Doctorate in Educational Psychology (DEdPsy)

'it was…a mixed time really…'
Becoming an adult during the Covid-19 pandemic:
Stories from mothers of young adults with Down Syndrome

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Abstract

The aim of this research was to explore the impact of the Covid-19 pandemic on transition into adulthood for young adults with Down Syndrome, from their parents' perspectives. The study adopted a qualitative methodology with an interpretative phenomenological analysis method (Smith et al., 2021). The researcher interviewed three mothers of young adults with Down Syndrome, between the ages of 20-24 years old at the time of interview, and who were 17-21 years old when the first lockdown commenced in Wales and England (March 2020). Interviews elicited the mothers' retrospective stories from the start of the pandemic, during it, and adapting to post-pandemic life in the immediate aftermath and the long-term. There was freedom within the semi-structured open-ended design to follow the mothers' foci such that they had an 'important stake in what (was) covered' (Smith et al., 2021, p. 4). The researcher upheld interpretative phenomenological analysis principles, whilst adopting a flexible and non-linear approach to data analysis, to evoke and derive meaning from the mothers' sense-making. Hence, themes were generated through the researcher's close and contemplative interpretation of the mothers recounting their/their young adults' experiences. The three themes are: *Autonomy – a kaleidoscope of forms*; *Routine – a multi-edged sword*; and *Parents striking a precarious balance*. Each theme is subject to in-depth analysis and discussion, whereupon researcher/practitioner relevance is highlighted, with specific attention paid towards considerations and/or implications for educational psychologists.

Summary of each part

Part One: Introduction and Literature Review

Part One provides an introduction which sets the context of the research topic and explains key terms.

The following literature review is introduced which is presented in three sections:

Section One:	*Transition into Adulthood for Young Adults with Down Syndrome.*
Section Two:	*The Covid-19 Pandemic and People with Down Syndrome.*
Section Three:	*Rationale for exploring Transition into Adulthood during the Covid-19 Pandemic for Young Adults with Down Syndrome.*

Section One is an integrative, thematic literature review exploring transition into adulthood for young adults with Down Syndrome; the themes generated give rise to four sub-sections. *Section Two* is a scoping literature review, providing an overview of the impact of the Covid-19 pandemic on people with Down Syndrome generally. *Section Three* integrates the two strands and returns to the group critiques of studies reviewed in *Section One* and *Section Two*, outlining the research rationale for the present study.

Part Two: The Empirical Paper

Part Two presents the researcher's empirical study. Sections include:

- *Rationale* (which relates *Part One* to the present research).
- *Purpose of the study.*
- *Research Questions.*
- *Ontology and Epistemology.*
- *Participants.*

- *Procedure.*
- *Methodology.*
- *Findings.*
- *Discussion.*
- *Conclusion.*

Part Three: Critical Appraisal

Part Three is a critical appraisal, offering the researcher's reflections upon the research conception, process, and outcome, as well as a reflexive stance upon their own influence and development as a researcher. This is illustrated in the four following areas:

- *Bracketing off my inspiration.*
- *Delving deeper into ontology and epistemology.*
- *Participants.*
- *Contribution to knowledge.*

Abbreviations

Please note, abbreviations appear in full upon first use in the main transcript and in titles/sub-titles; otherwise, they appear as the abbreviation in the interests of wordcounts. The list below is organised alphabetically.

ALN – additional learning needs

BASIC-Ph – Belief, Affect, Social, Imaginative, Cognitive, Physiological

BPS – British Psychological Society

C19P – Covid-19 pandemic

CEDs – Children's Exploratory Drawings

CR – critical realism / critical realist

CYP – children and young people

DSA – Down Syndrome Association

EP/s – educational psychologist/s

GET – group experiential theme

ID – intellectual disability

IEP – individual education plan

IPA – interpretative phenomenological analysis

LR – literature review

PERMA – Positive Emotion; Engagement; Relationships; Meaning; Accomplishment

PET – personal experiential theme

PPCT – Person; Process; Context; Time

RQ/s – research question/s

SC – social constructionism / social constructionist

SEN/SEND – special educational needs / special educational needs and disability

TEP – trainee educational psychologist

TIA – transition into adulthood

UK – United Kingdom

USA – United States of America

WG – Welsh Government

yo – years old (age)

YP – young people

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PART ONE: Introduction and Literature Review

Wordcount: 13,869

Introduction

Research papers about people with Down Syndrome tend to provide clinical definitions of Down Syndrome (e.g., Dyke et al., 2013; Hartman et al., 2000; Thomson et al., 1995). These focus on genetic underpinnings, typical phenotypic features, and commonly associated learning difficulties, disabilities/disorders. Such a definition is provided in Table 1 below.

