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# BEYOND PHYSIOTHERAPY: VOICES OF CHILDREN AND YOUNG PEOPLE WITH CEREBRAL PALSY AND THEIR PARENTS ABOUT 'PARTICIPATION' IN RECREATIONAL ACTIVITIES

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(VOCAL)



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# Title

Beyond Physiotherapy:  
Voices of Children and Young People  
with cerebral palsy and their parents  
about  
'Participation' in Recreationala Activities  
(VOCAL)

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## **Abstract**

This thesis is about children and young people with cerebral palsy and the emotional well-being impact from their level of participation in recreational activities. A literature review highlighted a gap in knowledge for non-verbal disabled children with limited mobility. They are usually excluded from research and have less choices for recreational activities than typically developing children. Very little is known about their perceptions of their own well-being. Social justice was promoted by centrally positioning their different voices at the centre of this enquiry. The research question explored how children and young people with cerebral palsy and their parents viewed, experienced, and chose their level of participation in recreational activities, to benefit their well-being. This was explored by observing their experiences and intentional behaviours and listening to their parent's views. Positioning theory was applied, which included a triad of their position, social forces, and their own stories-the opportunity to position the disabled child or young person at a recreational activity was the key to their storylines.

An exploratory comparative case study design was developed using visual methods. The storylines of the participants were socially constructed from the evidence of the social forces at play, at the activities where they were positioned. There were two groups, a Participatory Group (N=4) and a Limited Participatory Group (N=3). The participants were aged nine to sixteen years and were supported by their parents in the data collection. Each case included two interviews at the beginning and end of twelve weeks, during which time the parents also kept a diary. Observations were also carried out at one of their usual recreational activities during this time. Photographs were taken by the parent or the researcher, which were used to elicit discussion in the second interview.

Seven cases were analysed utilising an interpretative approach, using Braun and Clark's six stages of thematic analysis. First the Participatory Group were analysed, then the Limited Participatory Group, followed by the across case analysis. Three overall themes were identified from the findings, these included; demonstrating what 'enhanced' participation in recreational activities, including innovative designs and adapted environments; people who 'advocated' for the well-being of disabled children and young people as their 'champions', and people who 'hindered' their participation, by not adapting their communication or attitudes for their needs.



Positioning theory has been further adapted to include the non-verbal children's storylines, represented by a 'Kaleidoscope of Well-being'. This suggests that well-being can fluctuate in different environments, influenced by the social forces of advocates who promoted their needs, with specialist equipment. Participants also showed they could choose not to participate, to determine their own storylines, being their own self-advocates.

Policy makers and designers of equipment and environments should consider exploring how to increase the choices of recreational activities for disabled children. Practitioners should consider how they include participation as an outcome from their interventions. There is a need to explore how health and social care professionals perceive the role of advocacy with disabled children and young people, to enhance their participatory opportunities.

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## Dedication

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who died unexpectedly from COVID-19 in April 2020.  
Philippa was an inspiration to me,  
to keep going on my PhD journey.  
Despite her own arduous experience,  
Philippa never lost sight of  
the value of empirical research,  
to strengthen the physiotherapy profession.*

## **Glossary of Abbreviations**

AAC- Augmentative and Alternate forms of Communication  
APCP- Association of Paediatric Chartered Physiotherapists  
ARTA- American Therapeutic Recreation Association  
BCUHB- Betsi Cadwaladr University Health Board  
CASP- Critical Appraisal Skills Programme  
CFCS- Communication Functional Classification System  
CSP- Chartered Society of Physiotherapy  
DSW Disability Sport Wales  
DCCS- Disabled Children's Childhood Studies  
FCC- Family Centred Care  
fPRC- family of Participation Related Constructs  
GMFCS- Gross Motor Function Classification System  
GMFM-Gross Motor Function Measure  
ICF- International Classification of Functioning  
IPA- Interpretative Phenomenological Approach  
Levels I, II, III, IV, and V of GMFCS/ CFCS expressed as Roman numerals  
LPG- Limited Participatory Group  
MAPi- Method using audit and feedback to capture participation implementation  
MPOC- Measure of the Processes of Care  
MPOC-SP Measure of the Processes of Care for Service Providers  
NIHR- National Institute for Health Research INVOLVE  
NHS- National Health Service  
NICE- The National Institute for Health and Care Excellence  
PA- Personal Assistant  
PG- Participatory Group  
PMLD- Profound and Multiple Learning Disability  
RAs- Recreational Activities  
UK- United Kingdom  
UNCRC- United Nations Convention on the Rights of the Child

UNICEF-United Nations Children's Fund

USA- United States of America

VOCAL- Study's title abbreviation: Beyond Physiotherapy: Voices of Children and Young People with cerebral palsy and their parents about 'Participation' in Recreational Activities

WAV- Wheelchair Adapted Vehicle

WB- Well-being

WHO- World Health Organisation

WIMD- Welsh Index of Multiple Deprivation

## **Summary of chapters**

This summary will outline an overview of what the reader can expect in each of the eight chapters, to signpost how my thesis was structured. It begins with the constructs of existing meanings and progresses to explore how the voices of disabled children can be represented authentically. The findings are presented logically, then discussed and suggestions made for future research to expand physiotherapy beyond current practice.

### **Chapter 1: Background and introduction**

Chapter one sets out the background for this study outlining what is known about cerebral palsy, physiotherapy in relation to participation outcomes, family centred care and the current knowledge about disabled children's opportunities for participation in recreational activities. The diverse meanings of participation and well-being are explored, including the concept of self-advocacy. Childhood, adolescence and children's rights are described, introducing a new research paradigm of Disabled Children's Childhood Studies. An aim of this study is to position the voices of disabled children centrally, to include those without a physical voice, who communicate differently and have mobility limitations.

### **Chapter 2: Literature review**

Chapter two outlines the literature search strategy, with critique of relevant studies to reveal the lack of voices from disabled children and young people about the well-being effects from their participation in recreational activities. Positioning theory is introduced which has not been previously applied with physically disabled children and young people. Positioning theory is made up from a mutually determining triad of 'position, social forces and storylines'. This illustrates how the child's physical and metaphorical positions, people and environments can influence their experiences of participation in recreational activities, which then determines the storylines of disabled children. Some studies provided relevant evidence that creative approaches and a case study design could enable rich data to be generated. The gap in this literature review highlighted that little is known about the well-being impact for children and young people living with cerebral palsy, from their views, experiences, and choices from their level of participation in recreational activities. The research question and aims are outlined here to explore this further.

### **Chapter 3: Methodology**

Chapter three has three sections: the wider qualitative research approaches and theoretical basis; the components of the exploratory multiple comparative case study are covered, and the data collection and six stages of analysis are outlined. Each case was made up of two interviews, a diary, observations of the child or young persons' intentional behaviours and artefacts (photographs). There were two groups, a participatory group and limited participatory group to enable comparisons to take place. The ethical position as a form of social justice is described, to keep the voices of disabled children and young people central to this enquiry. Rigour in the management of the data is described, including my reflexivity during the process. Using an interpretative approach, meaning is socially constructed throughout the analysis.

### **Chapter 4: Findings: Within case: Participatory group**

Chapter four presents the within case findings of the four case studies in the participatory group. The data provides evidence of the storylines of the emotional well-being impact from the children and young people's high levels of participation in recreational activities. Key findings to come from this group were the innovative designs of equipment and the need to adapt these for appropriate indoor and outdoor environments. These created the participatory opportunities where the children and young people could be positioned, ready to participate in a recreational activity. It was reported that people in their communities did not know how to relate to and include the participants in arts and crafts activities. Changing places toilets and mobile hoists were key facilitators for participation in recreational activities. The participants also showed they could sometimes choose not to participate even when they had previously enjoyed the activity, demonstrating their own agency and self-advocacy.

### **Chapter 5: Findings: Within case: Limited Participatory Group**

Chapter five outlines the findings of the three case studies in the limited participatory group. The participants' limited ability to change their physical positions due to the complexity of their disability or preferred behaviours, led to pressure sores. Epilepsy was another factor that impeded participation in recreational activities. Additionally, perceived negative attitudes and lack of advertising of adapted activities also limited all their choices and reduced their own agency. Being treated differently was a concern when seeking to book online for activities including the theatre and cinema.

A new initiative of a relaxed orchestral performance was a bonus. All aspired for future participation in outdoor recreational activities, including theme parks, of which changing places toilets would be catalysts to enable this to happen.

### **Chapter 6: Findings: Across Case analysis**

Chapter six describes the three overall themes from the seven case studies which were participation enhancers; champions for disabled children and young people's emotional well-being and hindrances to participation. Their storylines were determined by a mixture of their intentional behaviours and the social forces of people, who could navigate the specialised equipment in environments suitable for them to be positioned, to choose their level of participation as self-advocates. Parents were the key advocates to promote their child's participation, and this was supported by some helpful professionals who also acted as advocates. A key enhancer of participation were innovative designs such as with surfing, bike riding and skiing. These were supported by volunteers, some of whom were equipped with training to support the reasonable adjustments. The hindrances to participation were parental perceptions of being treated differently by undermining attitudes and not making reasonable adjustments for the disabled child's needs. A lack of choice was evident in the limited participatory group due to the complexity of their level of cerebral palsy, although there was some overlap between the two groups of the types of activities that they participated in, particularly music and sensory based.

### **Chapter 7: Discussion**

Chapter seven discusses how positioning theory has been adapted to include the non-verbal disabled children and young people's responses to indicate well-being. A 'Kaleidoscope of Well-being' is proposed, with advocacy and self-advocacy central to the disabled children and young people's experiences, which enhanced their emotional well-being from their level of participation in recreational activities. The light reflecting through different colours in the kaleidoscope are explored in two figures, as metaphors to express the child or young person's emotions, such as joy or sadness. The three main theme's findings as discussed with reference to austerity and COVID-19. The lack of literature on positioning theory in this context, supports the notion that my work is adding to knowledge. The parents were key advocates for their child or young person, along with the connectivity with people who could support the design of new opportunities. Physiotherapy practitioners should consider



if well-being from participation in recreational activities could become an important feature of current practice, to begin to address the social injustice for disabled children and young people.

### **Chapter 8: Conclusion**

Chapter eight draws the thesis together presenting the original contribution to knowledge. Study limitations are acknowledged, publication and dissemination strategies to help inform impact are outlined, including my positionality and personal reflections upon the research journey. Recommendations for health and social care practitioners are made, including suggestions for future research.

## **Chapter 1: Background to the study: Definitions and context**

### **1.1 Introduction**

This first chapter will provide the background and context for my PhD, starting with an outline of the study. It is set up in this way to provide the reader with an idea of the main constructs and terminology used throughout. Cerebral palsy is described and how physiotherapists work within a framework of Family Centred Care (FCC). Participation in recreational activities (RAs) and well-being (WB) meanings are explored and models of disability outlined, related to the World Health Organisation's (WHO), International Classification of Functioning (ICF) (WHO 2001). This is then contrasted with the sociological discourse of childhood. The meanings of childhood and children's rights, obtaining consent and valuing the child's opinion, are introduced within the context of a new paradigm of Disabled Children's Childhood Studies (DCCS), where the child's voice is central to research (Curran and Runswick-Cole 2013). I make the case to ethically position their voices centrally in my study, to enhance their agency (an active force that promotes benefits). This chapter ends with a summary of the background and context for my study, signposting to the literature review chapter.

#### **1.1.1 Outline of the Study**

My thesis is about children and young people with cerebral palsy and their carer's perceived emotional WB impact, from their level of participation in RAs. The abbreviation for this study is VOCAL, the full title being "Beyond Physiotherapy: Voices of Children and Young People with cerebral palsy and their parents about 'Participation' in Recreationala Activities". Cerebral palsy is a non-progressive neurological disorder, affecting children and young people who now live into adulthood (Rosenbaum and Rosenbloom 2012). Their limitations include physical, communication and learning disabilities, which has limited their research involvement to date. Therefore, I make the case to include the children and young people without a physical voice, to ensure their representation in research is increased. My position, now as a researcher, was to explore the recreational activity possibilities for the non-mobile, non-verbal children, whom I had always felt challenged that I was not able offer enough signposting to, in my previous clinical practice. Cerebral palsy makes up

a significant proportion of children's physiotherapy caseloads and has the most condition specific research to date to draw upon, predominantly done with ambulant children (Pountney 2007; Kerr et al 2007; Kerr et al 2008; Kerr et al 2011; Colver et al. 2013). Physiotherapy practice with children and young people with cerebral palsy is described within the healthcare policy framework of FCC (The Kings Fund 2005). Emphasis is placed upon their individualised nature in their healthcare provision. Participation meanings are explored, and different perspectives of WB are defined and related to the context of cerebral palsy (Imms et al 2006; 2017; Adair et al 2018).

RAs are proposed to provide a positive emotional WB effect which promotes fun in the lives of disabled children and young people (Rosenbaum and Gorter 2012; Msall 2013; United Nations Children's Fund 2013; Lauruschkus et al 2015). Physiotherapists can signpost families to activities which match or stretch their children and young people's capabilities. Whilst it is not always possible to change the children and young people physical abilities, they can still benefit emotionally from participation at their level of capability, sometimes this can be through social participation (Park and Kim 2015; Van Mo et al 2015; Piskur 2017). However, although the WB effects from participation in a RAs is thought to be beneficial, these emotional benefits from participation are reported less in the research literature. Currently, very little is known about disabled children and young people's own perceptions of their WB.

In **my** study, children and young people with cerebral palsy (called disabled children and young people throughout this thesis to fit with the DCCS's principles) and their carers, were therefore asked about their perceived impact upon their emotional WB, from their level of participation in RAs. The aim of my research was to explore the disabled children and young people views, experiences and choices for RAs and how they and their carers perceived their level of participation impacted upon their emotional WB. The next section will describe what is known about cerebral palsy.

## **1.2 Cerebral Palsy**

In the context of childhood disability, cerebral palsy makes up a large proportion of children and young people in societies across the world (Colver et al. 2013; United Nations Children's Fund 2013). The term literally means, weakness of the brain, as translated from the Latin. Although Colver et al (2013) report that the prevalence of the condition in Europe has not changed over the past forty years, remaining stable at 2-3.5 per 1,000 live births, Sellier et al (2016) report a decrease to 1.7 per 1,000 live

births. Additionally, recent evidence from Australia has demonstrated the prevalence has now further decreased to 1.4 per 1,000 live births (Australian Cerebral Palsy Register report 2018). Whilst Australia may not be directly comparable, this data is not yet available in Wales.

### **1.2.1 Prevalence**

In Wales, current recording of the prevalence of cerebral palsy has a lack of consistency in the terminology used, making it difficult to estimate the total population of children with cerebral palsy (Office for National Statistics, 2015). A register for cerebral palsy in Wales is currently being developed, but this was not available at the time of writing (BBC, 2019). However, preliminary data suggest that in Wales, there are currently around 1,800 children with cerebral palsy under the age of eighteen years (Jenny Carroll, personal communication). However, Northern Ireland does have a register, here the prevalence of 0-18 years from 1994-2011 was 870 born with cerebral palsy and 139 acquired this, so a total of 1009. This gives a prevalence of 2.06 per 1,000 live births (Karen McConnell, personal communication 2020). For those aged nine to sixteen years, there were 439 children, of which, 195 (44.4%) were functioning at Levels III-V of the Gross Motor Function Classification System (GMFCS) (CanChild, 2021). This means they either used a walking aid or were unable to walk. Charity sources estimate that there are 30,000 children across the United Kingdom (UK) with cerebral palsy, a third of whom are unable to walk (PACE Centre, 2016). So, this is a significant number of children requiring support from healthcare providers, including physiotherapists, to achieve their best quality of life (QoL).

### **1.2.2 Clinical presentation and definition**

The clinical presentation of cerebral palsy has changed, due to a higher number of very low birth weight babies surviving. Today, fewer full-term babies are suffering from birth asphyxia, as a higher number of elective caesareans are being carried out, and more is now known about in-utero developmental malformations (Rosenbaum and Rosenbloom 2012; Colver et al. 2013). In summary, cerebral palsy is a non-progressive neurological condition, presenting in early childhood, resulting in motor and sensory disorders which can affect developmental progress. The latest consensus definition of cerebral palsy is:

*“...a group of permanent disorders of the development of movement and posture, causing activity limitations that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor*

*disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication and behaviour, by epilepsy, and by secondary musculoskeletal problems.”* (Rosenbaum et al. 2006 p.9)

This definition was achieved following much debate about whether cerebral palsy should be considered a disease, a condition, a diagnosis or a developmental disorder. Colver et al (2013) have now suggested cerebral palsy is called a syndrome, as it encompasses this group of associated and interrelated symptoms.

Physiotherapists are key professionals who provide some objective evidence of the child's early motor development to support or refute this emerging diagnosis, particularly around changes in muscle tone (Pountney 2007; Raine et al 2009; Mayston 2011). There are four types of cerebral palsy: spastic, dyskinetic, ataxic and hypotonic (Australian Cerebral Palsy Register report 2018). These different types with varying tone help in directing clinical staff and parents to appropriate management strategies. Early intervention will achieve the optimal outcomes, by influencing the neural development as the child grows, based upon the principles of neuroplasticity (Shumway-Cook and Woollacott 2012; Colver et al. 2013).

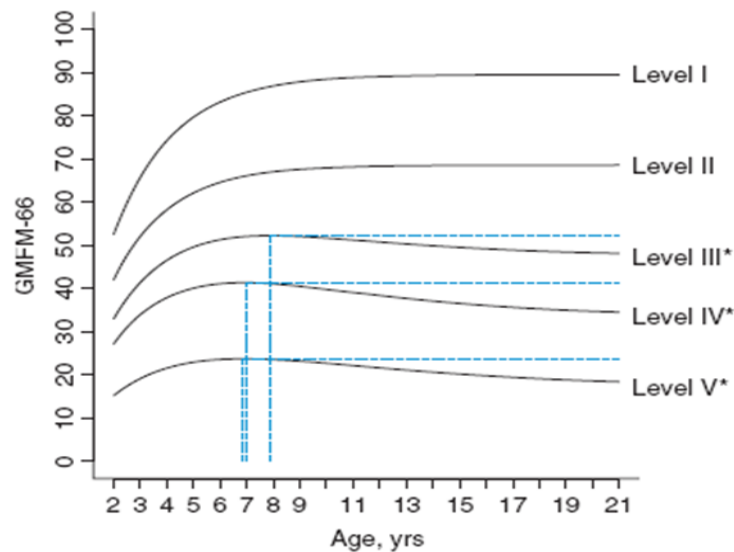
There is a limited evidence base to support what treatments are effective for cerebral palsy (Rosenbaum and Rosenbloom 2012; Novak et al 2013). Current approaches offer some hands-on treatment skills (known as facilitation), supportive and stimulatory equipment (including sleep systems, standing frames and specialised chairs), splints, orthotics (spine, ankle and wrist), surgical and injection therapies and a large role in educating parents to become experts in their child's management (Pountney 2007; Bower and Finnie 2009). The National Institute for Health and Care Excellence (NICE) developed two key guidelines for cerebral palsy, one specifically on spasticity management and one on overall management (NICE 2012; NICE 2017). The NICE (2017) guidelines were developed during my study's duration, one key suggestion for future research was to look at the emotional WB for these children and young people and their families. If families and children and young people could be engaged in participating in RAs, to take control of their own health and WB, this could be a positive step towards their empowerment and reduce their demands upon their health services.

### **1.2.3 Long-term effects**

The symptoms in cerebral palsy relate to the area of brain damaged by the original injury. However, although cerebral palsy is not progressive, as the child grows the

effects upon a growing skeleton with asymmetrical muscle control, can lead to muscle shortening, contractures and bony deformities. The age of puberty (from eight to fourteen years when there is a final growth spurt), can accentuate postural malalignment, sometimes resulting in the need for corrective surgery. This surgery is necessary to manage dislocated hips and scoliotic spines, to improve respiratory capacity, enable hygiene tasks and positioning in equipment to maintain comfort, alignment and to reduce pain (Lyons 2013).

The changes in muscle tone can affect balance reactions as well as motor control, impacting upon the children and young people's functional abilities. There are predictive curves based upon Gross Motor Function Measure (GMFM) scores at a young age (Russell et al. 2002), such as two years, which provide a trajectory of sitting, standing and walking abilities into adolescence (Hanna et al 2008; Palisano et al. 2010). As the level of brain injury can vary, reliable measures have been validated to seek to classify how the children and young people describe themselves, an example of the Gross Motor Function Classification System- Expanded and Revised (GMFCS E & R) is shown in Appendix 1 (CanChild 2021). There are two age groups to illustrate these GMFCS E & R levels; six to twelve; twelve to eighteen years. The descriptors are matched with illustrations of different levels of functional ability. Five levels of ability are described I-V, with I being an ambulant child able to walk upstairs carrying something, to V being totally dependent for all care and mobility needs. Children at Level IV and V are non-ambulant, and this lack of weight bearing reduces their bone density, leaving them prone to osteoporosis, fractures, hip dislocation and scoliosis. It is also much harder for GMFCS IV and V, to be able to participate in physical RAs, due to these limited weight-bearing abilities, especially as they grow into adolescence and require hoisting due to manual handling regulations (Manual Handling 1998; Association of Paediatric Chartered Physiotherapists 2016). Additionally, research by Hanna et al (2008), demonstrated a downward trajectory of gross motor function, particularly for the less mobile children and young people as shown in Figure 1.



**Figure 1: Gross motor predictions of ability by age (Hanna et al 2008)**

Figure 1 shows that in middle childhood, from around aged eight years, it is likely that the child's level of functional motor ability will decrease if at GMFCS III and this will occur from age seven, if at GMFCS IV and V (Hanna et al 2008). The young people's diminishing level of functional ability as they mature into adolescence, for GMFCS III-V, influences the types of RAs that they can participate in.

Another valid and reliable measure was developed by Hidecker et al. (2011), the Communication Function Classification System (CFCFS), which also has five levels I-V, and the degree of communication ability is correlated to the Levels with I being the most able and V the least able (Appendix 2). The CFCFS is key to the child or young person being able to relay their intentional choices and needs, enabling them to promote their own agency. When they cannot make their needs understood, their behaviour can change and, in some instances, self-harm can occur out of pain, frustration or boredom. These measures, the GMFCS and CFCFS, provide descriptive ways that does not overly medicalise the child's abilities. The next section will expand upon physiotherapy and FCC.

### **1.3 Physiotherapy and Family Centred Care**

Physiotherapists working with children and young people with cerebral palsy have a varied role. Part of this role may involve some hands-on treatments (Pountney 2007; Bower 2009; Raine et al 2009; Mayston 2012; Chartered Society of Physiotherapy (CSP) (2016). There is a need to optimise the alignment of the physical position of the

children and young people to maximise their participation in any activity. This always begins with a starting position, based upon the children and young people physical capability in relation to their resting muscle tone. Sometimes manual skills are used which are also taught to parents, water can provide buoyancy to support weak muscles or equipment is used, such as a specialised chair, to enable participation in an activity such as eating. Illustrations of two of these activities can be seen in Figures 2 and 3. Physiotherapists work in partnership with parents, to maximise the child's functional abilities, which then enables them to participate in RAs, from the choices in their community. These opportunities create the storylines of their lived experiences which can bring fun and enjoyment and enhance the WB of the disabled children and young people and their family.



**Figure 2 Child with cerebral palsy enjoying water-based activity**

[Found image  
<https://www.bing.com/images/search?view=detailV2&ccid=9CxvyPD7&id=A64E95B089905AC9BB01255B65783B85220E36D2&thid=OIP.9CxvyPD7IVu0uoR3x4yF2AHaE2&mediurl=https%3a%2f%2fwww.mycerebralpalsychild.org%2fwp-content%2fuploads%2f2018%2f02%2fcerebral-palsy-aquatic-therapy.jpg&exph=795&expw=1215&q=child+with+cerebral+palsy+images+free+to+use&simid=608046573376307718&ck=35724BD5E6969FE24A7C3F2C6F6FA5BC&selectedIndex=48&FORM=IRPRST&ajaxhist=0>] [Accessed 25.09.20]





**Figure 3 Child positioned in specialised chair to reach a computer**

[Foundimage<https://www.bing.com/images/search?q=Child+with+cerebral+palsy+playing&qpv=Child+with+cerebral+palsy+playing&form=EQNASM&first=1&scenario=ImageBasicHover>[Accessed 25.09.20]]

In the community, the disabled children and young people would need to be physically positioned at a RA of interest to them, to be able to choose to participate. Sometimes they would need additional equipment to make this possible such as an adapted trike (Pickering et al, 2012). The parents are the key people who would transport them to available RAs and physically position them ready to participate. The parents could have been signposted by an education, health or social care professional to these activities. This approach of signposting and providing additional information is part of FCC.

FCC is a philosophy and method of service delivery which recognises parents as experts in their child's needs and promotes a partnership between service providers and parents, supporting their role in decision making (Maggs et al, 2011; King and Chiarello 2014; McDowell et al. 2015). This philosophy of care underpins UK healthcare policy which claims to embrace FCC, but evidence suggests it fails to do this in practice, in some areas of healthcare (Jeglinsky et al. 2012; McDowell et al. 2015; Public Health Wales 2017). There are two reliable and valid measures, the Measure of the Processes of Care (MPOC) and the Measure of the Processes of Care for Service Providers (MPOC-SP) which were developed to measure FCC (King et al. 2004b). For example, my previous research, identified that professionals are not as effective as they could be, in providing information to parents of disabled children and young people, about wider opportunities and services to support them (Pickering and

Busse 2010a, b). This includes information about respite care and RAs that their child could participate in. It appears that current practice has not significantly improved, as shown by McDowell et al (2015) in that FCC continues to be limited in providing this additional information to parents.

In Wales, the context for this study, the policy is about 'Prudent healthcare' (Aylward et al. 2013). Prudent healthcare proposes that healthcare should fit the needs and circumstances of the person, avoid waste and harm, not continue with activities that do not bring benefits and make the best use of the limited financial resources. For children and young people living with long-term conditions, such as cerebral palsy, there is the possibility they could contribute as equal partners in co-production research, to develop a better understanding of how to improve their own emotional health and WB. This could then reduce their demands on the National Health Service's (NHS)<sup>1</sup> as they become empowered to self-manage. However, there is currently no evidence to suggest that disabled children and young people have been consulted about their WB in Wales. The data collected were not specific enough as the recent focus was on obesity not WB (Public Health Wales 2017). Hence the need for a cerebral palsy register where data, including WB outcomes could be collected.

Physiotherapists would usually focus on physical activity outcomes to enable the children and young people to improve the quality of their movements, but an emphasis towards 'activity' was changed, following Damiano's (2006) perspectives paper. The activity domain of the WHO is closely aligned to participation, encouraging practitioners to think holistically about the effects that their interventions have, which are delivered at the body structure and function domain (WHO, 2001). Damiano (2006) argued for the benefits to health and WB from staying as active as possible with neurological conditions. A recent scoping review by Buscemi et al (2019) suggested that novel approaches were needed to increase accessibility and engagement in physical activity irrespective of neurological disease type in adults. However, for children and young people with cerebral palsy, which is not neurodegenerative, activity is likely to be achieved through play activities that motivate and engage the children and young people. These are the types of RAs that physiotherapists may signpost families to but are often not captured as outcomes from

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<sup>1</sup> NHS- the National Health Service is the statutory health provision across the United Kingdom and is free at the point of delivery.

practice. Evidence so far in Canada and England, supports the low uptake of measuring participation outcomes from physiotherapy practice (Shikako-Thomas and Law 2015; Kolehmainen et al. 2020). The reasons for this are not yet fully understood, but the ambiguity of the meaning of participation could be contributing to this as well as a lack of understanding related to advocacy. Therefore, an exploration of the wider meanings of participation and advocacy were considered in my review of the literature, to include both medical and sociological lenses.

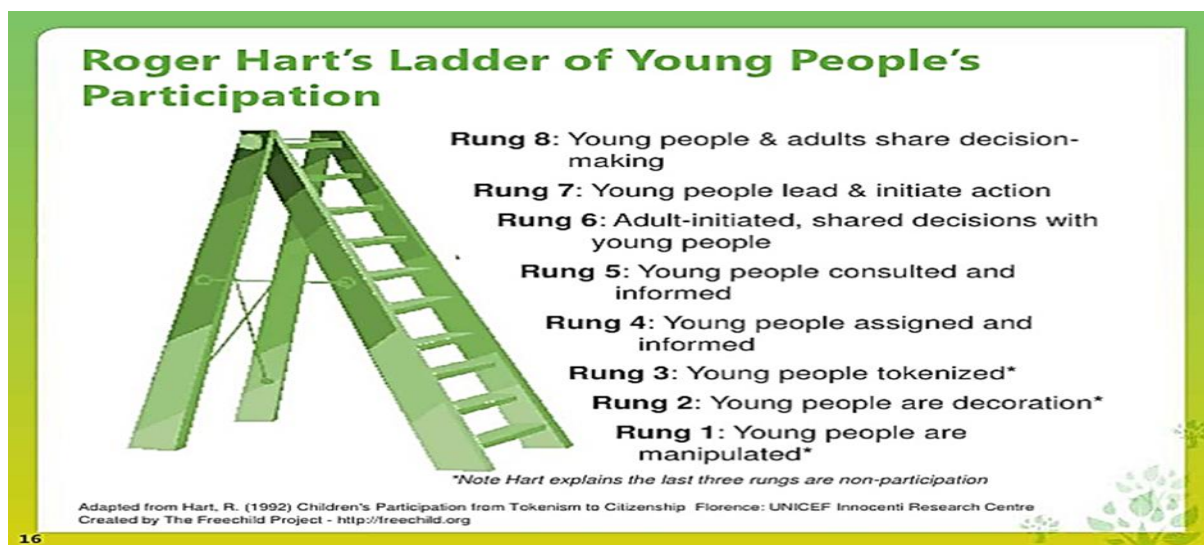
#### **1.4 Participation and Advocacy**

Participation is defined in different ways for health and social care contexts. The emphasis in health had been based upon the WHO ICF, defining the participation domain as '*involvement in life situations*' (WHO 2001 p.10). This WHO ICF model has now been redefined to include children and young people priorities for their health and WB (WHO 2007; 2012; 2015). The domain of participation has been researched since the inception of the WHO ICF in 2001. Granlund (2013) suggested the areas which remain under-researched by practitioners related to its conceptualisation, measurement and intervention.

Focusing more on the conceptualisation and seeking to determine what participation means, it is more usual in social science literature, not to be condition specific. The sociological perspective is about people, not medical conditions (Shakespeare 2014). Therefore, in the social science literature, participation has a different meaning, based upon children's rights (United Nations Children's Fund 1989). Kellet (2014) defines participation as the '*Act of doing and being involved*' where both voice and agency play a role in influencing change (Clark et al. 2014 p.34). Here, children and young people are valued as social actors and agents of change, which legitimises their voices being heard. Agency is defined as an active force that promotes benefits, which in my study relates to the WB of disabled children and young people (Collins English Dictionary, 2020). Agency is closely aligned to advocacy. Advocacy has been defined by Devakumar et al (2016) as '*speaking out on behalf of a particular issue, idea or person, acting as a catalyst for change*'. In my study, I am aiming to advocate on the disabled children and young people's behalf, through my findings, to promote change for future opportunities for participation in RAs to benefit their WB. The idea of social forces that position the disabled child where they can influence their choices to benefit

their WB, can include other people advocating for their needs, but they can also interact in the situations to advocate for their own WB.

Previously, Hart (1992) developed a ladder of participation, which gave a visual representation of hierarchical rungs where children's participation in decision making was deemed, at worst, to be tokenistic and, at best, to be taking the lead. This is shown in Figure 4 but although dated and not specifically based upon disabled children's experiences, it still has relevance to include those often marginalised in society.



**Figure 4: Hart's participation ladder (1992)**

Hart's ladder offers a basis for considering how effectively children and young people are engaged in a consultation process, about things which are important to their lives. Treseder (1997) then suggested a circle of participation, whereby the inclusive nature of a circle suggests it is less hierarchical, but a cyclical process where ongoing consultation is included. Additionally, my previous research about adapted cycling, illustrated the children's voices by using a wheel of participation, the hubs and spokes being the environments and people who influenced their participatory physical activity opportunities (Pickering et al. 2015). Furthermore, pilot work for my thesis, now published, has illustrated the voices of disabled children and young people about wider participation in RAs, celebrating their abilities using creative methods, including a digital story, collages and sandboxing (Mannay 2015; Pickering, 2018).

By combining the WHO ICF (2001) and the social constructs of participation, both can have a relevance to the lives of disabled children and young people. To promote their agency and voice in terms of RAs, this requires choices to be made available for them,

by those who might advocate for them. Whilst healthcare professionals and parents can anticipate the physical health and emotional WB benefits from participation in RAs, it is not known if children and young people with cerebral palsy understand what effect this can have, or how they might influence the development of new choices for themselves as self-advocates. Self-advocacy means “*the action of representing oneself or one's views or interests*” (Oxford Dictionary, 2021). Tideman and Svensson (2016) proposed that self-advocacy could promote a positive social identity for those with intellectual difficulties. Thus, their social and environmental participation can promote their involvement at a level they are comfortable with. However, whilst there is some evidence of social participation and environmental influences from international studies (King et al. 2013a; Lauruschkus et al, 2015; Majnemer et al. 2015; Piškur et al. 2017), the picture is unclear in Wales.

In chapter two, more studies relating to participation will be critiqued, however the most recent evidence to support the construct of participation in this context of disabled children and young people, is the family of Participation Related Constructs (fPRC) (Imms et al 2016; 2017, Adair et al 2018). The fPRC defines participation more broadly than the WHO ICF, focusing upon ‘attendance’ and ‘involvement’ as the two main factors. This makes ‘activities’ and ‘participation’ more congruent and applicable to any situation, at home or in the community. The fPRC offers a broadening of previous understandings of participation and less of a physical activity emphasis. The fPRC suggests it is possible, to explore more around emotional WB with children and young people with cerebral palsy, if they are not just being measured by their physical participation.

In UK healthcare contexts, due to organisational and service delivery constraints, participation is not usually a direct outcome from treatments currently offered by physiotherapists working in the NHS, rather by signposting to the available choices. Kolehmainen et al (2020) have developed a method using audit and feedback to capture participation implementation (MAPI). It is uncertain if physiotherapists working with children and young people with cerebral palsy, overtly consider the WB outcomes as equally important as the physical outcomes, from their signposting to participation in RAs. In Kolehmainen et al’s (2020) study, participation had a low (30%) uptake of being measured as an outcome from interventions.

#### **1.4.1 Reasonable Adjustments to support participation**

Despite the uncertainty of how physiotherapists measure participation, they are key professionals who can listen to families. They can advise about reasonable adjustments and risk assessments, to improve these RAs, although this is not part of the NHS provision. Although Mayston (2005) had suggested that WB was an important factor for the families of children and young people with cerebral palsy and that participation was a key feature to enhance this, it relies upon availability in the community, currently out of the NHS's influence. Reasonable adjustment is a term developed within the Equality Act (2010) to enable those with a disability, one of the nine protected characteristics (others are Race and Ethnicity, Age, Gender, Gender Reassignment, Pregnancy and Maternity, Religion or Belief, Sexual Orientation, Marriage and Civil partnership) to participate in life situations such as sport and recreation. Children and young people with cerebral palsy have had limited consultation about choices for RAs in Wales. This consultation process was started by the Bevan Foundation (2011), which is an influential Welsh think tank, aiming to help improve people's lives who are living with the effects of inequality, injustice and poverty.

One innovative approach in Wales, was a partnership set up between Betsi Cadwaladr University Health Board (BCUHB) and Disability Sport Wales (DSW) (BCUHB 2015). This arrangement was aimed to promote more activity amongst disabled people, covered both adults and children and involved a physiotherapist on secondment to the local authority, aiming to increase sport's participation. Whilst this was evaluated as a positive initiative, it has not been adopted by the Welsh Government to date (Catherine Chin, personal communication). However, for those children and young people at GMFCS III-V, their ability to change their physical activity behaviour is limited. Especially as they mature into adolescence, but their social participation may still provide emotional WB benefits, which can improve their QoL.

#### **1.4.2 Disabled Children and Young people's Choices for Recreational Activities**

Recent initiatives in the UK have seen investment from government, business, media and charities, to promote play activities for children. Sainsbury's supermarket has introduced the 'Active Kids: Eat well, Move well, Live Well' campaign, which sought to promote sport and cooking in schools, sports clubs and scout and guide organisations

by public voucher collection (Sainsburys 2016). This also had a disability emphasis and partnered with cerebral palsy Sport to maximise its impact.

Cerebral palsy Sport originated from the 1960s linked to the former spastic's society and the Stoke Mandeville Paralympic games, taking this title in 1978 and is an international organisation (cerebral palsy Sport 2015). cerebral palsy sport's strapline is 'Play, Participate, Enjoy', their mission being to promote participation in sport and RAs. However, a review by Weed et al (2012), of the legacy from the London 2012 Olympics and Paralympics, suggested that the success was captured in the festival event, rather than an increase in sports' participation in the population. Weed et al (2012) advocate that policy makers should consider how to promote community activities as fun events and not emphasize the sporting or competitive attributes. This would make activities more accessible to a wider audience, including disabled children and young people. It may encompass a sense of belonging, rather than always being achievement focused, which can be difficult for some disabled children and young people to engage with. This move towards increasing participation, introduced by cerebral palsy Sport, is as much about taking part, not just winning. The sporting activities which have been adapted which are available for disabled children and young people are wide and varied. These include, for example: horse riding, swimming, cycling, skiing, surfing, sailing, frame football, wheelchair and tag rugby, dance, athletics and more recently RaceRunning (Hansen 1991). These cerebral palsy sport's developments are encouraging and broaden the possibilities for wider participation, not necessarily competitive activities, to enhance the WB of disabled children and young people. WB definitions will now be explored.

### **1.5 Well-being and Expressions of Well-being**

Watson et al (2012) described emotional WB as both an embodied, subjectively experienced phenomena and a contextual and relational dynamic. Each child and young people does not exist in isolation from their family, school or community. It is however harder to express emotional WB if you have a communication or learning disability and experience either epilepsy, fatigue or pain (Opheim et al. 2009; Suave 2010; Voorman et al. 2010). Children and young people with cerebral palsy can express their distress by crying, shouting, self-harming behaviours such as biting and hitting, and increased spasticity, which affects their posture and reduces their comfort (Rosenbaum et al 2006; Lyons 2013). As they already have movement control

limitations, their position to minimise discomfort or pain needs managing, which is part of the physiotherapist's role. If this is not addressed, their WB is compromised, before they might consider participating in any RA.

Emotional WB has also been defined by the Mental Health Foundation as:

*“A positive sense of Well-Being, which enables an individual to be able to function in society and meet demands of everyday life; people in good mental health have the ability to recover effectively from illness, change or misfortune”* (Lite 2012 p.4).

Additionally, WB has been described by Huppert and So (2013), showing features of feeling and functioning behaviours, such as showing competence, emotional stability, engagement, meaning, optimism, positive emotion and relationships, resilience and vitality. These attributes can lead to empowerment, which enables an individual to be more self-determined and autonomous (Watson et al. 2012). WB can also be about a positive self-esteem, feeling good about yourself and being able to contribute to your community in a meaningful way (Langford et al. 2014).

Finally, WB is also defined by the World Health Organisation (2001 p.5) as:

*“a state in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully and is able to make a contribution to his or her community.”*

One way to enhance emotional WB for disabled children and young people, is to explore participating in a meaningful RA. Therefore, if opportunities are created to try new activities, this has the possibility to support their emotional WB. Additionally, a recent systematic review by Mpundu-Kaambwa et al (2017; 2018) confirmed that the Patient reported QoL measures used, which included aspects of WB, had not demonstrated reliability, construct validity or suitability for this population with cerebral palsy. These measures included the Health Utilities Index—Mark 2 and 3 (HUI-2 and HUI-3), the Assessment Quality of Life-4 dimension (AQoL-4D) and the EuroQol-5 dimension 3 level (EQ-5D-3L). The HUI-3 was reported to show the strongest psychometric properties but did not cover WB in any detail. Therefore, this remains unknown at the present time due to this difficulty in reliably measuring this with children and young people with cerebral palsy with communication and learning difficulties.

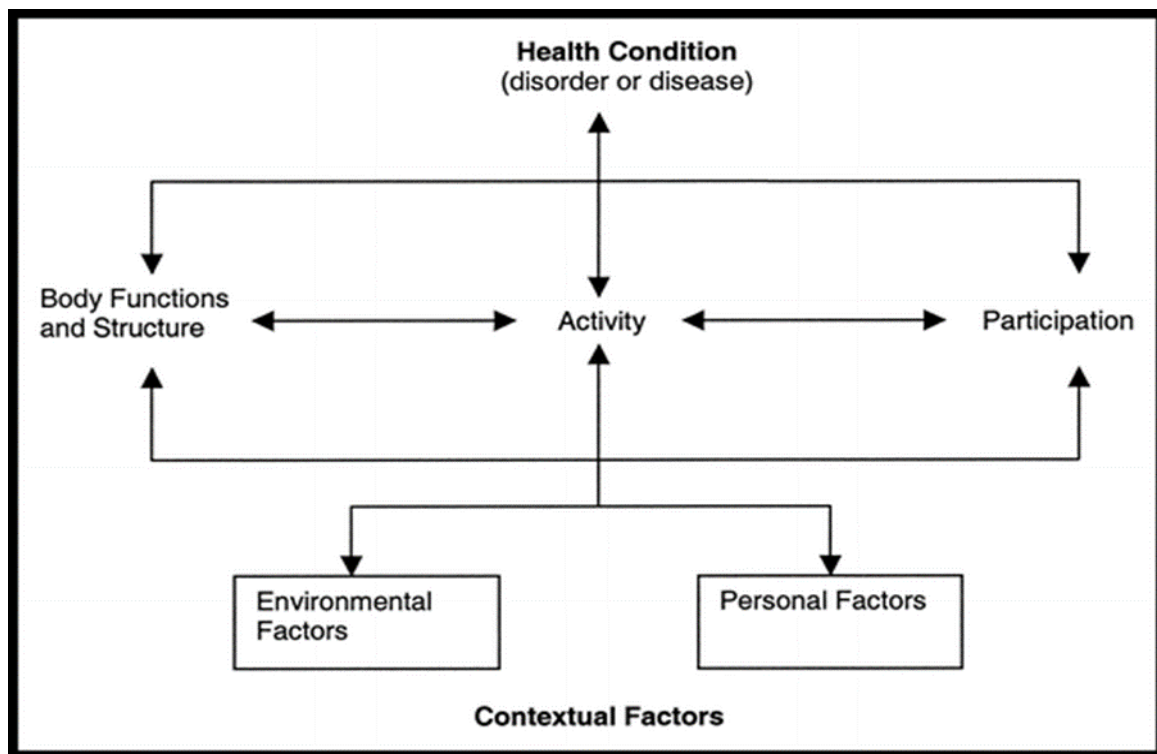


## **1.6 Models of Disability: Medical, Social and Affirmative**

Physiotherapy approaches to management are not always condition specific, the influence of the medical model has previously been the dominant force (WHO 1997; WHO ICF 2001). This medical model had given less direct credence to the voices of disabled children and young people, seeking instead to negotiate with parents on their behalf in a paternalistic approach, seeking to normalise the child (e.g. to achieve walking). Thus, when walking is not possible, it potentially projects failure to the family and child (LeRoy et al 2015).

The social model of disability (Swain et al 1993), in contrast, views that disability is framed by societal and environmental factors such as attitudes and physical barriers, which could be changed, e.g. steps or ramps to facilitate access (Shakespeare 2014). However, if things do not change, people can feel excluded and undervalued. A further suggestion is for an 'affirmation' model of disability where there is a positive identity with impairment, so rather than being considered deficient in some way, difference is celebrated and endorsed rather than changed to become 'normal' (French and Swain 2000; Gibson, 2016). If this were applied, then children could feel valued for who they are, not what they might become. This is a paradox with physiotherapy practice, whereby practitioners work with children and young people to build their capacity, to improve function, although this will never be 'normal' in cerebral palsy (Bower 2009). Then in adolescence, these young people may lose their mobility, as their bodies become taller and heavier, making walking less efficient to maintain (Donkervoort et al 2007). So, Gibson (2016) suggests that practitioners are complicit in reinforcing that a person is only valued if they can achieve 'normal'.

The WHO ICF (2001) model seeks to combine the health condition with the experiences of individuals within their culture and context. The WHO ICF includes both the medical and social models of disability and participation is one of the key domains, alongside body functions and structure and activity. This model is illustrated in Figure 5.



**Figure 5: World Health Organisation, International Classification of Functioning Disability and Health (WHO 2001)**

The bi-directional arrows indicate how important each of these domains are to each other for holistic care. Since the inception of the WHO ICF (2001), outcome measures were developed to capture participation effects from practice, which are outlined in Appendix 3. This gives a representation of how current physiotherapy practitioners in the UK could demonstrate effectiveness from their input with children (Majnemer 2012). Within these measures particular focus is given to physical health outcomes from participation in a range of activities. However, the WB outcomes are currently limited in their representation, suggesting that this could be perceived as less important as a direct outcome from physiotherapy interventions. Hence the need for my study, to explore the emotional WB impact from disabled children and young people level of participation, in their preferred RA. Emphasising the importance of considering not just the medical perspectives, but also to include the sociological discourse, to give them voice and agency. Agency is a contested topic as Coffey and Farrugia (2104) suggest that whilst a children and young people may have the freedom to choose at the micro level, their choices are constrained by the structures at the macro and meso levels. For disabled children and young people who wish to

participate in RAs, the lack of available choices, reduces their participation. Thus, by aiming to explore their experiences, their agency can be increased.

### **1.7 Sociological discourse**

In the sociological discourse, the medical condition such as cerebral palsy is often secondary to their lived experiences as children (Kehily 2009). From this sociological perspective, several aspects are introduced including the new sociology of childhood, representing children and young people rights, choices and decision making and the new discourse of Disabled Children's Childhood Studies (DCCS) (Curran and Runswick-Cole 2013;2014). The DCCS combines disability and childhood studies, seeking to celebrate the entrepreneurship that disabled children can bring to society (Curran and Runswick-Cole 2013;2014; Runswick-Cole et al 2018). Research from this field has shown that younger children can have a voice and contribute to decisions about their lives including healthcare (Alderson and Morrow 2011). It is however a challenge to represent the voices of those children and young people who do not have a physical voice and rely upon augmentative and alternate forms of communication (AAC) or have additional cognitive and perceptual difficulties. Additionally, poverty has consistently been shown to be a key disadvantage to disabled children and young people and remains a factor that also has an impact upon their participation and these will be explored further in the literature review chapter (Chief Secretary to the Treasury 2003; Hammal et al. 2004; Welsh et al. 2006; Davies 2012; Currie 2102; Institute of Education 2014).

### **1.8 Childhood and Adolescence**

From an initial understanding of the biological stages of childhood development, as in what 'nature' gives us, wider social influences were considered influential in developing the child in the form of 'nurture' (James et al. 1998). These bio-social dualisms, as they became known: 'nature versus nurture'; or 'being and becoming'; and 'agency and structure' illustrate the complexities of opposing influences upon a child. Furthermore, Prout (2011) suggested that these opposing constructs added to the 'hybridity' of childhood in late modern society, leading to confusion within this new sociology of childhood. Prout (2011) advocates that there is now a need for interdisciplinary understanding as society seeks to move forwards with this understanding.

Childhood is a time when children learn through play and the manifesto for children's play in Wales, seeks to promote play as part of everyday life. Suggesting that play is just as effective as sport and Physical Education (PE) in helping to tackle child inactivity and obesity (Play Wales 2013). Thus, reinforcing the importance that play can contribute to the WB and building resilience in children and young people, but play opportunities for disabled children and young people are limited. In terms of the autonomy of the children and young people with cerebral palsy, being able to voice their choices and take part in meaningful play activities, has the potential to increase their participation. It is possible this can reduce their social isolation and improve their sense of WB (Voorman et al 2010; Currie et al 2012).

Adolescence is a key physical growth period in a young people's life as well as the many social and emotional changes which occur. It is now thought to extend from eleven years up to twenty-five years of age, beyond puberty (Colver and Longwell 2013). Adolescence is also an age where typically developing girls particularly disengage with sporting activities and those with cerebral palsy also follow this trend (Keresztes et al. 2008; Claassen et al. 2011). Changing behaviour at this stage in a young person's life can influence their longer-term health and WB, so it is important to seek to engage them in appropriate RAs that can maintain or enhance their QoL (Damiano 2006; Fowler et al. 2007; Bania et al. 2011). The choices of what they can explore can be limited by where they live, whether urban or rural and wider socio-economic factors such as parental employment, disability transport availability, the level of social deprivation and what opportunities are offered locally (Hammal et al. 2004; Welsh et al. 2006; Colver et al. 2012). Therefore, if children and young people with cerebral palsy wish to engage in different RAs, then it is important to consider what choices they have that can influence them starting, continuing or maintaining their level of involvement, to benefit their WB.

### **1.9 Disabled Children's Childhood Studies**

This new discourse of DCCS problematizes the issue of not seeing disabled children and young people as being or having problems, but rather sees them having a childhood first (Curran and Runswick-Cole 2014). The end point of 'normal' is contested and it promotes a 'productive' childhood attribute rather than 'disabled'. As the predominant participation opportunities in society are aimed at typically developing children, this demonstrates ableism.

Ableism is the phrase used to indicate where the needs of the majority take precedence, and this influences decisions within businesses, policy and leisure (Swinton, 2012). As disabled children and young people are a minority group, their need for adjustments may be expensive and can go overlooked, especially when they do not have a physical voice to make their intentions known. DCCS seeks to bring both childhood and disability studies (with adults) agenda's together, with a key objective to build understandings from children and young people themselves (Curran and Runswick-Cole 2013; 2014). The importance of caution in not exploiting or misrepresenting disabled children's voices is a key ethical position of this new discourse. It challenges the current medical dominance in disability and gives voice to the children and young people themselves about their ordinary lives, promoting their creativity and productivity as valued citizens in society. This new approach changes the position of disabled children, whereby the

*'ethics and research design positions the voice and experience of disabled children at the centre of the inquiry'* (Curran and Runswick-Cole 2014 pg 1623).

DCCS contrasts with the medicalised world of physiotherapy, where measuring the normative is key to defining a child's abilities. Gibson (2016) suggests this raises questions about how practitioners send messages about the value of a child, if measurement is what defines them. Surely this is not what is intended but becomes implicit by practices that only follow quantified measures about their physical capabilities and overlooks aspects of their WB (Vargus-Adams and Martin 2011; Majenemer et al 2012; Stewart et al. 2012; O'Connor et al, 2019). The principles that my research is based upon will be outlined in the next section about children's rights, consent and autonomy and how this influenced my thinking to position their voices at the centre.

### **1.10 Children's Rights, Consent and Autonomy**

In terms of children's rights, the United Nations Convention on the Rights of the Child (UNCRC) (United Nations Children's Fund 1989), has been ratified in the UK. This rights-based approach has been embedded into many government policies, seeking to enable the child's voice to be heard (Chief Secretary to the Treasury 2003; Department of Health 2008; Welsh Government 2010; Davies 2012). Additionally, in Wales, there is the Rights of Children and Young Persons (Wales) Measure (2011), which supports the needs of all children to participate and Article 31 of the UNCRC

supports the child's right to play and leisure. For disabled children and young people to participate in play and leisure choices, the opportunity to engage with RAs has been shown to enable them to develop their self-confidence and determination (Ryan and Deci 2000; Majnemer et al. 2010; Hynan et al. 2014). However, this is underrepresented for the more complex children and young people with cerebral palsy, with limitations in moving, speaking and learning.

Under the Children Act (1989; 2004) children with disabilities are considered to be in 'need' and a range of health, social care and education professionals can offer treatments, advice and support for families, to optimise their function. In cerebral palsy, physiotherapists are key professionals along this journey throughout childhood into adolescence and ultimately adulthood (O'Brien and Rosenbloom 2009; Rosenbaum and Rosenbloom 2012). The context of practice, policy, ethical codes and standards for physiotherapy in the UK are closely aligned with the United Nation's Convention on the Rights of the Child (UNCRC) (United Nations Children's Fund 1989; Chartered Society of Physiotherapy (CSP) 2019).

The UNCRC convention has fifty-four articles which relate to respecting and including children. There are two specific articles which this research was built upon: Articles 12 and 31 of the UNCRC which state that every child:

*"12: has the right to say what they think in all matters affecting them, and to have their views taken seriously" (United Nations Children's Fund, 1989 p.5)*

*"31: has the right to rest, leisure, play and recreation and to take part in cultural and artistic activities" (United Nations Children's Fund, 1989 p.10)*

For children and young people with cerebral palsy due to their wide range of abilities, sometimes their chronological age, communication style and cognitive impairment, this can be a challenge to capture and represent their views. This is often why such children are excluded from research, as it is harder to gain their consent (Morris 1998; Curran and Runswick-Cole 2013). More recent initiatives have worked in partnerships with families and children and young people to design studies (Murray 2012; Bailey et al 2015; Graham et al 2017; Brady and Franklin 2019). Therefore, if a high level of patient and public involvement is encouraged, studies can be designed to embrace the uniqueness of disabled children and young people and not cause them harm, to promote rather than exploit their vulnerabilities (Northway 2014). Such research designs should embed the principles of unhurried listening and

representing all abilities (Clark and Moss 2011). Additionally, Carpenter and McConkey (2012) have suggested that it is all professionals “*moral imperative*” (p.9) to listen to the voices of disabled children and young people. So far, there is limited evidence that this has happened for children and young people with cerebral palsy with communication and learning disabilities (Wickenden 2011; Wickenden and Kembhavi-Tam 2014; Watson 2015).

To gain consent for research may be difficult with these children and young people, as Alderson and Morrow (2011) suggest the term ‘Gillick’ or Fraser competence has not been formally agreed. ‘Gillick’ competence refers to an English Law from 1985 when Mrs Gillick objected to contraceptive prescriptions being given to her daughter, then aged under 16 years. The courts in England and Wales deemed that under 16, if the young person understood, they could give their own consent (Hunter and Pierscioneck 2007). This principle of ‘Gillick’ competence has now been used in practice and research. Thus, if a young person under 16 understands, they can give their own consent. However, under eighteen they cannot refuse treatment and parent’s consent may be sought. On occasion, covert research without consent is carried out if this waiver of the child’s view is deemed not to affect their rights (Alderson and Morrow 2011). From an ethical perspective, this would only be acceptable in life or death and emergency situations as ignoring the child’s wishes would contravene their rights to express their views. Assent is an interesting term, as Alderson and Morrow (2011) suggest that it can mean that children understand some, but not all of the main issues required for consent and it can mean ‘at least not refusing’. Additionally, Renold et al (2008) proposed that assent was an ongoing process and should not be taken for granted. The ethical principles will be outlined in the next section, to reinforce the need to facilitate the voices of disabled children and young people being heard.

### **1.11 Ethics of Disabled Children and Young People’s Voices and Participation-self advocacy.**

The four principles or practice and research are: Beneficence (Do good), Non-maleficence (Do no harm), Justice (fairness) and Autonomy (choice) as outlined by Beauchamp and Childress (Beauchamp and Childress 1994; 2013). A book chapter exploring these ethical principles was previously published, so it is not repeated here (Pickering, 2018). In the new sociology of childhood, children are now perceived to

have their own voice and agency and to be social actors in their own right (James et al. 1998; Prout 2011). Therefore, disabled children and young people have equal rights to speak about the choices they would like for opportunities to participate in RAs. However, their choices for suitable opportunities in society are not offered on an equal basis as those for typically developing children, some of the reasons behind this can be costs, safety, and fear of risk of harm or not considering their needs. Although it can be postulated that the effects upon their health and WB can be positive from participation in RAs, there are limited voices from the disabled children and young people advocating for themselves (Bailey et al. 2015), hence the need for my research. It is the intention in my study to centrally position their voices from the outset and to support them to express themselves through their non-verbal communication and intentional behaviours.

### **1.12 Summary of Chapter 1**

This chapter has set the background for my study outlining cerebral palsy, physiotherapy, FCC and the current knowledge about disabled children's opportunities for participation in RAs. Emphasis has been placed on exploring the diverse meanings of participation and WB. Childhood, adolescence and children's rights have been described, introducing the new research paradigm of DCCS, to position their voices centrally which my study has adopted, to highlight their agency and promote their self-advocacy. The next chapter is the search strategy, the review of the literature and critique of the evidence. The theoretical framework of positioning theory is introduced, whereby the children and young people position, influenced by different social forces, determined their storylines.



## **Chapter 2: Literature review**

### **2.1 Introduction**

Chapter two will describe the search strategy for the literature review, establishing which papers were relevant in helping narrow down the research question and aims. Having established that participation in RAs was to be the topic for the study, it took more time to identify the specific, related gap in WB in the literature. The papers critiqued will be arranged under headings related to aspects of relevance to participation and WB, emphasising where it was possible to hear the children and young people own voices. In wider reading I became aware of positioning theory (Harré and Langenhove 1999). Positioning theory will therefore be introduced here as the theoretical framework for my study, whereby the children and young people experiences are framed around their 'positions'. These 'positions' include both their physical and metaphorical positions, whereby they determined their control in different situations. This theory was chosen for its potential to relate to disabled children and young people storylines, by exploring the social forces that might influence their WB. The children and young people cannot always position themselves ready to participate in RAs, however once physically positioned, they could choose how they positioned themselves to participate at a level they were comfortable with socially. This then enabled them to determine their own WB, even without a physical voice to speak about their choices. After this theory is explained, it is applied to some pertinent studies at the end of the chapter to explore its relevance in this particular context. Positioning theory will also be developed and adapted in the discussion chapter, to further inform the findings. This chapter will end with a summary of current research priorities for disabled children and young people and the research question and aims.

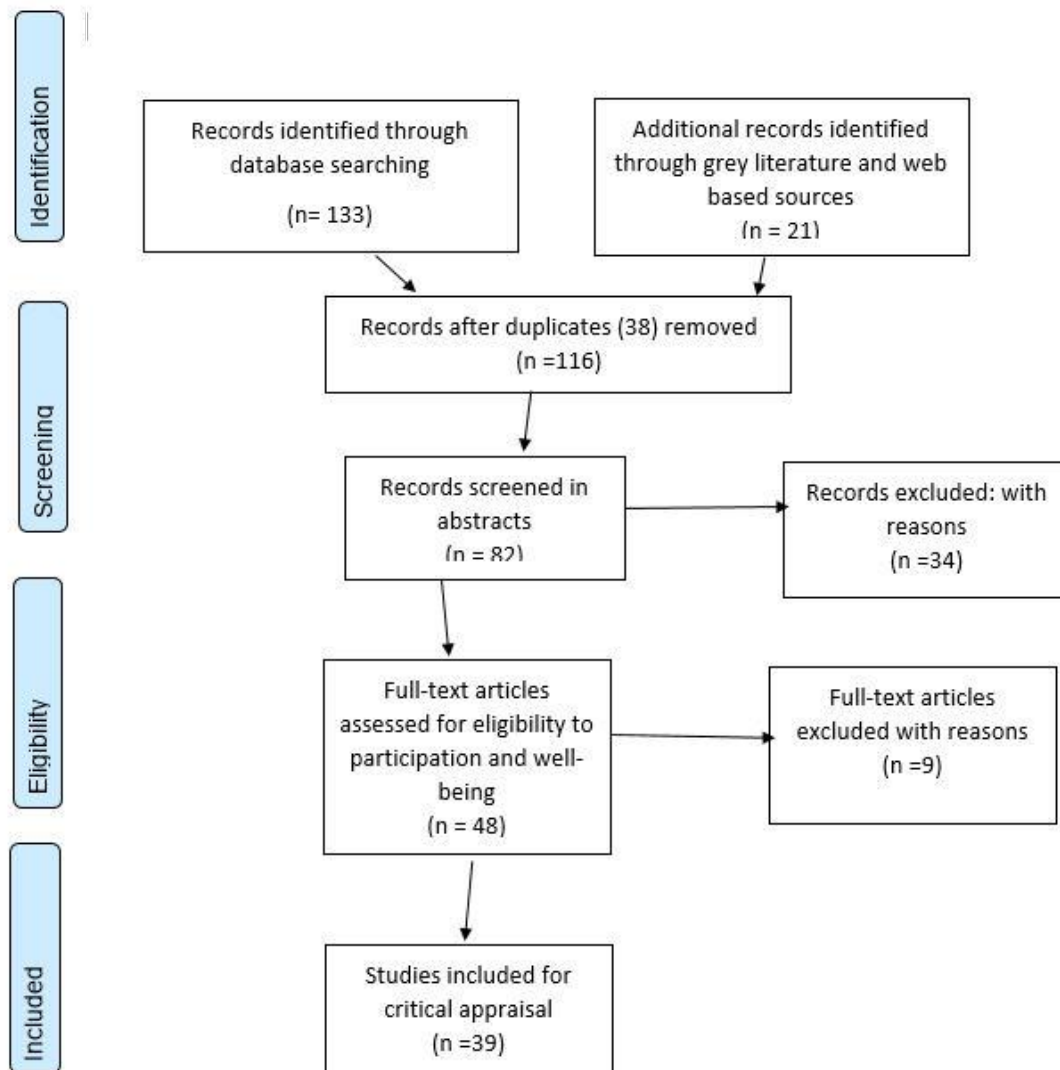
### **2.2 Literature review: Search Strategy**

The literature review was carried out in three stages, the first was in 2013 prior to developing the PhD proposal. Secondly, a more in-depth search was carried out in 2015 following PhD registration, utilising a reference manger Endnote. The databases searched were ASSIA, JSTOR, CINAHL, PubMed, Web of Science, SCOPUS and Zetoc over a 40-year period, initially from 1965-2015. This wide period was used as the prevalence of cerebral palsy was not thought to have changed in 40 years (Colver et al 2013). Thirdly, this search was updated prior to submission of my thesis. The keywords used were "Participation" and "Cerebral Palsy" and "Disabled

Children” and “Adolescent” or “Youth” or “Young person” or “Young People”, and “Voice” and “Leisure” or “Play/ Recreational Activities” and “Poverty” and “Well-being/ Well Being”. Poverty was included because it is highlighted as one of the national indicators that the Well-being of Future Generations (Wales) Act (2015) and is being monitored by the Welsh Government. English language only papers were included. Terms excluded were “preschool” and “adult”, as the focus for the research was to hear the voices of children and young people with cerebral palsy as they entered puberty and became adolescents.

