for PA participation. Furthermore, schools' priorities were educational, which meant time for PA was not an immediate priority, especially as C&YP aged.

Three families (families 4, 6 and 8) reported some difficulties with their local authority school allocation and difficulty with support for PA in school. These family narratives showed a link between local government authorities (political social world) and C&YP's school allocations, and the resources provided to schools, with some disagreement with local authorities over allocations and provisions. Strauss (1978) describes differing priorities and competition for resources being contentious issues between social worlds. Contention between family, school, and political social worlds was also illustrated in Sophie's reports of disability labelling affecting local authority provision of personal assistant hours to support Molly in school. However, numerous families reported no contention with mainstream schools' provision of personal assistants to support inclusion. Mario (PE Specialist) however did report lack of funding in his school for assistants to support C&YP in PE, which hindered disability inclusion. Zoe (PE Specialist) also reported not always having helpers available in schools to support disability inclusion. Both Zoe and Mario reported the need for funding to supply personal assistants and support disability inclusion. Kelly (Educational Psychologist) reported schools competed in clusters for local authority funding with some schools better resourced than other schools. Suggesting, C&YP's PA participation in school is reliant on school location, funding, staffing, and negotiation for resources between schools and local authorities (possibly affected by disability labelling).

Schools also facilitated PA participation outside of school through friendships made in school, which facilitated play in friends' homes, and with school friends in community neighbourhoods. Schools also facilitated C&YP's PA outside of school via enrolment in formal community sport programmes provided by sport organisations. Zoe reported her school accessing these programmes for typically developing C&YP and disabled C&YP. She reported having a head teacher who supported C&YP’s attendance during school time. Not all schools entered these programmes as only Zoe reported them. Families only reported attending other community programmes, and Mario reported not engaging with any programmes outside of the school environment. He reported C&YP linked to sport clubs by secondary school age (when he taught them), if interested in sport. Further, he reported there was limited time for PA in school due to his school’s academic education priority (something Zoe also reported).

Zoe worked in CITY1 while Mario worked in a school 21 miles outside of CITY1. The sport programmes Zoe described were located in CITY1. Thus, C&YP’s attendance in these programmes could be linked to schools’ location. Furthermore, C&YP’s age, schools’ engagement with the programmes, knowledge of the programmes, school management structure and resources could be influential on programme enrolment. There may be other influences not evident from the study findings.

Families who attended special schools mentioned numerous staff, including healthcare professionals supporting participation. Such family descriptions echo Vicky (Physiotherapist) and Harry (Product Designer) narratives of C&YP with complex needs requiring a high ratio of staff supervision for participation. Parents of C&YP who attended special schools described numerous opportunities for fun and diverse PA within school, as well as therapeutic exercise with healthcare therapists. Special schools also had accessible facilities to support PA participation, and some provided school holiday programmes for all disabled C&YP to attend, irrespective of attendance at the special school (reported by family 4). Family four, however, reported difficulty attending these holiday clubs because they were not sibling inclusive.

Not all families reported the school environment consistently supported participation. C-Jay (12 years, family 9) reported playing with friends/peers in school but also reported having difficulties. For example, not having the ball passed to him by peers. Harriet, Mark’s mother (family 6) similarly reported lack of peer interaction in the special school Mark attended, due to most of Mark’s peers lacking communication ability and having extensive physical limitations, which affected Mark’s ability to have informal and formal play with his peers. Harriet reported that Mark’s communication and physical limitations were not as severe as most of his school peers. C&YP

having friends to play with was an important consideration in the school social world and facilitated PA within, and outside of school, but not all C&YP had these experiences.

Organisational and management structures in schools affected participation. Mandy, Catherine's mother (family 7), reported Catherine's special school management structure limited mixing all C&YP, no matter their dis/ability type, and restricted staff training to specific dis/ability types (disability labelling). These practices hindered staff availability to support C&YP with any disability, and use of PA equipment with all C&YP. Frank, Bethany's father (family 8) reported dissatisfaction with Bethany's school allocation and inclusion. He reported Bethany was cognitively able to interact with typically developing school peers but not physically able to keep up. Therefore, Bethany had limited inclusion in school PE. Mario (PE Specialist) echoed these difficulties when reporting segregation of a young person in a wheelchair from his peers during PE management, due to inability to adapt PE to the young person. Bethany also had limited informal play at break times with peers, or after school in friends' homes (due to physical limitations and toilet access needs). Sierra, Sian's mother (family 11), similarly reported that Sian's play was restricted to the home after school and there was a lack of play in school friends' homes due to Sian's physical limitations and environmental toilet access needs. These family reports show that some C&YP are missing the childhood school social world experiences that facilitate informal play and formal play with friends.

The school social world intersected with healthcare in therapeutic support provided within special schools, and via ALNCo's in mainstream schools. Zoe reported working with the school ALNCo to ensure all C&YP with additional learning needs accessed the PE curriculum. Zoe asserted the ALNCo had access to information from physiotherapists and OTs to aid disability inclusion in PE and other forms of PA in school. Zoe also reported the ALNCo proactively, regularly discussed problems with C&YP's inclusion. Mario did not report similar ALNCo communication and easy inclusion of disabled C&YP. Contrastingly, Mario reported difficulty in accessing information from healthcare professionals to support disability inclusion. He reported healthcare professionals were not responsive to his requests for information, and he did not always receive information from parents. In these instances, Mario reported excluding C&YP due to concerns with safety, risk and liability. Thus, lack of connection between healthcare and school social worlds could hinder PA participation in school.

Other differences between Mario and Zoe's situations included their special needs training. Zoe reported previous experiences working with disabled C&YP in a special school (with a special needs teacher), which helped her with inclusion. Mario reported no such experience. Zoe reported easily adapting PA to fit C&YP's abilities, while Mario reported some difficulty. However, the age and stage of development at which Mario and Zoe worked in C&YP's lives was different, which could have played a role in their ability to adapt. Zoe worked with primary school C&YP who could be mobilised easier if having physical limitations, compared to the larger secondary school C&YP (Mario's situation). These provider findings are similar to family findings where families reported difficulties with participation and decreased participation as C&YP aged. Another difference related to age was that Zoe taught mainly fundamental movement skills and in later primary years used these in formal sport. In contrast, Mario taught formal sport and reported that C&YP who had not achieved fundamental movement skills by the age of 12 years (likely with some C&YP with neurodisability) would have difficulty accessing the secondary school age PE curriculum. Frank (family 8) reported this was Bethany's experience.

Both Zoe and Mario reported being able to adapt PA for disabled C&YP however, this meant placing C&YP into ability groups (parallel PA). Mario reported that managing large groups of C&YP was easier in ability groups when time was limited for each child/young person and there was a limited number of helpers. In ability groups, peers could be assistants for each other. Both Mario and Zoe reported using this approach. However, Mario reported needing assistants for disabled C&YP but assistants were rarely available. In contrast, Zoe described C&YP having helpers in the specialist disability unit attached to the school where C&YP sometimes participated in separate activities from the rest of the class, and then, at times, came into PE sessions with their adult helpers. These findings suggest some schools might be better resourced, organised, and managed to support disability inclusion than other schools. Additionally, the possibility of disconnection between schools and social worlds that could provide supportive information and resources.

The synthesis of family and provider interview findings within the school social world, and synthesis of associated political, healthcare, and sport social worlds shows that families and providers are likely to have different experiences of participation and inclusion. This appears dependent on the type of school (mainstream/special school), school location, the people involved, peoples' knowledge, training and experience, school management/organisational structures, connections to funders (e.g., local authorities) and schools' material resources e.g., funding. I illustrate the school social world and its related social worlds in figure 10.

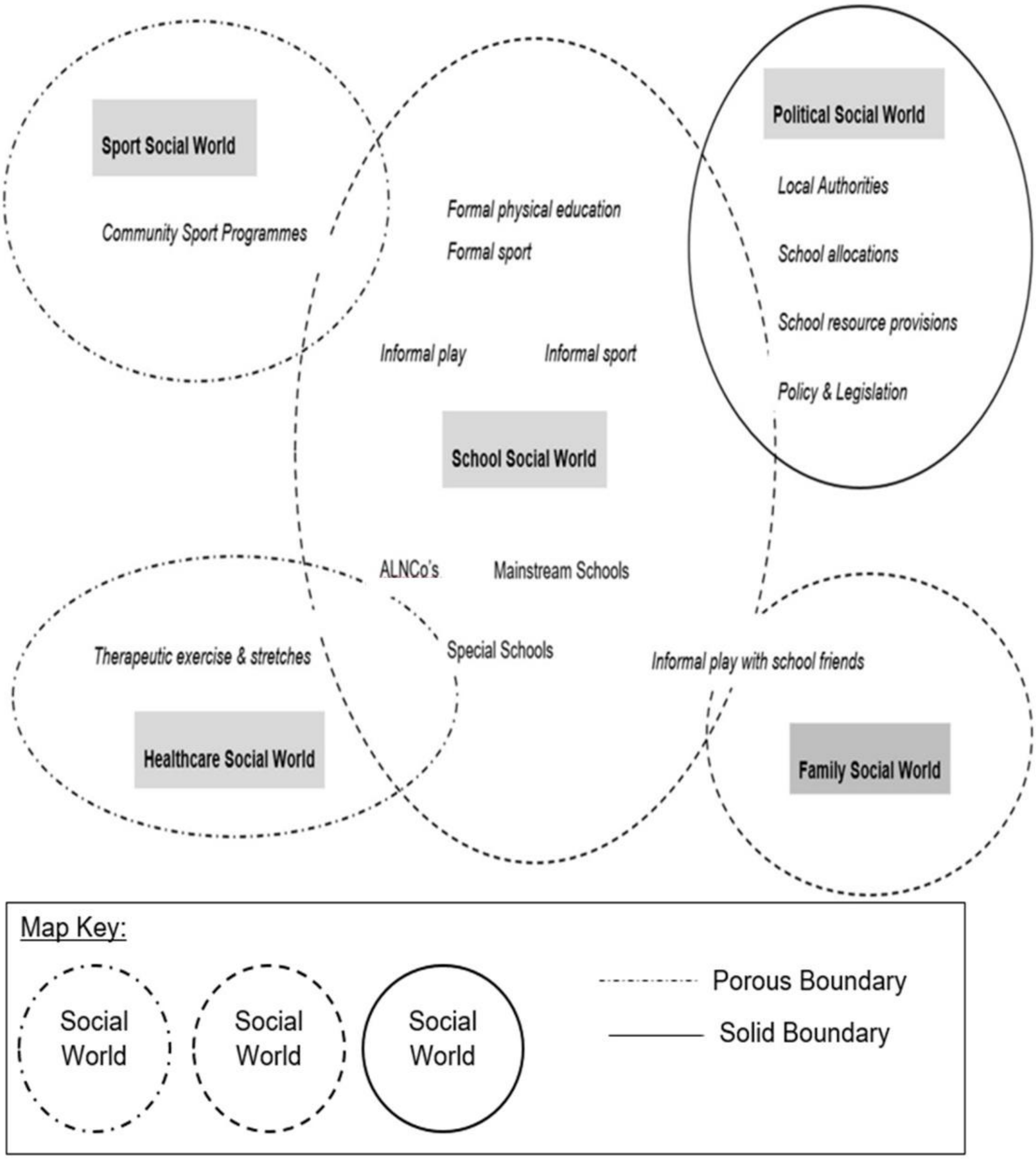


Figure 10: School Social World & Related Social Worlds

7.1.3. Sports

The sport social world intersected with the family via schools, if schools enrolled in community sport programmes. Furthermore, the sport social world linked with families if they attended community sport opportunities (clubs/groups). Families and providers reported that there were many sport opportunities and choices outside of school, delivered by sport clubs. Further, that collaboration between different sport organisations provided numerous community sport programmes. Providers who were not directly involved in the sport world e.g., Vicky (a physiotherapist) reported most community PA opportunities she was aware of, were sport. Families integrated into these opportunities in several ways e.g., via schools, signposting and actively seeking sport opportunities. Families 2, 5, and 12 reported accessing community sport programmes via a NDSO annual disability sport taster event. Providers (Saul, Gerry, and Twinkle-Toes) also knew of this event and signposted families to it. Sport professionals at the event also signposted families to ongoing participation at community clubs/groups (reported by Saul and families 2, 5 and 12). Zoe, a PE Specialist, described C&YP accessing community sport programmes via her school's enrolment in them. Zoe reported community sport programmes offered much choice and were available for school C&YP, both typically developing and disabled C&YP. Debbie (OT) and Kelly (Educational Psychologist) spoke of liaising with sport organisations such as leisure centres and the local authority disability sport development officers (DSDOs) to signpost C&YP into community sport opportunities. Gerry (NDSO executive) spoke of many community and performance sport programmes provided by NDSO in collaboration with other sport organisations e.g., NSO. Saul (a paralympian and table tennis coach) described working with NDSO, NSO and CITY1Sport organisations to provide disability specific table tennis opportunities and working within his community club to provide mainstream, disability specific and mixed ability table tennis opportunities for C&YP.

These family and provider narratives show sport opportunities organised into mainstream participation, i.e., inclusion with typically developing peers and disability specific participation, and that these formats were offered by different sport organisations/clubs/groups. Dwayne (family 1) and C-Jay (family 9) participated in rugby with a mainstream community rugby club. C-Jay however did not specifically play rugby but participated as a linesman, an alternative form of participation. Donny (family 2) and Trevor (family 5) participated in paralympic performance sport. Donny in table tennis and Trevor in athletics. Donny’s coach also came into his school once a week for his coaching, showing collaboration between sport and school social worlds. Donny also participated in all of the formats of table tennis participation (mainstream community and performance participation and disability community and performance participation). Saul reported that table tennis was easily adaptable for any dis/ability and any age, with different ages and abilities often playing together. Rugby did not have the same situation, with Dwayne previously excluded from a mainstream rugby club and reporting his only other option being to play wheelchair rugby, which he did not wish to do. However, he had eventually found a mainstream club where he could play rugby.

The sport social world is thus divided into numerous sub-worlds with some being more disability inclusive than others. Sub-worlds include different sport types and different formats of participation. There are also different levels to these sub-worlds e.g., community and performance levels. Gerry (NDSO representative) described these sub-divisions within the sport social world within her interview. She described sport-governing bodies being responsible for governing and administering their sport type, the different groups/clubs involved, and the different levels of participation. NSO was responsible for developing sport across the nation. NDSO delivered disability inclusive, and disability specific sport opportunities and choices and promoted disability inclusion in sport, working in partnership with sport governing bodies, and anyone willing to be partners. Gerry reported that, traditionally, NDSO had taken responsibility for disability inclusion in sport. However, recently the sport world had shifted focus, moving towards more disability inclusion across all sub-worlds. However, Gerry reported this socio-cultural change was not embedded across all sports and all levels of participation.

Strauss et al. (1964) and Strauss (1978) social world perspective speaks of divided sub-worlds within a social world and that sub-worlds need to gain legitimacy to obtain resources and recognition for their activities. Gerry reported NDSO started as a lone voice by promoting and delivering disability inclusive sport however this approach needed to gain legitimacy across the sport social world. Strauss et al. (1964) and Strauss (1978) describe how social worlds, and sub-worlds gain legitimacy by having a claim to worthiness and having different ways of doing activities (e.g., sport). Family and provider findings show including disabled C&YP in sport is not established in all sports. Strauss et al. (1964) and Strauss (1978) social worlds' perspective assert that to gain legitimacy, social worlds have to set standards for performance, and ways of judging those standards. The sport world has a competitive performance focus, which is part of their set standards, which could hinder some disabled C&YP's participation (as reported by Dwayne, Sarah, Mandy, Evelyn, Vicky, Kelly, Debbie, Saul, and Gerry). Furthermore, set standards for disability inclusion are not established or officially recognised in all sports, which can limit flexibility and choices as reported by families (chapter 5).

Disability sport participation is providing more opportunities and choices for PA but often involves a complex interplay of labelling/categorisation and identity. This was seen in the narratives of Dwayne and Sarah (family 1) and evidenced in the organisation of the sport social world (described by providers Gerry and Saul). While labels can help in categorising participation for a level playing field in competitive sport, as seen in the cases of Donny and Trevor (family 2 and 5), they can limit possibilities for participation by others e.g., Dwayne and Jack who struggled to find rugby (Dwayne) and gymnastics (Jack) opportunities. In these two cases, the providers did not provide inclusive sport opportunities, as reported by families. Other families (4, 6, 7, 8, and 11) reported similar incidents of lack of inclusion due to limited time given to C&YP, lack of differentiation for C&YP and lack of provider understanding in how to manage disability inclusion. This was something other providers also reported as a problem (i.e., Saul, Mario, Kelly, Debbie, and Gerry). Gerry (NDSO) reported the biggest barrier to inclusion being provider lack of inclusion understanding, having a dichotomy between treating everyone the same (equality) and the need to treat C&YP differently (equity), which is supported by family findings (chapter 5).

Labelling/categorising sport can aid in providing inclusion by providing options for competition and access to necessary resources for sport. However, it could restrict flexibility in approaches and provisions, which then hinders inclusion and different ways of participating. Labelling and categorisation within language and discursive interpretations influences social worlds' practices and their negotiations for resources (Foucault 1972; Strauss et al. 1964; Strauss 1978). This was visible in the organisation of sport and the narratives of Saul and Gerry regarding funding for sport, where funds were restricted to specific kinds of disability labels.

The shift towards inclusion in sport across sport sub-worlds and the larger sport social world does show possibilities for finding disability inclusive forms of PA. Finding new ways of doing sport to include more levels of ability and to push C&YP into MVPA (moderate-vigorous intensity PA) will enable more opportunities and choices for participation and achievement of HEPA (health-enhancing PA) (WHO 2020). Harry (Product Designer) described this possibility when advocating the need to fund the design and manufacture of more diverse products/equipment to support diverse ways of doing PA. Vicky (Physiotherapist) described this need in the desire to collaborate with other healthcare professionals, to find more ways to do PA with C&YP having complex needs.

Providers and families' findings reflect a situation of numerous sport opportunities and choices, yet still limited possibilities and choices for participation. The sport social world does however provide good examples of modifying and adapting PA for disability inclusion and provision of PA opportunity and choice. The multiple types, levels and categories for participation can however make the sport social world difficult for families to navigate to find their preferred sport. Families may additionally need to try out various options to find a suitable choice. However, family factors could hinder this (as reported in chapter 5). Additionally, location of sport opportunities can limit family attendance, especially when combined with juggling numerous family factors. Families 1, 3, 4, 10, and 11 reported difficulties attending disability specific sports opportunities, as they were located in CITY1, too far for these families to travel. Families 1, 3, 6, 11, and 12 did not know if there were disability inclusive or disability specific sport opportunities in their local communities. Illustrating a lack of cohesive, joined up information available for families.

I present the sport social world and associated charity, school, family, political and commercial social worlds in figure 11. The political social world provides funding, policy and legislation for disability inclusion in sport while the commercial world provides funding and insurance, as reported by sport providers. This study however shows there is a lack of knowledge and understanding of equity, equality and insurance provisions for disability inclusion within families, and within other community social worlds, which can hinder participation.

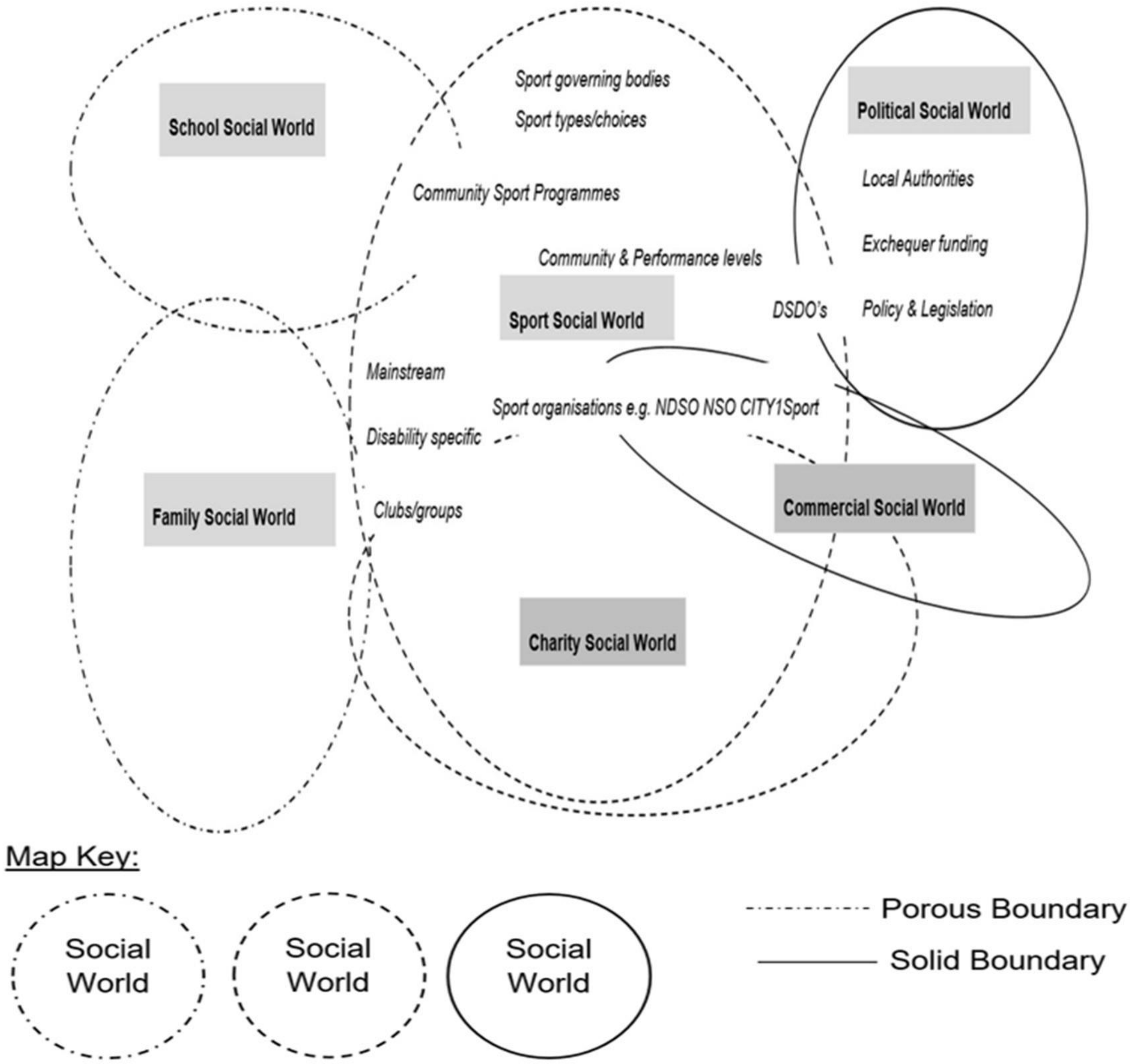


Figure 11: Sport Social World & Related Social Worlds

7.1.4. Charities

The sport and charity social world linked directly. Both the sport organisation representatives in the sample (Gerry and Saul) worked for sport organisations that were registered charities. Gerry shared that much of the funding for mainstream and disability sport development and delivery across the UK was supported by charity funding i.e., lottery funding. Furthermore, disability sport development officers (DSDOs) in the devolved nation's 22 local authorities also depended on lottery funding. The option for local authorities to increase funding for more DSDO hours in each area was available, if local authorities chose to do this. Thus, there are provisions for families and providers to connect with, within their local authority areas, but these are sport specific, and a potential exists for disparity in provisions depending on where C&YP live; something that families reported.

Other providers in the sample also described reliance on charity funding and either working or volunteering with charities. All families shared that they had accessed charity community groups for PA participation. These families regularly mentioned three charities specifically; a cycling charity in CITY1 which provided disabled C&YP with the opportunity to learn to cycle and participate in community cycling; a swimming charity which provided the opportunity for C&YP to learn to swim and participate in regular swimming, either freely or at subsidised rates; and NDSO (a registered charity). The swimming charity was a UK wide charity with links to local authorities' leisure centres to provide swimming opportunities but was not available in all communities. Families needed to know about these organisations and opportunities to access them and not all families did know. The disparate charity organisations and their opportunities for participation likely makes providing cohesive information to families difficult.

Other charity influences were in the provision of charity grant funding. Saul accessed charity grant funding to provide disability inclusive table tennis opportunities. He also gave much of his time as a volunteer. Vicky and Twinkle-toes worked for a charity providing therapy support to C&YP with neurodisability but received salaries for their work. Evelyn, Hermione, Kelly and Debbie volunteered in support of C&YP and their families by running community groups, giving their time and expertise freely. All these providers reported using charity funding to deliver their group programmes and used mainly volunteers to support the delivery of these. Providers also reported doing and being involved in fund raising events to deliver their programmes. The community situation illustrates transient people, workforce capacity and funding sources that have intersecting healthcare, sport, charity and more distantly, political economic social worlds, with no cohesive organisation, management or governance.

All providers reliant on charity funding (Saul, Kelly, Debbie, Evelyn, Gerry and Harry) reported finding grants, meeting funders' requirements and sustaining programmes, took time and effort, and funding did not secure lasting support for programmes.

Funders could place restrictions on where, how, for whom, and for how long funds were available. Additionally, this practice could continue a situation of disability categorisation and labelling with funding only available for specific types of neurodisability, which could restrict available opportunities for families (also reported by families). Kelly raised concern about the lack of governance in the charity social world, and therefore lack of governance of community PA participation, due to most community provisions supported by charity funding and volunteers. Harry's narrative echoed this situation when he described a lack of established governance of design and manufacture of products for disability participation. Dwayne's story of discrimination and exclusion from mainstream rugby without enforcement of disability legislation (chapter 5) further echoes a lack of governance. His story also illustrated a lack of knowledge regarding the commercial world that provides insurance to sport clubs. This was echoed in the narratives of families 4 and 6 regarding providers' cautionary and exclusionary disability discourses. The commercial world touched on the situation via provision of opportunities for participation by sports organisations that were also limited companies (Gerry and Saul) and in provision of commercial funding for PA opportunities (reported by Gerry).