<u>Table 1: Clinical definition of Down Syndrome</u>

Down Syndrome is the most common chromosomal condition affecting newborn babies, with an estimated prevalence of between 1 in 700 and 1 in 800 births (Wejerman et al., 2008; in Colvin & Yeager, 2017). It is characterised by an abnormality in chromosome 21, namely partial or full trisomy rather than the typical chromosomal pairing (Colvin & Yeager, 2017). People with Down Syndrome frequently have medical conditions affecting their cardiovascular, respiratory and immune systems (Colvin & Yeager, 2017). Down Syndrome is also associated with distinguished outer physical features, intellectual disability, developmental delay, and a higher risk of dementia (Antonarakis et al., 2020).

Notwithstanding the importance of biological understandings/explanations, these constructions, and the narrative created by the language of 'dis', delay/difficulty, appear to dominate the literature. This researcher adopts a social constructionist (SC) epistemology, specifically Burr (2015)'s depiction which considers knowledge to go hand in hand with social action, thus acknowledging the influence of language/narratives. Therefore, an experiential perspective is deemed warranted, from people with Down Syndrome themselves, whereupon this lens on Down Syndrome contributes to societal perceptions; not just the clinical side. Albeit not offering a definition per sé, Skotko et al. (2011) surveyed people with Down Syndrome [aged 12-51 years old (yo) with an average age of 23yo] from the United States of America (USA) in a mixed-methods questionnaire study. Quantitative findings indicated that the majority were happy with their lives, liked how they looked, and liked who they were. Qualitative findings primarily illustrated a positive attitude; acceptance of needs; and normalising/minimalising difference (although some did perceive their Down

Syndrome negatively). The prevailing focus, however, was on the concept of the individual, with their own friends, hobbies, dreams/aspirations. This is well-depicted in a 1.5minute video by the Down Syndrome Association (DSA), which only references trisomy 21 at the end, almost as an add-on; seemingly to demonstrate that there is so much more to people with Down Syndrome than their Down Syndrome:

We are... (youtube.com)

Following the experiential thread, this research explores the transition into adulthood (TIA) experience for young adults with Down Syndrome, as impacted by the prolonged, unprecedented and widescale life-altering experience of the Covid-19 pandemic (C19P).

The TIA phase is taken to refer to the age period of 18-25yo, following Arnett (2000)'s construction of 'emerging adulthood'. Integrating literature on TIA for young adults with Down Syndrome, and the general impact of the C19P on people with Down Syndrome, provides rationale for exploring what it was like when these experiences coincided, over and above the classification of people with Down Syndrome as 'clinically extremely vulnerable' to C19 infection [Down Syndrome Act, 2022, s.10, United Kingdom (UK) Public General Acts, c. 18], and their requirement to shield (Faundes et al., 2021). Pueschel (1996, p. 94) depicts optimal TIA for young adults with Down Syndrome as occurring 'in the least restrictive environment' which leads one to wonder about their transition within a nationally-enforced restrictive environment. Factors pertinent to TIA for young adults with Down Syndrome such as community participation, social connections outside the immediate family, and the development of independence and autonomy were likely significantly impacted by C19P-related conditions. Therefore, this project aimed to explore how the C19P impacted TIA for young adults with Down Syndrome, both at the time of the pandemic and in the longer-term, from accessing parents' experiences/perspectives.

This research is relevant to educational psychologists (EPs), where the Additional Learning Needs (ALN) Code for Wales (0-25 years) [Welsh Government (WG), 2021] and

England’s Special Educational Needs and Disability (SEND) Code of Practice: 0-25 years (Department for Education and Department for Health and Social Care, 2015) (both legislative codes pertinent to EPs) would apply to many young adults with Down Syndrome in the TIA phase, i.e., those who have been identified as having ALN or Special Educational Needs (SEN). The codes emphasise the importance of transition, and support/provision for young adults with ALN/SEN. Beyond ALN/SEN, EPs work on individual, group and systemic levels, in the service of facilitating positive change for all children and young people (CYP), from 0-25years. The focus, aligned with person-centred practice, is on CYP as holistic, unique individuals, and how systems/environments can accommodate their needs and promote their development/wellbeing, rather than preoccupation with difficulties they may face and a notion of changing the individual to fit society. Therefore, studying the experiential component of TIA for young adults with Down Syndrome is relevant to EPs. Moreover, EPs must keep abreast of changing contexts/developments, where the C19P brought about significantly-altered contexts. One principle of the British Psychological Society (BPS, 2021)’s Code of Ethics and Conduct is to continually develop one’s competence which can include enhancing one’s and others’ understanding via conducting empirical research. This study is unique in its combined focus/design, offering insights to EPs and practitioners generally in the post-18 and young adulthood sectors.