Some grey literature and policy documents were also sourced from web-based sources, as well as citation tracking and hand searches from the literature found via the main search. At the end of this search period there were 154 sources to review, after duplicates were removed there were 116. After reading the abstracts, 34 were excluded at this stage due to lack of focus on children and young people with cerebral palsy as these studies included cancer and autism. Full text articles were read from 48 papers and 9 were excluded due to their lack of focus on participation in recreation and leisure, thus 39 papers were taken forwards for critical appraisal. A flow chart of this search strategy can be seen in Figure 6.

**Figure 6: Flow chart of Literature Search Strategy 2015-2019**



The Critical Appraisal Skills Programme (CASP) checklists were used for relevant quantitative, qualitative study designs and systematic reviews (CASP 2013). This was to evaluate the quality of the studies to determine their rigour, trustworthiness and credibility (Greenhalgh 2014). Notes were recorded in End note, to assist recall for the writing up period. There was an emphasis in the earlier studies on measuring physical participation outcomes. However, there was a notable gap in the existing literature which revealed a lack of emotional WB reported from participation in RAs. The available studies were developed into a narrative synthesis, clustered under the headings of choices and experiences, recreational activity participation, measures of participation, factors influencing participation, the limitations of the changing behaviour cycle for non-mobile children and the voices of non-verbal children and young people. Positioning of the children and young people with cerebral palsy and

positioning theory are explained and how this can support the 'voices' of non-verbal children and young people's participation in decision making. These studies are now critiqued by publication date in a chronological order of the research in that field, under each heading, exploring the both the concepts and the methods used, to highlight the gap in the literature.

### **2.3 Children and Young People with Cerebral Palsy's choices and experiences**

In order to understand the current choices and experiences of participation for children and young people with cerebral palsy, six studies were found that are now critiqued to support the understanding of participation in RAs (Majnemer et al 2010; Stewart et al. 2012; Shikako-Thomas et al. 2014; Adair et al. 2015; Shikako-Thomas and Law 2015; Imms et al. 2016).

Stewart et al (2012) carried out a qualitative study with ten young people with cerebral palsy aged seventeen to twenty years. This study used a phenomenological approach using semi-structured in-depth interviews about social participation as part of a larger study in relation to mobility, QoL and exercise. This in-depth approach to explore this phenomenon of social participation was an appropriate method, which provided deeper insights. Four of the young people also took part in a second interview including one at GMFCS IV and V. Two of the participants acted as consultants for the data analysis to verify the themes, as well as the triangulation of three researchers carrying out the analysis. Thus, increasing the rigour and trustworthiness of this study.

These findings indicated four themes which were: experiences of social participation, barriers and supports, trade-offs and making choices (Stewart et al 2012). The social participation included online activities as well as physical contact, barriers included accessibility and attitudes and supports included mentorship as well as support workers. The recognition that to do some participatory activities, certain choices had to be made and time was a big factor in terms of transportation between activities. So, trade-offs were made between what they wanted to do and what was feasible in their environment and personal circumstances. Many recognised that they wanted to make their own choices and not rely on others making decisions for them. At this stage of their lives, at the transition to adulthood, the issues were focused around living independently and employment. One participant reported choices over using a

walker or scooter, recognising they got stiff if they did not use their walker. However, the trade off to use their powered wheelchair meant they had more energy for socialising with their peers. Their findings concur with other studies about the barriers and facilitators for social participation (Majnemer et al 2010; King et al. 2013a; Shikako-Thomas et al. 2014). young people wanted to make their own choices about social participation and there was a close relationship between their physical energy and WB, as fatigue impacted upon their level of participation. Hence, social participation was highlighted as beneficial for WB. A limitation of Stewart et al's (2012) study was the small sample, although the authors claimed to achieve data saturation even though only four of the ten participants were interviewed twice. As these four were more aware of this study's focus on social participation, rather than the larger study's design of mobility and exercise, they could have been influenced to respond to please the researcher, creating a potential bias.

Majnemer et al's (2010) study utilised the Dimensions of Mastery Questionnaire across a wide representation of GMFCS levels, revealing that children and young people with cerebral palsy are more motivated to persist with social tasks than cognitive and motor skills which prove too challenging. This prosocial (positive) behaviour revealed that their physical limitations were not always a barrier to their enjoyment. Perseverance in everyday tasks was shown to be higher for those children and young people with higher motor function, however they reacted negatively to failure, limiting their willingness to try more difficult tasks. If the family perceived a high care burden from their child, this was shown to affect their child's motivation. However, some adolescents had higher motivation scores than their parents, showing that their pleasure was not always related to their abilities. This study included participants from age five to twelve years and was a large sample size of seventy-four children and their parents. It was suggested that practitioners consider the level of challenge presented to the child, to motivate and not overwhelm, but provide opportunities to master failures. A limitation of this study was the difficulty that some children could not complete the questionnaire themselves. Thus, further consideration should be given to making appropriate adjustments in research for those with learning and communication difficulties. The opportunity to create meaningful goals, at the right level that motivates the child, is central to

rehabilitation in cerebral palsy. RAs can provide this 'just right' challenge, if there are opportunities to explore and try new things (Smith et al. 2015).

Adair et al's (2015) systematic review of studies aiming to improve participation outcomes for disabled children, showed that if participation was a secondary outcome to exercise programmes, there was little effect. Whereas, if the programmes were individually tailored education or mentoring programmes, participation outcomes were enhanced. Only seven randomised or pseudo-randomised studies met their inclusion criteria, and the authors judged these to be of mixed quality. Only one was strong in quality and evaluated a constraint induced movement therapy intensive circus programme for children with hemiplegic cerebral palsy (GMFCS I+II) (Sakzewski et al 2011). It was suggested that for those with mild to moderate impairments, that participation outcomes could be improved in terms of their physical frequency and intensity. A limitation was the lack of evidence of the emotional WB impact from their level of participation.

This raises the possibility however, that those children with more severe impairments (GMFCS III-V) have less potential to improve in their participation outcomes.

Therefore, for those at GMFCS III-V, it is not known whether they could maintain or change their level of participation, as the definition of what is meaningful to them is unclear and their capability to join in physical RAs are more limited, due to their muscle weakness, pain and fatigue. As participation is a complex multi-dimensional construct, Adair et al (2015) suggested that a more direct approach is used to influence participation outcomes, such as changing the environment, rather than an indirect approach, where body functions and structure were targeted. Thus, environmental change may have a more beneficial effect.

A further policy review in Canada highlighted the tax credits for adults which have been used to incentivise involvement in RAs by disabled adults and children and young people (Shikako-Thomas and Law 2015). This concept requires further consideration as part of exploring what might impact on young people changing their health behaviours. However, this may be limited for those at GMFCS III-V, whose capacity to physically change is limited, although Bryant et al (2012) did demonstrate short-term physical changes with children at GMFCS IV + V, as critiqued later in this chapter.

Imms et al's (2016) systematic review outlined a conceptual approach to clarify the meanings of participation for children and young people with impairments, proposing the new conceptual framework. This was done by extracting both quantitative measurement data and verbatim quotes to develop themes from the 25 studies which met their inclusion criteria. These themes were applied to the outcome measures used and the language compared with the quantified participation changes. There was discussion around the ambiguity of terms used including the cross over with 'QoL'. Educational settings also used the term 'engagement' interchangeably with 'participation'. Only two of the studies reviewed, were consistent in the terms used in the participation outcome measures. The results proposed the 'family of participation related constructs' (fPRC), with two key themes of involvement and attendance. This 'fPRC' proposed by Imms et al (2016), calls for greater consistency in how the participation construct is used in research and practice. A limitation of this review is that it leaves a gap in our understanding about the drivers which promote participation choices or how these impact upon WB, to potentially build self-confidence in children and young people with cerebral palsy. The opportunities for participation in RAs will now be outlined.

## **2.4 Recreational Activities for Children and Young people with Cerebral Palsy**

RAs for children and young people with cerebral palsy can be competitive or non-competitive, group or solitary activities. Availability of activities in a geographical area also varies by the socioeconomic demographics (Hammal et al. 2004; Welsh et al. 2006; Bevan Foundation 2011). The type of participation in RAs is also limited by the child's level of walking ability and so thought has to be given to how activities can be safely adapted (Forsyth et al. 2007). Sport has been a dominant participatory activity in all aspects of physical rehabilitation, highlighted by the development of the Paralympics (Haskell et al. 1985; Davis 1996; Seymour 1998; cerebral palsySport 2015; DSW 2015). However, sport is not the full picture of participation in RAs. Choosing to participate in activities which bring fun, may have an element of competitiveness, but for those with more complex disabilities, the idea of being competitive may be difficult for them to understand. Indeed, Rosenbaum and Gorter (2012) have proposed six 'F' words which describe attributes of childhood disability rehabilitation practice. These are that it should be about 'Fun, Fitness, Function, Family, Friends and the Future'. These are relevant to all levels of ability and require

further exploration to understand what these mean to children and young people with cerebral palsy. The aspects of what the children and young people think is 'Fun' in their lives, will be the focus in my study, to reflect their WB status from their level of participation in RAs.

An insightful qualitative study by Conchar (2014) in South Africa, explored the views of fifteen adolescents with disabilities, aged twelve to eighteen years, about their participation in sport and physical activity using an interpretative phenomenological approach (IPA). Some participants recognised that some young people avoided participation due to a variety of psychological and social factors. This included '*being laughed at*' (pg 106) and issues with feeling marginalised due to the sporting classification categories that they did not easily fit into. Some participants thrived on the competitive nature of their sport and '*winning*' (p. 95) was important to them. However, several participants described the lack of opportunities for those who were non-ambulant, who were only able to participate as spectators. This study was not carried out exclusively with adolescents with cerebral palsy and was in an overseas country with wide variations in available resources. This showed that their ambitions to participate were limited by attitudes and social pressures that made them feel embarrassed, rather than accepted for their level of ability. It was however, the first recent study using the method of IPA (Smith et al. 2013), which analysed from the three perspectives of descriptive, conceptual and linguistic, providing rich insightful data, but this is not easily transferable to the UK context due to attitudes towards disability potentially being different to South Africa. However, there may be some resonance with not feeling valued, for those who feel like they do not easily fit into pre-determined categories.

An additional paper by this research team, gave wider perspectives about sport's participation, for adolescents with disabilities (Bantjes et al. 2015). The evidence presented here supports both the physical health and emotional WB benefits of sport and exercise, suggesting the empowerment that results from participation, has a greater impact. However, the lack of opportunity and choice leaves many disabled adolescents with limited possibilities to develop their autonomy and many found the role of spectator boring and demotivating. Their desire was for opportunities to learn new skills in a structured and supportive way that did not leave them feeling incompetent, scrutinised and humiliated. Participation here was sometimes



considered tokenistic and promoted the need for advocates who could promote fair and inclusive opportunities. However, it was not clear who these advocates might be in this particular context.

Hodge and Runswick-Cole (2013) suggested that childhood peers might be able to develop empathy towards disabled children's inclusion in leisure activities, as a possible supportive avenue, if they considered what it was like for disabled children and young people to participate. This study carried out interviews with eleven disabled children and young people aged four to sixteen years and twenty-three of their carers or professionals. This is a wide age range to cover which may provide a breadth of experiences but may lose focus for specific age or gendered groups. An ethnographic approach was used to observe their activities in the community and this approach was helpful to gain insight for the non-verbal children and young people. A creative adaptation of their methods was developed to respond to their communication preferences including interviews, mapping, artwork and photography. One child did not want to be interviewed due to his communication limitations, but made his own film about his life, thus allowing a creative approach to data collection. The analysis was carried out by the research team, but it was not clear if the participants were asked to member check the data, although they got to keep their own artwork. The lack of opportunities for participation in leisure activities were highlighted for disabled children and young people, as there was a prevailing ableism in the provision of choices. Even when involved in inclusive activities, as Greg said: *'in football, they just didn't pass me the ball, they just like pass it to someone else'* (p 319), which did not always make him feel included. Bill went to a segregated youth club where the perception from the youth worker was this was best for him as he *'fitted in'*, but there was no discussion of how other facilities could be adapted for him. Whilst the separate impairment specific groups were observed to provide parental support, there was a danger that this labelling led to a reinforcement of their disability. This argument purports that by continuing with separate provision, unless you pass the near 'normal' test, then disabled children and young people choices remain limited for RAs. Hodge and Runswick- Cole (2013) suggest that there is a need to develop self-reflection and empathy in school children, for them to be able to consider an alternate childhood such as for those living with a disability.

This study was carried out in England but there are likely to be similarities in Wales, although this is not known at the present time.

There were six studies covering aspects of less competitive RAs, which included hippotherapy, cycling and ice skating (Frank et al. 2011; Bryant et al. 2012; Pickering et al. 2012; Pickering et al. 2013; Walsh and Scharf 2014; Pickering et al. 2015). Hippotherapy is a form of bare back horse riding, enabling the participants to feel the movement of the horse underneath them, through a blanket, thus stimulating their own body's balance mechanisms in response to the horse's movements. This single case study measured the effects of an eight-week hippotherapy programme on a six-year-old child with ataxic cerebral palsy GMFCS I (Frank et al. 2011). Measures used included the GMFM-66, the Pictorial Scale of Perceived Competence and Social Acceptance for young children (Harter and Pike 1984; Russell et al, 2002). In the results, the child improved in her GMFM scores but was already achieving high scores at baseline due to the higher level of function being at GMFCS I. This supports the lack of sensitivity known as the 'ceiling' effect (the upper limit of the scoring not being able to respond further to subtle changes), a limitation of this measure with higher functioning children. However, the perceived self-competence scores increased and maintained this improvement at the two months follow up. This study did lack the child's own voice, as it was not included in the single case study. It was indicated that hippotherapy had a positive emotional WB effect, by her choosing to continue with the activity, but this was not conclusive.

The study by Bryant et al (2012) was a parallel arm pilot randomised control trial, targeting the children at GMFCS IV and V, set within physiotherapy in a special school context. The comparison was made between a control group, treadmill training and a static bike in thirty-five children, aged eight to seventeen years, recruited from four schools. The children took part in the activity, three times per week for six weeks. The measures used were the GMFM version 66 and section D (standing) and E (walking, running and jumping) of GMFM version 88. These measures are valid and reliable and are the gold standard in gross motor function in cerebral palsy (Russell et al. 2002). Whilst significant results ( $p > 0.05$ ) were only shown in GMFM D-88 for both treadmill and static bike training, this effect had declined at the eighteen-week follow-up. Standing ability can maintain function for ease of transfers for transport, toileting and showering, so it was an important

finding. The rigour of this study was enhanced by blinding the assessor to which group the children were allocated to. This study added to knowledge about the ability to change function of children at GMFCS IV and V, in the short term, but had limited voice representation from the children and young people themselves, about what this participation in treadmill training or the static bike riding meant to them (Bryant et al. 2012). As it was set within a special school it has limited transferability to the child's home, where such benefits might be continued, as most families do not have treadmills at home. As the children's experiences were not captured, the WB effects were also not reported.

My previous research built upon these findings, by translating the static bike research onto adapted bike riding into the community (Pickering et al. 2012). The opportunity to develop a mixed methods study, combining lower limb muscle strength and length measures with qualitative interviews and a diary of physical activities, provided data including the children and young people with cerebral palsy's voices (Pickering et al. 2013; Visser et al. 2014). Whilst thirty-five children were recruited, aged between two and seventeen years, there was lower recruitment in the GMFCS IV (nine) and V (one), suggesting it is harder to adapt equipment for those with greater mobility difficulties. This study was able to represent the children and young people voices via diaries, which included some photographs taken by the children and young people and their original drawings, which were used to facilitate the second interview. Four to six-year-old non-verbal children responded to a sheep glove puppet as a way of communicating their emotions to the researcher. The diary was kept for six weeks which gave some insights into their enjoyment, but if it had been kept for a longer period more established patterns of behaviour might have been observed. The combination of this 'mosaic' data enriched the findings and began to make the children and young people voices audible about their participation in adapted cycling (Clark and Moss 2011; Pickering 2013; Pickering et al. 2015).

Another single case study measured the effects of an ice-skating programme with a five-year-old child at GMFCS I (Walsh and Scharf 2014). It was considered that her engagement with regular physical therapy had reduced, and this opportunity might achieve her physical goals more effectively. The effects measured showed a benefit to increasing strength (measured by Manual Muscle Testing), balance, posture (video tape analysis) and function (measured by the GMFM-88). A limitation of the

study was the lack of qualitative data to hear her voice of what this experience meant to her. Her own and family's motivation to participate in this activity were key facilitators for this to happen, as well as the physical therapist who initiated the reasonable adjustments. Thus, the parents and physiotherapist both acted as advocates to increase her participation in ice-skating.

In summary, there is some anecdotal evidence that these participatory opportunities benefitted the WB of the children and young people who took part. However, their voices were lacking from the research about what these participatory experiences meant to them. The focus was on the measurement at the body structure and function domains of the ICF. Examples of these measures, which were developed to encompass measures of participation outcomes in practice, will now be critiqued.

## **2.5 Measures of Participation in Practice**

Since the inception of the WHO ICF, several measures were developed seeking to capture data about frequency, environments and intensity of participation (WHO, 2001). These measures were developed that included all the domains of the ICF and people were considered holistically, not just in relation to their health condition (Michelsen 2010; Bult et al. 2011; Majnemer 2012). So, for example, in cerebral palsy, initial measures looked to capture physical capabilities such as range of movement, muscle strength, functional ability and level of spasticity (Morris et al. 2005). The limitations of these narrow perspectives soon became apparent, when families revealed that their children's wider health needs were not being met, so further measures were developed to address these domains more holistically (Beckung and Hagberg 2002; King et al 2013b; Wright et al 2008; Vargus-Adams and Martin 2011). It was clear that there was a strong link between good physical health and optimal WB. The context for disabled children and young people to develop optimal health and WB, was shown to vary between home, school and the community (Pratt et al. 2008; Darrah et al. 2011). Now that less time was spent in hospital and life expectancy had risen, children with disabilities now lived into adulthood and some could expect employment, housing and parenthood, as any other citizen in society. This WHO ICF model therefore encompassed all aspects of life in relation to a person's health condition and including QoL. It is the aspects of the participation domain, specifically WB, which my research will focus on (King 2013 b).

Most of the participation measures seen in Appendix 3, used a questionnaire design, with some opportunity for open responses. Shields et al (2015) used the Children's Assessment of Participation and Enjoyment (CAPE) and Preferences of Activities for Children (PAC) questionnaires which supported the need to listen to the child's activity preferences when planning out of school RAs. This study concurred with previous studies that had reported on frequency and environmental factors that influence participation, such as, the older the child becomes and the higher the level of impairments, the less they participated (Michelsen et al. 2009; Badia et al. 2013; Tuffrey et al. 2013; Park and Kim 2015; Shields et al. 2015). However, in these measures there was limited evidence from the children's own voices about their WB.

Another questionnaire example to measure participation was the Participation and Environment Measure for Children and Youth (PEM-CY), which had an online version. This made completion more efficient than just relying on postal surveys, if the participants could use a computer, however some disabled children and young people could not (Coster et al. 2012). Whilst preferences for participation could be identified, this did not always correlate into an increase in participation, and the PEM-CY did not overtly demonstrate WB effects from their level of participation. However, the need for a supportive environment was shown to be key and concurs with the notion of adjusting the environment rather than the body's structure and functions, as proposed by Adair et al. (2015).

The measure which used visual cards, the Pediatric Activity Card Sort (ACS), had no evidence for reliability, but had potential to use with the children and young people who were non-verbal and used eye pointing or gestures to show their preferences for participation (Mandich et al. 2004). Additionally, Boling et al (2016) demonstrated that the cerebral palsy QoL questionnaire for children, developed in Australia (Waters et al, 2006), was also valid and reliable in Finland. Boling et al (2016) also recommended that smiley emojis be used with the severely disabled children and young people to enable them to express their own WB. However, this would have limitations for children and young people who have a visual impairment.

However, Kolehmainen et al's (2020) study demonstrated that there was a low (30%) uptake of using these participation measures in clinical practice in England. Additionally, O'Connor et al (2019) demonstrated the negative impact of over

assessing the children's disabilities, to the detriment of their and their parent's motivation to continue with their rehabilitation. Thus, this potentially impacts negatively upon their WB, as being assessed and not showing improvement can be perceived as failing. In reality, for children and young people with cerebral palsy at Levels III-V of the GMFCS, maintaining their participation might be a realistic goal, for which these aforementioned measures would not change in their scores. Scores from outcome measures are usually used in practice to monitor the effectiveness of goals. For example, it might be suggested that a child swims once a week to maintain their endurance or cycle once a week, to build both muscle strength and endurance. These activities could be mapped to see if they occurred or not, but the difference they make to their enjoyment and fun in their lives, to enhance their WB, may not be recorded in current NHS practice. Furthermore, it is not easy to map from these participation measures, to see how the children and young people with cerebral palsy perceive the WB effects from their level of participation in RAs. So, whilst these measures have some value in reliably capturing participation intent or engagement, they are currently limited to determine WB with the disabled children and young people at GMFCS and CFCS Levels III-V. It would therefore seem important to gain further knowledge about their views, experiences and choices of RAs, to explore their perceived WB impact from their level of participation. Participation research related to hearing about the preferences of children and young people with cerebral palsy, from their perspectives, will now be critiqued.

## **2.6 Factors influencing preferences for participation.**

There were many factors which were found to influence preferences for participation, which included gender differences and pain levels. Six studies will be critiqued to illustrate these preferences. Shikako-Thomas et al (2009) explored the QoL of twelve, twelve to sixteen-year-old adolescents with cerebral palsy, using a constructivist grounded theory approach. A strength of this study is the narrower age band that was included, meaning as the participants were closer in age, and the topics were contained, possibly enabling data saturation to be achieved. The interviews explored what intrinsic and extrinsic factors contributed to their satisfaction with life. A team of four analysed the data, offering member checking with their participants, enhancing the credibility of their findings. Key findings were the choices that the adolescents had over who they participated with and having

supportive family to help them, feeling good about themselves and keeping positive. It is known that, as they get older, participation decreases, but their self-awareness and perception increase, the main theoretical construct to emerge was 'differential valorisation'. Differential valorisation meant that individual's preferences played a role in the value and enjoyment of the leisure activities. However, the lack of community opportunities impeded their participation and the reasonable adjustments needed, meant that both integrated and separate provision was still necessary.

The psychosocial benefits of participation for disabled children and young people were also highlighted by King et al (2013), which suggested that quieter RAs such as reading can also have a positive impact on emotional WB, for those who find physical activities difficult, due to fatigue, epilepsy or pain. Thus, non-mobile disabled children and young people can find it difficult to be physically active but can still participate in adapted RAs. Sometimes these may not have a physical effect but can still have emotional WB benefits for them and from being included as part of a social activity with other children.

In Canada, Shikako-Thomas et al (2013a; b) proposed that participation in leisure activities supports the health promotion for these children and young people, as a benefit to their health and WB. Further research by Shikako-Thomas et al (2014) identified that disabled male and female adolescents differed in how they participated, with evidence that girls participated more in self-improvement activities such as dressing independently. This study used a cross-sectional design with twelve to twenty-year olds completing the Children's Assessment of Participation and Enjoyment (CAPE), a valid and reliable tool (King et al. 2004b). Social participation was deemed the most important aspect. It represented all levels of the GMFCS and highlighted the lack of choice of adaptations to wider RAs. However, there was no obvious package of prescribed RAs for young people with cerebral palsy that practitioners could draw from in their signposting to community activities.

In Sweden, Lauruschkus et al (2015) explored the experiences of sixteen children with cerebral palsy aged eight to eleven years, about their physical activity participation. This inductive approach offered a choice of interviews or focus groups and included children with all levels of GMFCS ability, including four who used AAC. Interviews were carried out in a playful manner using pictures and figures to engage

the children in conversations about physical activities and two also needed a language interpreter present due to the researcher's unfamiliarity with AAC. The data were analysed by the three authors, who all had a background of working with disabled children and young people. Although it was stated that the research group were consulted, it was not transparent that member checking was carried out with the transcripts or themes which were identified. The analysis revealed opportunities, facilitators and barriers to participation, which were presented in a table with quotes to highlight their experiences. There was good evidence to support their understanding of the health benefits of physical activities, citing experiences where as they had grown, their interests had changed. This included not having a big enough swimming aid and developing a fear of horses. Facilitators included people's supportive attitudes and having a sense of belonging, thus social participation was again the most important feature which enhanced their WB, as the physical effort to participate was too hard for them. Hence, as social participation has been shown to be more important for some disabled children and young people, aspects of the limitations to them changing their physical behaviour will now be considered.

## **2.7 Limitations of changing behaviour cycle for non-mobile children**

Self-management behaviours have been promoted for children with chronic conditions, however it was suggested that it required a stronger evidence base to be more successful (Modi et al. 2012). One of the theories underpinning this was self-determination and this has been developed in other areas of physiotherapy practice such as chronic low back pain where behavioural and motivational strategies are used to increase physical activity (O'Sullivan 2012; Ryan and Deci 2000). Here seeking to influence and change the person's behaviour is the key to encouraging them to become more active. This is based upon Michie et al's (2011) Behaviour Change Wheel of three key factors: Capability; Motivation and Opportunity. This was demonstrated by Hamana (2017) with carers and relatives, who adapted their own physical activities, to support and accommodate for people living with a neuro-degenerative condition, Huntington's disease.

However, to become more physically active can be more difficult for some children and young people with cerebral palsy, due to their lack of capability, but it is still possible to influence and promote their emotional WB benefits. It is probable that the parents and carers need to be influenced, to change their behaviours, in order to



support the disabled children and young people. Some children and young people with cerebral palsy do experience epilepsy, fatigue and pain. Because of these physical symptoms, it does constrain their intentional motor and sensory behaviours and reduces their capacity for change. Also, their additional learning disabilities, may mean they lack the intrinsic motivation to change. Hence for disabled children and young people, the parents need to be able to seek out appropriate opportunities that they perceive would motivate their children and young people, within their capabilities, to potentially enhance their WB.

Verschuren et al's (2013) study with children with children and young people explored the three stages of the changing behaviour cycle, namely pre-intention (not aware of need to change), intention (intent to change) and action (doing something to change behaviour). This qualitative study used in-depth focus groups, with thirty-three ambulatory children and young people aged seven to eighteen years and their parents, followed by a questionnaire exploring facilitators and barriers to physical activity participation. This was a wide age range to include, as needs and experiences vary across these eleven years, pre-puberty to mid adolescence. Those families who were at the pre-intention stage had not considered what could make it easier or harder for them, however those at the intention stage had recognised environmental and social barriers and those at the action stage had found some solutions, to enable participation to take place. Thus, revealing their self-determination to move forwards. A grounded theory approach was used to analyse the narrative data by two of the research team using open, axial and selective coding. After four of the five focus groups, data saturation was reportedly achieved, thus supporting the notion that the researcher's findings were credible, improving the rigour and trustworthiness of the findings. The author's acknowledged a limitation of their study was that it only included those at GMFCS I and II, so those at GMFCS III-V remain underrepresented. For this latter group, participation in RAs is more difficult, requiring higher levels of adjustment in the environments and having suitable equipment to support their participation, where possible.

Verschuren et al (2013) offered suggestions to practitioners to recognise that families are at different stages of this changing behaviour cycle (pre-intention, intention and action) and therefore their expectations for the families' levels of engagement, should be adjusted accordingly. A suggestion for future research was

to use motivational interviewing, to explore the factors which influence these three different stages. It is linked to the Health Action Process Approach which distinguishes between motivation and volition, suggesting that there are intenders who think they might participate in physical activities and actors who do. There is a suggestion to consider the family as a whole and to explore the possibility of advocacy in changing levels of physical activity participation. It was not clear whose role this advocacy would be. Again, it is harder, for the non-mobile children and young people, to change their level of physical activity participation, but it could be maintained or managed when symptoms change. It will always require an adult to physically position the non-mobile children and young people with cerebral palsy, in an environment where their participation in an appropriate RA can be optimised. This idea of 'positioning' will be developed later in this chapter within the theoretical framework for my study. However, the child with children and young people ability to express how they choose to participate or not, is underrepresented in the literature. As the disabled children and young people voices are absent, in order to hear their voices, the next section will critique the literature about how their voices have been portrayed in relevant research to date.

## **2.8 'Voices' of non-verbal Children and Young People**

Most of us use our physical voice to express our experiences and feelings. This is not always possible for children and young people with cerebral palsy, as the control of the muscles around their face and tongue can make this difficult for them. So, in some cases they will use sounds, gestures and signing or AAC (Pennington 2012). This makes including them in research more difficult, as it takes time and effort to seek out their voice and sometimes their responses can be inconsistent and unreliable, such as those at CFCS IV and V (Hidecker et al. 2011). The few studies that have sought to represent their voices are outlined next, demonstrating the creativity needed and importance of the role of another person, to support interpretation of their preferred way to communicate.

Early studies utilised questionnaire designs, for example, Varni et al (2005) carried out a survey with children and young people with cerebral palsy in the United States of America (USA), to see if they could self-report about their Health-Related QoL (HRQOL). Whilst this was a large sample size of two hundred and fourteen, only sixty-nine (47%) children and young people were able to self-report, thus giving

some ability for their own voices to be heard. The results were compared with healthy children, showing lower mean scores for HRQOL: Overall Score/ Emotional functioning: Healthy N=12,010 (83.8/ 79.33), and cerebral palsy N=214 (65.9/ 67.19). Both the overall score and the emotional functioning scores showed a significance of  $p < 0.001$ , indicating that both parents and children and young people perceived HRQOL to be lower than for healthy children. It was the first example of research with some children and young people with cerebral palsy being able to self-report.

There were three examples of studies actually targeting children and young people who relied upon AAC (Wickenden, 2011; Hynan et al 2014; Dowling et al, 2018). Previously research had shown that communication difficulties in disabled children and young people led to a reduced level of participation and a lower QoL (Pennington 2012). Wickenden (2011) carried out an ethnographic study observing teenagers who used such means to communicate. The observations and interpretations of the nine participants in a range of environments, revealed they were more interested in ways they were like other teenagers, than identifying as being disabled. Thus, their identity as a person was much more important to them than their limitations. A key finding here was the frustration they experienced when people misunderstood their meanings and there was no opportunity for them to address this dissonance in interpretation (Wickenden 2011).

Hynan et al (2014) explored the use of the internet and social media for young people who use AAC, expanding current understandings of the potential for how to enhance their voices. This study used a constructivist grounded theory approach, as very little was known about the subject. They involved twenty-four young people and adults aged fourteen to twenty-five years, at GMFCS and CFCS V. It was a technically challenging interview schedule taking between 30 minutes to 2 hours, due to the additional time delay in using a communication aid. The analysis was consistent with grounded theory, with emergent concepts being taken into subsequent interviews. The results showed the value the young people placed upon the self-determination and self-representation that these opportunities bring, as it enriched their friendships. Thus, this had a positive emotional WB effect for these young people, by opening up these social possibilities. However, it was not possible without technological support, which involved reasonable adjustments which were time consuming.

Dowling et al (2018) carried out research with brain injured young people, some of whom had communication difficulties. They used a creative narrative method with collages, to help the young people create stories about their diminishing social friendships. Whilst some needed physical support to be positioned and supported to make their collage, this process helped them navigate their new identity. This was an excellent example of engaging young people who had acquired a disability, in research, to help them explore their WB and help them reconstruct their personhood. This need to be positioned and supported to participate in a RA is expanded in the next section and linked to positioning theory.

## **2.9 Positioning of the Child or Young Person and Positioning Theory**

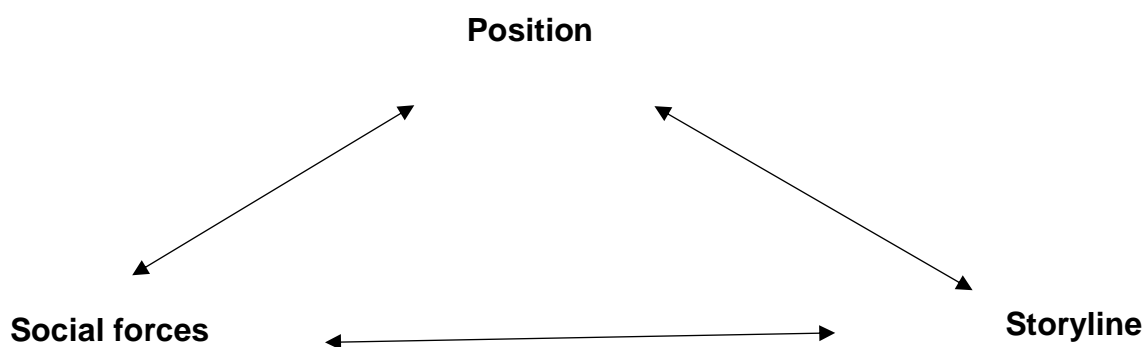
The idea of positioning the disabled children and young people ready to participate in any activity, is central to physiotherapy practice, which is about optimising movement and function to enable the child to achieve their potential (CSP, 2019). It may be interpreted that being positioned involves control from another person, however in this context of cerebral palsy, the facilitation of positioning the children and young people is for their benefit, to support their involvement either by physical handling using key points or adapted equipment (Pountney 2007; Raine et al 2009). I also became aware of positioning theory as a means of further exploring the storylines of disabled children and young people about their duties and rights, to understand the forces at play that could influence their WB outcomes (Harré and Langenhove 1999). So, this was more than just their physical positioning, but also about how they chose to socially position themselves, the degree to which they felt in control or empowered to be involved. Their level of participation was determined by their choice to engage with the recreational activity, once in attendance. Thus, the opportunity of being positioned in a physical place, did not always lead to their participation. Positioning theory was defined as the way that *“psychological and social phenomena are constructed and sustained, through discourse and activity, where individuals position themselves and others”* (Langenhove and Harré 1994 pg 361). As positioning theory was based upon social constructionism, I anticipated that it could have relevance for my study, where the aim was to position the children's voices centrally to their experiences, although the discourse would not necessarily be through the children and young people spoken language but their social engagement. Positioning theory's background will therefore now be explained.

Harré and Langenhove (1999) proposed that 'Positioning theory' should be the starting point of considering the varied presentations of social life to reduce the stereotypes in society and thus, better understand the social phenomena in any situation. The social phenomena being a fluid mixture of social and psychological realities, not as a fixed level of interaction in time and space. Positioning theory is based upon social constructionism, whereby the narratives are created in a social space, usually via spoken words. A social space was defined by Carter (2004) as a space '*produced by societies according to the spatial practices that exist within the society. The produced space is a set of relations between objects within the space*' cited in Oxford Reference (2020). Thus, a social space for disabled children and young people can include both themselves and objects such as wheelchairs or communication aids and the people who support their participation.

Within social constructionism, Guba and Lincoln (1989) proposed there are three stakeholders who are involved in creating these multiple social realities. The three stakeholders are the agents (e.g. people who promote participation in RAs), the beneficiaries (children and young people and their families) and the victims or those disadvantaged by the situation (those who do not have opportunities). In my study, the multiple social realities included the use of both verbal, non-verbal and AAC, also with the use of specialised equipment such as hoists. Thus, the social reality of participation in a RA was proposed to benefit the children and young people's WB. The multiple agents of change would be those who provide opportunities and positioned them ready to participate (e.g. parents or providers of RAs), thus if there were limited choices this would limit the potential benefits for their WB. They would therefore be disadvantaged by this lack of choice and remain isolated, possibly reducing their WB effect from a lack of participatory choices. Potentially, this could suggest the disabled children and young people and their families, are victims of a lack of sufficient thought to adapt for their needs.

Positioning theory was developed more than twenty years ago, in a period when social reality was in competition with the positivism of natural sciences (Denzin and Lincoln, 2013). This situation has changed with qualitative research now having greater recognition. In positioning theory, there is a 'positional triangle' of dynamic stability between the actor's positions (where a children and young people is placed), the social forces of what they say and do (how the children and young people

interact with others) and the story lines of what happens in each situation (what they do in terms of engaging with the RA). This is called the 'Mutually determining triad' and is shown in Figure 7 (Harré and Langenhove 1999). Here the arrows show a two-way flow of information between the three different aspects of the triad: position, social forces and the storyline. The idea of being mutually determining suggests that each of these components is equally important and if one is missing or out of balance, this triad would become distorted. Positioning theory proposes that the social world is created through conversations, but this has limitations when considering the disabled children and young people who cannot hold a verbal conversation. Alternatively, by considering the social forces involved in a situation, it is possible that social interaction can take place without spoken language. Thus, non-verbal children and young people's experiences have not previously been explored with positioning theory.



**Figure 7: Mutually determining triad from Harré and Langenhove (1999 pg.18)**

Positioning theory has been used previously mainly in educational settings but with some evidence from health contexts. McCloskey (2010), Baines (2011) and Lalvani and Polvere (2013) applied positioning theory to their data, but none of these were with physically disabled children and young people with non-verbal communication. McCloskey (2010) used positioning theory to explain the social interaction position of parents of disabled children in different contexts, both in medical and social cultural arenas. McCloskey carried out interviews with parents, arguing that the fluidity of the parent's position, in these different contexts, determined their storylines. The people in the medical (Doctor) or social (friend/ family) spaces generated forces that were deemed negative or positive in embracing their disabled child.

Baines (2011) further applied positioning theory in a series of case studies with video recorded observations and interviews with disabled young people, with emotional and behavioural problems. How the young people were positioned at school often led to low expectations by teachers of what they might achieve in adulthood. Thus, the negative stereotypes were reinforced.

Lalvani and Polvere (2013) used a narrative enquiry with parents of disabled children, to explore how the parents navigated their positions, through the medicalised measurements required to provide their child's diagnosis. Positioning theory was used to explain the fluidity of their storylines, which fluctuated between these medical and sociocultural environments where the language used in each was different. These had a varying impact upon the parents, related to the power and control they perceived they had in the medical world, where they felt disempowered and their own sociocultural environments, where they could make sense of the diagnosis and gain some sense of control again, feeling more empowered. However, these three studies who applied positioning theory did not represent the voices of non-verbal disabled children and young people.

Harré and Langenhove (1999) suggest that social interactions are subject to rights and duties within the moral order of where this social communication takes place. Social communication was defined by Pennington (2012) as a means of expressing oneself in a social space, which for disabled children and young people could include AAC or intentional behaviours. Hence spoken language is not necessary for social interaction to take place. In my study, as the participants were disabled children and young people, with mixed communicative abilities, and the study was informed by Article 31 UNCRC (1989), about the disabled children and young people rights to play and leisure, it was hard to justify that the children would have 'duties' in this context. The disabled children and young people could have a contribution to share their views and experiences, which could inform their rights. However, part of the duty lies with those who have the power to influence change, for their increased choices for RAs or to adapt environments and equipment accordingly. These are what Guba and Lincoln (1989) proposed as the agents of change. As the participants in my study had limited verbal communication, I anticipated that positioning theory would need to be adapted, to include their representation, without spoken language, but by interpretation of their intentional behaviours. So, their storylines would be

determined by the social forces of people and the environments surrounding them, supported by their parent's voices and the child's intentional behaviours or expressions of social interaction, to participate or not, in the RA offered. Although the physical positioning was essential when attending RAs, the choice to participate was still with the child or young person to decide the level to which they wanted to be involved. This would include equipment that they could be transported and positioned in, to facilitate their participation in the RA. Hence whilst people can be the agents of change, the disabled children and young people themselves can have a key role as well as being the beneficiaries from increased choices.

In positioning theory, Harré and Gillet (2010) referred to the agency of intentional behaviour, where a person's activity or response is in reaction to the things around them. Thus, a person can choose to be a participant by engaging or not in the activity. However, children and young people with cerebral palsy can demonstrate harmful intentional behaviours towards themselves, either due to internal painful stimuli or external environments they perceive as threatening, such as loud noises and bright lights. Thus, how they would choose to position themselves at a RA, could influence their storylines and enabled them to determine their WB responses from their level of engagement (Harré and Langenhove 1999). In relation to my study, I anticipated that the inclusion of children and young people without spoken language might be a challenge, but by including observations of their intentional behaviours, I considered that this theory could work. Thus, positioning theory as it was developed, will now be applied to several relevant studies, emphasizing how the children and young people's voices were subsequently positioned. This is to represent the 'voices' of those children who cannot speak verbally about their WB and further explore how positioning theory might fit. Positioning theory is also adapted further in the discussion chapter, in relation to my findings.

## **2.10 The 'voices' of non-verbal children's views about their well-being**

To seek to understand about children and young people with cerebral palsy's emotional WB there was some specific evidence (Heah et al 2007; Cussen et al 2012; Foley et al 2012; Simmons and Watson 2014; Watson 2015; Gibson 2011; Teachman 2013). Heah et al (2007) in a phenomenological study looked at experiences of eight disabled children and their parents about out of school activity participation by interviews. This had a clear analysis and coding strategy and



although the numbers were small, not enabling data saturation to be reached, the voices of the children were audible with the value of social opportunities being high on their agenda. The importance of involving families in developing community opportunities was also emphasised. These social opportunities provided enjoyment for the disabled children which potentially enhanced their emotional WB. These opportunities involved being positioned at RAs in the community, which in most cases was done by families transporting them there.

Cussen et al (2012) utilised photo elicited interviews with children and young people with cerebral palsy, which enabled their voices to be heard. The ten young people aged fourteen to sixteen years represented GMFCS I-IV and they took part in two interviews. Following the first interview, they took ten photographs which were used to represent their future aspirations. These were used in the second interview to facilitate discussion and one child used AAC. The methods in this study demonstrated excellent trustworthiness, participant validation of the transcripts was used, and the team's triangulation of the data analysis ensured agreement with the themes found. Three themes were identified which were: keeping close relationships, choosing a future life of one's own and leisure in the years ahead. Leisure pursuits included 'doing and being with others' and 'doing things by myself'. The types of RAs described varied from group to solitary participation such as listening to music, drawing, playing the guitar, computer games and walking the dog. Future ambitions including going to the gym, bowls, camping and acting classes. A weakness of this study is acknowledged that it is set in an urban city and those with less physical capacity such as GMFCS/ CFCS V were not represented. There was a suggestion that advocacy is required to facilitate an increase in leisure pursuit opportunities, for those with childhood cerebral palsy living into adulthood. Bantjes et al (2015) had also promoted the need for advocates to promote participation in RAs. However, it was not clear who these advocates might be, but part of their role would be to facilitate how the young adults could be transported and positioned at an activity.

Foley et al's (2012) study used focus groups with twenty children with disabilities to explore what participation meant to them. There were six themes that emerged the most dominant being about having meaningful RAs to choose from. Children's voices were transparent about opportunities to have RAs adapted in different

environments and how attitudes of people were so important. Feeling good about yourself was a further theme, as well as strategies to develop resilience, to overcome adversity. This highlights the positive emotional WB effect from participation in meaningful RAs. There was limited transparency about the analysis in this study, limiting its credibility, however the children's voices were clear and the discussion focussed on participation as involvement rather than activity measurement. Involvement can mean being present and spectating not always actively participating. However, to be present, the child needed to be positioned in that space, then they had a choice to participate or not.

There were two separate in-depth studies found by Simmons and Watson (2014) and a different Watson (2015). Simmons and Watson's (2014) study was an ethnographic single case study recorded about a child with a Profound and Multiple Learning Disability (PMLD). Here nine year old 'Sam' attended both a special school and a mainstream school and the observations revealed that whilst in the special school, Sam was more passive, whereas in the mainstream school there was much more evidence of intentional, active, happy, behaviour as he sought to relate to those around him and they to him. Here spoken language was not used, but a series of non-verbal gestures and eye pointing to demonstrate his intentionality. Thus, the different environments enabled data collection in a variety of ways to reveal Sam's interactions. The richness of data created from these observations must be treated with caution, as it is only one case study, so cannot easily be transferred to other contexts. However, this concept of intentionality requires further exploration with children and young people with cerebral palsy, due to the nature of their altered postural and motor control and varied communication styles.

The children and young people with cerebral palsy's intentionality can be misunderstood, as they may not be able to control their movements and speech in a reliable way. From a positioning theory perspective, the disabled children and young people can demonstrate intentional behaviours when taken to and placed at an activity, thus physically positioned, ready to participate. So, the children and young people can join in physically if they can, or socially if they choose to or not join in at all. So, Sam in Simmons and Watson's (2014) study demonstrated a range of different intentional behaviours, according to the environments and people he was

with. This supports the idea that environmental change is important in influencing levels of participation, but people's attitudes are also important.

The importance of people to support the disabled children and young people was also highlighted by Watson's (2015) PhD research, which was a series of case studies that explored playfulness with children with PMLD by observations. Watson (2015) demonstrated that it was possible to stimulate playfulness with the children and this was a window to help them show their level of happiness and engagement in situations with other people. A term was introduced of 'mindful interdependency' demonstrating that the person with the child needed to engage with them is some form of play, to generate a response. The 'attunement' of the play staff was key to enabling this to happen, which meant someone being able to tune into the child's bespoke way of playing (Watson and Corke, 2015). A suggestion was made for a play passport, a document that travels with the children and young people to different places, to inform people of their play preferences, which has yet to be evaluated to see if it can demonstrate their WB (Watson et al, 2018).

Gibson et al (2011) interviewed six children and young people, aged between seven and eighteen years, and their parents, about the importance of walking, which is considered a social 'norm'. The methods included role play with puppets, photographs depicting children's geographies, sentence starters and cartoon captioning. These were all used selectively to engage children and young people in vignette stories about choices to do with walking or using their wheelchair. Thus these creative tools enable them to create their 'storylines' in an unconventional and creative way. Their results reveal how the social value of walking as a 'normative' experience dominates, as there are few alternative positive discourses of disability in western society (Gibson et al. 2011; Gibson et al. 2012). Gibson and Teachman's (2012) study represented parental voices, but the disabled children and young people voice was also clear, facilitated by the open questions used skilfully as the quotes cited illustrated. The children and young people views showed more ambivalence about the value of walking than their parents, in fact they were more excited and accepting of alternative modes of mobility, that socially marked them as 'disabled', such as a powered wheelchair. Suggestions from this study asks for healthcare practitioners to consider how they engage parents and children in the rehabilitation of walking, as current practice is sometimes adding to parental anxiety

and doubt and contributing to children's negative self-identities. Thus, choosing to walk or not, affects both physical and social participation, however this social 'norm' of walking has a dominant discourse in society and physiotherapy practice. It is known that the ability to walk, influences choices and abilities for participation in RAs, so those non-ambulant children and young people with cerebral palsy do have less choices, but the emotional WB of this is unknown at the present time (Palisano et al. 2010; Stewart et al. 2012).

Teachman and Gibson (2013) further argued for the value of single qualitative interviews where the methods highlighted three important components. These were parental collaboration, a toolkit of adaptable interview techniques and consideration for the power differential in child-adult researcher interactions. This iterative approach built upon visual approaches used with children and is novel being used here with disabled children and young people. A limitation here was that only one interview may not have captured their full views, as the researcher's relationship with the child takes time to build and leaves little time to adapt to their preferred communication style.

Furthermore, Teachman (2016) in her PhD thesis achieved a series of interviews with young people who used AAC, as photographs were taken and the young people related these to where they felt positioned in 'belonging circles'. This was then critiqued in relation to Bourdieu's social and linguistic capital revealing that those with limited verbal communication found many social situations '*terrifying*' due to their lack of control. The strength of this study is that it had the young people's voices at the centre of the enquiry and revealed anxieties for them about social situations, suggesting for them, that social participation might have a detrimental WB effect. Especially if they cannot make their needs and wishes understood, this might hinder their participation in RAs with other people. Teachman et al (2017) go on to argue that standard interviews have limitations for those whose use AAC, therefore more creative approaches for data collection should be considered. The next section will critique evidence related to non-verbal children and young people ability to voice their decisions and choices.

### **2.11 Non-verbal disabled Children and Young People's participation in decision making.**

There were three key papers that referred to involving disabled children and young people at the highest level of participation in decision making, in keeping with the eighth highest rung of Hart's participation ladder where 'young people and adults share decision making' (Hart 1992; Figure 4 pg 11). Firstly, a project was set in Northern Ireland called the Sixth Sense (Murray 2012). The young people were involved as consultants to the Health and Social care Board, to inform them about involving disabled young people in decision making about their health and social care. Barnardo's provided training in advocacy and IT skills and all mediums of communication were used to enable those with alternative forms to participate. These included specialist IT, music, drama, digital media including a blog and video conferencing. The young people felt empowered as their voice was listened to, thus being their own advocates, however they did not always get the results they were hoping for, so could be disappointed sometimes with the outcomes.

Secondly, the VIPER (Voice. Inclusion. Participation. Empowerment. Research) (National Children's Bureau, 2012) study, was the only example that had disabled young people central to the research design from the outset and throughout the whole process. This literature review was set up by the Children's Society to explore how disabled young people were involved in decision making around participation choices. Kirby's et al's (2003) model of participation in decision making was used to help review their level of involvement based upon Alderson and Montgomery's (1996) work. There were four levels of their proposed involvement: '*being informed, expressing a view, influencing the decision-making process and being the main provider*' (VIPER, 2012 pg 10). Thus, participation was proposed as a process of being involved in decision making not just a one-off activity.

Thirdly, a systematic review identified nine examples of involvement in decision making of disabled young people from twenty-two studies found (Bailey et al. 2015). The benefits to the young people reported an increase in self-esteem and confidence, however one of the challenges highlighted the gap in knowing how to include young people with non-verbal communication. This had relevance to my study, when considering the choices that children and young people with cerebral palsy have for participation in RAs. It is not known how they are being supported to

influence decisions about the RAs that might be adapted for their needs, to benefit their emotional WB. As my PhD study was set within the context of research priorities for disabled children and young people in the UK these are outlined in the next section.

## **2.12 Research Priorities for Childhood Disability**

A research priority setting exercise, funded by the James Lind Alliance and the British Academy of Childhood Disability (BACD), sought to engage young people in the research priority setting for the context of childhood neuro-disability (Morris et al. 2015). This consultation process involved eleven disabled young people who supported the process, together with partner organisations which included thirteen charities and eight professional associations. So, their voices contributed to this research priority setting within the UK, but as this was only 0.03% of the total of people (11/369) who participated, it appeared tokenistic. Whilst this opportunity is welcomed, the nature of some of their issues raised, did not always translate into a direct research question. The results were a combination of the survey and focus group data which led to twenty-five research priorities. Number sixteen relates to participation in recreational and leisure activities: *'Are child-focused strategies (e.g. one-to-one or group social and skills training) effective to improve confidence, self-esteem and promote participation in recreation and leisure activities for children and young people with neuro-disability?'* (Morris et al 2015 pg. 9). To date, this study has not been commissioned from this priority setting exercise, it is however unclear what is meant by child focused strategies. It is good that the young people's voices were included in this research priority setting exercise. However, there remains a lack of choice for them to participate in RAs, relying on what has been adapted for their use in their geographical area. It is not known what the emotional WB impact is for them from their level of participation, it is therefore difficult to determine how their confidence and self-esteem might change.

## **2.13 Summary of Chapter two**

In summary, the literature has been critiqued to reveal the lack of voices from disabled children and young people about the WB effect from their participation in RAs. Positioning theory has been introduced and has not been previously applied with disabled children and young people, this includes both the physical positioning and metaphorical social positioning, which indicates their control in the situation. The

studies which used creative methods, gave voice to those often traditionally excluded from research and provided insights previously unknown (Wickenden 2011; Gibson and Teachman 2012; Teachman 2013; Simmons and Watson 2014; Watson 2015). This provided evidence that creative approaches and case study design can enable rich data to be generated. Thus, from this literature review, what is currently unknown is how the children and young people living with cerebral palsy choose their level of participation in RAs, and what their views and experiences of the emotional WB impact is from their level of participation is. To address this gap in the literature, the following question and aims were formulated:

## **2.14 Research question and aims**

Research question:

- How do children and young people with cerebral palsy and their carers/parent's view, experience and choose their level of participation in recreational activities?

The aims of my study were to explore participants':

- Views, experiences and choices for Children and Young People's level of participation in Recreational Activities, including barriers and facilitators.
- Perceptions of the effect of their level of participation upon Children and Young People's emotional Well-being.

My research focused on non-verbal children and young people with limited mobility (GMFCS and CFCS III-V), exploring their motivations, facilitators and barriers to initiating, maintaining or changing their level of participation in RAs. Further knowledge was gained about their perceived WB benefits, from their level of participation by having two groups, a participatory group and a limited participatory group. The next chapter outlines the methodology developed for this study.

## **Chapter 3: Methodology**

### **3.1 Introduction**

This chapter consists of three sections about the development of the methodology. The three sections are the qualitative approaches and theory, the details justifying a case study design and the data generation and management. My study used an exploratory multiple comparative case study design, with participatory visual methods (Yin, 2018; Mannay, 2015). Yin's (2018) case study design was chosen because it offered a clear structure to build multiple case studies in two different groups, to enable comparisons to take place. This was to capture and compare the views, experiences and choices of children and young people with cerebral palsy, aged nine to sixteen years in a group that participated a lot in RAs (PG) and a group that had limited participation (LPG). As the children and young people communicated differently, visual methods were incorporated to represent the WB effects from their participation. The children and young people were supported by their parents, exploring their level of participation in RAs for their perceived emotional WB effects, considering the barriers and facilitators. The participants either used a walking aid or were non-ambulant and all had communication and learning difficulties. This level of disability meant that they could find sporting activities difficult, so recreational participation in broader contexts were explored.

My study was positioned within social justice values that sought to advocate for the importance of fairness for this group of disabled children and young people, by providing them with a way to express their choices, to represent their voice (Beauchamp and Childress 2013; Mertens et al, 2011). McKibben (2019) has proposed that subjectivity could be considered a positive attribute in learning disability research, where researchers review the emotions, context and observations when interpreting the data. I used reflexivity to manage my feelings, ideas and preconceptions when undertaking my research by audio recording my initial responses and later typing these up to reflect and consider their meanings. My position as a former children's physiotherapist gave me insights into the likely issues the children and young people and their parents might face. However, I acknowledge there was the potential risk of bias in me assuming that I knew what they meant. To address and minimise this effect, to increase the rigour in my study, my reflexivity is focussed in sections 3.7.3, 3.9.6 as well as Appendix 8. Here I aim to protect against



any adverse influence I might have had in influencing the data collection process and my interpretation of the data from my position as a former practicing children's physiotherapist.

### **3.2 Structure of methodology chapter**

Section one begins by discussing the wider choices of qualitative research methodologies, justifying why a case study design was chosen. Emphasis is placed upon emancipatory principles, to position the 'voices' of the participants' central to the enquiry. The adaptation of visual and participatory methods was required to engage with them, due to the nature of their different communication styles, with support from their parents. The theoretical bases of the ontological, epistemologically and axiological frameworks are described with my study's emphasis explained (Creswell 2014). The meanings were socially constructed from the participants, the people, environments and objects of adapted equipment which supported their level of participation. The emotional WB impact from their level of participation was interpreted in relation to positioning theory which is adapted and developed in the discussion chapter (Harré and Langenhove 1999).

In section two, the details of the case study are justified, with each component making up the individual case described. These are two interviews; a diary over twelve weeks, including photographs of the children and young people sent by their parents; field notes and photographs from the observations of their usual RAs. These multiple data sources, within each case study, represented the views, experiences and choices of disabled children and young people and their parents, about their perceived emotional WB impact from their level of participation in RAs. Hence, by comparing and contrasting the two groups, it was possible to understand new meanings about their emotional WB from their views, experiences and choices.

The third section focusses on data generation, management and risk. These are the consultation process, ethical approval, pilot data, recruitment and purposive selection, the inclusion and exclusion criteria, main data collection and how the analysis was carried out. The qualities that ensure that my research demonstrates rigour and trustworthiness are discussed including reflexivity, acknowledging my position as the researcher, as a strength in this context (Burnard et al, 2008; Nind and Vihna 2012; Houghton et al 2013; Mannay 2015). This section ends with the ethical considerations of carrying out research with participants who are physically

disabled minors and have limited understanding and communication difficulties (Alderson and Morrow, 2011). Therefore, emphasising the importance of my research with this marginalised group of children and young people, not to exploit their positions, but to represent their voices authentically (Runswick-Cole et al, 2017).

### **3.3 Section 1: Qualitative approach and theory**

#### **3.3.1 Wider Qualitative Approaches**

As this is an exploratory study about emotional WB with participants who have been excluded from traditional research, and to address the study aims, a qualitative approach was necessary. This is because qualitative approaches can be flexible and creative (Pink, 2013; Mannay, 2015). They are better suited to support the engagement of children and young people in research, especially those with additional needs (Beresford, 2012). Whilst quantitative approaches have been used to measure many physical aspects and QoL related to participation with this group of children and young people, less is known about their emotional WB. By exploring their views, experiences and choices for RAs this can give further insights, which can improve our understanding of their experiences. Imms et al's (2016) systematic review had revealed the lack of consensus on the understanding of what 'participation' means in childhood disability. Therefore, this limitation also hinders the understanding of emotional WB in relation to participation. Thus, a qualitative research approach can advance this knowledge.

Denzin and Lincoln (2000) provide an overview of qualitative methodologies, including case studies and ethnography. After defining the research question and aims, I then considered what could work methodologically. I had to think laterally when considering the methodology, especially as my intention was to give these participants a 'voice', to represent their agency.

Crotty (1998) discusses the concept of 'bricolage' in research. A bricoleur is someone who develops something new out of left-over materials. This metaphor had parallels when developing my research approach, to generate meaning with participants who do not have usual means of communicating. This is not a linear or tidy process and is more complex. Rogers (2012) highlighted this, emphasising the flexibility and plurality of such an approach.

Initially my research ideas had focused on phenomenology, more specifically IPA (Smith et al, 2013) as a means of exploring participants' experiences. This included descriptive, linguistic and conceptual components of analysis, which seemed it could give multiple perspectives. Several studies in this context had used an IPA approach of exploring disabled children and young people lived experiences (Mulderij 1996; Heah et al, 2007; Stewart et al, 2012; Conchar 2014). However, when refining my research question and aims, I realised that once I had narrowed my inclusion and criteria down to include those with more profound learning and communication difficulties, the linguistic component of IPA would be unrealistic to achieve. This was because I was not going to be able to generate typical language-based interviews with some of the children and young people. So, further consideration was given to combining different data sources and a case study design, which included some visual methods, seemed to offer the best opportunity (Yin, 2018; Mannay 2015). Especially as Tisdall (2012) had suggested that visual methods can contribute towards an understanding for those with alternate forms of communication, to support their social constructions from experiences. My intention was to empower my participants, to enable their voices to be heard, by observing their intentional behaviours and listening to their parent's views, an emancipatory approach was considered, but not used.

Barton and Hayhoe (2020) outline that emancipatory research seeks to transform power to the disabled individuals. This research paradigm examines the contextual and environmental factors that either facilitate or impede a disabled person's integration into society. It seeks to empower the participants at all stages of the research process, from design to dissemination, by maximising their involvement and reducing the power relationship between researcher and participant (Nind 2009). The focus of emancipatory research is on the strengths and coping skills of the people with disabilities rather than their deficits. This ethos resonated with my intention to empower the participants and represent their 'voices', whilst recognising their parents or carers would need to support them to achieve this (Hodge 2008; Wickenden and Kembhavi-Tam, 2014; Bailey et al, 2015). However, emancipatory research has its limitations, as there can be issues about who makes the decisions in the analysis of the data, what gets published and whose intellectual property the

data belongs to. This could have been an issue with my study, which potentially could have exploited the children's vulnerabilities.

My study sought to empower the children and young people participants, but as Mietola et al (2017) has critiqued, current emancipatory research does not include those without a physical voice, which my study did. Frankena et al (2015) had proposed the active involvement of people with intellectual difficulties in health research, but this is presently limited to those with mild to moderate difficulties, which was not the case for my study.

Kramer-Roy (2015) suggests that participatory and creative methods can facilitate an emancipatory approach, to engage family members supporting those with learning difficulties at all stages of the research process. Indeed, I recognised that the parents support would be needed to achieve data collection, as the participants would not be familiar with me, or I with their preferred means of communication. However, for the disabled children and young people with more complex needs, this emancipatory approach had limitations due to the need to consult with participants for member checking and to help develop the analysis, which would have been difficult (for the reasons already outlined above) and therefore I decided not to use this approach. However, I was keen to enable the children and young people to participate and reduce the power differential in how I related to the participants. Additionally, Mannay (2015) proposed that participatory methods can enable the researcher to facilitate participant's engagement in producing meaningful data together.

I therefore considered that a case study design would best facilitate the voices of the disabled children and young people to be heard, based upon research critiqued in the previous chapter (Gibson 2011; Teachman 2013; Simmons and Watson; Watson 2015). However, I was not able to engage the disabled children and young people at all stages of the research process, but the main focus for their participation in my study, was on their participation on the consultation and data collection phases (Lewis and Porter, 2004; Porter 2007). Case study method will now be outlined in more detail.

### **3.4 Case study design and method**

Case study design is especially useful if the aim is to explore the how and why of a topic, where the researcher has little or no control over the events which are

contemporary, rather than historical (Stake, 1995; Yin, 2018). It can be used to study organisations as well as individuals. Flyvbjerg (2006) suggested that a good case study enables the researcher to get close to the reality of their participants, to explore the viewpoints and behaviours that characterise them as social actors. This provides depth rather than breadth in data collection, therefore small numbers are appropriate. The purpose is to understand the details of what is happening to the participants. Additionally, Thomas (2015) emphasised the value of a case study to be able to look at things in detail, which was necessary in this study to explore the WB impact from the children and young people level of participation. Thomas (2015) also proposed that a case study is a good scientific approach, due to the thoroughness of data capture and analytical insights gained. Thinking about the type of mixed data generated within case studies, enables connections to be made that have many strands and directions. Hence enabling the topic to be viewed in depth from many angles, so a small sample size is sufficient.

A case study is a method that enables the researcher to combine different data sources to make up the 'case'. Yin (2018) proposes six sources which can provide evidence to make up each case. These are documentation, archival records, interviews, direct observations, participant observation and physical artefacts. By collecting the same type of data in each case, comparisons between cases is made possible. Although these different sources can make up the case study, it does require a clear boundary to explore the research question. Section two will provide the detail of what made up each case study in my study.

The next part will outline the theoretical perspectives which underpin my thesis. These are the ontological, epistemological, and axiological continuums which provides the background for centrally positioning the voices of these children and young people in my research enquiry.