Gerry was the only provider who reported securing funding from commercial organisations e.g. supermarkets and banks. The providers reported that securing funding to support PA for C&YP with neurodisabilities was challenging. The UK's Chief Medical Officers guidelines for PA among disabled C&YP, has only recently been published but could be used to support funding applications by demonstrating the need (GOV.UK 2022; Welsh Government 2022). Additionally, organisations exist that provide information on potential funding sources. For example, both Saul, Debbie and Kelly spoke of linking with the NDSO to find funding sources and being able to secure funding from a large well-known children's charity. Debbie (OT) also explored funding and participation options with the DSDO in her local authority. Greater interlinking between social worlds could make funding possibilities and processes more overt. There are funding possibilities but finding them, applying for them and meeting all the funders' requirements takes time, which providers reported was not readily available. The providers' narratives show that collaboration helped overcome funding challenges and secure funding, but a dichotomy exists in providers simultaneously, potentially, competing for funding. Strauss et al. (1964)

when discussing elements of social world theory describe arenas being where social worlds negotiate and can be in competition for the same resources. This may be the case in the situation, which could hinder collaboration for resources. The situation also shows a need to inform funders of the funding difficulties and challenges within the situation, so that funders can consider these in their funding provisions. The multiple overlapping social worlds related to, and part of the charity social world, adds to the complexity of the situation (figure 12).

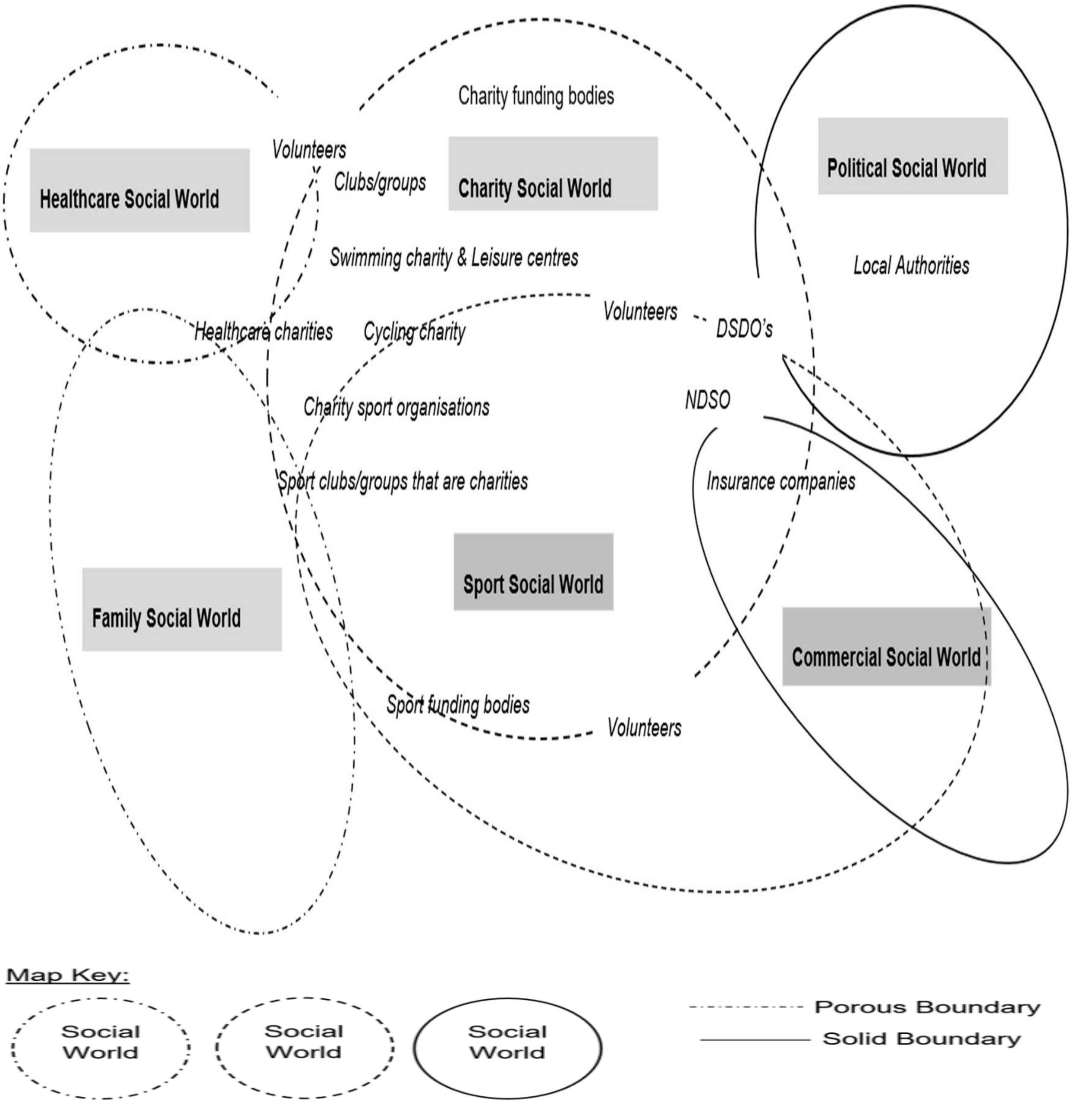


Figure 12: Charity Social World & Related Social Worlds

7.1.5. Healthcare

The healthcare social world intersected with school, charity and sport social worlds in numerous ways. For example, families 6, 7, and 10 reported C&YP received regular physiotherapy and OT input in the special schools they attended. These healthcare professionals supported PA in the forms of exercises, hydrotherapy and rebound, although Mandy (family 7) reported not all physiotherapists were trained in rebound. Frank (family 8) felt Bethany did not receive sufficient therapy due to not being in a special school. Harriet (family 6) reported Mark now received sufficient therapy since moving to a special school. Families 3, 4, 11 and 12 (C&YP aged 5, 7 & 8) did not attend special schools but reported seeing healthcare therapists intermittently, following a therapeutic programme. The remainder families (n=5) did not report ongoing therapy but reported previously seeing therapists and receiving exercises, mostly stretches, which they did intermittently.

The healthcare social world intersected with the charity social world through employment (Vicky), or volunteering (Debbie, Kelly, Hermione and Evelyn). Additionally, it intersected with the sport world through collaboration e.g., Debbie collaborated with the local authority DSDO to find funding and sport opportunities for the C&YP in her charity group. Gerry reported that the NDSO delivered disability inclusion training to physiotherapists who otherwise lacked confidence in supporting disability inclusion in school PE. The lack of physiotherapists trained to support community PA participation, or focused on community PA participation, was evidenced in Mandy's narrative (family 7), who reported not all physiotherapists were trained in rebound work in Catherine's special school.

The debate on the role of physiotherapy in supporting community PA participation (such as in PE, other school programmes, and community groups) was visible in the situation via the narratives of Vicky, Evelyn and Hermione. Vicky reported participation as a potential outcome of therapy but that physiotherapy strengths lay in task analysis, physical performance and function interventions, which would lead to better participation; despite the lack of evidence of this effect (Palisano et al 2012; Ross et al 2016; Novak et al 2020). Evelyn reported the need for physiotherapists to be part of participation situations to find solutions. Hermione (physiotherapy student volunteer) reported many physiotherapy skills applicable to community PA participation situations, which she felt should help physiotherapists to be able to provide informed social prescribing/signposting to families. Diverse physiotherapy approaches to support PA participation may provide more ways to tackle the problem of limited PA participation by C&YP with neurodisability but lacks a cohesive approach and these providers did not refer to research evidence for their approach. Lack of connection to referenced evidence is illustrated in figure 13 with the absence of Higher Education Institutes and research bodies within the healthcare social world map, and its associated social worlds.

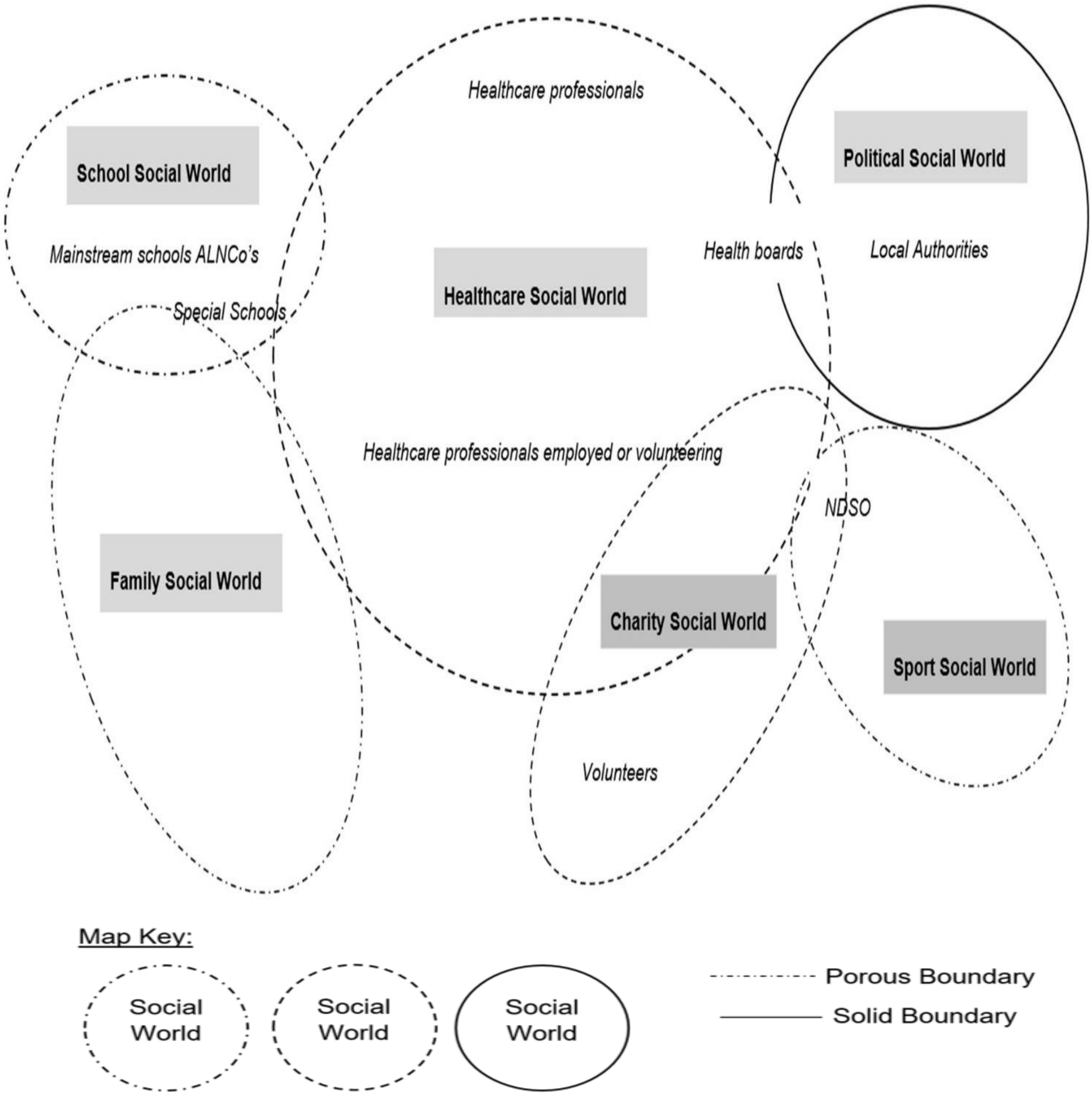


Figure 13: Healthcare Social World & Related Social Worlds

7.1.6. Politics

The political social world had indirect connections with the situation. All families were linked to the political social world via schooling. All families went to local authority schools and required local authority support for C&YP to access schooling and PA in school. Families 3, 4, 8, 11 and 12 were all linked to local authority economic support via the provision of personal assistants to support disability inclusion in school. Families 1, 2 and 5 had previously had personal assistants but C&YP become independent as they aged, thereby, reducing connection to the political-economic social world. Providers in school (Zoe and Mario) reported the need for personal assistants to support disability inclusion in school and in PE, particularly in large groups of C&YP with different abilities. They were indirectly requesting increased links to the political-economic social world.

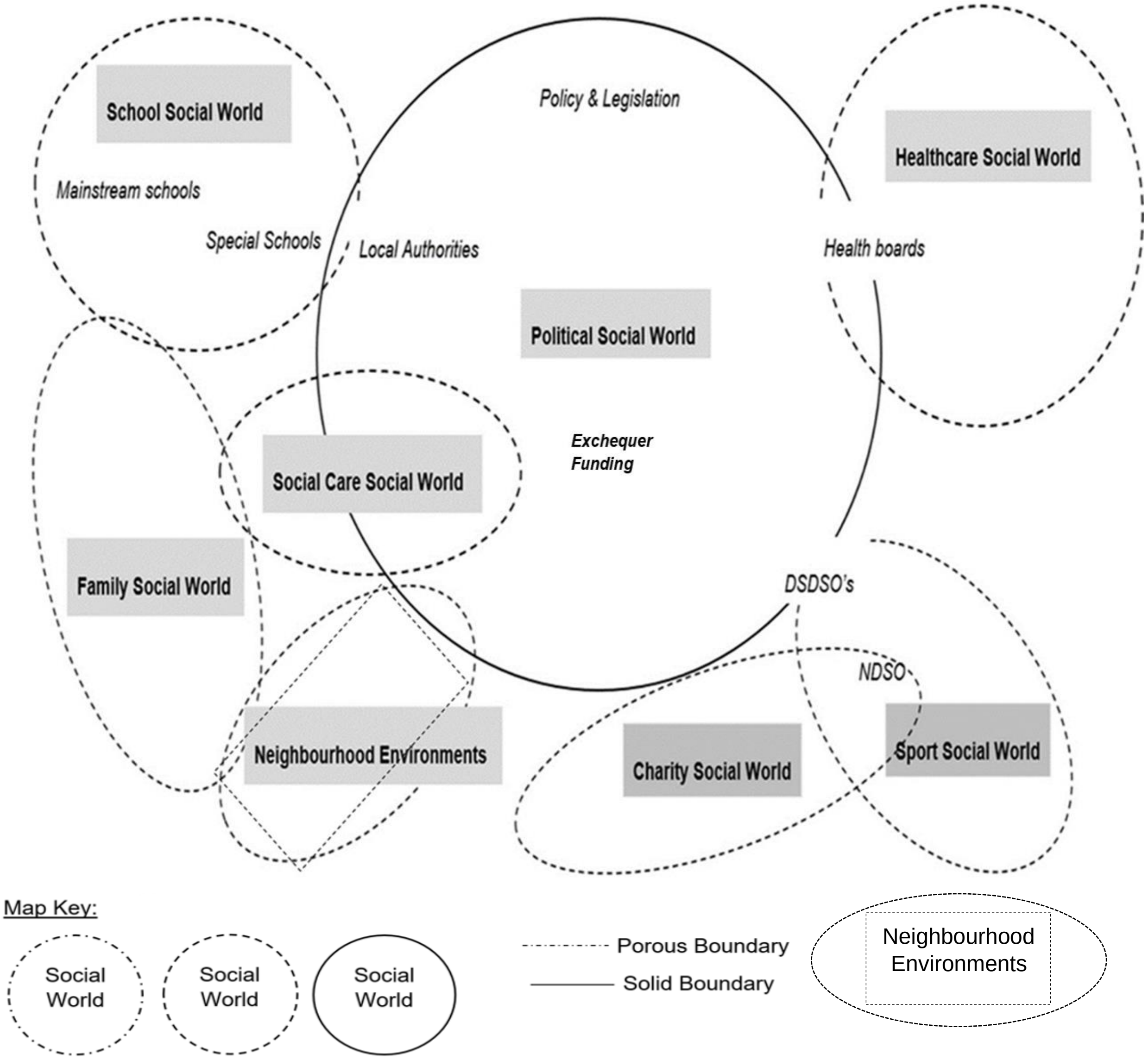
Mario reported excluding disabled C&YP from PE if he did not have the information, he needed from the healthcare social world and from the family (parent) social world, and if he did not have sufficient personal assistants/helpers for C&YP (provided via links to the political-economic social world). Family 4 reported requiring an additional disability label to gain political-economic support for more personal assistant hours in school. Families 6, 7 and 10 had more than one personal assistant i.e., were supported by many staff in the special school environment. This echoed Vicky’s narrative of the many support personnel needed for C&YP with complex needs, and echoed Frank reporting that funding constraints on personnel provisions in mainstream schools limited the support available for Bethany’s inclusion in PA.

Other indirect connections with the political social world were seen in families 4, 6 and 9. Family 4 reported accessing social care benefits (direct payments) to support weekly swimming participation. However, they were considering withdrawing application for this economic support due to the onerous and stigmatised processes involved. Family 6 reported not being able to access this support due to not meeting the social care assessment criteria to receive it. Additionally, the family reported difficulties with the local authority supporting access to personal daily activities such as washing and toileting. Therefore, the family were taking legal action against the local authority. Family 9 reported housing needs and difficulties getting agreement with the local authority about the need for storage space for equipment e.g., specialist chair, wheelchair, trike and frame runner. Overall, there was a lack of trust between these families and their local authorities.

More than half of the families (n=7) reported difficulties taking part in walking and cycling in local communities due to inaccessible environments and felt local authorities could do more to make these more accessible for the use of large mobility assistive equipment. Family 7 felt more could be done to mandate access requirements and provide signage. Family 4 felt more could be done to share unused facilities e.g., community halls, to provide better opportunities for participation. Vicky and Evelyn felt local authorities could do more to mandate and provide access e.g., provide more disability changing spaces, signage and enforce access requirements.

Enforcement of access and inclusion policy and legislation was also missing in other areas e.g., community sport participation. Family 1 reported exclusion from rugby due to a lack of insurance provision demonstrating a lack of situational knowledge regarding the Disability Discrimination Act (1995), the Equality Act (2010) and lack of political/legislative enforcement thereof. Mario described legislation enforcing schools to provide disability access within schools. However, he reported exclusion of C&YP due to the lack of necessary knowledge, collaboration, or staffing to ensure safe inclusion. Thus, providers and families' narratives show legislation, and policy can set standards for practice but can be ineffective at ensuring standards are followed in practice. This is especially the case if the funding, knowledge, people, collaboration and willingness is not in present within the situation. A need exists to have policy makers, legislators and funders join conversations with other providers and families in the situation, to make a difference and change the status quo. However, I note the absence of funders, policy and legislation representatives from the situation, from community conversations, and within this thesis. I approached policy makers, legislators and funders for inclusion. However, although they spoke with me, they would not consent to research participation.

I illustrate the political social world and its associated social worlds in figure 14. I represent lack of access to the political social world with a solid line surrounding the world. The figure shows the political world associated with many social worlds that influence families, yet families do not have direct access to the political social world.



DSDO's: Disability Sport Development Officers; NDSO: National Disability Sport Organisation

Figure 14: Political Social World & Related Social Worlds

7.2. The Arena of Community Physical Activity Participation

The arena (illustrated in figure 8) includes numerous social worlds - family, school, healthcare, sports, charity, political, and commercial. There may be more involved but illustrated are those found within the situation as represented by the family and provider sample. Community PA participation is distributed across a range of people, organisations and social worlds that do not necessarily work together and may be in competition for the same resources. The wide distribution could reduce awareness of the need to take responsibility for disability inclusion and participation, as there are many worlds and sub-worlds involved, and the perceptions could be that other organisations and/or social worlds are responsible/taking responsibility. All people and organisations are however responsible according to disability inclusion legislation. There is evidence that the historical exclusion of disability (i.e., prior to the Disability Discrimination Act [1994] and Equality Act [2010]) continues within the community PA participation arena, although providers spoke of socio-cultural change happening, and political policy and legislation influencing a move towards disability inclusion. The study findings show there were still disability discourses affecting inclusion and participation. For example, discursive positions of disability being something to fear, C&YP being more at risk of injury or C&YP not being able to participate. Additionally, social world institutional/organisational/managerial practices used labelling/categorisation, which provided choice and a level playing field in sport, but could also limit opportunities and choices for participation, and limit flexibility for participation.

There was also a dominant position of resource insufficiency evident in the arena, which hindered finding ways to provide and support disability inclusion. For example, the report by a rugby club of the lack of insurance stopped their need to find solutions to provide Dwayne’s inclusion. Insufficient staff stopped the legal requirement to provide inclusion for Sian in the holiday club, and there were several other reports of insufficiency in family and provider findings. There are several resources for individual people and organisations within the different social worlds to provide inclusion. Their sources were political economic, local authority social-care teams, charity, sport, and commercial funding sources. Political economic and political social care support/resources were however difficult to acquire, and some processes to gain support were stigmatised and onerous. Additionally, not all families were eligible for these resources. Providers from political and commercial social worlds declined to be part of the thesis interviews (illustrated behind a solid boundary line in figure 8) showing these social worlds not readily accessed by the participants. The only participant who mentioned use of commercial funding and partnerships with commercial organisations was Gerry from NDSO. The remaining social worlds within the arena are illustrated having porous boundaries in figure 8, showing they were accessible to all participants. However, not all participants accessed all these social worlds or collaborated across social worlds. Where collaboration did occur, there was sharing of resources and more opportunities and choices for families’ participation. Overall, people were active in and across different social worlds, but their work and actions were not well distributed and poorly integrated across these worlds, as were resources and information sharing.

Visual examination of the arena (figure 8) shows that the families overlapped with the school social world directly. All schools played a key role, i.e., seeing C&YP daily and providing opportunity for daily PA. It would be interesting to see if all schools provided opportunity for 60 minutes MVPA as recommended for health by WHO (2020). Informing schools of this recommendation for health and finding innovative ways to provide such participation could support schools. However, Mario and Zoe described tensions in time allocation for PA and PE in school and C&YP reported doing PE either once a week or only every two weeks in school. Schools also played a key role in linking to sport organisations in the situation, although not all schools did so. Schools also provided a space for facilitating relationships between typically developing peers, disabled C&YP, and their respective families. This happened for some but not all families. Such relationships could offer more opportunity to break down barriers around disability, but some families reported C&YP lacked such peer interactions.

NDSO remains a key organisation in the situation and many families and providers therefore mentioned NDSO. NDSO is the only organisation in the situation that has links to people and organisations in all of the social worlds illustrated in the arena (figure 8). NDSO is a sport organisation therefore the dominance of sport as a choice for community PA participation is not surprising. Analysis of the situation shows most work on disability inclusion and provision of opportunity and choice has been achieved through the collaborative work of NDSO with a variety of partners, and in the work of charity support groups providing opportunities (often sport opportunities e.g., skiing, swimming, cycling). The many distributed and poorly integrated social worlds, organisations and people in the situation shows why it may be difficult for families to find opportunities and choices for participation. This remains the case if they do not know of key organisations, the information about opportunities and choices is fragmented, and they have limited resources.

7.2.1. Discursive Positions

In figure 8, I illustrated the arena of community PA participation. Arenas are places where all the social worlds are visible, come together and negotiate, including over contested issues (Clarke et al. 2018; Strauss 1982; 1984). There were several contested issues within the arena, such as debate over responsibility for inclusion and participation; possibilities for inclusion; safety and risk; and resource allocations. I considered contentious issues using Clarke et al. (2018) positional mapping (example in Appendix 19). These contentious issues had associated language, behaviour and perceptions. Discourse encompasses the use of language in social contexts, associated knowledge and beliefs, and includes interactive aspects of communication where meaning creation occurs. These aspects have foundations in SI theory (Blumer 1969) and the theories of Foucault (1972), both foundational theoretical roots of SA.

The possibility of inclusion and participation was a contested issue in the situation despite legislation and policy advocating the need to provide inclusion (Disability Discrimination Act 1995; UNCRC 1989; UNCRPD 2006; Equality Act 2010). There were discursive interactions and constructions between community providers and families regarding whether inclusion and participation was suitable or advisable and interactions that did not create mutual understanding of what inclusion entailed. This happened predominantly in mainstream community groups outside the home and school. The situation led to negative experiences for some families. Repeated negative experiences could lead to a cycle of exclusion and reinforcement of negative language and meaning construction between families and providers. There were some reports of families who were quick to back away from participation when encountering cautionary provider language and began to anticipate further negative outcomes for future interactions (Families 4, 6, 8, and 11). As an example, the families came to expect rejection, and the need to withdraw from PA participation interactions, not persisting in communication or attempts at participation when encountering difficulties. Providers' repeated experience of insufficient knowledge and time, fears of disability risk, and insufficient knowledge/skill on how to provide inclusion, could similarly make them wary of attempting inclusion and be quick to say they did not have the required resources. Thus, the situations that providers and families perceived as real, could lead to them becoming real within their interactions, and future interactions, as in Thomas' theorem (Thomas and Thomas 1928). Breaking these negative discursive cycles between providers and families requires conscious effort at individual and organisational levels to foster inclusion and reinforce that inclusion is possible, and that disability is welcome within communities. Mediating interpretations is a way of gaining mutual understanding (Blumer 1969). To create effective disability inclusion there needs to be creation of mutual understanding of inclusion possibilities and practices between providers and families. Providing forums for providers and families to meet and discuss issues and find mutual solutions may be a way forward to creating mutual understanding, collaborative solutions and support networks to improve inclusion and provide effective inclusion.

Another contested issue between providers and families was the perception of risk versus safety and C&YP's abilities to participate. Figure 15 illustrates, via a positional map (Clarke et al. 2018) the risks of injury versus the ability to participate in PA for C&YP with neurodisability.