Aligned with a person-centric view of people with Down Syndrome, person-first language is advised by organisations like the DSA (2021); and the importance of this highlighted in a personal parent account (Stephens, 2021). Therefore, this researcher utilises person-first language.

Literature Review

Introduction

This literature review (LR) is divided into three sections:

Section One: **Transition into Adulthood for Young Adults with Down Syndrome**

Section Two: **The Covid-19 Pandemic and People with Down Syndrome**

Section Three: **Rationale for Exploring Transition into Adulthood during the Covid-19 Pandemic for Young Adults with Down Syndrome**

It is hoped that this LR:

- offers a sense of the complexity, nuance, and gravity of the TIA experience for young adults with Down Syndrome and their parents/carers;
- highlights the impact of C19P-related conditions on people with Down Syndrome generally, and;
- through illuminating the apparent incongruency between thematic exploration of the TIA phase and C19P life, the case for the researcher's study is justified.

Please see Table 2 for section summaries.

Table 2: Section summaries (Part One)

Section One: Transition into Adulthood for Young Adults with Down Syndrome

This is the largest section, since TIA for young adults with Down Syndrome is the principal phenomenon under study in the current research, as affected by the C19P. Studying qualitative literature on TIA for young adults with Down Syndrome enabled in-depth exploration of experience/meaning-making, as packaged by researchers' interpretations, which coheres with the present researcher's philosophical foundations, methodology, and method, as outlined in *Part Two: The Empirical Paper*. *Section One* is presented as an integrative LR (Snyder, 2019; Torraco, 2005). Themes were derived and integrated across qualitative studies on TIA, and the perspectives of young adults with Down Syndrome on quality of life/wellbeing; the review is structured by these themes:

- Practical independence: not an only or a must.
- The role played by parents, what this is like, and the impact upon their lives.

- Experiences with systems.
- Meaning of quality of life and wellbeing to young adults with Down Syndrome.

Quantitative research is excluded from the main body of *Section One* because the aim is to thematically explore the experiential component, as offered by researchers' interpretations in qualitative studies. This also upholds regard for establishing coherence within the thesis, as recommended by Yardley (2000), where the predominant focus of the LR is intended to be cogent with the conception/design of the empirical study. Although some quantitative studies are briefly outlined in Table 3 at the beginning of *Section One* to provide context.

Research on TIA for typically-developing peers or young adults with other developmental conditions/complex needs is not explored, since the focus is on young adults with Down Syndrome specifically. One may propose potential for a comparative lens, but it can be tempting when comparing groups to find descriptive opposites or to quantify experience, as more or less, easier or harder, better or worse. For example, Dyke et al. (2013) interviewed mothers of young adults with Down Syndrome and mothers of young adults with Rett Syndrome; whilst the perspectives of each group were captured, the focus substantially concentrated on comparison between the two. Contrastingly, this researcher delves into participants' experiences, interpreting them within their own right and exploring complexity/nuance which could be lost through comparison.

Please see Appendix A for the process followed to arrive at the bank of qualitative studies explored in the main body of *Section One*; and Appendix B for a breakdown of studies reviewed in the main body of *Section One*.

Section Two: The Covid-19 Pandemic and People with Down Syndrome

This is a scoping LR (Munn et al., 2022), offering an overview of the C19P impact on people with Down Syndrome. Due to a paucity of research on the experiential component of the C19P for young adults with Down Syndrome and, indeed, people with Down Syndrome generally, both quantitative and qualitative literature are briefly reviewed in *Section Two*. The purpose is to offer a sense of what has been prioritised in research regarding this area, whereas *Section One* provides the primary in-depth review of literature. As this section is a brief scoping review, no formal guidance was followed. This approach is warranted as general discussion of the C19P impact on people with Down Syndrome justifies its relevance to the primary phenomenon under study; that is, TIA for young adults with Down Syndrome.