### **3.5 Theoretical Perspectives**

Braun and Clarke (2013) suggest that qualitative research methodology relies upon both the ontology and epistemology continuums. Additionally, Creswell (2014) describes the need for an axiology or values in research which underpins the methodology. On the ontological continuum, in contrast to quantitative research, where realism predominates with one truth, relativism offers multiple truths where interpretation of knowledge has many facets. In between these two extremes is

critical realism which suggests one can only ever partially know the reality. It is compared to a prism, which filters the view and although some aspects may be revealed, it can only ever partially be known. In the epistemological continuum distinctions are drawn between an archaeologist who digs for the truth to be found and a sculptor who produces the reality (Braun and Clarke, 2013). It is the latter that had relevance for my study's design. It was down to me as the researcher, as a sculptor, to interpret the findings to represent the reality of the participants' lives. Or as Brinkman and Kvale (2015) suggest, being a traveller who walks with them on their journey to explore their lives. In my study, I adopted an axiological approach as the values I set out aimed to promote the voices of those previously underrepresented in research by doing research 'with' them not 'on' them. These theoretical terms will now be expanded upon, in the context of my study.

### **3.5.1 Ontology**

Ontology is about '*what is*' and is the study of the nature of existence (Crotty, 1998 p.10). Seeking to understand how the children and young people and their parents made sense of their worlds. The uncertainty of the outcomes in cerebral palsy has often led to pessimistic predictions of what their meaningful reality might be (Colver et al, 2006, 2010; Van Mo et al, 2015). For disabled children and young people, who now live longer, there is an emerging evidence base recording the reality of their lived experiences with a physical activity and sport's bias (King et al, 2013; Bantjes et al, 2015). However, this emphasis needs to broaden and the new paradigm of DCCS has added more insight into the everyday experiences of disabled children and young people, moving away from the perceived 'norms' of the medical model and re-imagining a different future (Curran and Runswick-Cole, 2013; Runswick-Cole et al, 2017). The world in terms of a disabled children and young people 'participation' has not always been there, and there have been low expectations from many people including the children and young people themselves (Hodge and Runswick-Cole, 2013). In the post-modern era, new inventions and adaptations have been created, that can have a benefit for enabling the children and young people to participate in wider RA, including in the arts and culture. For me as the researcher to construct a meaningful reality in the 21<sup>st</sup> Century, an interpretivist approach was necessary, to understand their social reality (Watson, 2012). So, from an ontological perspective my interpretation of participants' views, experiences and choices,

brought a contemporary view of how they participated in RAs and ‘what’ their lives were like.

### **3.5.2 Epistemology**

Epistemology deals with the nature of knowledge and ‘*what it means to know*’ and there are a range of different epistemologies (Crotty, 1998 p.8). Firstly, objectivism relates to seeking objective truth which is separate from a consciousness about that object. This is difficult to apply to children and young people with communication and learning difficulties as their perception of objects may be difficult to obtain. Secondly, constructionism suggests that there is no objective truth waiting to be discovered and that ‘*meaning comes into existence in and out of our engagement with the realities in our world*’ (Crotty, 1998 p.8). This constructionist stance has more resonance with the idiosyncratic nature of each children and young people with cerebral palsy (Watson, 2015). A third epistemological stance is subjectivism, where meaning is constructed out of nothing. As the perspectives of children and young people with different communication strategies are hard to capture, this was not feasible. However, their unique responses brought fresh insights to add to knowledge. Thus, the data captured their level of participation in RAs contributing to an understanding of their emotional WB. So, both the people, the environments and objects that helped them to participate, provided data interpreted by me, to add to this meaning. Based upon constructionism, how this data was interpreted holds a degree of subjectivity. Hence the filter of my understanding has epistemologically facilitated some new meanings about the emotional WB impact from the children and young people level of participation in RAs.

### **3.5.3 Axiology-Ethical Stance**

Creswell (2014) discusses the axiology of research, which is the role of ‘*values*’ in research. These values could be ethical, political or religious biases which could underpin a study. My study was based upon the ethical bias which sought to position their voices centrally, so their agency was represented as part of social justice and autonomy (Beauchamp and Childress, 2013). Justice (fairness) as these children and young people are marginalised in society and currently underrepresented in research studies. Daley (2015) argued that if they remain excluded from research, their voices will remain invisible. Their voices deserve to be heard so that their agency is represented in society as autonomous individuals (Watson, 2012; Daley,

2015; Yoshida, 2018). Swinton (2012) suggested that it is still the negative reactions from people in society that creates their disability, which had previously been proposed from the social model of disability (Oliver, 1990; Swain et al, 1993; Oliver, 2013; Shakespeare, 2014).

There were four policy documents which underpinned my study to support this ethical stance. Firstly, Article 31 of the UNCRC explores children and young people “*Right to rest, leisure, play and recreation and to take part in cultural and artistic activities*” (United Nations Children’s Fund, 1989 p.10). Secondly, this right is also supported by the Welsh children and young people Participation Policy which states that ‘*participation means it is their right to have a voice and a choice*’ (Welsh Government, 2010 p.1). Thirdly, the Rights of Children and Young Persons (Wales) Measure (2011) validates the need for all children and young people to be able to ‘*participate freely in cultural life and the arts*’ p.17. In seeking to reflect their participation opportunities in RAs in the data collection, their autonomy (choices) were heard, thus reinforcing their agency. These disabled children and young people may have different ways to show their choices, but these are still valuable insights, which can inform us about their WB. Thus, enabling their ‘voices’ to be heard, by using the participatory methods, contributing towards what Yoshida (2018) described as their ‘social justice’. Fourthly, the Well-being of Future Generations (Wales) Act (2015) was enacted at the start of this study and shows promise to the future lives of disabled children and young people as they mature into adulthood, that their WB needs will be considered and not overlooked.

This axiological ethical stance aims to carry out research ‘*with*’ children not ‘*on*’ children. Hence, the aspirations of disabled children and young people and those who cherish them are emphasised. Thus, my study aims to bring fresh perspectives from the disabled children and young people themselves, seeking to reduce the adult power relationships that have prevailed previously in research (Porter, 2007; Alderson and Morrow, 2011; Alderson 2012). Indeed Alderson (2012) called for the need to balance children’s rights against adult power by involving them at all stages of the research process as a way of advocating for them. In my study this can have benefit for health, social care and educational practitioners, who by listening to their voices, from empirical research such as this, can fulfil the ‘*moral imperative to listen*’, as proposed by Carpenter and McConkey (2012 p.258). By asking, listening and



observing, data were interpreted from the participants, recognising only partial knowledge was generated, as their disability may have filtered a deeper truth that may remain unknown (Lewis, 2011; Braun and Clarke, 2013).

### **3.6 Summary of Section 1**

This section has described the wider qualitative research choices, positioning the participants within the ontological, epistemological and axiological continuums from a constructionist perspective of social justice. A case study design has been selected using participatory and visual methods. Section 2 will describe and justify the details of the case study.

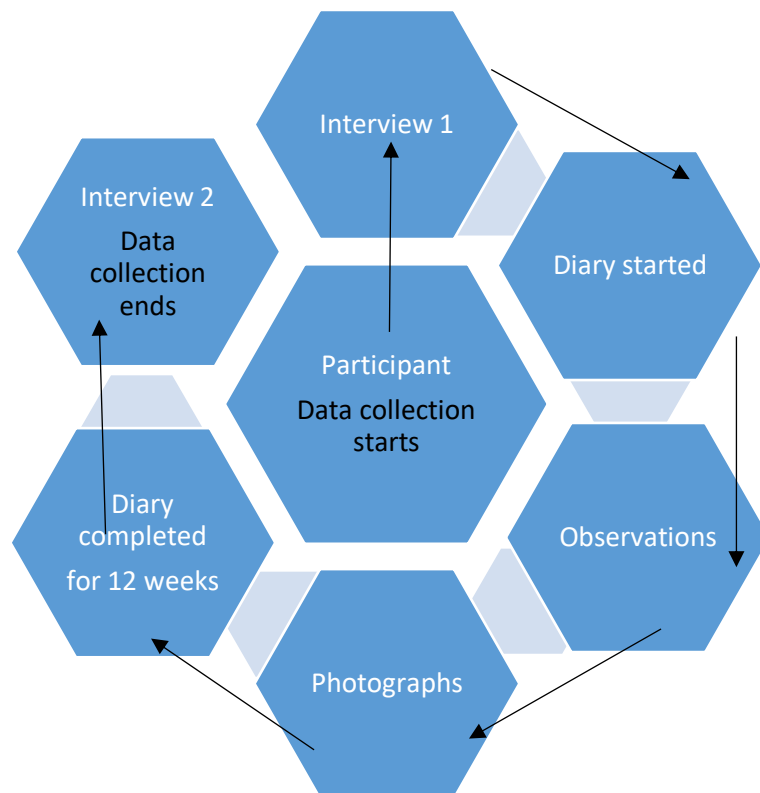
### **3.7 Section 2: Case Study details**

A series of case studies were carried out in, sometimes overlapping in time, and this is known as a 'parallel' design (Thomas, 2015). Starting with the PG and then moving onto the LPG. The aim was to recruit a sample size of eight, four in each group. The data was collected for a limited time period of twelve weeks and this period of time is known as a 'snapshot' (Thomas, 2015). The data provided evidence from which to draw conclusions about their emotional WB during the data analysis stages, by looking for evidence of their enjoyment, feeling safe and being valued as person (Hammersly and Atkinson 2007; Mannay 2010; Pink, 2013). A flow chart of my case study design adapted from Yin (2018) can be seen in Appendix 4. The different sources of data I chose from the six possible outlined by Yin (2018) included documentary (diary), interviews, direct and participant observation and the use of physical artefacts. The reason I did not use archival records was because they would not have enabled me to answer the research question and there was not an obvious source where the WB effect from their participation in RAs would be recorded.

A case study is not usually generalizable to wider populations; however, it can give insight into participants with similar characteristics (Yin, 2018). This was facilitated by being able to 'close in' on their real-life situations and analysing the data as the story unfolded. Thus, by combining the different data sources within each case, the triangulation of these components enabled me to analyse and answer the research question and fulfil the aims. The opportunity to reflect upon this process by taking a

considered approach, increased the logical flow and rigour of my study (Barbour, 2001).

These different accounts from the different data sources constructed in each case study, can be described as a 'Mosaic'; this illuminated participants' lives and enabled me as the researcher to explore their emotional WB from my interpretations (Gibson et al, 2013; Pickering, 2013; Pickering et al 2015). This 'Mosaic' is illustrated in Figure 8. As shown by the arrows, starting with interview one, followed by commencement of the diary, observations during the twelve weeks including photographs taken by myself and the parents as part of the diary completion and interview two at the end.



**Figure 8: 'Mosaic' of individual data sources to make up single case study over 12 weeks.**

This exploratory multiple, comparative, snapshot, parallel case study used an interpretative approach to study participants based in South, Mid and West Wales. Comparison of the cases in the two groups of participants (PG and LPG) has enabled new meanings to be derived. If only those who participated frequently were looked at, less new meanings would have been added, and to my knowledge, participation in RAs with disabled children and young people, has not been

researched in Wales before. Only my previous research about adapted cycling is evident from the literature (Pickering et al, 2012; 2013; Pickering, 2013; 2017). It was this gap in the literature that led to the inclusion of the LPG.

Within my case study design there was the need to justify the choice of the participatory and creative methods, involving the participants directly in some form of data collection due to their different communication styles and learning needs (Nind, 2011; Pink, 2013; Mannay, 2015; Pickering, 2013; Kramer-Roy, 2015). Each data source which made up the individual case study will now be outlined to justify these choices: namely interviews, diaries, observations and artefacts (symbolic toys and photographs).

### **3.7.1 Interview design and content**

An interview is structured in a way to engage participants in a purposeful conversation. This can then be captured by an audio device for research purposes (Silverman, 2006; Jones et al, 2013). It can take many formats; in my study it was directed by the research question and aims. Interviews could be structured, semi-structured or use open style questions (Gill et al, 2008). A semi-structured interview was selected to fulfil the aims of exploring how the participants viewed, experienced and chose their level of participation in RAs (Creswell, 2014; Flick, 2014). The interview questions were based upon the literature reviewed (and in relation to the study aims) and adapted once I had met the children and young people and their family (Appendix 5). This was done at an initial visit, to explain my study and gain their consent or assent, which is covered in more detail in section 3.

I aimed to interview the children and young people themselves to keep them at the centre of the enquiry, but in recognition that some children and young people were not able to communicate their views, I realised I would also need to interview their parents or carers. Open interviews were not suitable due to the participant's limitations with communication and learning. The semi-structured approach was adapted for the participants who used AAC, needing to be more structured. The AAC varied from computer-based touch screens, iPads and Eye-Gaze technology. Questions needed to be phrased in more of a closed style for those using AAC, so that they had the choice from their vocabulary to express their answer (Hynan et al, 2014). The interviews were facilitated by the researcher, supported by their parent, but directed by how long the participant could concentrate for. These interviews were

developed in an individualised creative manner, according to their interests, offering a choice of talking, drawing, symbolic play in a sand box and using various artefacts to support their engagement (Pink 2013; Mannay 2015). This approach took longer and generated data that was unique for each individual, including some musical expression.

The adaptation of the symbolic play was based upon the premise that as children develop their language and cognition, usually at an earlier age than nine to sixteen years, they use toys to represent concepts (Buckley, 2003). This helps them to understand what objects are and what they are called. The symbolic use of toys to represent the RA offered a level of engagement for me with my participants, when verbal language was absent. However, there is a lack of symbolic toy representation for longer term disabilities, with the main emphasis being on bandages and crutches, suggesting a temporary injury (Graham et al, 2015). Additionally, Mitchell (2012) had explored the use of play objects to enable children to express their emotions but again the representation of disabled children was absent. So, the RAs that my participants were interested in, were explored when meeting them at the initial visit, to gain their consent or assent to take part in the study. After reflecting upon this meeting, the ideas for suitable symbolic toys were generated on an individual basis, hence these became the artefacts used in the data collection. In order to captivate and maintain their interest during the interview, these artefacts included 'La La Loopsy' on a trike and trampoline as seen in Figures 9 and 10. Such artefacts were used to engage the participant in a conversation about what they enjoyed doing as a RA.



**Figure 9: Artefact: Symbolic Toy: Trike**



**Figure 10: Artefact: Symbolic Toy: Trampolining**

A sand box had been used previously with children to explore difficult experiences in their lives such as being 'looked after' (Mannay, 2015). This sensory medium of sand

with the toys, engaged some participants in a meaningful conversation about what they enjoyed doing outside of school. The symbolic play toys that were offered with the sandbox can be seen in Figures 11 and 12 as the artefacts to support data collection. In addition to tell their stories, they used a combination of ‘found’ pictures, their own picture books, drawings, musical instruments or these toys (Mannay, 2015; Rose 2016). The key skill here for me, as the researcher, was listening to their accounts of participation in RAs, via their electronic communication devices in combination with these play activities using these varied artefacts.



**Figure 11: Artefact: Sandbox**



**Figure 12: Artefacts: Symbolic toys offered for play**

The interviews took place in the participants' homes which provided privacy and less distractions than a public space. They varied in time due to the level of concentration



and fatigue of the participants but ranged from 35 to 97 minutes. I was able to respond during the interviews with different activities, as I sensed the participants losing interest; these activities also included musical instruments and vibratory/ light toys (Figure 13) and a drawing activity (Figure 14). The drawing activity was designed by myself on a laminated sheet, using images from a previous publication (Pickering and Pickering, 2015). However, their participation was limited due to their difficulties with fine motor coordination to hold a felt tip pen.



**Figure 13: Artefacts: Musical instruments offered for play**

**Natalie is thinking about what she would like to do to relax and play can you help her by adding your ideas?**



**Hussain is thinking about what he would like to do to relax and play can you help him by adding your ideas?**



**Figure 14: Laminated Drawings of Natalie/Hussain 'Relax and Play' offered**



There was some scope with the separate parental interviews, to divert from the semi-structured format, to explore their views in a more open style. These followed a process of open questions, active listening, probing in a mutually constructed manner, whilst being sensitive to any emotive topics raised (Silverman, 2006; Brinkman and Kvale 2015). The photographs of their children and young people participating in a RA helped to elicit discussion in the second interview. I was able to probe to gain deeper meaning and richer data when the parents mentioned aspects which lent themselves to further exploration. For example, when they said their child was 'fading' I asked 'what do you mean by this?' I was able to show empathy with the participants by the active listening skills developed from clinical practice with disabled children and young people and their parents. However, recognising that my position was now different as a researcher, to listen and not problem solve their issues.

Murray et al (2009) suggested that a series of interviews can give more depth as a one-off interview might be quite superficial in this context (Brinkman and Kvale, 2015). Thus, a series of two interviews provided the ability to develop a relationship with the participants, both the children and young people and their parents, hopefully showing that I was interested in what they or their children and young people would do over the next twelve weeks. It was not too long a period so that the participants would forget who I was (Clark et al, 2014; Shirani et al, 2016). This rapport was important to engage with participants in a researcher relationship, which would come to a natural end when the data collection was completed.

The first interview questions were built upon the literature, related to the perceived facilitators and barriers to participation (Colver et al, 2013; King 2013). I sent the interview questions to the parents one week in advance and took a printed copy to the interview (Appendix 5). I did this in advance to allow them to think about what I would be asking and to give them the opportunity to decline to answer anything they were uncomfortable with. The interviews started with general questions for the participants to tell me about themselves or their child and what they enjoyed doing, to explore what might be 'Fun' in their lives (Rosenbaum and Gorter, 2012). This was followed by prompts to seek deeper understanding of the factors which impacted upon their emotional WB.

The second interview was based upon the diary and the findings from the first interview and any observations, including visual images that some of the parental participants had sent during the intervening weeks. It was possible to explore the context of some of these images during the interview. The diary entries then facilitated a more in-depth second interview, exploring what they had recorded which included some photographs to augment their story. When the children had been able to speak to me via their AAC, a separate interview was carried out with the parent without the children and young people present. This was because it would have been rude to talk to the parent to gain the depth required and the children and young people needs could not be ignored during this time. These interview schedules can be seen in Appendix 5.

### **3.7.2 Diary as a documentary evidence**

A diary is a record of events which can capture emotional responses (Shirani et al, 2016). A researcher-directed diary is one produced solely for the study, as a primary data source, (Braun and Clarke, 2013) as was the case in my study. This contrasts with a personal diary which someone might chose to keep, but then would be a secondary source of data, if permission was later given for analysis. A researcher-directed diary can take many formats including a hard copy, handwritten, typed online or emailed electronically, audio or video recorded diary or a creative scrapbook. A more recent approach has used mobile texting diaries with typically developing children and adolescents living in different family structures (Malinen et al, 2015). However, with my participants, texting was not a feasible option, due to their fine motor and cognitive limitations.

In keeping with the emancipatory approach, a video diary might have been an effective way for my participants to record their experiences. However, there were two drawbacks here. Firstly, their fine motor coordination meant they could not actually do the videoing themselves. Secondly, there was the need to protect their anonymity and confidentiality. These concepts will be expanded upon in section 3 under the ethics of doing research with disabled children and young people.

However, although visual methods were included, the consent was that only non-identifiable images to provide context would be used. So even though some of the parents sent me some pictures of activities, these were subsequently adapted to ensure they are sufficiently anonymised in my thesis. The diaries collected in my

study were offered as an A4 soft bound coloured booklet, or computer based typed up, to be emailed later. As it was the parents who would complete these, the children and young people had a limited choice in these preferences, due to their limited coordination with speaking, writing or typing. The parents hand wrote in the diary, the children and young people usual experiences of RAs over the twelve-week period. The parents also sent me photographs of their activities or placed these into the diary with a written commentary, thus conveying information about their child's experiences for me to see and read.

The diary structure was framed around the six 'F' words (Family, Function, Fitness, Friends, Fun and the Future) proposed by Rosenbaum and Gorter (2012). The aim in my study was to explore what RAs they perceived as 'Fun' which would have a positive effect upon their WB. These 'Fun' opportunities were set within their family structure, determined by their level of function and fitness, whether they had friends to do these things with or did them alone and if they had any future aspirations for participation. This was harder to capture with the LPG. The diary instructions can also be seen in Appendix 5.

### **3.7.3 Observations**

The observations included in the case study, were a mixture of participant and non-participant observation (Bryman, 2016; Spradley, 2016). For participants who could not communicate in a verbal interview, observations provided the only opportunity for me to capture their experiences. Observation of at least one of their usual activities was a feasible possibility during the twelve weeks, whilst not being too invasive of their privacy. This enabled me to immerse myself in the sensory aspect of data collection using my own senses of sight, hearing, touch, taste and smell. Additional negotiation took place with the relevant gatekeepers in an attempt to make my identity clear, as this was an overt observation. These included charities, voluntary sector organisations, uniformed clubs, special schools and private physiotherapists in Wales. The negotiations with these gatekeepers were all straightforward and in fact embraced by all parties in a positive way.

LeCompte et al (1993) provide a useful checklist of headings from which to generate field notes of the observations, which was adapted and used alongside Spradley's (2016) question matrix. The checklist table with the headings developed can be seen in Appendix 6. Photographs were also taken to provide context and rough field notes

were written in an A5 notebook at the time of observation. These were then typed up later into a narrative of the observation with the photographs immersed. The opportunity to observe some of their participatory experiences added value, as they could not report their own feelings about their experiences. Thus observing smiling and laughter during the activity, or refusal and self-harm behaviours such as biting, and hair pulling, helped me to interpret their emotional WB responses during the RA (Williams 2011; Simmons and Watson, 2014). These observations included one participant using Eye-Gaze technology, designed by Lokhande and Dharkar (2013), to help him establish a means of expressing choices, as he was at a pre-linguistic stage of communication. This enabled him to make simple choices about RAs, but he was inconsistent in his responses. The different observations lasted around 90 minutes each and took place at both indoor and outdoor facilities.

Silverman (2006) argues that observational data can combine insight with rigour if field notes are kept consistently and logically. I therefore initially recorded my thoughts about the observations into a Dictaphone, specifically how the child or young person had reacted to the RA, the equipment that made this possible and how they related to the people surrounding them. I later typed these up into detailed field notes as soon as was feasible. One example of this was Matthew's skiing event, an extract from my reflexive diary is provided here to illustrate the relevance of this:

*"Thoughts before adapted skiing observation: I am in the process of transcribing Matthew's Mum's interview – so my observations will be geared towards the behaviours Matthew displays and the emotional expression on his face during the skiing experience and the social time afterwards. He reportedly shows aggressive behaviour at home which I have not observed. I am intrigued to see how disabled children and young people master this activity as I tried it once about 30 years ago and found it hard. This will be an overt non-participant observation...."*

*Observation. I am introduced to some of the other parents, but it is very low key and I am pleased I do not stand out as an 'observer'... I continue watching Matthew and time how long it takes to go up the ski lift (photo 5), down the slope (30 seconds) and then how long he waits in the queue (photo 6)...Matthew continues skiing with his volunteer, sometimes they zig-zag across the slope, other times they come straight down which is faster or go down the bumps at the side. Matthew is more vocal, shouting with excitement and lifts his arms in the air, the faster they go, it was a joy to watch... I observed Matthew come off at 11.15am- so 1 hour and 5 minutes. I estimated that I observed him come down the ski slope around 22 times during this time. Mum explains to me that it is getting busier now, so to let everyone have a turn, Matthew will come off... Mum sends his sister off to get some drinks, she*

*feeds him Kettle crisps which he enjoys. He can chew these but does not seem to initiate feeding himself (I think he can do this)... I speak to Matthew and say hello – he looks at me and smiles and reaches out to hold my hand. I was very touched by Matthew's initiation of this action, as he had only met me once before, at home, and although he was not able to understand and give me written consent, I saw this as an accepting gesture towards me as a researcher and assent for me to observe his enjoyment".*

The observations also included photographs and care has been taken with these images and other digital data to protect the identity of the participants (Edwards and Holland, 2013; Pink 2013). An example from these field notes can be seen in Appendix 6. Another example from an observation that I witnessed, included a challenging situation when Nick's father got angry when people had parked inappropriately in the disabled parking bays. That was an awkward moment where I felt compelled to take action to request help from the centre's staff. They offered to put cones in the bays, that the families could then remove to park, but it was hard to police and was a tension that I witnessed on several occasions. It was hard to remain neutral in this situation. This was later discussed with my supervisors and I explored my own reflection of my action to support the families, to prevent this happening at that venue. It fed into my interpretation of such data examples, where I felt there was injustice for my participants.

All the visual images taken by me as the researcher, served as an aid memoir of the observational experiences and are also called artefacts as a source of evidence in the case study. These were used later in the analysis process to explore how the children and young people were positioned, in the adapted equipment, in the environment, with the people who impacted upon their emotional WB (Pink, 2013).

### **3.7.4 Photographs as artefacts**

Photographs are a visual record of an event in place or time, which have been made much more accessible by the advent of digital images (Pink, 2013). Photo elicited interviews have been used with looked after children and those living in relative poverty, where the problematizing of potential exploitation of vulnerable participants was explored (Renold et al, 2008; Mannay 2015). Photo-voice has already been used with some disabled children and young people to enable them to speak about their lives (Runswick-Cole, 2011; Hodge and Runswick-Cole 2013). McLaughlin and Coleman-Mountain (2018) also demonstrated that for some disabled young people, photo journals enabled their participants to portray an image of themselves as

happy, active and independent. This was in contrast to how these participants perceived that society viewed them, as vulnerable and to be pitied.

However, the children and young people in my study did not have the fine motor coordination to take the photographs themselves. The photographs were either provided by the participants' parents, during the twelve weeks of diary collection or taken by myself during initial visits or observational field work. This limits how the children and young people could give voice to which images they wanted me to take for my study. I took pictures of equipment such as an adapted surfboard and sit-ski and engagement in activities such as music and dance which were meaningful to the participants, as these were the activities I was invited to observe. Parents sent me pictures of different contexts such as parks and museums that the participants attended. Careful thought was given during the analysis about which photographs were selected, to portray an authentic 'voice' on behalf of the participants. Auteur theory relates to different perceptions around visual imagery, in that the person who took the image may have certain intentions, but others can view it with a different lens, thus changing the original meaning intended (Sarris, 2007; Pink 2013). Auteur theory was applied to my analysis of the visual data, having asked the participants' parents why they created certain images during interview two (Mannay, 2010; McLaughlin and Coleman-Fountain, 2018). This was further clarified with parents by ensuring what the meaning of each image was that I chose to use in the findings. This was to ensure credibility and add to the trustworthiness of my data interpretations (Guba and Lincoln 2015).

I questioned from the data sources what they had wanted to portray through these images, to show and tell others about their child's experiences, thus building their storyline in the context of where the picture was taken. This was part of the parent's agency to inform me about their child's participation, as it was not possible to observe everything that they did during the twelve-week period of data collection. These images were related to the RAs recorded in the diaries, as the written record in the diary mapped to the image sent to me. As the children and young people were not able to be so active or independent due to their level of disability, I have sought to be true to what the visual data has revealed without exploiting or prioritising what story should be told. This has been achieved in partnership with their parents by mutual agreement.

### **3.8 Summary of Section 2**

This section has described the detail of the multiple, parallel, snapshot, comparative case study design. The justification for the interviews, diary, observations and photographs have been discussed. The next section 3 will describe the data generation and management.

## **3.9 Section 3: Data Generation and Management**

### **3.9.1 Consultation with stakeholders**

The National Institute for Health Research (NIHR) INVOLVE group were approached for a suitable parent and child for advice on the design of the adult, nine to eleven and twelve to sixteen year old participant information sheets, consent forms and poster adverts (Bailey et al, 2015; NIHR, 2015). A parent and nine-year-old girl with cerebral palsy (GMFCS III), advised on these documents to ensure readability and clarity. There were some minor changes to the children's form with clearer illustrations requested in an A5 booklet format.

Whilst developing the research proposal, to inform my study's design, I consulted with a group of young adults with learning disabilities, as a stakeholder event, carrying out a focus group in May 2016. School ethical approval had been granted for this (Appendix removed for confidentiality reasons prior to publication on ORCA). I aimed to explore what they thought was important to them for participation in RAs and what their perceived health and WB effects were, from their participation. Here they expressed their future ambitions for RAs which culminated in them creating their own collage. I learnt from this that they needed guidance with understanding the terms I used and that my level of language needed to be straightforward to engage and keep their interest. It was also of note that one participant with cerebral palsy was unable to create her own collage and needed assistance with this fine motor task. This made me reflect upon the tasks I would include in my data collection and collage was too difficult for those with fine motor difficulties.

### **3.9.2 Pilot data**

I also had the opportunity to carry out some pilot data as part of testing out the aims and the methods for feasibility to further inform my case study's design, prior to the main data collection. At this point I had not narrowed the criteria sufficiently to exclude ambulant children and young people or reduce the age range from five to twenty-five years. Two pre-pilot cases were therefore carried out, based upon the

initial ideas of using two interviews and a diary for twelve weeks with nine (GMFCS III) and twenty-one-year-old (GMFCS II) females, 'Becky' and 'Katie'. Although these data have not been used in my thesis, a few things were learnt from these two articulate physical activity ambassadors. Mainly that it was good to offer a choice of diary format, so a computer as well as a paper version was subsequently offered to my research participants. Secondly, as they were ambulant, they had a lot of choices and were highly motivated by their successes (Pickering 2018).

Building on this pre-pilot data, through previous research network contacts, I recruited nine-year-old 'Mary' (GMFCS II) and sixteen-year-old 'Captain America' (GMFCS I) to further test these methods. Two interviews were carried out with them recording the potential use of a paper diary for the intervening twelve weeks. A computer diary was offered but they both chose the paper version. Both of these highlighted the gap in choices for RAs for the more disabled children and young people. Mary had enjoyed playing with a wheelchair figure and creating a story about herself and how her parents coped with her disability. I had offered for Mary to play in the sand box with these play figures, but she did not like the medium of sand, so declined. This led me to think about the sensory choices I provided for the participants to tell me about their views, experiences and choices. They had both illustrated their diaries, which were used to facilitate their second interview, by probing and asking about the entries they had made. However, Captain America's did not back up the activities he had told me he did in interview one. This made me consider my position as the researcher which could have influenced this, in that I suspect he may have told me what he thought I would like to hear. Neither participant could think of ways the RAs that they enjoyed, could be adapted for children who could not walk. This was part of helping me to narrow down my perspective as I thought possibly, these pilot participants, might have some insights into what could be possible for non-mobile disabled children and young people.

### **3.9.3 Sampling**

I was aiming for four participants in each group (PG; LPG) which would have made eight case studies. The reason for this small sample size is because case studies generate depth from the multiple data sources. Being a qualitative study alone, the variety of data sources promised a variety of perspectives to answer the research



question and fulfil the aims. The participants were children and young people with cerebral palsy, aged nine to sixteen years. This age range was selected as it fits with the natural downward trajectory of physical decline in cerebral palsy for GMFCS III-V (Hanna et al, 2008). As the literature had shown that less is known about those with the highest levels of physical disability and communication, participants were selected from GMFCS III-V, Levels I and II of the Communication Function Classification System (CFCS) or Levels III-V reported by proxy with support from the parent. Prospective participants were recruited using the inclusion and exclusion criteria outlined in Table 1.

**Table 1: Inclusion and Exclusion Criteria**

<u>Participants</u>	<u>Inclusion Criteria</u>	<u>Exclusion Criteria</u>
N=7 4 cases participating in RAs outside school (PG)  3 cases with limited participation in RAs outside school (LPG)	children and young people with cerebral palsy aged 9-16 years and their parent/carer.  Level III, IV or V of the GMFCS.  Level I-II of the CFCS Level III-V of the CFCS -Parent to report by proxy if child or young person unable to communicate wishes.  Able to give consent or assent (able to engage in research activity).	children and young people with cerebral palsy outside this age range 1-8;17-18 years.  Levels I or II of the GMFCS.   children and young people Unable to give consent or assent.

I had originally intended to have a non-participatory group and spent time in seeking out suitable participants but decided it would have to be a limited PG rather than non-participatory, as recruitment to this group was difficult. This difficulty with recruitment to a non-participatory group could have been underpinned by a fear of criticism, where safeguarding issues of neglect might be raised from their non-participation (Welsh Government, 2008). It is not necessarily a lack of intention to engage in RAs as there are limited choices available for those with the more complex physical, communication and learning disabilities (Foley, 2012; Stewart et

al, 2012; King, 2013; Verschuren et al, 2013; Chiarello et al, 2014; Novak, 2014; Anaby et al, 2015).

### **3.9.4 Recruitment and Participants**

In seeking to recruit appropriate participants into the study, approaches were made to a variety of gatekeepers at voluntary sector organisations from January 2017. The importance of having someone else to recruit, minimised the potential coercion effect from me as the researcher, influencing voluntary participation in the study (Moule 2020). A gatekeeper is someone who will both protect and promote the interests of the potential participants, who in this case were children and young people with physical, communication and learning difficulties (Nind, 2009; Nind and Vinha, 2012). Even though the participants may not directly benefit from this research, they should not be coerced into taking part, just to please the researcher or anyone else. The gatekeepers needed to be persuaded that the research was of good enough quality that the findings could benefit similar people in the future. This involved me visiting various charities and schools and explaining the study to them and the need for the two different groups. The gatekeepers were able to promote this study by personal recommendation and via their email networks, Facebook, Twitter, newsletters and a poster was displayed in some centres (Appendix 7). The gatekeepers were a variety of third sector organisations (e.g. disability sports clubs, special schools across South Wales, cerebral palsy Cymru). The parents were the final gatekeepers who gave me access to my participants.

Initially, there was a good response for the PG, by email or telephone, from nine participants across Wales. I followed these prospective respondents up, to discuss the study, sending out the participant information sheet for them to consider participating. Three who enquired did not meet the inclusion criteria. One who was not quite old enough at that time, did not respond after follow-up. One boy who showed initial interest, decided he was too busy to fit me into his schedule. If they did volunteer, an initial visit was arranged, when questions arising from the information sheet were dealt with and the diary explained to clarify what was involved. At this initial visit, consent was obtained from the parent and where possible assent from the children and young people, demographic information was also collected. This was then mapped onto the Welsh Index of Multiple Deprivation (WIMD) to ensure maximum variation in my sample to ensure I was being representative across

different socioeconomic groups (Sandelowski, 1993; Welsh Government, 2014). If they agreed, they signed the consent form prior to any data collection at this initial visit. Four children and young people were recruited to the PG, ready to start data collection at the end of March 2017.

When no one had come forward for the LPG by May 2017, I approached a local special school. The family support worker along with the deputy head offered to recommend my study to four families, whom they knew met my inclusion criteria and found participation in RAs difficult. They arranged for me to meet the families at the school to explain the study in June 2017. Only one parent came on that day, but I was able to follow up a further two, one of which also came into the study. The other, whilst initially very keen on the telephone, did not respond after further contact. Data collection of these two in the LPG commenced in July 2017. A further opportunity to attend a workshop run by Play Wales, about accessible playgrounds, provided a new network of people. Through the chairperson of this group, a third participant was recruited for the LPG in October 2017. One of the voluntary sector organisations also wrote individually to families where they knew participation was difficult in September 2017. However, no new families had volunteered for the LPG up until March 2018 and due to time constraints with the PhD, the data collection phase needed to be completed in a timely manner.

### **3.9.5 Data collection**

Data were collected between March 2017 and March 2018. The first interview was arranged within a few weeks of the initial visit to maintain the momentum of the family's interest. This initial meeting was where the participants chose their children and young people pseudonym to protect their anonymity. The initial visit and the two interviews took place, by agreement in the participant's homes, a minimum of twelve weeks apart, with the diary entries being kept by the parents during the intervening period. Therefore, three separate visits were made to the participant's home. The participants were reminded they were free to stop the interviews and withdraw at any time without any prejudice.

The participant's parents hand wrote in their paper diaries over the twelve weeks of data collection, using free text structured by the dates of entry. The diaries were offered back to the participants after they had been scanned and transcribed. This opportunity to give the original data back to the participants, enabled those who had

emotionally enjoyed the diary collection, to keep their own original contributions. Four of the seven accepted these back as a memoir of being involved in my study.

Additionally, field notes were written up, after these interviews, to assist with recall of information, feelings and thoughts not collected in the audio recordings (Emerson et al, 1995; Mannay 2015). These notes recorded the non-verbal behaviours and child's involuntary movements during the interviews, which were part of the participants' ways of expressing themselves. These included self-injury and reflex spasms (Simmons and Watson, 2014). The field notes from the observations were typed up and were written in a chronological order, with photographs added in the order they were taken to support the observational data's context (See Appendix 6).

Upon discussion with my supervisors, I decided that the rich data in the three cases in the LPG would be enough to compare with the four in the PG. Although at this stage I had not fully completed the analysis, similar topics were occurring in the data's coding, so it was likely that I would get closer towards data saturation.

Therefore, data was collected from seven case studies in total, generating sixteen interviews and seven diaries (212,843 words), two hundred and twenty photographs and fifteen hours of observational data.

### **3.9.6 Reflexivity**

Reflection is a process that involves fixing careful consideration and thoughts upon something (Oxford Dictionary, 2020). In a research context, reflexivity is described by Creswell (2013) as a concept that enables the researcher to position themselves in a way that takes account of their own values, biases and experiences that they bring to the study. I wrote reflections (as soon as I was able to) about each research encounter, about how I felt about the research process and the impact it had upon me. These reflexive notes were initially handwritten based upon conventions suggested by Silverman (2006) and later typed up. I also acknowledged my own experiences and understanding from a practice background and recorded the methodological decision trail in a reflexive journal, aligned to the Gantt chart of the study's progress (Seale, 1999; Alvesson and Sköldberg, 2009). My position from this practice background gave me insight into the struggles these families went through in order to participate and I was aware of their limited choices. I responded during the data collection with an empathic manner, but sometimes felt sad or angry when listening to their experiences at the apparent lack of social justice for them, as

described above for Nick. I reflected on this to minimise potential for bias when interpreting the data and extracts from other reflections can be seen in Appendix 8.

### **3.10 Data Analysis**

In keeping with Yin's (2018) case study design, I looked for a logical way to bring all the data sources together to be able to interpret the findings. I chose to use the six stages of Braun and Clarke's (2006) guide for qualitative data. This was because this offered this logical guide with the variety of data sources. At stage one, the interviews were digitally recorded then transcribed verbatim as soon as was feasible using conventions proposed by Flick (2014). Some were transcribed by me, others were sent externally to manage the pace and volume of data collection. When I had completed the transcriptions, I found it quicker to immerse myself in the data at the analysis stages, as this thinking process had already started. When the transcripts had been externally transcribed, it required extra listening and checking the transcript prior to member checking (Burnard et al, 2008). This is where the transcripts were sent back to those who wanted to read them and the content was verified, then it was anonymised. Five of the seven parents did reply with some minor comments, where words had been inaudible, to clarify meanings. There was a risk that participants could have withdrawn their data at this point, however the benefits were that it enhanced the rigour and trustworthiness of the raw data as being an accurate representations of their views, experiences and choices.

The analysis was managed in NVIVO 11 (Edhlund and McDougall, 2017). However, whilst the NVIVO programme enabled large amounts of data to be stored securely, including audio files and visual images, it only assisted my analysis, which I found limiting. The nodes and trees once set up were difficult to edit and as ideas changed, I found it constraining. It was sometimes unreliable and freezing in the middle of work which caused me to lose confidence with it. It was also difficult when working at home or at the University to have consistent versions. Therefore, my analysis was also supported by using Microsoft Word, with the review and highlighter features within this programme that could then be imported into NVIVO. It was necessary to convert these Microsoft Word documents into PDF's to be able to view the annotated comments written in the margins in the NVIVO programme.

The handwritten diary's text was transcribed by myself. Some diaries contained visual data of photographs, which were covered to ensure they were not identifiable.

The visual images that were generated by families or from myself at the observational opportunities, were catalogued by pseudonym and context and then analysed to explore the use of adapted equipment and the emotional WB impact upon the participant from the people and environments (Pink, 2013).

This second stage of Braun and Clarke's (2006) analysis involved identifying codes which were then used to identify meanings that related to the research question and aims. The context for my study was exploring the participant's views, experiences and choices about their level of participation in RAs, particularly for the effect upon their emotional WB. These concepts therefore set '*a priori*' ideas which provided a guide for the coding during this analysis stage. This was achieved by each interview and diary transcript within case data being annotated with analytic memos for ideas and thoughts, including those appearing across cases as the analysis progressed (Silverman, 2013). Additionally, the visual images were annotated with comments for meanings. This data abstraction and translation of the visual into meaningful text also gave the opportunity to think about how participation had been made possible through invention and design (Pink, 2013). This later analysis was however done in isolation from the participants, relying on my interpretation as the researcher, which may have detracted from what that image meant to them if that had not been possible to explore during the second interview. These images and digital materials were used with caution to maintain their confidentiality and anonymity in the data representation (Murthy, 2008; Prosser, 2013; Pink 2013; Rose, 2016). An example of coding an image from the non-participant skiing observation can be seen in Appendix 9.

Hand written field notes from my observations were typed up and then annotated with analytic memos to develop understanding of the context, giving particular emphasis to the visual images for the next stage of coding (Silverman, 2006; Hammersly and Atkinson, 2007; Silverman, 2013; Pink, 2013).

At stage 3, these codes were revisited within each case to consider what categories could be developed across the cases (Braun and Clarke 2006). The four in the PG were analysed between July 2017 and January 2018; the LPG between April and December 2018. This involved several stages of reading and re-reading the interview transcripts, re-listening to the audio files, writing comments with initial

thoughts, highlighting words as coding for analytical ideas. These were mapped to the '*a priori*' concepts for their views, experiences and choices looking for evidence of their emotional WB. This was created into a table and colour coded for ease of analysis in Microsoft Word. An example of the coding and the table can be seen in Appendix 10. The initial stages of the analysis of the first interview data was completed before the second interview with all cases, to be able to inform these questions (Flick, 2014). The diary was collected at the second interview and was then transcribed. The second interview was also transcribed verbatim and then sent back to those participants who had requested it for member checking.

The field notes of observations were analysed in a similar way with coding and the visual images coded for possible meanings. Also, what the families chose to take pictures of was analysed in the same way. The opportunity to explore this in the second interview enabled me to start to understand why they contributed their images, to represent the participant, thus aiding the analysis process (Pink, 2013). Thus, each case had several data sets, adding to the triangulation of sources from which to draw conclusions (Barbour, 2001; Flick, 2014). A summary of each case study was written before moving onto the next one (Yin, 2018).

Larger ideas were developed after stepping back and reflecting upon the codes and categories which were then refined and redeveloped as a bigger overview identified the pertinent findings related to the research question and aims. I was seeking to understand the how and why of their WB responses from their participation in RAs and reframe this knowledge. Braun and Clark (2013) described two types of coding, data derived which are based upon the semantic meaning and researcher derived, which are based upon interpretation. This coding stage was not rushed, I worked through each data item within each case, before moving onto the next case study. I approached this in an inclusive and systematic manner ensuring that I captured the diversity as well as the patterns across the data. Each case had unique codes but within each data source, the mapping of the ideas started to form, by reflecting upon the research question. This then enabled me to move on to stages four and five, where these codes were condensed further and developed into themes. I did this by a process known as the constant comparative method, using my own intuition to seek meaning from the data (Thomas, 2016; Yin, 2018). The identification of themes

was an active, iterative process, which involved the identification of patterns across the data (Braun and Clarke, 2013).

The final stage of analysis involved within-case and across case analysis of the two groups. This was carried out supported by a process known as intuiting, which is *'the critical reflection and identification of themes as they are found in the accounts of the multiple respondents'* (Ayres, et al, 2003 p875). To evoke the understanding of the participants' emotional WB, the intuited themes were developed by free writing, asking questions from the data, utilising flip chart paper and highlighter pens. This more kinaesthetic approach was more in tune with my preferred way of learning by physically handling the data (Fleming and Bauma, 2006). Images of these flip charts can be seen in Appendix 11.

### **3.11 Quality in Research**

Rigour, or trustworthiness of qualitative research is needed to assure that the research is carried out authentically and that the findings are valid and credible (Sandelowski, 1993; Hammersly and Atkinson, 2007; Houghton et al 2013; Creswell, 2014). This provides the quality assurance that the study was carried out with a high level of integrity. Reflexivity is also considered an essential part of rigour, Houghton et al (2013) discuss the importance of a reflexive diary in case-study research, as the researcher's self-awareness is key to the quality of the research. Indeed, my own reflexive diary was kept throughout the whole PhD journey and helped me to record my thoughts and feelings along the journey. Aspects of this were discussed with my supervision team along the way.

Miles and Huberman (1994) suggest there are four main aspects to this trustworthiness. These are credibility, dependability, transferability and confirmability. There is some debate about how these can be demonstrated in qualitative studies. Sandelowski (1993) argues that predetermined criteria are not relevant for credibility, but that aesthetic judgement is. Whereas Lincoln and Guba (1986) consider that member (participants) or peer checking is the most important aspect of credibility. Guba and Lincoln (2015) suggest that this triangulation of member checking forms part of the rigour to establish trustworthiness in research. The initial transcripts were sent back to the parents and five out of the seven reviewed these and sent amendments back for clarification. I also sent anonymised images back to the participants to check they were happy with this representation. The parents were



also consulted about the identified themes to verify their opinions about my data analysis, including a visual representation using the word 'VOCAL' (Appendix 14) and a Powtoon presentation of the findings for the children and young people participants who could not read (<https://www.powtoon.com/s/eh8O41X6xP1/1/m>).

Peer checking is where another peer qualitative researcher reviews the themes and theoretical development, to protect against lone researcher bias and misinterpretation, to enhance the credibility and dependability of the findings (Sandelowski, 1993; Burnard et al 2008; Silverman, 2013). This peer checking was achieved within the supervision team, during the analysis phase of this study. This process involved the team reviewing anonymised transcripts of interviews, diaries, field notes and photographs and my initial ideas for codes and themes. As the analysis progressed, the codes and themes developed during this iterative process, started to enable me to see overarching patterns, which added to my study's trustworthiness. The findings were not binary as might have been expected from the two groups, but multifaceted. As I reflected and became more aware of similarities and differences this helped me move towards data saturation. Although, due to the small numbers there may still be some hidden realities.

In a case study design, it is not usual to expect transferability of the findings to be able to generalise these to a wider population. In fact, Thomas (2015 p.89) argues that such an aim would distract from the '*curiosity at the heart of the inquiry*'. In qualitative research the importance of reflexivity is much higher, because as the researcher, I was the measuring tool and my position and role have determined the quality of what I have produced with my participants. I have socially constructed new meanings about their WB, from this data within the contexts of the environments and the children and young people intentional behaviours.

The confirmability was demonstrated by the triangulation of the different data sources and the respondent validation of giving both the transcripts and the tentative themes back to the participants in each of the groups for their comments as part of member checking (Silverman, 2006; Lincoln and Guba, 1986). The use of an 'audit trail' in this study has ensured confirmability and transparency by outlining how each stage changed and developed. As I had several opportunities to present my work both inside the university and externally with posters and free papers in the UK,

Europe, Canada and the USA, this adds to the confirmability with external peer-reviewed recognition for the quality of my work.

### **3.12 Ethics of Research with Disabled Children and Young People**

My own ethical values support the importance of fairness in providing equitable choices for disabled children and young people based upon the Equality Act (2010) as a form of social justice. This contrasts with the prevailing ableist provision for typically developing children (Hodge and Runswick-Cole, 2013). In my study, I applied sensitivity towards my participants, respecting their dignity and privacy, recognising that the visual data could compromise these ethical values, if not handled carefully (Prosser, 2011). Indeed, it is not without its ethical challenges to include this group of children and young people in research (Williams, 2011; Beresford 2012; Nind and Vinha 2012). Whilst my focus was on children and young people's WB, it was not possible to separate this from the WB of their families, as the NICE (2017) guidelines had proposed, because the two are integrally related.

#### **3.12.1 Research Ethics Committee**

Successful ethical approval was achieved in January 2017 from the School of Healthcare Sciences at Cardiff University: Reference 358 REC. The participant information sheets were translated into Welsh and would have been translated into other languages if the need arose. It was not necessary to obtain NHS ethical approval due to the possibility to recruit from the third sector and special schools. The consent included signing for the taking of non-identifiable photographs to provide context.

#### **13.12.2 Informed consent**

Due consideration was given to confidentiality and anonymity with research participants especially as they are minors (Alderson and Morrow, 2011). If they were 'Gillick' competent, they could give their own consent (Hunter and Pierscionek, 2007). I worked with the parent to establish the children and young people level of understanding to ascertain if they were 'Gillick' competent. However, not all my participants were able to give consent, but rather assent. Assent is where the child or young person agreed to take part in the research, when another person, in this case the parent, had given their consent (Lewis, 2011). This was achieved in a creative manner. Pictures were used to support the children and young people engagement with my research topic. Their level of competence was difficult to ascertain, with

varying levels of interest in the information sheets and consent forms. Hence all parents gave their written consent, but for the children and young people, if they continued to be engaged with me during data collection, consent was considered to be from their ongoing assent (Hunter and Pierscioneck, 2007).

### **3.12.3 Anonymity and confidentiality**

It is essential to protect the identity of any child research participants who should give their voluntary contribution without coercion (Alderson and Morrow (2011). Prosser (2013) suggested setting up an 'ethical covenant' to permit publication of only mutually agreed upon visual materials. This has limitations when participants are disabled minors and do not fully understand what this means. As a researcher, I was not comfortable with the risk of exploiting my participants' identities, as once in print, images cannot be retracted, and they could change their mind later. That is why I specified non-identifiable photographs on my consent form. Therefore, all attempts have been made with the data to protect their anonymity and confidentiality by the parents choosing pseudonyms, I changed place names and covered any identifiable features, whilst still endeavouring to reveal the effect upon their emotional WB from their level of participation.

### **3.12.4 Risk Management and Data Governance**

A risk assessment of this study required me to be competent and confident to follow the All Wales Child Protection Procedures (Welsh Government, 2008) and Cardiff University's Safeguarding Children and Vulnerable Adults policy (Cardiff University, 2016). When the participants discussed something of a sensitive nature, such as challenging behaviour, further probing ensured if they were already receiving relevant support services e.g. respite care. Action would have been taken to signpost or refer on as appropriate to relevant services, if a previously unidentified need had arisen. As my research involved going into family homes by myself, a buddy system was set up with my supervisory team members, to comply with Cardiff University's lone worker policy (Cardiff University 2020).

All data collected from this study has been anonymised and stored confidentially on password protected computers, backed up on the secure drive at Cardiff University. An encrypted memory stick was used to store and transfer data between home and work computers. Identifiable paper data was stored separately to the participants' research data in a metal locked filing cabinet. As no participant withdrew, all data

were able to be used. Paper files were only accessed by the researcher, shared as appropriate with the PhD supervisors.

This data remains the intellectual property of Cardiff University, who provided the employer and public liability insurance for this study. The data will be stored for the mandatory period after the research has ended, up to fifteen years (Cardiff University, 2015).

### **3.13 Summary of section three**

To summarise, section three has covered details of the data generation and management processes. The trustworthy qualities which make up good qualitative research are described. Finally, the ethical approval and concerns of safeguarding my participants' identities were explored.

### **3.14 Summary of Methodology Chapter**

To summarise what has been covered in the three sections of this methodology chapter. Firstly, the wider qualitative research approaches and theoretical basis have been described. Secondly, descriptions of the components which made up my multiple comparative case studies has been covered: interviews, a diary, observations and artefacts (photographs). This has stated my ethical position and the emphasis to keep the voices of children and young people central to my enquiry as a form of social justice. Finally, the data collection and six stages of analysis have been outlined. Rigour in the management of the data has been described to produce credible and verifiable findings, including my reflexivity during the process, acknowledging that I was influenced from my physiotherapy practice background, but in a positive way, by recognising that this group were under researched and deserve better opportunities. The ethical position of centralising these participant voices in the enquiry has been made clear, by using an interpretative approach, to socially construct meaning throughout the analysis. Therefore, the chapters four, five and six will describe the findings of my study: firstly, the four PG cases then the three LPG cases, then the synthesis of the seven across case analyses.

## **Chapter 4: Findings: Within Case Participatory Group (PG)**

### **4.1 Introduction**

This chapter will present the within case analysis of the four PG case studies. Their pseudonyms were Clare, Lily-May, Nick and Matthew. How the children were 'positioned' will be emphasised at relevant points in the findings, as it relates to positioning theory (Harré and Langenhove 1999). This is both in terms of their physical and social positioning, revealing their agency to show their choices, influenced by a variety of social forces, to express their storylines. The case studies are presented in the order in which they were recruited and the narrative flows under the respective themes and subthemes for each case that I identified in the analysis. Each case starts with their demographic information and the context for each participants' participation. The themes are illustrated by using quotes and images from the different data sources, to highlight the emotional WB impact from children and young people participation. If photographs were referred to during an interview, a relevant, found image has been used to represent these, to aid the reader's understanding. The chapter ends with a summary of the PG's findings.

### **4.2 Clare**

Clare was nine years old and had dystonic quadriplegic cerebral palsy (GMFCS IV; CFCS III-IV), affecting her whole body, and was recruited via a charity's parental network. She was described by her mother as '*very happy*' most of the time as she smiled and laughed but was sensitive to noise and did not like clapping, which was a limitation to her participation in group activities. She lived with her mother in a rural area, her father lived close by and was involved in her daily care, arriving at seven am to carry out a nebulizer for Clare's additional respiratory condition. Dad was musical and this had influenced Clare's interests. Clare also enjoyed reading stories and dancing with the toys in her sensory box. She expressed herself using a computer communication aid and some gestures. She attended her local primary school but as she was not able to walk, she needed hoisting to change positions or to be manually lifted by two people. Although Clare did have direct payment money for 3 hours, for a personal assistant (PA), to attend activities after school, there were two factors which limited this. Firstly, Clare had to do the nebulizer at four, five and seven pm, which limited her free time in the evenings. Secondly, living in a rural area Mum had not been able to recruit anyone to this job.

During the two interviews, Clare's position varied between her chair and standing frame and her vocal sounds varied in intonation, sometimes indicating happiness or being quiet when fatigued. She sometimes moved her arms around in a vigorous manner when excited and this included reaching out to touch me during the interviews. I saw this as a positive gesture that Clare was assenting to continue with the interview. Due to this variation in her muscle tone, Clare's position in a stable piece of equipment (chair or standing frame) was essential to be able to engage in the interview with me. This enabled her to express herself to tell me her storylines, demonstrating her own agency, to reflect her WB. However, her mother was the key person who positioned her in this equipment at home, ready for the interviews.

Clare told me about her experiences and choices, partly through pointing to words below photographs in a scrap book about her activities, which mum read out. Her emotional reactions were sometimes hard to read, where she did smile on images, a smiley face 'emoji' has been used to depict this. A separate interview was carried out with Mum a few months later, as I was not able to explore Clare's own views about her participation choices due to her limitations with communication. Thus, Clare's storylines were a combination of hers and her mother's words, the diary extracts and my observations about the social forces which influenced her WB.

Clare's themes and subthemes are shown in Table 2.

**Table 2: Clare's Themes and Subthemes**

<b>Theme</b>	<b>Subthemes</b>
Equipment to enhance participation	Expressing musical choices Trike riding Changing place toilets Mobile hoists
Time to emotionally adjust to activities	Charity groups Accessible spaces

#### **4.2.1 Equipment to enhance participation.**

The equipment which enhanced Clare's participation in RA's included her communication aid to express her musical choices. The extent of her participation was also determined by the availability of changing places toilets and outdoor hoists at outdoor venues such as theme or safari parks.

#### 4.2.2 Expressing musical choices.

Clare very quickly drew me into her creative storytelling and musical compositions through her communication aid. However, the conversation via this was disjointed and repetitive at times. Despite this there was always a positive feel to Clare's engagement with me. An illustration of her participation choices is shown in Figure 15.



**Figure 15: Clare pointing on communication screen to her participatory choices**

In Figure 15 it can be seen what different choices Clare had on the touch screen, including her bike; 'beamz' seen at the bottom right below her thumb, was her lazer music making device, and above this was 'stories' which enabled her to create spoken words to tell a story. Thus, her creativity could be expressed in this way. A picture of the 'beamz' can be seen in Figure 16.



**Figure 16: 'Beamz' laser musical toy**

The 'beamz' musical toy responded to hand movements across laser beams of light, which cannot be seen in figure 16. These electronic sounds were varying in tempo and Clare enjoyed playing it to me, which was fun for her, she usually played with this every day. Thus, by being positioned to reach this musical toy, Clare could generate her own storyline, producing musical sounds that were meaningful to her. This storyline showed her enjoyment with music making which enabled her to express her creativity.

Clare also played various musical instruments to me which included a guitar, steel drum and an accordion. An image of the accordion can be seen in Figure 17, by clicking on this link you can hear the sound Clare created during the interview.





Press Ctrl+ click to access sound file: [https://cf-my.sharepoint.com/:u:/g/personal/ferridayr\\_cardiff\\_ac\\_uk/ETQqXklsVdNMvDY4I1HAUVsBKkBH82gVw9gsao5yBQv4bw?e=LGV5er](https://cf-my.sharepoint.com/:u:/g/personal/ferridayr_cardiff_ac_uk/ETQqXklsVdNMvDY4I1HAUVsBKkBH82gVw9gsao5yBQv4bw?e=LGV5er)

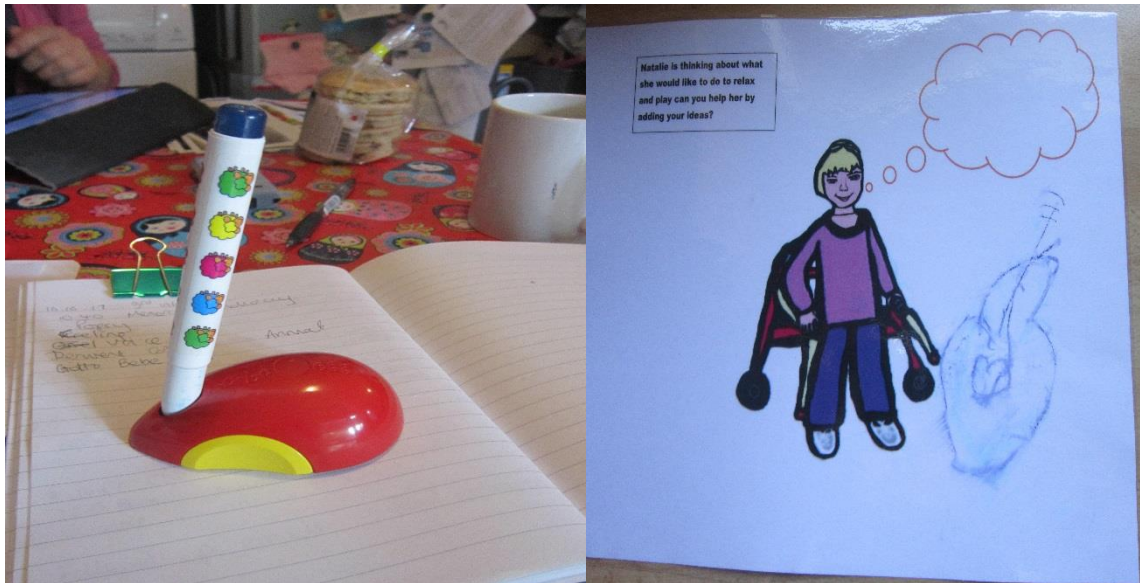
**Figure 17: Clare's Accordion**

Her musical choices were also highlighted in a diary extract completed by her mother:

*"I like to have music wherever I go. I listen to all types of music, children's songs, that's hip hop, pop, classical, reggae, choirs and rock. But I don't like blues, it makes me sad"*

Although Mum wrote in the diary, it was written in the first person as if it were Clare's voice talking directly to me. These musical expressions suggested to me that Clare could discern what music made her happy and sad, giving an indication of her emotional responses to music, demonstrating her own storyline about her WB. I found the sound of intent framework to help me interpret Clare's interactions with music which can be seen in Appendix 14 (Ockelford, 2000). I experienced a mixture of Clare's reactive, proactive and interactive behaviours through music, indicating her engagement and enjoyment. I have outlined the areas in red on this framework, where I perceived she was performing in the interviews. Thus, Clare used musical composition to generate some of her stories about her WB, demonstrating her own agency.

When invited to draw a picture on the laminated sheet, Clare used a special pen support and drew me a picture as seen in Figure 18. Thus, her drawing also reinforced how important music was to her, as she chose the guitar.



**Figure 18: Special pen holder and drawing of guitar**

The diary data source gave me the most insight into Clare's emotional WB as shown in the next quote which was supported by Figure 19. Clare was reported to have played the keyboard for three hours, which I interpreted as a having positive WB effect upon her. Clare was smiling, which reinforced what the diary extract had described. I deduced that Clare was able to self-regulate her emotional WB though music by stably being positioned in her chair (seen here) to achieve this.

*"After lunch I played on Nanna's electric keyboard. I loved it, I played for about 3 hours pressing all the different buttons to change the instruments and playing the keys. I also danced and sang along. At bedtime while I was having my nebuliser we listened to a music and dance CD and used my sensory box to pretend with. I used something different for each song. It was great fun. Me and Mum went to 'Touch Trust'. It was a bit different today. This time it was based on the gingerbread man story. I really liked it. We still did dancing and played musical instruments but this time they were kitchen utensils. They made a great clanging sound, banging the saucepan and sieve with a metal spoon. There were 4 other children there too with their parents or helpers. I loved all the music. I really enjoyed it. I have been looking forward to it all week. I keep asking about it on my computer."*



**Figure 19: Clare making music on the keyboard**

#### **4.2.3 Trike riding**

Music also influenced her trike riding in the community:

*“Yes, she loves cycling because she has a little basket on the front, we put music in the front, and she is as happy as Larry... She cycles, we do about a mile and a half she goes down, along the river path, the old railway track, it is a bit sort of off-roading and then back to the church and then along this road or she goes that way around the park. So long as she has got music, she’ll do most things.”*

The addition of music to the trike basket, demonstrated the positive emotional WB impact from Clare’s participation in cycling. A photograph from the diary shown in Figure 20, shows her enjoyment of this. Music was a thread throughout Clare’s data collection, which highlighted the WB effect from her participation. It was necessary for Clare to be positioned to reach the musical activities and her mother was the key person who supported this, thus being an important social force in Clare’s life.



**Figure 20: Clare riding her trike**

Clare's smile (Figure 20) indicated her enjoyment with her cousin, aunt and uncle who walked alongside her on this country walk.