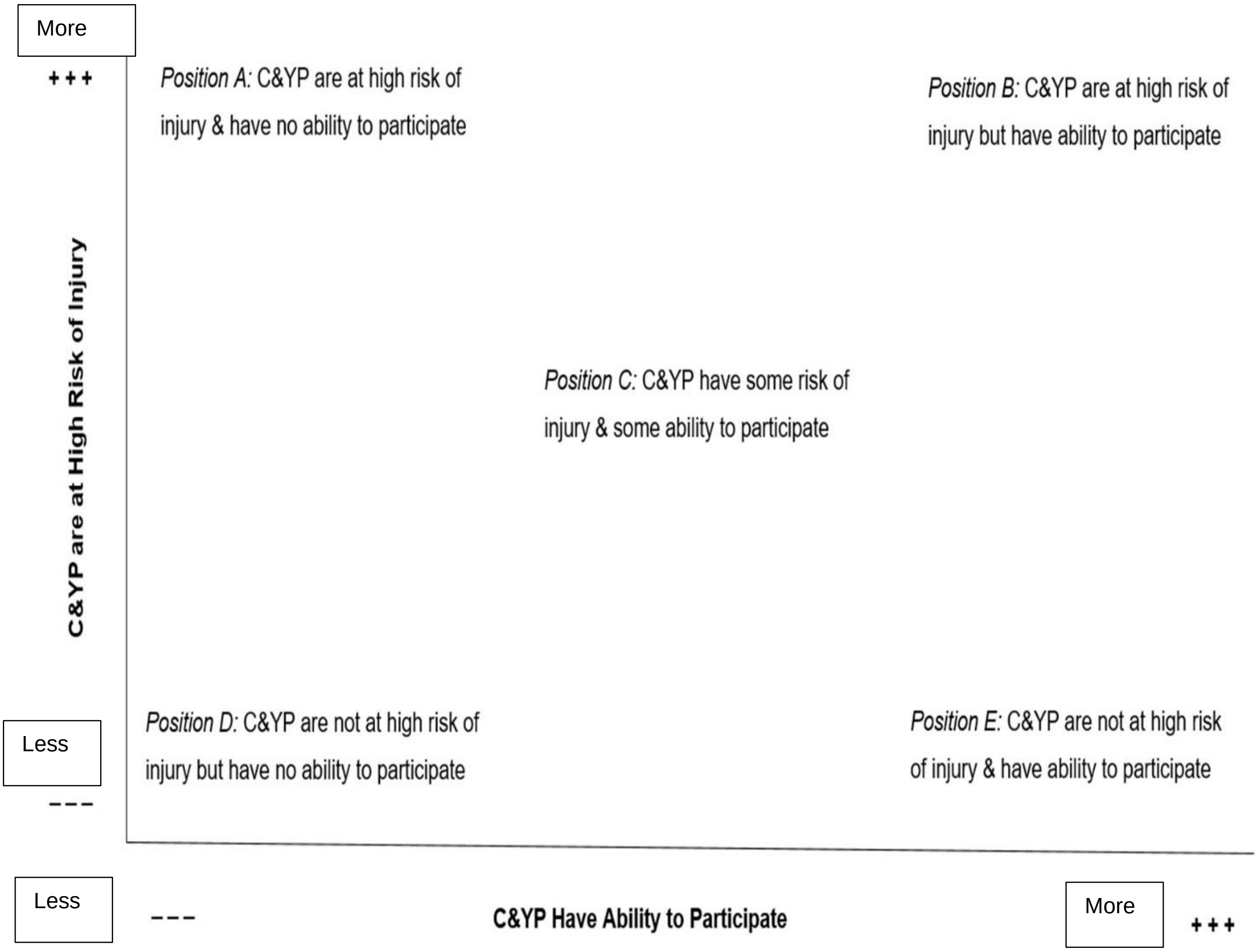


Figure 15: Positional Map on Risk of Injury and C&YP's Ability to Participate

Position A in Figure 15 indicates a position of high expectation of injury and low expectation of C&YP’s abilities. My SA findings have shown that position A is present within communities and dominant in the presence of disability discourses that view C&YP as a risk for participation. Families reported providers were cautionary and exclusionary, fearing risk and lacking confidence, which resulted in negative experiences for families and families expecting C&YP’s exclusion, with subsequent reductions in families attempts at participation. Assessing a participation situation as C&YP being at high risk of injury and low ability to participate, requires reducing risk and adapting participation to suit C&YP’s abilities for inclusion to occur. This will likely require time, problem solving, persistence, extra resources and knowledge that providers and families do not readily have – as is shown in my SA findings. Low expectations of attaining/having resources and of C&YP’s abilities to participate is likely to make position A difficult to move away from, and result in C&YP’s exclusion. Providers need to find ways of including C&YP to meet policy and legislative requirements but may find reasons not to if they are in position A, lack resources and skill, and are in competitive environments - such as sport environments. Such an example is found in chapter 5, Family 1, when Dwayne was excluded from rugby participation.

The different positions in the map in figure 9 show an interplay of the need for risk assessments and the reduction of risk aversion, combined with the need to increase expectations regarding C&YP’s abilities, and the need to adapt PA to fit with C&YP’s abilities, in order for participation/inclusion to occur. The map (Figure 15) therefore reveals influences on participation that policy makers, legislatures, funders, providers, and families need to be aware of and helped to manage to provide inclusion. The different influences identified show that resources required include the need to increase knowledge and skill in managing risk, adapting PA/sport to fit C&YP, adapting environments and equipment, and providing resources that facilitate knowledge, skill and adaptions to environments and equipment. The availability of resources to manage these factors will further influence the situation. Synthesis of family and provider findings showed the situation was often compounded by a lack of resources, both in terms of time, knowledge, equipment, accessible indoor and outdoor environments and available people/staff. This scarcity hinders the creation of inclusive environments where every individual child/young person has the opportunity to participate fully and benefit from PA.

Within the situation, the organisation of participation according to disability labels and categories provided opportunity and choice in terms of different ways to participate e.g., separate, specific or mainstream inclusion, as well as providing a level playing field for competitive formal sport participation. However, the organisational practice also had the potential to limit opportunities and choices when C&YP did not neatly fit into a labelled opportunity or category. Furthermore, when the providers' knowledge and practice was limited to a specific label because this could limit providers' abilities to adapt and be flexible to provide inclusion. Labelling individuals, particularly C&YP with neurodisability, could restrict the flexibility of approaches and provisions. It could lead to preconceived notions that limit exploring new possibilities for participation. This rigidity could stifle innovative ways of doing and managing community participation. The family and provider findings show adaptability is essential for the development and support of inclusion within and across multiple community settings, organisations and social worlds.

The gathered thick situational analytics provided information to answer the three research questions, obtained through synthesis of family and provider findings. I summarise these in the following section.

7.3. Answering the Research Questions

There were three research questions. In the following sections, these are answered in turn.

7.3.1. Question One

What community PA participation opportunities are available for C&YP with neurodisability and where do they participate?

The findings show the main PA opportunities and choices available for C&YP were participation in formal sport programmes provided by NDSO and a collaboration of NDSO and other sport organisations. These sport opportunities and choices were in mainstream and disability specific clubs/groups. However, most of the disability specific opportunities were located in the large cities (usually CITY1) and mainstream disability inclusion did not happen in all formal sports, or in all geographic locations.

There were also opportunities and choices for PA participation via attendance at community charity groups. The sample included examples of four specific charity organisations/groups, namely NDSO, cycling, swimming, and a skiing group. NDSO provided numerous mainstream disability inclusive and disability specific sport programmes The cycling group was for typically developing C&YP and C&YP with any type of disability; usually participating separately and/or within families. The swimming group was free or financially subsidised and for disabled C&YP only, having any type of disability. C&YP usually participated separately but could move into a mainstream swimming group once reaching a set standard of swimming ability. The skiing group was specifically for C&YP with ASD.

PA opportunities and choices were also available in schools, through informal play with peers and formal exercise and sport in PE sessions. Informal play with friends after school also provided opportunity and choice for PA participation. C&YP could also play formal sport in school sport teams and schools could enter teams of C&YP into community sport programmes provided by key sport organisations. Schools could also bring sport providers into school to provide sport opportunities and choice (although this did not appear to happen often) and signpost to community opportunities and choices for participation.

Informal play also happened in families in the home and in neighbouring communities. This happened mainly when C&YP were ≤ 8 years and decreased as C&YP aged, especially if C&YP were independently mobile.

7.3.2. Question Two

What are the facilitators and barriers to participation?

There were several facilitators and barriers. Comparing families and provider findings, I organised the most common facilitators and barriers across families and providers into eight situational matrix categories: individual people, organisations, resources, information, organisational/institutional, discursive, environmental, and temporal (aging and development over time). I summarise these highlighting the relevant categories in italics.

Individual people and *organisations* facilitated community PA participation. People supported, and championed participation and also provided social interactions. People with intrinsic skills of problem solving, attitudes of persistence and beliefs in the benefits of PA, as well as people who were physically active themselves, (PA role models) were more likely to facilitate participation and sustain participation. Parents were key people, followed by siblings, friends, teachers and sport coaches.

Organisations required such *people* to facilitate participation, as well as *resources* and *organisational/institutional* working practices that supported participation. These included collaboration between organisations, sufficient inclusion training/knowledge, funding, equipment, helpers, time, information and the ability to adapt PA, equipment and environments to fit with C&YP's abilities, and the PA task. *Organisational/institutional* management structures facilitated obtaining the necessary *resources*, and allowed for adaptability and time to provide inclusion, which further facilitated participation.

Families' *resources* also supported participation such as having the personal characteristics previously listed, and transport, time, money, and equipment, as well as sibling childcare. *Environmental* access to indoor and outdoor spaces and places also facilitated participation e.g., having places with accessible toilets, and changing spaces. Further facilitators were *information* about participation opportunities that facilitated families' attendance.

Barriers to participation were numerous. *Organisational/institutional* limitations in the number of opportunities and choices for participation, geographic/*environmental* far located opportunities and choices, all hindered participation, particularly when combined with family factors (such as limited resources) that hindered attendance. The lack of *information*/knowledge of suitable and available opportunities and choices within communities also hindered attendance. There were also a limited number of available accessible *environment*s for indoor and outdoor PA participation.

Disability discourses hindered participation and created negative experiences for families, which hindered future attempts at participation. The negative experiences included perceptions of unwelcoming, cautionary and exclusionary providers. C&YP's and parent's perceptions of not fitting in and a lack of provider knowledge, confidence, adaptability and flexibility to facilitate fitting in, hindered participation. The providers reported a similar story from their perspectives. The adaptability required to fit PA to C&YP and provide inclusion relied on their knowledge, experience, time, equipment, facilities and helpers, and sometimes collaboration with others, which was not always readily available to them. The lack of *information*, collaboration, and *resources* hindered the providers' ability to facilitate inclusion and appeared to increase their risk aversion and the likelihood of C&YP's exclusion. This was more apparent in the presence of disability labelling and categorisation. The organisation of inclusion and participation into disability labels and categories facilitated training and resources for providers, and facilitated inclusion, and participation for C&YP, but not by all providers and for all C&YP. For some, these *organisational/institutional* practices hindered providers training, experience, their resources and flexibility, as well as subsequent opportunity and choice for C&YP.

The fragmented organisation of participation hinders collaboration, sharing of information, expertise and resources, as well as the monitoring, evaluating and enforcement of policy and legislation, ultimately hindering accountability and governance. Without increased collaboration, resources, accountability, and governance, the situation could continue as the status quo and may even deteriorate, as seen in temporal situations such as Covid-19 (Cadwgan et al. 2022). Temporal situations can leave lasting legacies and discursive influences that hinder change and improvement, as seen in the continued influences of historical disability segregation and exclusion, despite recent equality legislation (Equality Act 2010).

Families and providers struggled to navigate the situation particularly when C&YP had developing and changing needs. These were transitioning *temporal* stages to participation affected by age, stage of development, physical mobility, resource availability and environmental influences. Thus, PA participation could reduce over time, as C&YP aged and developed.

7.3.3. Question Three

What key areas need further action to increase community PA participation and increase support for participation?

The participation of C&YP with neurodisability in community PA is a multifaceted issue, influenced by a variety of factors. Thick situational analytics provided by using SA (Clarke et al. 2018) of family and provider interview data enabled identification of several key areas for action to increase participation and support for participation. These action areas included increasing families and providers' physical literacy, managing transitioning phases of childhood to ensure PA participation, integrating community PA participation and healthcare services, and focusing on improving structures/infrastructures supporting community PA participation. Following, I present a brief summary of these key action areas.

Physical literacy: A key action area identified is to increase families' physical literacy and providers' physical literacy in supporting disability inclusion. Physical literacy is a concept defined as valuing and taking responsibility for PA participation to improve/maintain health and involves knowing, understanding and valuing the importance of PA for health (Whitehead 2010; Whitehead 2019; Liu and Chen 2020). SA findings and published evidence shows families and providers need physical literacy specific to disability inclusion and participation. Ways in which healthcare providers could help families attain increased physical literacy is by identifying individual family and child/young person beliefs about PA and educating and encouraging beliefs that support PA participation, and support PA participation through childhood transitioning phases. Additionally, alongside these approaches helping families and C&YP set PA goals and supporting their achievement of these will likely help. Ways in which healthcare providers could assist themselves and other providers in gaining greater knowledge and informed practical skill application that supports disability inclusion (i.e., increase their own disability inclusion physical literacy) is by providing relevant information to community providers where necessary e.g., regarding C&YP's strengths and abilities, by interacting with providers and C&YP within community participation settings to mutually problem solve solutions, and by being part of stakeholder forums that focus on finding ways to ensure and provide disability inclusion.

Target early years and transitioning phases: Due to C&YP's changing PA participation status with age and development, another key area to focus on is supporting PA in early years and during transitioning phases of growth and development. By focusing on this, there is potential for sustaining community PA participation. The majority of the family participants had some physical literacy, i.e., were already physically active. The sample predominantly included physically mobile C&YP who were physically active. Yet, despite this bias in the sample, the findings showed that these families still faced barriers and sometimes struggled to initiate participation, and/or sustain participation. The two key action areas listed thus far, match the WHO (2018) GAPPA aims of increasing PA participation by increasing beliefs in the benefits of PA, to provide social norms and attitudes that promote and increase PA participation. Increasing providers' physical literacy for disability inclusion will also increase workforce capacity to promote these social norms and attitudes (Pushkarenko et al. 2023), which is listed as another aim of GAPPA.

Integrate community PA participation and healthcare services and increase cross-sector co-ordination: Another key action area is to integrate community PA into healthcare practices and include targeted support for community providers in that integration e.g., school providers' abilities to support PA participation in schools. Schools play an important role in providing regular opportunity and choice for participation, yet do not always have the support they need to provide inclusion. Upskilling healthcare professionals in this area and increasing collaboration, and collaborative interventions between community providers, could increase support for participation. GAPPA (WHO 2018) advocates incorporating community PA into healthcare services to increase support and provision of people, programmes and opportunities. This approach, including other social worlds as well, could increase support for participation. The SA findings showed collaboration across organisations in sport social worlds and its sub-worlds, and collaboration across different social worlds e.g., school and sport, increased people, programmes and participation opportunities. Collaboration as a solution to problems that involve many stakeholders who tend to work individually, is an easy solution to suggest and appropriate based on study findings, but collaboration is not easy to achieve. There are examples from the SA findings that show collaboration resulted in successful inclusion and participation e.g., Zoe the PE specialist worked with the head teacher to ensure resources were available for inclusion and collaborated with the ALNCo to ensure solutions were found to provide PA inclusion within school. Contrastingly, the PE specialist Mario, reported no such collaboration and struggled to include C&YP. Gerry, NDSO executive, provided some examples of collaborative partnerships that ensured disability inclusion in sport but also gave examples where stakeholders did not collaborate with each other, which reduced knowledge sharing and disability inclusion. It may be that there needs to be a step back from the goal of collaboration, due to the individual contexts involved within the situation, and the difficulties involved in achieving collaboration across all the social worlds within the situation.

Rather, a focus could be to make the network of resources and stakeholders within the situation more evident to all stakeholders. This could aid stakeholders' ability to support participation, i.e., by increasing their knowledge of resources and of other stakeholders within the situation who could assist them; thereby indirectly increasing collaboration. For example, providing a map of resources and stakeholders showing how they are connected within the situation and what each provides, possibly a single source of information/map, could increase stakeholders' awareness, their potential to collaborate and ability to navigate the situation. Identifying and providing co-ordinators within this network, which is now made visible, could additionally help e.g., providing a lead person within and across social worlds. This integration of mechanisms, individuals and social worlds/groups would require acknowledgement from people of the need for a shift in knowledge and actions to increase participation. Providing forums for all stakeholders to share and communicate regarding these matters may assist as well.

Information structures/infrastructure: Another key action area within what has already been described includes providing tailored information for families specifically to enable them to navigate community PA participation successfully and find what they need. This would include supporting families in using information systems and in the knowledge needed to be empowered and autonomous in community PA participation. Empowerment and autonomy could additionally be increased by involving families in producing information systems along with other stakeholders.
Advocacy for change, including in structures/infrastructure for accessible environments: A further key action area is to increase advocacy for change, to increase support for participation and effective enforcement of legislation and policy. Included in this advocacy, is the need to increase environmental access to indoor and outdoor spaces for families with disabled C&YP. This is something families specifically requested and which SA findings demonstrate remains necessary to increase community PA participation.

Chapter 8. Discussion

This chapter summarises and discusses the research findings. It considers the outcomes of the study and its contribution to the research evidence. It reviews existing policy and makes recommendations for increasing community PA participation for C&YP with neurodisability. It outlines my plans for progressing the research and makes suggestions for practice and further research.

8.1. A Thesis Summary

This thesis reports on a SA study of community PA participation by C&YP with neurodisability designed to address three research questions:

4. What community PA participation opportunities are available and where do C&YP with neurodisability participate?
5. What are the barriers and facilitators to their participation?
6. What are key action areas to increase participation and support for participation?

A SA framework was deployed to analyse interview data from families (parents and C&YP) and service providers to generate a thick description of the factors that condition community PA in C&YP with neurodisability.

Data was generated in two overlapping interview stages, with family interviews informing participants for provider interviews, and provider interviews informing family interview questions. I used SA data analytic mapping tools (Clarke et al. 2018) to code interview transcripts, categorise data and map the situation using situational, social worlds/arenas and positional cartography. I employed iterative cartography and extensive reflective memo writing to aid analysis and synthesis of findings and increase research trustworthiness (Bryman 2012).

The use of SA data analytic cartography identified where and how C&YP participated in community PA, and the facilitators and barriers to their participation. Family and provider findings were synthesised to gain a deeper understanding of the action and interaction of the facilitators and barriers within the situation, from both families’ and providers’ perspectives. This aided in-depth understanding and provided thick situational analytics. Additionally, this method provided a form of data analytic triangulation (Bryman 2012), which involved the perspectives of families and providers to identify key areas for future actions to increase participation.

The findings showed that C&YP participated in PA in several social worlds (Strauss 1978), most immediately in the family and school social worlds. C&YP participated in informal play within the family social world with their parents, siblings, and with friends. Friends were family friends or friends from school. All C&YP attended school and participated in informal play and informal sport in unstructured sessions in school. They participated in formal sport in structured PE lessons and sport competitions within schools and within school community sport programmes. Not all schools were enrolled in the latter, which meant not all C&YP participated in these programmes. Furthermore, not all C&YP were able to play with school friends after school in their homes or school friends' homes owing to environmental access barriers.

C&YP also participated in PA opportunities outside of school, via attendance at community groups, and/or sports clubs. Attendance was either at mainstream or disability specific groups/clubs. Most community groups that provided unstructured (informal) and structured (formal) PA opportunities were charity and sports groups. Most of the community opportunities and choices for PA participation were aligned with sports, and sports clubs were often registered charities. Thus, most opportunities relied on charity funding and volunteers. Most disability specific opportunities were in large cities. There were a limited number of disability specific and mainstream inclusive opportunities and choices for participation across all geographic locations.

C&YP who attended special schools participated in therapeutic exercise with healthcare professionals and in other forms of PA such as rebound and hydrotherapy, using special schools' resources e.g., staff and accessible facilities. C&YP in mainstream schools reported less contact with healthcare professionals and less use of specialist equipment and facilities in school. These families reported having previously seen healthcare specialists and been given exercises, mostly stretches, which they continued intermittently.

Facilitators and barriers to participation fitted into eight main categories: people, organisations, resources, information, organisational/institutional, discursive, environmental, and temporal (C&YP aging and development over time). Barriers and facilitators connected and interacted in a complex network of relations that enabled or hindered participation. All the organisations and associated social worlds/sectors involved in the situation, including their practices, knowledge and resources, could facilitate participation. However, disjointed and fragmented participation practices, knowledge and resources within and between organisations and social worlds/sectors could hinder participation. This fractured situation could make navigating participation difficult for families and providers. Influential disability discourses (Foucault 1979) could hinder participation, while C&YP's age and stage of development altered participation over time.

Previous research on participation in community PA has analysed barriers and facilitators separately (Rimmer et al. 2004; Verscheuren et al. 2012; Shields and Synnott 2016) but few studies have considered their connection and inter-relations in a socio-ecological manner (Martin Ginis 2016). Nor has previous research considered the presence and influence of discourses within participation situations. Previous research has often considered families (Rimmer et al. 2004; Verscheuren et al. 2012; Shields and Synnott 2016) but rarely providers and their interactions with families. By examining the connections and interactions of barriers and facilitators, and the social worlds involved, their practices and discursive influences, this study has provided a rich descriptive analysis, synthesis, and understanding of the situation from the perspective of both families and providers. By including both families and providers, and using SA's cartographic analytic tools, key areas for future actions to support and increase PA participation, have been identified. These action areas include:

- Increasing families' physical literacy e.g., exploring PA beliefs and goals with families and their difficulties in PA participation to find solutions and increasing physical literacy to sustain participation (especially in early years and during transitioning phases e.g., making and having transitional plans for PA participation)
- Increasing community PA providers in all social worlds/sectors ability to adapt their approaches to enable disability inclusion e.g., by providing them with the resources they need e.g., sports and school providers being given information from healthcare providers on C&YP's strengths and abilities.

- Increasing participation focused healthcare approaches, and knowledge and supports for this approach e.g., by educating healthcare professionals in participation-focused healthcare.
- Targeting healthcare providers' support into community programmes (including in schools) e.g., by educating healthcare professions on this need.
- Tailoring support for families by providing a cohesive, integrated information system to enable them to navigate community PA participation successfully, which would include increasing families' skills and confidence in using the information system/s.
- Advocating for improvements in support structures and infrastructures to address the gap between legislation, policy and practices within social worlds/sectors and organisations within the arena.
- Increasing environmental access (social, attitudinal, physical) to indoor and outdoor spaces and places for families with disabled C&YP e.g., by increasing healthcare providers focus and knowledge regarding ecological influences, doing environmental access audits and advocating for change.

The action areas have a family focus, community social worlds'/sectors focus, healthcare practitioner focus, and an arena structures and infrastructure focus.

In the following sections, I consider the thesis findings in relation to previous research and policy and discuss recommendations for future actions. I discuss my original contribution to the field of knowledge, how the thesis has progressed understanding, how I have contributed to the field thus far, and my planned future actions.

8.2. Community Physical Activity Participation Re-Defined in All its Complexity

Community PA participation for C&YP with neurodisability is complex and the presence of facilitators does not guarantee participation due to facilitators and barriers being multi-factorial and inter-connected. Examining the connection, disconnection, interaction and lack of connection and interaction of facilitators and barriers, and the actions and practices of the organisations involved, enables re-definition of participation in all its complexity. In the following sections, I re-interpret the influences on participation within the situation considering the thesis findings, policy, and research literature.

8.2.1. A Temporal Concept

The thesis findings confirm existing evidence that C&YP have reduced PA participation as they age (Bult et al. 2011; Shields and Synnott 2016; Imms and Adair 2017; Edwards et al. 2018; Ward et al. 2018) thus PA participation is a temporal changing concept. This situation is true for all C&YP (Ward et al. 2018), however, disabled C&YP are likely to find PA more difficult with aging due to increased weight and size that can increase physical impairments and decrease physical mobility (Shortland et al. 2009; Lieber 20010; Bult et al. 2011; van Vulpen et al. 2017; Orsso et al. 2019). Family findings showed how the temporal dimensions of PA interacted with other elements within the situation, which combined to hinder participation. For example, C&YPs' increasing impairment difficulties with age linked to providers' PA sport focus within opportunities as C&YP aged, which excluded C&YP unable to keep up with peers, or where a level playing field in competitive sport excluded some C&YP. With limited opportunities for inclusion and the lack of accessible community environments, C&YP's community PA participation reduced with aging. Shields and Synott (2016) similarly found a decrease in PA as disabled C&YP aged. Their findings indicated that with age there was an increased competitive sport performance focus within PA opportunities and a decreased ability of disabled C&YP to keep up with peers, which could decrease motivation for participation. My research confirms these findings but adds to the available evidence by showing there is a complex interaction of multiple elements affecting PA participation with aging and development. These include the change of PA opportunities from fundamental movement skill performance to sports performance, a socio-cultural competitive sport performance focus within communities, decreased ability of C&YP to keep up with peers, changing PA interests with development, increasing impairment limitations, increasing self-awareness, and the increased need for environmental adaptions. Managing and overcoming these changing challenges over time was difficult for families and providers, which resulted in reduced PA participation for some C&YP, indicating the need for more resources in this area and increased targeted consideration and intervention to help sustain PA participation over childhood development.

The study showed that those families with strong beliefs in the benefits of PA, who had PA interests, problem solving skills and persistence in the face of difficulties, were better able to sustain PA participation with aging, and when facing challenges. Cairney et al. (2019) list some of these intrinsic personal characteristics that sustain participation as being inherent in the concept of physical literacy. Shikako et al. (2013) also showed that persisting to master activities positively influenced participation in C&YP with neurodisability. The findings of my study, in conjunction with the wider evidence, indicate that increasing families' mastery of PA participation and their physical literacy are connected concepts that could sustain PA participation with aging. This indicates the need for interventions to support physical literacy from an early age, and target and support physical literacy during transitioning developmental stages, to help families engage in community PA participation and sustain PA as C&YP age and develop.