#### **4.2.4 Changing Places toilets**

Mum was advocating for the need for a changing bed with overhead tracking hoist in toilet spaces in all public buildings. This was a relatively new concept to me which Mum explained was linked to promoting the 'National Changing Places' campaign (Changing Places 2020). In fact, her campaign to get a changing places toilet in the local hospital had now been addressed, by her complaining that this should have been developed in the design phase, not as an afterthought. Mum was now part of the consultation group for future adaptations. If such a changing place was not available, it was very difficult to change Clare in a standard disabled toilet. She also reported using Euan's<sup>2</sup> guide, a website like trip advisor, for disability access advice and to be able to post reviews (Euan's' Guide, 2019).

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<sup>2</sup> Euan's guide is a website, like trip advisor, that is set up for disabled people to find out about accessibility at venues.



#### 4.2.5 Mobile hoists

In addition to changing places toilets, at home Mum wanted to have a hoist for outdoor use to get Clare on her trike, as this was getting increasingly difficult:

*“...one of things I’ve been looking at, is when they build the extension, the OT (Occupational Therapist) brought a Rep to look at an outdoor hoist but he said there isn’t an outdoor hoist, but the company would adapt an indoor one. I said I can’t believe there is no outdoor hoist, why? The OT said ‘because people in wheelchairs don’t go outside that much’. What!! How can you say that! That’s all we do, get used to it, they don’t do outdoor things much! Really!! Well we do now, the next generation coming up, we are doing outdoor stuff.”*

Mum’s expectations for outdoor activities was driven by her desire to maintain Clare’s participation in RAs, but it seemed surprising to her, that equipment designs had not yet been developed to accommodate for such possibilities. It is possible that her perception of what was said was not accurate, as it was reported to me and I did not witness this. It does however seem plausible that hoists are not usually provided by social services for outdoor use. Possibly due to the safety of maintenance of electrical equipment. However, this was a negative social force as it did not support the WB impact from Clare’s participation in cycling.

#### 4.3 Time to emotionally adjust to activities

Mum had explored activities within a 50-mile radius to be able to access more choices for Clare, this included a five hour round trip to access an adapted skiing group. I was able to observe Clare at this adapted skiing group and she seemed quite overwhelmed by the speed at which she came down the slope. This was later validated by her mum in her interview:

*“I’m not 100% sure she liked it (skiing), I think she was just a bit shocked by it, it’s a bit of an overwhelming experience. I don’t think she didn’t like it, cos she likes fast, she likes going on roller coasters and things, but I think she was just a bit overwhelmed and I think the more you do these things and go back, the more she knows what she is expecting, she’s happier to do things. I’ll always try something once and then if she doesn’t like it, you can tell if she doesn’t like it.”*

The need to allow time for Clare to adjust to a new activity meant she might need to try it a few times before Mum could be sure, although Clare was reported to be keen for fast experiences. The only activity she had not enjoyed was feeding giraffes at a farm which had been discussed in the mother’s interview where she had reported that Clare frowned and turned her head away from the giraffes. Clare had been able

to try canoeing through the school, as well as a previous outdoor activity holiday at the Calvert Trust<sup>3</sup>. Here she had participated in horse riding, abseiling, zip wire and crate stacking. Mum reported she had enjoyed these activities as they were tailored for her needs and without the opportunity to attend the Calvert Trust, Clare would never have had these experiences. Therefore, the social forces of such an accessible holiday venue with people to support these activities created a positive storyline for Clare which enhanced her WB.

#### **4.3.1 Bespoke Charity Groups**

A particular facilitator for Clare's participation that enhanced her WB was being able to join in '1voice' residential event, which had a music theme that year. Mum illustrated how much Clare had enjoyed this event:

*"'1 voice' is a national group for children who use AAC and each year they have a residential weekend and this year they were doing music. It was all accessible. As a group they wrote a song and added bits on their computers to add into the song and playing instruments and things and it was a group of children, she's never seen another child using AAC, she really enjoyed it"*

This national opportunity had clearly enabled Clare to demonstrate her musical creativity with a peer group of other children who also used AAC. I therefore deduced from this data that this was a positive emotional WB experience for her as it was set up in a bespoke way by skilled people, for a group of children and young people who used communication aids. This experience generated a new storyline for Clare from these social forces when she was positioned to attend the event.

#### **4.3.2 Accessible Spaces**

The environments were both indoor and outdoor where Clare participated, sometimes on her own but often in groups. A local fund-raising initiative by a bereaved family, had paid for an accessible roundabout where Clare could now use her wheelchair. This meant she could be included in her community. A found image in Figure 21 illustrates this.

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<sup>3</sup> The Calvert trust is a charity who provide outdoor activities to disabled children and adults  
<https://calvertexmoor.org.uk/>



**Figure 21: Found image of accessible roundabout** (<https://www.walesonline.co.uk/news/local-news/new-wheelchair-friendly-roundabout-been-11755696>)

Other opportunities related to the local charity group who went on day trips and holidays together. A holiday in Menorca with them was described as '*brilliant and fantastic*' by Mum. As well as the accepting attitudes of people, there was more access with ramps onto beaches and beach wheelchairs for hire, which she showed me pictures of during the interview. A found image of the type of chair she showed me is shown in Figure 22.



**Figure 22: Found image of beach wheelchair** (<https://www.israel21c.org/beach-wheelchair-makes-sand-and-water-available-to-all-2/>)

When asked what was so good about the holiday Mum replied:

*“Accessibility. I was so surprised how accessible Menorca was, compared to Britain, even my local town isn’t accessible. You know, you can’t get into the grocers, you can’t get into the shops, but everything there was just easy. I mean we didn’t go out of the resort; we just went down to the beach or to the pool, it was just easy”*

Mum reported she had felt refreshed by this holiday, which was not usually the case. These social forces of adapted equipment and environments enabled this to be a storyline of enriched WB for Clare and her mother.

There were other issues on day trips in the UK related to restricted access to a literary festival and a palace gift shop, with the excuse ‘no prams in here’. Clare’s powered wheelchair was large and would take up a lot of space, which potentially could provide a trip hazard. These day trips were facilitated by the hire of a Jumbulance, which is a specially adapted coach. Additionally, Clare had also been labelled a ‘fire hazard’ by the managers of the arena, when seeking to attend a pop concert. Her needs meant that she had to be treated differently for evacuation purposes. However, Mum was concerned about being in a locked room upstairs as her quote highlights:

*“That’s really bad, I refuse to go there now. They stick anybody in a wheelchair upstairs, you go up in a lift and I said what do you do if there is a fire? How do we come back down again and they said...oh no you don’t come back down, we lock you in a room and it’s supposed to last for 3 hours in a fire. Then the fire brigade come and rescue you...I was I’m not bloody doing that, what member of staff is going to volunteer to be locked in the room with us...none of you I should think. Are you going to rely on the fire brigade to be able to get into an inferno and get you out within 3 hours? No, I’ll be coming down the stairs with Clare, I’m not coming here again”.*

It was clear that this risk to Clare was not one Mum was prepared to take, so she had now boycotted this venue. This barrier to participation was driven by one interpretation of Health and Safety regulation and limited her engagement in a musical event, thus minimising the potential positive emotional WB impact for her. Thus, her storyline in terms of a WB effect was hindered by this restriction to inclusion. However, Clare had access to a hospice twice a year for respite care and this was the only place that offered completely accessible RAs in one area.

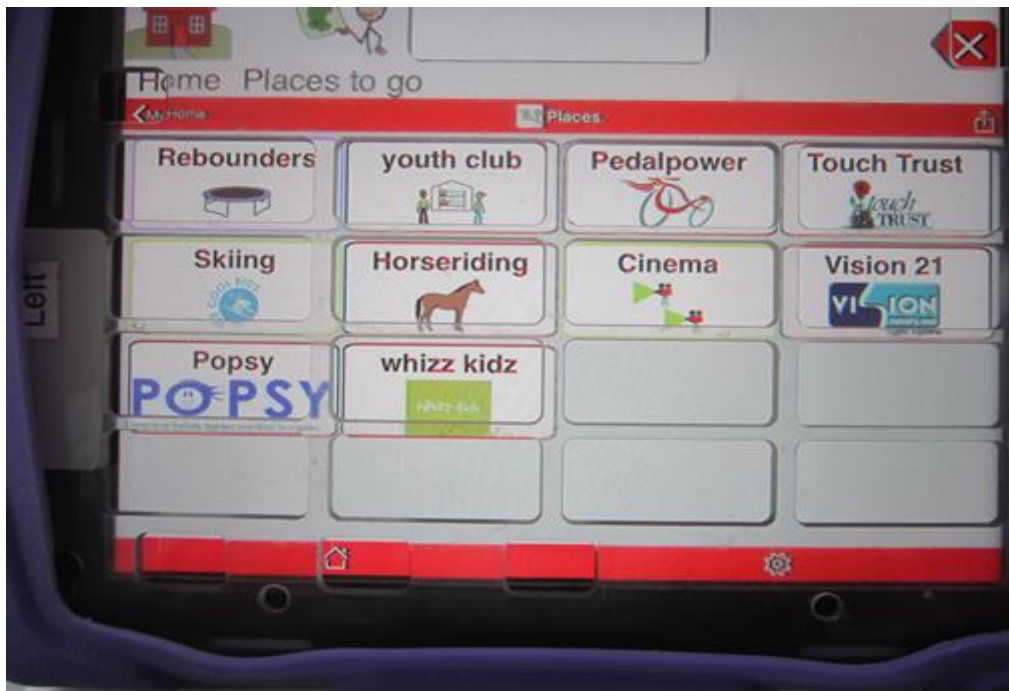


#### **4.4 Summary of Clare's case study**

Clare had been able to participate in a range of RAs that had shown benefit to her emotional WB. Despite her lack of verbal communication, I was able to experience first-hand Clare's enjoyment of music and storytelling during the interviews. Clare seemed able to self-regulate her WB by occupying herself with these creative activities. Her experience of participation was enhanced by accessible equipment and spaces so she could be positioned safely, to participate if she chose to. National and local bespoke charity groups provided opportunities that enabled Clare's WB to be promoted outside her home. Clare was limited in participation of RAs by the lack of changing places toilets and mobile hoists. Her storylines were enriched by people's attitudes and skills to adapt for her needs as well as her own ability to compose music.

#### **4.5 Lily-May**

Lily-May lived with her mother and younger sister in a city, she had her own bedroom and bathroom downstairs. She was sixteen years old and attended a local charity run school. Lily-May was recruited via a disability parent's network, I did an initial visit with Mum where field notes were made about her style of communication and interests to help inform my interview schedule. When I met Lily-May she was very engaging with eye contact and vocalising but had limited verbal communication (CFCS IV). She reliably used the communication App. on her iPad to speak her words, with a grid from which to choose her activities as shown in Figure 23. This was however a limitation with the choice of pre-programmed vocabulary, making probing to explore her views difficult.



**Figure 23: Lily-May's iPad communication for activities grid**

Lily-May had dystonic diplegic cerebral palsy (GMFCS III) which meant her arms were strong enough to use a walking aid. Lily-May could walk short distances, but she could be unstable and fall. She had retained a startle reflex, which meant sudden noises could make her lose balance. Thus Lily-May's position could fluctuate, and she needed adapted equipment to help her participate in related RAs. Lily-May loved social contact with people and that was what motivated her to join in activities, sometimes to the extent that she was distracted by this and did not stay on task, meaning that she did not always get the full WB benefits from her participation. Two interactive interviews were carried out with her using her iPad. Lily-May vocalised with varying intonations, occasionally 'yeah' was heard. The interviews were supported by a play activity with a sandbox and figures to represent her experiences and choices, as well as the drawing activity. Lily-May clapped and vocalised in a high-pitched manner when she enjoyed telling me about herself and her RAs. She used her emotion grid to tell me "*I'm happy*" during both interviews. Her mother wrote in the diary over the twelve weeks about factual events with some reference to what she enjoyed the most, which were sensory and music sessions. Sleep disturbances were referred to across the data sources, demonstrating that when tired, Lily-May was irritable, which limited her energy for participation. The themes and subthemes I identified through the analysis are shown in Table 3:

**Table 3: Lily-May's Themes and Subthemes**

Themes	Subthemes
Well-Being effects from participation choices	Enablers to participation Limitations to participation
Parental advocate to enhance participation	Treated with disrespect

These themes and subthemes are now expanded.

#### **4.5.1 Well-Being effects from participation choices**

Lily-May clapped and vocalised in a happy manner many times during both interviews which Mum said was a sign of enjoyment. This was how she responded when asked if she wanted to play with the sandbox and I saw this as her assent to continue with the data collection. When engaged with the sandbox Lily-May was quieter, as this multi-tasking activity demanded more concentration and made her drool. She enjoyed putting the symbolic toys in and out of the sandbox, playing with small musical instruments, horses, trampolines, La La Loopsy on the trike and trampoline, pouring the sand over and burying them. These symbolic toys captured Lily-May's interest for quite some time during the interviews, as La La Loopsy was one of her favourite soft toys.

When invited to carry out the drawing activity, Lily-May chose a purple pen. She engaged with this activity possibly because the character 'Natalie' was using a walker like her own. This activity was difficult for her, but she drew a swimming pool which got smudged by her hands and Mum wrote the word 'swimming'. Although Lily-May's drawing was difficult to interpret, I was pleased she engaged in the activity, to express that she thought 'Natalie' would like to swim to relax and play.

Lily-May had a vast choice of activities, with something on most nights of the week and weekends. These included both indoor and outdoor pursuits such as: boat rides, boccia, cinema and theatre, cycling and bike club, dancing, horse riding, lazy spa, outdoor ice-skating, park, sailing, sensory storytelling, shopping, swimming, skiing, table tennis, tennis, trampolining, Touch Trust, wheelchair basketball and dancing, Whizz Kid's ambassador youth club and zip wire. Lily-May was most motivated by musical rather than craft activities. Some weekends Lily-May went to respite at her school, which provided RAs such as hydrotherapy and bike riding. Although Lily-May

was 16, there were still aspects of the local playground she enjoyed such as the basket swing. The data illustrated what enriching opportunities she currently had, thus positive storylines about the WB effect from her participation in RAs.

#### 4.5.2 Enablers to participation

A frequent topic related to Lily-May's WB was about her sleep patterns. If she did not sleep well, she was fatigued during the day and less motivated to participate. If she was able to do *'lots of walking, she slept well'*, but this was not always the case as Lily-May's routines meant that some days she did not have the opportunity to do as much walking. Sometimes, it would take her two hours to settle and then she would wake up after two hours. Her restless sleep was partly due to her dystonic movements at rest, for which a weighted blanket had helped. Her retained startle reflex meant that she also woke up with sounds and a white noise machine had helped to reduce this. During the study's period, her sleep was significantly disturbed so Mum had sought help from her OT and was able to borrow a large cot bed which had *'been life changing, it's just been amazing, we're so much calmer'*. However, there was now a dispute about getting one funded between health and social services, as the quotes had varied between £5,000 and £9,000. This bed had made Lily-May feel safe and secure and she had slept well at night for several weeks, since trialling it. Figure 24 shows the cot bed on loan. In Lily-May's case, this had improved the emotional WB for all the family, as they could also get an undisturbed night's sleep.



**Figure 24: Cot Bed on Loan**

This cot bed had a hydraulic power supply to enable it to be raised and lowered, thus enabling Lily-May to control getting in and out of the bed. Also, her younger teenage sister was able to settle her in the evenings, which now only took ten minutes compared to the two hours previously. Since sleeping better, the fatigue had reduced, and this increased her energy for participation. Thus, by being positioned in the adapted equipment of the cot bed, Lily-May could relax and sleep, giving her more energy for the social participatory RAs she enjoyed, which benefitted the WB of her and her family.

Another way to manage her fatigue involved considering how hard the task was for her. For example, in the side by side bike she rode at the bike club with her sister, the pedals were disengaged halfway round. This meant she was not too tired to enjoy the social tea and cake that followed this activity, which was a great motivator for her. Social interaction contributed significantly to Lily-May's positive emotional WB as shown by Mum's quote:

*"She likes to be part of a group. No matter what role she has, she just likes to be a part of things."*

Thus, Lily-May was a happy young people and liked to engage with people in the activities that she participated in, creating her own storylines about her WB.

There had been the opportunity to go on several day trips including visiting stately homes and a 'festival of light'. Holidays at home and abroad were arranged with the same charity and adapted skiing group that Clare was involved in. These were all supported by personal and group fund raising and included an overnight sleepover at an aquarium and a visit to a snow dome. The skiing holiday was described as '*fabulous and amazing*' and this opportunity had also enabled her sister to learn to ski. Mum felt that all RAs should include the siblings, as this makes it easier for single parents like herself, who may not have anyone to leave their younger child with, during the disabled child's RAs.

Lily-May had three paid carers from her direct payments and the carer got in free to many RAs. These carers could do things with Lily-May, so Mum could spend time with Lily-May's sister. Lily-May was motivated by other wheelchair users and enjoyed socialising with a group of other disabled children and young people in a safe

environment. When she attended the Whizz Kids Ambassador's club, they provided carers all day. This meant Mum could leave her, as she recorded in the diary:

*"Ambassador club! Fantastic. Wheelchair sports- dancing, tennis, table tennis, boccia. Able to leave Lily-May as has health care professionals there – much more fun for Lily-May without me there, she laughed and shouted the whole time."*

Mum perceived that Lily-May had more fun without her present, this could be an indication of Lily-May's emerging self-determination, to express herself freely. Alternatively, it could be that the freedom it gives her mother to step out of the 'carer's' role for a break, enhanced this perceived WB effect. Thus, by being able to be positioned separately from her mother, Lily-May was able to develop more independence herself, becoming her own agent of change to determine her own storyline related to her WB.

#### **4.5.3 Limitations to participation**

The activities were always limited by Lily-May's needs, as someone needed to assist her with eating and taking her to the toilet. Direct payments could pay for a PA to meet these needs, otherwise Mum had to go at break times which Lily-May did not like. As Lily-May approached adulthood, the horse riding for her disabled group would stop at 18 years. The fact this group would end was a concern for Mum as she did not know if there was a disabled riding group for adults. It was also getting increasingly difficult, due to Lily-May's height, to get her onto the horse without a hoist, which this riding group did not have. Lily-May was still enjoying this activity and a diary entry showed she had done this without stirrups for the first time, showing her balance was still improving. One of her carer's now took her, as this activity did not include her younger sister. As she had got bigger, swimming had become more difficult, especially as the jerky movements of using the hoist, to get her in and out of the pool, set her startle reflex off, making her limbs stiffer. One limitation was that the range of specialist equipment that could facilitate participation, such as a beach wheelchair, were expensive and bulky to store. Mum suggested that having a store area somewhere in the community, where you could hire this equipment, could help.

Indoor activities were limited by Lily-May's difficulties with fine motor control as she tended to trash the arts and craft activities. This was a barrier to Lily-May

participating independently, and the support she needed was shown by her mother's quote:

*"A lot of the activities are arts and crafts, and if you put arts and craft in front of her, she just likes to trash it on you really. So she needs support doing that, then (when craft based) she just gets frustrated, just sitting waiting, so we go if they do a musical workshop, or dance and movement, then we'll join in with that."*

If there was no appropriate stimulation, she could be passive and got bored and started to chew her hands, so she needed direction with all the RAs that she did. She concentrated better if she watched others first, then joined in. Otherwise she was too distracted by the others as these diary quotes illustrate related to the trampolining:

*"Trampolining-  
Week1:*

*Difficulties*

*Lily-May has poor concentration + more interested in watching other participants.*

*My plan –move trampolines so Lily-May is further way.*

*Watch other participants for a while before taking her turn*

*Sister able to take part in another class.*

*Week2:*

*Went last so had time to watch others first.*

*Went on different trampoline so vision obscured somewhat.*

*Coach not very assertive + not keeping Lily-May's attention but better when props added e.g. rings, peanut ball*

*I suggest using something like castanets (a click) to bring Lily-May's attention back. Language needs to be clear and concise.*

*Week3:*

*Good session, Better concentration, Good balance on peanut ball".*

Thus, Lily-May needed precise instructions to maximise her attention, which this coach did not seem to recognise. Therefore, to enhance her engagement and enjoyment, her mother had some strategies, showing her initiative to advocate for her needs. As the weeks progressed her engagement in trampolining increased, thus her Mum's intuitive awareness enhanced the WB effects from her participation. This highlights the key position her mother played in supporting the storylines to maximise the WB effects from her participation.



#### **4.6 Parental advocate to enhance participation.**

As well as advocating for Lily-Mays' needs, Mum was an advocate for other disabled young people. She was also part of a Parent's Federation who were campaigning for Changing Places toilets. Even though this was not an issue for Lily-May, as she could transfer and sit on the toilet. Mum was also confident to address issues that Lily-May was not directly involved in. Mum had also commented about restricting access to those who can obtain a 'Radar' key (this is a special key for disabled toilets in the UK). Lily-May's mother felt this would help to maintain their cleanliness and only allow those people who really need it, to use it.

##### **4.6.1 Treated with disrespect.**

Mum described that when attending hospital appointments, the disabled toilet was sometimes used as a dumping ground for a television and blood pressure monitor as Figure 25 illustrated, which she felt was disrespectful. It was not possible to find out why this had happened, but it could relate to time pressures in clinical areas in the NHS, whereby staff do not consider the impact of this behaviour. It did not appear very welcoming when using the toilet and Mum contacted her local councillor to address this issue. This image was shared by Mum in her interview which had made her 'cross' because she felt it portrayed the needs of disabled people were less important:



**Figure 25: Disabled toilet at children's hospital**



#### **4.7 Summary of Lily-May's case study**

Lily-May had a wide variety of RAs that she participated in. Motivated by the social contacts with other people, she was able to express her enjoyment in these situations and this demonstrated positive emotional WB effects as shown by vocalising and clapping. A future ambition for Mum was for Lily-May to participate more without her being present, thus by being positioned independently. Mum perceived her limited communication was her biggest barrier to participation in RAs. The things which enabled her participation in RAs have been illustrated, with a PA and specialist equipment, such as the cot bed, to assist her sleep patterns. This had reduced her fatigue, preserving her energy for fun RAs. These positive storylines were influenced by people with skills to support Lily-May's participation in RAs to benefit her WB. The limitations to participation in RAs were related to the lack of ability of people to adjust to cater for Lily-May's limited concentration such as at trampolining. Her mother was an advocate for both Lily-May's and other disabled young people's needs, to help improve the opportunities and choices for RAs and address the perceived disrespectful attitudes towards those with disabilities.

#### **4.8 Nick**

Nick was thirteen years old and lived with both parents, his older sister and younger brother in a purpose-built house, adapted for his needs in a Welsh city. This also had an indoor swimming pool. Nick had spastic quadriplegia (GMFCS IV) and was deaf, having a cochlear implant. He was able to do standing transfers with assistance. Nick used Makaton signing and eye gestures to communicate with minimal vocal sounds (CFCS III). He loved the buzz of being in social gatherings and was able to control his powered chair to move around his environments enabling him to control where he went, once positioned in the chair. Nick was recruited from the leader of the RaceRunning club. Nick's Dad predominantly carried out the interviews with a small contribution from Nick's mother. Two interviews were carried out fourteen weeks apart, with the diary being handwritten by all Nick's different carers during this time. This gave me different voices, some written in the first person. Three participant observations took place at the RaceRunning club, both at the indoor and outdoor facility. The themes and subthemes which were identified from Nick's data sets are shown in Table 4:

**Table 4: Nick's Themes and Subthemes**

Theme	Sub-themes
Enablers for participation	Volunteers, Respite choices
Well-Being indicators	Nick's behaviours, Parent's emotional responses

#### 4.8 Enablers for participation

The RAs that Nick participated in included trike riding, swimming, horse riding, rebound, touch and music therapy, RaceRunning, trampolining, car drives, indoor and outdoor museums, parks, and cubs. A highlight was purchasing his own trike after the school had shown a video of him cycling by himself, after years of supported cycling, with Dad taking him to a cycle hire centre:

*"So we went to school and saw him riding the bike, the surprise was he was just riding a bike around on his own...after we had seen the video, we just thought Ah this is fantastic! This is something he can do at home or at the local park or we take him with the bike in the back of the van and take him elsewhere to do it" (Dad's interview)*

*"Dad came up to school today with a big surprise. My new bike!! 😊 It took quite a while to set it up for me, but then I went for a ride around the school. We're going to keep it at home, so I can go riding whenever I like, I was very happy" 😊 (Diary entry from Mum)*

Thus, Nick was very happy about his new trike which provided more choices of where he could go at home and in the community by pedalling himself once positioned on the trike. His position on the trike enabled him to determine where he went. This gives an indication of a positive emotional response from this participatory opportunity with adapted equipment. Nick would still need someone to steer him, but it did empower him to move intentionally once it was set up. Having access to a mobile hoist was a key facilitator to participation in the community, although Dad preferred to lift him because he said, *"I can't be arsed with the hassle of the hoist"*. Nick sometimes got agitated with the hoist, which Dad said then also made him agitated. An outdoor hoist was available at the RaceRunning indoor and outdoor observations as shown in Figure 26.



**Figure 26: Mobile hoist used at RaceRunning observations (indoors and outdoors)**

At RaceRunning the hoist had volunteers trained to use it. It was a tension that Dad talked about a lot that Nick would soon be too big for him to lift. Thus, providing the equipment, did not necessarily mean it would be used. To get Nick onto the RaceRunner needed two people, as he tended to cross his legs when standing. Figure 27 shows the size of the RaceRunner that Nick used. Although the mobile hoist was available at both the indoor and outdoor venues, only the outdoor venue had invested in a 'changing places toilet'.



**Figure 27: Race Runner at indoor facility**

At the first observation, Nick propelled himself about 4 laps around the track in the hall using 2 feet together, sometimes alternate feet. After he had finished on the RaceRunner, I observed Nick absorbing the social atmosphere by driving his chair around, he gave me good eye contact and a smile. However, at the second and third observations Nick only managed 1 lap outdoors. Dad thought this was possibly attributed to a recent spinal brace to manage his scoliosis, which was uncomfortable for him to wear and restricted his movements. Thus, Nick was offered the opportunity for RaceRunning, but he chose to engage with this in a fluctuating way, determining his own WB from his level of participation, creating his own storylines.

A separate trip took place with RaceRunning to England which was recorded in the diary by Dad:

*“It was a lovely day, with the sun shining. I drove my chair around the track and then went on my RaceRunner for a few laps and had a race with ‘L’! I enjoyed the men singing songs and playing guitar, had a very nice burger for lunch from the barbeque. Then in the afternoon, I tried the recumbent bikes, I enjoyed that, but did find it difficult to pedal, so Dad had to push me, which made me laugh a lot, because he kept forgetting to steer as well!”*

The diary extract demonstrates Nick’s enjoyment of this activity, evident in his laughter at Dad’s steering. A recumbent bike is where the person sits in a reclined position with their legs in front and steers from the side. A found image is used to illustrate this in Figure 28.



**Figure 28: Found image of recumbent bike**  
(<http://www.londonrecumbents.co.uk/> [Accessed 23.02.18])

Dad expressed how hard it was when he was not convinced Nick was enjoying something, after all the effort to include him. An example was of a previous adapted skiing opportunity:

*“Although the thing about Nick is that he’s quite benign and tolerant and I don’t think it (skiing) was awful for him. But if it’s bloody awful for you...there comes a point in time when I think you say, I’m sorry but I’m not going to put myself through that and feeling that way, whether he’s enjoying it. I wouldn’t say enjoying it, as Nick can be difficult to read, he tolerates a lot. He does express enjoyment, but he tolerates quite a bit of stuff and you wouldn’t really know if he was just bored. So, what I’m trying to say is that if he spent part of the weekend being like, I don’t really care if I’m here or not, then what’s the point of doing it?”*

As Nick was ‘difficult to read’ emotionally, Dad was questioning why they might not do some things, as Nick was ambivalent about participating. This highlights the emotional impact upon his parents, who also had two other children to consider.

Nick really enjoyed his weekly visits to the outdoor museum with his PA. The staff there were welcoming and most of the outdoor space was accessible with his all-terrain chair. The diary quote illustrates this showing the positive WB effect for him:

*“Went to outdoor museum from 2-5 with ‘carer’, went into all the little houses, drove myself around. Lots of people, lots of laughing, a good day” (Male PA).*

Thus, the equipment to get outdoors provided a fun activity for Nick, where he could choose to drive himself around and see people, increasing his participation with a carer’s support. He reacted to this experience by laughing and felt this was a good day. So, the combination of adapted equipment and people enhanced his WB from his participation in this environment. Thus, enablers to participation were a combination of environments, equipment, and people. Whilst some were paid carers, others were volunteers, which had both strengths and limitations which are discussed further below.

#### **4.8.2 Volunteers**

Many RAs were run on a voluntary basis, which required people giving up their own time to support these initiatives. So, without volunteers, these adapted RAs could not happen. However, Dad reported frustration with the lack of training of volunteers to use a hoist when setting up his bike at the cycle hire centre:



*“I had a couple of episodes there that I regret, I spoke badly to the staff there, but you know you get frustrated sometimes. Because I thought that the bike hadn’t been properly adjusted, I was worried for Nick’s safety and they’ve got a hoist there in the back of a broom cupboard that no one knows how to use and so if I wanted to use the hoist, it’s such a difficult process then to get it, that it just puts you off completely even bothering.”*

Thus, it can be seen even with the intention to engage in an adapted RA, there were issues with safety due to the perceived lack of training of the volunteers, which made Dad feel like not bothering. One previous experience of an art workshop highlighted the lack of adaptations for Nick’s level of ability:

*“You may go in and you’re in a room with a group of people, they don’t know what to do and the worst can be they can’t really be bothered. It’s very easy then to ignore you and you’re left by yourself. There was a local art workshop, Nick was making Christmas lanterns and enjoying making a mess with glue everywhere, one girl up there certainly came over a couple of times and said, ‘how’s he getting on’. Whereas we were left to our own devices and there were 2 or 3 kids there who were ‘wow’ these wonderful creations they got quite a lot of attention, whereas Nick’s was very modest”.*

Dad felt they came over as not caring or valuing Nick’s contribution to art on this occasion, as they could not be bothered. It was not clear if this was the case, but Dad’s perception was they did not know how to relate to a young person with Nick’s level of disability. Dad commented about the unrealistic expectations of what volunteers can do as they are not employees:

*“It’s difficult because by and large these groups are charitable, and they are predominantly staffed by volunteers. It’s unreasonable and unrealistic to expect them to behave like employees because they’re not. So, what’s the answer to that?”*

Nick attended cubs with his PA, but he had not progressed to scouts as it was considered too active. This was suggested to be related to the attitude of the volunteers in the scout movement, as Dad described:

*“Nick just remained at cubs, when he turned 11, we were thinking oh well he’s got to go up to scouts now and I got in touch with 4 or 5 of the local scouts troops and they were not in the least bit interested. When I’m faced with somebody who says ‘Well how disabled is he?’, We do climbing and canoeing, I just walk away, I was very disappointed but as I said to you, they’re volunteers and on the one hand I think it’s not great for the scout movement to, on the face of it, in my experience, to have a “can’t do attitude to the disabled”. You know the place he goes to cubs, like I said, he accesses the cub troop and he quite enjoys the buzz, the peer to peer, social side, but*

*that's the problem with a lot of stuff that Nick does, it's a bit of a social activity, but his participation is always limited".*

Therefore, Nick's participation was restricted by the volunteer scout leaders who possibly had limited experience of adapting RAs like climbing to include disabled children and young people like him. It was suggested this was a lack of knowledge in how to adapt activities. However, Nick always enjoyed the social participation. This exclusion from scouts contrasted with his special school's sports day recorded in the diary and seen on a video on his iPad that had included him climbing up a wall in his wheelchair:

*"It was sports day in school I came home very excited + full of beans after going up a climbing wall!"* (Mum's entry)

Thus, adapted RAs were possible, but took a lot of effort and was not easy to achieve when the disabled child was in the minority, as potentially Nick would be at scouts. So, Nick's special school's sports day had provided the accessible climbing activity that had not been considered possible by the scout leaders, who declined to include him in their troops. It is unclear if this is a funding or safety concern. However, the lack of opportunity to be included at scouts, meant that Nick's position was as an outsider, so no WB benefits could be seen, from being excluded in this way. Therefore, his storyline of any WB effects from participation in that RA were diminished.

#### **4.8.3 Respite choices**

Nick's physical care needs meant his parents appreciated a break using different choices for respite. The family employed PAs using their carer's allowance. This gave them periods of respite during the week, both at home and if they went out. Nick attended the same charity school as Lily-May, which also offered respite, but during the study period Nick had only stayed after school for tea, not overnight. Partly due to the expense of an overnight stay (£250). They valued these short breaks as his care needs were physically tiring. Family holidays with 'carers' had not been successful due to a variety of factors related to the level of Nick's disability and lack of training in how to relate to him. Whilst the family had been away without Nick, he had only been away for one week on a charity trip to Lourdes without them. They reported that he did not want to get off the bus when he came home, which they interpreted positively. A future idea was for all the family to go on holiday to the

Calvert Trust in Devon, which caters for disabled children and young people to participate in a wide range of RAs, where Clare had been.

## **4.9 Well-Being indicators**

### **4.9.1 Nick's Intentional Behaviours**

It was important to interpret Nick's behaviours for indications of his WB in relation to participation in the RA. Dad reported that Nick showed happiness by clapping his hands, smiling, and laughing a lot. Dad felt when Nick was happy, he was '*a delight to them*'. Appetite was a good indicator of Nick's emotional WB according to his father, thus if he was well, he was '*ravenously hungry*'. Diary entries showed how much he enjoyed his food and trips to the shop in his wheelchair to buy treats, illustrating his good appetite. However, he did not eat and went very quiet when he was not happy. Nick usually slept well for 7-9 hours per night and he enjoyed a lie in at the weekends. There were four records of Nick being in a bad mood in the diary. I did not observe any bad moods, but I observed that he was sometimes not engaged at RaceRunning. It was not clear if he was unhappy, in pain or bored on these occasions.

Nick enjoyed musical events especially the circus experience, where he got cross because they had to leave:

*"I loved the circus, especially the beginning when they all had large spinners. We enjoyed motorcycles, acrobats, trapeze and I really loved the Ice-cream. I had both vanilla and chocolate. I got cross when we left as I wanted to stay for more as I was trying to sing to the music"* (Dad's Diary entry).

Thus, these behaviours were indicators of his emotional WB. In the absence of him being able to verbalise this himself, Nick was able to show his determination by his intentional behaviours to create his own storyline about his WB, which fluctuated at times.

### **4.9.2 Parent's emotional responses**

Dad had described many frustrations with hoists and volunteers, but he did have a future ambition to take Nick sailing, as he had heard about disability sailing from one of the carers, who also worked with a disabled adult:

*"(Male PA cited): "When I take him (disabled adult) sailing, they just take him off me. They take him away and they do the sailing with him and he loves it" ... and this is a disabled adult and I'm thinking 'Wow that would be fantastic for Nick'.*



Dad's expectation was that Nick would do the sailing without him. The style of boat meant that he could do this in his wheelchair. Dad did not mention any other specific participatory RAs for Nick's future. Mum had future aspirations for Nick's inclusion in the community, but felt that would be unrealistic in his lifetime:

*"I'm not so sure about the sports stuff, I'd like him to do everyday things ... Nick likes to move from one thing to another. So if he was in a shop by the till, he would love that, I'd like Nick just to be included more with his community with this peers in the village, because he's not really included in his village. I think that would be fairly easy to do but culturally it would be difficult.....it would have to be a major cultural shift; it's never going to happen in Nick's lifetime will it?"*

What Nick's mother was proposing was the possibility that he could be positioned in a community space such as a shop, so that socially he would feel included, but her perception was this was unlikely to be achieved in his lifetime.

#### **4.10 Summary of Nick's case study**

There was more evidence of physical RAs that had been adapted for Nick, which contrasted with the lack of adaptation for arts and craft activities. This was concerning as Nick was maturing and becoming less physically able, so potentially he would have less choices for participation as an adult, due to his physical decline. A mobile hoist and a changing place toilet facilitated his inclusion at RaceRunning, however no other places at Nick's RAs offered that. Nick's powered wheelchair improved his access, but he did not always choose to engage with RAs. A future ambition of his mother's was for him to be more included in his community, but there was no evidence to show that this was already happening. Thus, Nick's WB storylines were influenced by some key people and adapted equipment and environments but also himself, as he showed his own agency not to participate at times.

#### **4.11 Matthew**

Matthew was aged fourteen years at the start of the study, he lived with both parents and his younger sister and brother in a coastal town. The family enjoyed a holiday abroad, as well as in a caravan in Wales during the study's period. I did not meet Dad, as he was working, but he took Matthew to football and darts as a spectator, as recorded in the diary. Matthew attended the local comprehensive school which provided adapted activities such as boccia (a precision ball sport, related to boules),

football, golf and tennis. Matthew was recruited via a parent's cerebral palsy Facebook page. The data sources which made up Matthew's case study included two home interviews with Mum, two observations, one at skiing and one at surfing, plus the diary completed by Mum. This took place over five months.

Matthew had spastic quadriplegic cerebral palsy (GMFCS IV) and was unable to walk, although he could do standing transfers. He had minimal verbal communication (CFCFS IV), he screamed to show enjoyment in an excited tone of voice and threw his arms up in the air. He also screamed in a distressed tone of voice when unhappy and would hit out aggressively with his left arm. Matthew was incontinent, requiring assistance for changing. Matthew had been able to participate in a wide range of RAs from a young age which he enjoyed. However, he was not good at occupying himself alone and needed a high level of supervision to manage his challenging behaviour. At my initial visit he was occupied by flicking through a catalogue and did not really respond to me at all. He attended an overnight respite centre twice a month, but it had taken him a while to settle there.

Mum had 3 hours of direct payments for him to attend a youth club, where he participated in a variety of cultural and sporting activities. He also received the higher rate of disability living allowance which Mum used to pay for some RAs and his wheelchair adapted vehicle (WAV). Matthew's themes and subthemes are shown in Table 5.

**Table 5: Matthew's Themes and Subthemes**

Theme	Subthemes
Innovation in Designs	People who adapt for disability needs Parental Advocacy for Emotional Well-Being
Challenging behaviour	Respite care that managed emotional Well-Being, Changing facilities affects participation.

These themes will now be expanded.

#### **4.11.1 Innovation in designs**

Matthew's mother described a range of participatory RAs that he had started to do from the age of three years. Many of these were successful from innovative designs. These included a trike, which was illustrated by a photograph, discussed in the first interview as to how well he looked from his initial period of illness with cranial

arteritis, which had caused his multiple strokes. He had participated in skiing from the age of seven years and surfing from the age of twelve years and had been involved in the actual design of this surfboard. The emotional WB impact from these RAs was both displayed in photographs around the house with Matthew smiling and videos shown on mum's phone and iPad during the interviews, where he was '*screaming with pure joy*'. A found image of the adapted surfboard is shown in Figure 29.



**Figure 29: Found image of Adapted surfboard**  
(<http://www.cerebra.org.uk/category/cic/page/4/> [Accessed 03.05.17])

Matthew had been involved in the development of this surfboard with a charity and an engineering school in a Welsh university. Matthew was not strapped into this reclined seat on the surfboard and as he was unable to swim, he would fall out if the waves were quite big which was termed a '*wipe out*'. He loved this and there were many references to him screaming and laughing with joy in the interviews. I was also able to observe this first-hand during my participatory observation where I got into the water alongside him and the two surfing instructors. He was visibly shaking with excitement and grunting very loudly, he became hoarse by the end of the session. In the second interview with Mum, a video was shown on the iPad of a TV programme with the surfing instructor and Mum commenting:

*“ Voice of surfing instructor: ‘Just because he’s disabled doesn’t mean that he doesn’t want to get radical, he really does, he loves it when we catch a big*

*wave or we get a big splash from the wave, especially when we get wiped out and pushed over, he finds it hilarious’(video and sound of Matthew laughing).’Mum’s voice: This is the best feeling ever, to see your child so happy, you can forget about all the worries or hospital appointments and just for that moment see him on the waves, it’s amazing’.*”

So, Matthew found the surfing experience thrilling and was happy at this activity, indicating a positive emotional WB effect from his active participation. An image of Matthew can be seen in Figure 30 positioned in his beach wheelchair, prior to surfing.



**Figure 30: Matthew ready for surfing in beach wheelchair**

I also observed Mum changing Matthew out of his wetsuit, in this beach wheelchair, in the back of their WAV, after the surfing session. She managed this, but it was not ideal, thus creating a manual handling risk. The WAV can be seen in Figure 31.



**Figure 31: Wheelchair accessible vehicle (WAV)**

Matthew had been involved in the design of this surfboard which was able to provide enjoyment not just for himself, but others also. The drawback of these innovations was the increase in manual handling risks for the parents and staff involved. This innovation in design was also mirrored by initiatives from other people who created local opportunities, one of these was adapted skiing.

#### **4.11.2 People who adapt for disability needs.**

The skiing group that Matthew belonged to, had been set up by a group of physiotherapists. It was supported by competent skiers who were volunteers and was held in a country park area. This centre had a disabled toilet and one lift, but no changing places toilet. I observed Matthew at this adapted skiing activity as a non-participant. Matthew was supported in a sit-ski, whilst an adult volunteer skied behind him on reins. The sit-ski is illustrated in Figure 32.





**Figure 32: Sit-Skis**

Matthew can be seen in Figure 33 waiting to go up the ski lift and then come down the ski slope. I observed him come down '*shouting with delight and shaking his arms in the air, he is smiling when it finished*'. The faster he went, the louder he shouted, I deduced from this that he was enjoying it. Thus, once Matthew was positioned in the adapted equipment, supported by a competent skier to descend the slope, he could express his joy, determining the WB effect from his participation in this RA. Thus, generating a positive storyline about his experience without spoken language.

Matthew came down so fast I was not able to capture this motion in a still photograph. However, the incline of the dry ski slope gives an indication of the distance travelled. His loud vocalisation indicated his enjoyment which I could hear and observe from the spectator's decking. It was a moving experience to observe him exhilarated by this participatory opportunity and evidence of a positive emotional WB effect for him.



**Figure 33: Matthew waiting to go up the ski lift in a sit-ski; ski slope**

Mum's perception was that the physiotherapists involved in Matthew's care had been instrumental in signposting her to all these RAs, she saw them as great advocates for him. She also felt that this was because she had engaged in the exercises, they gave her for Matthew. Mum felt that many people loved Matthew because he was so sociable and so people wanted him to join in as her quote highlights:

*"....Matthew, he always looked normal, not special needs, he has an infectious laugh, people wanted to spend time with him, they wanted him to go and do things...like the physios...cos I always went to things and I always carried out my physio, the physios wanted to help. So, anything that came up I would be the kind of first person they would ring-do you want to go and try this? So, you know, I think we were just really fortunate you know..... everyone always thought that about Matthew, cos the way he looked, so handsome, he never looked as if he had a disability and he was so cheeky, so I think alorra things have come his way by his personality I think, who he is..."*

Mum's perception was that because she has complied with her physiotherapy exercises, she was given more opportunities on top of his NHS provision.

Additionally, there were some factors about Matthew, how he looked and who he was, that she perceived drew people towards him. Especially when he showed such

positive emotional responses during his participation, despite him not speaking verbally, he sought to engage with people.

#### **4.11.3 Parental advocacy for emotional Well-Being**

Matthew's mum was positive in her attitude to get on with life and she wanted the best for him and her other two children as this quote shows:

*"I'm not one of them people who feel sorry for themselves and I think a lot of people get consumed with their child's disability, oh everything's so bad, and so, Matthew's got a disability and so we'll move on."*

Therefore, they were engaged with a lot of groups of people and she saw this as a positive factor that enhanced Matthew's participation. Mum also recruited others to participate as this quote illustrates:

*"Well I'm always telling people and I got alorra people into it (surfing) actually and I think it's good for parents cos I think alorra parents get a bit down thinking, there's nothing, I can't do anything, and there is stuff, you've just got to try it, I am really social, that's how we are as a family regardless of Matthew's disability you know, we are and we've got loads of good friends and it's really good"*

Mum described herself as '*not highly educated*' but as an outgoing sociable person. Her enthusiasm had influenced other families who perhaps had been discouraged that there were not things they could do with their disabled child, as Mum's quote shows:

*"I think also living round here, this area is classed as a deprived area, so I think alorra parents of children with disabilities are not very well educated and some of them have got special needs themselves, so they wouldn't think to do it (surfing)"*

Mum suggested that the factors which influenced other families living in relative poverty, were a mix of both financial and limited understanding, which impacted upon their ability to engage in participatory experiences. Matthew's family liked to keep busy with family and friends and these routines helped him to be suitably occupied when in company. This indicated he was happy and reflected a positive WB state.

The two RAs where I was able to observe Matthew, gave me first-hand evidence of the positive emotional WB impact from his participation. These opportunities were directly attributable to these innovative designs and showed evidence of him thriving as he engaged fully in the opportunities provided. So Matthew liked to be positioned



with people outside his family, however, in contrast to this, when he was not occupied with such thrilling RAs or with other people, he could be aggressive and difficult to keep happy as the next theme illustrates.

#### **4.12 Challenging Behaviour**

Whilst I had observed Matthew thriving at his participatory opportunities, I did not observe any challenging behaviours during my visits. It was therefore only reported by Mum in her interviews. The diary did not reveal this either, mainly being factual about his activities and holidays. I had no reason to doubt the reality of his difficult behaviour, but I was reassured that they had received specialist help from a challenging behaviour group and an action plan was now in place to support them from social services with bathing and dressing. The words used to describe his behaviour were ‘*aggressive, horrendous, brutal, ridiculous and dangerous.*’ Now two PAs came into shower and get him ready each school day morning, which had transformed the family’s experiences into more positive ones. One of the reasons why his Mum enjoyed taking and watching him at all the RAs was because she felt he was happy and could enjoy himself as her quote illustrates.

*“And to be honest his behaviour is so bad at home at the moment, it’s nice to see him happy and just not performing. So, I quite like that side of it just thinking well, life isn’t that bad all the time, cos he’s enjoying this you can see he’s enjoying this.”*

##### **4.12.1 Respite care that managed emotional Well-Being**

Matthew attended a local respite facility for overnight stays, but this had been mixed during the study’s period. At first, he liked it, then he hated it. It was not clear what changed his response, other than if he went straight from school he did not settle well and was distressed and aggressive to others. It needed some negotiation, via the social worker, that he only went on weekends and not straight after school to improve his enjoyment of it. This quote highlights these difficulties:

*“It’s been really difficult, he hated it and then we managed to get him to like it and then what would happen was the dates they were giving me he would go straight from school, then he used to hate it, then things became really, really good to the point where one session he actually drove himself out of the car and knocked the door to go in which was like the best thing ever”.*

It had been both Mum and his social worker who established that he was bored at the respite centre as he was not receiving appropriate stimulation. This had been

from the follow up of Mum attending a parenting course where she had described his challenging behaviour. Social services had then initiated Matthew receiving help from a challenging behaviour organisation. They had observed him at the respite centre and made constructive suggestions, to reduce his distressed behaviour with some suitable RAs. This was a turning point, illustrating that it is not sufficient just to position Matthew in a place, without adequate adjustments and stimulation for his needs. So skilled people were required who could tune into his moods and engage with him non-verbally, to create positive storylines. The evidence of the emotional WB indicators for Matthew at the respite centre were highlighted in interview two:

*“It’s (respite) gone well, if he slept well, the indicators for the respite centre would be that he wouldn’t eat his food and Matthew loves his food, so that was a sign that he wasn’t happy. Crying, screaming, attacking me, trying to get back out and while he was there...he was very upset and took a lot of calming. Or it would be that he’d be ok for an hour and then he’d be start again and they’d talk him down and he’d be fine, but that’s all gone now. So, it’s kind of stages really when he’s got a bit more comfortable there. And the other behaviours when he’s happy is that he’s happy he’s not attacking or screaming at me, or he’s laughing.”*

Thus, evidence that he ate, slept well, laughed and was calm were positive indicators for his emotional WB at the respite centre. If he did not settle there, his participation was limited in the activities with the other children and staff, thus isolating him in his distressed, aggressive state. Moving onto activities where changing facilities were needed, this will now highlight how this impacted upon Matthew’s level of participation, influencing his WB storylines in both positive and negative ways.

#### **4.11.2 Changing facilities affected Matthew’s level of participation**

A recent experience at a local new swimming pool had been limited by the lack of a transit chair to get Matthew into the pool, although adapted changing facilities were provided. Mum had dealt with some barriers when seeking to negotiate for Matthew to attend an ‘inclusive sports’ event. Her argument was that the social media advert did not match inclusivity. His personal care needs were a barrier to him going, as he needed a PA to change him and there was no money to pay for this. Mum felt the advert was misleading to suggest it was inclusive, the sports may be inclusive, but the participants needed to be independent with toileting needs. Mum advocated to the organisers on Matthew’s behalf how excluding this event was for Matthew as her quote shows:

*“.....you need to have a nice little paragraph underneath where you say you are inclusive for everyone, because you’re not inclusive for everyone...  
...They took it by putting on their Facebook page, which really, really infuriated me ‘cos it was aimed at me...to say that don’t forget that next week is our all-inclusive sport’s things but we need to tell you that we cannot provide one-to-one services for personal care... it was kind of that’s for me that was and I was really, really annoyed by that...because Matthew is in a wheelchair he is automatically written off...”*

In contrast, a positive experience for Matthew was the Festival of Sport he had attended in the school holidays:

*“It is yeah and in the summer holidays they did a Festival of sport which is at S. Park for a week and that was for children with disabilities. He went all week on his own and did all these sports and stuff and he stayed there during the day 10 til 3, I’d drop him up there and pick him up. He done all this archery, rock climbing and canoeing, they just change him on the floor...”*

This participation in these activities had been achieved through volunteers, who had managed his personal care needs adequately, but it is not clear if they followed safe manual handling regulations. Having or not having suitable changing facilities, paid and trained staff, affected the participatory opportunities that organisations could offer Matthew. Mum’s future ambition was for him to be able to do things without her being present, to improve his independence:

*“I think Matthew would love to be more independent with everything really but I think sport is his kind of his thing he likes to do and I think he would love to be able to do it on his own without me, because nobody else has got their mother there.”*

She felt that Matthew understood that other young people did not have their parent’s present, but with the present constraints with his toileting needs, this was limited. So, he displayed aggressive behaviour when Mum was present, suggesting to her that he was happier when she was not present. In Matthew’s case, his mother’s position seemed to affect his behaviour in a detrimental way, as his behaviour changed when she was present, to be more aggressive. Contrastingly, Matthew demonstrated that he could behave in an engaging manner at some of his RAs, but this was not consistent.

#### **4.12 Summary of Matthew’s case study**

Matthew’s case study has highlighted the opportunity for co-designing the adapted surfboard and his involvement in the adapted skiing group. These provided positive

emotional WB effects for him from his level of regular participation. In contrast to this, Matthew had some challenging behaviours when he was not appropriately occupied and stimulated, changing his storylines to show less WB benefits. The issues had been addressed at the respite centre to help him settle and there was now evidence of a more positive emotional WB effect from his participation there. Matthew's safe participation was limited to places that could provide support for his toileting needs. Care needed to be given in how activities were marketed via social media to promote participation for disabled children and young people.

#### **4.13 Summary of within case Participatory Group**

This chapter has presented the within case findings of the four case studies in the PG. There was some overlap of findings but some unique features in each case. The priority with the data was to give evidence of the storylines of the emotional WB impact from their level of participation in RAs. The key ideas to come from the PG were the innovative designs of equipment and the need to adapt these for appropriate indoor and outdoor environments, to create the participatory opportunities where the children and young people could be positioned, ready to participate in a RA. All reported that people in their communities did not know how to relate to and include the participants in arts and crafts activities and yet there was an expectation that they could be respected and included, if attitudes could be changed. Social media was both detrimental and positive in promoting the accessibility and RAs for disabled children and young people. The changing places toilets and mobile hoists were key facilitators for participation in RAs. A visual representation of these findings has been drawn to be able to communicate with the participants directly about the results. This is shown in Appendix 14 and was sent to the parents to show them that I had listened to their experiences and choices and sought to represent these visually for the children and young people benefit (Digicreates4u.com, 2018). This chapter outlined the experiences of the PG participants, who were positioned to actively engage in participation in RAs, and there were still some difficulties. The next chapter will present the three case studies from the LPG.

## **Chapter 5 Findings: Within case: Limited Participatory Group (LPG)**

### **5.1 Introduction**

This chapter will report the findings of the three participants in the LPG. Their pseudonyms were James, Bree and Poppy. The effort to participate was much harder for these participants, due to the level of complexity of their disability, and related issues, such as pain, pressure sores, dietary intolerances and epilepsy, which limited their ability to participate in RAs. Positioning theory will be applied as appropriate to each child's case, to highlight the social forces which influenced their level of participation, which determined their WB effects (Harré and Langenhove 1999). Their physical position was often compromised by lack of appropriate environments and equipment to cater for their complex needs, feeling overlooked and having reduced choices to change or influence their participation in RAs. Bree's mother's work patterns limited her participation, and she was on a waiting list for a disabled children's swimming group. They all encountered negative attitudes sometimes. The chapter will end with a summary of the LPG's findings.

### **5.2 James**

James was the first participant recruited to the LPG. James was fourteen years old and lived with his long-term foster mother (Mum) in a city. I met his Mum at the special school to explain my study and I went to meet James at home before data collection started, to interact with him so that my voice would become familiar to him during any observations as his level of communication was CFCS V. James had spastic quadriplegic cerebral palsy (GMFCS V), epilepsy and was gastrostomy fed. He was cortically blind but responded to light and dark. James loved sensory stimuli such as touch, taste and smell. He had developed a kidney stone and was managed by the palliative care team for this pain. Mum spoke of the importance of observing James's behaviours to interpret his pain levels. It was unusual to hear about a child with cerebral palsy being under the palliative care team, who reportedly would support him up to the age of twenty-five years. James had no verbal communication, but was able to indicate discomfort by grimacing, going red and having silent tears. Thus, I was not able to directly capture James's views, experiences and choices, instead relying upon his Mum to describe this for me. However, I did observe James once at a play-scheme during the data collection period.

James was unable to weight-bear and required hoisting for all changes of position such as from the bed to his wheelchair. Due to James's complex level of disability he was not able to initiate his own choices, but rather responded to what opportunity was provided to him, in an engaged or disinterested manner. James had to be physically positioned in his wheelchair in a space where he could participate in a RA. He had previously had surgery to put spinal rods into his back to manage his scoliosis, this now limited his participation in physical activities such as trampolining, which he had previously enjoyed. Also due to his re-dislocated hips, he had been unable to learn to ride a trike, which he had tried in the past. Two interviews were carried out with his Mum, three months apart, she wrote in the diary and sent me pictures of his RAs during this time. I took photographs and wrote field notes up from my observation. During the study's period, James had ankle surgery for a pressure sore. This took him a while to recover from, restricting his ability to participate in RAs outside the home such as swimming, which he did in school.

In my analysis of the data, I identified two main themes of Internal: Personal Well-Being and External about Attitudes towards Disability, which are shown in Table 6.

**Table 6: James's Themes and subthemes**

Theme	Subthemes
Internal: Personal Well-Being	Observed behaviours Intentional play
External: Attitudes towards Disability	Behaviours in public spaces Reasonable adjustments explored

These themes and subthemes will now be expanded.

### **5.3 Internal: Personal Well-Being**

#### **5.3.1 Observed behaviours**

Mum reported that she had to observe James's behaviours, to be able to gauge his WB:

*"So I go on how he's behaving. He was really uncomfortable Saturday night. He'd gone bright red and had a funny rash which is when he gets hot and bothered. And he was doing this with his hands (shows flapping), sort of agitated. And if he held your hand, he squeezed really hard and then had tears."*

Thus, James was communicating by his non-verbal behaviours that indicated distress on this occasion. James was only able to respond to his environment with the support of pain and antiepileptic medication. Managing his epilepsy was a

challenge, which limited how far Mum was prepared to travel, always carrying his emergency medications. However, despite these limitations, Mum found RAs with a sensory emphasis, which promoted James's WB.

When asked how James expressed happiness Mum said that he did smile, but if he was bored, he would close his eyes and pretend to be asleep. Most of the time he was calm and not moving but needed a person to engage with him through touch and sound, to compensate for his limited vision. Mum reported that his calmness had a positive impact upon others.

*"James's very placid. He's so laid back. Sometimes that can be a bit of an issue because you can't quite motivate him to want to do things. Because he doesn't care. But then to be quite honest after you've been with him a while you feel exactly the same. (Laughter) He has a calming effect on you."*

Indeed, at my initial visit to meet James he responded well and engaged with the shaving foam activity that I carried out with him (see my field notes Appendix 6). I carried out this activity based upon Mum's advice, to get to know him where a verbal conversation was not possible. James spread this shaving foam over his tray and clothes with his right arm. As I observed James, he seemed quite unresponsive at times, having small fits. I spoke to him during this activity with a calming voice, this was to help him orientate to me, in preparation for my observation. Mum had emphasised that I should not be carrying out research with James before I had met him. However, as James was cortically blind, he would not recognise my face, but perhaps my voice at the observation. Thus, this was reassuring for him when I was present at the observation, by Mum's invitation.

In their local area there were accessible walks, but having a WAV meant they could get out to other areas, as Mum's quote shows:

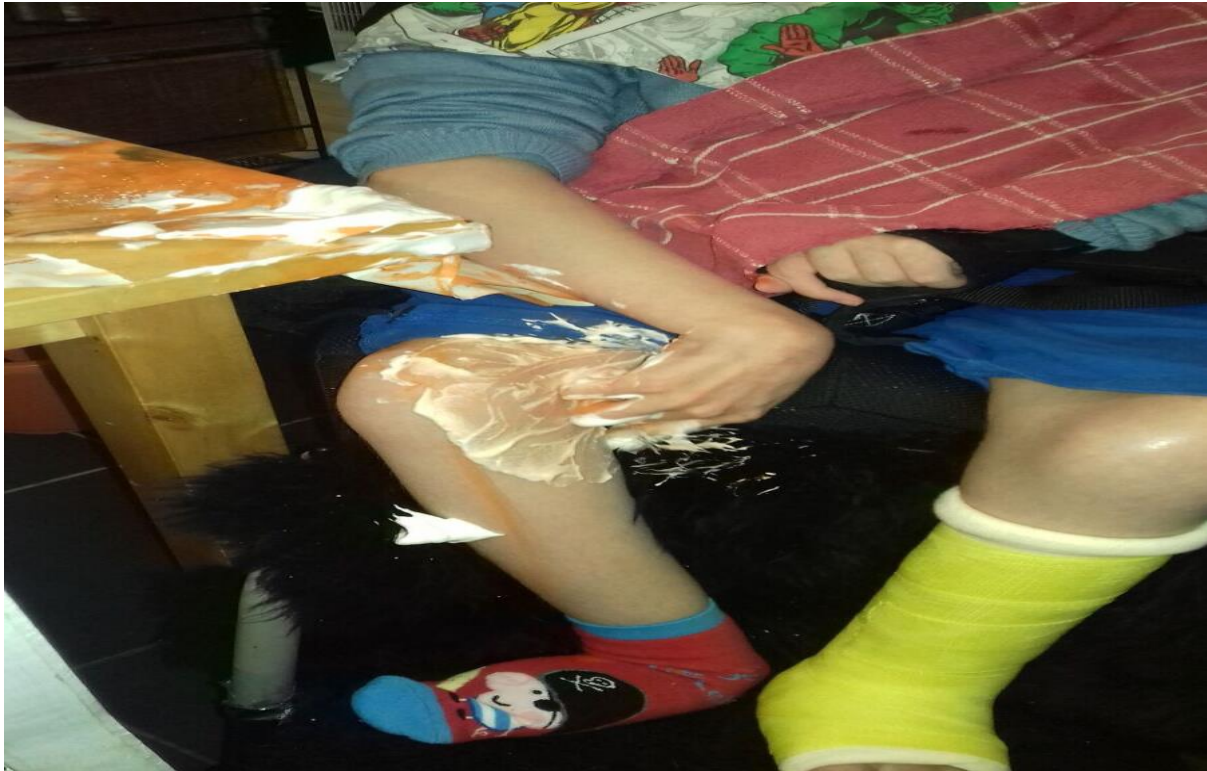
*"So, we can walk there. Or, I'll take the car and go up to the canal ....and that's a nice walk because it's flat. Because then you get the bird sounds, you've got the trees moving, you've got the water. And there's some horses there so sometimes a neigh as well, so that's quite nice."*

James enjoyed the touch, sounds and smells of the birds, trees, water and horses as Mum was able to anticipate his sensory needs and take him to places, he would enjoy thus increasing his participation in the environment. It was evident in James's data that he responded to nature, when given the opportunity to be positioned, where he could hear and smell things around him. Thus, James needed to rely upon

wider sensory experiences when being pushed in his wheelchair to take in the surroundings in the local area.

### 5.3.2 Intentional Play

As James could not speak about his choices for play, the effort he put into engaging with a RA offered to him, was perceived as intentional play. This is illustrated by Figure 34 where James is shown participating in a sensory activity with paint and shaving foam.



**Figure 34: James participating in sensory activity**

In Figure 34 James is seen enjoying feeling the shaving foam in his hand and smearing the orange paint onto his leg. This intentional behaviour was interpreted as a positive activity for him, so potentially enhanced his WB. If he did not enjoy this activity, he would not have participated. This reflects the choices that Mum made available to him for RAs, that she anticipated he would enjoy, thus advocating for his needs and positioning him ready to participate, if he wished. Her insight into his choices was invaluable to gain understanding about his emotional WB. Mum actively chose to position James, in order that he could engage, within the capability of his motor and sensory abilities. Thus, without her insight, James's WB could not be reported.



As Mum was perceptive to James's needs, she sought to vary the different environments that he could participate in. Figure 35 shows James during my observation of a sensory story, where he was assisted to touch the drum, which represented a storm.



**Figure 35: James during sensory story**

Mum positioned his hand onto the drum for maximum effect. My observational field notes related to this image reported that '*James does not respond vocally to the singing but smiles in response to P. playing his drum*' thus suggesting a positive emotional WB impact for James.

However, James was selective and did not like all music genres and had become distressed during an orchestral carol concert. James responded well to Touch Therapy which is a sensory based activity with music and lights. James did this in school and sometimes in the holidays, but this was an expensive activity costing around thirty pounds per session. The expense of this meant that it was not something they could afford to do every week, thus reducing his participation and the potential WB effects.

This section has explained the internal factors that gave evidence from observed behaviours and intentional play about James's emotional WB. The next section will

develop the external factors that related to James's complex level of disability, his ability to participate in RAs and attitudes towards disability.

## **5.4 External: Attitudes towards Disability**

### **5.4.1 Behaviours in Public Spaces**

As James was gastrostomy fed to maintain his body weight, it was interesting at the summer play-scheme to see him being fed outside. This would be unusual to see in a local park area, but in this space, there were several families doing the same and no one seemed perturbed by this, as it appeared acceptable behaviour in this context. This is shown in Figure 36.



**Figure 36: James being gastrostomy fed outdoors at the play-scheme**

James can be seen in Figure 36 enjoying the music time whilst being fed, thus participating in a meaningful activity for him. In Figure 36 the hoist slings can be seen between his legs as poignant reminder that he needs to be hoisted for all changes of position. So, should he have needed a nappy change during this activity, a mobile hoist would have been required, which was not available. However they purposively only stayed a few hours, to help avoid the need for this. Thus, James's participation in RAs was restricted by his toileting needs.

#### 5.4.2 Reasonable adjustments explored

There were some barriers to his wider participation, particularly not having enough dropped kerbs to be able to get James's powered chair up and down, as Mum's diary quote shows:

*"I mean even the disabled parking at P. Park, the kerbs like that (indicates high) I can't get the wheelchair up there, I have to walk round, on the road until I find somewhere. So, I'm in the traffic trying to find somewhere to get up, it's not safe. Disabled parking is a pain there as the kerb there is too deep, I can't get his electric wheelchair up or down."*

This quote illustrates that even to get James's powered wheelchair out of the car and up the kerb, was not straightforward. A key concern was if someone parked behind the WAV that she could not then get James back into the car. She would not be able to open the boot behind with the 3 meters clearance required, to drive the powered chair up the ramp. This reflects the design and limited availability of dropped kerbs and designated parking spaces for wheelchair users who need to be positioned to gain access to RAs.

Another barrier was lifts that had broken down which occurred at two-day trip places, a museum, and a castle. Access was given via a service lift at the museum, however using this lift was not easy, as it was not really designed for a large, powered wheelchair as Mum's quotes show:

*"Went to museum to see dinosaur exhibition with friends. Lift not working so needed to ring and be admitted through staff entrance (Diary)*

*... And I don't think people realise that you are that reliant on it. They think, oh yes, there's an alternative, but the alternative isn't as easy as the other one, because it's a very small lift, so it's really hard to actually get in there with a wheelchair and my grand-daughter..." (Interview).*

The museum was a successful trip as Figure 37 shows James was able to get close to hear and touch the dinosaurs, thus being positioned close to these artefacts.



**Figure 37: James at the dinosaur exhibition**

However, James was not able to visit the castle as the lift was broken and was not fixed during the data collection period. Mum felt that it was such a lot of effort to find out if venues had an accessible lift that she wondered why people bothered sometimes, as her quote illustrates:

*“I thought well, you (Castle) should know if your lift's working and if it's accessible for a wheelchair.....I haven't heard back so we've arranged to go somewhere else now for Christmas anyway, but you just think, well, is it worth bothering? It's a wonder people don't go out.....It's just stressful doing anything!”*

James's mother expressed how stressful it was going out, to participate in RAs, which revealed the added emotional distress when appropriate adjustments were not made for his complex disability. Therefore, this had a negative impact upon the mother's WB but this also had an indirect effect upon James's WB, as he could not be positioned to create a storyline about the WB impact from his participation.

A local garden centre had improved recently, with widening the pathways, to enable his powered wheelchair to get through and turn. This enabled James to see the lovely Christmas light displays and hear the birds, which he liked. In contrast to this, a farm they had visited had fences at his eye level, meaning he could not view the animals:

*“We went to G. Farm once and all the fences were across his eye level so all he could see was fences, he didn't see anything in them....I think people need to be more aware of what heights you put fencing and things, or have Perspex or something, so he can see through it, because he does like the fish tanks at the Garden Centre because they are quite big and he can see all those.”*



Mum expressed how frustrated at times she gets with James's lack of choices for RAs.

*"...he is restricted with what he can do and that really frustrates me at times. Because I think there should be something else he can have a go at..."*

Mum actively looked for opportunities that James could appreciate even if his physical participation was limited. He was able to join in bowling due to the adjustment with ramps for the bowls. This is highlighted in Figure 38 where James is seen behind the ramp having been assisted to roll the bowl down the slope towards the skittles.



**Figure 38: James at Bowling**

Mum also had found that some people could make the reasonable adjustments to include him in craft activities as described below.

*"Yeah you have to think outside the box sometimes. We went to a very nice country fayre once and he built a bird box with a hammer. That he was helping James to do it. And he loved it..."*

Mum was intuitive in finding activities for James. She was really impressed with her local vet who made a ramp for James to attend with her when she attended with her pets. This contrasted with her GP's surgery, where access remained restricted if she had an appointment in an upstairs room, which meant James would have to be left unattended downstairs, which was not acceptable due to his unpredictable fits.

Mum reported that when booking for the theatre or the cinema you cannot book online like everybody else, you must phone up, so she questioned why this had to be different:

*“... when you book anything, you can't just book online for anything if you've got wheelchairs, you have to phone, which I can't understand, in this day and age, why you can't just book online and have a map of the auditorium where the wheelchair seating is and then you could pick, I want Aisle 5, Seat 10..... even with the cinema, you can go and just turn up and hope that there's a wheelchair space, otherwise you have to phone through, which really annoys me, because in this day and age, with all technology, you should be able to do it online like everybody else...”*

This example highlighted the way in which many disabled people are treated differently when online booking is available for everyone else, it was not clear why this technology was not capable of managing their booking.

James had pureed food so if the family ate out, he could have food mashed up which meant he could be included at accessible restaurants. Mum's comment was that accessibility was good at restaurants if they can get through the door and sit at a table. He was described as very happy on one recent occasion:

*“..we went out for meal a couple of weeks back, and he was really happy.....He was laughing his head off. He was so happy, it was lovely to see him that happy...”*

Thus, the data had shown that James had happier periods when he laughed out loud, when able to participate in RAs.

There were also some future ambitions for participation. One aspect that Mum felt she would like to do, was to get onto a beach, especially as it would give him the sensory feedback that he enjoyed:

*“...I'd love to be able to get on the beach. Because I miss that. I like walking through the waves and things would be really nice if we could do something like that. Because he'd get the sensory feedback about that and it's the fresh air. But, I can't get him on the beach ..... There's a ramp down but your electric wheelchair sinks.....They have got beach wheelchairs, but they haven't got a hoist. So, I can't get him into one.”*

As Mum showed, not having a mobile hoist was a barrier to getting him down onto the sand and into the sea water. It was also apparent at a human-made beach area created in the summer that it was not designed for children in wheelchairs. It was not just the design feature that was a barrier but also the negative attitudes:

*“I mean you can take the children, and they can walk around and look at everybody else enjoying it, but they can't get into the sand, they can't get to play with the water, in fact, that's even worse than not having anything, just sitting there and watching..... But the staff weren't very nice.... Because I had*

*a friend that went down with her little boy in his wheelchair and they were quite rude to her...”*

These apparent negative attitudes were off putting, and the lack of hoist was not just a feature at the beach but also on a nature trail as the diary entry showed:

*“F. Park, did a nature trial with RSPB. They have a wheelchair you can use but no hoist to transfer, so not much good to us...”*

Thus, the provision of these RAs was focussed on those who did not have disabilities.

Changing place toilets were also not easily found, but Mum’s expectation was that they would not be out that long due to his epilepsy, so she would not need to change him. However, some key public buildings did have this facility such as the Senedd. Hydrotherapy pools, other than the one at James’ school, were not easy to access, however as James had ankle surgery, this was contraindicated during the data collection period. Thus, Mum’s expectations meant that she worked within the limits of what was available, as it required so much effort to try and change the attitudes of people and related environments. This did restrict James’s opportunities and limited his participation in RAs, reducing the storylines about the potential WB impact from his low level of participation.

## **5.5 Summary of James’s Case study**

James had demonstrated areas of participation in RAs that showed he enjoyed being involved. Despite his pressure sores, surgery, and epilepsy he was able to be positioned in the community and enjoyed the countryside. His sensory preferences were accommodated for in the environments where he participated. The limitation of not being able to use online booking for the theatre or cinema spaces illustrated how the main provision is geared for those without disabilities. There were also areas which he could not participate in, due to the need for a mobile hoist such as at the beach and the nature trail. Thus, not being able to be positioned in such equipment, limited James’s participation in RAs. Unreliable lifts limited his participation in older buildings and made planning trips out more complicated than they needed to be. Although the lack of changing place toilets was not a factor that influenced Mum’s decision to not go out, having more of those facilities would mean he could stay longer at RAs.

## 5.6 Bree

Bree was nine years old at the start of the study, she lived with her Mum and Dad, older stepbrother, and younger sister in a city. Mum was recruited to the LPG from the family support worker at the special school that Bree attended. Mum described it as difficult for Bree to join in mainstream activities, because her social interaction and mobility needs were different to her younger sisters. So, although she was recruited to the LPG because Mum stated participation was hard to achieve, in fact she did participate to a similar level as some in the PG, by the end of the study. Perhaps Mum's perception was that she could not participate alone, like her sister. I arranged to meet the family at home just before the summer holidays. Bree had diplegic cerebral palsy (GMFCS III) with ataxia, which meant she was unsteady on her feet and she also had a hearing impairment. Bree could walk with a walking aid, but was unreliable in her mood, so would not always cooperate, which meant taking her out could be a challenge. Bree was being toilet trained, but she still wore nappies. Mum changed her standing up, where Bree could hold onto something stable when they were out, thus they did not need a changing places toilet. Bree used her Go talk App on her iPad to choose her play activities. Although she vocalised sounds, she only had a few reliable words with those who knew her well (CFCFS IV). Mum worked part-time including some Saturdays, this meant regular participation in RAs was limited to some weekdays after school.

The themes and subthemes which I identified from the different data sources are shown in Table 7.

**Table 7: Bree Themes and Subthemes**

Theme	Subtheme
Opportunities for play	People who support, Accessible Environments
Emotional Well-Being indicators	Sensory processing, Barriers to participation

These themes and subthemes will now be described.

## 5.7 Opportunities for play

### 5.7.1 People who support

A key person who had signposted Mum to suitable RAs was a special needs health visitor, now retired, but not replaced. When asked how Mum anticipated what Bree might like to participate in, she spoke about trying things out:



*“Well you just go and try it and see if she likes it (laughs). Because I found out about touch therapy by going to a meeting for parents who had children with special needs, organised by the ‘Well Child’, as part of that first meeting they had somebody come from the touch trust to talk about what they did at after-school-club and he sort of did a mini session, and I thought that she'd like all the clapping, (laughs) because she loves clapping and that form of praise, she gets really excited about clapping and I thought it would be something different to do, to get out of the house with them and I think that was one of the first things we started and it corresponded with us getting our first direct payment helper.”*

The Well Child organisation<sup>4</sup> had provided Mum with information about the touch therapy, which was aimed at disabled children and young people and their siblings. The local authority's 'Index' magazine also provided information about new opportunities. A course called 'The incredible years', run by the school, was reported as helpful to learn how to reinforce positive play for Bree, to reduce her 'throwing toy' behaviours. Bree was only able to join in horse riding and brownies by having a PA, which was funded by direct payments. Bree also had two term-time student volunteers, who varied with what they could support her in, but she interacted with them in a positive way:

*“Yes and you can see when she comes back she's beaming and she's ‘chatting’ to them because she doesn't talk in school, it's nice that she's had that opportunity to engage that way with them.”*

Thus, the student volunteers enhanced Bree's ability to participate in RAs. So, the choices for Bree were enriched by the people who supported her to participate, both by physical positioning at the activity and facilitating communication. These agents provided the social forces that influenced Bree's storylines, which gave insights into her WB responses.

Mum was always looking for both health and WB effects from activities, for example, she saw balance improvements after horse riding:

*“School had taken photographs of her at horse riding and she had a huge smile on her face, and I thought well she's got to be enjoying that and you are getting this effect of improved balance, it's like win, win isn't it?....She's enjoying it and at the same time it's helping her core and her stability and her balance.”*

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<sup>4</sup> The Well Child Organization is a charity that aims to enable CHILDREN AND YOUNG PEOPLE with long term disabilities to thrive <https://www.wellchild.org.uk/>

Clearly Bree was engaged in participating in horse riding which as well as improving her balance, it had a positive emotional WB effect for her as interpreted by Mum, from her smiles and engaged behaviour. This was, however, only possible with PAs to support her physical and communication limitations.

### **5.7.2 Accessible Environments**

During the study period the family had hired a trike, which Bree really enjoyed as the multiple diary entries show:

*“We went to CH where I had an assessment for a bike. They decided a Tom Cat Trike was the best one for me I went for a ride along the caravan site and I really enjoyed it... In the afternoon my mum, dad, sister and I went to CH where I rode the Tom Cat trike for an hour, I had a brilliant time....After school I went to after-school club where the people from CH had brought my Tom Cat Trike. I had lots of fun encouraging the PA's to make me go faster!”*

From these extracts Bree was also enjoying this new activity at the after-school club, as well as the cycle hire centre. Mum commented how surprised she was at her cycling achievements:

*“We went into the park, down to the river and back...(laughs)...yeah she surprised me, I wasn't sure how she would take to it ....but the last time we went, I was trying to get her to do some of the pedalling, and she was, it was more than just the momentum of the bike, you could feel her actually putting more of the effort in, not a clue about steering yet (laughs).”*

This new activity for Bree had enabled the whole family to participate together in an accessible environment in something that she enjoyed. As well as the physical benefits of pedalling the bike, it had a positive effect upon her emotional WB. Thus, by being positioned to try this new activity, Bree had shown her own agency in participating successfully and having fun with her family.

Mum also reported that Bree had enjoyed a ‘relaxed’ orchestral performance which she felt enabled Bree to express herself freely:

*“It was brilliant, that was really good ...really, really good and she loves music and I think they should do more...everything from start to finish and they had somebody signing for those kids that needed signing, it was just so inclusive it was really....they had pupils come on from one of the valleys special schools who play instruments, they had been practicing with members from this orchestra. That was amazing, that was really lovely to see that and you could get up, you could dance at the end they sort of came into the audience with some of these musical instruments so she could have a go with it, it was just really well thought through and organised...”*

This was the first time Bree had experienced this and as it was so accessible, she could participate through music and dance. She also did this at touch therapy, where I observed Bree responding to music and subtle lighting as shown in Figure 39. Bree was observed clapping and dancing during the hour's session and appeared to enjoy herself, although tried to chase her sister first to cuddle and kiss her, then to pull her hair. It was reported by her carers that when the family were not there with her, Bree behaved differently and was calmer. Multiple diary entries reported how much she enjoyed the percussion and dancing.



**Figure 39: Touch therapy room and Bree at touch therapy**

Bree can be seen in Figure 39 moving in her preferred manner of bottom shuffling to collect paper leaves which she then tried to push up her nose and eat. She still needed close supervision in all activities.

Another participatory experience was reported in the diary of bowling:

*"I enjoyed the bowling and had a big smile every time it was my turn. I managed to score 80 points and finished 3<sup>rd</sup> in my team of 6. One of my brownie friends helped me to get my ball and I pushed it down the ramp"*

Thus, Bree was assisted by a brownie friend to participate in the bowling, showing the positive social forces that others can have to influence WB.

I observed Bree's behaviour at brownies, where she became restless and started banging the table and throwing things, as she was seeking attention. I saw Bree

supported with all the craft-based activities offered, as shown in Figure 40. When she was distracted the PA took her for a walk.



**Figure 40: Bree at Brownies craft table and assisted walking**

Mum also felt she benefitted socially from seeing the other children at brownies as her quote illustrates:

*“I like her going to brownies because I think she gets to see other children who are walking and talking....in the hope that she will sort of socialise, or at least take it in...”*

The social benefits of mixing with other children did appear to help Bree to feel included, but without the PA, this participation was not possible. I did hear her vocalising, but apparently in school, she was completely silent. However, it was uncertain whether she would move up to guides in the future, due to her communication and mobility limitations. It possibly would be challenging to accommodate Bree with older girls, when her level of attention, expression and mobility restricted her capacity to comprehend and participate in more adolescent RAs.

Holidays with Bree were organised with the family's touring caravan. Securing her in a bottom bunk bed required innovation to ensure she could not climb out. Occupying her on the long journey was a challenge as she got bored without the internet:

*“Yeah, it really is challenging and lots of putting her CD’s on, that works for a while and then she gets bored and then gets like that grabbing ‘L’ again ...but then you’re almost rewarding the bad behaviour cos as soon as she gets grabbing her sister, you give her something to eat or putting her music on ...”*

It was hard for her sister ‘L’ who had to endure this hair pulling and grabbing, which I witnessed on my initial visit and at touch therapy. The family were working on modifying Bree’s behaviour to reduce this hair pulling behaviour by a positive reward chart.

Once they had arrived in a new holiday area, trying to find accessible parks or walks was not straightforward as Mum commented:

*“...but when you look at all the play equipment they have got, if there’s three things Bree can go on, that’s a win (laughs) basket swings are really good but then you have to lift her onto it, so it’s a bit of a manual handling nightmare, cos she really likes those and they can go on together. See saws, and there are some roundabouts suitable if it’s got a seat on it. Some aren’t and she loves the slide but quite often the way you get up to the slide isn’t suitable for Bree...if it had a ladder she could do that...you know they make them a bit fancy these days and they’ll have like a climbing wall (laughs) or a rope and that’s absolutely no use whatsoever...”*

Thus, having an accessible area where she could play with her sister ‘L’ was helpful for the family, but were hard to find in new areas. Bree also loved fast rides at theme parks and so far, has been able to try everything that she was tall enough for. Bree enjoyed the thrill of moving fast on rides, as this potentially gave her a positive emotional WB feeling. The final opportunity was trying trampolining, which was at a birthday party, but Mum felt they did not have a spare evening, to fit this new activity in. Thus, Mum’s working pattern was also a limitation to Bree’s participation.

## **5.8 Emotional Well-being**

### **5.8.1 Sensory processing**

Bree’s preferred way of moving was bottom shuffling, but this had previously led to a pressure sore in her buttock area. Mum felt she did not feel pain in the same way as other children as Bree had not been aware that this sore had developed as her quote highlights.

*“She doesn’t feel pain I don’t think, like in the same way that normal children do. She will have an injection, you know, she won’t bat an eyelid, she doesn’t cry. She was in nursery and they let her on the floor for free play and she bottom-shuffled and her dress and tights and she’d shuffled so much she*

*wore a hole in the tights and her skin was dragging along the floor, she got a really bad friction burn, and they didn't realise until they changed her and she ended up with a giant wound and we had to have special dressings and she had a hole basically where she'd bottom shuffled....It didn't bother her. She was still trying to bottom-shuffle. That was really, you know how that cannot be causing you pain?"*

Thus, Bree's pain response was not protective to prevent this pressure sore. The prevention of the reoccurrence of this pressure sore was managed using an innovative scooter, but this was only useful inside the house on a smooth surface, limiting Bree's outdoor play opportunities on uneven ground (Scoot, 2019).

Mum described Bree as a happy child who:

*"...runs along in her walker and she smiles. She also shouts but you can tell by the tone of the voice whether she's happy or not.....I think we're really lucky that she's generally a pretty happy child.....and even if she's not, you just have to sing something to calm her"*

Conversely, when she was not happy:

*"Well she'll let you know if she's not happy...She whinges and she shouts and if she's in her walking frame, she won't move."*

Thus, Bree can demonstrate her emotional WB state by the tone of her voice and choosing to move or not when positioned in her walker, determining her own agency.

### **5.8.2 Barriers to participation**

All of Bree's participation opportunities would not have been possible without the six hours of direct payments and employment of a PA to support her attending RAs such as the touch trust and horse riding without her sister. During the study's period this PA had to finish for personal reasons and finding someone new was proving a challenge. This was because it was part-time after school hours which did not seem to attract suitable candidates. So, despite living in a city, where potentially there are more people to employ, it was still difficult to recruit to this part-time work.

A key barrier to Bree's participation was being on a waiting list for a disabled children's swimming group. Bree had been on this list for over a year and was 19<sup>th</sup> on the list. Bree loved the water, and this had made Mum feel 'despondent' as recorded in my field notes from the initial visit. A good thing was that by the end of data collection she had just been offered a place to start this swimming group.

Another barrier to participation was access to suitable holiday play-schemes as Bree fell between criteria for what she could access:

*“... The council children’s play officer, she did say what they can do is give you funding to have a one-to-one to send Bree to a regular play-scheme. But when I spoke to the regular play-scheme people, they basically didn’t want to take her because they don’t have changing facilities and because she can’t walk, would they be able to get her on a bus, cos they go out for day trips, how would they manage to get her up and down stairs on the bus and wherever they go how do they know if there would be suitable changing facilities? So basically, I don’t want to send her there to people who don’t want to look after her (Laughs) ....and I think there is a summer scheme that runs at her school, but Bree is not disabled enough to attend it (Laughs) I think the ones that go to her own school’s summer scheme are the ones that need nursing care.....So she’s not disabled enough to go to her own school’s summer play-scheme and she’s too disabled to go a mainstream play-scheme (Laughs).”*

I interpreted Mum’s frequent laughing during the interviews as a coping mechanism, when the situation was emotionally difficult to explain. So, Bree had needs that could not be met at a mainstream play-scheme, but she missed out on her own special school’s play-scheme as she was not disabled enough. The policies of excluding incontinent children are influenced by staffing ratios, where extra staff would be required to meet these needs, as well as needing a private accessible changing area. Bree’s limited mobility created a barrier to participation in RAs as she needed one-to-one supervision due to the risk of falling. These barriers gave Mum the negative perception that people did not want to look after her. This may not have been the case as the staffing ratios are determined by health and safety requirements. As the lack of support perceived by Mum was distressing for her and limited the storylines for the WB effect from Bree’s limited participation in RAs.

## **5.9 Summary of Bree’s case study**

Mum’s perception was that Bree had limited participation opportunities compared to her able-bodied sister. She was only able to participate in RAs due to direct payments funding for a PA to support her concentration and mobility needs. The temporary student volunteers were a bonus. The family had enjoyed a new activity of adapted cycling during the study that had been brilliant for them all to do something together. Bree had demonstrated her own agency here by joining in. Respite overnight was described by Mum as ‘amazing’ and this facility also encouraged participation in RA, including cycling. Finding accessible play spaces was difficult in

new holiday areas. So, although Bree's Mum perceived participation in relevant RAs to be difficult, there were some highlights where it had worked well. One of these had been the relaxed orchestral performance where Bree could express herself freely through clapping and dancing. The final opportunity of the disabled swimming group place potentially would enhance the WB for Bree, as she loved water-based activities.

## 5.10 Poppy

Poppy was the final case recruited for the LPG. His parents chose the pseudonym Poppy, (usually a female name but in this case referred to a male participant as the parents would have given him this name if he had been a girl). He was aged nine years and lived with both his parents in a coastal town. Poppy had diplegic cerebral palsy (GMFCS IV), with fluctuating low muscle tone and some autistic tendencies. Poppy had atypical cerebral palsy and was having further investigations. This included dietary intolerances and a previous two-year period of illnesses, reducing his participation in RAs. Poppy had been learning to use Eye-Gaze Technology to increase his receptive and expressive vocabulary. However, Poppy was inconsistent with this and so was currently unable to have one prescribed as a communication aid (CFCS IV). I observed him hyperventilating and heard him shouting to express himself, sometimes with joy and excitement, but I did not hear any clear words during my visits. Thus, it was not possible to enter into a dialogue with Poppy about his views, experiences and choices. It was necessary to observe his communication, to be able to establish his emotional responses, when he chose to engage with the RAs, people or the environments or chose not to. It was also essential to capture Poppy's parent's opinions to gain their insights into his emotional WB.

The themes which I identified from Poppy's case are shown in Table 8.

**Table 8: Poppy's Themes and Subthemes**

Theme	Subtheme
Intrinsic: Idiosyncratic ways to communicate Well-Being	Non-verbal communication to express emotion, Poppy's behaviours that challenge, Technology assists choices
Extrinsic: People's attitudes towards disabled children	Being treated differently, Adapted equipment and environments



These themes and subthemes will now be expanded.

## **5.11 Intrinsic: Idiosyncratic ways to communicate Well-being**

### **5.11.1 Non-verbal communication to express emotion**

Poppy's non-verbal cues and behaviours were key to understanding his emotional WB. It was hard to know what Poppy felt, but he was described as happy by his mother. However, he was sad when unwell with stomach pains, which were frequent and came in bouts of weeks at a time. Mum reported when Poppy gets agitated, he starts to rub the side of his chair, hits his head, and then starts moaning. These behaviours were seen if he was in pain or did not get his own way. Water was shown to have a calming effect upon him and would keep him occupied for long periods. An example of this was illustrated in the diary, supported by Figure 41:

*“Poppy had more water play in the kitchen sink, standing helping me wash some dishes and then throwing the bowl and the water all over the kitchen. He hasn't wanted to do this for a long time, it used to be something he did every day. He loved playing in the water, he was stood at the sink splashing for over an hour... It has been very calming for him and also distracted him from the pain.... It was very good exercise for his legs and his balance”*



**Figure 41: Poppy standing by the sink for water play**

Thus, Poppy enjoyed and was calmed by water play, as well as this helping his balance development. Poppy chose to participate and continue with this water-based activity for over an hour, thus giving evidence of his own agency, to choose to stay engaged with this home-based RA, that had been initiated by his mother. This indicated a positive emotional WB response and showed increased participation at home, where he seemed happiest.

### 5.11.2 Poppy's behaviours that challenge

I saw some challenging behaviours during one observational visit at school when Poppy was frustrated with the Eye-Gaze technology. This is shown in an extract from my field notes:

*“Poppy is huffing, puffing and shouting and hyperventilating, he places his hands on his ears and hits his head with his right hand. He lurched forwards flexing his body in half in his wheelchair, then sitting upright...”*

This type of behaviour had previously been captured during the school's observations of Poppy, using the Leuven scale of Well-Being and involvement. The school took this evidence from the non-verbal children every six months, by a classroom assistant observing them for a week. In Poppy's case, some data were missing due to his illnesses, his data is shown in Table 17 (Appendix 18). It can be observed from Table 17 that Poppy's emotional WB had previously moved from moderate (2) to good (3.8), the point of data collection. However, it was difficult to record during my observations how Poppy felt, due to his lack of verbal communication and inconsistent body language.

Poppy himself was not bothered about playing with other children and did not like them invading his space, thus he used his agency to disengage and restricted his storylines of participation with others. However, the difficulty of other children knowing how to play with him was an unresolved issue as Mum described:

*“....We were saying that he's not really bothered with other children, to play with other children ....they don't want to play with him....they're not interested, because he can't do what they can do.... they just run around playing hide and seek and things which he obviously can't do, but they don't bring themselves to his level...”*

Whilst it can be hard for children to know how to relate to disabled children, it may reflect their own parent's limited experiences to be able to guide them. Alternatively, it could be the non-verbal body language which Poppy portrayed which discouraged engagement with him, as this is a challenge for children to know how to interpret and respond to this.

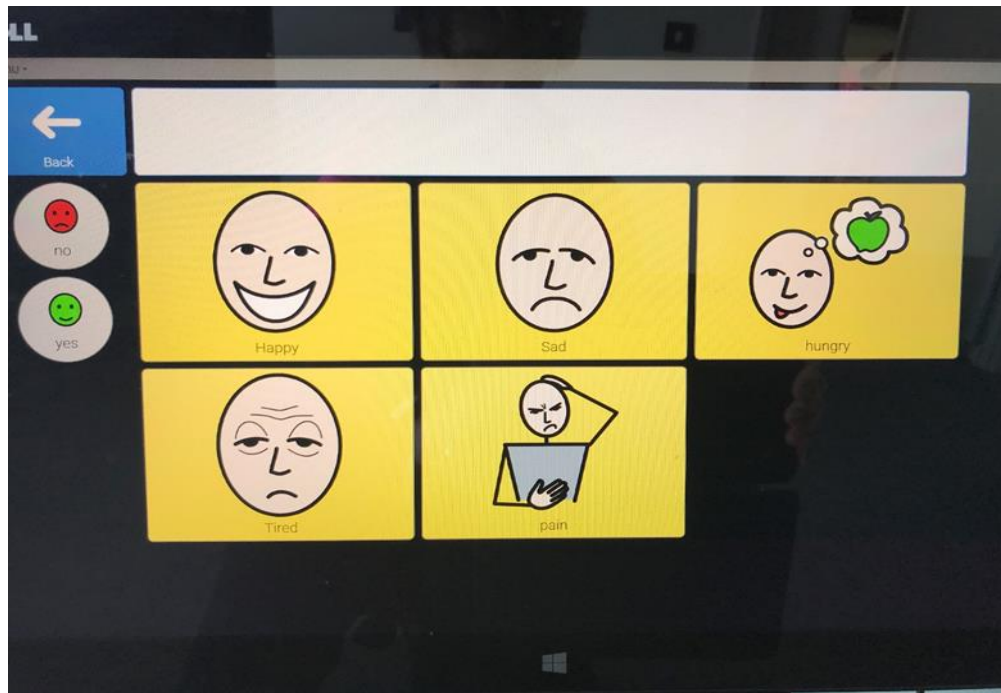
### 5.11.3 Technology assisted choices

To help develop his communication and social skills, Eye-Gaze technology was being used to help him choose activities. I was able to see the emotions page that had been set up. It was reported that he had chosen 'tired' and 'sad' when his

parents had recently been away. This was confirmed by Mum in the second interview:

*“...then the last few days he was really grumpy and really sad and when he was in school... he was in his Eye-Gaze, they were doing emotions with him, he kept picking sad all the time, he's never done it before....they said they think that he had started to miss us....”*

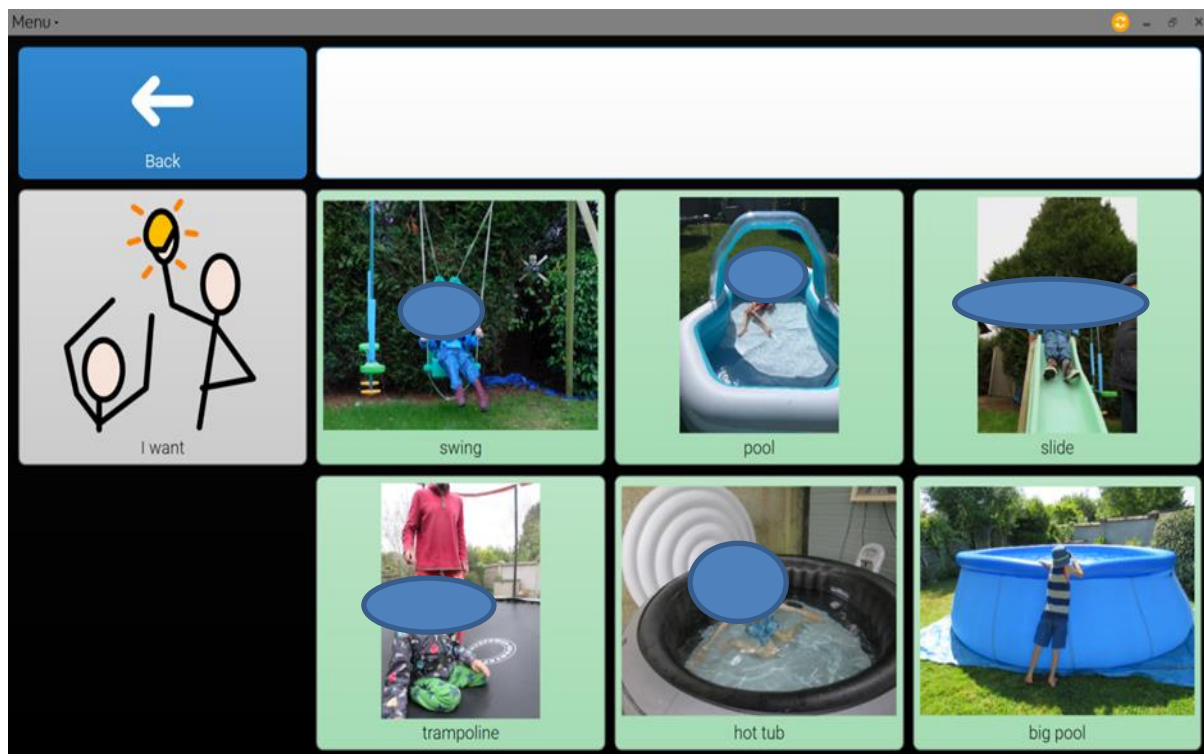
The emotions page from Poppy's Eye-Gaze is shown in Figure 42.



**Figure 42: Poppy's Eye-Gaze choices for emotions**

During my observation, Poppy was seen to glance at this screen which was set up to respond after 0.8<sup>th</sup> of a second. It was not clear from my observations how he was feeling other than being restless with his arms and legs, which could have been involuntary movements. The technology teacher did not know if he was bored or choosing not to engage with the Eye-Gaze, thus making it difficult to interpret his behaviours. Thus, it was not possible to state with confidence what Poppy felt emotionally, it was a tentative indication of his possible sad reaction, that the technology helped him express.

I observed Poppy choosing from the RAs on his Eye-Gaze screen in school, as shown in Figure 43. The family had got everything set up at home for him to participate in these activities during the summer months.



**Figure 43: Eye-Gaze screen about choices for Recreational Activities**

However, it was more challenging in the winter months, to participate in these activities in their garden and so Poppy's participation was restricted during the data collection period (October-February), even though he might choose these from this activity page.

In summary, the evidence from Poppy included idiosyncratic ways to demonstrate his emotional WB, which showed his uniqueness and fluctuations in his responses. This variation in his behaviours makes it difficult to be certain about the emotional WB effects from the participation opportunities offered to him. The next theme will cover the extrinsic factors that impacted upon Poppy's participation in RAs.

## **5.12 Extrinsic: People's attitudes towards disabled children**

### **5.12.1 Being treated differently**

The parents found older people's attitudes towards Poppy harder to deal with as shown by their experiences:

*"Mum: We always found it was old people were the worst. I get really irritated and really upset about people staring."*

*Dad: Normally old people. Because of their generation, they're maybe well that child ought to be in a home... you'd take him out to places and you can't help but slightly worry what other people you think are going to think and then you grow in to it, you thicken up to it, and if anything I love it when he shouts, I*

*might join in with the shouting around the supermarket anyway and I'm overly shouting with him....."*

Poppy drew attention to himself in public due to his loud shouting and being in a wheelchair. This was his way of expressing himself, but it could be distracting for other people who did not always know how to react, to stare or ignore, thus reducing his potential participation in RAs. Dad was able to celebrate and join in with this, but Mum found it upsetting. So, the parental responses were not identical to the same situation, meaning they varied in their attitudes towards taking him out to public spaces, with Dad being more willing to do this.

In some situations, although they said they were inclusive, the organisers of RAs that Poppy did attend, did not behave in that manner, as Poppy's pottery experience showed from the diary entry:

*"Pottery at X Farm. We were a bit disappointed with this activity, we were sat just inside the doorway which wasn't very wide and had a big lip to get his chair over. We weren't offered an apron as the other children were. We felt very rushed and Poppy wasn't given very much time to do the activity in his own time. We were rushed out of the room before the activity had actually ended whilst everyone else carried on with their pottery.... Poppy did however enjoy the very brief pottery class...but it was really disappointing"*

It is difficult to know if the staff did not feel comfortable with how Poppy presented. They clearly treated him differently, not providing an apron or giving him enough time to do the pottery himself or be in the room with other children. It was unclear why this happened, possibly due to their lack of staff to relate to those with additional needs. Poppy can be seen in Figure 44 doing this pottery with Dad.



**Figure 44: Poppy and Dad at pottery**

It is hard to know if Poppy was emotionally aware of the impact of how he was treated differently, but his parents were.

Poppy's parents were also keen for him to have a go at more outdoor RAs and perceived that even his special school did not include the children in wheelchairs on as many trips as Mum's quotes show:

*"...when you look and you see the pictures it is always the same group of children. They don't give every child the same opportunity..... they concentrate more on the kids that are mobile, that are able to achieve, they have these disabilities and it just seems like, as long as they are able to achieve, they concentrate on them..."*

It is difficult to know the full reasons why Poppy did not get to go on school trips, it was alluded to that being non-mobile presented greater transport difficulties with his wheelchair. It was not clear why this was the case, or whether it was related to additional manual handling and/or toileting needs.

Whilst feeling his choices were limited in school, Mum was particularly frustrated about the lack of advertising for disabled children in the community:

*"But nowhere advertises, like you see they advertise sessions and things, but nowhere has got anything on there, or any sort of documents to say 'this is what we can do for people who are less able than others. Yes, we can help a child who can't talk, won't take instruction, or who can't walk'...."*

Thus, Poppy's level of disability did not fit easily into mainstream activities which is the dominant provision for RAs. To find out about accessibility at events did not just involve online booking but also a phone call to confirm:

*"Mum: When you book your ticket online, I'll look out for your name and then I'll put a note next to it saying that two adults are going to be working with him, so it is good, but it's sad that you do have to phone up in advance and let people know"*

So Mum was sad that this extra effort was needed and even then, there was no guarantee it would be successful. This leads onto the next subtheme about examples where adaptations had been made to the equipment or environments to facilitate participation in RAs.

### **5.12.2 Adapted equipment and environments**

Poppy could ride his own trike having started at the age of three with a local club.

Dad commented that:



*'...we thought it's a waste of time, he's not going to want to do anything here, we got him on the little bike and my God, he started pedalling didn't he? Like Oh my God, he's actually pedalling!!...'*

Poppy was now getting irritable on his own trike. It was not clear why this was the case, other than the bike was becoming too small for him now. It was difficult sometimes for his parents to interpret this irritable behaviour and they had to make assumptions which could have been incorrect.

At a farm event, Poppy had been unable to access a bat crawl due to the fence being too low. This was illustrated in the diary by Figure 45.



**Figure 45: Poppy excluded from bat crawl**

It was evident that this bat crawl activity was aimed at children who could physically crawl, and the fence was too low to enable him to get in with his wheelchair, thus limiting his participation. His parents were disappointed that this activity had not been adapted to help Poppy view the bats. This physical barrier reduced Poppy's agency to access the activity and therefore also potentially limited the storyline of the associated WB effects for him.

It was not possible to ask Poppy if he would enjoy something new and the lack of accessible opportunities was a limitation. However, despite previously being part of a disabled swimming group, his parents felt the facilities in many other local pools did not have suitable changing facilities for disabled people, reporting swimming facilities as cold and dirty:

*“Mum: ...he's doubly incontinent ....because he gets so excited.... the water pressure makes him go to the toilet....We'd have to go in and there would be nowhere to put anything and no toilets for us to sit him on..... and you just have to shower him and shower all the stuff off him.... there's nowhere to go for privacy with communal poolside showers as in some pools....C. Leisure Centre has got a disabled changing room with a toilet and a shower and a bench and it is awful, it is filthy.....there's green stuff coming out of the walls, it's hideous....”*

So, despite Poppy's enjoyment of this water-based activity, the changing facilities did not always provide a clean, private environment. In fact, 'Changing places toilets' was a determinant as to whether the family ventured out for the day, as Poppy was now too tall to change in the back of the car. A diary entry also illustrated limited changing facilities:

*“Poppy went for a lovely walk, through the leaves and watching the river... we stayed in the park for about an hour. It's very difficult to stay out any longer in places that don't have changing facilities, particularly in winter because it's too cold to change him on the floor”.*

The parents reported that some motorway service stations now have these changing places toilet facilities, which had meant a trip last year to a theme park had been 'brilliant'. Thus, this provision expanded Poppy's family's horizons about what was possible to broaden his choices for participation in RAs, enabling his storylines about the WB effects from participation to be illuminated.

Poppy had an all-terrain wheelchair which enabled him to access uneven ground and the family chose to use this on day trips as shown in this diary extract:

*“We had no accessibility issues as we took his all-terrain chair, but there was only a disabled portaloo which wouldn't have been big enough for him had we needed to change him- so we would have gone back to the car to change him.... It lasted about 2 hours”.*

Thus, Poppy was able to participate and enjoyed an activity lasting a few hours, only because of the all-terrain wheelchair, but the lack of changing facilities limited the time they stayed.

A holiday abroad had been better than expected as their trip to Finland was included in the study's period. The diary extract and Figure 46 illustrate his enjoyment:

*“Poppy had an absolutely brilliant time in Finland. We weren't sure whether he was going to enjoy it or not as he hasn't really played in proper snow...! Every day he played in the snow, laying in it, rubbing his hands in it, putting his face in it. He had a sledge which we didn't for one minute expect him to want to*



*use, but he loved being on it, he enjoyed being pulled around the town, pulled up slopes and then going down the slopes on his own, very daring indeed. Poppy can't communicate to us that he wishes to try something, so we just tried different things with him and if he enjoyed it then we did it again. He fed reindeers with our help, he stayed in a glass igloo, he went on a one-horse open sleigh ride at night, he went on a husky sleigh and a reindeer sleigh. He met Father Christmas twice!! This was the very best holiday we have ever had with him, he had so much freedom in the snow, it amazed us how much he loved it."*



**Figure 46: Poppy sledging in the snow**

Poppy had clearly amazed his parents and exceeded their expectations for what he would enjoy in the cold, snowy weather. This was possibly due to the cold sensory input from the snow, which he enjoyed. His engagement with these activities suggested he was able to fully participate during this holiday. This gives an example of a positive emotional WB effect for all the family. In fact, a future ambition was to:

*"...take him to a lot of places and show him the world really, what he can see, and things he can enjoy. We'd love to take him to Texas to a special needs accessible theme park and water park there where you just go on everything in your wheelchair..."*

Thus, Poppy's parents were optimistic about potential participation experiences as he grows older, although with some concerns about their ability to continue to lift him, if his mobility did not improve as he matured and grew taller.

This theme has explored the extrinsic factors which impacted upon Poppy's participation. These are being treated differently and attitudes which influence environmental and equipment adaptations that did or did not adjust for his level of

disability. There was some evidence of his enjoyment of outdoor activities which were time limited, in relation to accessible changing facilities which restricted his participation in RAs and reduced his storylines about the WB benefits.

### **5.13 Summary of Poppy's case study**

Poppy's participation in RAs varied but there was tentative evidence of adaptations that enhanced his WB such as the eye gaze technology and accessible paths at farms. These were influenced by intrinsic factors within him and extrinsic factors in other people, equipment, and environments. Poppy would sometimes also choose not to participate. Attitudes towards Poppy were apparently not always inclusive of his needs even at his special school. In the community, there was also evidence of being treated differently or not given the same amount of time to complete relevant activities such as the pottery experience. However, it was unclear if this was a lack of training in dealing with non-verbal children.

### **5.14 Summary of limited participatory group**

There were distinct factors that made the experiences of this group of children and young people harder to participate in RAs. Pressure sores were a barrier to participation for James and Bree, which were related to their inability to move in a way to prevent these happening. Thus, their limited ability to change their physical positions caused them harm and reduced their WB potential, although they reacted differently to pain. James was on high doses of morphine and Bree appeared not to feel the pain. Negative attitudes and lack of advertising of adapted activities also limited all their choices and reduced their own agency. Being treated differently was a concern when seeking to book online for activities including the theatre and cinema. A new initiative of a relaxed orchestral performance was a bonus for Bree. All aspired for future participation in outdoor RAs, including theme parks, of which changing places toilets would be catalysts to enable this to happen. The next chapter will report the across case analysis where similarities and difference between the cases are developed, to report the synthesis of the main themes of the study's findings.

## **Chapter 6 Findings: Across Case Analysis**

### **6.1 Introduction**

This chapter will draw together the key themes discussed in chapters four and five to synthesise these findings. I was expecting there to be more differences between the PG and the LPG, but it was not as polarised as I was expecting. The analysis of the data indicated there were more similarities than differences, possibly because the two groups were not as distinct. As I had originally intended to have a non-participatory group, the limited participatory group participated to a lesser extent in physical RAs but more sensory and music based. I reviewed the full data sets many times to explore what stood out to me as evidence of their emotional WB from their level of participation. I achieved this by re-reading all the transcript data, re-listening to the audio files and reviewing all the photographs and diaries. The idea of how positioning theory might be further developed from this data, started to be crystalized at this stage, as the picture became clearer with meanings uncovered related to their physical and social positions, in different environments and with adapted equipment and the social forces of people who influenced their storylines (Harré and Langenhove 1999). The chapter will start with the demographics of all the participants and give an overview of the findings, before detailing the process of how I decided on my final three across case themes. These across case findings are then reported under each theme heading. The subthemes are expanded in each section and new data used to illustrate the points. The chapter ends with a summary of the across case analysis.

### **6.2 Demographic information**

There were seven case studies, three females and four males, as summarised in Table 9. However, there were limited gender differences in the choices of RAs, apart from the uniformed clubs of cubs and brownies, which are male and female, respectively. The children and young people mean age was 12 years 1 month.

Participatory group(PG)/Limited participatory group(LPG)	Pseudonyms	Age	Gender	Type of Cerebral Palsy	Muscle Tone	Gross Motor Function Classification System	Communication Function Classification System	Welsh Index of Multiple Deprivation
LPG	Bree	9	Female	Diplegia	Ataxia	Walking Aid III	Non-verbal/ IV	99%
PG	Clare	9	Female	Quadriplegia	Dystonia	Non-ambulant IV	Communication aid III-IV	29%
LPG	James	14	Male	Quadriplegia	Spasticity	Non-ambulant V	Non-verbal/ V	52%
PG	Lily-May	16	Female	Diplegia	Dystonia	Walking aid III	Communication aid IV	96%
PG	Matthew	14	Male	Quadriplegia	Spasticity	Non-ambulant IV	Non-verbal/ IV	4%
PG	Nick	14	Male	Quadriplegia	Spasticity	Non-ambulant IV	Non-verbal III	99%
LPG	Poppy	9	Male	Diplegia	Ataxia	Walking aid IV	Non-verbal- Eye- Gaze Technology/ IV	96%

**Table 9: Demographic Summary of Seven Case Studies**

The participants lived across a range of socio-economic areas on the Welsh Index of Multiple Deprivation (WIMD) from 4% to 99% (WIMD, 2014). The WIMD is a statistical database that ranks geographical areas across Wales according to their relative poverty. For example, 4% means a high level of deprivation, which is correlated with lower employment and higher social housing. However, there was not a clear distinction between the two groups of socio-economic deprivation and less participation. For example, Matthew participated in many RAs but lived in the most deprived area (4%), whereas Poppy lived in an area of low deprivation (96%) and achieved less participation. It was therefore a more complex picture.

Bree, James, Lily-May, Nick and Poppy attended special schools, Clare and Matthew were integrated into mainstream primary and secondary schools, respectively. Nick and Lily-May's special school was a private charity and had a stronger emphasis on sensory and physical programmes. All the special schools had overnight respite facilities, which gave the parents a break, as and when appropriate and some of these hosted RAs such as cycling and swimming. Poppy's parents had not felt ready to take this respite service up due to Poppy's varying abdominal pain episodes.

Poppy's parents did most things with him together, in contrast Nick parents did many things separately to give each parent time with their other two children. Clare attended the children's hospice twice a year with her Mum, she was only eligible because of her secondary life limiting respiratory condition. This gave her access to many RAs under one roof. James was fostered, so his foster mother had nurses from the palliative care team come in to relieve her, twice a week, although this was not a reliable service. These nurses sometimes took him out into the park for a walk by the river or to the shops to look at the toys.

In the LPG, their level of participation was also related to lack of choices for RAs due to the complexity of their disabilities, including their level of pain, mood, and epilepsy. Additionally, in James and Bree's cases they both had some pressure sores requiring medical attention

which reduced their ability to participate in RAs safely. Although James responded appropriately with pain to these pressure sores, Bree seemed oblivious to the open wound and did not respond as was expected. It was therefore possible that her pain perception was altered. Mood and epilepsy were also factors which hindered participation in RAs. As these features of pain, mood and epilepsy fluctuated, more evidence of this was found in the LPG. As I reviewed positioning theory and considered the positions of the disabled children and young people, the social forces influencing their participation and their resultant storylines, an idea of a 'Kaleidoscope of Well-Being' began to form. This imagery supported the idea that when participation in RAs was limited, the WB 'colours' were diminished and duller, like a proverbial veil coming over the brightness. This related to their social engagement as much as their physical positions and revealed their own self determination and control. This is expanded and developed further in the discussion chapter.

### 6.3 Final theme identification

The themes and subthemes I identified in each case study are summarised in Table 10. This was achieved after the within case analysis was completed for both groups. Colours were then used which helped me to identify topics to group them together under an umbrella theme. I was then able to see dominant patterns across the data, which enabled me to reflect, to further explore my research question.

#### Table 10: Summary of Within Case Themes

Colour codes were used to map patterns across cases to identify the themes and subthemes:

1. Orange: Enablers to participation- innovative designs, equipped volunteers, reasonable adjustments
2. Red: Being treated differently- undermining attitudes, untrained volunteers
3. Green: Parental advocacy- helpful professionals
4. Blue: children and young people Emotional Well-Being indicators- non-verbal cues

Name	Theme	Subtheme
Bree(LPG)	<p>Opportunities for play</p> <p>Emotional wellbeing indicators</p>	<p>People who support, Welcoming Environments</p> <p>Sensory processing, Barriers to participation</p>
Clare(PG)	<p>Equipment to enhance participation</p> <p>Time to emotionally adjust to activities</p>	<p>Expressing musical choices</p> <p>Trike riding</p> <p>Changing place toilets</p> <p>Outdoor hoists</p> <p>Charity groups</p> <p>Accessible spaces</p>
James(LPG)	<p>Personal WB</p> <p>Attitudes towards Disability</p>	<p>Observed behaviours</p> <p>Intentional play</p> <p>Pain responses</p> <p>Behaviours in public spaces</p> <p>Reasonable adjustments explored</p>
Lily-May(PG)	<p>WB effects from participation choices</p> <p>Parental advocate to enhance participation</p>	<p>Enablers</p> <p>Limitations</p> <p>Treated with disrespect</p>
Matthew(PG)	<p>Innovation in Designs</p> <p>Challenging behaviour</p>	<p>People who adapt for disability needs</p> <p>Parental Advocacy for Emotional WB</p> <p>Respite care that managed emotional WB,</p> <p>Changing facilities affects participation</p>
Nick(PG)	<p>Enablers for participation</p> <p>WB indicators</p>	<p>Volunteers,</p> <p>Respite choices</p> <p>Nick's behaviours,</p> <p>Parent's emotional responses</p>
Poppy(LPG)	<p>Idiosyncratic ways to communicate WB</p> <p>People's attitudes towards disabled children</p>	<p>Non-verbal communication to express emotion,</p> <p>Poppy's behaviours that challenge,</p> <p>Technology assists choices</p> <p>Being treated differently,</p> <p>Pain responses</p> <p>Adapted equipment and environments</p>

As I stepped back and reflected upon the research question and aims, I wanted to see how children and young people felt their level of participation had affected their emotional WB, from where they had been physically positioned ready to choose to participate in a RA. The emphasis in the analysis has been given to show how I perceived that my participants chose their level of participation in RAs, despite not having a physical voice. When I was able to ask Clare and Lily-May who could respond with their communication aids, I could gain their perspectives of enjoyment. This helped me interpret their emotional WB from what they chose to participate in, when positioned there. However, I felt a tension between how I could represent the limited ‘voices’ of the other five children, whose parents had to report by proxy. When the children could not express themselves verbally in an interview, the children’s emotional WB was interpreted from my observations of their intentional behaviours and the parental reported diaries and interviews. The parental emotional responses to situations related to their child’s level of participation and other people’s reactions to them which was transparent in the data.

It was difficult in the two groups to distinguish specific differences in participation, as their experiences overlapped with some attending the same activities with varying frequencies as those in the LPG had more pain and epilepsy which impacted negatively on their ability to participate in some RAs . The activities of the seven cases are summarised in Table 11.

**Table 11: Regular participation in Recreational Activities**

<b>Recreational activity</b>	<b>PG (n=4)</b>	<b>LPG (n=3)</b>	<b>TOTAL</b>
Touch trust, Music based	4	3	7/7
Cycling, Swimming, Horse Riding	4	2	6/7
Museums, castles, festivals	3	2	5/7
Skiing	2	0	2/7
Surfing, Trampolining	1	0	1/7

The absence of innovative designs that would have helped to facilitate many RAs may not have been a deliberate omission. Instead, it was,



perhaps, simply a case that no one had yet thought about how any reasonable adjustments might be made for participation such as for Poppy at the bat crawl, as shown in Figure 45 (pg158).

After reflecting upon the themes highlighted from the within case analysis, the across case themes were condensed into three main themes as shown in Table 12 with subthemes:

**Table 12: Final across case themes and subthemes**

Theme	Subthemes	
<b>1. Participation enhancers</b>	i. Parental advocacy	ii. Innovative designs
	iii. Reasonable adjustments	iv. Equipped volunteers
<b>2. Champions for disabled children's emotional WB</b>	i. Expressing choices to indicate Well-Being-self advocacy	ii. Professional advocacy
<b>3. Hindrances to participation</b>	i. Undermining attitudes	ii. Parental views of being treated differently
	iii. Impact of pain on participation	

These themes will now be presented to illustrate the across case findings.

## 6.4 Participation enhancers

### 6.4.1 Parental Advocacy

Advocacy is defined as “*public support for an idea, plan, or way of doing something*” (Cambridge English Dictionary, 2021). Advocacy, in this context, refers to instances where the parents were pushing on behalf of their disabled children and young people to provide and improve access to opportunities for RAs. All parents expressed that they wanted their children to have fun, however some parents were more vocal than others. Clare, Nick and Poppy's parents felt they were

not listened to by people who provided RAs, such as the creative art and pottery activities. Their ambitions for participation in RAs were different to what was available. For example, Clare's Mum discussed about the lack of availability of an outdoor hoist to support her getting on and off the trike.

Matthew, Lily-May, Nick and Clare's mothers also got involved as fund raisers for clubs such as the skiing and charity groups for holidays. Lily-May's mum was concerned that the horse riding would discontinue after she reached 18 years. Bree, James and Poppy's mothers were less vocal in their communities and these were in the LPG. For James and Poppy, it could be because they were dealing with more illnesses with their children and for Bree, as Mum was working, she perhaps had less time to engage with her community. Of all the case studies Bree's Mum seemed to be seeking the most advice about participation in RAs. She had experienced more challenges with Bree's moods and unpredictable behaviours. For example, sometimes Bree would walk with her walker, but not at other times, as highlighted in the following interview quote:

*"PA tends to take her in the wheelchair to the playground, Dad will take her in her walking frame, I'm a bit too scared... (laughs) Cos' she will...walk ....but whether she wants to walk back...(laughs).. her sister will bring the walking frame and Dad will have to hold Bree's hand... But then sometimes she will decide she doesn't want to walk any further and she will sit on the floor..."*

Thus, it was difficult for her family to take her to activities as she was unpredictable in her engagement. Figure 39 (pg 146) had shown how Bree preferred to move around by bottom shuffling. This action had previously caused the pressure sore that she was unaware of, thus increasing her infection risk and restricted her participation in RAs for a period, whilst it was treated. Bree's unpredictable behaviour meant it was difficult to commit to RAs as she may choose not to engage once there.

Other parents of disabled children and young people were a resource for each other, as Nick's Dad highlighted when asked how he had found out about RAs:

*"I honestly can't remember, we started going to the cycle hire facility when it was a porta-cabin, a shipping container in the car park, I think it was possibly other parents, word of mouth, possibly Bobath<sup>5</sup>?"*

The opportunity to meet other parents enabled these networking opportunities to facilitate finding out about RAs. All parents advocated for their children to be able to try new things, but there was a lack of choice for those living in more rural areas, as Clare's mother highlighted:

*"...it is difficult to find things that she would like and that would be accessible ....I am always on the lookout for something that we haven't done or ... but everything is so far away around here".*

Although social media played a role in disseminating opportunities, parents often also had to check up by email or telephone to check toilet and changing facilities. There were some useful websites such as Euan's guide<sup>6</sup> and Changing places toilets<sup>7</sup> that aided them in navigating accessible venues. However, although the internet played a role in enabling information to be found, it was not always a reliable source, as some websites were not always updated.

All the parents were intuitive to their children and young people needs for participation. For example, Nick's Father thought that sometimes the barriers were too hard to overcome:

*"for the future, I think a lot of these activities that are potentially out there, the barriers for those with Nick's selection of disablements, the barriers in using them are sometimes too hard. They are not insurmountable but there's not enough hours in the day.... Say to turn a trip to the cycle hire centre, spending half an hour getting him onto the bike and of course he gets frustrated ...that it just puts you off completely even bothering"*

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<sup>5</sup> Bobath is a voluntary sector charity that provides interdisciplinary therapy for children with cerebral palsy- now known as Cerebral Palsy Cymru <https://www.cerebralpalsycymru.org/>.

<sup>6</sup> Euan's Guide <https://www.euansguide.com/>

<sup>7</sup> Changing places toilets <http://www.changing-places.org/>

Here his father is reflecting on how Nick got fed up with waiting whilst the bike was set up for him. This affected Nick's WB in that moment, but once the bike was set up safely, he was reported to enjoy it. For Dad, as it took so much effort, he questioned why he bothered to participate in RAs at times. Additionally, Nick was most happy when occupied with this spinner toys as shown in Figure 47, which was relatively simple to implement and less tiring for him.



**Figure 47: Nick with his spinner toys at RaceRunning venue**

Being disabled meant it was much more effort to participate in the limited choices of RAs and was therefore tiring for all the children and young people parents. All participated in RAs that they were assured were accessible and supportive, but as Clare's mother pointed out, she could not expect they could cater for Clare without a lot of phone calls, as indeed Poppy's mum had also found out on their holiday.

In the PG, the participation was regular, which was a pattern I observed in the diaries. Two examples of regular activities in Lily-May's and Nick's original diaries are shown respectively in Figures 48 and 49:

Week 13

Monday 17th April

[redacted] park for walk

Tuesday 18th April

National Trust Membership (carer goes free)  
 Visit to [redacted] Garden lovely picnic & walk with Ruth

Wednesday 19th April

Sense [redacted] Key Create session  
 - sensory story - with Dave

Thursday 20th April

Whizz kids @ [redacted] Campus Ambassador club! Fantastic.  
 Wheel chair sports - dancip, tennis, table boccia  
 Able to leave Lily-May has health  
 care professionals there - much

more fun for Lily-May with out me here. Went back  
 lunchtime for food but don't think I would in  
 future - cramping Lily-May's style.

**Figure 48: Lily-May's diary: School Easter holiday week**

Lily-May had a different routine in the holidays to her weekly activities.

This was made possible by flexible direct payments to pay for extra PAs in the holidays.

Saturday 25/03/17 - Day 6

Got up late and lounged about after breakfast. Played on my iPad and squidged about on the floor before lunch.

Then Carer came to take me out...

I went to Outdoor museum today - I ENJOYED DRIVING MY CHAIR AROUND. WE WENT TO THE FARM SECTION AND SAW A GUINER FOWL, SOME SHEEP AND SOME PIGS. WE THEN STROLLED AROUND THROUGH A WOODED AREA WHERE WE SAW SOME SQUIRRELS, AND LOOKED AT THE OLD BUILDINGS THAT WERE THERE.

**Figure 49: Nick's diary: Saturday's routine**

Nick's regular trip to the outdoor museum was enjoyable because he could drive himself around in his powered chair. This was supported by his PA whose handwriting is seen in capitals. A future ambition was to try disability sailing which Dad had found out about at a disability exhibition on day trip to England.

Whilst these diaries were written by the parents, they were powerful data sources to reveal the emotional WB of the children and young people from their participation in RAs both at home and outside the home. This was the parent's way of telling me about their children's experiences in their own time and advocating for what was fun in their lives, thus supporting this parental advocacy theme. When analysing these diaries, I was struck by the verbs used to describe their response to these experiences: 'Lovely picnic and walk; more fun...lounged, squidged, enjoyed'. These suggest positive experiences for Lily-May and Nick to relax and play. These positive emotional WB experiences were also echoed in the other participant's diaries such as James:

*"Funday at school, Hawaiian theme dressed up and enjoyed sensory story. Saw fire engine and listening to the music men. Love having an Ice-cream cone."*



This diary entry was supported by a photograph of James eating this Ice-cream dressed in his Hawaiian costume as shown in Figure 50:



**Figure 50: James eating an Ice-cream cone**

As illustrated in Figure 50, Mum showed her creativity in fancy dress with his costume, and this was the first time James had eaten an ice-cream cone by holding it himself, as he usually preferred to be fed it from a bowl.

Poppy's Dad was also creative and made him a 'Trick or Treat' chariot as shown in Figure 51:



**Figure 51: Poppy's 'Trick or Treat' chariot**

Matthew's Mum was also a key advocate for him to participate but she also influenced other parents as this quote shows:

*“Yeah I’m a good advocate for the Surfability<sup>8</sup> and the Ice-Cool Kids Skiing<sup>9</sup> Group. Yeah cos I get out there and I know how much we as a family have got out of doing these things...I think more people should....Well I’m always telling people and I got alorra people into it actually and I think it’s good for parents cos I think alorra parents get a bit down thinking, there’s nothing, I can’t do anything...and there is stuff, you’ve just got to try it...”*

Matthew’s Mum was promoting the two key opportunities he had enjoyed participating in. Her account supports the point raised earlier that parents of disabled children and young people can be an excellent source of information and support for each other. The importance of parental advocates was central to the children and young people storylines, contributing to the social forces promoting disabled children’s positioning, ready for participating in RAs.

#### **6.4.2 Innovative designs**

Most examples of RAs in my study were physical activities that had been adapted for the disabled children and young people, where they could be positioned, ready to participate if they chose to. Matthew had been able to co-design the surfboard which was now being used with many other disabled children and young people and adults. Matthew also had his own beach wheelchair that enabled access to the beach, although at that time, there was no hoist or changing facility available. Matthew therefore had to be changed in his chair in the back of their WAV as was illustrated in Figure 31 (pg 124). This was not an easy task as he was a tall teenager, making this an added challenge to his participation in this surfing activity. Figure 52 shows Matthew positioned ready to surf, holding his fishing net.

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<sup>8</sup> Surfability is a bespoke organisation that provides surfing opportunities for disabled people.

<sup>9</sup> Ice Cool Kids skiing group is a charity that provides skiing experiences for disabled children.





**Figure 52: Matthew positioned ready to surf in beach wheelchair**

This was the highlight of his week on a Saturday and extra sessions in the school holidays. Thus, Matthew was positioned in specialist equipment to enable participation to take place, the social forces included both the skilled people and natural resources such as water, wind and waves, creating stability, movement and buoyancy.