Physical literacy is not discussed or used much within healthcare research (Paponetti et al. 2023) but it is central to education and sport research (Paponetti et al. 2023; Cairney et al. 2019; Brown et al. 2020). Exploring the perspectives of providers from different social worlds (healthcare, sport and education) within this study has enabled the synthesis of sport provider perspectives with that of education and healthcare providers, and families' perspectives. The synthesis of different family and provider perspectives is a novel contribution of this study, as combining family and different provider perspectives is not typical in the research literature. This has aided identification of physical literacy as a common factor across the research approaches used by education, sport, and healthcare researchers, despite the fact that this approach is not integrated into healthcare research (Palisano et al. 2012; Cairney et al. 2019; Reedman et al. 2019; Paponettii et al. 2023). Comparing these approaches and the need to increase and sustain PA via persistence, problem solving and beliefs in the benefits of PA, has indicated physical literacy as a vital component to sustain participation.

With so many different and disparate social worlds active within the situation, a synthesis of the different stakeholder perspectives, their knowledge and experiences, could increase knowledge and resource sharing, and collaborative support for participation; and find common ways forward. Thesis findings showed that collaboration between stakeholders and social worlds provided enabling situations for community PA participation and more opportunities and choices for participation. Taking a multi-sector (social world) collaborative approach is additionally something that WHO (2018) GAPPA recommends for increasing community PA participation within population groups.

Palisano et al. (2012) and Reedman et al (2019) describe a process for aiding community participation that involves numerous steps for C&YP and families to gain autonomy and empowerment in PA participation. These are similar to the processes and steps reported by Cairney et al. (2019), Brown et al. (2020); and Paponetti et al. (2023), which aim for C&YP to gain autonomy and empowerment in PA i.e., physical literacy. Paponetti et al. (2023) provides the most detail on their processes/steps and the questions to ask C&YP and families when setting collaborative goals for PA participation. Synthesising the research evidence shows the steps involve: asking C&YP about their preferences for participation, exploring their participation experiences, beliefs, and aspirations, and thereby setting collaborative goals for PA participation. Furthermore, assisting practice of PA in real life community settings and application of suitable environmental modifications to reduce environmental barriers, including social and physical environmental barriers (WHO 2001; Anaby et al. 2018; Reedman et al. 2019). Steps that the healthcare researchers' employ (Palisano et al. 2012; Reedman et al. 2019) also involve providing appropriate contextual interventions, when necessary, to support participation e.g., strength training and skills/task practice within real life settings. Final steps used by all healthcare, sport and education researchers include providing connections to community resources for ongoing participation support (Cairney et al. 2019; Reedman et al. 2019; Brown et al. 2020; Paponetti et al. 2023). Reedman et al. (2019) implemented all these steps in their community PA participation intervention, which they report is the first of its kind in healthcare research. Thesis findings support the need for such individual, contextual, and collaborative approaches to increase community PA participation in C&YP with neurodisability.

The steps described in the research evidence can be incorporated into a participation-focused therapeutic healthcare approach, as demonstrated by Reedman et al. (2019), and advocated by Palisano et al. (2012). Such practices would integrate PA participation-focused approaches into healthcare practices, which is a GAPPA (WHO 2018) recommendation to increase community PA participation. Using and applying theoretical models within these approaches, may further increase their effectiveness (Reedman et al. 2017; Reedman et al. 2019). Anaby et al. (2015), Kolehmainen et al. (2020) and Reedman et al. (2017), however, describe sparse healthcare evidence and practices applying theoretical models to increase community participation in C&YP with neurodisability, or practices using participation outcome measures within collaborative goal setting (Adair et al. 2015; Adair et al. 2018). The use of suitable participation outcome measures within exploratory conversations on PA participation with C&YP and families, and during the initial steps to collaborative goal setting, may further assist the process of collaborative goal setting and family empowerment in community PA participation. Such a practice could aid participation-focused healthcare that includes targeting participation outcomes and monitoring and evaluating these outcomes (Kolehmainen et al. 2020). My findings suggest such approaches are necessary as they take a socio-ecological approach to community PA participation that includes consideration of the multi-factorial influences on participation (Martin Ginis et al. 2016) and concurs with the thesis recommendations on key action areas for increasing community PA participation.

Increased physical literacy is associated with increased PA across childhood transitioning phases (Brown et al. 2020), which this study and previous evidence confirms is necessary, especially with the decline in PA that is evident with aging (Shields and Synnott 2016). The research showed involvement and attendance at opportunities became more difficult for some families over time, which resulted in a lack of attendance. Attendance was also influenced by location of opportunities and family resources e.g., lack of time and sibling childcare to be able to travel to far located opportunities. Attendance and involvement are two concepts within the participation construct (Imms et al 2016; Imms et al. 2017) therefore important to consider. This study shows PA attendance and involvement are susceptible to reduction with aging and in the presence of environmental barriers and insufficient family resources, confirming evidence by Shields and Synnott (2016) who found similar results when using healthcare practitioner and family focus groups to explore facilitators and barriers to community PA participation.

8.2.2. An Environmental Concept

Anaby et al. (2015) and Shields and Synnott (2016) show common environmental barriers to participation for disabled C&YP are the physical environment, particularly for C&YP with physical disabilities; evidence which is confirmed by my findings. Physical environmental barriers included lack of accessible buildings/facilities, outdoor environments, public transport, and toilet and changing facilities. Evidence shows physical environmental barriers negatively correlate with participation in after-school activities for disabled C&YP (Anaby et al. 2015; Shields and Synnott 2016), which was similarly demonstrated by my findings, although this study did not test a correlation.

My research demonstrated that geographic location barriers interact with family factors, such as limited resources of time and sibling childcare, to reduce attendance at PA opportunities, especially when these opportunities are not local, and opportunities are limited in number and location. The findings showed that families struggled to attend PA opportunities when these were not local due to the stress and difficulty of juggling time, transport and other family commitments, including sibling childcare. This was more difficult for families with fewer resources, such as single parent households, which confirms previous research evidence of this effect (King et al. 2003; Shimmell et al. 2013; Shields and Synnott 2016). The families in my study living in rural areas particularly struggled with attendance, a finding that is supported by other studies (Tidswell 2006a; Tidswell 2006b; Shimmell et al 2013; Shields and Synnott 2016). The published evidence confirms the environmental barriers identified in the thesis extend beyond the thesis sample and its contextual location.

The families in this study struggled to find opportunities for outdoor walking and cycling due to lack of local accessible environments. GAPPA (WHO 2018) policy recommendations include policy actions to provide safe environments for walking and cycling within neighbourhoods but do not overtly include disability access within these policy actions. The UK has met one of GAPPA environment policy actions by implementing strategies for safe crossings for pedestrians and cyclists (Guthold et al. 2020) however, there is no mention of disability accessibility within these policy actions, either by WHO (2018) or in their implementation by the UK (Guthold et al. 2020). Previous research has shown the need for accessible environments and equipment within communities for disabled C&YP and their families to be able to participate in community cycling (Pickering et al. 2013; Pickering et al. 2015), and that having this opportunity provides enjoyable community opportunities for participation that can increase body structure' functions e.g., muscle strength (Visser et al. 2012; Visser et al. 2014). Evidence suggests that increasing muscle strength in C&YP with neurodisability could reduce the impact of disability impairments (Shortland et al. 2009; Scholtes et al. 2010; van Vulpen et al. 2017).

Providing fun opportunities to participate within communities is important for health and wellbeing, and childhood development (Rosenbaum and Gorter 2012). Play Wales (2022) showed there is a lack of accessible community areas for PA in the form of accessible play. Play is an important and fun PA for young C&YP. My study confirms evidence of this lack of opportunity within communities due to lack of accessible spaces and places. Providing spaces for fun PA meets policy recommendations on play sufficiency (GOV.UK 2012) and working to promote childhood futures (Well-being of Future Generations (Wales) Act 2015), and ties to recommendations on providing fun opportunities for participation within childhood disability healthcare clinical practice and research (Rosenbaum and Gorter 2012; Palisano et al. 2012). However, despite evidence and policy recommendations (GOV.UK 2012, Play Wales 2022) my findings show C&YP with neurodisability remain disadvantaged in access to community play areas and areas for walking and cycling.

My research highlighted the limited number of community opportunities and choices for PA participation and the number of inaccessible environments, increased barriers families already faced to attending PA opportunities, and to accessing community environments. Existing research lists these barriers to participation (Verscheuren et al. 2012; Shields and Synnott 2014; Jaarsma et al. 2015; Shields and Synnott 2016) but does not show their connection and interaction and how this exacerbates an already disadvantaged position for families. Researchers have shown SA as a novel research methodology and methods package that is useful for considering public health for disadvantaged population groups (Anderson and Whitefield 2011; Uri 2015; Martin et al. 2016; Spyropoulos et al. 2022). The thesis findings show that the interaction of numerous barriers and disparate focus of social worlds, along with historical segregation and slow change to disability inclusion, places families in a position of disadvantage.

Families may not feel heard and understood (Campbell 2008; 2009) if they are perceived as concerned over a barrier to participation and providers, policy makers and funders are not aware of how this single barrier interacts with others to create an increased disadvantaged position for disabled C&YP, and their families. This lack of disability awareness and understanding illustrates insufficient disability inclusion and advocacy situational knowledge, and the possible silent unacknowledged presence of ableism and lack of attunement (Campbell 2008; 2009). The study findings confirm this aspect of the situation, evidenced in families' narratives describing C&YP unable to fit into participation opportunities, and providers unable to adapt opportunities to fit to C&YP. The lack of mutual understanding between families and providers in their interactions, the strength of disability discourses, and the absence of monitoring and enforcement of policy and legislation and absence of disability advocacy, coalesced to hinder participation. It is therefore not surprising that families with less resources e.g., single parent families (Arakelyan et al. 2019) are unable to overcome barriers to participation and sustain participation as C&YP age, which becomes more difficult due to multi-factorial interacting influences (Shields and Synnott 2016; Martin Ginis et al. 2016).

My study demonstrated the connections and interactions between barriers and facilitators within the situation, and the presence of ableism, and lack of attunement, inaccessible environments and lack of reasonable adjustments, reduced opportunities and choices for participation. The interacting influences were both overt and covert, and all made more evident when exacerbated by Covid-19 restrictions, which made them subsequently, more visible within the situation. This is confirmed by additional published evidence since the global pandemic that shows families at a disadvantage and the need for increased support for community PA participation since 2020 (Cadwgan et al. 2022; WHO 2022).

Environmental barriers to participation include the social barriers described i.e. attitudes and perceptions, and physical barriers within environments. The ICF (WHO 2001) includes attitudes e.g., perceptions of disability within communities as a component of the ICF environmental domain, alongside physical barriers. Similarly, King et al.'s (2003) conceptual model of participation for disabled C&YP, and Shikako-Thomas et al.'s (2013) model of determinants for participation by C&YP with neurodisability shows environmental barriers as attitudinal and physical. My findings confirm this evidence and additionally highlights how disability discourses are environmental influences on behaviour and action, which are visible in language, behaviour, and actions within the situation. Disability discourses placed some providers as viewing disability inclusion as something to fear, a high risk, and placed C&YP as having inability to participate. Evidence shows that low expectations of C&YP's abilities to participate hinders their participation (Verscheuren et al. 2012). Providers could also lack understanding of inclusion and the need to provide reasonable adjustments for inclusion. This was evident in provider language and behaviours that some parents perceived as unwelcoming and exclusionary, and in provider narratives regarding exclusion of C&YP in the absence of supports for disability inclusion, and knowledge on how to manage safety and risks. These findings confirm previous evidence showing that providers can have exclusionary attitudes and behaviours that create barriers to participation and that providers can lack supports necessary to provide inclusion (Shield and Synott 2016; Martin Ginis 2016). The published evidence illustrates that the problem is more widespread than the geographic context of this thesis.

Foucault (1979) asserts that dominant discourses constrain the emergence of new knowledge and actions that keep situations in the status-quo. Disability discourses and labelling were evidenced in participants' narratives as part of the social system and organisational structures and practices that influenced individual people and organisations' working practices, and which hindered the emergence of new, inclusionary knowledge, behaviour and action. This was evident in the families' stories, and in the slow change from a historical position of disability exclusion and segregation in sport to a position of disability inclusion in sport. Additionally, the dominance of the status-quo was evidenced in providers' stories of their difficulty in providing inclusion despite policy and legislation requiring inclusion (Disability Discrimination Act 1995; Equality Act 2010; WHO 2018; GOV.UK 2022) and demonstrated in the difficulties they found in providing disability inclusion within mainstream school settings that are primarily set up for the majority typically developing C&YP (Hodge and Runswick-Cole 2013; Reid 2016). Furthermore, the dominance of the status quo and lack of emergence of new knowledge and its translation into practice was seen in the ambivalent and uncertain position found within the thesis regarding the role of physiotherapy in participation. This position confirmed published evidence on the limited use of participation interventions and outcomes in therapeutic clinical practice (Anaby et al. 2015; Adair et al. 2018; Kolehmainen et al. 2020).

8.2.3. A Healthcare Concept

My findings showed the need to integrate PA participation into healthcare to inform community service providers regarding healthcare and disability inclusion related matters. This could be a way for physiotherapists to play a role in supporting and increasing providers' physical literacy for disability i.e., their disability awareness, knowledge, and adaptability for facilitating disability inclusion. Reedman et al. (2019), in their community PA participation context-specific intervention, included healthcare environmental support for providers and collaboration with providers to facilitate the intervention. Community collaboration could additionally lead to healthcare practitioners accessing community environments for intervention programmes as in Reedman et al. (2019) and Shields et al. (2019) research studies. Shields et al. (2019) used collaboration with providers in community leisure centres to facilitate a mentorship programme for PA participation by C&YP with neurodisability. C&YP with neurodisability were paired with a physiotherapy student mentor to assist them in PA within community leisure centres. Practicing PA with C&YP in real life contexts, as advocated by Palisano et al. (2012), provides opportunity for collaboration with providers and integrates community PA with healthcare practices into communities, thereby facilitating participation-focused healthcare (Anaby et al. 2015; Kolehmainen et al. 2020). The WHO (2018) GAPPA asserts the need to integrate community PA and healthcare services to increase community PA participation. However, Shields et al. (2019) reported difficulties accessing some community leisure centres to deliver mentorship programmes (without providing contextual details on these difficulties) and Anaby et al. (2015) and Kolehmainen et al. (2020) identified barriers to participation-focused approaches in practice due to no behavioural supports for this approach and organisational/institutional barriers to integrating healthcare practices into community settings.

GAPPA (WHO 2018) policy actions propose the need for increased multi-sector (social world) collaboration to increase community PA participation. Increased collaboration within real-life community settings could be a way of achieving mutual understanding of participation by all (i.e., between families and providers, and between all providers). Additionally, could facilitate reduction in barriers to participation-focused healthcare (Anaby et al. 2015; Kolehmainen et al. 2020), and provide a means of enabling providers to adapt their physical literacy approaches to disability (Pushkarenko et al. 2021; Pushkarenko et al. 2023). Reedman et al. (2019) used a community contextual intervention with collaboration to support modifying environmental barriers (attitudinal and physical), when conducting their individualised, context-specific PA participation intervention. The intervention resulted in increased PA goal performance and satisfaction in C&YP with CP. Shikako et al. (2013) have shown that increased mastery in physical goal performance positively influences physical participation and Cairney et al. (2019) and Paponetti et al. (2023) detailed self-perceptions of performance as part of the physical literacy construct. Imms et al. (2017) have additionally shown perceptions of self are part of, and influential within the fPRC (family of participation related constructs).

8.2.4. A Communal Concept

My study showed that community providers were cautious in the absence of disability knowledge, demonstrated fear of risk in their language and behaviour, and could exclude C&YP as a result. Furthermore, families reported a lack of healthcare support for community PA participation and providers reported a lack of support from healthcare professionals to assist them in managing risks. Murphy and Carbone (2008) suggest it is necessary for healthcare practitioners to provide informed support to manage risks and informed signposting into community PA opportunities to ensure opportunities are appropriate for C&YP and the WHO (2020) suggests, disabled C&YP/families may need to consult healthcare professionals on what is suitable for community PA participation. Yet, evidence shows that healthcare practitioners lack information to signpost community PA participation opportunities (Martin-Ginis et al. 2016; Shields and Synnott 2016), which was confirmed by my findings. Increasing collaborative links between community PA providers, families and healthcare providers could assist informed signposting and support into community PA participation e.g., through social prescribing. Chin and Reid (2015) showed social prescribing in a collaboration between health and sport sectors/social worlds could lead to increased community PA participation in disabled individuals (adults and C&YP). My research suggests the need for informed social prescribing and increased collaboration between providers and families to facilitate this process. Where there was collaboration between providers from different social worlds/sectors to support families and C&YP into participation, my findings showed there was more inclusion and more opportunity and choice for participation. Furthermore, C&YP had support for participation that aided their attendance at community PA opportunities.

Supporting C&YP into community PA participation includes risk assessment and risk management. My research revealed that this issue is contentious between families and providers. Shields et al. (2019) and Shields et al. (2024) in their FitSkills approach to increasing community PA participation through provision of community mentors, showed that mentors and leisure centres needed assistance with safety considerations, especially for complex C&YP. Instead of being critical of providers' cautionary approach, it is preferable to assist providers with information, risk assessments, adaptations, and environmental modifications to ameliorate risks, as a positive way forward. Shields et al. (2024) showed, however, that there can be resistance within communities to entry into new locations for mentoring PA participation, which could hinder the feasibility of this approach. This study confirms previous evidence that physiotherapists can lack training and confidence in disability inclusion application within communities, which could hinder their support for providers in managing risks, especially for complex C&YP (Reid 2016; Shields et al. 2021; Shields et al. 2024). Additionally, the lack of participation-focus within therapeutic practices may hinder gaining knowledge on how to support providers in risk management and disability inclusion within communities (Anaby et al. 2015; Kolehmainen et al. 2020). This area of safety and risk needs more training for all involved and collaborative discussion and management, as it negatively, and often silently, acts as a strong influential barrier to participation.

8.2.5. An Infrastructure Concept

The thesis findings show community PA participation for C&YP with neurodisability is reliant on resources such as people (and their personal characteristics), knowledge and information, organisations, disability inclusive practices, adaptability, time, transport, funding, equipment and accessible environments (indoor and outdoor). Cohesive structures and infrastructures providing these resources and connecting these resources is essential to facilitate participation but is lacking. Funding needs to connect intelligently (informed) to opportunities to provide opportunities that families can attend, including those that restricted funding and disability labelling disallows, whilst still providing families with choices in participation e.g., mainstream inclusive, disability specific or separate participation. Funding also needs to provide for ongoing long-term maintenance of participation programmes. The number of accessible environments must increase to provide more opportunity for indoor and outdoor PA participation. The disparate nature of the situation lacks cohesive and supportive infrastructure. GAPPA (WHO 2018) policy action area four calls for systems' actions that develop, integrate and strengthen the support structures and infrastructures for PA participation e.g., policy governance, advocacy, finance mechanisms, data integration systems, and research and development.

Improved funding, transport, and access infrastructures are essential to facilitate participation. Martin Ginis et al. (2016) conducted a systematic review of reviews on PA participation for disabled C&YP and identified the need for improved funding structures for PA programmes so that community providers could reduce costs for families. Reduced costs to families for programme attendance is something my research has shown as important in supporting families' attendance at community PA programmes. Furthermore, Martin Ginis et al. (2016) identified improvements required in funding for providers' training in disability inclusion. This study also identified this need and identified specific organisations supporting disability inclusion training, particularly in sport; however, not all sport organisations, and not all organisations in all social worlds/sectors accessed disability inclusion training. Furthermore, training programmes were reliant on charity and commercial funding, which took organisations a lot of time and effort to source, secure, and manage. Additionally, although the NDSO' InSport programme for disability inclusion in different sports provided disability inclusion accreditation for different sport organisations, within different sports, organisations could opt out of the training and accreditation, and compliance with disability inclusion legislation and policy, was not enforced.

Supportive infrastructure for disability inclusive public transport and environmental access is also lacking in the situation. All families in the study sample relied on their own transport to access PA opportunities and to travel to accessible community environments for PA. None of the families in my study did not have their own transport, however, evidence does show that families involving disabled C&YP are more likely to be financially disadvantaged (Arakelyan et al. 2019; Cadwagan 2022). It is possible therefore that there are families who do not have their own transport, or access to suitable public transport to access community PA, placing them in a more disadvantaged position. Colver et al. (2011) when comparing environmental access to PA and QoL across 9 Europe regions found Denmark to have greatest access and best QoL. One of the key differences in Denmark is the presence of a disability accessible transport infrastructure that transports C&YP to after school activities. Many families in this study described some difficulties accessing after school activities and community spaces and places, confirming existing research evidence (Shields and Synnott 2016) and the need to advocate for change (Martin Ginis et al. 2016), especially to support families having socio-economic disadvantage. The WHO (2022) global status report on PA participation shows population groups most socio-economically disadvantaged are making the slowest progress to achieving HEPA targets.

Expanding advocacy across the socio-ecological system could support C&YP and families' ability to express their voices/preferences and choices, enable their autonomy (Palisano et al. 2012; Pickering 2013; Cairney et al. 2019; Paponetti et al. 2023), and increase providers disability advocacy and inclusion practices; these processes can reduce ableism within communities (Campbell 2008; 2009; Hodge and Runswick-Cole 2013). In this study, however, families faced many barriers and stressors that reduced their ability to self-advocate. In this context, support from professionals can be helpful (Campbell 2008; 2009; Hodge and Runswick-Cole 2013). Therefore, increasing disability awareness, awareness of ableism and lack of attunement in the situation, is important to aid professionals and families be disability advocates (Campbell 2008; 2009; Hodge and Runswick-Cole 2013). Collaboration and integration of PA participation and healthcare could be a way to increase disability awareness, knowledge sharing to promote community inclusion practices, increase disability advocacy, and enable information sharing regarding opportunities for participation.

Policy (Social Services and Well-being (Wales) Act 2014) makes it a legal requirement for government local authorities to provide information on community opportunities to disabled C&YP and their families. GAPPA (WHO 2018) additionally advocates this approach to supporting increased participation. My findings showed that families struggled to find information, however, and there was a lack of cohesion in information provision and signposting from relevant professionals and community providers, to aid families navigate participation. Where signposting was informed e.g., NDSO participation event, the process aided integration of C&YP into community programmes that sustained their community PA participation. Evidence suggests the need for cohesive, integrated information availability to enable families navigate community PA participation successfully and aid professionals/providers in appropriate signposting (Murphy and Carbone 2008; Martin Ginis et al. 2016).

8.3. The Way Forward

Consideration of my research findings in the context of existing research evidence and policy recommendations confirms the need to take a socio-ecological approach to increasing participation, which includes a family, healthcare practitioner, collaborative community, and support systems focus. In the next section, I provide recommendations for practice and research arising from the study.

8.3.1. Reflections on My Unique Contribution

I conducted a SA on community PA participation by C&YP with neurodisability which has provided an ecological systems perspective not previously provided for this population group. The use of SA gave me an opportunity to analyse the situation using three different forms of cartography. The use of positional analytic cartography enabled me to examine contentious issues in the situation such as risk aversion and disability exclusion and show how discursive constructions and positions on these matters could hinder participation. Positional analytic mapping alongside situational and social worlds/arenas mapping also showed that discursive constructions and positions hindering participation were not always overtly acknowledged in the situation, thus could be silently influencing participation. Use of SA additionally showed me that community PA contained a network of relationships between different elements e.g., human, non-human, historical and discursive, and that these network relationships, within and between different social worlds, could create situations that hindered participation. For example, disability discourses that positioned C&YP at high risk of injury when connected to discursive positions of C&YP having limited ability to participate, and connected within and across social worlds with limited resources (e.g., information, time, people and equipment [human and non-human elements]) resulted in situations where providers were unsure of what to do, how to include C&YP, and where families had negative participation experiences, and/or C&YP were excluded - despite legislation and policy supporting inclusion. The unique contribution of using SA makes these links/connections and their consequences visible within the situation which aids identifying areas for action.

Based on my SA findings, I recommend that a shift is needed in providers' thinking and practice, and that co-ordination is needed for the facilitating components of the situation, to make them connected and visible. If the facilitating component parts are co-ordinated, connected and made visible, this could aid families and providers navigate community PA participation successfully. Connecting and co-ordinating facilitating components of the situation can be done in a variety of ways. Changing providers thinking and practice will require educating and upskilling service providers, making relevant information and resources visible and accessible to them, and providing them with safe spaces to discuss and manage concerns and problem-solve to find solutions. Working with families in safe environments to do this will further help.

My literature review and SA confirms that a shift is needed in physiotherapy providers' thinking and practice to move physiotherapists from a traditional medical disability model lens to a social and affirmative disability model lens, and to move them from a one-to-one focus on C&YP alone, to a wider focus that includes other people e.g., community service providers. Based on my literature review and SA findings this shift in focus and practice also needs to include consideration of ecology, e.g., how to manage environmental factors (social and physical) to enable C&YP's community PA participation. As a Senior Lecturer in higher education, I am uniquely situated to contribute to this shift in focus and development of physiotherapy education (thinking and practice).

My SA has provided an in-depth understanding of the situation of community PA participation from a systems perspective, which shows individual family and provider situations are not either/or in relation to facilitators and barriers but there is a mix of overlapping and connected facilitators/barriers within individual and collective situations that can work together to facilitate or hinder participation. Therefore, participation needs to be considered in an individualised, as well as collective way.

Providing individualised as well as collective focus requires making the situation of community PA participation more visible to individuals and collective individuals, and co-ordinating the different individual and collective elements involved. A more co-ordinated visible situation could assist families and providers navigate participation successfully. I have therefore divided my practice recommendations into three action areas which should each influence the other positively.

1. **Develop** Physiotherapy **Education**
2. **Co-ordinate** Situation Elements
3. **Aid Navigation**

8.3.2. Recommendations for Practice

In the following subsection I discuss my recommendations for practice within each of the three recommendation action areas – Education, Co-ordination, Navigation.