A key piece of engineering that all, but James had enjoyed, was trike riding. James was not able to do this due to his re-dislocated hips, which meant he had never been able to learn to pedal as his limited hip movements restricted this. For Clare, cycling had opened up her world at the age of two. As shown in Figure 20 (pg 99), for Clare this cycling opportunity gave her freedom that she did not have in many other activities, thus demonstrating a degree of agency with her participation choices to explore the environment with relatives. As many children and young people were getting bigger, it was getting harder to get them on the trike without a mobile hoist. It was suggested to Clare that mobile hoists were not available for outdoor use, but I observed this being available for Nick at RaceRunning. So, it was possible to overcome the manual handling difficulties. Although, during the study's period, RaceRunning was the only RA where I observed a hoist being available.

All this equipment was large and therefore challenging for them to store and move around. A suggestion was made by Lily-May's Mum to have a communal equipment area to loan out as required, as storing big items at home, such as the beach wheelchair, were difficult.

*"I think that there is a lot of this equipment, like people use them for when they're travelling, for sleeping, that sort of thing, buggies, is not something you want every day, and we haven't got room to store all these things. So almost have like a communal pot of equipment that you could just loan, as and when you needed it, a hoist, a number of people don't go, like to Llangranog<sup>10</sup> for the skiing, people don't go because they can't manage their children, whereas in fact, Llangranog approached a company and got a hoist one in for the week so their child could go there, but you do almost need this pot of equipment that you can just access as and when you need it...."*

To overcome some of these issues, changing places toilets with overhead tracking hoists have started to be provided at some service stations and public buildings, this had opened new opportunities for Poppy as the family could travel further for day trips. However, overnight arrangements were much harder with disabled children and young people, without additional equipment to support their RAs.

As well as equipment, there were examples of environments that had been designed to facilitate participation for disabled children and young people and their families, such as the bike trail Bree's family encountered, whilst on holiday in the UK, as this diary entry from Mum shows:

*"My Mum, Dad, sister and I went to Thetford Forest. We hired a special bike where Dad pedalled, and I sat on a seat in the front. We all rode the Shepherd trail which was 5 1/2 miles and took us 1 1/2 hours. I really enjoyed it. I then went in my walking frame and we did the Gruffalo Trail. I enjoyed the basket swing, slide and balance beams in the playground."*

So, this opportunity had enriched their family's holiday experience by a thoughtful design. All these innovative designs enabled the families to feel their children and young people were valued. Because someone

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<sup>10</sup> Llangranog is a welsh coastal outdoor pursuits centre that most schools take pupils in year's 5/6, this was a charity event for Lily-May and Matthew with the skiing group, it has a dry ski slope.

had thought about their needs and adapted equipment and environments for them for them to be positioned ready to participate. Thus, these social forces of innovative designs, enabled the children to participate and generate their own storylines about the WB impact from their level of participation.

### **6.4.3 Reasonable adjustments**

Parents discussed the value of reasonable adjustments being made to RAs to enable the participants to join in. Lily-May had tried one trampolining group where access onto the trampolines was difficult, so she had then been on a waiting list for a more accessible group. Here siblings were included as well as at brownies, cubs, the trike hire centre, surfing, skiing, and Touch Therapy. In cases where brothers and sisters were included, this appeared to enhance participation as the parents could manage the needs of all their children. However, disability specific activities such as horse riding for the disabled or the disabled swimming groups, in my study, did not include opportunities for the participants' siblings. This was a barrier to participation, as the siblings got bored just watching and sometimes cold when outdoors and complained to the parent who had to manage both theirs and their disabled child's needs.

It was especially harder for Bree and Lily-May's mothers to attend when they had younger siblings who could not be left home alone, so the employment of a PA facilitated the ability for the disabled children and young people to attend these without their parents. This was only made possible by direct payments. Another barrier was the lack of hoists, especially in public swimming pools, some of which were dirty and the lack of availability for the use of special school's hydrotherapy pools outside the school's hours. Some of these activities were reasonably priced such as the play-scheme at £1, RaceRunning at £2.10, but others were quite expensive such as the Touch Trust and Surfing that cost £30 for individual sessions. This reflected whether an activity was supported by paid employees or volunteers, as if it was paid employees, it was more expensive.

Outdoor play areas were an important part of WB for the participants in my study. Poppy's Dad had worked for the council and gave me insight into the cost of building accessible playgrounds. According to him, these costs varied from £30,000 to £250,000, depending upon the type of floor surface used or the need to excavate the land for an accessible roundabout as shown in figure 21(pg102). However, as Bree's Mum reported, playgrounds varied in what was accessible for her:

*"See saws, and there are some roundabouts which are suitable if it's got a seat on it. Some aren't and she loves the slide but quite often the way you get up to the slide isn't suitable for Bree..."*

A positive example of a reasonable adjustment was illustrated by Poppy's Mum when he had attended a Halloween event that she recorded in the diary as shown in Figure 53:



**Figure 53: Poppy supported at Halloween event**

The diary quote below supports that Poppy was able to participate in this experience as the people had adapted to his needs by providing an accessible path:

*"We went to H. Halloween event. It's a farm so we took his all-terrain wheelchair. He joined in collecting ingredients for a magic spell, met lots of witches, wizards and scary people dressed for Halloween. He went on a Terror Trail where characters jumped out on him to scare him. They were all very sensitive to his needs."*

This was a good example where people had been able to make the reasonable adjustments to include disabled children and young people

like Poppy, when he was positioned in his all-terrain wheelchair to navigate the accessible path. Bree and Matthew had experienced good adjustments from staff at their respite centres to cater for their needs, by finding suitable RAs to occupy them such as bike riding, musical choices and computer games. Clare had also had a positive experience at a safari park with a private toilet space being created for her, after an advanced phone call from Mum, to establish their changing facilities. Bree was able to participate at brownies with her PA who adapted when the activities were not suitable for her, as Mum described:

*“...she (PA) does come back and say we couldn’t join in today the activities weren’t suitable. She does take a bag with her and if they aren’t suitable her PA does alternate activities with her. They have bean bags and they practice throwing, she tries to get her to do, one of our physio things is making her walk in a circle....”*

So, although Bree was present in the space where brownies occurred, she was not always able to fully participate. Although I observed her joining in with the brownie promise as shown in Figure 54. Bree is outside the circle, due to needing support for standing, from her PA. Thus, a level of participation was achieved at brownies which was meaningful for Bree and enhanced her WB. I have covered her face with a smiley emoji to indicate her enjoyment at brownies.



**Figure 54: Bree participating at Brownies**

It was always necessary to do a risk assessment, to consider if reasonable adjustments could be made. For example, in Matthew’s

case there was evidence of a voluntary sector group including him and a different organisation not including him in sporting activities, due to the need for hoists and people to change him. This was echoed by Bree's experience of not being able to access the play-scheme. Thus, for some activities it was possible to make the adjustments necessary to enable participation in RAs, but not for all. It was usually related to lack of funding for trained staff and adequate changing places to support the activities. This additional cost to support disabled children and young people to participate, was a barrier to their participation in RAs and was a negative social force.

Some initiatives for RAs had been thought through, such as the positive musical opportunity for Bree at the 'relaxed orchestral performance'. Here the children could interact which would be unusual in a classical orchestral concert. Mum's reported this enhanced Bree's emotional WB. This might not suit people who enjoy listening to music without distractions but was one example where a positive adjustment had been made specifically for disabled children and young people, thus a positive social force.

Social participation was important for both Nick and Lily-May, sometimes more so than the physical participation, which was often tiring for them. When I observed James being gastrostomy fed outside at the Saturday disability play-scheme, he was accepted along with several other families of disabled children and young people who were doing the same in this public space.

Many of these RAs were supported by volunteers who were equipped to relate to and manage the needs of disabled children and young people, and the role of such volunteers will be explored in further detail in the next section.

#### **6.4.4 Equipped volunteers**

Volunteers were an asset to enable increased participatory opportunities. Some volunteers appeared to have received adequate training to facilitate participation in the RAs. I observed this at the RaceRunning and Skiing where volunteers were predominant. Here I



saw volunteers working in teams to support the disabled children and young people to participate, thus enabling them to feel included and potentially benefitting their WB.

There was more evidence of volunteer support for disability sport's activities making the reasonable adjustments, with a reported lack of support for volunteers who knew how to adapt for their levels of disability in the arts and craft activities, as Clare, Poppy, Lily-May and Nick's experiences had indicated. For example, Clare's Mum has been disappointed with an arts-based activity that she felt she could have done at home:

*"..Clare did an art thing which was a bit pants...it was artist and it was come and learn how to teach your child how to paint and I was like 'ok if you're going to do something different' by a resident artist, you know a professional artist and I thought well ok something different. And really, she just gave us a load of old scraps of paper and some poster paints and that was it! .....I thought well I could have done this at home....and saved myself a fiver (laughs).. I was like-Really!!...."*

As this was not a bespoke disability arts activity and it is possible that other parents also felt disappointed with this. The effect of less availability in the arts and crafts, influenced the parent's confidence to try out new activities and reduced the participatory opportunities for the children. It was important for the children and young people to explore what they might like to participate in, as without such opportunities there was no possibility to evaluate the children and young people emotional WB responses. Most of these opportunities for RAs relied upon volunteers, some of whom did appear to have some limitations in terms of their social confidence to relate to disabled children and young people. However, the next theme emphasises those who were championing the emotional WB of disabled children and young people who were a mixture of volunteers and employed staff.

## 6.5 Champions for disabled children and young people's emotional well-being

### 6.5.1 Expressing choices to indicate well-being-self-advocacy.

Each children and young people had a bespoke way to express themselves regarding their choices. Clare and Lily-May had electronic means to do this and Lily-May gave me the most insight into her WB as her quote shows:

*“LM: My feelings....I am happy [clapping]...I have a question....what are you doing?*

*INT: What am I doing? I am talking to you about what you like doing for my research. Trying to find out what children like to do after school. I really want to know the things that make you feel happy.*

*LM: [Clapping] Yeah [excited sounds]. Why?*

*INT: That's a very good question, why. So that we can help more children in the future to have more choices about what they do”.*

I was not expecting this questioning, but it was good reinforcement that she was happy to continue with my research. So, Lily-May's inquisitive engagement with me during the interview revealed a level of happiness expressed verbally via her communication aid and by clapping.

Nick, Matthew, Poppy, Bree and James were less reliable in their expressions. Their observed intentional behaviours were a more consistent way to determine their emotional WB. Poppy was reported to have used the Eye-Gaze technology to indicate he was sad when his parents went away during the data collection period. Louder volume in the children and young people vocalisations was usually an indication of WB and they often went quiet when unhappy. Appetite was also a key indicator of WB for all the children in that if they were contented, they would eat well. James who was gastrostomy fed could have top ups of food when he was not maintaining his body weight with the enteral feeds. Nick was able to drive his powered chair to the fridge, to indicate he was hungry. So, a loss of appetite was an indicator of lower WB as Matthew had also shown, when he did not like the respite centre. Thus, he could use his behaviour to demonstrate his



unhappiness in the absence of vocabulary, to vocalise his choices and express his own agency, as his way of self-advocating his needs.

Restful sleep was also an indicator of WB, but I was surprised that many of the teenagers still went to bed by 8 pm, as Nick's father illustrated in his quote:

*"...we usually put him to bed between 7 and 8 o'clock on week nights for sure, I suppose he sleeps between 7 and 9 hours per night...well maybe a bit longer actually but he's quite tired in the mornings on week days. On weekends he'll go to sleep at the same time....we don't necessarily keep him up much later unless we're doing something on the weekend. He won't actually wake up until half past 9, 10 o'clock on a Saturday and Sunday...We're quite happy to leave him to sleep so he gets as much rest as his body needs and also it means that it's a bit more relaxed in the mornings."*

The right amount of rest was important for Nick to have the energy to participate in the RAs he enjoyed, such as visiting the outdoor museum, trike riding and swimming.

When the parents were asked what they thought emotional WB meant for their children, there were mixed replies. Clare's Mum felt that it was about confidence building and creating memories for her to think about:

*"...her happiness... confidence in social situations ...and in herself to try different things and just being a more rounded person, I think, having different experiences and things that she can relate back to..."*

Whereas Poppy's Mum felt that it was more about him being at peace with himself and joining in activities that he enjoyed:

*"Being at peace with himself. He's happy when there's things he wants to do..."*

Additionally, Matthew's Mum told me he screamed with joy at the surfing:

*"it's all you can hear is Matthew screaming with just pure joy and Jamie was surfing with his friend and you could just hear him calling Jamie well he can't speak, he's just shouting and the two people like he's splashing them, you can see how Matthew is ...you have to see it..."*

Indeed, when I observed this, Matthew became hoarse with screaming at this surfing activity. At the skiing activity I observed him to be equally vocal, but then he was relaxed afterwards and quite calm, even reaching out to hold my hand. There was also diary evidence of him being a spectator at events with his Dad. Football and darts were meaningful for Matthew with his father, even when physical participation was not an option due to the complexity of his disability. Thus, my interpretations of the children and young people emotional WB, related to their perceived happiness and having opportunities to join in RAs that they wanted to do or watch as spectators.

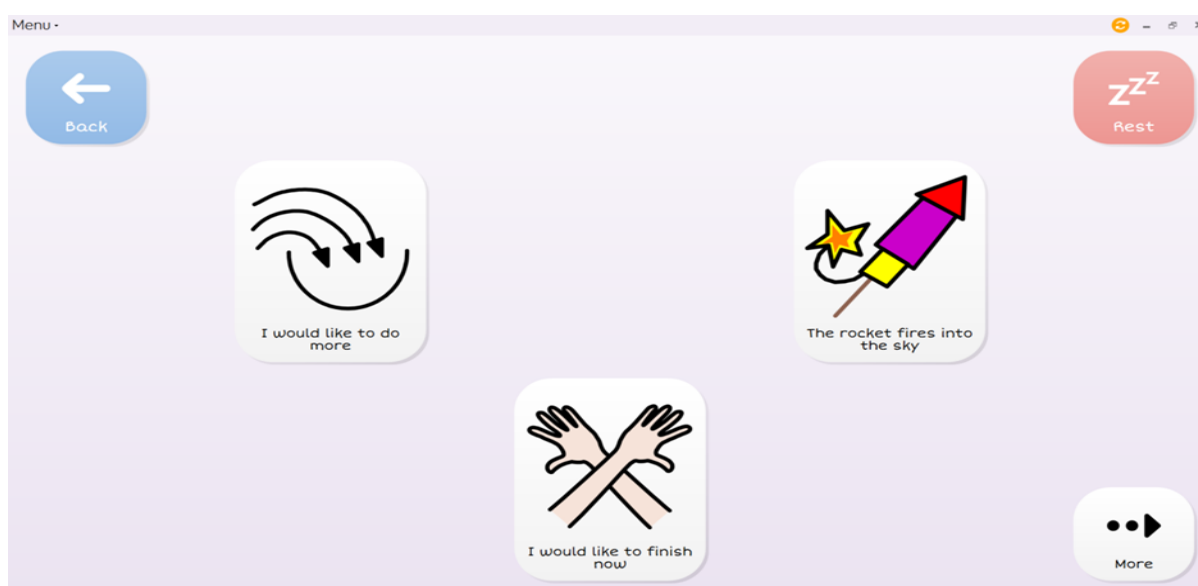
However, in my observations, I was not always sure how to interpret some of the children's behaviours as many did not smile, which would be a typical expression of enjoyment. I felt that if they continued to join in an activity, this was a positive encounter for them, but that was not always consistent, revealing mood swings that could affect their level of engagement. For example, Matthew was very focussed on other people to participate with but was reported to be grumpy and aggressive when home alone.

In the absence of spoken language, the parents were able to report to me what their non-verbal cues meant in terms of their WB. This varied hugely from James's silent tears, Nick biting himself, Poppy hitting his head, Bree grabbing and pulling her sister's hair, to Matthew's aggressive shouting and hitting out. Each of their expressions required a response from the parents, seeking to promote or maintain their WB and reduce these behaviours. The choice and frequency of RAs could support their WB, as several were able to associate days of the week with certain activities. For example, Matthew loved his Saturday surfing and Lily-May her Thursday horse riding. However, in the LPG, illness states, such as for Poppy and James, meant they were not always well enough to participate, even at home and needed medication to relieve pain or fits. So regular routines of participation were not possible to achieve, hence their participation was limited. Their WB was enhanced when they were well enough to participate, but this was unpredictable. So, in the LPG they could not plan or commit to regular RAs.

All of the children and young people behaviours showed an intent to communicate but the only way they could choose their RAs was by being given options of what they might like to do, from the limited choices of available activities such as swimming or bike riding. The weekly routines facilitated this for regular activities, however, to try something different involved a lot more effort. This was sometimes amidst conflicting family priorities, with uncertainty about if they would enjoy it, such as when Nick and Clare were unsure about the skiing.

Although Nick loved swimming, there were times he did not want to do this, even when it was available at home. I also saw him choose not to engage in RaceRunning but go off steering his powered chair and explore the sport's hall, to watch the tennis. Thus, he expressed his own choices, not to participate, despite not having a physical voice, but by his intentional behaviours, he self-advocated his wishes not to stay involved.

Poppy was beginning to make choices with his Eye-Gaze technology as shown in Figure 55:



**Figure 55: Poppy's Eye-Gaze choices**

Poppy could choose to do more, or finish the activity, thus showing simple choices for participation preferences by using his vision. This was at an early stage of being a reliable means for Poppy to

communicate his choices in school. However, at home, Poppy showed that he did not always want to participate in bike riding:

*“We've always left it to him whether he wants to do bike riding or not. Like we might think we'll take him out for a walk on his bike, and put him on his bike, and he doesn't want to do it, and gets really grumpy... he gets agitated because he's starts to rub the side of his chair and the side of his head and then he'll start moaning...”*

Poppy showed his distress by hitting objects, himself and then moaning, he got happier once his parents took him off the bike. It could have been uncomfortable for him. Thus, both Poppy and Nick demonstrated their own agency, by these choices they made not to participate, determining their own storylines and advocating their own needs, to manage their WB.

Bree responded to RAs she enjoyed by smiling and clapping and this had drawn Mum to try the Touch Trust, who used a lot of clapping in their routines. Lily-May and Nick also clapped to show enjoyment. In contrast, Clare had found loud noises difficult and had been unable to tolerate the sound of clapping. However, over a period of three years, Clare had been able to learn to tolerate louder noises. Clare was the only child who I observed self-regulating her emotional WB through music and sensory play, which she could do at home. Music had been a strong feature of the second interview with her. An example of Clare's sensory box and play activities is shown in Figure 56 with a quote from her diary underneath. When Clare played with these sensory toys, she was shown smiling in the diary. Thus, demonstrating the importance of having access to sensory toys which had a positive emotional WB effect for her which were a mixture of stimulatory and calming objects that gave her pleasure.



**Figure 56: Clare's sensory box**

*"This is my sensory box. I like to feel these things or dance with them.....At bedtime while I was having my nebuliser we listened to a music and dance CD and used my sensory box to pretend with. I used something different for each song. It was great fun...."*

Fun was also a feature for Poppy when he used his sensory suitcase which he liked to climb into and play as shown in Figure 57.



**Figure 57: Poppy in suitcase**

Poppy's mother had provided this opportunity by positioning him in the suitcase with the popcorn in the bowl, to motivate him to engage.

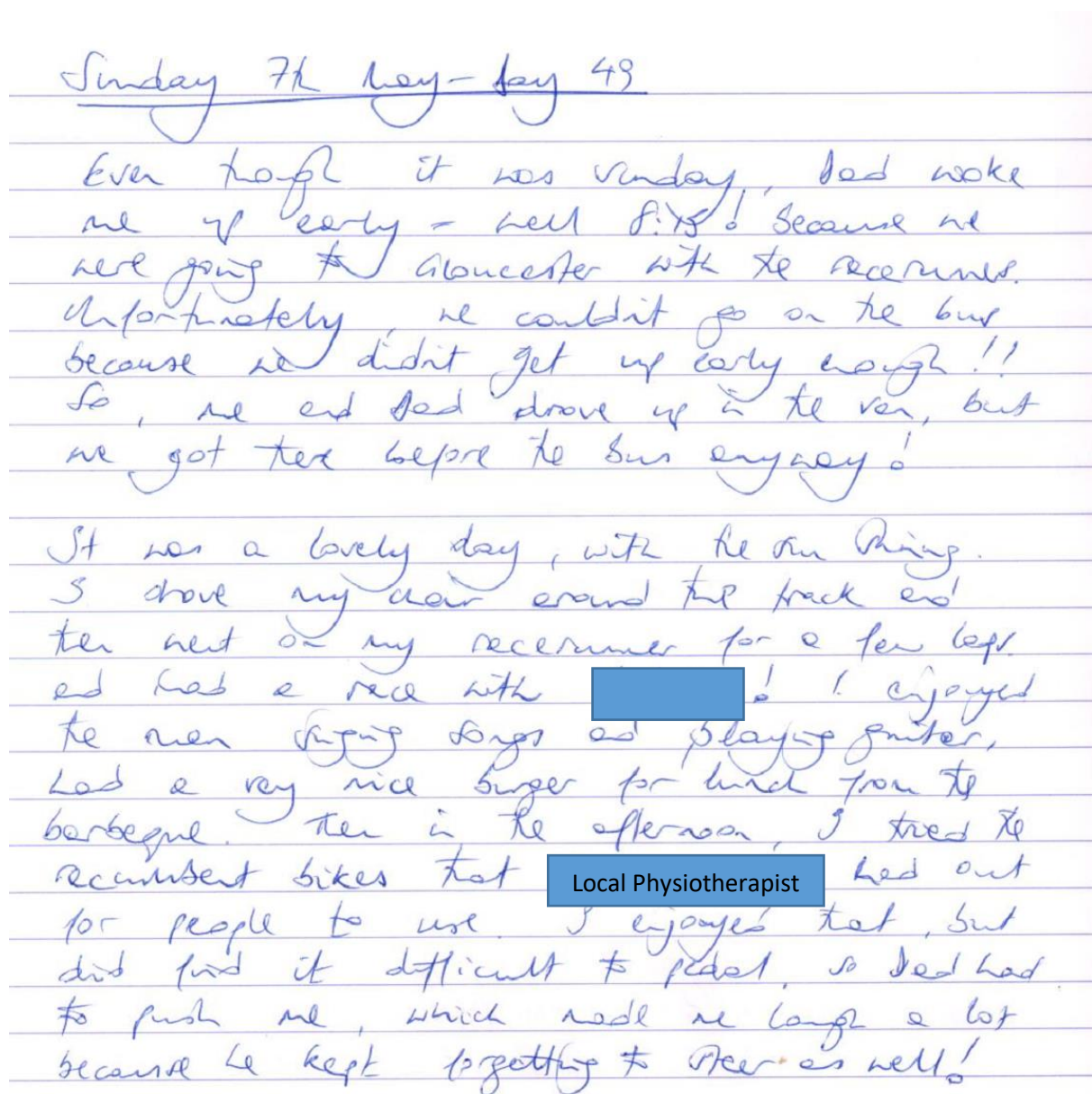
Poppy loved this sensory experience of playing and throwing the popcorn on the floor. Thus, he chose to stay in this position by himself in control of the objects surrounding him that created his own storyline where he was suitably occupied in a RA at home.

James loved the sensory experiences at the museum to touch and feel the exhibits such as a cow's skull. However, Matthew did not appear to enjoy sensory activities other than music, he needed the adrenalin type of fast activities to keep him occupied in a constructive way such as the skiing and surfing. Nevertheless, these were not available every day and he found occupying himself alone difficult. All the participants needed a high level of supervision to meet their physical care needs, so when there was time and energy for RAs this was a bonus. This was all made possible by parents who were tuned into their need to have fun and advocated on their behalf for opportunities to enhance their WB. However, although the parents were important social forces who positioned them at RAs, hoping this would occupy their energy for positive WB effects, the children and young people showed they could advocate not to participate to manage their own WB.

### **6.5.2 Professional advocacy**

In addition to parental advocacy, there were some health and social care professionals who also advocated on the disabled children and young people behalf. So, those who acted as advocates, facilitated support for the disabled children and young people, who without this support, might otherwise not have had any opportunities to participate in RAs. In my study, physiotherapists had initiated Skiing, RaceRunning and Trike riding. As well as physiotherapists, some had also found other helpful health and social care practitioners who advocated for disabled children and young people participation in RAs, such as Bree with the special needs health visitor, Matthew with the social worker and Lily-May with the occupational therapist.

The two examples of physiotherapists initiating activities where parents were now jointly running these, were Skiing and RaceRunning. This gave some indication it was possible for professionals to work in partnership with parents of disabled children and young people, to increase their choices for participation in RAs. This is outside the NHS's provision (although professionals could signpost families to available choices) and relied upon these professionals volunteering in their own time. Lily-May and Matthew enjoyed the skiing, Nick had enjoyed the RaceRunning but seemed to lose interest in this as the study went on. One highlight was a Sunday trip to Gloucester to join in a RaceRunning event as his Father's diary entry showed in Figure 58:



### **Figure 58: Nick's diary entry: RaceRunning event**

Figure 58 documents how one of the local physiotherapists, who was a volunteer, had provided the opportunity to try a recumbent bike as shown in Figure 28 (pg115). You needed to steer this from the back which Nick could not do, and Dad forgot, so this made Nick laugh, thus having a positive effect upon his WB.

Arguments had been made for Matthew with adjustments at respite by his social worker, thus advocating for his calmness. Additionally, a special cot bed for Lily-May was advocated for funding by the occupational therapist, to reduce her fatigue to enable her to enjoy her many RAs. So, in addition to the parental advocacy, the parents perceived some practitioners supported them. However, this varied across organisations as there was variation about the age at which children and young people services ended, from sixteen in social services, to nineteen in education and to twenty-five years in palliative health care. This lack of consistency meant there was limited joined up thinking for an integrated service provision for my older participants James, Nick, Matthew, and Lily-May.

## **6.6 Hindrances to participation**

When exploring across the data sets what the barriers were to participation in RAs for disabled children and young people, three subthemes were identified. These were undermining attitudes, being treated differently and the impact of pain on participation. These were all social forces which curtailed the emotional WB benefits for the children and young people. Most parents had flexible working arrangements which helped regular participation, but Bree's Mum worked on a rota which limited her time to support Bree with participating in RAs.

### **6.6.1 Undermining attitudes**

There were some examples of where the parent's felt their child was not given respect by behaviours perceived as unhelpful. Lily-May had experienced the disabled toilet as a 'dumping ground' and Poppy's parents perceived that even his special school did not include him as



much in school trips, due to his inability to walk. Bree's Mum encountered difficulties when trying to organise the school holidays, as the special school's play-scheme was planned at the last minute when some funding became available. This made it hard for them to organise their family holiday as Bree's Mum's quote highlights:

*"It's completely random, I only found out 2 weeks before that they were actually running it, they have to manage to scabble bits of funding, then this year there was a problem with a license that they had applied for. I don't know what it was for, but it seemed to take forever to get hold of it, so they couldn't send details out until about 2-3 weeks before term ended. It was really, really difficult."*

It was not clear what the licence was for that delayed these arrangements for the disability play-scheme, possibly for insurance purposes. However, it added to the stress for the family, who had to work around this uncertainty, to organise their own holidays with their touring caravan. So even in specific disability activities, there were issues with uncertainty of funding that restricted parents' choices to send their children and young people.

Clare's Mum experienced negative attitudes when seeking to enter some venues as the large, powered wheelchair was placed on par with a pram at the literary festival. Also, Matthew's Mum was infuriated by the 'inclusive' sports event that could not cater for his care needs. Additionally, Nick's Dad was very disappointed with the attitude that the scout movement could not accommodate him, when he had become too old for cubs. Although he continued going to cubs, this would have to end at some point when he matured into adulthood. So, when he was met with these undermining attitudes, Dad was discouraged. These negative attitudes highlighted being treated differently to the children's siblings and made the families feel less valued.

James's Mum reflected how attitudes towards him affected her family adversely, as her quote highlights:

*"But James's older brother was quite aware of people staring. I said don't let it get to you. It's their problem not ours. Old people make me laugh because, it's not so bad now he's a bit bigger,*

*but when he was little, they always used to go and pat him on the head and some people can be downright rude and they will ask awful questions and you think I don't know what James can take in. And I certainly am not going to talk about his brain damage in front of him."*

Poppy's parents also felt that older people were more prone to stare or pat him on the head as well as others who asked inappropriate questions in front of the children and young people, as if they were not there. So, these negative social forces hindered the children and young people storylines, as if they were invisible. These parents were both in the LPG and had to find constructive ways to handle public perceptions of their disabled children and young people. The other participants did not overtly mention staring but described many situations where their differences made them stand out and drew attention to themselves.

#### **6.6.2 Parental views of being treated differently**

Each child or young person was unique and required some level of adjustment to cater for their needs. It was usually necessary to make some reasonable adjustment to make participation in RAs possible for disabled children and young people. However, sometimes the way that people reacted to the children and young people made the parents feel they were being treated differently, in a negative way. The parents often found other people's reactions stressful and so often chose to participate separately. For example, Poppy's parents tended to avoid big crowds because he did not relate to other people and sometimes how people reacted to his noisy shouting by staring, made Mum feel embarrassed. An example of Poppy participating on a fairground ride is shown in Figures 59.



**Figure 59: Poppy at fairground ride**

Poppy enjoyed the ride as reported in the diary, so he and his parent's WB was supported by their decision to go when it was quieter, but it did not increase his social participation.

Some parents felt their children and young people were not included to the same level as typically developing children in RAs. When they had other children, they could compare what was on offer for their siblings, such as Matthew, Bree, Lily-May, Nick and James. One example of where some of the participants perceived they were treated in a negative way to others, was across the online booking for cinema and theatre tickets. This was James's, Clare's and Poppy's mother's experiences. If you were disabled you did not seem to be able to book online like everyone else and be confident it had worked, it always involved at least one phone call as well. Even then, at some venues, as Clare's mother highlighted with the fire hazard at the music arena, it did not ensure that any safe reasonable adjustments to enable participation were made.

Holidays were another area where sometimes they were treated differently. This was highlighted by Poppy's parents on their holiday to Finland:

*"Mum: I made about 18 phone calls before we went, the flight was brilliant, they were all prepared for us, but they hadn't contacted the resort to tell them that we were there with a*

*disabled child. They didn't help us going on any trips, to get on the bus, or to save a seat at the front, so we didn't have to cart him all the way to the back of the bus, wearing full on five layers they didn't ask anyone, you know, can you just move back a couple of seats so, they didn't help at all..."*

So, on this holiday experience Poppy was treated the same as everyone else, but his needs were different. This lack of recognition to adjust for his needs, made this stressful for Poppy's parents, but possibly he was unaware of the impact upon them.

Another holiday example of being treated differently was highlighted by Clare's Mum about going on an aeroplane. Advice on the website suggested buying a special 'Crelling' harness, which was then contradicted by the airline staff who would not permit her to use it, due to their revised policy:

*"I did have to buy a 'Crelling' harness which was 100 and something quid... So she could sit on the aeroplane with a harness to hold her up otherwise she would just fall over sideways..... when we got on there they wouldn't allow us to use it (laughs) and they only had one extra one of their supportive harnesses, which another child had because she's worse at sitting up than Clare, so we had to use this luggage strap under Clare (laughs) to hold her and wrap her with pillows to prop her up and stuff....."*

Thus, Clare's comfort and safety on the flight was adjusted in a bespoke way, to enable her to be positioned to participate in flying and to go on the holiday. However, Mum had to adjust her expectations as she perceived that the advice on the out of date website was not helpful to prepare adequately for the flight and had cost her unnecessary money. This lack of consistency was confusing for Clare's Mum and made her feel Clare's needs were not adequately considered. It was not clear if Clare was aware of this emotional impact upon her mother or if affected her in any way.

Access to older buildings remained a challenge, where ramp access varied. Lifts were temperamental and often broken, restricting access to buildings such as castles and museums. Nick's father had also commented about a hotel in Europe only having one lift:

*“...the European theme park was not good, the hotel was really dreadful in many ways, you know 1 lift in a hotel, which is constantly full of families with pushchairs, never mind a disabled chair with the wheelchair brigade. You know it’s a Theme Park hotel and at what time of the year aren’t there families with young children with pushchairs? And the only way you can get down to the restaurant with the pushchair is to use the lift or make them walk down, hopeless...”*

This was a frustrating experience for them when they had gone as part of a charity group trip. Nick’s Dad’s description of this being ‘*dreadful*’ and ‘*hopeless*’ emphasised the distress felt when the needs of disabled children and young people were not thought about sufficiently. This was stressful for Nick’s whole family on this holiday. Whilst there was no direct evidence from the children and young people about the negative impact on their emotional WB from these limited accessible buildings, it did however, restrict their participation. Thus, indirectly it affected the children’s potential enjoyment by restricting their choices to participate.

Being treated differently in public spaces also highlighted pressure points for the parents. For example, dropped kerbs were a necessity to get across roads, access parks and disabled parking bays. Parking spaces were not always long enough to enable three metres access behind the WAV to get the wheelchair back in up the ramp, as James’s Mum had described. Nick’s father had commented at RaceRunning that people parked in the disabled bays when they did not need to, which I had observed, which made him very angry. Clare’s Mum spoke about the limited access to venues, such as the literacy festival and stately home they visited where there was a more ‘accessible’ gift shop, which had less choices to purchase. It was not clear why the children and young people and their families should have less choices, possibly it was a health and safety decision. It was perceived by Clare and Lily-Mays’ mothers as excluding them and having an indirect effect upon the children and young people WB. Here it can be seen that they were treated differently but not necessarily to meet their needs appropriately.

Even at social events it was not always possible to ensure their participation, to be able to see what was going on, as Clare’s diary entry by her Mum showed:

*“...Christmas party.... there was a magician, but I couldn't really get close enough to see what he was doing....”*

Clare's experience was at a disability group event, where there were several children and young people in wheelchairs. It was not clear if other people were standing in front or that the numbers of wheelchairs prevented this lack of proximity. Additionally, Nick's Mother had also had trouble in an overnight trip to the aquarium with the charity group, where she could not get to the mobile hoist. This was reported to me by Dad at one of my observations:

*“...the hoist was not accessible as there were a load of blow up beds in the way. P. felt guilty that she didn't feel she could advocate on Nick's behalf to get the hoist to get him on the floor. Nick slept on a blow up bed, she was on a filthy floor. Nick did not sleep at all...”*

Thus, Nick's mother felt disempowered to access the hoist to use for him because of these obstacles in the way. So even at disability activities there were additional barriers to participation. However, the version written in Nick's diary by Mum, gave a different perspective:

*“Went away for weekend with my Mum and charity group and stayed overnight in the sea life Aquarium in 'B'. In the glass tunnel watching the fish all night whilst sleeping on a blow-up bed. Had pizza, burger king and breakfast at Frizzy Ed.s. Had a lovely time with 5 friends. Really enjoyed myself on coach watching the cars go by. But very tired when I got home, didn't want to do anything except go to bed early”.*

Clearly Nick had enjoyed himself, so despite the issues that made it harder for his Mum, he enjoyed participating in this activity.

Although being treated differently was not always a negative outcome, as some were able to cater for the disabled children and young people needs by making some reasonable adjustments. For example, James had been supported to make the bird box and the vet had built a ramp. Thus, this craft activity leader and vet had been able to adjust and include James, whereas those where Nick and Poppy attended, seemed not to have thought about it. This was across both groups, but it was not clear how the children and young people felt, as they could not verbalise their responses, when they were being ignored or stared

at. So being left out of activities made the parents feel rejected, but it was not clear if the children were directly aware of this thus the WB impact of less participation was more of an issue for the children and young people parents.

All of my participants had physical disabilities that made them stand out as different, but some physical spaces did not take account of their additional needs or make any reasonable adjustments. For example, heights of fences were an issue which either restricted the views at zoos and farms such as outlined in James's case study, or limited entry, such as for Poppy with the bat crawl. Thus, these environmental factors excluded the disabled children and young people. This had a negative effect upon the parent's WB but was not always clear if the children and young people in my study understood this. So, it was not possible to say if there was a direct impact upon the children's emotional WB from these limitations, other than it limited their participation choices, which reduced their storylines.

### **6.6.3 Impact of Pain on Participation**

Pain was not evident in the participants in the PG, so this is where the differences between the two groups were greatest. Two out of the three in the LPG, James and Poppy, had pain which had a detrimental effect upon their level of participation in RAs. They seemed to have less fun in their lives and less evidence of WB due to pain and illness. Their diary extracts show how their epilepsy and pain limited their participation in Figures 60 and 61 respectively:

18/7 Jam on to and ward for ankle surgery - Stayed from midnight, first on operating list. Very Sleepy and reluctant to wake up after general Anesthetic. Had to have foot plaster loosened as toes very Swollen.

19/7 Review from Orthopedic Surgeons cut plaster again and toes swollen more and going blue. Home by dinner time.

20/7 Quiet day with leg elevated as his foot is still Swelling.

21/7 Still very quiet but he's got his smile back 😊.

22/7 Had visitors in the afternoon and he was very pleased to see some familiar faces. Eating a little better today.

23/7 Showered him today with plastic boot on, and it seemed to tire him out.

24/7 Pa came and kept shower and he was pleased to see her. Went out for tea although very Sleepy gave him milk feeds today as not awake enough for safely feeding although he did manage choc fudge cake sauce and some ice cream. More awake in the evening. Think a change of scene was good for him.

25/7 Lots of Seizures Not a good day at all. Very Sleepy Buccal.

26/7 Very Sleepy and more Seizures. Buccal.

27/7 Much more awake today and eaten much better, toes are going back to normal and sitting in his chair for longer periods. Had a walk over to Jexo in the evening. a breeze of fresh air. Did some painting with his niece although he wasn't very interested.

**Figure 60: James's Dairy entry: Appetite, Epilepsy and Tiredness**

James had surgery during the study's period and following this he 'got his smile back' which was positive evidence of his WB. Although he did not feel up to doing much as he had several fits which required



emergency oral medication- referred to as ‘buccal’<sup>11</sup>. James’s level of ability meant he was sleepy and not always hungry, which were signs of low WB that needed close monitoring. His lack of appetite could be supplemented with milk via his gastrostomy tube. James’s Mum was the key advocate who tuned into his complex needs in the most sensitive manner, as she “*loved him for who he is*”. This enabled him to participate when he was well enough.

Handwriting difficult to read from scanned diary copy, therefore Poppy’s diary transcript used:

Tuesday 14th November 2017

*There hasn’t been very much going on lately. Poppy has been getting a lot of tummy pain again. This is very upsetting for all of us as he doesn’t want to do anything or go anywhere. He hits his head a lot with the pain and cries a lot. This has gradually been building up for about a week.*

*The only playing he has been interested in, has been spending a long time playing in the shower. He has been doing this a couple of times a day for the past few days for about an hour each time. He stands up and walks to the sink turns on the taps and splashes in the water around him on the floor. It has been very calming for him and also distracted him from the pain.*

3rd January 2018

*Poppy went for a lovely walk around C. Gardens, through the leaves and watching the river. We intended going to Winter Wonderland but it was very, very windy, so we stayed in the park for about an hour. It’s very difficult to stay out any longer in places that don’t have changing facilities, particularly in winter because it’s too cold to change him on the floor.*

**Figure 61: Poppy’s diary entry: Pain, Head Hitting, Water Play and Lack of Changing facilities**

In Poppy’s diary entry, shown in Figure 61, he found playing in water calming and a distraction from his tummy pain, which caused him to hit his head. This was evidence of a low emotional WB state and was an intermittent pattern of behaviour seen in the diary. The calming behaviour of water play improved Poppy’s emotional WB showing a more positive state. This tummy pain increased Poppy’s bowel activity, which meant access to changing places toilets were paramount for any

<sup>11</sup> Buccal is an oral medication put into the mouth as an emergency medication for epilepsy

participation in RAs outside the home. As can be seen in the 'lovely walk', the lack of changing facilities limits how long they could be out. Poppy's parents were strong advocates for his need to participate, but it was challenging for them with his fluctuating levels of pain.

## **6.7 Summary of across case analysis**

In summary, the three themes were Participation enhancers; Champions for disabled children and young people's emotional WB and Hindrances to participation. Whilst some had many choices, some had few, but the children and young people themselves could choose not to participate, even when present at the RA, demonstrating their own agency. Thus, their storylines were determined by a mixture of their intentional behaviours and the social forces of people, who could navigate the specialised equipment in environments suitable for them to be physically positioned, to choose their level of participation.

I observed intentional behaviours with Bree, Nick and Poppy choosing not to participate, demonstrating their own self-advocacy. There were some examples of bespoke disability activities such as RaceRunning and the relaxed orchestral performance. Such choices helped meaningful participation in RAs for these children and young people making it fun for them, thus enhancing their emotional WB. Parents were the key advocates to promote their child's participation and this was supported by some helpful professionals who also acted as advocates. A key enhancer of participation were the innovative designs in RAs such as the bike riding, surfing and skiing. These were supported by volunteers, who were equipped with training to support some reasonable adjustments. These helpful attributes in people and designers of specialised equipment made the parents feel their children were valued, as their needs had been considered.

The hindrances to participation were parental perceptions of being treated differently by undermining attitudes and not making reasonable adjustments for the children and young people needs. Pain remains a hindrance that limits participation in RAs. The lack of choices was evident in the limited activities the children and young people did, with

many participating in the same groups. There was also a waiting list for the disabled swimming group which affected Bree. These factors contributed towards the parents feeling their disabled children and young people were less valued, as there were less choices for RAs for them in society. The next chapter will discuss these findings in relation to positioning theory and how I have adapted this, to include the non-verbal children's storylines.

## **7. Discussion**

### **7.1 Introduction**

This chapter will discuss my findings in relation to positioning theory and relevant literature about participation in RAs for disabled children and young people. The proposed attributes of the participation concept are redefined (Imms et al 2016; Adair et al 2018). The process to develop a metaphor of a 'Kaleidoscope of Well-Being' by adapting positioning theory is outlined. How I have adapted positioning theory to include the non-verbal children and young people storylines, by their intentional behaviours, rather than by spoken language, is described. Thus, illustrating their own social forces and control. The disabled children and young people showed they were agents of change, as well as the people, equipment and environments that adapted for their needs, which all influenced their WB responses. The discussion is then developed under the three main themes from the across case analysis: participation enhancers, champions for emotional WB and hindrances to participation. Contemporary factors are explained that have an impact on my study's findings. The affirmation model of disability and physiotherapy moving forwards are discussed, ending with a chapter summary.

### **7.2 Participation concept redefined**

Building upon Hart's (1992) participation ladder and Treseder's (1997) circle of participation for decision making and my previous proposed wheel of participation for physical activity choices (Pickering et al 2015), Imms et al's (2016) systematic review now suggests that researchers and practitioners should now agree on how to define the 'participation' concept, to encompass a wider understanding. This is moving away from the WHO ICF's (2001 p.10) definition of involvement in life situations, which was illustrated in Figure 5 (pg 17). Imms et al (2016) proposed the fPRC, with two main ideas of attendance and involvement. These are supported by preferences, activity competence and sense of self, including motivation and social connection. Thus, this definition of participation is more specific to disabled children and young people and is a welcome suggestion, to advocate for their

needs. Thus, participation can be thought of as being in attendance and involved in some way, according to the children and young people preferences.

Adair et al (2018) has reviewed the measures that captured the fPRCs of attendance and involvement, suggesting that it was sometimes difficult to separate these two out, revealing the complexity of participation. Adair et al's (2018) review only included quantitative measures, which for the non-verbal children and young people were reported by proxy, thus being a limitation of the children and young people's own experiences. As my research has focused on non-verbal children and young people with limited mobility (GMFCS and CFCS III-V), these aspects of their own attendance and involvement are brought out within each theme, telling their stories. This is related to positioning theory, which I have adapted, due to its previous focus on spoken language, to express their storylines from the children and young people intentional behaviours (Harré and Langenhove, 1999). Because of the disabled children and young people's fluctuating storylines about their WB effects from participation in RAs, I will now outline how I came to view and represent my data as a kaleidoscope and how this influenced my decision to adapt positioning theory as previously illustrated in Figure 7(pg 45).

### **7.3 Kaleidoscope of well-being**

My findings were not binary, in relation to the two groups of participants (PG; LPG) as there was overlap between their views, experiences and choices. It was more like a kaleidoscope with a blurring of boundaries between the two groups (Cambridge English Dictionary 2020). A found image of a kaleidoscope is illustrated in Figure 62.



**Figure 62: Kaleidoscope found image (publicdomainpictures.net, 2020)**

As the colours of a kaleidoscope vary with the degree of 'light shining through', how I interpreted the children and young people variations in WB was reflected by different colours that mirrored the differences between the WB effects from their level of participation. Some patterns in the data showed enhanced participation that colourfully and brightly illuminated the children and young people WB, showing joy and fun in their lives as if the 'light shining through' lit up the vibrancy of their emotions. Some data were blander, reflecting the barriers to participation in RAs and evidence of a lower WB effect, suffering pain or making them and their parents sad, angry, or indifferent. I saw these colours as darker and a dampening their emotions as if the 'light could not shine through'. Colour preferences are subjective, but how the colours were represented in my interpretation is related to how much light could shine through to indicate their WB state from their preferred level of participation in RAs. The children and young people themselves could determine their level of participation, by choosing either to join in

or not, when attending an activity. Their own internal WB acted as their own barometer, despite the positive initiation of their parents, staff or volunteers to enable them to attend, they sometimes chose not to be involved. So, the children and young people determined their WB by choosing to be involved or not, thus creating their own storylines by actions not words (Harré and Langenhove 1999). This was challenging for everyone supporting them, who had perceived the children and young people main aim would be to join in. The non-verbal children and young people had more control than I realised at the beginning of the study, showing **me** their own self-determination in an unexpected way.

#### **7.4 Positioning Theory Adapted**

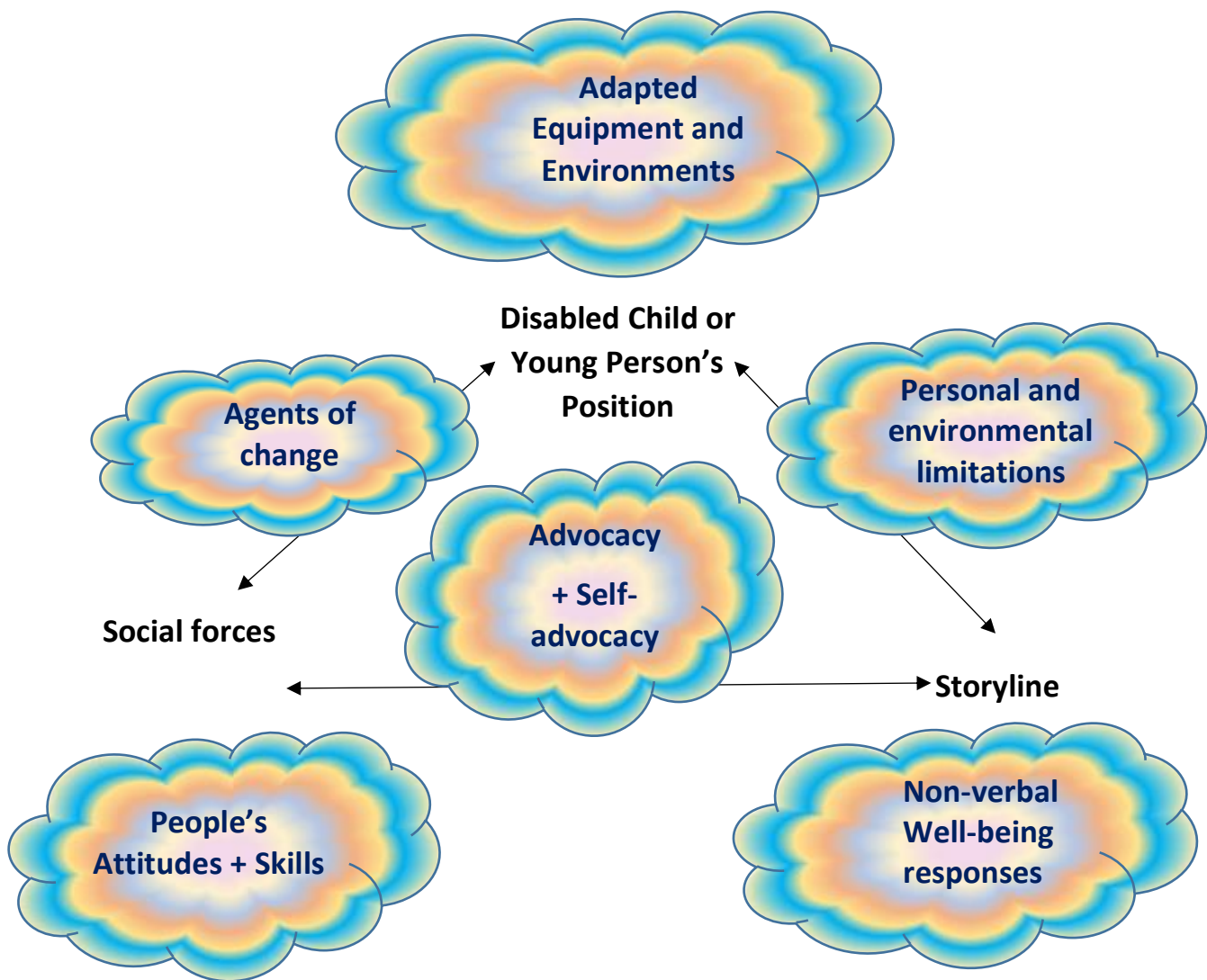
My study initially focussed on the physical positioning of children and young people with cerebral palsy at the RA in order for them to choose to participate to benefit their WB. As data collection progressed, I realised that it was more than just their physical position that was important, their social position was equally valid and, in some cases, more important to the child participants themselves as expressed by their intentional behaviours. Therefore, I am now reasoning that from a positioning theory perspective, it is possible to adapt this theory, previously based upon spoken language (Harré and Langenhove 1999- Figure 7-pg 45), to include those with non-verbal communication. The children and young people determined their level of participation by their intentional behaviours, when positioned both physically and socially at the RA, which reflected their fluctuating WB states in their storylines. Hence, showing they could be their own agents of change, self-advocating their WB. The children and young people's storylines were also influenced by the social forces of people's attitudes and skills, to advocate for their needs, as well as having adapted equipment and environments to support their participation in RAs.

Harré (2012;2015) defined 'Positions' as beliefs about the rights and duties in a given social condition, whereby the powers and vulnerabilities of those in the storylines can be contested, refused or assigned. Parents may well contest the lack of opportunities for RAs, but the participants in my study could not easily express this

themselves, but only act in response to opportunities provided. James (2015) also suggested that other discourses, as well as speech, could be utilised in the storylines within positioning theory. Thus, I needed to adapt the storylines in my study to include the children and young people's intentional non-verbal behaviours, rather than speech. The intentional behaviours are the actions the children demonstrated with intent, to choose to participate or not in the RA which they were attending (Simmons and Watson 2014). As far as I am aware this theory has not been applied to children and young people with cerebral palsy. I am therefore reframing this and, I believe, adding to existing knowledge.

The people, adapted equipment and environmental factors including the children and young people themselves, became the agents for change, to facilitate and enhance participation in RAs. This was despite the children and young people not having a spoken voice, I believe that their intentional behaviours illustrated their choices, and they were able to self-advocate their wishes. As these experiences varied with availability of equipment, suitable environments, different people's attitudes and the child's health state, the colours of the kaleidoscope fluctuated according to whether the child chose to join in and participate, if they enjoyed the experience and benefitted emotionally. This is represented in Figure 63 below:





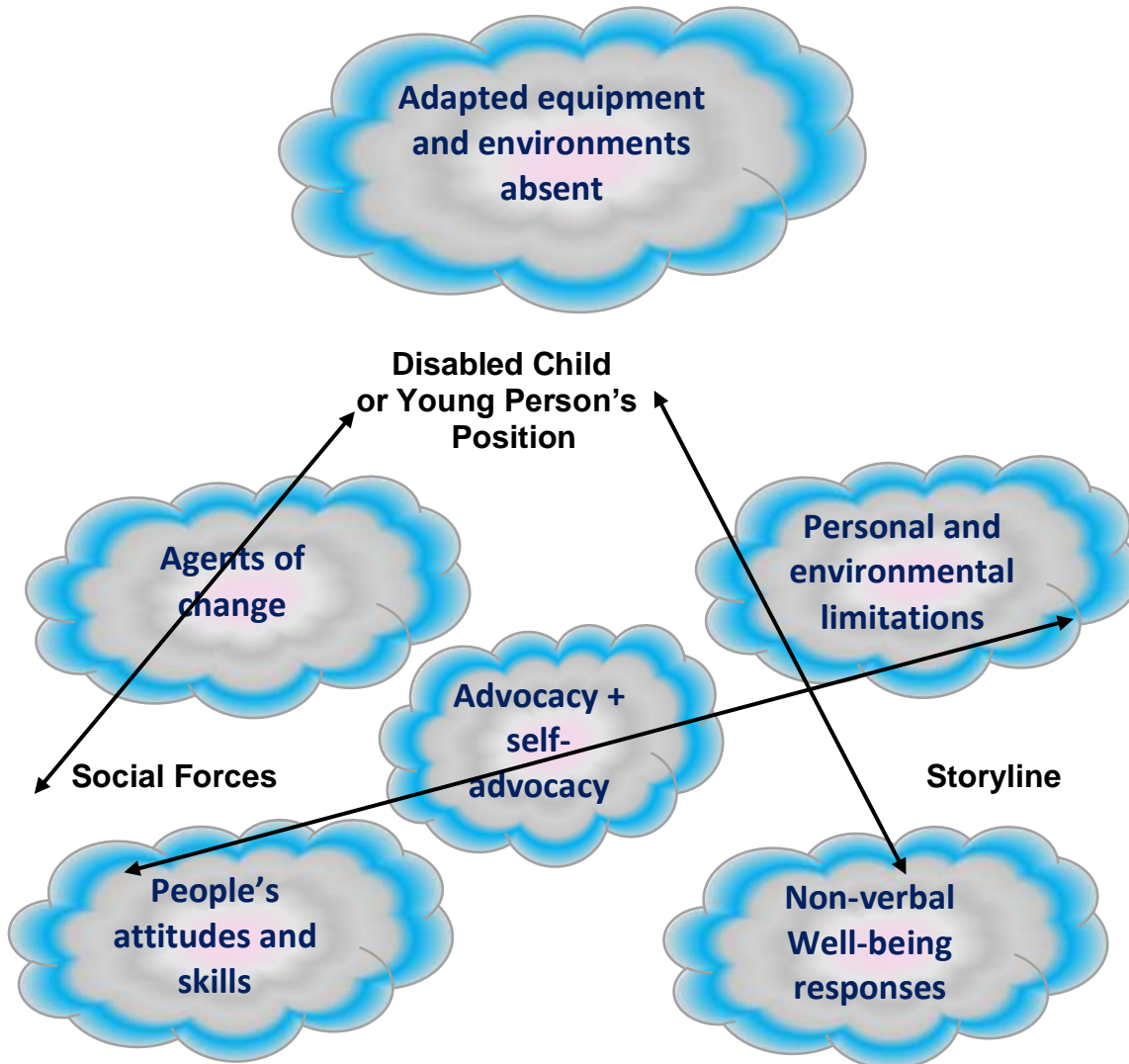
**Figure 63: 'Kaleidoscope of Well-being' for disabled Children and Young People's participation in Recreational Activities - adapted from mutually determining triad from Harré and Langenhove (1999 pg. 18).**

Figure 63 illustrates my proposed 'Kaleidoscope of Well-being', adapted from the mutually determining triad as previously shown in Figure 7 (pg 45). Figure 63 demonstrates the triad of the disabled children and young people's position in adapted equipment and environments, engineered to enhance participation in RAs; the social forces of attitudes and skills which could enhance participation and the resulting storyline that showed the WB effect from their participation in RAs, expressed non-verbally. Central to this, is the role of advocacy to promote their participation, including self-advocacy and both the

designs in equipment and environments, together with the people, including the children and young people themselves, acting as the agents of change, facilitating their WB responses. All the clouds are in front of the arrows illustrating the priority given to each dimension that contributed towards their WB from their level of participation in RAs. The bright colours and the symmetry of the triad illustrate when positive WB is evident from their attendance and level of involvement in the RAs. I have chosen to illustrate this with Bree's case study. Bree was able to start cycling, continue with the Touch Trust and enjoyed the relaxed orchestral performance. The joy and fun she experienced are reflected in the bright colours in Figure 63's Kaleidoscope of well-being. Even when she chose not to participate, as described when walking to the playground, sometimes she would just sit down and not move, Bree was showing her own agency through this behaviour, determining her own control as a way of self-advocating her wishes.

However, if any of the factors were not supporting the children or young people to participate, the whole kaleidoscope was skewed and had duller colours as shown in Figure 64. Figure 64 illustrates that when the adapted equipment or environments were absent, the child or young person could not be positioned to try the RA, thus their choices were diminished. The arrows are shown going across the factors that influenced their level of participation in RAs, as an indicator of barriers. The arrows between the child's position, the social forces and their storylines were disjointed and asymmetrical, resulting in limited storylines that support WB. The misshapen arrows do not form a mutually determining triad and are seen crossing, as a barrier to participation in RAs. This can be due to wider issues, such as a lack of consideration for their needs, in terms of environments being adjusted or adapted equipment being provided, negative attitudes or possible staff training needs. In Bree's case study this was highlighted by the lack of access to a suitable play scheme that could cater for her toileting and mobility needs. This duller kaleidoscope represents a lack of agency for the children and young people, whose voices remain silent, as if veiled by a lack of choice and voices unheard. This

potentially reduces their ability to self-advocate for their own WB and the overall impact is a lower well-being effect, with my participants remaining unrepresented in RAs.



**Figure 64: 'Kaleidoscope of well-being' illustrating a skewed mutually determining triad, with grey clouds when factors adversely affected well-being.**

Disabled children and young people are not meant to live in isolation, so will always be dependent upon others to optimise environments, design equipment and support them to participate in RAs, if they wish to join in (Vogts et al 2010; Palisano et al. 2011a,b; Colver et al 2012; Anaby et al 2013; Shields et al 2015). So, by being connected to others who embraced their limitations and celebrated their WB, their participation was enhanced. Hence the colours of the kaleidoscope

reflected their WB responses, but ultimately, they could be their own agents of change, by choosing their level of participation as a way of self-advocating their wishes. However, the choices available were not on an equal basis as those for typically developing children.

Slater (2013) has argued that the identity of disabled youth is constrained by the predominant ableism in society, whereby normative prevails suggesting that they are somehow deficient as people. Slater (2013) suggests that there is a paradox between liberating and oppressing disabled youth. In my study, the disabled children and young people were active agents and yet were constrained by the limited choices available to them. Thus, an imbalance of some RAs which had been adapted and some with the potential to still be developed. A choice between the freedom to participate and the oppression of a lack of reasonable adjustments for RAs not sufficiently thought through. Disabled children and young people identity was therefore compromised, by this lack of adaptation in RAs choices, reducing their ability to be positioned or express their preferences.

In my study, whilst the children and young people were physically positioned by someone else, ready to participate, the spaces in which they were able to be positioned did often constrain their social interaction. Smith (2017) using an ethnomethodology with adults, including participant observation with some visual images, argued for the importance of positionality in a space to enable communication to take place. The children and young people in my study chose whether to socially interact, by non-verbal means, not spoken language. However, they had to be physically positioned to interact in their preferred manner, in a suitable environment and sometimes using adapted equipment. It was never possible that the children and young people in my study could do this without other people to support them, which links to Nicholls et al's (2016) idea of connectivity.

Nicholls et al (2016) describe connectivity as a concept that defines people's abilities by their relation to other entities such as people, technology, environments or objects. In my study, based upon adapting

positioning theory, these entities helped to construct the social forces, which affected the potential for the disabled children and young people participation in RAs and influenced the impact upon their WB. Thus, the kaleidoscope effect of their fluctuating and changing emotional responses to their experiences, which were supported by different equipment, people and environments as shown in Figures 63 and 64 (pg 207, 209).

The three themes from my findings will now be discussed in relation to the literature supported by participant's examples. It is not my intention to repeat the data extracts, but where relevant the Figure (pg number) will be referred to for clarity.

## **7.5 Participation enhancers**

The attributes which enhanced participation in RAs for my participants, included some innovative equipment and environmental designs such as the adapted surfboard and some reasonable adjustments for example the changing places toilets. These were successful with parents and the people who advocated on their behalf and volunteers who were equipped with the equipment and relevant skills for the activity offered for participation in the RA. More will be developed around advocacy under the second theme of champions for WB. The focus here will be on what enabled and enhanced their participation by some form of reasonable adjustment to equipment or environments, which reflected the 'can do' accepting attitudes of the people involved. All the children had to be 'positioned' to enable their participation in RAs to take place and fatigue was a factor that often limited their physical participation.

Thus, from a positioning theory perspective, their storylines were illustrated from the RA they participated in and the people who supported these, in the accessible environments (Harré and Langenhove 1999). This was in keeping with Article 31 of the UNCRC about their right to relax and play (UNICEF 1989 pg10). By positioning the disabled children and young people in readiness for participation at the RA, they had the choice to be involved, if they wanted to be. Thus,

showing their own agency when they declined to participate, advocating their own WB.

### **7.5.1 Innovative designs**

Luck (2018) proposed that engineering designs for disabled people should be inclusive and involve them in the designs to accommodate for their needs. However, as my study was with children and young people, the only evidence I had where this had happened, was with Matthew as he had been involved in designing and testing the surfboard. Another key design was the tricycle, which six of the seven participants were participating in. For Clare's Mum, this had opened up positive thoughts about the future when she had been only two years of age, but it was getting difficult to get her on and off the bike, as she was taller and heavier, needing to use a hoist. A mobile hoist that could be used outside was the key to achieving this, but this was still a work in progress during the study's period. Getting on and off the trike was also now proving difficult with Poppy, and Nick's Dad was persevering with lifting him. Bree had experienced cycling for the first time during the study and this had enabled the whole family to do a fun activity together for the first time. The children and young people still needed to be positioned on the trike to cycle and sometimes they did not seem to want to participate, as some storylines highlighted, again demonstrating the children and young people could be their own agents of change.