Develop Physiotherapy Education

The aim of developing physiotherapy education is to shift physiotherapists' thinking and practice to include a participation focus that can support families and C&YP's community PA participation. A shift in focus, thinking and practice will require raising physiotherapists awareness of the need to shift their focus, thinking and practice, and require development of the physiotherapy education curriculum. Curriculum development should be led by research evidence. Published evidence and my SA shows that the situation of community PA participation is multi-faceted. An understanding of participation and the different elements involved is therefore necessary e.g., human elements (individual and collective), environmental elements (physical and social), and disability discourses - including social and affirmative disability model discourses. Thesis participant stories could be used as learning and teaching resources to explore these topics. Linking classroom/academic learning with practice-based learning (clinical placements) would further support education in this area. As would providing students with opportunities to reflect and share their experiences e.g., reflecting on action and for action.

I have already started a process of curriculum development by scheduling new learning and teaching sessions in the previous and current academic year cycles e.g. a participation-focused healthcare keynote lecture in the undergraduate physiotherapy and child nursing programmes and in a postgraduate (MSc) neurorehabilitation module. I have additionally scheduled tutorials to discuss approaches to increasing participation and evaluating participation in C&YP. I will use family and provider stories as learning and teaching materials for these sessions. Within existing learning and teaching sessions that focus on goal setting, I aim to supplement these sessions with stories from thesis participants to increase awareness of the need for collaborative participation goal setting with families and the need to work collaboratively with service providers to achieve community PA participation goals. Literature evidence reviewed shows there is a need to increase clinical practitioners use of participation outcome measures. I therefore intend to include consideration of outcome measures related to community PA participation by C&YP within participation focused learning and teaching sessions. Furthermore, I have already included community providers within taught sessions in the academic years 2023/2024 and 2024/2025 e.g., representatives from NDSO and their health partnership programme have delivered a session on social prescribing. I am also looking for opportunities to supervise research at undergraduate, postgraduate and PhD level within this topic area to develop support for C&YP, families and service providers more specifically. I aim to monitor and evaluate my healthcare participation-focused research, curriculum development and its delivery, and disseminate my research and education evaluations in national and international healthcare education and research forums.

Co-ordination

The situation of community PA for C&YP with neurodisability is multi-faceted, and very disparate and disjointed making it difficult for providers and families to find preferred opportunities, resources and support. The segregated nature of separate groups according to disability labelling and categories also forms part of the multi-faceted situation. This segregation can be advantageous in providing safe opportunities and advantageous in providing a level playing field in sport but can exclude C&YP that do not fit into the specific label or category that defines the participation opportunity. The process of including C&YP that fit a specific label also limits providers from finding ways to include more C&YP with different functional abilities in more PA and sport opportunities/choices, within more community settings. There is therefore a need to co-ordinate people, resources and information to show what is available, what is missing, and where and how to find resources that can support inclusion and participation. There are numerous ways in which such co-ordination could be provided:

- By creating a centralised resource hub to co-ordinate information and resources. This could be done using information technology and involving all stakeholders.
- By providing forums for all stakeholders (families and providers) to get together to align goals, share resources, and find solutions to problems (e.g., risk assessments and risk management, equipment adaptations).
- By providing/appointing a community lead/co-ordinator who could co-ordinate information and resources and communicate regarding these to families and providers.

I aim to contribute to co-ordination in my volunteer work as a Trustee for a frame running charity group through my network with other frame running groups in England, to the NDSO and to other third sector organisations. Currently, there are disability sport development officers employed in community councils (usually part-time) who use some of their time to coordinate disability sport inclusion/participation. They have set up links with community organisations such as the frame running group, I am a Trustee for. They additionally have links to NHS physiotherapy services following recent government funding facilitating this disability sport health partnership. Growing this network and identifying community leads to help co-ordinate people and resources the various social worlds/sectors involved, could lead to co-ordination of community PA participation and its many elements e.g., people, information and resources.

Navigation

There is a need to support families and providers in navigating community PA opportunities, choices, and resources to support them in participation. There are numerous ways families and providers could be assisted. One way is by making information on opportunities, stakeholders, and the support available for community PA participation visible to families and providers and easily accessible. This could be done in numerous ways. For example, by providing community leads/co-ordinators who do this work, and/or by providing a cohesive system of information, possibly a comprehensive single source. This could be available online or in other formats that are accessible to families and providers.

Another method to aid navigation is via healthcare practitioners' conversations with families in clinical practice, where healthcare professionals share relevant information and discuss PA participation preferences, goals, outcomes and support, signpost families to suitable opportunities and choices, and assist them in persisting to achieve participation. This approach could be part of the participation-focused healthcare education development within physiotherapy education.

8.3.3. Recommendations for Research

The literature reviewed and my SA show that defining and measuring PA participation in C&YP with neurodisability is challenging; challenging when using interview data descriptions and not having, or using, feasible, accurate, valid and reliable outcome measures that are specific to the construct of community PA participation. Measures of PA participation that are available are not always accurate, often rely on proxy reports, and some are invasive/not child friendly, which can lead to altering participation. Participation definitions suggest that measuring attendance and involvement is required, but PA involvement also requires measuring energy expenditure. Measuring attendance and diversity of attendance can be done simply by counting the number of times C&YP attend activities and counting the diverse activities they attend. This measurement does not however give a measure of energy expenditure (i.e., PA involvement), or provide a measure of the length of time C&YP spent at different levels of energy expenditure, and at what stages of the participation event. My SA shows that numerous elements e.g., human, non-human, discursive, social, physical, psychological and environmental can influence PA participation and the level of involvement/engagement/energy expenditure. Based on these challenges, plus the literature reviewed and my SA, I suggest observing participation using ethnographic research designs could lead to feasible, valid and reliable measurements of community PA participation e.g., in the form of an observational scale. Such a scale could be especially useful for C&YP with more complex needs e.g., C&YP with CP classified at GMFCS levels IV and V. Without good descriptions of what health-enhancing community PA participation looks like for C&YP with neurodisability, it will be difficult to measure it, and work to achieve it.

Research also needs to focus on healthcare professionals because my SA has shown that a shift in their thinking and practice is needed. Within healthcare education there is a need to examine how to upskill professionals in their support of families and providers e.g., in use of collaborative goal setting, and facilitation of families and providers physical literacy specific to disability inclusion - especially over childhood transitioning phases. Thus, research should also investigate transitional plans for C&YP to sustain their community PA participation as they age and develop. To assist healthcare providers further, I suggest research explore the feasibility of creating a shared decision-making tool to use with families and providers to increase C&YP's community PA participation, and research be conducted to examine the tool's effectiveness.

My literature review and SA has shown that the environment (physical and social) has a large influence on community PA participation. There is some evidence, though sparse, that individualised ecological approaches can increase community PA participation. This area needs to be further researched and ecological approaches to increasing community PA participation investigated, to explore what ways are effective at improving participation when using an ecological treatment approach or management strategy. Ecology includes social and physical environment elements, which my SA confirms inter-relate and can connect in ways that hinder participation. Physical environmental access forms part of these connections which families reported needed change e.g., they requested more accessible changing spaces and indoor and outdoor spaces and places for participation. There is a need therefore to find more effective ways of monitoring and evaluating physical access and implementing changes to provide access across all social worlds. Specific targeted areas related to community PA participation include accessible changing spaces and access to community walking and cycling. Investigating best ways forward in providing community access information to the public (families and providers) is also recommended.

8.3.4. Strengths and Limitations

The thesis is the first study to undertake a SA of community PA participation by C&YP with neurodisability therefore provides a unique contribution to evidence on the multi-faceted nature of the problem of limited community PA participation by C&YP with neurodisability. Previous evidence has explored barriers and facilitators to participation, but it is only recently that there have been calls for the need to examine and address community participation in this population group using a socio-ecological approach (Martin Ginis et al. 2016). Whilst previous research has reviewed and examined barriers and facilitators to participation (King et al. 2003; Colver et al. 2011; Verscheuren et al 2012; Shikako et al. 2013; Shields and Synnott 2016), they have not examined the barriers and facilitators in a socio-ecological manner. Using SA has provided an in-depth understanding of the situation and the connection and inter-relations of multiple factors that create a disadvantaged position for C&YP and their families. Providing such evidence can help all stakeholders in the situation identify, address and co-ordinate the many factors involved in the situation to improve participation for C&YP, which suggests the need to leverage these multiple factors to improve C&YP's participation and not focus on only one factor. A novel contribution of the use of SA is the identification and exploration of the influences of disability discourses, highlighting the ongoing presence of ableism and lack of attunement to C&YP and families. These findings provide evidence of the need for change, and the thesis has provided key action areas and dissemination plans, to do so. The thesis has confirmed existing evidence but increased evidence by synthesising family and provider data analysis with the use of SA. The confirmation of existing national and international evidence on barriers and facilitators, and synthesis of thesis findings with national and international healthcare evidence, and evidence from other sectors e.g., education and sport, demonstrates that the thesis findings are transferable to wider contextual settings than the population and geographic area involved in the thesis. SA of families and providers' interview data provided data analytic triangulation, which increased the trustworthiness of the findings (Bryman 2012). Additionally, including the perspectives of the people involved in the situation, provided a form of participatory research (Bryman 2012), which increased the pragmatic relevance of the research findings (Bignall et al. 2014).

All research has limitations. In this study, the sample was biased towards C&YP with CP and physically able and physically active C&YP with CP. This may be due to the recruitment process that advertised a study exploring PA participation and those C&YP and families already physically active consequently responding. Research that includes more complex and severely disabled C&YP e.g., GMFCS-E&R levels IV and V (Palisano et al. 2008) is needed to explore ways for these C&YP to achieve HEPA participation. Covid-19 social restrictions, which happened during data collection, slowed recruitment and was an additional factor limiting recruitment of complex C&YP e.g., those with limited communication abilities. Inclusion of more C&YP and families having complex needs, and families who do not participate in PA, and/or have no interest in community PA participation, is required to involve a wider community of C&YP with neurodisability and find ways to involve them in HEPA.

The research sample is small which has potential to limit the transferability of findings to a wider more diverse number of people and community settings and suggests data saturation to ensure a comprehensive exploration of the whole situation may not have been reached. The family sample of C&YP has a male gender bias, which could be confirming published evidence that more males participate in community PA than females (Bult et al. 2011; Ward et al. 2021) or could be due to chance. Inclusion of more females within study samples is necessary for the research to be more representative of all C&YP with neurodisability, and to address the support needs of female C&YP with neurodisability. The lack of sample females, physically inactive C&YP and families, ethnic minority groups, and those families having greater socio-economic deprivation (e.g., all families in the sample owned a car) means the intersectionality of these variables with community PA participation could not be examined and is not represented in the situation. Consideration of the intersection of these variables with community PA participation, needs examination; to find effective ways to include these community population groups within community PA and support their participation.

The study sample additionally has missing providers from the analysis e.g., ALNCo’s in schools, personal assistants, commercial insurance providers, government local authority personnel. Therefore, not all providers’ perspectives are included. I attempted to recruit these providers without success meaning they do not have representation in the situation, other than via the narratives of families and other providers. Covid-19 social restrictions also slowed recruitment of providers and made communication with them more difficult, which was an additional factor limiting recruitment of community providers. Future research should include provider participants from a wider range of social worlds/sectors to provide an even greater understanding of the socio-ecological system in action.

The sample recruitment processes involved gatekeepers in education, health, charity and sports, which could have influenced the sport and charity provider predominance in the sample. Furthermore, family interviews informed recruitment of providers, which could have led to a bias in recruitment towards charity and sports within the provider sample, due to families' involvement with sports and charity groups. For future research, a wider recruitment strategy would ensure inclusion of more families and providers from more varied social worlds/sectors and organisations. However, triangulation of families and providers data, and comparison of the data to published literature (Tidswell 2006a; Tidswell 2006b; Bevan Foundation 2011; Chin and Reid 2015; Reid 2016), suggests the sport and charity provider predominance in the sample is representative of the situation and not due to recruitment and data generation strategies, or chance.

Another limitation in the study is in the methods and methodology package employed. SA actively seeks and analyses discursive positions in a situation e.g., positions on equity, equality, and power relations, which Allen (2010) asserts could lead to making assumptions in data analysis. Therefore, I needed to work to identify when I was making assumptions and how and why I was making assumptions regarding a matter. This was not always easy or apparent to me, especially as a new researcher, and a researcher new to qualitative research. However, repeated use of the data analytic mapping tools and reflective memo writing (a recognised form of limiting researcher influence [Bryman 2012]), as well as gaining the perspectives and feedback from two research supervisors, helped me minimise my assumptions and influence on data generation and analysis. Recommendations for future use of SA in healthcare research is to ensure the repeated and extensive use of reflective memo writing, and use of moderators where possible, to reduce the influence of the researcher on data generation and analysis.

A final limitation is in the methodology-methods' link to GT and employment of purposive theoretical sampling. Clarke et al. (2018) describes SA as having GT foundations and following theoretical sampling; however, the research does not need to produce substantive theory. The study followed these guidelines and has not produced substantive theory but thick SA. It could be argued that the thesis has missed an opportunity to contribute further to evidence by not producing theory, and that claiming a GT foundation without following GT principles e.g., in theoretical sampling and theory production, is jargonising GT (Glaser 2009). This thesis does not claim to use GT but to use SA, it has not used theoretical sampling but purposive theoretical sampling where previous data generation informed future data generation (Bryman 2012; Clarke et al. 2018). However, there were limitations in this, as the data was constrained to interviews due to ethical approval constraining evidence to interviews, and the time limits and constraints available within models of doctoral programmes.

8.3.5. Personal Reflections

My journey to the thesis topic started with my paediatric clinical practice supporting C&YP in community settings and in my MSc research where I deployed a functional muscle strengthening home exercise programme for C&YP with CP. I examined the effects of the programme on C&YP’s muscle strength and walking ability. During data collection, I encountered several parents who shared with me their difficulties in identifying suitable community PA choices for their child. Subsequently, my first funded research study grew my desire to examine community PA participation. This research examined effects of an adapted cycling community programme for C&YP with CP. Quadriceps muscle strength showed significant increases (Visser et al. 2012; Visser et al. 2014) demonstrating a community PA participation intervention could positively affect body structure and functions while providing fun, child-friendly PA (Pickering et al. 2015). When disseminating study findings, I encountered resistance from some physiotherapists regarding whether there was a role for physiotherapists in community PA participation settings, which grew my desire to examine the topic. My first ideas for a thesis research study in this area were to provide and examine, a specific community PA participation intervention, evaluating its uptake and outcomes, or to develop a shared decision-making tool to support professionals and families in community PA participation. As I explored my thesis ideas and relevant literature in discussion with supervisors, I realised I needed to understand the situation in greater depth to provide informed support. Therefore, I chose to deploy a SA of community PA participation by C&YP with neurodisability.

SA has appeal for healthcare researchers but is challenging for those without an established background in sociology as it presupposes an understanding of the traditions on which the perspective draws. Not having a background in sociology and this being my first time managing a qualitative research study meant I was a novice researcher, which made making sense of the data and providing synthesis to answer the research questions, time-consuming, laborious, and difficult. Making decisions on the most relevant/salient findings that answered the research questions and were most important to take forward, was difficult. I have left out much data that could have been included to substantiate findings further.

Completing the SA, I have been able to reflect on my education practice as a physiotherapy Senior Lecturer, and how to inform, and support future healthcare practitioners, and their influence on C&YP with neurodisability, and their families. I aim to develop participation-focused therapy learning and teaching materials and sessions within the BSc undergraduate, MSc pre-registration, and MSc post graduate taught physiotherapy programmes, informed by the thesis and research literature. I have already started this by providing post-graduate participation-focused learning and teaching, and an undergraduate social prescribing session, in collaboration with NDSO, in the past academic year. I have also been exploring the possibility of clinical placements for students with NDSO within their health partnership programme (Chin and Reid 2015; Disability Sport Wales 2024b), thereby integrating community PA participation and healthcare in future physiotherapists' practice. Additionally, I have recently started developing, in collaboration with a colleague, undergraduate learning and teaching sessions involving behavioural change theory (Michie et al. 2011; Reedman et al. 2017) and links to clinical reasoning and person-centred/family-centred care, to promote these considerations in future healthcare practitioners' interactions with patients. I am considering how to further develop these areas, and monitor and evaluate these learning and teaching developments for scholarship dissemination, to broaden the discussion and debate regarding participation-focused healthcare within the wider academic field.

8.3.6. Publication and Dissemination Strategy

The first step in my dissemination plan involves disseminating the findings to the thesis participants to inform them and provide them with feedback on the research conducted and in which they were involved. Dissemination platforms will be appropriate for the sample population group e.g., such as a cartoon video/powtoon for young children. Another immediate dissemination plan involves disseminating the findings within my education practices, using research literature and my study findings I will share and disseminate new knowledge from the thesis to fellow education colleagues and the healthcare students. Alongside this, I aim to publish my research findings in peer-reviewed journals using participant stories to show the multi-faceted nature of community PA participation and the need to shift healthcare focus to support C&YP, families and providers. Additionally, I plan to disseminate findings within education and research networks/forums via oral and poster conference presentations e.g., the WHO HEPA Europe, European Academy of Childhood Disability, CP International Sports and Recreation Association (CPISRA), and Association of Paediatric Chartered Physiotherapists. A long-term goal is also to disseminate findings to government agencies, funding bodies and other social worlds/organisations identified within the situation. This dissemination could be via reports, information leaflets, infographics or other more suitable options that makes the information accessible and visible to these worlds. I will need to explore options regarding this to find the most suitable ways to effectively inform and reach these audiences. Policies and reports have not been shown to be successful at creating change so it may be that there are other more effective ways to disseminate findings to these audiences that will need to be identified.

8.4. Conclusion

In utlising SA, the thesis findings show community PA participation is a networked socio-ecological concept that has multiple connections between different facilitators, barriers, discourses, and social worlds, as well as having missing connections and interactions, all of which can work to hinder or facilitate participation. The thesis is an original contribution and extends the field of knowledge because a SA of community PA participation by C&YP with neurodisability has not previously been conducted, and only recent calls for using a socio-ecological approach have been evidenced. This thesis has taken a socio-ecological approach confirming existing evidence on barriers and facilitators but providing new knowledge in how these interact and influence each other in social situations related to community PA participation. The SA findings have increased knowledge in showing that interventions and strategies to increase community PA participation will need to co-ordinate multiple socio-ecological levels and not just one level, whilst still taking an individualised approach to fit with each child/young person and family. The findings show that although policy and legislation is present, it is not working through all individual and collective situations, or all social worlds in the situation, to ensure inclusion and participation for C&YP with neurodisability. Furthermore, that a shift in providers' thinking and practice is needed and overt consideration of contentious issues such as risk and inclusion to find solutions. SA showed that inclusion is a contentious issue in numerous social worlds within the situation. Including multiple perspectives of C&YP, families and providers and using multiple theories and cartographic analysis has revealed silent discursive positions that hinder participation, positions that are often not overtly acknowledged. No previous research has included the perspectives of C&YP, parents and multiple providers in a SA of community PA participation. The thesis has thereby provided a unique contribution to the evidence that enables greater understanding of the situation, and which provides recommendations for new ways forward. The thesis thick situational analytics has aided an in-depth understanding of the problem of limited community PA participation by C&YP with neurodisability and identified key recommendations for practice and suggestions for future research.

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Appendices:

Appendix 1: Reflective Memo Excerpts

It looks like I am using my clinical experience in a way that can distract from the interview aims i.e., I started exploring his [Dwayne] physical signs and symptoms and physiotherapy interventions! This is a well-trodden path from physiotherapy subjective interviews. Sitting with families in their home seems to be bringing back my clinical tendencies. I need to ensure I do not fall into physiotherapy subjective assessment interview formats/content! I need to ensure I am prompting to explore the situation of community PA participation. Stay on track with the research focus!

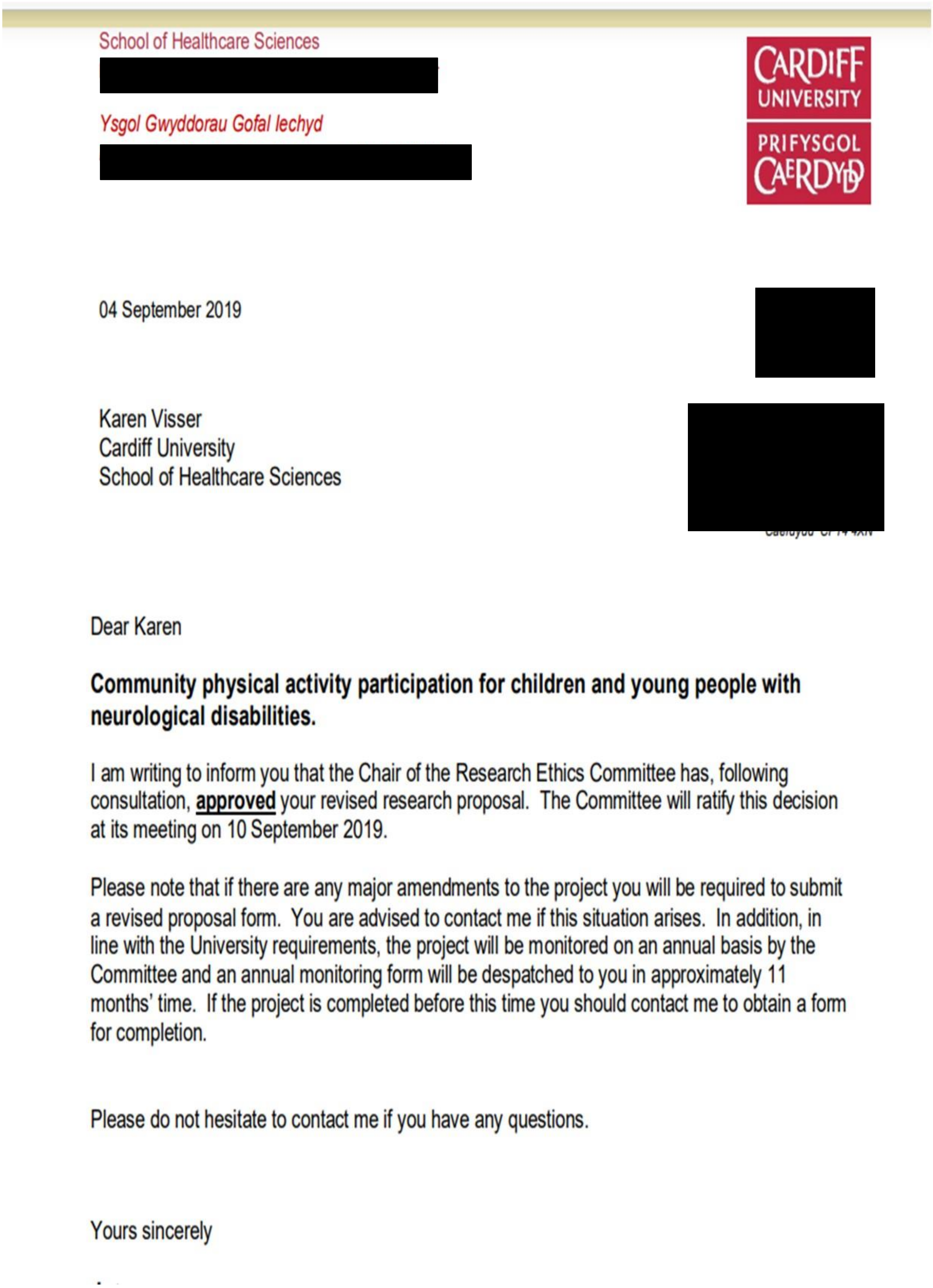
It is interesting to note the same description of learning to ride a bicycle - the joy it brings in the emotional reaction/tears from both Buster-Snare and Donny's fathers. It was nice finding similarities like that in the data that mean so much to people and have such a resonating experience between two families. I wonder if it will come up in other family narratives? I don't want to make assumptions and lead anyone anywhere! I notice I sometimes finish people's sentences when they pause. I need to hold myself back and let them speak, even if there is a long pause/silence. I know I want them to feel heard and understood, which may be why I help them finish their sentences! Listen, listen, listen and then prompt. Don't assume what they are saying. Be relaxed with silences and wait.

(Reflective excerpt: March 2020)

I sometimes find it embarrassing to listen to myself ask questions, when listening to the transcripts. I want to really listen though. Really, find out from people how they are and what happens. Not my suppositions. I want to hear about people's experiences, those of parents and children if I am able to, and the other people involved. I am struggling with the central point for all PhD students - I want the work to make a difference. With that in mind, just do it, to the best of your ability, to get the end result. How to involve children in interviews effectively? That would be something good to learn and engage in both now and in future work.

(Reflective excerpt: August 2020)

Appendix 2: Research Ethics Approval Letter



School of Healthcare Sciences
[redacted]

Ysgol Gwyddorau Gofal Iechyd
[redacted]

CARDIFF
UNIVERSITY
PRIFYSGOL
CAERDYDD

[redacted]

04 September 2019

Karen Visser
Cardiff University
School of Healthcare Sciences

[redacted]

Dear Karen

Community physical activity participation for children and young people with neurological disabilities.

I am writing to inform you that the Chair of the Research Ethics Committee has, following consultation, **approved** your revised research proposal. The Committee will ratify this decision at its meeting on 10 September 2019.

Please note that if there are any major amendments to the project you will be required to submit a revised proposal form. You are advised to contact me if this situation arises. In addition, in line with the University requirements, the project will be monitored on an annual basis by the Committee and an annual monitoring form will be despatched to you in approximately 11 months' time. If the project is completed before this time you should contact me to obtain a form for completion.

Please do not hesitate to contact me if you have any questions.

Yours sincerely

Appendix 3: Study Advert

The GASP Research Study

Games, **A**ctivities, **S**ports and **P**hysical activity

Do you support a disabled child or young person?

Can you help me?

My name is Karen Visser, I am a physiotherapist and senior lecturer at Cardiff University.

I am doing a PhD research study investigating support for physical activity participation by disabled children and young people.

I am including parents, children who have neurological disorders (aged 4-17years) and all people who support children and young people with physical activity.

I would like to chat to children, young people and anyone else involved, about their experiences.

If you and/ or your child would like to participate, I can chat with you face-to-face or online, on a day and time convenient to you.

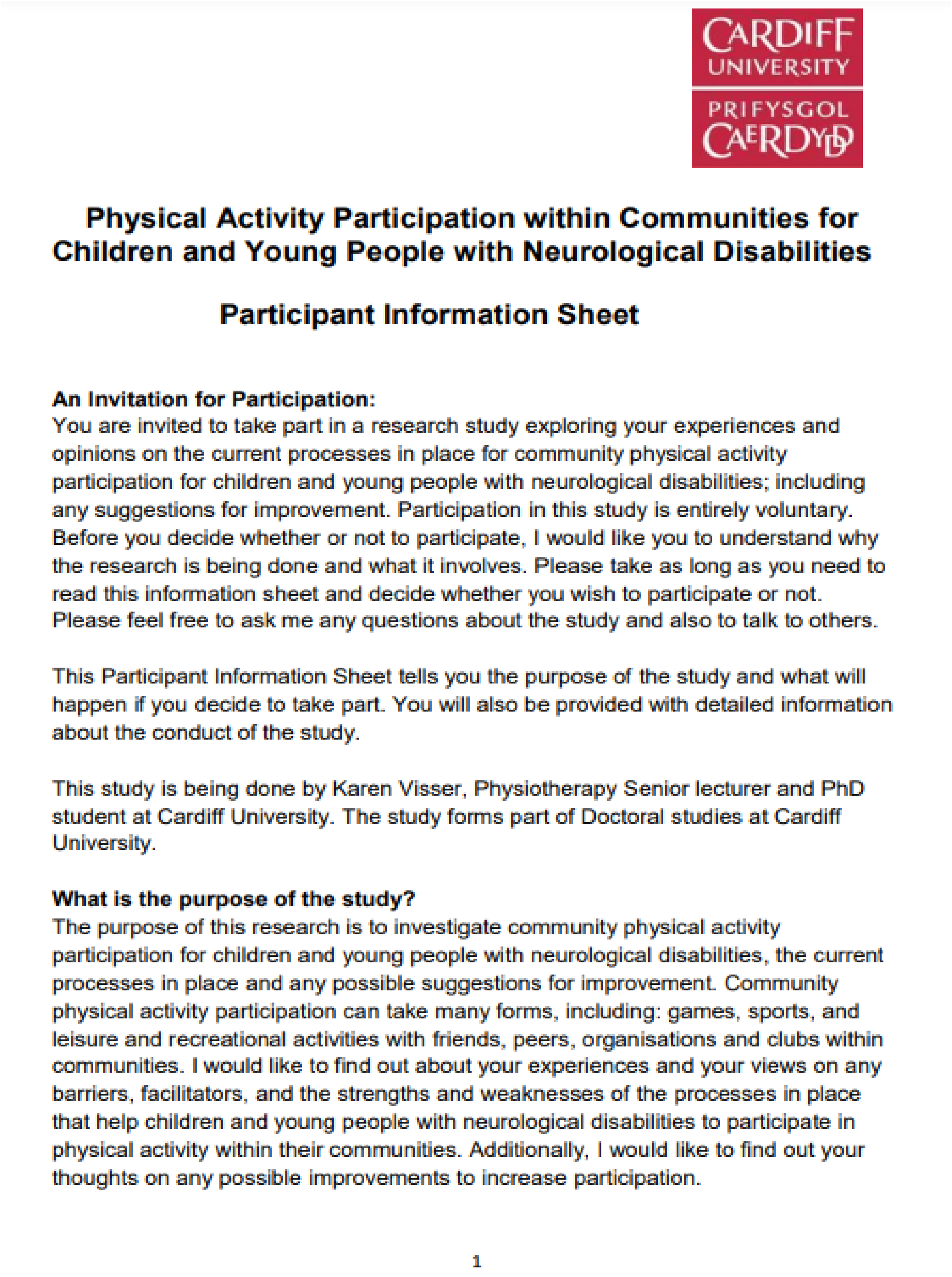
If you and/or your child would like to be involved, please contact me, **Karen Visser:**

Telephone number: [redacted]

Emai

Thank you!

Appendix 4: Adult/Provider Participant Information Sheet



CARDIFF UNIVERSITY
PRIFYSGOL CAERDYDD

Physical Activity Participation within Communities for Children and Young People with Neurological Disabilities

Participant Information Sheet

An Invitation for Participation:
You are invited to take part in a research study exploring your experiences and opinions on the current processes in place for community physical activity participation for children and young people with neurological disabilities; including any suggestions for improvement. Participation in this study is entirely voluntary. Before you decide whether or not to participate, I would like you to understand why the research is being done and what it involves. Please take as long as you need to read this information sheet and decide whether you wish to participate or not. Please feel free to ask me any questions about the study and also to talk to others.

This Participant Information Sheet tells you the purpose of the study and what will happen if you decide to take part. You will also be provided with detailed information about the conduct of the study.

This study is being done by Karen Visser, Physiotherapy Senior lecturer and PhD student at Cardiff University. The study forms part of Doctoral studies at Cardiff University.

What is the purpose of the study?
The purpose of this research is to investigate community physical activity participation for children and young people with neurological disabilities, the current processes in place and any possible suggestions for improvement. Community physical activity participation can take many forms, including: games, sports, and leisure and recreational activities with friends, peers, organisations and clubs within communities. I would like to find out about your experiences and your views on any barriers, facilitators, and the strengths and weaknesses of the processes in place that help children and young people with neurological disabilities to participate in physical activity within their communities. Additionally, I would like to find out your thoughts on any possible improvements to increase participation.

1

Why have I been invited to participate?

You have been invited to participate as you have experience and / or understanding of community physical activity participation for children and young people with neurological disabilities.

Do I have to take part?

Participation in this study is completely voluntary. You do not have to take part and refusal to take part will not affect you in any way.

What will happen to me if I take part?

If you wish to take part in the study, you will be invited to an interview to discuss your experiences and opinions. The interview will be conducted by the study researcher, Karen Visser, Physiotherapy Senior Lecturer at Cardiff University. The interview will take place in a format suitable to you and at a time and place convenient to you. The interview could be done via telephone, Skype, or face to face, depending on what is most convenient to you. The interview will explore your experiences and opinions on community physical activity participation for children and young people with neurological disabilities. The interview could take anything from 20 minutes, up to or over an hour, dependant on what you have to say and how much you wish to share and discuss.

What will I have to do?

You will be asked to share your experiences and opinions regarding community physical activity participation for children and young people with neurological disabilities. This will require taking part in an interview to discuss your experiences and opinions on this topic. The interview will happen in a form, place and time convenient to you and could take anything from 20 to 90 minutes, depending on how much you wish to share and discuss.

What are the possible risks or disadvantages of taking part?

There are no obvious risks or disadvantages to taking part other than giving up some of your time to participate in an interview. You may find sharing some experiences distressing, however the risk of this is low, as you do not have to talk about anything you do not wish to. You are also able to refrain from answering any interview questions that you wish to, without having to provide a reason.

What are the possible benefits of taking part?

You will be given the opportunity to share your experiences and discuss your views on community physical activity participation for children and young people with neurological disabilities and any suggestions for improvement. The information and knowledge you share will be used to inform the ongoing research process, research study findings and any research recommendations made. You will therefore be contributing to knowledge gain and knowledge sharing regarding this topic and its associated issues.

What happens when the research stops?
Anonymised study findings will be used to map the current processes in operation for facilitating community physical activity participation for children with neurological disabilities; including possible solutions for improving the processes and increasing participation.

Will my taking part in the study remain confidential?
Yes, your participation in the research study will remain completely confidential. No one will be informed of your participation and only you and the researcher will know you have participated. In order to ensure accuracy in representing your experiences and opinions, the interview will be audio-recorded using a Dictaphone. The Dictaphone can be switched off at any time during the interview. The audio recording of the interview will be written into an interview transcript and the audio recording then destroyed. All interview transcripts will be anonymised using a pseudonym so that study participants are not identifiable; all places/ organisations and contexts discussed will also be anonymised in order to ensure confidentiality is in place throughout the study.

What will happen if I do not want to carry on with the study?
Participation in this study is entirely voluntary and you can withdraw from this study at any time without having to provide a reason. Should you decline to be part of this study or withdraw at any stage, then the care you receive from any relevant service e.g. NHS will not be affected in any way.

What will happen to the results of the research study?
Anonymised study findings will be written up within a Doctoral thesis and discussed at the PhD viva in order for the researcher, Karen Visser, to obtain a Doctorate in Philosophy from Cardiff University. Anonymised study findings may also be published within academic journals, presented at professional conferences or used for educational purposes. You will be provided with a final study report. No individuals, yourself included, people or places will be identifiable within the study findings, study written material and report.

Who is organising and funding the research?
The research study has no direct financial funding from any organisation. The research is organised by Karen Visser, PhD student and Physiotherapy Senior Lecturer at Cardiff University.

Who has reviewed the study?
This study has been reviewed and study ethical approval received from the Cardiff University School of Healthcare Sciences Research Ethics Committee.

What if I have a complaint?

If you have a complaint, please speak to the researcher who will do their best to answer your questions. Study researcher: Karen Visser, at: [redacted]
Tel: [redacted]

If you wish to complain formally, you can do this by contacting the School of Healthcare Sciences Director of Research Governance ([redacted] [redacted].

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against Cardiff University but you may have to pay your legal costs.

Safeguarding of children

If I become aware of any information that suggests that a child might be at risk, I will follow (local authority) social services child protection procedures.

What do I need to do if I want to participate?

Should you wish to participate in this study please contact the researcher, Karen Visser, via email at: [redacted] or via telephone on: [redacted]

Appendix 5: Child/Young Person Participant Information Sheet Aged 4-11 Years

Child Participant Information Sheet: Age 4 – 11 years August 2019 v3

Researcher:

Karen Visser

Researcher contact details:
Researcher, Doctoral Student,
Physiotherapy Senior Lecturer
Cardiff University

[redacted]

CARDIFF
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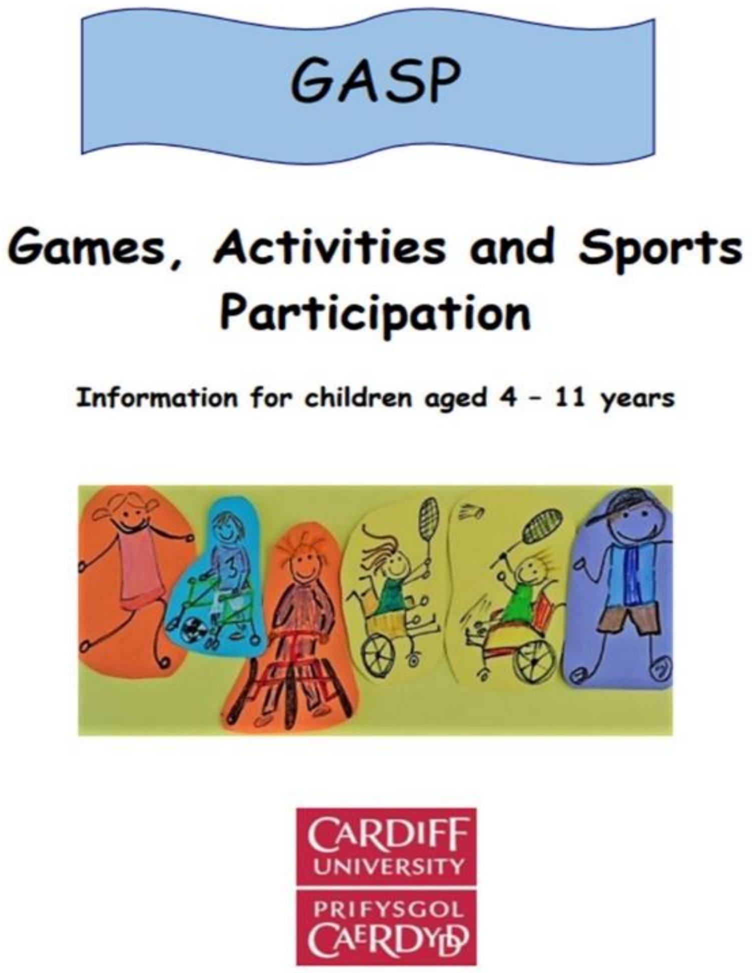
This research has been approved by Cardiff University
School of Health Care Sciences Research Ethics Committee



GASP

Games, Activities and Sports Participation

Information for children aged 4 - 11 years

CARDIFF
UNIVERSITY
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CAERDYDD

Child Participant Information Sheet: Age 4 – 11 years August 2019 v3

Who am I?

I am Karen Visser. I teach physiotherapy at Cardiff University and I am doing the GASP research study.

What do I want to find out?

I want to find out about the games and sports you play.

Why do I want to know?

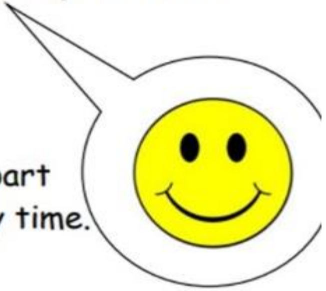
I want to help children take part in games and sports.

What will happen?

You can chat to me about the games and sports you play or want to play. You can also have another person help you chat to me. I will record our talk. I may take a photo of any equipment you use to take part in games and sports, but I will not take a photo of you.

What will I do with what you tell me?

What you tell me will be used in documents and talks to tell people how to help children take part in games and sports. Sometimes your exact words may be used but no one will know it is you. You can ask for what you tell me to be taken out the study at any time.



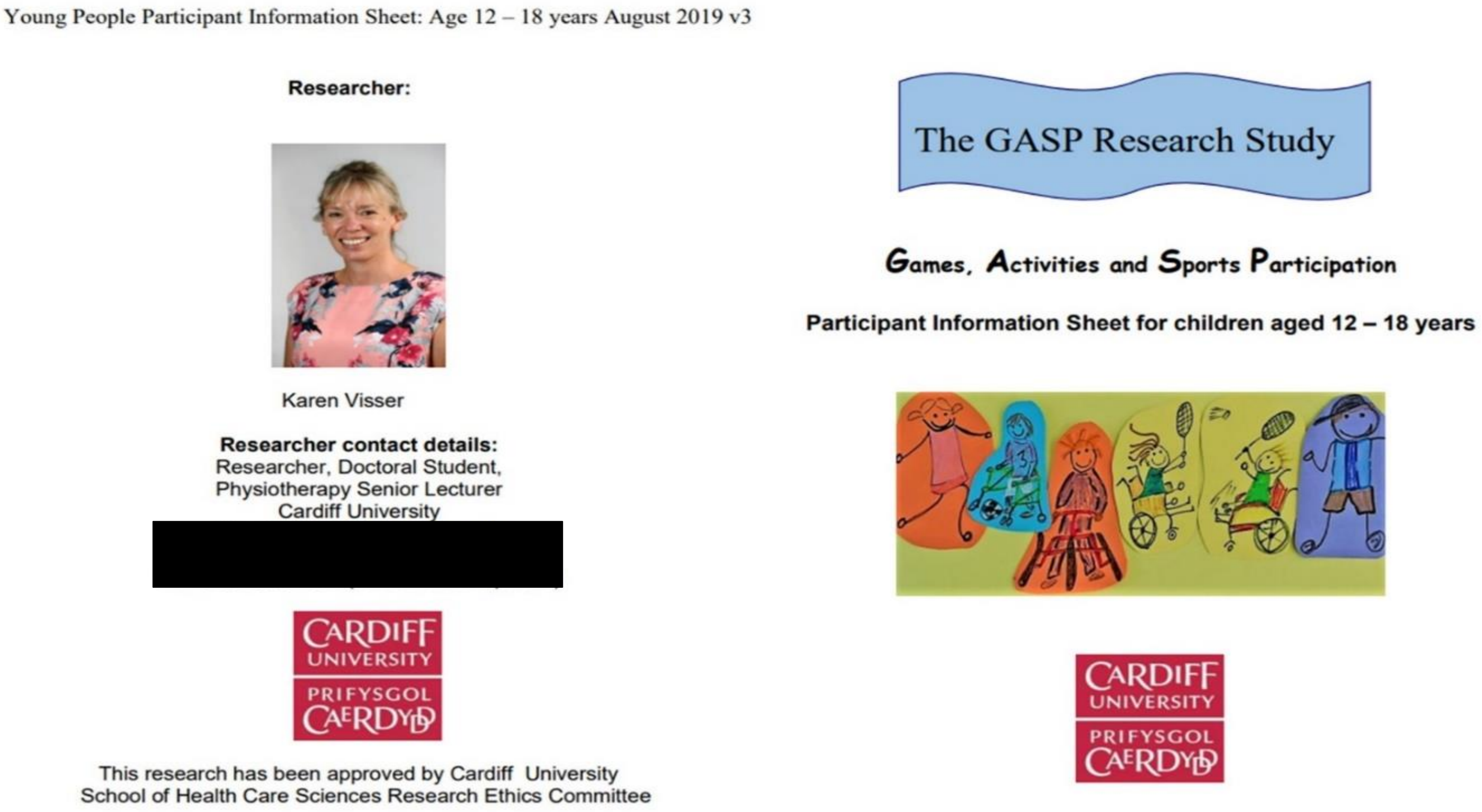
Do I have to take part?

No. You can choose if you want to take part and you can also change your mind at any time.

Being Safe

Your safety is very important. If you tell me about something or someone in danger this will be told to a social worker or policeman.

Appendix 6: Child/Young Person Participant Information Sheet Aged 12-18 Years



Young People Participant Information Sheet: Age 12 – 18 years August 2019 v3

Researcher:

Karen Visser

Researcher contact details:
Researcher, Doctoral Student,
Physiotherapy Senior Lecturer
Cardiff University
[redacted]

CARDIFF UNIVERSITY
PRIFYSGOL CAERDYDD

This research has been approved by Cardiff University School of Health Care Sciences Research Ethics Committee

The GASP Research Study

Games, Activities and Sports Participation

Participant Information Sheet for children aged 12 – 18 years

CARDIFF UNIVERSITY
PRIFYSGOL CAERDYDD

Young People Participant Information Sheet: Age 12 – 18 years August 2019 v3

Who am I?

My name is Karen Visser. I teach physiotherapy at Cardiff University and I am doing research for a PHD.

What is the GASP research study about?

I want to know about the games, sports and physical activities children and young people take part in, especially ones where you use a lot of energy and may become short of breath. I would like to know who you play with in these activities such as friends, members of your family, children and young people or others. The activities could be in different places, at school, in sports clubs, places you visit, or near where you live.

Why am I doing this?

The United Nations Convention on Children's Rights says you have the right to take part in fun and enjoyable games, activities and sports; and that people should help you take part. We know that taking part may be difficult for you and you may not always be able to do the activities you want. I want to know about:

- the physical activities that you do, where you do them, what makes them fun and enjoyable or difficult.
- any help you need, who helps you and if you use equipment.
- activities that you do not do but would like to.

Talking about these things will help us learn about participation in games, sports and physical activities for children and young people who may face difficulties taking part and learn about the systems in place to help; so that people working with children and young people can help them take part in physical activities, games and sports.

What is involved?

I would like to ask (interview) you about the games, sports and physical activities that you do or would like to do, and I will record our talk. This can be at a place you choose, in your home or at one of the activities that you do. I may take a photo of any equipment you use but I will not take a photo of you. If you find it difficult to talk about your activities, you can have another person help you tell me about them. After the chat, if you or I remember something we did not talk about, we can arrange a second meeting to talk about this.

What will this research be used for?

The information you give me will be used in documents and talks to tell people about how children and young people take part in games, sports and physical activities and how this could be made better. Sometimes your exact words may be used to tell people, but no one will know it is you.

Do I have to take part?

No. You can choose to take part, but you can also change your mind at any time. You can ask me to remove anything you tell me from the research study, at any time.

Safety and Wellbeing

Your safety is very important. If you tell me about something or someone in danger this will be told to another adult in authority.

Appendix 7: Child/Young Person Assent Form Aged 4-11 Years

Child Participant Assent form: aged 4-11 years, August 2019 v3

Researcher:

Karen Visser

Researcher contact details:

Researcher, Doctoral Student,

Physiotherapy Senior Lecturer

Cardiff University

[redacted]

CARDIFF UNIVERSITY
PRIFYSGOL CAERDYDD

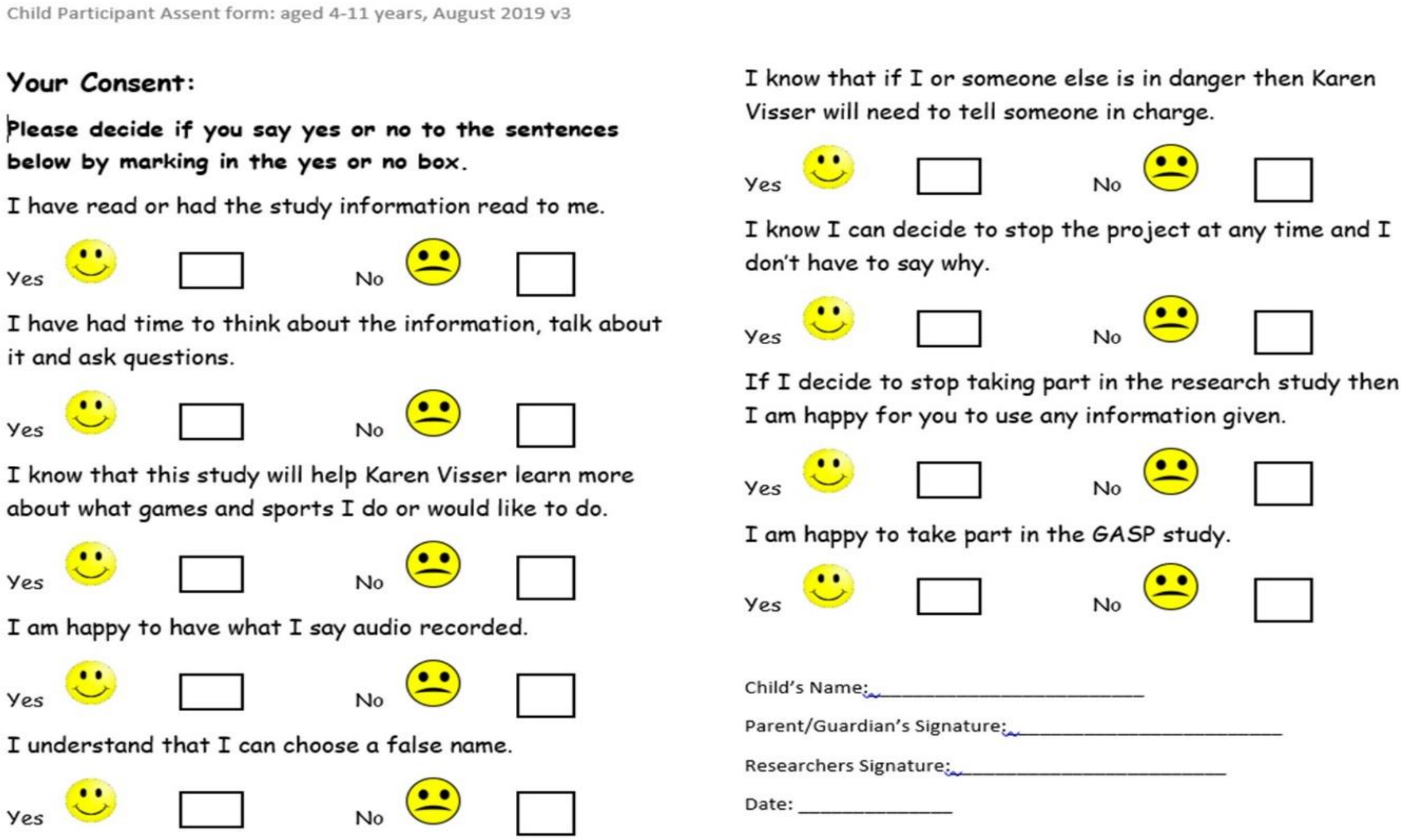
This research has been approved by Cardiff University School of Health Care Sciences Research Ethics Committee

Gasp

Games, Activities and Sport Participation

Participant Consent/Assent form for children aged 4 – 11 years

CARDIFF UNIVERSITY
PRIFYSGOL CAERDYDD



Child Participant Assent form: aged 4-11 years, August 2019 v3

Your Consent:

Please decide if you say yes or no to the sentences below by marking in the yes or no box.

I have read or had the study information read to me.

Yes ☐ No ☐

I have had time to think about the information, talk about it and ask questions.

Yes ☐ No ☐

I know that this study will help Karen Visser learn more about what games and sports I do or would like to do.

Yes ☐ No ☐

I am happy to have what I say audio recorded.

Yes ☐ No ☐

I understand that I can choose a false name.

Yes ☐ No ☐

I know that if I or someone else is in danger then Karen Visser will need to tell someone in charge.

Yes ☐ No ☐

I know I can decide to stop the project at any time and I don't have to say why.

Yes ☐ No ☐

If I decide to stop taking part in the research study then I am happy for you to use any information given.

Yes ☐ No ☐

I am happy to take part in the GASP study.