Playgrounds were also an area that varied in accessibility, Woolley (2013) suggested that designers and service providers lacked knowledge of how to plan such spaces for disabled children and young people. To support adaptations, Play Wales (2017) developed a toolkit for designing accessible outdoor play spaces and there was evidence from Clare and Bree that there were areas local to them that were adapted. However, if they travelled elsewhere it was hard to locate accessible playgrounds, making it more difficult on holiday to find suitable spaces in unfamiliar environments as most of the provision was for typically developing children and young people. Hodge and Runswick Cole (2013) had researched the play experiences of disabled children, suggesting that all children could develop empathy towards

disabled children. It was however difficult to see evidence that designers of playgrounds always considered disabled children and young people's needs, more could be developed. There remains a gap in online/virtual games that represents and includes disabled children and young people needs, and there is significant potential to explore the virtual platforms that could enhance their participation in imaginative games in the future (Mitchell 2012).

### **7.5.2 Reasonable adjustments**

As well as the physical activities, there were some musical and craft-based activities which others found enjoyable such as the Touch Trust that Bree, Clare, Lily-May and James enjoyed. A relaxed orchestral performance was quoted as really good by Bree's mother. Accessible cinema showings had helped Poppy, Clare, James and Lily-May. James had fully participated in the play-scheme, being gastrostomy fed outside with no one staring at him (Figure 34 pg 135). Thus, there were some less physical RAs which enabled the children and young people to participate in something meaningful for them.

To demonstrate features that can enable effective participation in RAs, Maxwell et al's (2012) systematic review had proposed five attributes which are accessible, available, acceptable, accommodating and affordable. In my data, there was evidence of adjustments being made to regular activities to accommodate for the disabled children and young people to make them available, such as the bike riding, horse riding, skiing, surfing, swimming and the musical and cinema events. The acceptability varied as some participants did not enjoy some activities showing their own preferences by choosing not to participate, demonstrating their own agency. Affordability also varied with preference and whether something was volunteer led or provided by employed staff, such as thirty pounds per session for surfing.

There were less choices than for typically developing children, so availability varied. This is the area that was the most contested by parents, the lack of choices for their disabled children and young people, when no one had considered how reasonable adjustments

could be made to support their participation in RAs. Thus, their positive storylines were highlighted, when RAs were offered that included their siblings and were not too expensive, especially when they made adjustments for their learning and communication disabilities, as well as the equipment and environments being adapted. When this did not happen, the WB effect was reduced, dimming the colours of the kaleidoscope. The sensory types of activities that promoted WB are discussed in the next section.

### **7.5.3 Sensory Based Activities, Self-improvement and Social Participation**

Dodds et al (2015) had shown an increase in health related QoL for children with complex disabilities, from some form of adapted physical activity, including those which were sensory based. This research also showed that this physical activity had beneficial effects to sleep patterns (Dodds et al 2016), which was supported in my data by Lily-May's and Nick's data. Pavão and Rocha (2017) suggest that sensory based therapies could improve function, making a proposal for future research, to look at interventions to increase participation in the community. However, Novak et al (2013) suggested that sensory based activities have a limited evidence base, proposing that more evidence-based alternatives exist, but this review was based upon outdated concepts, so has limited credibility. My study has explored views, experiences and choices for participation in RAs, revealing a mixture of sensory and self-improvement activities, some of which had a social element to them that benefitted the children and young people WB.

What was already known in the literature about social participation related to '*differential valorisation*' which means that the individual's preferences played a role in their enjoyment of leisure activities (Shikako-Thomas et al. 2009 p.8). Stewart et al (2012) and Shikako-Thomas et al (2013 a, b; 2014) both explored social participation revealing the effects of fatigue upon the children and young people physical energy and WB. Some participants in their studies chose social participation over the physical participation as it was too demanding for them. Key findings were that a supportive family and



staying positive, helped them to feel good about themselves. Bult et al (2011) and Livingston et al (2011) had also highlighted the importance of a supportive family to enhance social participation for disabled children and young people. The families in my study were all supportive of enabling their children and young people to participate but sometimes, the children and young people had few choices to be able to explore what they might enjoy doing, thus reducing their agency.

When considering the illustration of the Kaleidoscope of WB, as shown in Figure 64 (pg 210), if the opportunities are not there, then the children and young people cannot be positioned ready to participate in a RA. Then there are no storylines about the WB benefits from their level of participation. The children and young people themselves were not physically able to create spaces to enable even social participation in a RA to happen, thus their agency was diminished, and the colours of the kaleidoscope were duller.

Additionally, Majnemer et al's (2010) study revealed that children with cerebral palsy were more motivated by social tasks, than cognitive or motor tasks, which were too tiring. Indeed, their scores for motivation were higher than their parents scored them, showing the children's perception was different to their parents and that their enjoyment was not always related to their limited physical abilities. Shields et al (2014; 2015) found that across all disabilities, children were only limited in physical activity participation by nature of the severity of their disability. So, their opportunities for social participation were not limited by the extent of their physical disabilities, but those with intellectual disabilities were found to participate less from a younger age. What supported their participation were adults who facilitated this. It was suggested that future research should look at WB and enabling participation with peers, without the parental input. However, in my study, the children were not as easily able to communicate their WB themselves from their social participation, I therefore also needed the parental voices. Thus, the social forces at play that affected their storylines were observed during the data collection by their non-verbal intentional behaviours and parental reporting. These included volunteers with engaging attitudes,

prepared to relate to non-verbal children and young people and staff who were skilled at managing adapted equipment or adapting environments. Whilst my study has found evidence to support the WB effect from their level of both physical and social participation, there was limited data that this was achieved separately from their parents. Therefore, this is an area for potential further investigation.

However, in the LPG, participation was the most challenging for James, who was GMFCS V. It was not that his mother had not considered him participating, it was that there were limited choices for him due to the complexity of his disability. This was similar for Bree (GMFCS III) and Poppy (GMFCS IV). So, from a positioning theory perspective, they did not have the choices to participate as the opportunities were not there. Hence the social forces at play, where people might advocate for their needs and make the reasonable adjustments with equipment and environments were absent. This meant a storyline about their participation in a RA could not be created and they were left socially isolated, potentially reducing the impact on their WB.

Park and Kim (2015) had shown in their questionnaire design study in Korea, that there was significantly less participation from children at GMFCS V compared to Level I. In agreement with Shakiko-Thomas (2009), Park and Kim (2015) proposed that the factors that affect participation are related to the environment, family preferences, and individual interests. Kanagasabai et al (2017) explored choices for twenty-two physically disabled children aged six to twelve in New Zealand. This creative methodology enabled the participants to draw about their experiences of participation in leisure activities. This was analysed through IPA. Although they described having fun, being challenged and achieving something from participation, it did not include children with learning or communication disabilities. Therefore, my study has added to knowledge from this group, but they have limited choices, which is discussed later under the theme of hindrances to participation.

#### **7.4.4 Positive Attitudes that support participation**

Foley et al (2012) reported that the attitudes of people towards disabled children and young people were so important and that their participation may be as 'involvement' rather than activity measurement, which is further supported by Imms et al's (2016) fPRC. Thus, considering how to involve a disabled children and young people might not require additional equipment but a change in attitude. There was some evidence that this had occurred for Bree at brownies (Figures 40 pg146 and 54 pg179) and at the relaxed orchestral performance, James making the bird box and for Nick at cubs.

Lauruschkus et al (2015) did include children who used AAC in their study. They also supported the idea that social participation was the most important feature, and that people's supportive attitudes enhanced participation, which gave them a sense of belonging. In my study, positive attitudes of volunteers or staff were pivotal to all the children and young people WB. This was highlighted for example, by James at the Touch Trust and the play-scheme, Matthew at surfing, skiing and his respite centre, Lily-May at the trampolining park and her Whizz Kids ambassador's club. It was not always clear that they felt a sense of belonging, as their communication styles limited this. Although for Clare at the '1voice camp' this had been a unique opportunity to make music with other children and young people who used AAC. My participant's intentional behaviours were indicators of their storylines from the social forces of supportive people, when the children and young people were positioned at an activity and then chose how they wanted to act. Without the opportunity to attend activities, the children could not express their choice to participate or not and demonstrate their own WB in that moment. The children required support to attend the RAs and those who championed their WB will be discussed next.

#### **7.5 Champions for disabled children's emotional well-being**

The anticipation of participation in a RA for the parents of the disabled children and young people was this could have a positive WB effect. There was also some evidence of employed staff and volunteers who championed their involvement. All of my participants could not

necessarily verbally express a wish to try a new activity. Although how parents heard about things in the community were typically ad-hoc conversations, and it was difficult to find out about adaptations for disabled children and young people. A local authority 'Index' newsletter advertised accessible events in an urban area and Nick, Lily-May and Clare were part of a local charity group organising day trips and holidays. The skiing, surfing and bike riding had all had physiotherapists involved from the beginning, but these had in part now been taken over by parents or voluntary groups. The idea of advocates had been proposed in Cussen et al (2012), Murray et al (2012), Verschuren et al (2013) and Bantjes et al's (2015) studies, but it was not consistent who these advocates were or might be. However, advocacy came out as a clear theme in my study that promoted the WB of the children and young people.

#### **7.5.1 Adult Advocates for Well-being**

Parents and some professionals were the key advocates in my study. Schleien et al (2014) demonstrated the role of parental advocacy using focus groups, their child's safety and WB being their top priorities. Parents in this study were disappointed at times with the lack of positive attitudes to support their disabled children and young people participation in RAs, adding to their stress burden and reducing their QoL. In my study, the parents were the key people who advocated for the children's positive WB states. If they did not advocate for their child, they were not confident others would. In Matthew's mother's interviews, we discussed how she was an advocate for other parents with disabled children in her socially deprived area. Matthew's mother had described the relative poverty in her locality, being in the lowest 4% on the Welsh Index of Multiple Deprivation (WIMD, 2014). In contrast to the literature by Hammal et al (2004), Welsh et al (2006), Davies (2012) and the Institute of Education (2014), where poverty is shown to have a negative effect on disabled children and young people participation, Matthew participated in many RAs. So, he did not appear disadvantaged by his socio-economic deprivation. In fact, Poppy who lived in the top 96%, seemed to have less choices. Therefore, the

factors which impacted upon their choices for participation, were a more complex picture than just the level of deprivation, as some of the children and young people had complex health issues especially in the LPG. Positive attitudes were also key to enabling participation and supporting WB.

Lily-May and James's mothers were anxious about the future, as they were navigating the transition into adulthood where it was unclear what their opportunities for RAs would be. This anxiety was supported by Cussen et al (2012) who had explored future aspirations with adolescents with cerebral palsy. This study used a narrative inquiry method, with two interviews and photographs about the participant's future aspirations including leisure engagement. Their suggestion was for advocates, such as clinicians, to enhance their skills and capability. However, Cussen et al (2012) did not include those at GMFCS V, thus for James this has limited transferability. James had the palliative care team who were advocating for his comfort with pain management with his pressure sores and kidney stone. His foster mother was his greatest advocate and she saw his new social worker pivotal to get on her side, to improve his opportunities into adulthood. Her hope was for a day placement in a sensory based centre, to maximise his enjoyment. Thus, James's storyline was fluctuating in relation to his epilepsy, pain and social forces outside the family unit, which could influence if his WB could be maintained.

Thus, it was clear in my data that the parents championed their children and young people participation and were the key advocates that supported their positive WB as they enjoyed the joy and fun their children could experience. The physical effort of taking them to activities was hard enough, if once there, they did not always perceive the attitudes were positive towards them, as Poppy's pottery experience (Figure 44 pg156) and attempt to get into the bat crawl showed (Figure 45 pg158). In terms of their storylines, the parents managed the social forces by embracing those who affirmed and accepted their children and ignoring, avoiding, or boycotting those who made them feel undervalued.

Powrie et al (2015) support the notion of the importance of a sense of belonging to enhance the WB of disabled children and young people, thus if parents perceived people were not interested in their disabled child they did not feel this sense of belonging. For my study, this influenced how I saw the 'kaleidoscope' of the children and young people WB being illuminated, to maximise the fun in their lives, as Rosenbaum and Gorter (2012) proposed.

Banjtes et al (2015) carried out research in South Africa, about the sport's provisions for disabled adolescents. Their findings also suggested the need for advocates to support the adolescent's aspirations as the demand for opportunities exceeded their availability. It was not clear whose role this would be policy makers, coaches or families. In my study, I explored wider RAs not just sporting opportunities, but there were similar findings in a lack of opportunities particularly in the arts and cultural activities. The mix of urban and rural geographies in Wales, makes opportunities less frequent in the rural communities, such as where Clare lived, as the Bevan foundation (2011) had previously shown. There were parallels in my study with the lack of availability of choices as Bantjes et al's (2015) study had shown.

Whilst the parental role of advocacy was evident in my data, there were also some other professionals who were perceived to advocate on the children and young people behalf, as Cussen et al (2012) had recommended, but this was wider than clinical staff in my study. In my study, Matthew's social worker had negotiated the times he went to the respite centre to optimise his positive behaviours. Franklin and Sloper (2006) had conducted a survey of social services to explore how disabled children were being supported to participate in decision making, which at that time was limited. More recently, Stalker et al (2015) reported on the impact of recession on social work services in Scotland, stating it was under resourced and families with disabled children and young people were not getting enough support.

So, the fact that Matthew had received support was encouraging, that the social worker advocated on his behalf for his WB. This support that

his family received to help them manage his behaviour had made a big difference for them. However, I was not fully informed about all the circumstances that had led to his aggressive behaviour. During my study, Matthew was observed and reported to engage in the RAs offered to him, which had both an energizing effect and calming influence for a period of time. Some of his RAs had been started by physiotherapists. Matthew's mother perceived his invitation to participate in these, was directly related to her level of compliance with the exercises and advice the physiotherapists gave to her. Thus, when Matthew was positioned to take part, his emotional WB was influenced in a way to create a positive storyline with the support of advocates, from both health and social services.

In my study, I looked for the people who were central to their storylines of participation in the RAs to benefit their WB. Thus, by providing advocates to support their involvement, their storylines could be influenced by these people. Therefore, from a positioning theory perspective, when the children did not have a voice themselves and could only act intentionally to show their WB, these advocates facilitated their position to enable participation to take place, thus acting as agents of change, to influence their storylines.

### **7.5.2 Evidence from child and young people participants of self-advocacy for their own well-being.**

The importance of WB in cerebral palsy was identified in the NICE guidelines for under twenty-five (NICE, 2017). NICE (2017) stated the importance of measuring the impact of pain and epilepsy upon their WB. However, this may be a limited way to view their experiences. Despite these symptoms, children and young people may still aspire to participate, by attending and being involved in RAs that can enhance their WB. I was looking for evidence of joy and fun in the children and young people lives as indicators of WB. Lily-May was the only participant who as an ambassador for the Whizz Kids club, showed some evidence in the diary of developing into being her own advocate, with support for her communication style (Figure 48 pg172).

Advocacy from children and young people was illustrated by a recent study, by Brady and Franklin (2019), called 'Research into Plans: Skilled team with Ambition, Rights and Strength (RIP: STARS), who included disabled young people who used AAC. This study revealed that the disabled young people had often felt unable to trust adults, as they had been disappointed with the lack of change in response to their issues in the past. This co-led study sought to redress this balance by providing a creative approach to training, to equip these young people as researchers. This was encouraging that this had included those with different styles of communication. Thus, they were able to become their own advocates to represent themselves, to promote their own WB.

Feeling accepted is another aspect of WB, which was sometimes missing for my participants. Only Poppy's school gave me evidence of WB with his Leuven scales (Laevers 1996; Appendix 18). However, the Leuven scale is quite old and has limited evidence for its reliability and validity. Additionally, Dillon and Carr (2007) sought to report about indices of happiness and unhappiness studies with PMLD children and young people. Their summary of the research studies demonstrated that it was possible to change the environment and the level of social interaction to improve perceived happiness and reduce self-harming behaviours. Hence, the enriched environments and people could change the children and young people WB, but it was not always consistent revealing the idiosyncratic responses of the children and young people. This resonates with my data where the participants were not consistent in their responses and reinforces how difficult it is to measure WB with non-verbal children. However, their intentional behaviours gave insight into their own ability to advocate for their WB.

More recently, Vos et al (2010; 2013) captured the physiological responses from children and young people with PMLD about their breathing and heart rates in response to different stimuli during in a school day. This was to determine what they perceived as harmful or enjoyable. Although this is an invasive approach to doing research on children not with them, this validated the children's behavioural observations as emotional responses to noxious or pleasurable stimuli.



Additionally, Lyons (2013) in her PhD thesis, developed her own observational scale from their emotional responses to positioning in equipment, which was less invasive. Lyons et al (2017) reported that attentive and experienced caregivers can read the behavioural expressions of disabled children and young people, which can indicate their WB status. The children's positive WB responses included being calm and relaxed, smiling, a lack of extensor spasms and clapping. I observed and had these types of behaviours reported to me during my study, but there was a lack of consistency in their intentional behaviours, sometimes making their responses unclear to me. For example, it was difficult for me to distinguish a grimace from a smile, indicating pain or pleasure.

However, the parents were the key people who tuned into their children and young people emotional WB responses at RA's in my study, to help me interpret their intentional behaviours. This ability to attune to another's needs has been called '*empathic attunement*' by Carnevale (2009 p.173), this is based upon a hermeneutic concept of understanding another's emotion as a fluid state that can change. The context of Carnevale's work is suffering, whereas I was looking at the opposite, for evidence for WB, but he argues that emotion is not an objective truth and can vary. Carnevale et al (2017) propose that children with complex health needs are relationally embedded agents, whilst still dependent upon their parents to support their interests. This was more apparent in the LPG children who had more complex health issues. Carnevale (2020) further proposes that children's voices provide a morally meaningful expression of agency, including those who communicate differently, which my study has highlighted from both groups. My proposed 'Kaleidoscope of Well-Being' illustrates the children and young people variation in emotional responses from their participation in RAs. Their determination to participate or not, showed their agential choices to manage their own WB. Whilst the children and young people showed their own determination to express their WB, there were some hindrances to their participation, which are discussed in the next section.

## **7.6 Hindrances to participation**

My interpretation of the data suggested that factors which acted as hindrances to participation were a lack of opportunity and choices, personal illness factors, non-verbal communication, resistant attitudes and the limitations of volunteers.

### **7.6.1 Lack of opportunity and choices**

In Wales, the disability sport's opportunities such as adapted cycling, skiing and surfing, had received some investments which was supported in my data. However, the wider arts and cultural activities were underdeveloped for disabled children and young people. Therefore, if this is not on the policy maker's agendas, then those who provide RAs in the community may not consider their needs. So, the disabled children and young people wider participation opportunities and choices remained patchy and limited. Hence, their storylines were determined by their social opportunities according to where they lived in Wales (Bevan Foundation 2011). Clare, who lived in a more rural area, had to travel the furthest to access adapted RAs, thus her position geographically influenced her choices, making it more of an effort to participate, due to the additional travel time required.

As discussed earlier, the lack of choices did not necessarily appear to relate to their level of deprivation but to the complexity of their disability (WIMD 2014; Institute of Education 2014). In the LPG, Poppy had additional digestive problems and autistic traits, Bree had unpredictable behaviours and pressure sores and James had epilepsy, pressure sores and chronic pain. Thus, in terms of their positions in their storylines, these factors which limited their participation in RAs, created a mist over the Kaleidoscope of WB, meaning their emotional WB was shrouded and not always evident. These unpredictable factors made it difficult for them to attend the limited choices for participation.

Shakiko-Thomas and Law (2015) analysed disability-related leisure policies in Canada, identifying that few policies exist to support leisure promotion specifically for disabled children and young people.

However, in Canada there are now financial incentives such as tax credits, for increased participation across society, although this has yet to be formally evaluated. It is not yet clear how Canadian policy makers are addressing the needs of non-mobile disabled children and young people, to develop new opportunities. Thus, from a positioning theory perspective, the social forces at play at policy maker level, could potentially influence the storylines for disabled children and young people emotional WB, if more investment for their needs were considered to increase their choices. In Wales, it is not clear if this is an active process to focus on the needs of non-mobile disabled children and young people, to determine who might be the agents of change, to influence increasing their opportunities and choices moving forwards.

Parents expressed frustration at the lack of choices for RAs that could enable their child to play and have fun. For example, Poppy's mother felt there needed to be better signposting for how things could be adapted for disabled children and young people who cannot follow instructions. Graham et al (2015) explored parent's understanding of play and amongst their findings the 'burden of play' was revealed. This illustrated how parents of children with cerebral palsy found it challenging with of the amount of time and energy needed to initiate play and the burden of finding someone else to support their child with this. In my study, those who had other children or extended family close by, utilised them (Nick, Lily-May, Bree, Poppy and Matthew) where possible. However, Clare needed a wider network to help achieve meaningful play and participation due to living in a remote rural area. This wider network included parental led charity support groups, which arranged day trips and holidays. For James, who was fostered, there was more evidence of nursing respite and day care, to give his mother a break, rather than participatory choices, due to the complexity of his disability, evidenced by pain and epilepsy. Relating this to positioning theory, these hindrances to James's participation created a veil over the kaleidoscope, making the colours dimmer in terms of his WB. James's physical symptoms masked his WB, making it difficult to determine his

emotional responses at times. Thus, for James, the effects upon his emotional WB were less transparent from participation in RAs.

The disabled children and young people's position at the activities influenced their storylines, where sometimes the opportunities for participation were with their siblings and sometimes without. From the child's perspective they may enjoy doing things without their brothers and sisters, but it was logistically difficult for the parents with younger siblings. Parents of Bree, James, Lily-May, Matthew and Nick therefore wanted opportunities that included the siblings some of the time. The disability activities which did not include their siblings were horse riding and swimming. This was partly due to the numbers of volunteers required and health and safety factors. Hence the vibrant colours in the Kaleidoscope of WB could be reduced to duller colours or be veiled by this lack of choices.

#### **7.6.2 Chronic Pain**

Chronic pain was also a barrier for James and Poppy in the LPG to participation in RAs in my study. Dang et al (2015) explored the impact of pain in cerebral palsy, with seven hundred and forty-three participants, using the valid and reliable Parenting Stress Index (Short Form); Strength and Difficulties Questionnaire and LIFE Habits questionnaire (Abidin 1995; Goodman 1997; Noreau et al 2004). Dang et al (2015) demonstrated that pain, psychological factors and parental stress were significant factors ( $p < 0.01$  to  $p < 0.001$ ) that impacted on less participation in adolescents aged thirteen to seventeen years. As this was a follow up of previously studied group of young people, at the ages of eight to twelve years, this large sample size gives confidence in the findings, reflecting the power in the study's design. However, a limitation of this study was the lack of transparency in representing non-verbal children. A recommendation was made to consider interventions in childhood to reduce pain, manage psychological difficulties and parental stress prior to adolescence, which are considered to be modifiable factors. In my proposed Kaleidoscope of WB, pain was evident as a personal factor which hindered participation. Pain remains

a barrier to participation in RAs due to the limitations of not being able to be positioned in suitable equipment, possibly due to contractures.

### **7.6.3 Barrier of Non-verbal Communication**

Lily-May, Nick, Clare, Bree and Poppy's parents all felt that their children's limited verbal communication was the biggest barrier to participation, limiting the verbal aspect of their storylines. This was across both the PG and LPG. In Bailey et al's (2015) systematic review, the benefits for disabled children and young people from participation, included an increase in self-esteem and confidence, however, they had not been able to represent those with non-verbal communication, thus they remain an under-represented group. My study has contributed knowledge from these non-verbal children about their WB by demonstrating their enjoyment of some adapted RAs. However, it is difficult to demonstrate an increase in their self-esteem and confidence, as there are not currently clear indicators of how this could be evaluated for these children and young people. Although, if they attended and continued to be involved in the activity, this at least maintained their level of participation, both physical and social, and meant they were involved, to the extent they chose, thus benefitting their WB.

### **7.6.4 Resistant Attitudes**

The reported negative attitudes of some people such as volunteers or older members of the public, either directly or indirectly were strong features in the interview and diary data. I did not observe these attitudes directly, but that could have been the researcher effect of me being present, making people behave differently during my observations (Creswell 2013). The perceptions from the parents of these people's responses were conveyed to me during the interviews. Examples of this were Nick's father talking about the craft event he went to when they seemed disinterested in Nick's 'modest creation' and Poppy's experience at the pottery group, as well as how people were reported to react to him in the community with his loud shouting. Bree's mother had encountered resistance from play staff to accepting her at a

play-scheme and this was echoed by Merchant and Merchant (2018). Wendy Merchant (2018) had the same issues with her son Jamie, when seeking to access a play-scheme in order to work. These issues were related to the level of supervision and toileting needs. However, Merchant and Merchant (2018) suggest these barriers were related to a wide range of factors that included limited policies, poor design of services, the boundaries of professional ethics and practices, and the constraints of the law.

These reported resistant and negative attitudes could be a lack of readiness to 'empathically attune' into the disabled children's play needs as proposed by Carnevale (2009). Or it could be a reflection of their lack of experiences and social confidence in relating to non-verbal children, having enough time to respond appropriately or a lack of sufficient resources. These parental perceptions influenced the children's storylines in a negative way, reflecting the social forces that would counteract the children's emotional WB, pulling them away from the storylines of potential enhanced benefits, from attending and being involved.

Odongo and Davidson (2016) applied positioning theory to explore attitudes of Kenyan teachers towards inclusive education. This was a mixed methods study which looked at how the teachers positioned themselves and their pupils, to enable them to have a positive sense of themselves as learners. This study had one hundred and forty-two participants in the questionnaire stage and twenty in the focus groups. A limitation of this study was the lack of validation for the Horne and Timmons (2009) questionnaire used and although the focus group questions were transparent, there was limited discussion of the trustworthiness of data analysis, undermining its credibility. Odongo and Davidson (2016) refer to intentional and interactive positioning by the teachers and demonstrated that the years of experience they had teaching with disabled children, influenced their positive attitudes with a significant correlation  $p > 0.05$ .

Although this was a useful study, applying positioning theory more recently, it has to be treated with caution as it is from an African country, where positive attitudes in society to disabled children are still evolving from a position of shame and punishment (McKenzie and Chataika, 2018). If Odongo and Davidson's (2016) study supports that experience is an important factor in positive attitude development for teachers, who have a professional training, it is possible that this might be a factor which could influence positive attitudes in volunteers. Hence the limitations of volunteers, who have not received training in how relate to disabled children and young people, will be discussed in the next section.

#### **7.6.4 Limitations of Volunteers**

Whilst volunteers were essential for many of the RAs to take place, there were mixed reports of their helpfulness. Nick's father was particularly critical of the bike hire facility, whose hoist was not accessible, and the volunteers were apparently not trained in how to use it. Bree's mother had two university student volunteers but as one of them could not swim, they could not take Bree swimming. This would really have helped Mum as she could not manage on her own to take Bree and her sister together.

Lindsay and Cancelliere (2018) explored the experiences of child volunteers with disabled children to see how their social confidence developed. Their study analysed thirty in-depth interviews, with both disabled and non-disabled children, who were the volunteers. They found that the volunteering enabled them to develop appropriate communication skills, positive attitudes and empathy which built their social confidence. Participants expressed being taken out of their comfort zones in relating to people different to themselves, quoting that they had felt uneasy before volunteering around disabled people. This included disabled children relating to their peers with different disabilities, which was innovative and demonstrated the benefits of volunteering. Thus, Odongo and Davidson (2016) showed that the

intentional and interactive positioning of teachers can enhance their experiences by building their confidence to relate to disabled children, it is also possible, as shown by Lindsay and Cancelliere (2018) that disabled children and young people can learn to relate to other disabled children and young people and vice versa.

## **7.7 Contemporary factors influencing my study's findings**

The three main themes have been discussed in relation to my findings, however there are two additional contemporary factors related to austerity and COVID-19 that have do have bearing on the context of my study which will now be discussed.

### **7.7.1 Austerity and COVID-19**

Austerity in the UK is related to Government decisions to reduce expenditure that have made hardships for people disadvantaged in society, such as families living with disabled children and young people (Churchill, 2018). Horridge et al (2017) carried out a large European survey about the impact of austerity on both families and health and social care professionals. This revealed that families felt their disabled children and young people health and WB needs were not being met, compared to three years previously. Horridge et al (2017) compared areas across Europe, with and without austerity, and found that for the families whose children were totally dependent (GMFCS V), that their needs had not been met for ten years. So, whilst the embracing of disabled children and young people needs and rights at a local authority and policy level, has the potential to expand their horizons for RAs. When seen in the wider context of austerity, it may seem unlikely that advocates for WB from participatory opportunities, may be difficult to achieve, unless the austerity changes.

In my study, the small sample had maximum variation from the Welsh Index of Multiple Deprivation ranging from 4-99% (WIMD 2014). The data did not show that those living in the most deprived areas had less participation choices, as Hammal et al's (2004) study had previously shown. It would appear to be more complex than this. To allow greater choices for participation in RAs, there needs to be investment, not just



of money but time and skills to develop or adapt existing RAs. These choices will increase their opportunities and have the potential for more positive WB effects for them in the future. However, there remains a challenge for how their voices can be heard at a policy level, to influence such decisions.

This situation of less choices has been further impacted by the COVID-19 global pandemic, where social distancing has prevented meeting up in public spaces and stopped all participation in RAs. The long-term consequences of COVID-19 for disabled children and young people has yet to be determined, but it has stopped all their participatory RAs outside the home, during lock down. Thus, my proposed skewed Kaleidoscope of Well-being in Figure 64 is not just veiled, but opportunities in the community have been completely absent. Bree's mother replied after watching the Powtoon I had sent, saying how hard it had been as her behaviour had regressed:

*"It's been a nightmare!! No swimming, no touch therapy, no cycling, no brownies, no trampolining, no school, no overnight respite, no carers and in the beginning not able to travel anywhere where it was suitable to use the walking frame. Bree's behaviour steadily declined and became increasingly difficult to manage. We needed an emergency consultation with a psychologist at one point. It's slowly starting to improve, our carers have come back, cycle hire has reopened, we've had 3 overnight respite stays but I can't wait for school to reopen properly and for Bree to have a proper routine again!"*

This reinforced the positive WB effect Bree's participation in RAs had made for her, prior to lock down, which were just beginning to start up again. Therefore, during this lock down period when everything had to stop, Bree's mental health needs were increased, which appeared to have an impact on related health and social care services and also increased the stress for her parents. This perhaps further illustrates the positive impact that participation in RAs can bring, as when these were removed, the regression in challenging behaviour, in this particular instance, led to increased demand upon relevant services.

Additionally, a recent survey by the Disabled Children's Partnership (2020) has highlighted the plight from 4,000 families, feeling locked out and abandoned by UK Government and society. Whilst the data from my study was collected prior to COVID-19, the impact from this pandemic will be far reaching and detrimental to the WB of disabled children and young people. Thus, adding further barriers to their participation in RAs. Lund and Ayres (2020) have also proposed the need for non-disabled advocates to support the value of a disabled life, where fears of rationing of health resources, have made disabled people feel undervalued in this pandemic and this has further impacted upon their WB. This also relates to families with disabled children and young people and navigating a safe way forward to enable participation again is still evolving at the time of writing. It is possible, moving forwards, that the work of Mitchell (2012) involving children in the cyber frontiers of the internet, could be further developed to represent and include disabled children and young people adapting for their needs. However, policy makers and local authorities should consider ways to enable participation in RAs to safely begin again by listening to children and young people voices to provide some choices that can be achieved within socially distanced parameters.

The next section will discuss my study's findings in relation to the affirmation model of disability.

### **7.8 Affirmation model of disability**

Swain and French (2000) introduced the affirmation model of disability as a way forward, from the medical and social models of disability. They proposed that these did not celebrate the disabled person's life, as they were deficit or blame based. Their definition of the affirmation model of disability was:

*"...essentially a non-tragic view of disability and impairment which encompasses positive social identities, both individual and collective, for disabled people, grounded in the benefits of a lifestyle of being impaired and disabled"* (Swain and French 2000 pg. 569).

Additionally, the new discourse of DCCS promotes the emphasis on celebrating the disabled children and young people life as a positive narrative, to counteract the medicalised abnormal storylines, which potentially project tragedy and sadness (Curran and Runswick-Cole 2014; Runswick-Cole et al 2018). Gibson (2016) also suggests that the disabled children and young people differences should be embraced, and that physiotherapy should move away from seeking to 'normalise' but rather affirm the disabled children and young people strengths. By focusing on what the disabled children and young people can do, their affirmation as a person can be enriched as a positive storyline, not as a deficit scored on a scale, which is not sensitive enough to pick up on their fluctuating emotional WB state. As Mpundu-Kaambwa et al's (2017; 2018) review had shown there is not yet a suitable reliable or valid measure for emotional WB for children and young people with cerebral palsy.

The limitations for the disabled children and young people choices for participation in RAs in my study made them stand out as different, to typically developing children. Whilst the environments and equipment were changed to accommodate for some of their needs, some reported volunteer's attitudes were sometimes a hindrance to participation such as at the pottery experience for Poppy. The parental perceived negative attitudes directly influenced the children's storylines, as these social forces adversely affected the families' experiences. If it was possible to change attitudes, it might enable these people to see the potential of each disabled children and young people and the unique contribution they can bring into our lives. Their participation does not have to be normalised, but rather celebrated for what it is, not necessarily achievement focussed. The disabled children and young people WB and enjoyment of RAs is paramount. As Imms et al (2016) have shown in their fPRCs that attendance and involvement are key components of participation for disabled children and young people.

Thus, by providing choices for participation, the disabled children and young people can make their own decision to participate or not. Those in the PG did not necessarily have access to more choices than those in the LPG. The latter had more adverse health issues such as pressure sores (causing pain) or epilepsy, which affected their physical health, making them lethargic and unresponsive at times. All the participants in my study chose their level of participation from where they were physically positioned, so in attendance. Where this level of engagement was embraced, by people empathically attuning into their needs and involving them, their storylines were then positive, empowering them, thus enabling the children and young people themselves and other people to be their agents of change (Carnevale 2009).

### **7.9 Physiotherapy moving forwards**

Yoshida (2018) has further developed Nicholls et al's (2016) idea of connectivity, suggesting that physiotherapy needs to move towards becoming a socially just profession. Social justice is about supporting people disadvantaged by circumstances to improve their QoL (Smith 2012). Children's physiotherapists are key professionals who address functional abilities with children with cerebral palsy, to optimise their QoL, to help them live well with their long-term condition (CSP, 2019). In the context of my study, social justice for a disabled children and young people is about having equal opportunities for participation in RAs in society. Yoshida (2018) proposed that embodied experiences are related to other people and it is important for practitioners to be able to relate emotionally and show empathy and care for others. Children's physiotherapists are in a prime position to do this, to promote appropriate opportunities for participation in RAs. This must be done within a network of other relevant disciplines, to canvas for the children and young people needs to be considered in an equal way to typically developing children. To work towards achieving social justice, the profession in the UK is in the process of reviewing its priorities, so this may change.

The Chartered Society of Physiotherapy is currently revisiting the four pillars of physiotherapy practice (Frontline 2020). The present standards set out by the CSP are underpinned by a code of values and behaviours which have four principles (CSP 2019). These are that members take responsibility for their own actions, behave ethically, deliver an effective service and strive to achieve excellence. These principles include advocacy which is emphasised in relation to the quality of care and protecting people from harm. However, there is limited transparency into roles to develop and support disabled children and young people participation in RAs or evidence around a discussion related to social justice in the profession.

Additionally, Kelland et al (2014) in Canada proposed advocacy as a core competency based upon in-depth interviews with key workers. Eight attributes of advocacy in physiotherapy were identified. The key three attributes were communication, collaboration and scholarly practice whilst the other five were humility, management, professionalism, passion, and perseverance. In my study, I could observe, from parent reported experiences of professionals who advocated for their children, evidence of good communication, collaboration, passion and perseverance. The other attributes may have been there, but I did not observe these directly. Furthermore, Delaney et al (2019) in Australia, used focus groups to explore physiotherapy roles across many specialities including paediatrics. A key finding under their ethics theme identified, was the need to advocate for patients to navigate the complex health and care systems. Physiotherapists working with children in the UK may fulfil this role, but it is not reported overtly in the literature. In my study, when it was reported to me that this had happened, it was positive to see advocacy on behalf of disabled children and young people and their families, to enhance their participatory RAs opportunities.

In my study, there were several examples of physiotherapists being involved in setting up and running physical RAs e.g. Skiing, Bike Riding and RaceRunning. Some of these were now run jointly with or by parents. It was not known if these started from altruistic motivations.

However, there was less evidence from physiotherapists for initiatives in the arts and cultural activities. However, in keeping with the UNCRC's Article 31, this demonstrates an imbalance with sport being prioritised. Additionally, the Rights of Children and Young Persons (Wales) Measure (2011), reinforces the importance of giving voice to all children and young people, including disabled children and young people preferences. Part of physiotherapy becoming a socially just profession, would be to address this imbalance of only sport's-based activities being promoted. If physiotherapy is to move towards greater social justice, then all aspects of disabled children and young people interests should be developed. This cannot be done in isolation and will need partnerships with many interested, relevant parties, to move this agenda forwards. These could include policy makers, design engineers, human geographers and town planners. If research were able to adopt a more integrated cross-disciplinary approach, this might provide a stronger evidence base, to move towards achieving this.

In addition to this policy agenda, children's physiotherapy practitioners should consider whether they wish to promote wider participation-focused interventions to demonstrate an impact upon disabled children and young people WB. Van Wely et al. (2014) in a randomised trial demonstrated that a physical activity stimulation programme did not increase physical activity in children aged seven to thirteen (GMFCS I-III). However, WB was not investigated with these children. As my study included GMFCS III-V there is less expectation of physical improvements due to their declining abilities (Hanna et al 2008). However, it is not known how the children and young people themselves feel about their declining abilities. The dominant provision for them in terms of participation in RAs has been sports biased, which my participants were unable to achieve, due to their physical weaknesses. Additionally, the disabled children and young people may disengage with activities perceived to be too hard for them physically. Physiotherapists need to signpost families to available choices for RAs, but there also needs to be people with ideas to initiate and develop new opportunities. It is not clear in society who is embracing disabled

children and young people needs or indeed if their voices are being listened to. My study has contributed new knowledge about their voices being represented in a novel way. Nevertheless, as practitioners, physiotherapists can consider if they wish to adopt and broaden participation goal setting in their practice with disabled children and young people and signpost families to what is available (Missiuna et al 2004; Gibson et al 2016; Kolehmainen et al 2020).

The Method for using Audit and Feedback in Participation Implementation (MAPI), shows promise to facilitate moving this participation agenda forwards in practice (Kolehmainen et al 2020). Since the inception of the WHO ICF (2001) 'Participation' has been a construct that has been applied across physiotherapy practice to varying degrees. Although in principle it has been agreed participation is important for FCC, and measures developed accordingly, its implementation into practice is still evolving in the UK (Majnemer 2012 [Appendix 3]; King 2014). This recent audit of case notes in England by Kolehmainen et al (2020) revealed that despite good intentions, only 19.7% of therapists (24/122) were measuring participation outcomes from their interventions with disabled children and young people. Additionally, only 13.1% (16/122) involved parents and/or children in the decisions about participation outcomes, whereas 30.3% (37/122) had actually targeted participation outcomes. The issues reported from staff were a lack of skills, social support and behavioural regulation of therapists, to enable these good intentions to be translated into practice. Kolehmainen et al's (2020) study concurs with Anaby et al's (2015) Canadian findings, that the implementation is related to practitioner's adapting to this change, in adopting participation outcomes as part of their routine practice. It is not currently known what the level of participation outcomes are with therapists practicing in the NHS in Wales. However, it is unlikely this would be greater than these studies carried out in England and Canada, which means there is likely to be low implementation of participation goal setting and outcomes for disabled children and young people in practice.

If participation is not being captured from practice at present, the possibility to demonstrate the WB impact from the child's level of both physical and social participation is a missed opportunity. This audit, showing the low levels of implementation, provides a baseline which reflects current practices. If the MAPi is used through repeated audit and feedback cycles, this could increase staff awareness and improve participation outcomes being addressed and not ignored and potentially capture the children and young people's WB effects from participation.

## **7.9 Summary of Discussion**

This chapter has discussed how I have adapted positioning theory to include the non-verbal disabled children and young people responses of WB. I have proposed a 'Kaleidoscope of Well-being', with advocacy and self-advocacy being central to the disabled children and young people's experiences, which enhanced their emotional WB from their level of participation in RAs. I have discussed the three main theme's findings in relation to relevant literature with reference to austerity and COVID-19. The lack of literature on positioning theory supports the notion of my work adding to knowledge. The children showed they could be their own self-advocates. The parents were also key advocates for the children and young people, along with the connectivity with people who could support the design of new opportunities, both are suggested to embrace the affirmation model of disability, to celebrate their involvement. Physiotherapy practitioners should consider if participation outcomes could become an important feature of current practice, to begin to address the social injustice for disabled children and young people.



## **Chapter 8 Conclusion**

### **8.1 Introduction**

This final chapter will draw together my thesis summarising my VOCAL study, presenting my original contribution to knowledge from my work. I recognise the limitations of the case study design and propose my publication and dissemination strategy to help inform impact. I suggest areas for future research and recommendations for practitioners, including my reflections upon the research journey. How I propose to move forwards considering this new knowledge is outlined.

### **8:2 PhD VOCAL study**

My PhD, abbreviated to VOCAL, developed a case study design to incorporate disabled children and young people and their carer's views, experiences and choices about the children's WB impact from their level of participation in RAs. There were two groups represented, a participatory group (PG) and a limited participatory group (LPG). These represented children and young people across GMFCS and CFCS Levels III-V. To answer my research question and fulfil my aims, I found out about their experiences and choices from the children's intentional behaviours, and their parents gave me their views. There was evidence of a variety of physical and social participation activities in the PG which had a positive WB effect. In the LPG, pain, mood, pressure sores and epilepsy were key factors which hindered their participation, as well as lack of appropriate choices. Their participation was less and thus the emotional WB effects for them were perceived to be less by their parents. The children's non-verbal communication styles were also thought by their parents to be a limitation to social participation in both groups.

### **8:3 Originality in my research**

Building upon my previous team research project, in my PhD VOCAL research, I have used an original technique. I intentionally included those children and young people whose 'voices' have been excluded from previous research. I created visual data that protects the identity of the individuals, whilst still providing the context of the environment and equipment, to illustrate the WB effects from their level of participation.

This area of WB with disabled children and young people, GMFCS and CFCS levels III-V, has not been previously explored within physiotherapy. Whilst their physical capability may not have the capacity to improve, it could be maintained, and their emotional WB promoted by providing suitable choices. Additionally, the value of social participation, one of my key findings, had been under reported in physiotherapy. The children and young people showed their own advocacy. However, the role of other advocates to promote participation for disabled children and young people was not consistent across professionals and yet many families reported it was important. So, my findings strengthen the idea of advocacy from health and social care professionals, to support appropriate participation choices for disabled children and young people, to enhance their WB. This evidence can support the idea of professionals who consider the need for social justice for disabled children and young people but requires further exploration.

Positioning theory has been adapted to include the non-verbal children and young people storylines which have been illuminated through the creative and visual data (Harré and Langenhove 1999). Whilst some positive examples were given, there were limits to their choices for RAs. The opportunities were influenced by disability sports, innovative designs and environments where policy makers, town planners and design engineers had considered their needs.

There were many examples where this had not happened, particularly in the arts and cultural RAs attended. I have brought fresh insights into positioning theory and added the 'voices' of the non-verbal children and young people into their storylines, which is represented by my proposed 'Kaleidoscope of Well-being' shown in Figures 63 and 64(pg 208, 210). This shows how their WB can fluctuate with the children and young people own preferences for participation, in the different environments, with different people and equipment. Advocates who could influence their experiences, to benefit their WB were central to my adapted

mutually determining triad. The disabled children and young people showed they could be self-advocates as their own agents of change when attending a RA, by choosing their level of involvement. This 'Kaleidoscope of Well-being' builds upon and further expands Imms et al's (2016) fPRC, whereby attendance and involvement are central to current understanding of participation for disabled children and young people.

#### **8.4 Publication and dissemination strategy**

It is my intention to publish my findings in journals which target representing the voices of non-verbal disabled children and young people. Preliminary research has identified that International journal of language and communication disorders, the International Journal of Disability and Social Justice and Physical and Occupational Therapy in Pediatrics would be good journals to start with. I would also like to further contribute to the parental index magazine, to support families with their disabled children and young people (Vale of Glamorgan County Council 2018).

The opportunity to influence Welsh policy is an area I will explore, following a training session related to research implementation in December 2020. There may also be the opportunity to apply for further research funding to support 'evidence to impact' by gaining 'access to expertise'. There may be the opportunity to obtain further funding to develop ideas of new initiatives such as virtual reality games that represent and include disabled children and young people as their avatars. My varied dissemination plans are designed to maximise reach and impact from my research. My own research network has broadened since start of my PhD and my potential influence is now international. I discussed my findings online at a research group called 'Beyond Giving Voice' based in Canada, led by Dr Gail Teachman in October 2020. This platform provided a space to enable me to explore problematizing this issue of giving voice, to those who communicate differently.

### **8.5 Study limitations**

Qualitative research is not intended to be generalizable to wider populations as the sample size is small, the aim being to dig deep to probe for new knowledge (Barbour, 2001). However, the findings can be transferable to other relevant contexts. It was necessary to use purposive sampling to drill down and explore the research question with relevant participants, but recruitment was difficult, especially for the LPG. I had planned for eight case study participants, four in each group to compare and contrast the data, but despite recruiting eight, one in the LPG did not consent to participate. This child was GMFCS V and the youngest of three children. It was possible that the mother's care burden, with three children, was too great to fit in research interviews and keeping a diary. Especially when there were no obvious immediate benefits for her child, from participation in my study.

It was difficult to recruit another participant for the LPG, despite the gatekeepers promoting the study. It was possible that parents did not come forward as they perceived they were considered to be neglecting their child if they did not participate in anything. Thus, it is possible that my findings may not be representative of this cohort of non-mobile, non-verbal disabled children and young people. My data were less representative of disabled children and young people GMFCS V, so this remains an area for further research. Despite the overlap of findings between the two groups, it was not possible to state that I achieved data saturation, as the sample was small, but I moved towards this goal (Creswell and Poth 2017). It is therefore plausible that there are still more aspects to participation for disabled children and young people that remain hidden, still to be uncovered.

Whilst my intention had been to centrally position the voices of the children and young people, I was not able to do this in isolation from the parents. This was due to the nature of the children's communication and cognitive difficulties. However, there was some transferability in the findings due to the rich data that illuminated the lived experiences for non-mobile and non-verbal children and young people. Once I had

completed my analysis, I was only able to share this with the parents, I had not designed a follow-up chat to share my findings with the children. Thus, I was not able to find out what the children thought of my visual representation as shown in Appendix 14, of my interpretation of theirs and their parents combined findings. I wanted to represent their findings visually, as written communication would be difficult for the children and young people to read. Therefore, I developed the 'Powtoon', voiced over with my findings and action points, which was sent to my parental participants for them to share with the children and young people. This current lack of member checking, to gain participant validation, is acknowledged as a limitation to ensuring the study's confirmability and credibility (Lloyd et al 2006; Burnard et al 2008). However, I was able to represent the children and young people voices authentically by the visual data that provided a unique dimension, concurring with Carnevale et al (2009) that it is possible to hear the voices of those who communicate differently.

My data were socially constructed from the parents and the children's voices combined. Combining the interviews, visual data, diaries and observing them, I was able to see first-hand their emotional reactions to participation in the RA. Although, I cannot completely share this view with the reader, due to the need to protect their anonymity. Whilst the two participants, Lily-May and Clare, could interact with me via their communication aids, for the other five, I had to rely on parental reporting. This reflects the challenge of being able to tune in and understand children and young people with limited verbal communication, when involved in data collection. However, my reflexivity and ability to attune into each participant's bespoke way of communicating was a strength that came from my clinical background and adds to the rigour and trustworthiness of my study.

Therefore, whilst I did fulfil my aims to explore the emotional WB impact from their level of participation, I was not able to find out why they chose sometimes not to participate, when their parents and others had

put so much effort in. This was pertinent for Nick, Bree and Poppy and I was not expecting to find this. So, I found myself at the observations and in the interviews, unsure of how to react. My own initial bias promoted that participation would lead to a positive WB effect. This could have limited my exploration of their lived realities, particularly for the LPG. However, as the study progressed, my interviewing techniques improved, with less leading questions and more probing and I also continually reflected on my own thoughts and behaviours to limit the potential for any related bias. Some of the earlier interviews may not, therefore, have generated such rich data or such relevant images as the latter ones did, but this is also an important component of the PhD experience.

I was not able to represent families from different ethnic groups as I did not recruit anyone other than 'White Welsh', through my advertising and recruitment. This was despite one of the special schools having a higher representation from ethnic minority groups. This lack of recruitment could have been influenced by a previous PhD student who had recently only looked at disabled children and young people family's experiences from Black and Ethnic Minorities (Kent 2017). However, despite my study's limitations there are some relevant recommendations and suggested areas for future research.

## **8.6 Recommendations for policy makers, designers and practitioners in health and social care**

### **8.6.1 Policy makers**

Those who create local and government policies and charities who provide facilities should consider the maintenance of equipment for disabled children and young people. Examples of these are lifts which are broken that should have standards of a time frame within which they should be repaired, to maintain access for disabled people. Wider investment in training relevant staff and volunteers should be considered, to equip people to develop their social confidence to relate to non-verbal disabled children and young people. Organisations, such as Dynamix, offer consultancy and training for different groups to

support this moving forward (Dynamix.coop, 2020). There is also a need to provide hoist training for staff or volunteers to become competent and safe with manual handling.

### **8.6.2 Designers of environments and equipment**

Those who design environments such as geographers, should consider the needs of disabled children and young people in their planning. So that the children and young people opportunities to participate in RAs can be increased. For example, Spinney (2020) argues that cycling is sustainable from a commuting perspective, but that the recreational aspects of cycling have not been more widely considered, which includes adaptations for disabled people's participation. One initiative that occurred during my study's writing up period was the local opportunity for getting onto Barry beach using a hoist and beach wheelchair. This can be viewed on the RaceRunning Dragons Facebook page and was used by James and his mother:

<https://www.facebook.com/racerunningdragonscardiff/>:.

Designs for adapted equipment in the UK are limited and the small number of children and young people who use this equipment, makes their manufacturing expensive and thus less affordable for individual families (Clarkson et al 2013). One example of this is the adapted trike which costs in excess of £800 but there are many charities which will fund these (Tom Cat UK Ltd 2020). One initiative in the UK is Designability (2020), whose aim is to help disabled people to live with greater independence. Their principal engineer, Dr Tim Adlam, has offered advice to me about equipment to adapt for sailing for physically disabled people. This will feed into a new association called 'Sealegs2' that will offer sailing experiences for children and young people and adults with a range of disabilities in West Wales. This is an active project that I am involved in as a volunteer secretary and will take forward post COVID-19.

Potentially then, if environments and equipment can be adapted, the future for disabled children and young people could look different, in that all community areas such as parks and museums could have a changing places toilet, and everyone could feel confident to relate to the children and young people. They would be valued and accepted as people in their own right, with warmth shown to them as they are embraced into all aspects of society, without any barriers. All relevant health and social care staff should, where possible, advocate on their behalf, to influence designs of equipment and environments, to enhance their participation in the community. Additionally, people who work with the disabled children and young people should observe and take notice of their intentional behaviours to indicate their WB. No aspect of society across sport, arts and cultural activities should be off limits. This would enable the disabled children and young people to have the same choices as all children and young people and to live well with their long-term condition of cerebral palsy. This would provide fairness of opportunities and demonstrate social justice for them, enhancing their WB and giving them fun and joy in their lives, to enhance their QoL. Additionally, disabled children and young people should be involved in research designs about what matters to them, as the James Lind Alliance had previously demonstrated (Morris et al 2015).

### **8.6.3 Practitioners**

Physiotherapists can and should signpost families to the appropriate, available RA choices, however, in my study there was some evidence of these being created by some innovative physiotherapists. This was not expected from NHS practitioners and was a voluntary initiative. The key appeared to be motivated enthusiastic parents, but it was not always clear how some RAs were being sustained. Whilst it is not necessary for practitioners to be involved in this; it is important to signpost parents to the available choices. Other key professionals such as health visitors, occupational therapists, and social workers also signposted families in my study.



However, it would be a bonus for families and their disabled children and young people, if relevant new initiatives could be developed, such as the disability sailing that Nick's Dad spoke about, but that is likely to need a wider skill set than physiotherapists alone possess. Indeed, their skills and problem-solving abilities make physiotherapist's key professionals who can support this process, but finances and professional priorities and scope of practice are factors that constrain this creativity in the NHS. Practitioners in the NHS could consider if they wish to include wider participation goals to include WB outcomes, if physical change is not possible. They could consider continuing working in partnership with families in a family centred approach, to promote increased choices and opportunities for disabled children and young people to participate in RAs.

It is possible physiotherapists in the independent and charity sectors can initiate further development of RAs. This would need to be done in partnership with the disabled children and young people and their families, alongside advocates in other professions, supported by volunteers. Wider advocates could include engineers and town planners who can adapt the equipment and environments accordingly. Whilst the design and promotion of RAs seems to be varied, there is no one specific group, outside of disability sport, that seems to be actively marketing RAs for disabled children and young people. A unique successful example of this is Gympanzees, initiated by a children's physiotherapist, which is a pop-up leisure facility for disabled children and young people and their siblings, which is a non-for-profit social enterprise in Bristol, England (Gympanzees, 2017). More initiatives like this would further support disabled children and young people and their family's WB.

Many stakeholders, such as the NHS, social services, education, and voluntary agencies, who support disabled children and young people and their families, work in silos. In 2012 Carpenter and McConkey published the importance of the voices of disabled children being central to any enquiry, proposing a schema for future investigations which included policy, society and practice, as well their family. This

includes them being involved at all stages of the research process where possible as part of the Patient and Public Involvement required for ethical approval and grant funding (Frankena et al 2015). My study has moved forward with this schema by positioning the disabled children's voices central to my enquiry.

An interesting provision in America is the profession of recreational therapists (American Therapeutic Recreation Association (ATRA) 2020). I became aware of this when I attended the International Conference of the American Academy of Cerebral Palsy and Developmental Medicine in September 2019. The aim of the ARTA is to improve the QoL for disabled people by helping them to participate in leisure activities, thus reducing the social isolation that they might experience. It incorporates adults as well as children. In Wales and the UK, no such profession exists, the closest to this was the Society for Remedial Gymnasts, which was amalgamated into the CSP (The Society for Remedial Gymnasts 1995). So, whilst some elements of this might still be evident in practice, it is not clear who would take this role on in the UK.

The best example I found was the initiative of the Health Disability Sport Partnership (Chin and Reid 2015) which despite its success, has not been rolled out across Wales. Here a physiotherapist from BCUHB and DSW in one North Wales local authority, pooled their resources and showed an increase in physical activity participation of four hundred and forty three people over a two year period, who were signposted into physical activity via this health route. This also included nine hundred and forty-three healthcare professionals being upskilled. A limitation of this initiative was the focus on sports-based activities with artistic and craft activities not being promoted to the same level. Thus, there is scope to broaden the choices of RAs for disabled children and young people, but current funding streams seem to overlook this wider need. This oversight reduces the potential well-being effect for the children and young people from their participation in RAs, which then increases

the demands upon health and social care services and reduces parental coping mechanisms.

### **8.7 Areas for future research**

My VOCAL study has explored with children and young people with cerebral palsy and their carers, their perceived emotional WB impact from their level of participation in RAs using creative methods within the comparative case study design. I have shown that visual methods have a place in research with disabled children and young people that does not exploit them but validates their experiences by representing their voices authentically. Additionally, the diaries captured their participation in a range of activities and reported the WB impact that was not always observed. Creating visual data can support participants without language, to be able to provide meanings, which can help them to be more involved in co-creating the findings. Visual methods should be considered for future studies to work on co-producing data with participants with limited verbal language, which has relevance to many health and social care contexts.

Positioning theory, as adapted in my study, shows promise, to include those who cannot speak verbally, to enable them to indicate their fluctuating WB as proposed by my 'Kaleidoscope of Well-being'. This has enabled the fun and joy in their lives to be expressed but has also highlighted the attitudes that made them feel not accepted in some contexts. Further research could explore with volunteers and disabled children and young people, how to develop social confidence to relate to disabled children and young people. This may help to promote positive attitudes and reduce the fear and stigma associated with the perceived negative attitudes reported in my study. My adapted version of positioning theory could be used in further studies to explore the WB of other people living with long-term conditions with cognitive and communication limitations.

The current statistics on the numbers of children and young people with cerebral palsy in Wales remains unknown. It is imperative that the

funded cerebral palsy register is completed in a timely manner, as this will be the building block for future studies (BBC, 2019). Without this data, this population are invisible, and their needs are not adequately represented in policy. This register will help policy makers to understand the wide range of abilities across cerebral palsy. This can enable better planning and development of environments and equipment, to increase participation and social opportunities for disabled children and young people across different leisure sectors.

The lack of a rigorous observational scale for emotional WB for non-verbal children requires further consideration. The Leuven scale was only used by a school with one child (Laevers, 1996). Whilst the 'Participation and environment measure for children and young people' (PEM-CY) has components of WB, there is no valid and reliable outcome measure that only focusses on WB for this group of children and young people to determine their QoL (Coster et al 2012; Mpundu-Kaambwa et al. 2018). This is a gap in existing knowledge at the present time.

The role of advocates was beneficial to enhance participation, but apart from the parents, it was inconsistent who considered this to be part of their role. Boyczuk et al (2019) have proposed advocacy as one of the top ten attributes of physiotherapy in Canada. In physiotherapy in the UK, advocacy is proposed as a key principle of practice, but it is not overt how this is worked out in children's physiotherapy (CSP, 2017). This could be explored further with children's practitioners, to see how they view this role in their practice. This could be achieved through a qualitative approach to investigate how children's physiotherapists perceive how they act as advocates, to enhance the emotional WB of disabled children and young people. As this does not have a physical outcome it may be debated if WB is a relevant outcome for physiotherapists to record and measure. However, I would argue that it is central to what physiotherapists hope to achieve, by managing the children's physical capabilities. It would therefore be timely to re-

conceptualise the physiotherapy profession to encompass WB as well as physical health outcomes for disabled children and young people and their families. It would be interesting to compare the independent and charity sectors with the NHS, to explore how they perceive the role of advocacy for WB of disabled children and young people is worked out in their different contexts.

An area for future research would be to include disabled children and young people in designing virtual reality games. This would be where they see themselves represented as characters and have the ability to play the games, adapted to meet their needs. Particularly as their physical participation is currently restricted due to the COVID-19 lock down regulations, in the interests of public safety from the virus.

### **8.8 Reflection**

The opportunity to carry out this research was a privilege, to work with parents who volunteered to support their children and young people, to express their views experiences and choices about their WB, in response to their participation in RAs. I thought with my physiotherapy practice background that I had the emic perspective, but I now realise this was an incorrect perception, as I was not a parent of a children and young people with cerebral palsy (Creswell 2013). I did feel sadness at times with the data as to how parents reported they were treated, but I also experienced joy at their exhilarating experiences. My practice background enabled me to view participation at a level of joining in that was not competitive but embraced the everyday activities that were meaningful for the disabled children and young people interests. Thus, showing my empathy for the different aspirations that disabled children and young people can wish for, but still leaves me uncertain if my physiotherapy colleagues wish to adjust their goals to embrace these differences. Thus, it was the parents and children and young people who gave me the emic perspective.

I was most definitely an outsider with the etic perspective, which gave me objectivity with interpretation in my data analysis. This sometimes

made me feel uncomfortable as the findings evoked some strong feelings related to the social injustice at the lack of choices for them. As I was socially constructing meaning from the children and young people storylines, although I sought to be neutral during my contact times with the families, it is possible that my empathy with their situations came through. I was aware of my position as a researcher being different to that of a practitioner, when visiting participant's homes. However, I did not see my empathic position as a weakness as it facilitated rapport and encouraged appropriate disclosure of difficult experiences from both mothers and fathers. This reflexivity of my position adds to the rigour in my study.

Abbott (2012) had commented about 'being a good guest', during his data collection in young, disabled men's homes. It is possible being female that bias may have made some more willing to speak to me, but I felt that the two fathers were as equally open and frank about their children and young people experiences, as the seven mothers I interviewed. I did think about what I wore as casual wear, not to distract from the child who was the centre of my attention. I was in admiration for all the parents of my participants, who were often making the best of limited opportunities. I feel the need now to advocate on their behalf to improve their choices in order to influence their WB in a positive way. I therefore aim to disseminate my findings to relevant targeted audiences, such as physiotherapists, social workers, human geographers, design engineers and qualitative researchers promoting visual methodologies to represent their voices and inform change, to enhance their WB.

### **8.9 Concluding remarks**

My study has explored, using a comparative case study design, the WB impact with seven children and young people with cerebral palsy, aged nine to sixteen years, from their level of participation in a range of RAs. The PG and LPG groups had similar enhancers and hindrances to participation in RAs, with more illness episodes affecting those in the

LPG. My participants all had mobility, learning and communication limitations, but were still able to demonstrate their intentional behaviours that I could observe. They showed their own self-determination in choosing to participate or not, which reflected their WB state at that point in time and demonstrated self-advocacy. This fluctuated with different environments and people and has been represented by adapting positioning theory to include the non-verbal children's intentional behaviours. I have proposed the 'Kaleidoscope of Well-being' from the data, that has illuminated their experiences and choices and shown hindrances to their participation. The parents were able to provide their views about their children and young people's participation opportunities and this partnership in data collection was essential, to support the children and young people voices.

Thus, to answer my research question and fulfil my aims, I have found out about the parents and carer's views and the children and young people experiences and choices for RAs. Their level of participation was determined by available opportunities and their choice to join in or not. Sometimes their level of pain, mood or epilepsy limited this, as well as their preferences for social rather than physical participation. Although there were two groups, a PG and a LPG, there was overlap in the findings. It was evident that those at GMFCS IV and V had less choices for physical RAs due to their complex health issues, preferring more musical and sensory based choices.

The creative methods enabled inclusion of non-verbal children and young people and provided a catalyst to reveal their lived experiences. The visual data from the diaries especially highlighted their barriers to participation and supported their stories being told, without the vocabulary of spoken language. The encouraging aspects were the opportunities that the participants had taken part in, which included their siblings and wider family. The trike riding stands out as one of these positive RAs, as well as the relaxed orchestral performance. However, the perceived lack of support in the artistic and cultural activities represented in my data, warrants further exploration, to investigate if training of volunteers to develop their social confidence

around disabled children and young people could help. As it was shown in the disability sports activities, that such embracing attitudes were possible, to enable participation at whatever level the individual wanted, not necessarily being competitive. Above all, RAs should be joyful and fun for the children and young people, which can be interpreted by their family and people who know them well.