Yes ☐ No ☐

Child's Name:__________________________

Parent/Guardian's Signature:__________________________

Researchers Signature:__________________________

Date: ______________

Appendix 8: Child/Young Person Assent Form Aged 12-18 Years

Young People Participant Consent / Assent form: aged 12-18 years, August 2019 v3

Researcher:

Karen Visser

Researcher contact details:

Researcher, Doctoral Student,

Physiotherapy Senior Lecturer

Cardiff University

[redacted]

This research has been approved by Cardiff University School of Health Care Sciences Research Ethics Committee

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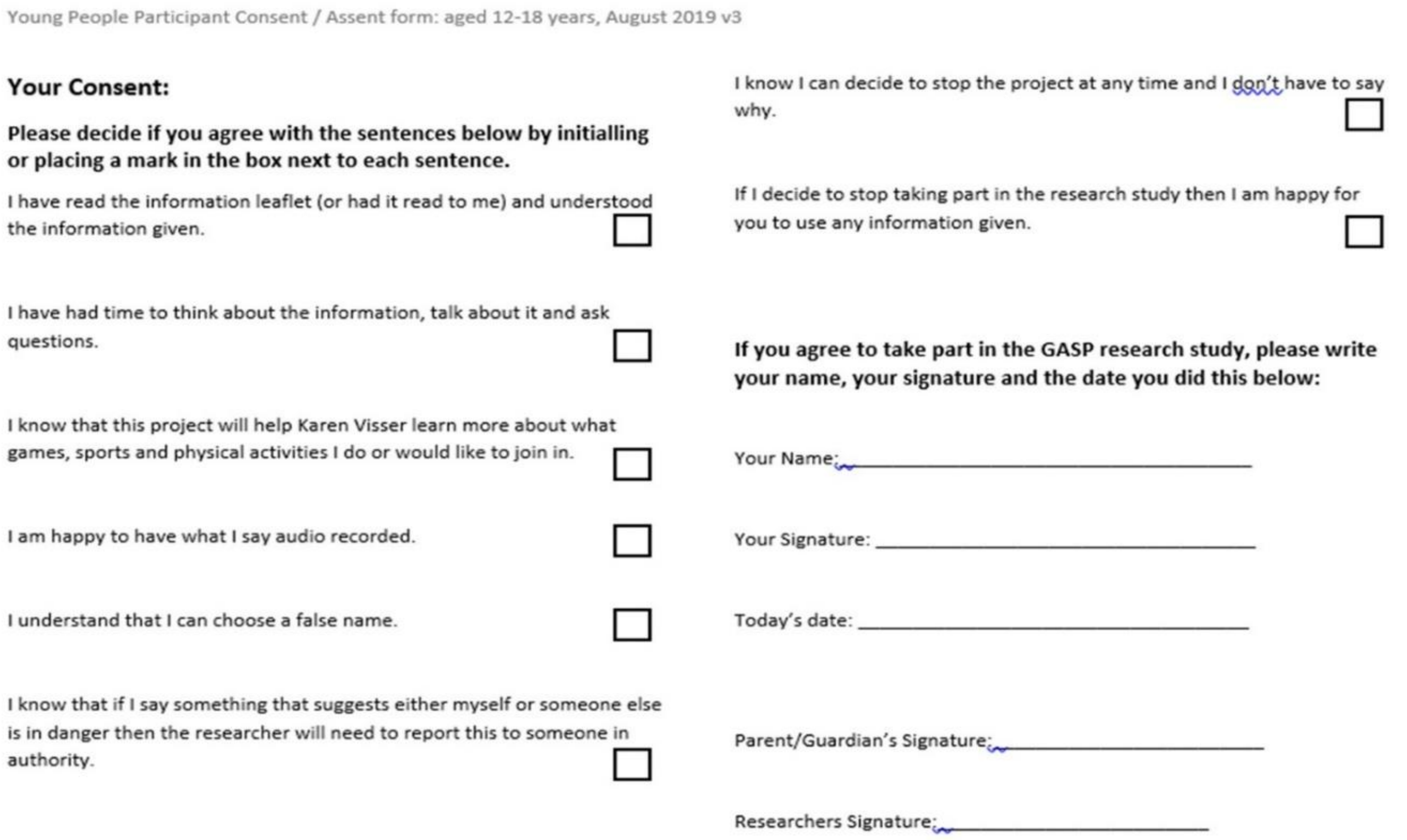
The Gasp Research Study

Games, Activities and Sport - Participation

Participant Consent/Assent form for children aged 12 – 18 years



Young People Participant Consent / Assent form: aged 12-18 years, August 2019 v3

Your Consent:

Please decide if you agree with the sentences below by initialling or placing a mark in the box next to each sentence.

I have read the information leaflet (or had it read to me) and understood the information given. ☐

I have had time to think about the information, talk about it and ask questions. ☐

I know that this project will help Karen Visser learn more about what games, sports and physical activities I do or would like to join in. ☐

I am happy to have what I say audio recorded. ☐

I understand that I can choose a false name. ☐

I know that if I say something that suggests either myself or someone else is in danger then the researcher will need to report this to someone in authority. ☐

I know I can decide to stop the project at any time and I don't have to say why. ☐

If I decide to stop taking part in the research study then I am happy for you to use any information given. ☐

If you agree to take part in the GASP research study, please write your name, your signature and the date you did this below:

Your Name: ______________________________

Your Signature: ______________________________

Today's date: ______________________________

Parent/Guardian's Signature: ____________________

Researchers Signature: ____________________

Appendix 9: Adult/Parent Participant Information Sheet

Physical Activity Participation within Communities for Children and Young People with Neurological Disabilities

Participant Information Sheet

An Invitation for Participation:

You and your child are invited to take part in a research study exploring your experiences and opinions of taking part in community physical activities for children and young people with neurological disabilities; including any suggestions for improvement. Participation in this study is entirely voluntary. Before you decide whether or not you and your child want to participate, I would like you to understand why the research is being done and what it involves. Please take as long as you need to read this information sheet and decide whether you wish to participate or not. Please feel free to ask me any questions about the study and also to talk to others.

This Participant Information Sheet tells you the purpose of the study and what will happen if you decide to take part. You will also be provided with detailed information about the conduct of the study.

This study is being done by Karen Visser, Physiotherapy Senior lecturer and PhD student at Cardiff University. The study forms part of Doctoral studies at Cardiff University.

What is the purpose of the study?

The purpose of this research is to investigate community physical activity participation for children and young people with neurological disabilities, the current processes in place and any possible suggestions for improvement. Community physical activity participation can take many forms, including: games, sports, and leisure and recreational activities with friends, peers, organisations and clubs within communities. I would like to find out about you and your child's experiences and your views on what works and what does not work to help children and young people with neurological disabilities to participate in physical activity within their communities. Also, I would like to find out what you and your child's thoughts are on any possible improvements that could increase participation.

Why have I and my child been invited to participate?

You and your child have been invited to participate as your child has a neurological disability and you are a parent of a young person with a neurological disability. You and your child are therefore likely to have experience and / or understanding of what it means to take part in community physical activities for children and young people with neurological disabilities.

Do I and my child have to take part?

Participation in this study is completely voluntary. You and your child do not have to take part and refusal to take part will not affect you or your child in any way.

What will happen to me and my child if we take part?

If you and/or your child wish to take part in the study, you will both be invited to an interview to discuss your experiences and opinions. The interview will be conducted by the study researcher, Karen Visser. The interview will take place in a format suitable to you and your child, at a time and place convenient to you both. The interview could be done via telephone, Skype, or face to face, depending on what is most convenient to you and your child. The interview will explore your and your child's experiences and opinions on community physical activity participation. The interview could take anything from 20-60 minutes, dependant on what you and your child have to say and how much you wish to share and discuss.

What will I and my child have to do?

You and your child will be asked to share your experiences and opinions regarding community physical activity participation for children and young people with neurological disabilities. This will require taking part in an interview to discuss your experiences and views.

What are the possible risks or disadvantages of taking part?

There are no obvious risks or disadvantages to taking part other than giving up some of your time to participate in an interview. You and/or your child may find sharing some experiences distressing, however the risk of this is low, as you and your child do not have to talk about anything that you do not wish to. You and your child are also free to refrain from answering any interview question that you wish to, without having to provide a reason.

What are the possible benefits of taking part?

You and your child will be given the opportunity to share your experiences and discuss your views on community physical activity participation along with any suggestions for improvement. The information and knowledge you share will be used to inform the ongoing research process, research study findings and any research recommendations made. You will therefore be contributing to knowledge gain and knowledge sharing regarding this topic and its associated issues.

What happens when the research stops?

Anonymised study findings will be used to map the current processes in operation for facilitating community physical activity participation for children with neurological disabilities; including possible solutions for improving the processes and increasing participation.

Will my and my child's taking part in the study remain confidential?

Yes, you and your child's participation in the research study will remain completely confidential. No one will be informed of your participation and only you, your child and the researcher will know you have participated. In order to ensure accuracy in representing you and your child's experiences and opinions, the interview will be audio-recorded using a Dictaphone. The Dictaphone can be switched off at any time during the interview. The audio recording of the interview will be written into an interview transcript and the audio recording then destroyed. All interview transcripts will be anonymised using pseudonym/s so that study participants are not identifiable.

What will happen if I and/or my child do not want to carry on with the study?

Participation in this study is entirely voluntary and you and your child can withdraw from this study at any time without having to provide a reason. Should you or your child decline to be part of this study, or withdraw at any stage, then the care you and your child receive from any relevant service e.g. NHS will not be affected in any way. You can contact the researcher and request that your and/ or your child's anonymised interview information be withdrawn from the research thesis any time before submission of the thesis (approximate date: 2022). Should you request removal after this date, the information requested for removal, will be removed from any subsequent research material produced.

What will happen to the results of the research study?

Anonymised study findings will be written up within a Doctoral thesis and discussed at the PhD viva in order for the researcher, Karen Visser, to obtain a Doctorate in Philosophy from Cardiff University. Anonymised quotes from you and your child's interview will form part of a Doctoral thesis and be used for educational, publishing and presentation purposes. Anonymised study findings may also be published within academic journals, presented at professional conferences or used for educational purposes. You and your child will be provided with a final study report. You and your child will not be identifiable within the study findings, study written material and report. The data will be destroyed after 15 years.

Who is organising and funding the research?

The research study has no direct financial funding from any organisation. The research is organised by Karen Visser, PhD student and Physiotherapy Senior Lecturer at Cardiff University.

This study has been reviewed and study ethical approval received from the Cardiff University School of Healthcare Sciences Research Ethics Committee.

What if I and/or my child have a complaint?

If you and/or your child have a complaint, please speak to the researcher who will do their best to answer your questions. Study researcher: Karen Visser, at: [redacted]

If you wish to complain formally, you can do this by contacting the School of Healthcare Sciences Director of Research Governance [redacted] [redacted]

In the event that something does go wrong and you and/or your child are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against Cardiff University but you may have to pay your legal costs.

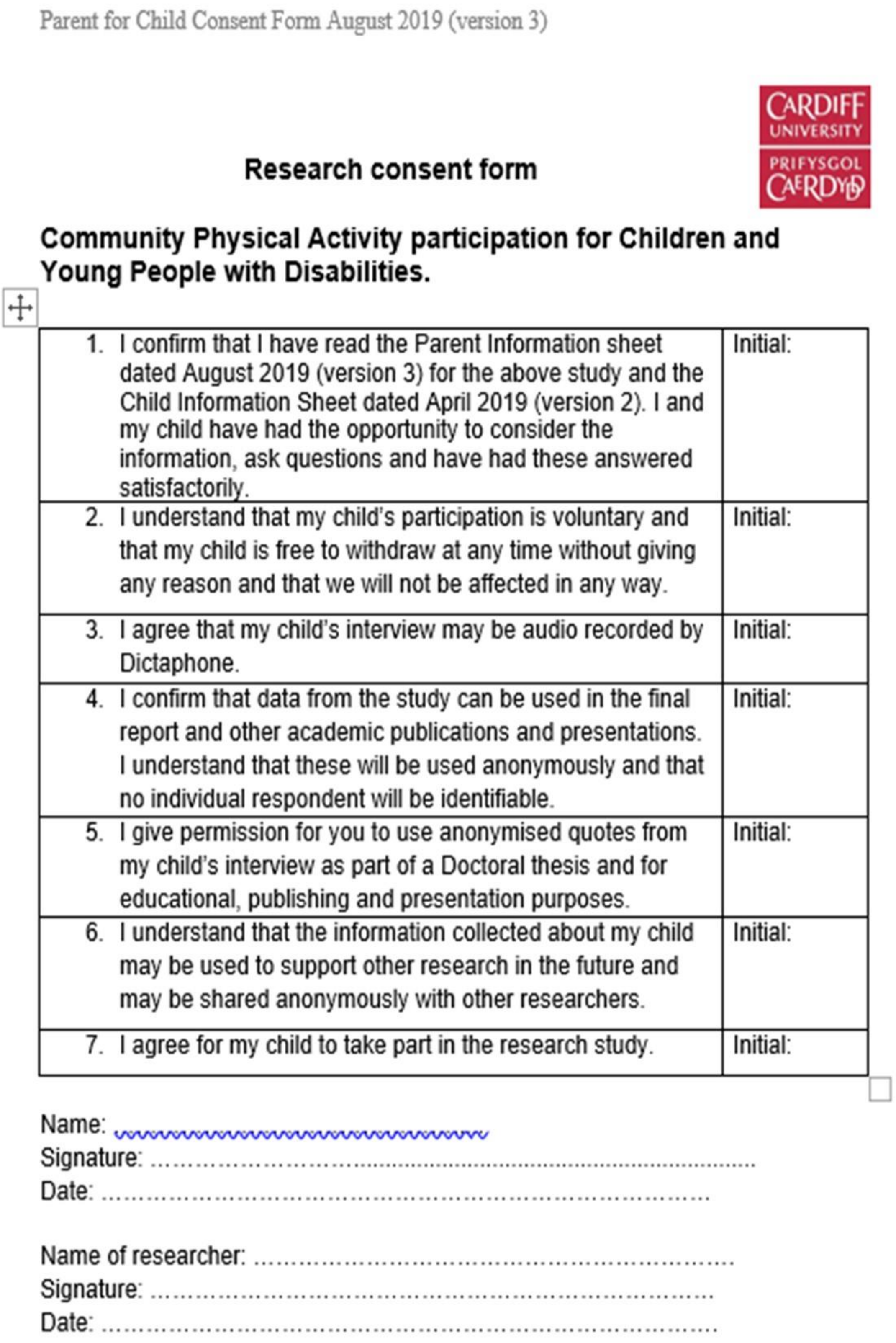
Safeguarding of children

If I become aware of any information that suggests that a child might be at risk, I will follow (local authority) social services child protection procedures.

What do I need to do if I and my child want to participate?

Should you and your child wish to participate in this study please contact the researcher, Karen Visser, via email at: [redacted] or via telephone on: [redacted]

Appendix 10: Parent for Child Consent Form



Parent for Child Consent Form August 2019 (version 3)

CARDIFF
UNIVERSITY
PRIFYSGOL
CAERDYDD

Research consent form

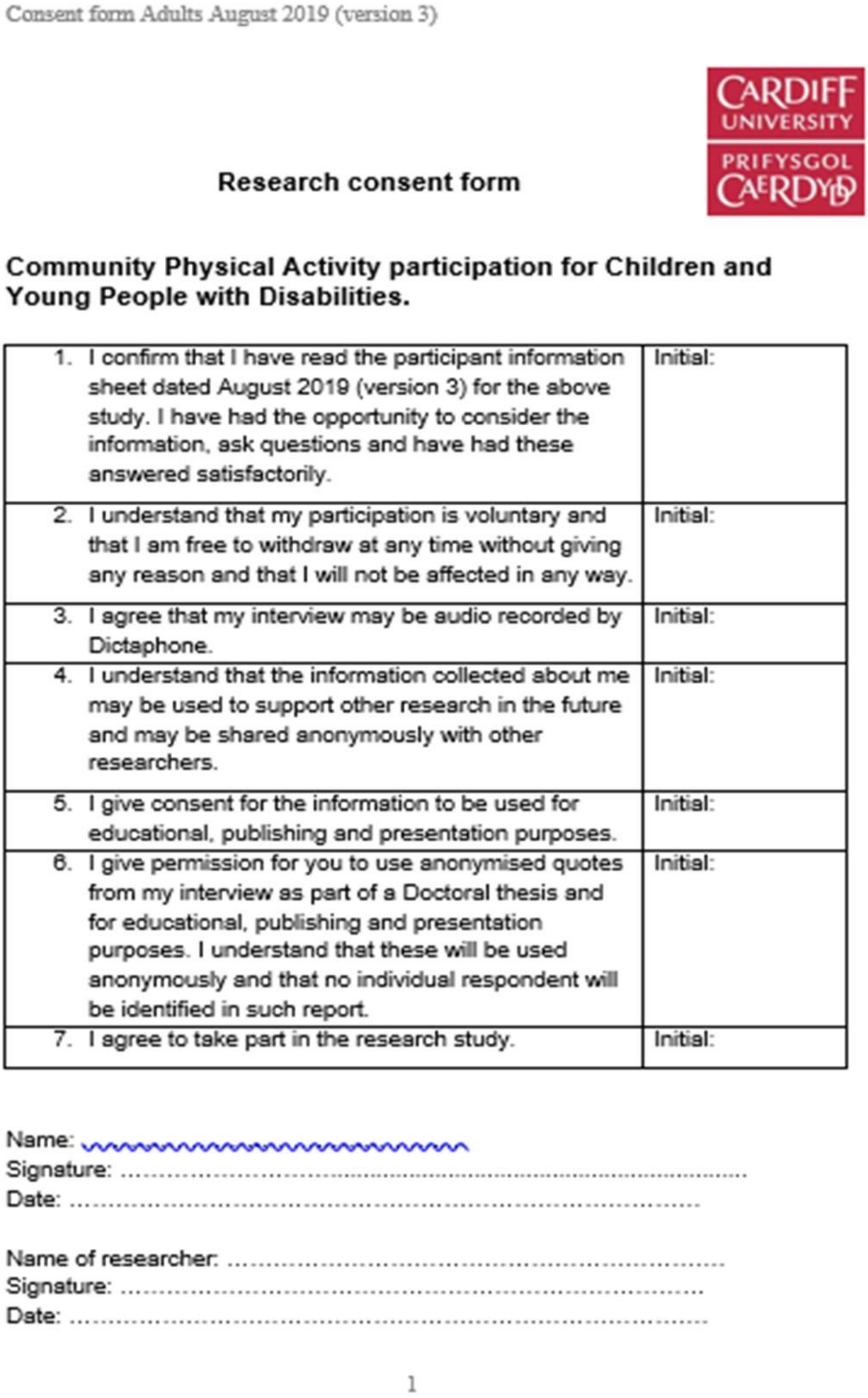
Community Physical Activity participation for Children and Young People with Disabilities.

1. I confirm that I have read the Parent Information sheet dated August 2019 (version 3) for the above study and the Child Information Sheet dated April 2019 (version 2). I and my child have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	Initial:
2. I understand that my child's participation is voluntary and that my child is free to withdraw at any time without giving any reason and that we will not be affected in any way.	Initial:
3. I agree that my child's interview may be audio recorded by Dictaphone.	Initial:
4. I confirm that data from the study can be used in the final report and other academic publications and presentations. I understand that these will be used anonymously and that no individual respondent will be identifiable.	Initial:
5. I give permission for you to use anonymised quotes from my child's interview as part of a Doctoral thesis and for educational, publishing and presentation purposes.	Initial:
6. I understand that the information collected about my child may be used to support other research in the future and may be shared anonymously with other researchers.	Initial:
7. I agree for my child to take part in the research study.	Initial:

Name:
Signature: ……………………………………………………………………
Date: ……………………………………………………………………

Name of researcher: ………………………………………………………
Signature: ……………………………………………………………………
Date: ……………………………………………………………………

Appendix 11: Adult Consent Form (for Providers and Parents)



Consent form Adults August 2019 (version 3)

Research consent form

Community Physical Activity participation for Children and Young People with Disabilities.

1. I confirm that I have read the participant information sheet dated August 2019 (version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	Initial:
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and that I will not be affected in any way.	Initial:
3. I agree that my interview may be audio recorded by Dictaphone.	Initial:
4. I understand that the information collected about me may be used to support other research in the future and may be shared anonymously with other researchers.	Initial:
5. I give consent for the information to be used for educational, publishing and presentation purposes.	Initial:
6. I give permission for you to use anonymised quotes from my interview as part of a Doctoral thesis and for educational, publishing and presentation purposes. I understand that these will be used anonymously and that no individual respondent will be identified in such report.	Initial:
7. I agree to take part in the research study.	Initial:

Name:
Signature: ……………………………………………………………………………
Date: ………………………………………………………………………………

Name of researcher: ……………………………………………………………
Signature: ………………………………………………………………………
Date: ………………………………………………………………………………

Appendix 12: Gross Motor Function Classification System (GMFCS) Descriptors

GMFCS Family Report Questionnaire: Children Aged 4 to < 6 Years

Please read the following and mark **only one box** beside the description that best represents your child's movement abilities.

My Child …

☐ **Has difficulty sitting on their own and controlling their head and body posture in most positions**

and has difficulty achieving any voluntary control of movement

and needs a specially-adapted supportive chair to sit comfortably

and has to be lifted or hoisted by another person to move

☐ **Can sit on their own but does not stand or walk without significant support and adult supervision**

and may need extra body/ trunk support to improve arm and hand function

and usually needs adult assistance to get in and out of a chair

and may achieve self-mobility using a powered wheelchair or is transported in the community

☐ **Can walk on their own using a walking aid** (such as a walker, rollator, crutches, canes, etc)

and can usually get in and out of a chair without adult assistance

and may use a wheelchair when travelling long distances or outside

and finds it difficult to climb stairs or walk on an uneven surface without considerable help

☐ **Can walk on their own without using a walking aid, but has difficulty walking long distances or on uneven surfaces**

and can sit in a normal adult chair and use both hands freely

and can move from the floor to standing without adult assistance

and needs to hold the handrail when going up or down stairs

and is not yet able to run and jump

☐ **Can walk on their own without using a walking aid, including fairly long distances, outdoors and on uneven surfaces**

and can move from the floor or a chair to standing without using their hands for support

and can go up and down stairs without needing to hold the handrail

and is beginning to run and jump

GMFCS Family Report Questionnaire: Children Aged 6 to < 12 Years

Please read the following and mark **only one box** beside the description that best represents your child's movement abilities.

My Child …

☐ **Has difficulty sitting on their own and controlling their head and body posture in most positions**

and has difficulty achieving any voluntary control of movement

and needs a specially supportive chair to sit comfortably

and has to be lifted or hoisted by another person to move

☐ **Can sit on their own but does not stand or walk without significant support**

and therefore relies mostly on wheelchair at home, school and in the community

and often needs extra body/ trunk support to improve arm and hand function

and may achieve self-mobility using a powered wheelchair

☐ **Can stand on their own and only walks using a walking aid** (such as a walker, rollator, crutches, canes, etc)

and finds it difficult to climb stairs, or walk on uneven surfaces

and may use a wheelchair when travelling for long distances or in crowds

☐ **Can walk on their own without using a walking aid, but needs to hold the handrail when going up or down stairs**

and often finds it difficult to walk on uneven surfaces, slopes or in crowds

☐ **Can walk on their own without using walking aids, and can go up or down stairs without needing to hold the handrail**

and walks wherever they want to go (including uneven surfaces, slopes or in crowds)

and can run and jump although their speed, balance, and coordination may be slightly limited

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GMFCS-E&R Family Report Questionnaire: for Young People Aged 12 - 18 Years

Please read the following and mark **only one box** beside the description that best represents your child's movement abilities.

My Child/ I …

☐ **Has difficulty sitting on their own and controlling their head and body posture in most positions**

and has difficulty achieving any voluntary control of movement

and needs a specially adapted chair to sit comfortably and be transported anywhere

and has to be lifted or hoisted by another person or special equipment to move

☐ **Can sit with some pelvic and trunk support but does not stand or walk without significant support**

and therefore always relies mostly on wheelchair when outdoors

and can achieve self-mobility using a powered wheelchair

and can crawl or roll to a limited extent to move around indoors

☐ **Can stand on their own and only walks using a walking aid** (such as a walker, rollator, crutches, canes, etc)

and finds it difficult to climb stairs, or walk on uneven surfaces without support

and uses a variety of means to move around depending on the circumstances

and prefers to use a wheelchair to travel quickly or over long distances

☐ **Can walk on their own without using a walking aid, but needs to hold the handrail when going up or down stairs**

and therefore walks in most settings

and often finds it difficult to walk on uneven surfaces, slopes or in crowds

and may occasionally prefer to use a walking aid (such as a cane or crutch) or a wheelchair to travel quickly or over longer distances

☐ **Can walk on their own without using walking aids, and can go up or down stairs without needing to hold the handrail**

and walks wherever they want to go (including uneven surfaces, slopes or in crowds)

and can run and jump although their speed, balance, and coordination may be limited

Appendix 13: Research Study Risk Assessment

The research study assessment risk using the Cardiff University, School of Healthcare Sciences, Research Study Risk Assessment form, accessed via Cardiff University, Learning Central, Research 1 module (HC2131). The assessment uses information from Cardiff University Operational Safety Health and Environment Unit (July 2011).

I present the risks, who is affected, potential for harm, risk likelihood, risk severity and actions required to reduce the risk in Table 1.

Table 1: Study risks and risk management

Hazard	Who is affected?	Potential for harm	Risk likelihood	Risk severity	Reducing the risk
Emotional stress	Participants Researchers	2	1	2	The questions used in the interviews will be considered beforehand to avoid any distress or uncomfortable feelings. Should a question cause any stress during interview the participant will be reassured that they do not have to answer and a different line of questioning will be pursued or the interview paused. All information sheets and consent forms will contain details regarding this. Should distress be high the participant will be encouraged to contact their GP for further support.
Lone Working	Researcher	2	1	2	The Cardiff University Health and Safety guidance for lone workers will be followed. When visiting participants for interview the location and time of interview will be given to a work colleague who will be messaged on the

					researcher’s safe return from the interview.
Car travel to interview location	Researcher	2	1	3	All road traffic laws and regulations will be adhered to; car and travel insurance maintained.

Overall study risk score is, three. Therefore, no further action is required.

Appendix 14: Semi-Structured Interview Guidance - Families

Broad, open questions, with prompts:

C&YP:

1. Tell me about what you like to do?
    - Tell me more?
    - When/where/how/why do you do that?

2. Is there anyone you do that with?
    - Explore friends/family/school/groups/online/neighbourhoods?
    - Who/where/how/why?

3. Do you need any help to do that?
    - Tell me more?
    - What helps/who helps/where/how/why?

4. Do you play/do any games/activities/sports?
    - Tell me more?
    - When/where/how do you do that?

5. Is there anyone you do that with/would like to do that with?
    - Explore friends/family/school/groups/online/neighbourhoods?
    - Who/where/how/why?

6. Do you need any help to do that?
    - Tell me more?
    - What help/who helps/where/how/why?

7. Would you like to do any play/games/activities/sports?
    - Tell me more?
    - What/when/where/how/why would you like to do that?

8. If you had a magic wand and could do anything, what would you like to do?
    - Tell me more?
    - What/when/where/how/why

Parents:

1. Can you tell me a bit about your child?
    - Tell me more?
    - Does that affect his/her PA?
    - How?
    - When?
    - Why?

2. What does your child do/participate in?
    - Tell me more?
    - How much?
    - How far?
    - How often?
    - Where?
    - When?
    - How?
    - Why?

3. Is there anything particularly that they really enjoy doing or that you've found that they really enjoy?
    - Tell me more about that?
    - Why?
    - What?
    - When?
    - Where?
    - How?

4. What/who is helpful to you?
    - Tell me more about that?
    - Why?
    - When?
    - Where?
    - What?
    - How?

5. What is challenging/difficult?
    - Tell me more about that?
    - Why?
    - When?
    - Where?
    - What?
    - How?

6. What would you do if you had a magic wand?
    - Tell me more about that?
    - Why?
    - When?
    - Where?
    - What?
    - How?

Appendix 15: Semi-Structured Interview Guidance - Providers

Broad, open questions, with prompts:

1. What do you do?
   - Can you tell me more about that?
   - How/when did you start?
   - What/who helps you?
   - Any difficulties/challenges?
   - Why?

2. Where do you do that/it?
   - Can you tell me more about that?
   - How did you get to be there/ in there?
   - Does anyone/thing help you?
   - Any difficulties/challenges?
   - Why?

3. How do you do that/it?
   - Can you tell me more about that?
   - Does anyone/thing help you?
   - How?
   - Why?

4. What works?
   - How?
   - Why?

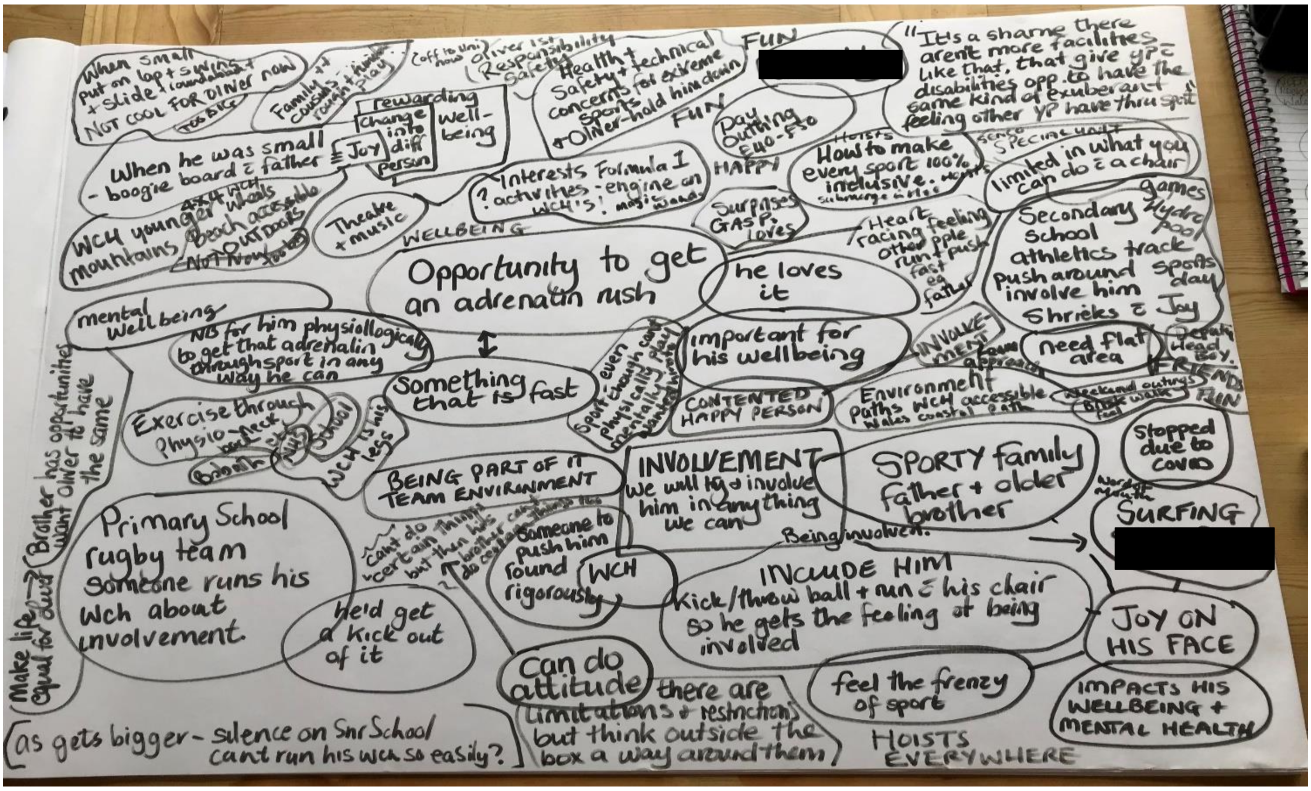
5. What doesn't work?
   - How?
   - Why?

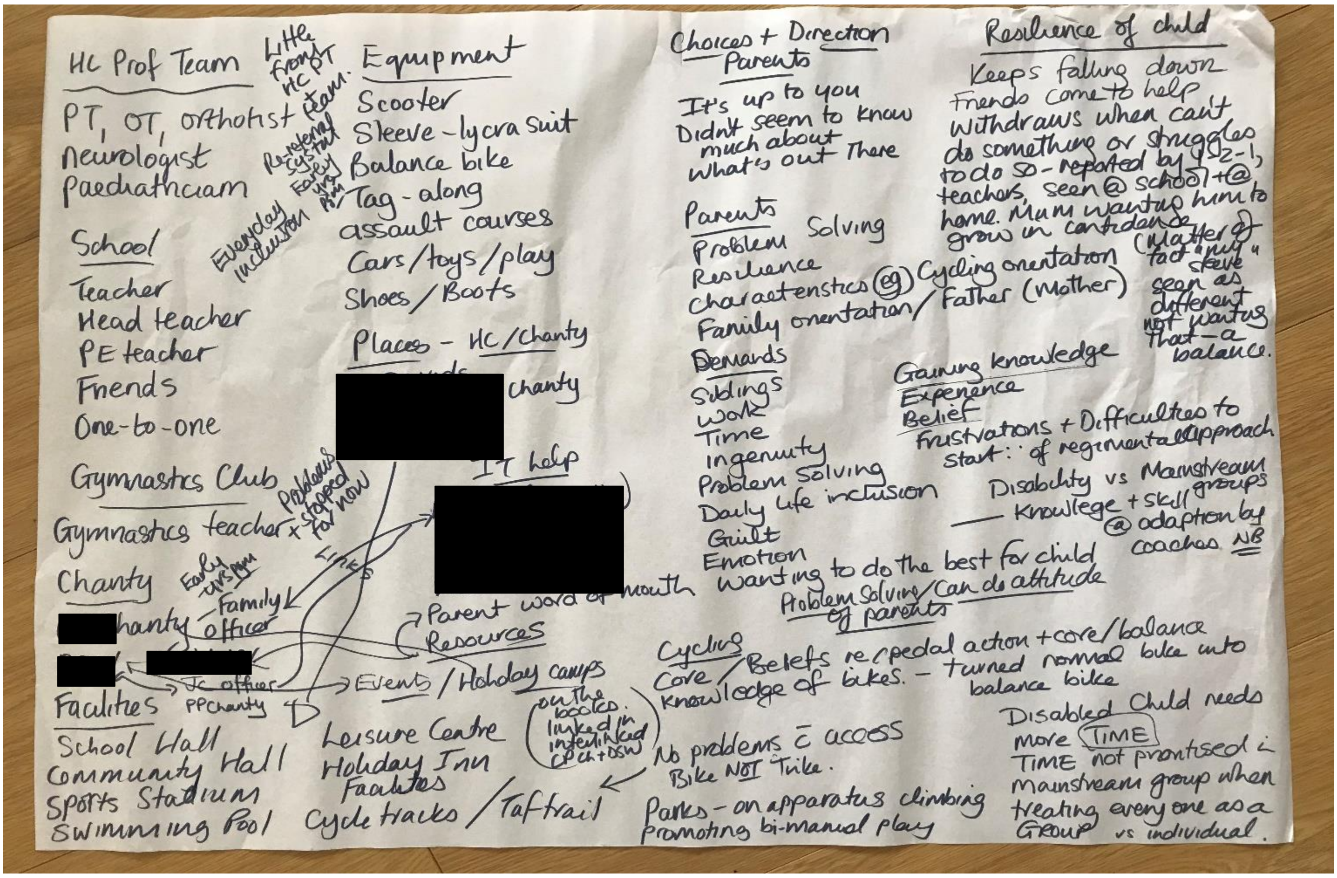
6. What would you change?
   - Why?
   - How?

7. If you had a magic wand, what would you do with it?

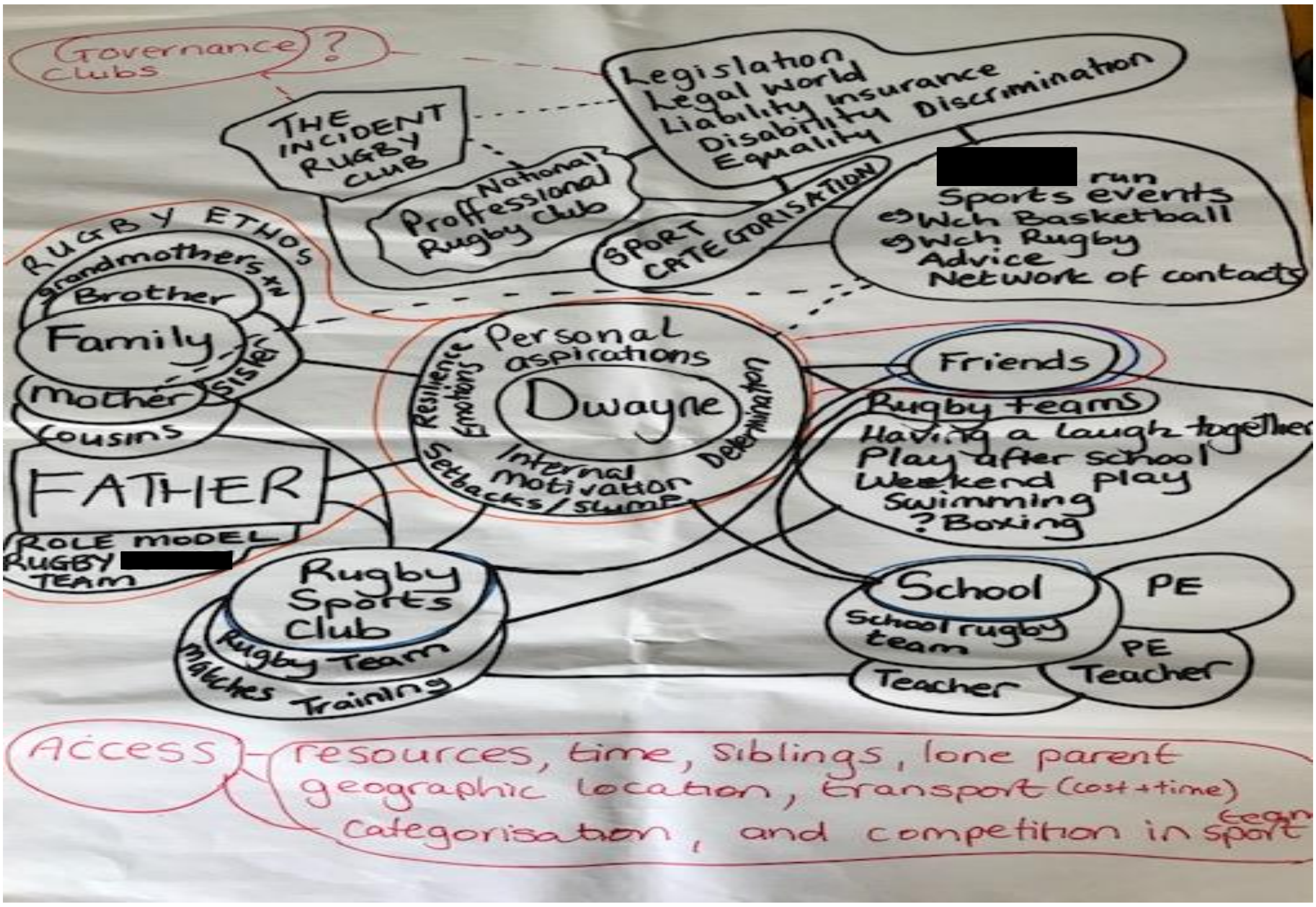
Covid-19 adaptions - break the interview into three sections - 1. Consider the situation before covid-19 restrictions and answer questions related to that 2. Consider the situation within/during covid-19 restriction period and apply the questions to that situation 3. Consider aspirations for coming out of covid-19 restrictions and looking into the future and apply the questions to that.

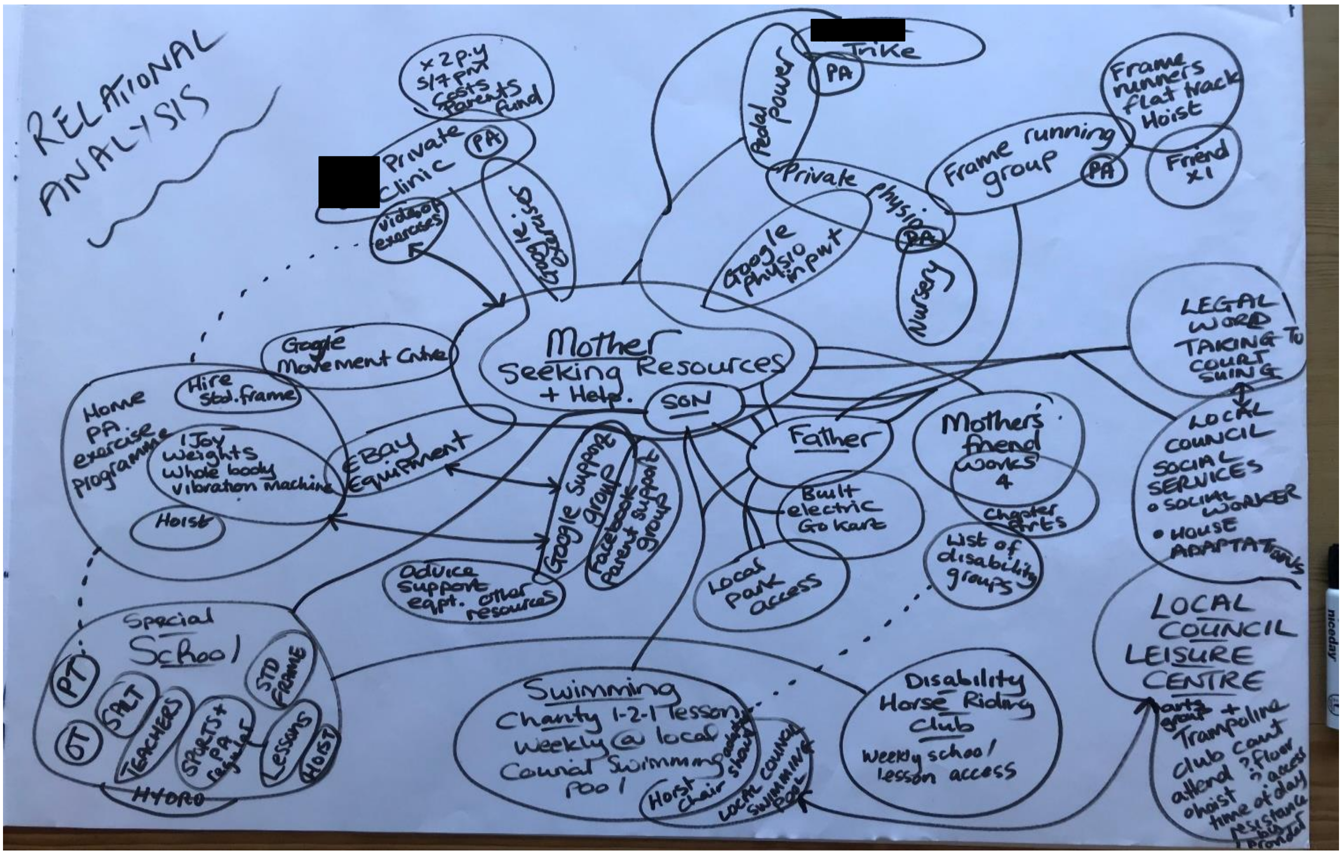
Appendix 16: Messy Situational Maps - Examples





Appendix 17: Relational Analysis within Messy Situational Maps - Examples





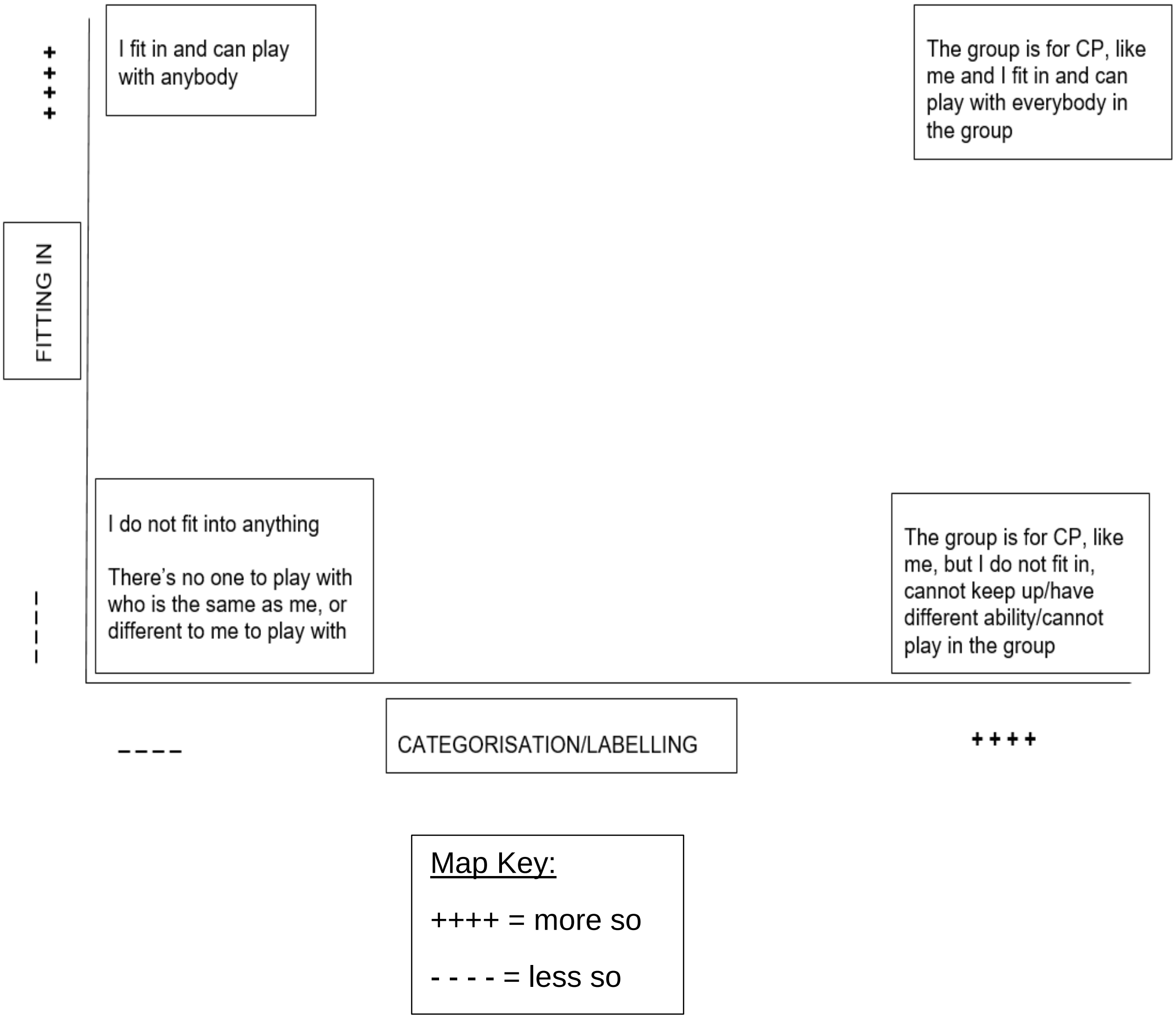
Appendix 18: Organised Situational Map - Example

INDIVIDUAL HUMAN ELEMENTS/ACTORS	**NONHUMAN ELEMENTS ACTANTS**
Phillip Older brother Father Mother Physio OT Friend at school School teachers Therapy charity staff Large family - many cousins	Wheelchair Flat surfaces Accessible athletic track Accessible flat paths Wheelchair adaptations - 4x4 wheelchair wheels, formula 1 wheelchair built around him Surfboard, surfboard adaptations, seating Balls, rugby ball Hoists Boogie board Money Car Coastal path, beach path = flat, accessible Slides Swings Roundabouts Adapted surfboard Hydropool at school - twice a week, every week participation - he adores Environmental Access - Can’t take swimming in local pool anymore as parent/s - not accessible - too big and too much work = Clarify Technology Equipment Computers
COLLECTIVE HUMAN ELEMENTS/ACTORS	**IMPLICATED/SILENT ACTORS/ACTANTS**
School special unit team =SENCO - special educational needs co-ordinator, teachers, healthcare team - physiotherapists, occupational therapists Senior school - games, sports days Primary school - rugby, sports, play Friends - school from primary through to secondary Surf charity - staff, organisation CP charity Wheelchair services Assistive technology service teams	Age - less able or appropriate to rough and tumble, be on the floor and roll, interact, go with parents on boogie board, park equipment = not cool Age - wheelchair changes - change in weight, height, size means not as able to have 4x4 wheelchair and access to beach, up mountains, have to stick to paths Wheelchair is his legs - he cannot mobilise his wheelchair (no arm, hand or leg movements) therefore needs… Fit people, aware and motivated to race him around and involve him in things Hoists are essential for him to access anything He will need to be secured, held down on apparatus for sport - health and safety and technical aspects implicated

	Skills and knowledge in tech and relevant people with skills and tech know-how are implicated Interests and motivation for Phillip and for others involved Money for equipment, tech and knowledgeable staff, staff time, staff know how, staff willingness Willingness, motivation, can-do attitude, problem-solve, think outside the box Common sense
DISCURSIVE CONSTRUCTIONS OF INDIVIDUAL AND/OR COLLECTIVE HUMAN ACTORS Family has an interest in sport therefore motivated to involve Phillip in sport - family needs to be interested in order for the child to be included in sport and PA Fit people need to assist disabled C&YP who are wheelchair dependent to move them fast, give them that adrenalin rush and motivate movement mentally and increase heart rate physiologically as best as can be achieved within the limitations and restrictions Sports need to be made 100% accessible - society responsibility, sports clubs and charities responsibility Friends are important for social and mental wellbeing - very important for disabled C&YP - being together in primary and secondary school, consistently enables this Logistics and limitations of ability to get the adrenaline rush and increased heart rate with no mobility/ movement Responsibility of health and safety of the PA provider, inclusion, involvement, fun	**DISCURSIVE CONSTRUCTIONS OF NONHUMAN ACTANTS** The wheelchair is his legs Engines on wheelchairs, give children the fast adrenaline rush feeling and fun feeling Special athletic tracks to enable access for disabled C&YP on motorised equipment Hoists everywhere - aid access to swimming, submerging in water, up mountains, on beaches ****hoists and changeable changing room with wheelchair accessible beach wheelchairs Importance of assistive technology, wheelchair adaptations and technology equipment for involvement and access

POLITICAL/ECONOMIC ELEMENTS Inclusion everywhere, hoists everywhere ****hoists and changeable changing room with wheelchair accessible beach wheelchairs Political and economic responsibility by politicians, councils - shift responsibility to charities - charities then need to fund raise and it is not tax payer and political responsibility, therefore, not seen as society responsibility - it is just a charity - if we feel generous not a MUST	**SOCIOCULTURAL/SYMBOLIC ELEMENTS** Involvement Inclusion everywhere, hoists everywhere Sport - all sport needs to be 100% accessible for all - who is responsible for making this happen? Charity - only if we are generous, not a MUST
TEMPORAL ELEMENTS Age related changes - accessibility and involvement less able as get bigger - increasing height and weight Time to get to surf charity - a day out for Phillip	**SPATIAL ELEMENTS** Wheelchair - access Wheelchair - flat, accessible areas Securing for participation vs health and safety on extreme sports - hold him down? Spatial?
MAJOR ISSUES/DEBATES (USUALLY CONTESTED) Charity vs Government responsibility Society vs government responsibility Health and safety responsibility Legal responsibilities - keep someone safe Civic responsibilities - give them fun Health responsibilities - keep people physically active Personal assistants need to be fit and focused on getting the person they are with physically active in whichever way possible - re: mental involvement, adrenaline rush Adrenaline rush and mental involvement sufficient health benefits? Heart rate sufficiently raised with involvement without personal movement - being rushed about and involved - excitement, shrieks, joy Joy is very important for wellbeing	**RELATED DISCOURSES (HISTORICAL, NARRATIVE, AND/OR VISUAL)** Disabled children and young people hidden and not included More inclusion and involvement as the ages / decades completed Access is good at airports, hotels, so family can get away on holidays Access is not 100% on sport The ability to get movement, involvement is dependent on charities and willingness, can-do attitude of others and family motivation towards sport For very disabled children like Phillip, the only exercise able to get, is therapeutic - is there a way to increase that?
	OTHER KEY ELEMENTS GMFCS Level V - is adrenaline rush enough of a heart rate increase, how do you get heart rate increase when you cannot move?

Appendix 19: Positional Map - Example



I fit in and can play with anybody

The group is for CP, like me and I fit in and can play with everybody in the group

I do not fit into anything

There's no one to play with who is the same as me, or different to me to play with

The group is for CP, like me, but I do not fit in, cannot keep up/have different ability/cannot play in the group

Map Key:

++++ = more so

- - - - = less so