The concept of advocates to promote WB for disabled children and young people is essential for them to thrive, but it remains unclear who considers that to be part of their role, although the participants in my study showed they could be their own self-advocates. Physiotherapists and other health and social care professionals have the skills to provide this role, but it is not an automatic responsibility that was identified in the wider RAs. The least they can do is to signpost families to possible choices, but as no one has this designated role, it can be missed in routine practice. Thus, if an integrated, across disciplinary approach promoted the WB of disabled children and young people, the families may receive advice from many sources, signposting to the same activities. This would be preferable to not receiving any advice at all and be more aligned to Family Centred Care (King et al 2004 a; Pickering and Busse 2010 a, b; McDowell et al 2015).

Participation as a construct has developed in the literature and narrowing of these perspectives would help future research to focus on the important aspects of attendance and involvement as proposed by Imms et al (2016) and Adair et al (2018). The social confidence to relate to disabled children and young people is important and without this skill, I could not have attempted such a creative qualitative PhD, to add to knowledge. It was evident that social confidence is not present for many people, who were perceived as unhelpful by the parents, but possibly have never received any training.

Building upon the knowledge and experience I have gained throughout this PhD journey; I would aim to take this further by applying for further research grants in the future. By influencing practitioners to change their practice, I would seek to increase advocacy for disabled children



and young people voices to champion for their needs. Being a volunteer myself, I can make a difference to a few disabled children and young people, but to influence policy or practice could have a far greater impact for them. I will therefore publish (and further disseminate via conferences, social media and networking and engagement activity) my methods and findings to work towards this goal. From my study, it was clear that participation in RAs has the potential to enhance the WB of disabled children and young people. I would like to see more champions for their WB and less hindrances that stop disabled children and young people from having fun in their lives.

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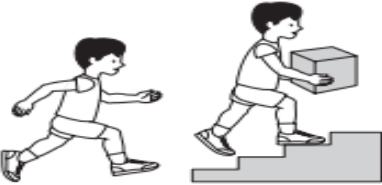




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## Appendix 1: Gross Motor Functional Classification System- Expanded and Revised (CanChild, 2021)

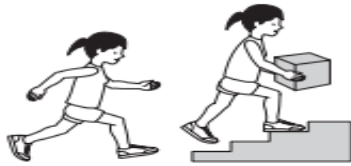




### GMFCS E & R between 6<sup>th</sup> and 12<sup>th</sup> birthday: Descriptors and illustrations

	<p><b>GMFCS Level I</b></p> <p>Children walk at home, school, outdoors and in the community. They can climb stairs without the use of a railing. Children perform gross motor skills such as running and jumping, but speed, balance and coordination are limited.</p>
	<p><b>GMFCS Level II</b></p> <p>Children walk in most settings and climb stairs holding onto a railing. They may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas or confined spaces. Children may walk with physical assistance, a hand-held mobility device or used wheeled mobility over long distances. Children have only minimal ability to perform gross motor skills such as running and jumping.</p>
	<p><b>GMFCS Level III</b></p> <p>Children walk using a hand-held mobility device in most indoor settings. They may climb stairs holding onto a railing with supervision or assistance. Children use wheeled mobility when traveling long distances and may self-propel for shorter distances.</p>
	<p><b>GMFCS Level IV</b></p> <p>Children use methods of mobility that require physical assistance or powered mobility in most settings. They may walk for short distances at home with physical assistance or use powered mobility or a body support walker when positioned. At school, outdoors and in the community children are transported in a manual wheelchair or use powered mobility.</p>
	<p><b>GMFCS Level V</b></p> <p>Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.</p>

GMFCS descriptors: Palisano et al. (1997) Dev Med Child Neurol 39:214-23  
CanChild: www.canchild.ca

Illustrations Version 2 © Bill Reid, Kate Willoughby, Adrienne Harvey and Kerr Graham,  
The Royal Children's Hospital Melbourne ERC151050

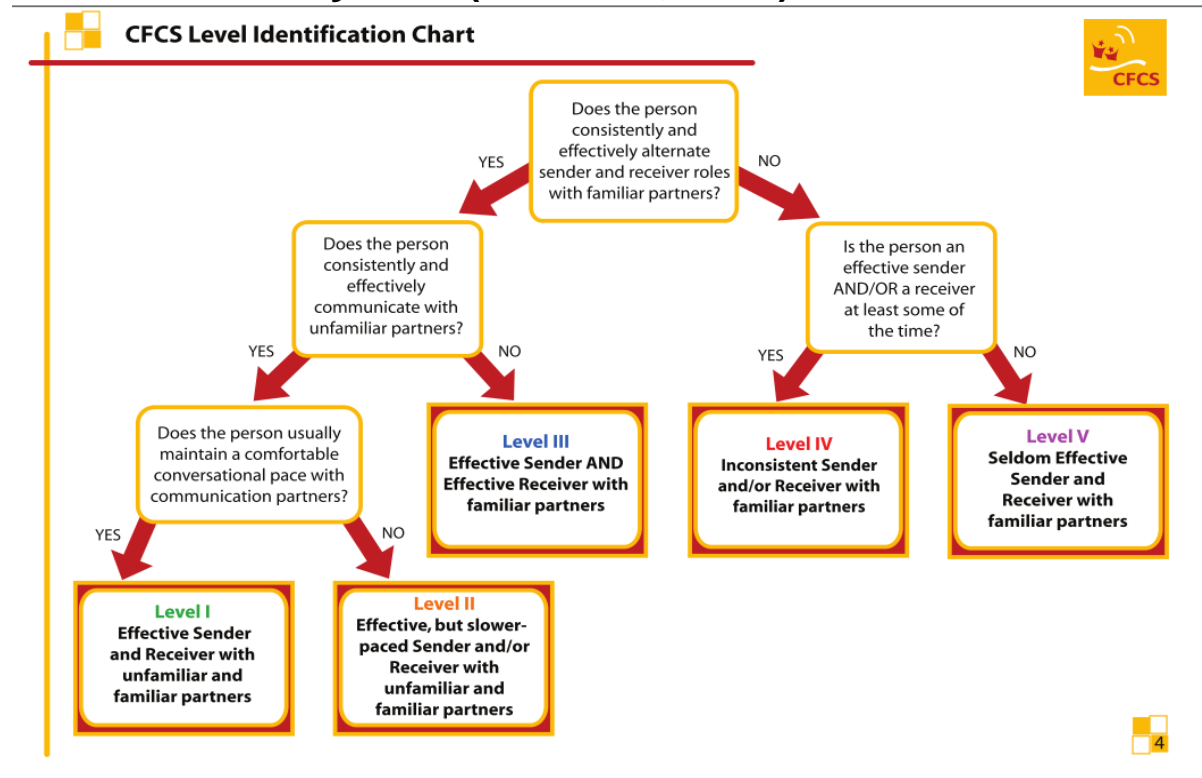
## GMFCS E & R between 12<sup>th</sup> and 18<sup>th</sup> birthday: Descriptors and illustrations

	<p><b>GMFCS Level I</b></p> <p>Youth walk at home, school, outdoors and in the community. Youth are able to climb curbs and stairs without physical assistance or a railing. They perform gross motor skills such as running and jumping but speed, balance and coordination are limited.</p>
	<p><b>GMFCS Level II</b></p> <p>Youth walk in most settings but environmental factors and personal choice influence mobility choices. At school or work they may require a hand held mobility device for safety and climb stairs holding onto a railing. Outdoors and in the community youth may use wheeled mobility when traveling long distances.</p>
	<p><b>GMFCS Level III</b></p> <p>Youth are capable of walking using a hand-held mobility device. Youth may climb stairs holding onto a railing with supervision or assistance. At school they may self-propel a manual wheelchair or use powered mobility. Outdoors and in the community youth are transported in a wheelchair or use powered mobility.</p>
	<p><b>GMFCS Level IV</b></p> <p>Youth use wheeled mobility in most settings. Physical assistance of 1-2 people is required for transfers. Indoors, youth may walk short distances with physical assistance, use wheeled mobility or a body support walker when positioned. They may operate a powered chair, otherwise are transported in a manual wheelchair.</p>
	<p><b>GMFCS Level V</b></p> <p>Youth are transported in a manual wheelchair in all settings. Youth are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements. Self-mobility is severely limited, even with the use of assistive technology.</p>

GMFCS descriptors: Palisano et al. (1997) Dev Med Child Neurol 39:214-23  
CanChild: [www.canchild.ca](http://www.canchild.ca)

Illustrations Version 2 © Bill Reid, Kate Willoughby, Adrienne Harvey and Kerr  
Graham, The Royal Children's Hospital Melbourne ERC151050

## Appendix 2: Communication Function Classification System (Hidecker, 2011)



### Appendix 3: Summary of Participation measures (Majnemer 2012)

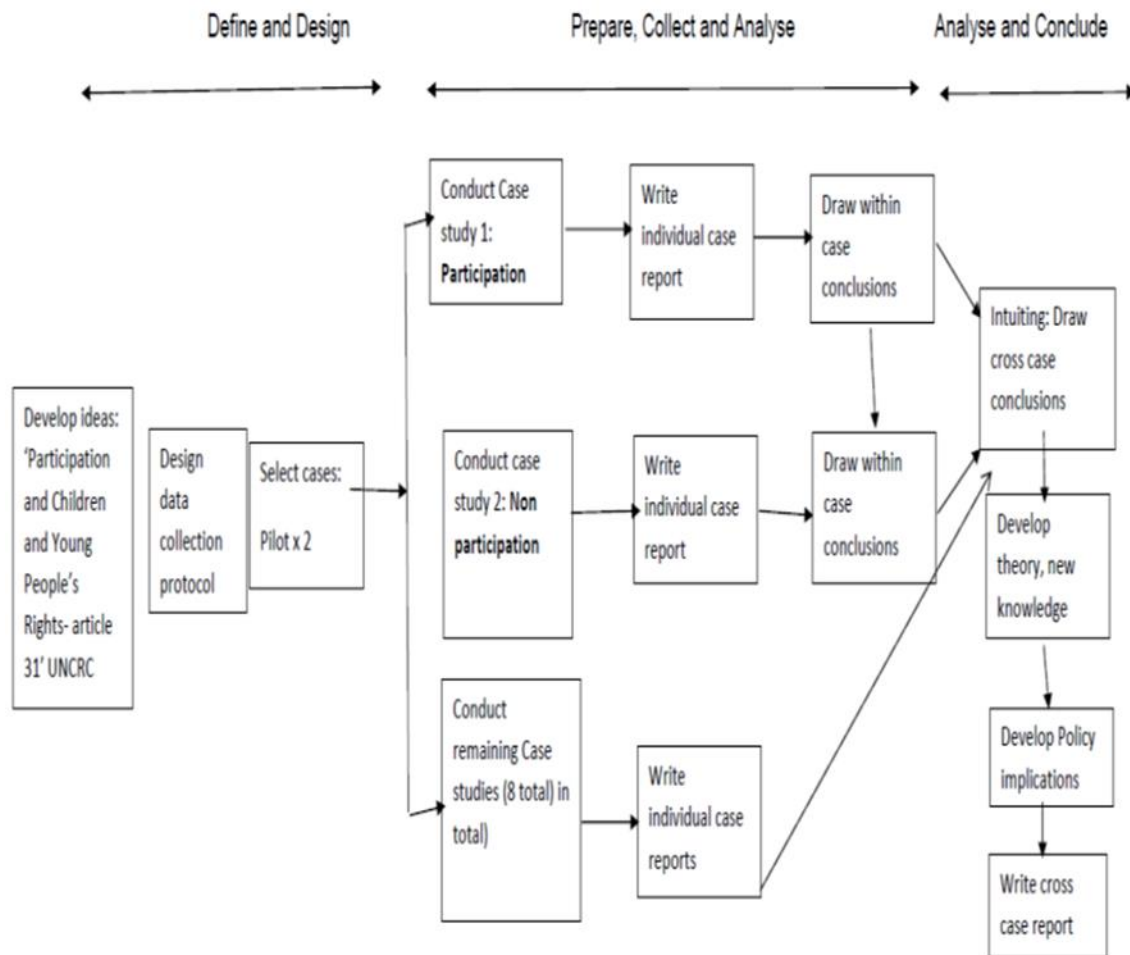
Measures of Participation in Community, Social and Civic Life [D910-D950 of WHO ICF-CY]	Age range	Reliability and validity	Areas measured
Children's Assessment of Participation and Enjoyment / Preferences for Activities of Children (CAPE/PAC) (King et al. 2004a; King et al. 2007)	6-21 years, card sorting of 55 activities choosing which they would, would not or might like to do. CAPE 30-45 minutes, PAC 15-20 minutes	CAPE: Test re test ICC 0.64-0.77(moderate to good)-diversity, intensity and enjoyment, 0.12 (poor) active physical activities- 0.73 (good) RA PAC: Internal consistency Cronbach's alpha 0.84 formal domain and 0.76 for informal domain	Everyday activities outside school-recreational, active physical, social, skill-based and self-improvement
Child and Adolescent Scale of Participation (CASP) (Bedell 2004; Bedell and Dumas 2004; McDougall et al. 2013)	3-22 years, 15 minutes Questionnaire, some open ended questions about barriers and supports to participation	Internal consistency Cronbach's alpha 0.98 and 0.96, ICC 0.94	Home, school and community activities
Pediatric Activity Card Sort (Pediatric ACS) (Mandich et al. 2004)	5-14 years, 20-25 minutes, Prioritise which 5 activities would like to do.	No evidence for reliability	Personal care, school productivity, hobbies/social activities, sports
Preschooler ACS	3-6 years, 30 minutes	Reliability inter-rater 0.91, test re test r=0.93	Self-care, domestic chores, social interaction,



(Berg and LaVesser 2006)			high demand leisure, low demand leisure, community mobility and education
Perceived Efficacy Goal Setting System (PEGS) (Missiuna et al. 2004)	6-9 years Pictures of activities/ questionnaire when older used to set goals where would like to improve, 20 minutes	Internal consistency Cronbach alpha 0.85 fine motor and 0.91 for gross motor. Test re test 92% chose same activities.	Self-care, school and leisure.
Canadian Occupational Performance Measure (COPM) Interview with experienced therapist (Dedding et al. 2004; Law et al. 2005)	Adults and children If have cognitive ability can be interviewed, 30-40 minutes	Internal consistency 0.86 performance, 0.82 satisfaction. Test re test 0.79, 0.75. Moderately correlated with Goal Attainment Scaling	Self-care, productivity and leisure.
Participation and Environment Measure for children and youth: (PEM-CY) (Coster et al. 2012)	5-17 years Completed by parents or guardians. Online version: 30 minutes	Internal consistency 0.59-0.91 test re test ICC 0.58-0.95	Home, school and community. Children with disabilities have less frequent and lower levels of involvement in participation with less overall environmental supportiveness

**Table 13: Summary of Participation measures (Majnemer 2012)**

## Appendix 4: Multiple Case Study Design adapted from Yin (2018 p.58)



## **Appendix 5: Interviews and Diary schedules**

### Interview 1

First interview: To explore young people's own views, experiences and choices about participation in RA. Supported by parent with use of communication aid and some objects to symbolically represent their choices as discussed in the initial meeting.

Length of interview: 30-45 minutes.

Venue: children and young people home address.

Date: March 2017- March 2018

Topic to be discussed: (Recreational) Fun activities that participant or parent knows about, has experienced and chosen to participate or not to participate in.

Specific question guide:

Can you tell me about yourself?

Can you tell me what fun things you like to do outside of school?

How do you find out about what fun activities you could try?


Can you tell me what helps you to join in fun activities?


Can you tell me what hinders you joining in?


Could you record in this diary the fun activities you will do over the next 12 weeks and we can discuss this next time I come?


Diary Front Cover and Guidance


**VOCAL Research Study Diary**  
**Dawn Pickering**





**Fun**  



**Future**  


**Fitness**  


**Family**  


**Friends**  


**Function**  




Name: Poppy

Date started: 28/10/17

Date finished: 19.2.18

64 lined microperforated • 120 pages

**Clairefontaine**

VOCAL Study Diary about Activities you enjoy outside school

I hope you will enjoy keeping this diary about the activities you enjoy for 12 weeks.

These activities could be at home or outside the home, these are activities done outside of school or work, when you are not asleep. I am interested to find out what you choose to participate in, how often, who goes with you and for how long each time. If you do not have any current activities you participate in the community, you can write about what you do at home with your family and friends, including how you use the internet to support your enjoyment in life.

These may include: Cultural activities or visiting another area



or Craft based activities

Or Sports



Or Reading

Or Playing a musical instrument

Or TV/ Film/Cinema



or Internet based devices/games

Or Spiritual activities



Additionally, periods of rest can be recorded including any episodes of illness, fatigue and/ or pain. Some of you will also be carrying out therapy programmes, please record these as well. This will help me to understand all the things you join in with. It is not essential to record every minute of every day outside of school. I will contact you after 6 weeks to see how it is going. Anything which contributes to your enjoyment can be included. This diary will be collected by me at the end of the second interview for the research analysis, but it can be returned to you after the study has ended, if you wish.

Thank you for participating in this VOCAL Research study.

## Interview 2

Second interview to be recorded with a Dictaphone: To explore Parents/ Child or Young person's views, experiences and choices about young people's participation in RA.

To explore Parents/ Child or Young person's views perceived effect of participation upon young people's emotional WB.

Length of interview: 45 minutes- 1 hour (maximum).

Venue: children and young people home address.

Date:

Topic to be discussed: Diary kept for 12 weeks about (Recreational) Fun activities that young people and you have helped him/her to choose to participate or not to participate in.

Specific question guide:

Discuss observations and any images sent.

Are there any aspects from the diary you would like to highlight about what young people has done for the past 12 weeks?

How are you able to detect young people's emotional WB? What behaviours does he display when he is happy or angry?

What has helped young people to participate?

What has hindered young people's participation?

Thanks for being part of my study: Gift voucher £30 given.

Separate parental interview(Clare and Lily-May's mothers)

To explore parents' views about the experiences and choices that children told me using their communication aids (in 2 previous interviews) about their participation in RA.

Length of interview: 45- 60 minutes.

Venue: children and young people Home address.

Date: 2017/2018

Topic to be discussed: Mother's perceived impact of participation in RA upon child's emotional wellbeing; what helps or hinders their participation choices.

Specific question guide:

1. Thank you for agreeing to carry out a separate interview with me so I can further understand your views about the effect of your child's participation in RA upon their emotional wellbeing.

To start with what do you understand by the term emotional wellbeing?

2. In what ways do you feel that your child's participation in RA affects her emotional wellbeing/ happiness (use mother's own language term here from response to Qu.1)?
3. What helps or hinders their participation?
4. Thank you for the diary which was kept for the 12 weeks. Use diary to explore some of activities and how Mum knows if child is enjoying them or not?
  - a. There were a lot of times when your child verbalised quite loudly- how do you determine if they are enjoying something?
  - b. What behaviours or mannerisms do they display?
  - c. Are there any obvious postures that they adopt to show how they are feeling?
5. How did you find out about the Charities and the funding to support your child's participation?
  - a. Do you use direct payments?
  - b. Who are the key people who influence how they can make a choice to participate in RA?
6. Do you have any future ambitions or concerns about your child continuing participation as she matures?



## Appendix 6: Checklist for Observations adapted from Spradley (2016)

Minutes	Time 0-10	Time 11-20	Time 21-30	Time 31-40	Time 41-50	Time 51-60
Space						
Object						
Act						
Activity						
Event						
Time						
Actor						
Goal						
Feeling						

### Example from observational field notes:

Date 17<sup>th</sup> April 2017

'Space': Race Running Dragon's club indoor facility in City:



Large indoor space inside a large sports hall, indoor tennis at other side, contained within a perimeter fence, goals posts at either end for sledge hockey. Smooth non slip surface for running. Bench seats around the outside of plastic see through perimeter.

Objects

10 Race Runners different sizes



Pump, tool box with spanners and alum keys, spare seats and chest plates:

Table for paper work, chair, hoist. Balls and cones, tape measure. Table and hoist for manual handling.



#### 'Event'

Run/ walk around track in clockwise direction on own with volunteers, with parents/ siblings. Rest at side, play with balls or take part in races around and between cones. Stand around chatting or socialising at bottom end of track closest to where RR's are.

#### 'Actors'

Female Leader, 4 female volunteers: 2 physiotherapy students, 1 5<sup>th</sup> form pupil, Me-Researcher. Four participants in Race Running today: Parents: 2 mothers, 2 fathers, siblings (2 sisters) and 4 runners: 3 male, 1 female. 2 young adult males (20 'T' and 21 'B' years) who are friends from college, **14 year old boy 'Nick' (research participant)** and 6 year old girl 'S'.

#### 'Time'

2 hours-5-7pm

Nick arrives steering his powered wheelchair with Dad alongside:  
5.25pm

Activity: 5.30pm. Leader brings hoist over towards Nick, but Dad says 'I can't be arsed with that today'

#### 'Feeling'

I feel uncomfortable with his decision as this breeches manual handling regulations

#### 'Activity'

We align the Race Runners ready whilst Dad lifts him from his chair into standing, then pivots him around, we assist in ensuring his legs go astride the runner.... The saddle Nick uses has sheepskin padding as he is very slim and without this he has not been comfortable. Nick does wear nappies which provide extra padding.

'Activity and goal' 5.38pm Nick goes round the track clockwise with Dad, Nick uses 2 feet together and Dad keeps the spinner going in front to encourage Nick to move forwards. I walk alongside, encouraging Nick to keep going.

### **Example from field notes written after interviews**

#### **Field notes from visit to 'James' prior to parental interview**

Date 30<sup>th</sup> June 2017

Time 4-5pm

Observations: James is in his wheelchair facing the door as I enter. I greet his mum and niece, then speak to James and touch his hand to introduce myself. James is breathing quite heavily and drooling, he is wearing a bib and dark clothes. He has brown curly hair. His right hand is moving freely, his left hand has a splint and seems fixed in a posture where his thumb and is between his middle and ring fingers. James ankles are supported in transparent inflatable splints as he is awaiting surgery and cannot tolerate footwear as it causes pressure sores.

James does not focus on me as he is cortically blind, his eyes are moving and rolling in a haphazard way. He responds to my voice and a slight smile or grimace appears on his face with excessive drooling. He looks comfortable in his chair, and is smiling intermittently, the hoist sling is left underneath him to assist transfers. The room has overhead tracking to assist this process (picture 2). It is a cramped living room full of toys and furniture. There is a cat on the windowsill and 2 dogs in the kitchen, although they did not bark at me when arriving.

Picture 2: Overhead Tracking Hoist



I had agreed with Mum that to introduce myself I would bring along a few activities to engage with James to help him recognise my voice and touch. I had explained that I would not feel comfortable interviewing her if I had not met him- we agreed: 'no decision about me, without me'. She had suggested he liked shaving foam. So I talk to James, explain who I am and that I will be interviewing his mum next week about the things he likes to do. So to help me get to know him I have brought along some shaving foam to play on his tray with his right hand. Mum moves the tray in front and I spray some white shaving foam onto the tray. James is assisted to place his right hand in the foam, I also then use my hands to spread the foam up his forearm, massaging his hand and spreading the foam all over. James appears to be happy with this, it is difficult to know if he smiles or grimaces, he does have a few jerks or small fits. I tap the foam and clap my hands, James seems to respond to the sound of this. We continue for around 15 minutes, James gets the foam all over his clothes by spreading his hand across the tray and onto his body. He does not try to eat it. He does not move his left arm or hand at all. I keep talking to him, pretending to make a snowman and his niece begins to join in. The cat jumps over onto the table close by, intrigued, but does not jump into the foam. James spreads his fingers out and seems to enjoy the smooth feeling of the moisture and how his hand can glide across the table. When I sense he is losing interest, I suggest to mum that perhaps we can clean him and up and look at some of the other toys I have brought. She goes to get damp tea towels from the kitchen. She cleans James, I clean myself.



## Appendix 7: Poster for Recruitment

There is an opportunity to be involved in a PhD study based at Cardiff University's School of Healthcare Sciences. Dawn Pickering's PhD study '**VOCAL**' is seeking participants who are children or young people with **cerebral palsy** aged between **9-16 years** who **use a walking aid** or are **unable to walk**. Dawn especially wants to represent all 'voices' of children and young people and will work with parents and carers to include those who do not have a physical voice.

Based upon **Article 31** of the United Nations Convention on the Rights of the Child which state that all children and young people:

***'Have the right to rest, leisure, play and recreation and to take part in cultural and artistic activities'***



<http://www.playwales.org.uk/eng/>

**Dawn especially wants to hear from those who find participation difficult.**

If you would like to be involved please contact **Dawn Pickering**:

Telephone number: 02920 687741

Email: [pickeringdm@cf.ac.uk](mailto:pickeringdm@cf.ac.uk)

## **Appendix 8: Reflections**

### **Initial visit to a participatory group participant:**

“...Mum offered me a drink and we stay in the kitchen area where Clare (9 years) is standing in her standing frame, using her computer with her voice synthesiser. I introduced myself and told Clare and her Mum about my research study. I showed her my Dictaphone and how I will record her talk. We discuss if she would be happy to take part and sign a consent form. They are happy to take part and sign the consent forms. Clare was looking at her book of activities that she had done the previous year. I sit besides her looking at the pictures. I became aware that Clare was not always looking at me and Mum told me that she has a visual impairment. We discuss where it would be best for me to sit to optimally engage with her (*To the left and in front- so I reposition myself*). She takes hold of my hand and wants me to read as she points to the words. I was very touched that she engaged with me as I thought this was a good indication that she wanted to take part in my study. This book had amazing experiences of sculpture parks, bike rides and outdoor sensory parks. As mum does this every year, I suggest that the first interview could be based upon last year's activity book. I was encouraged to meet Clare and came away feeling positive about the opportunity to interview Clare on 2 future occasions.... ”

### **Initial visit to Limited Participatory group participant:**

“...Bree (9 years) is sitting on the floor with her iPad and the TV is on C Beebies with subtitles (mum explains that she has a hearing problem so they are on all the time). I then get on the floor close to Bree and we show her some toys I have brought in a small box. Her sister plays quite happily with the items, Bree mainly ignores them. I try to engage with Bree but she is absorbed with the iPad, swiping the pictures. She says the odd word such as yes and no but not reliably in response to the conversation. I sit for a while showing her the light toys and musical instruments, Bree intermittently picks them up and throws them down, shuffling around at floor level. Bree is wearing some pink ankle splints and is wearing grey shorts with her school T-shirt, she wears glasses

and has long dark brown hair tied in bunches. I discuss my study with Mum, who has read the information sheet. I ask if she has any further questions. She says it seems fairly straightforward, about keeping a diary for 12 weeks. I show her the paper diary and get out the information sheet for Bree. Bree looks at the paper and I point to my picture and explain that I will be coming to talk to Mummy about the things that she does outside school and coming to watch her at some of her activities. Bree throws the leaflet down and crawls away towards mum and pulls herself up with difficulty to sit on mum's lap. So I am unsure if she understands who I am and what I am intending to do? Mum however is keen as she says it is very hard for them to participate. So I accept Mum's written consent on Bree's behalf, considering that I sought to engage her in the consent process but she is not able to comprehend sufficiently to write her own consent, so I will consider this is her assent unless she indicates otherwise during the data collection period .....

#### **Following participant observation of Matthew surfing:**

"....They ride the waves several times like this, Matthew still shaking, shouting and enjoying this experience. He has a deep masculine voice which is quite gruff and he is making himself hoarse. I can see how he is visibly shaking with excitement and shouting and waving his arms. This is such a privilege to be part of, although I am not able to balance very easily in the water. I could not have seen his reactions from the shore. So I was pleased I had got into the water to experience Matthew's excitement and enjoyment of surfing on the adapted surf board close up. To hear his loud screams and observe him laughing helps me to capture his emotional WB. It is a lot of physical effort from several people to enable this to happen. It's great there is a dedicated place for disabled people to try surfing... I feel so excited that I have recruited such an enthusiastic family into my research, although challenged as to how to authentically represent this in the data without breaching anonymity.... "

#### **Poppy's case study reflections**



Initial visit: I was struck by Mum's emotional reaction when shown the six 'F' words illustration about participation, at the front of the diary, that she was tearful that Poppy had no friends and did not seem interested in engaging with other children or they with him. I felt it was appropriate to pause and allow her this space to express her sadness. Poppy seemed unaware and was in his own world, playing with toys on the floor. I did show this picture to him and explained in simple words about the diary about his participation but got no reaction from him to indicate he understood. Although I felt my effort to engage him was important, I was not deterred by his disinterest but rather felt it was my effort to explain the research and offer him the choice to be involved. Because of his response I was not able to gain his consent, so whilst disappointing I had to rely upon his parents to provide consent by proxy.

Data collection period: Poppy's Mum was prolific in sending me photographs during the twelve-week data collection period, between the two interviews. The Bat crawl (Figure 45) stood out to me because it illustrated Poppy's exclusion from a recreational activity. I thought this was probably not deliberate, but no further thought had been given how to adapt this for children who could not crawl. I felt sorry for his parents who were making such efforts to enable him to participate. Another image about the pottery event (Figure 44) had given me the impression that he had enjoyed this participation, but later when I received the diary and carried out the interview, the picture only gave part of the story. I felt these images in advance of the second interview, helped me to frame my open questions to probe further.

Data analysis: When coding and identifying ideas, the visual data in Poppy's case, strengthened the narrative I wished to tell. Revisiting Figure 45 I felt upset about the injustice for Poppy. The apparent lack of thinking of how this activity might be included for disabled children left me feeling sad and angry. It made me more determined to use my data to advocate for disabled children at all opportunities to encourage people to go one step further and think about how their recreational activity could be adapted.

## Appendix 9: Photograph of Participant on Sit-ski

Coding shown in text boxes

Matthew in sit-ski waiting to go up ski lift with **volunteer**- here they are safe skier- so **skilled**



Matthew waiting to go up, screaming with excitement - **+ve EWB**

**Siblings** included – Matthew's sister who had learnt to ski here- inclusive activity- **enhances participation**

## Appendix 10: Coding and Table of codes

### Coding

102	Mum: From as young as possible....I always found that...I was always	
103	looking for social groups and socialisation groups for him...that was what I	Commented [DP4]: Looked for social opportunities
104	was looking for...so school were very good...he always had opportunities	
105	to participate in sport. It was really good like a mainstream school unit he	Commented [DP5]: School gave sporting opportunities
106	always done sports days so I'd go every year for the sports day. And	
107	they'd always go to City for gymnastics so he'd always win, he'd always	
108	amaze me my boy doing gymnastics. They took him and then he'd come	Commented [DP6]: Gymnastics-medals
109	back with loads of medals that he'd won....so school really was quite good	
110	in doing it and then they'd start running a bike club, a trampolining club	Commented [DP7]: Bike club
111	after school. So it slowly built up from him being young. I think it was	Commented [DP8]: Trampoline
112	skiing.... Skiing Group actually ...I think that really got me into sport's I	Commented [DP9]: Skiing
113	think with him...cos	
114	DP: What age did you start the Skiing Group?	
115	Mum: He must have been about 7 I think...it must have been, because	Commented [DP10]: Skiing aged 7 years
116	he's been going quite a long time now....I think he was about 7 when he	
117	started there. So that was kind of our thing and then we've always done	
118	bikes, he's always been into his bike so we've always done that sort of	
119	thing. So if they've organised bike clubs and stuff we've gone to that....	
120	Since he was about probably 7 actually, 7-8, there's been a sports festival	Commented [DP11]: Sport's festival: Archery, rock climbing
121	at 'G' Park. So, I was really lucky that one of the staff from the school took	
122	him. He was a bit young to go but because everybody knew Matthew and	
123	everything, they allowed him to go didn't they. So since 7 he's been going	
124	to this sports festival where he's been doing like archery and he's been	
125	doing rock climbing...	

Table of Codes mapped to Research Question

<b>Matthew</b>	<b>Views</b>	<b>Experiences:</b>	<b>Choices</b>	<b>Emotional WB indicators</b>
<b>Data sets</b>				
Interview w 1 with Mum	<p>People loved Matthew- didn't look disabled, had an infectious laugh.</p> <p>Mum wanted him to socialise</p> <p><b>Proud</b> of him</p> <p><b>Amazed</b> by him</p> <p>Wheelchair and personal care needs limit participation</p> <p>Matthew wants to do things without his Mum.</p> <p>Dad struggles but does not see all the amazing things Matthew does.</p>	<p>Massive Stroke 1 year old</p> <p>Trike riding 3 years</p> <p>Skiing 7 years- likes to go fast, especially when rains. Used to stand and ski but too tall and flexed now.</p> <p>School: Bike club, Gymnastic competitions- medals, Trampoline club</p> <p>Sport's festival: Archery, Rock climbing</p> <p>Football</p> <p>Swimming- loves this. New pool did not have transfer chair for pool.</p> <p>Surfing 11 years- risky sport. Screams and</p>	<p>Looked for social opportunities</p> <p>Sport through school</p> <p>Physio at Children's Centre- started some of activities</p> <p><b>Innovation</b> - created new surf board</p> <p>Matthew can't make his own choices.</p> <p>Bike riding and swimming alternate in school terms.</p> <p>Direct Payments 3 hours per week.</p> <p>Respite twice a month: When enjoying it would drive</p>	<p>Picture: Happy riding Trike</p> <p>Winning medals</p> <p>Screams and shouts when happy</p> <p>Also screams when not happy</p> <p>Enjoys activities- Mum likes to see this.</p> <p>Physically strong but can use this sometimes to lash out when upset or angry.</p> <p>Hated respite – but had support and now only goes from home not school.</p> <p>Gets bored quickly then gets distressed.</p> <p>Intentional behaviour to knock on door of respite centre</p>

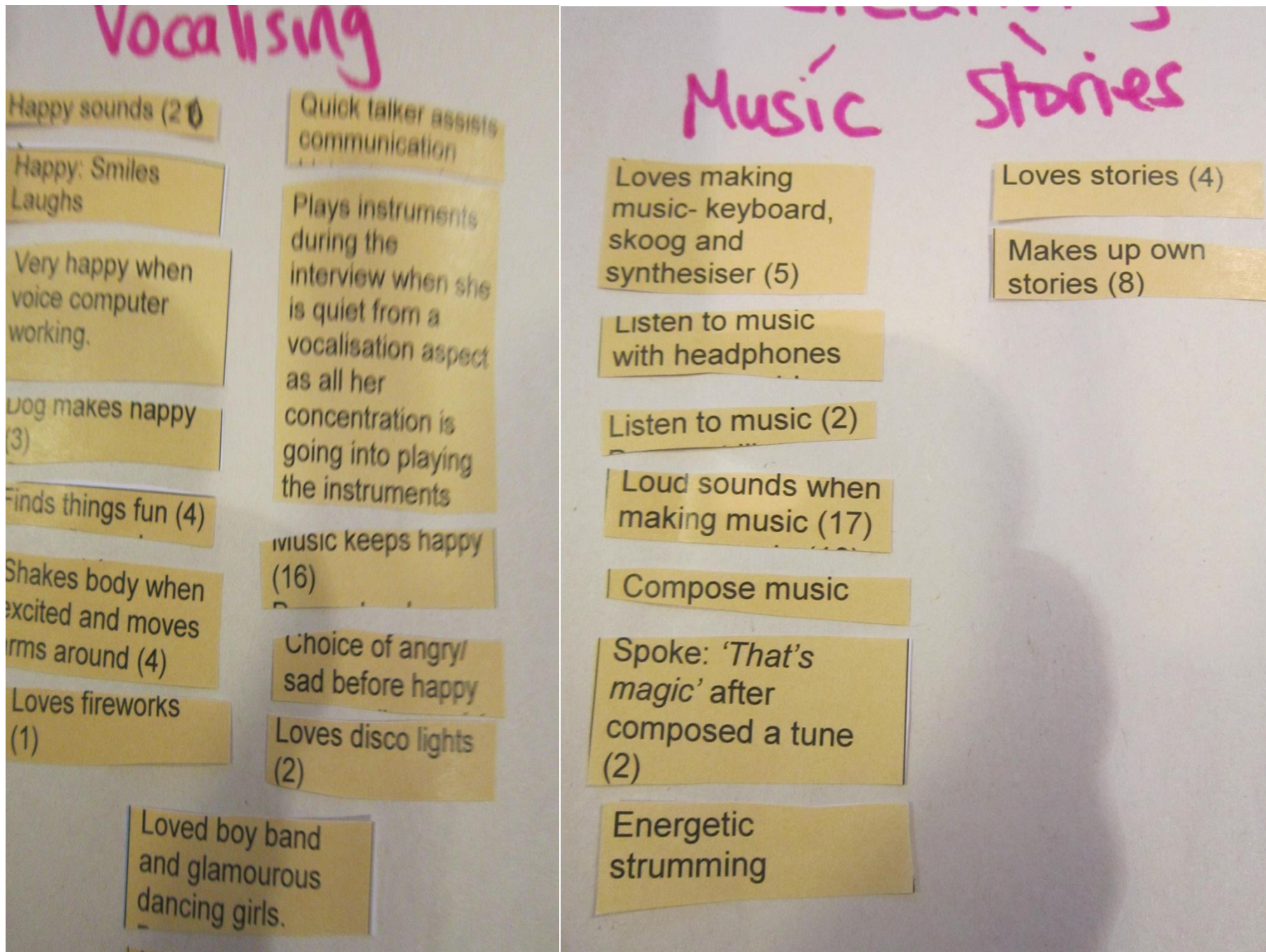
Matthew needs to be supported and stimulated with appropriate activities as he can't occupy himself.	shouts with delight Weekly social club- cinema, bowling. Didn't get school transport. Likes music on iPad.	himself out of car (in wheelchair) and knock on the door to go in.	
--	---	--	--

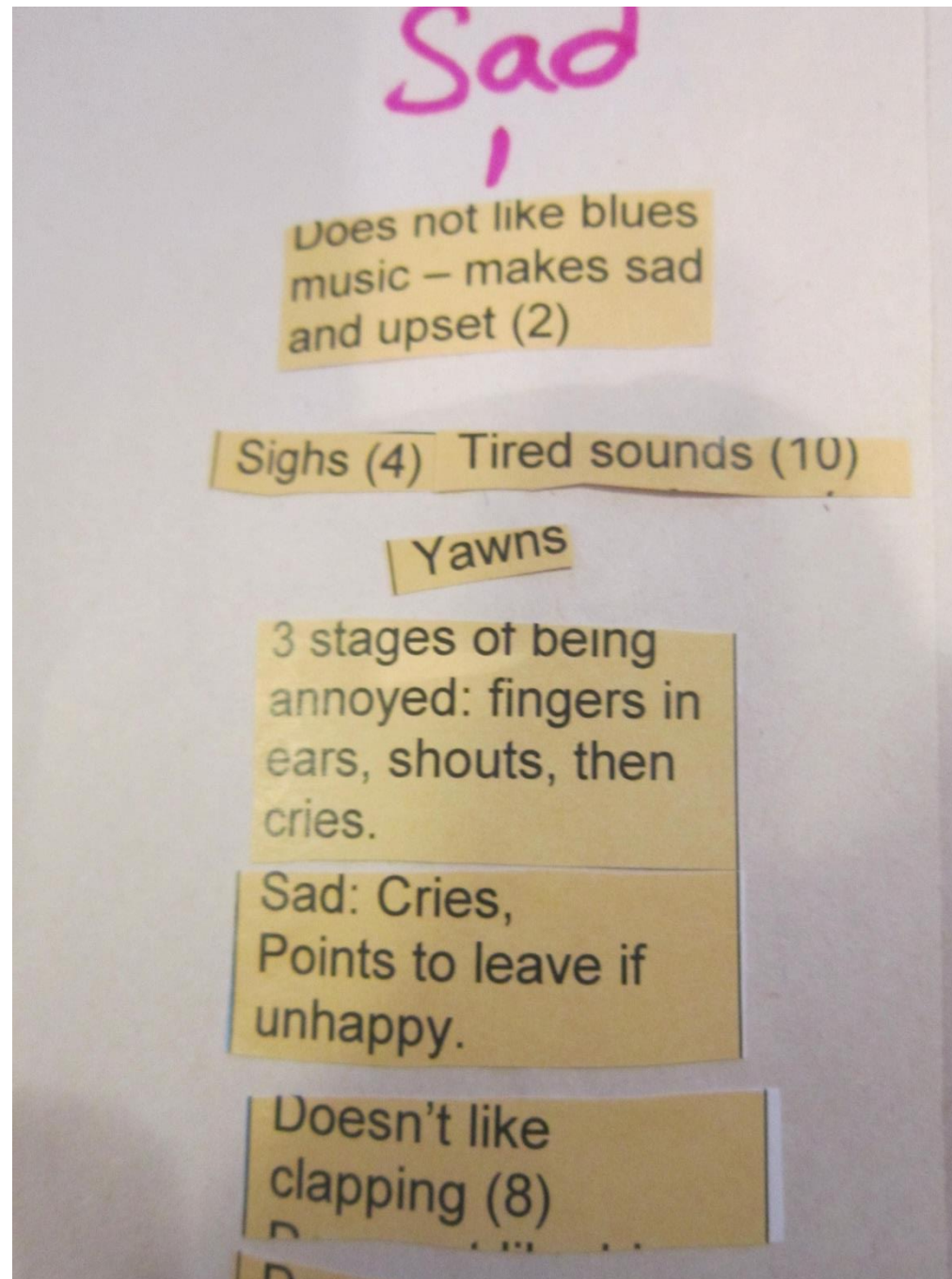
Observation Surfing	Member of public comments this is marvellous (comment 23) Can't appreciate how much he enjoys it until I've seen it Reflection notes- observe likes to go fast	Wears wet suit, uses beach wheelchair (picture 4)- <b>Innovation</b> Indoor facility in winter months Wheelchair adapted vehicle (picture 7) Surfing risky sport- wipe out.	Picture 1: Adapted surfing- <b>Innovation</b>	Pg.6 Matthew grunting with excitement Comment 27 shaking with excitement Comment 35, 38 Shaking + shouting with excitement- becoming hoarse 41: Engages with me by tapping with fishing rod
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## Appendix 12: Participant Information Sheets (9-11 years, 12-16 years, Parents) and Consent Forms: version 5

### Do I have to take part?

No, you can volunteer and change your mind at any time.

### Safety and Well-being

Your safety is very important, if you tell me about something or someone in danger this will have to be reported to another adult in authority.

### Your Consent

I have read the information leaflet (or had read to me) and understood the information given.  
I have had time to think about the information and ask questions.  
I know that this project will help Dawn Pickering learn more about what activities I like to join in with.  
I am happy to have what I say audio taped.  
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 a social worker or the police.  
I know I can decide to stop the project at any time and I don't have to say why. If this is the case then I am happy for you to use any data recorded.

Your Name: \_\_\_\_\_

Your Signature: \_\_\_\_\_

Today's date: \_\_\_\_\_

Parent/Guardian's Signature: \_\_\_\_\_

Appendix 2 Version 5, PIS, Consent 9-11 years, Mar 2017

### VOCAL Research Study



### Who am I?

My name is Dawn Pickering. I teach Physiotherapy at Cardiff University and I am carrying out some research.



### What is the VOCAL Project about?

I would like to know what children and young people with cerebral palsy think about joining in recreational activities. These are activities you do outside school. The picture opposite shows some areas I would like to hear about in your life. These are Family, Function, Fitness, Fun, Friends and the Future. You can talk to me and I will record this chat. If this is difficult for you, another person can also help you to express yourself or speak on your behalf. If this is the case I will also arrange to watch you at one of your usual activities. I will write notes up about this event.

### Why am I doing this?

This project is informed by Articles 12, 23 and 31 of the United Nations Convention on the Rights of the Child, which is about enabling you to express your views and have access to play and leisure activities to help you relax and enjoy yourself. We know

there are limited play and leisure choices for you. If you choose to be part of this research we can learn more about what makes it easier or harder for you to join in. We can then help other children with disabilities to explore what they might like to join in with.

### What is involved?

I would like you to take part in two chats (interviews) and keep a diary of the activities you join in, over a three month period. These can take place where you choose at home or at one of your activities that you join in with. I may take pictures of any equipment you use but not of you.



### What will this research be used for?

The information you give me will be used for talks and documents to inform people who write policies that affect your choices of play and leisure activities. Sometimes this may be the exact words of what you said, but no one will know it is you.

Appendix 2 Version 5, PIS, Consent 9-11 years, Mar 2017

Folded A5 sheet

**Do I have to take part?** No, you can volunteer and change your mind at any time.

## Safety and Well-being

Your safety is very important, if you tell me about something or someone in danger this will have to be reported to another adult in authority.

**Your Consent** I have read the information leaflet (or had read to me) and understood the information given.

I have had the opportunity to consider the information and ask questions.

I know that this project will help Dawn Pickering learn more about what activities I like to participate in.

I am happy to have what I say audio taped.

I understand that I can choose to have 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 a social worker or the police.

I know I can decide to stop the project at any time and I don't have to give a reason.

Your Name: \_\_\_\_\_

Your Signature: \_\_\_\_\_

Today's date: \_\_\_\_\_

Parent/Guardian's Signature: \_\_\_\_\_

Appendix 2 Version 5, PIS Consent, 12-16 years, Mar 17

**Voices of children and young people with cerebral palsy and their carers, about 'Participation' in recreational activities**

**(VOCAL) Research Study**



**Who am I?** My name is Dawn Pickering. I am a senior lecturer in Physiotherapy at Cardiff University and I am carrying out some research for a PhD.



## What is the VOCAL Project about?

I would like to know what children and young people with cerebral palsy think about participating in activities outside school. The picture opposite shows some areas I would like to hear about in your life. These are Family, Function, Fitness, Fun, Friends and the Future. You can talk to me but if this is difficult for you, another person can also help you to express yourself or speak on your behalf. If this is the case I will arrange to observe in one of your usual activities to capture your emotional responses by writing notes afterwards.

## Why am I doing this?

This project is informed by Articles 12, 23 and 31 of the United Nations Convention on the Rights of the Child which is about enabling you to express your views and have access to leisure activities. We know there are limited leisure choices for you. If you choose to be part of this research we can learn

Appendix 2 Version 5, PIS Consent, 12-16 years, Mar 17

more about what makes it easier or harder for you to participate. We can then help other children with disabilities to explore what they might like to participate in.

**What is involved?** I would like you to take part in two chats (interviews) and keep a diary of the activities you participate in, over a three month period. These can take place where you choose at home or at one of your activities that you join in with. I may take pictures of any equipment you use but not of you.



## What will this research be used for?

The information you give me will be used for presentations and publications to inform policy makers that affect your choices of leisure activities. Sometimes this may be a direct quote of what you said. You will need to choose a false name so no one will know it is your words.

Folded A5 sheet

# Dawn Pickering PhD Thesis VOCAL

## Participant Information Sheet for Parents and Carers

School of Health Care Sciences  
Head of School and Dean Professor Heather Waterman

*Ysgol Gwyddorau Gofal Iechyd*  
*Pennaeth yr Ysgol a Deon Yr Athrawes Heather Waterman*



*School of Healthcare Sciences/ Ysgol Gwyddorau ofal Iechyd*  
*College of Biomedical Sciences/ Colg y Gwyddorau Biofeddygol a Bywyd*  
*Cardiff University/ Prifysgol Caerdydd*  
*Room GF1.1/Ty Dewi Sant*  
*Heath Park/ Mynydd Bychan*  
*Cardiff CF14 4XN*  
*Tel/ Ffon: +44 (029) 20 687741*  
*Email/EBost: pickeringdm@cf.ac.uk*



**PhD study:** Voices of children and young people with cerebral palsy and their carers, about 'Participation' in recreational activities (**VOCAL**).

### Who is the researcher?

My name is Dawn Pickering; I am a senior lecturer at Cardiff University's School of Healthcare Sciences where we educate Healthcare professionals (Physiotherapists, Occupational Therapists, Radiographers and Operating Department Practitioners) and Nurses and Midwives. I am carrying out PhD research and the topic I want to explore is about the children and young people with cerebral palsy's 'Participation' in recreational activities, including choosing not to participate.

### Why am I doing this 'VOCAL' research?

I would like to hear what children and young people with cerebral palsy think about participating in recreational activities. I would like to hear about their 'family', how they 'function' in everyday life, what they think about 'fitness', what is 'fun' for them, how they make and keep 'friends' and what they think about their 'future' participation in recreational activities. This project is informed by Articles 12, 23 and 31 of the United Nations Convention on the Rights of the Child, which is about enabling children and young people to express their views and have access to leisure activities.

### How am I going to find these things out?

This will be achieved by two unstructured chats (interviews) using a variety of creative ways to engage your views and hear about your experiences, including recording in a diary. I am aware that some children and young people find it hard to speak verbally and

PIS Parent and Carer Version 5 Mar 17

## Dawn Pickering PhD Thesis VOCAL

so I will work with you to find creative ways to capture their emotional responses by observation at one of their usual participation activities. You as the parent or carer can also talk to me about their participation in recreational activities. The interviews may be held at a mutually agreeable location, which could be at your home, Cardiff University or at one of the activity locations they participate in. Pictures may be taken of any equipment used, but not faces, so your child will remain anonymous.

### **How can I get involved in the VOCAL study?**

Contact me to express an interest in being included in this research study either by (Email: [pickeringdm@cf.ac.uk](mailto:pickeringdm@cf.ac.uk) or Telephone: 02920 687741).

### **How long will participation in the VOCAL study take?**

The research will include two chats (interviews) or observations of a usual activity with the child or young person. These will take place approximately 3 months apart and completing a diary about the usual recreational activities they take part in during that time. You can also chat to me in a separate interview or interviews on behalf of your child or young person.

### **Is there any payment for taking part in this research?**

Should you incur any travel expenses attending for the interviews these will be reimbursed. Your child or young person will receive a £30 gift voucher at the completion of the study.

### **What will happen to the information we collect?**

It is known there are limited play and leisure choices for children and young people with cerebral palsy. If you choose to be part of this research I can learn more about what makes it easier or harder for them to participate. I can then help other children with disabilities to explore what they might like to participate in. They will be given a false name (pseudonym) to protect their identity and the data will be stored securely at Cardiff University on password protected computers. Their personal details will remain confidential and they will be anonymous. The information given will be used for presentations and publications, with your consent, to inform policy makers who can influence play and leisure opportunities. Sometimes a direct quote of what they or you have said may be used. If you agree, I will inform your GP about your voluntary participation.

### **What if I am worried about any aspect of the research?**

If you are concerned about any aspect of the conduct or dissemination of this research you can contact my main PhD supervisor Dr Paul Gill email [GillP3@cf.ac.uk](mailto:GillP3@cf.ac.uk); Tel 02920 688605. Alternately, you can contact Dr Kate Button, Director of Research Governance, Cardiff University Email: [ButtonK@cardiff.ac.uk](mailto:ButtonK@cardiff.ac.uk) Telephone: 029 20 687 734. Cardiff University will act as the sponsor for this research and provide public liability insurance.

### **Safeguarding of children and vulnerable adults**

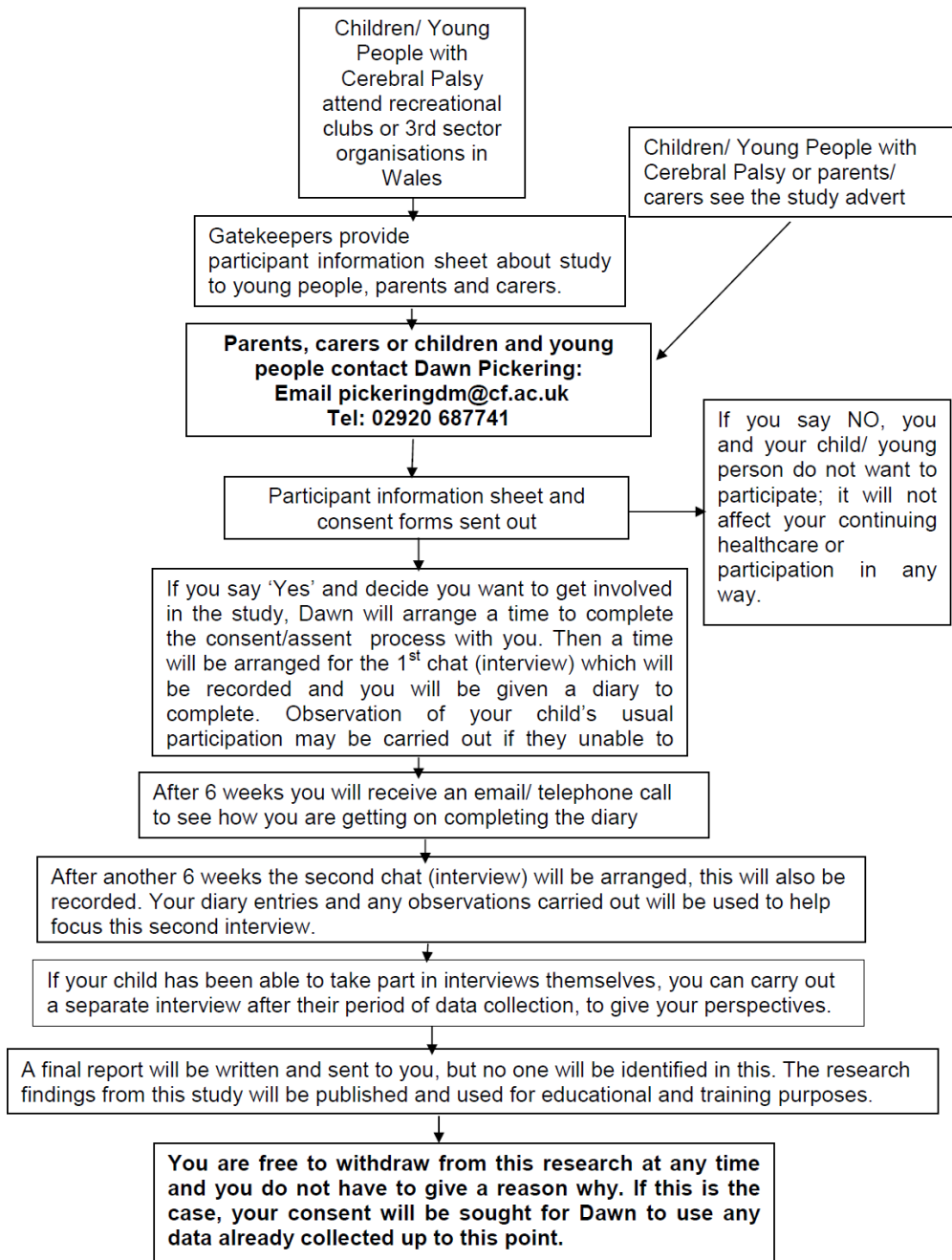
If I become aware of any information that suggests that you or another person might be at risk of harm, the local authority safeguarding children and vulnerable adult's procedures will be discussed with my supervisors and followed if required. This is keeping with Cardiff University's policies.

### **Contact details:**

Dawn Pickering, Senior Lecturer at Cardiff University; School of Healthcare Sciences, Ty Dewi Sant, Heath Park, CF 14 4XN Email: [pickeringdm@cf.ac.uk](mailto:pickeringdm@cf.ac.uk)



How do people take part in this VOCAL study?



PIS Parent and Carer Version 5 March 2017

# Dawn Pickering PhD Thesis VOCAL

School of Health Care Sciences  
Head of School and Dean: Professor Heather Waterman  
Ysgol Gwyddorau Gofal Iechyd  
Pennaeth yr Ysgol a Deon Yr Athrawes: Heather Waterman  
Cardiff University/ Prifysgol Caerdydd  
Room GF11/1, Ty Dewi Sant  
Heath Park/ Mynydd Bychan  
Cardiff CF14 4XN  
Tel/ Ffon: +44 (029) 20 687741  
Email/EBost: pickeringdm@cf.ac.uk



## Dawn Pickering's Research study: Research consent form parents and carers

Voices of children and young people with cerebral palsy and their carers, about 'Participation' in recreational activities (VOCAL)

1. I agree to take part in the study.	Initial:
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason.	Initial:
3. If I decide to withdraw from the study any data already collected can be used.	Initial:
4. I agree that my interview may be recorded by Digital Recorder.	Initial:
5. I agree that photographs may be taken of any equipment used by the child or young person to provide context for the study.	Initial:
6. Confidentiality will be adhered to and a false name (pseudonym) will be chosen to protect mine and my child or young person's anonymity.	Initial:
7. I understand that my data will be stored confidentially on password protected computers at Cardiff University. Only Dawn Pickering and her supervisors will have access to this data.	Initial:
8. I understand that I can receive a copy of the report.	Initial:
9. I give consent for the information to be used for educational, publishing and presentation purposes. This includes direct quotes of our words.	Initial:

Name of Child/ Young person: .....

Name of Parent/Carer: .....

Witness: .....

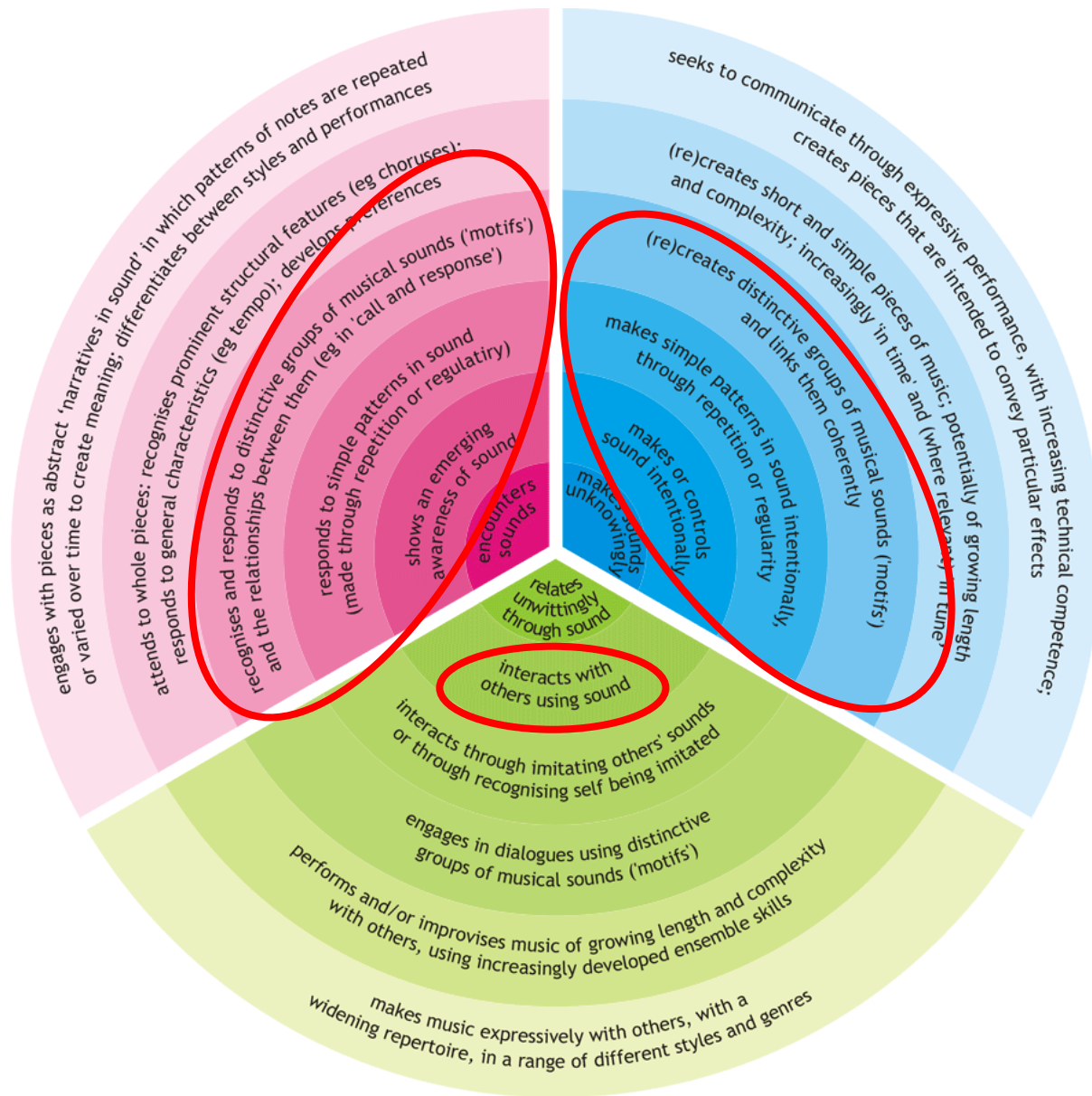
Signature: .....

Date: .....

## Appendix 13: The Sounds of Intent Framework (Sounds of intent.org, 2019)

R Reactive

P Proactive



I Interactive

Clare's responses during interview 2

## Appendix 14: VOCAL illustration of findings for participants

DigiCreates4u.com



This 'VOCAL' picture representation shows a ramp with various activities the participants spoke about which included adapted cycling, surfing, skiing, musical events and RaceRunning. All of these were easier if there was access to a changing places toilet and a mobile hoist.



## Appendix 15: Leuven Scale of Well-Being and involvement (Laevers, 1996)

Table 14: Leuven Well-Being scale

Level	WB	Signals	Signals individual to the pupil
1	Extremely low	The learner clearly shows signs of discomfort such as crying or screaming. They may look dejected, sad, frightened or angry. The learner does not respond to the environment, avoids contact and is withdrawn. The child may behave aggressively, hurting him/herself or others.	
2	Low	The posture, facial expression and actions indicate that the child does not feel at ease. However, the signals are less explicit than under level 1 or the sense of discomfort is not expressed the whole time.	
3	Moderate	The learner has a neutral posture. Facial expression and posture show little or no emotion. There are no signs indicating sadness or pleasure, comfort or discomfort.	
4	Good	The learner shows obvious signs of satisfaction (as listed under level 5 or from personalised list). However, these signals are not constantly present with the same intensity.	
5	Extremely good	The learner looks happy and cheerful, smiles, cries out with pleasure. They may be lively and full of energy. Actions can be spontaneous and expressive. The learner may talk to him/herself, play with sounds, hum, sing. The learner appears relaxed and does not show any signs of stress or tension. He/she is open and accessible to the environment. The child expresses self-confidence and self-assurance.	

## Appendix 16: Poppy's Leuven Scale

Table 15 : Poppy's results

Leuven Scale (1 Extremely low-5 Extremely high)	
Nov 15	Absent
May 16	2
Nov 16	3.4
June 17	Absent
Nov 17	3.8