The researcher offers three group critiques evaluating the literature (Baumeister & Leary, 1997), which relate to the rationale for the present study. Two are offered in *Section One* (one for exploration of literature regarding the first three themes, and one for the fourth theme, since these are considered separately, as papers reviewed for the latter exclusively accessed the perspectives of young adults with Down Syndrome themselves), and the third group critique applies to *Section Two*. Please see Appendix C for more information about the group critiques.

Section Three: Rationale for Exploring Transition into Adulthood during the Covid-19 Pandemic for Young Adults with Down Syndrome

An integrative approach is re-adopted in this section, where TIA and C19P strands are combined. Integrative LRs are appropriate 'when there is change in a trend or direction of a phenomenon…and when research emerges in different fields.' (Torraco, 2005, p. 359). The C19P, as a phenomenon that emerged, affected uncountable lives the world-over, and holds particular relevance to people with Down Syndrome who were classed as 'clinically extremely vulnerable' (Down Syndrome Act, 2022, s.10, UK Public General Acts, c. 18) and hence required to shield (Faundes et al., 2021), and especially young adults with Down Syndrome, who were concurrently TIA. Aligned with Braun and Clarke (2022)'s perspective on the goal of LRs, this researcher is not highlighting a research gap, even if their study is unique in its combined focus/design. Rather, the researcher proposes potential for discovery/learning were one to explore TIA in the context of the C19P for young adults with Down Syndrome. The group critiques are also amalgamated into this section and, through an evaluative lens, they offer what would be helpful for the present researcher to consider in conception and design.

Section One: Transition into Adulthood for Young Adults with Down Syndrome

This section begins with a summary of quantitative studies to set some context for TIA for young adults with Down Syndrome, alongside the rationale for the refined focus on qualitative research, as outlined in Table 3 below.

Table 3: TIA for young adults with Down Syndrome – quantitative research summary and rationale for the refined focus on qualitative research

Researchers have attempted to quantify outcomes related to TIA for young adults with Down Syndrome such as employment, further education, economic self-sufficiency, living independently (e.g., Foley et al., 2013; Thomson et al., 1995). Thomson et al. (1995) investigated the transition pathways of 35 adults with Down Syndrome in Scotland over a six-year period following the point they left school (hence from when they were 16yo to 22yo). This was a secondary analysis of research reported elsewhere (Thomson & Ward, 1994a; Ward et al., 1994; in Thomson et al., 1995). The most common pathway was to transition from school to an adult resource/training centre (74% of the adults). Only 6% of the adults were in further education, and 6% gained employment. Both figures are low, but the latter is particularly noteworthy given that only 6% of the adults were not seeking work, implying that the remaining 88% were seeking employment but had not been successful in the six-year period. 88% of the adults remained in their family home, whilst 6% moved into a residential setting. If one concentrates on the aforementioned outcomes regarding TIA, this study appears to indicate limited opportunity and relatively low prospects for young adults with Down Syndrome. However, this study is quite mature and, as the researchers highlight, data were collected prior to more inclusive ethe and legislation affecting practice in Scotland.

Foley et al. (2013) present more recent outcomes for young adults with Down Syndrome (aged 15-30yo) in Western Australia, as reported by their parents in a questionnaire study, where the following percentages were accurate in 2009: of 164 adults who had left school, 26% were in open employment, 10% in training, 39% in sheltered employment, and 25% in alternatives to employment; figures that seem more promising. Although, young adults with enhanced functioning in the areas of self-care, and community/communication skills, as reported by their parents, were more likely to gain open employment than their counterparts, implying room for development regarding promoting high expectations/inclusion for young adults with Down Syndrome generally following school.

Foley et al. (2013) found that health status was only weakly related to post-school occupation. However, Pikora et al. (2014) present somewhat contrasting findings. Pikora et al. (2014) found that various health conditions are commonly experienced by young adults with Down Syndrome (aged 16-31yo; median age of 24yo), and often more than one, for example, eye/vision, ear/hearing, cardiac, respiratory, musculoskeletal, body weight, skin and/or mental health. Again, they utilised a parent-report questionnaire design, recruiting their sample from the same research database of young adults with Down Syndrome/parents used by Foley et al. (2013), hence these findings also concern Western Australia. The parental felt impact of these health conditions included restricted opportunities to engage in employment, community leisure activities and concerns around their young adults' safety, where only a small number of parents perceived no impact. Combined, these studies imply that young adults with Down Syndrome may be disadvantaged regarding their attainment of outcomes like open employment, or their participation in community life beyond school, due to their levels of functioning and/or health conditions.

Leonard et al. (2016) recruited their sample from the same research database in Western Australia; parents of young adults with Down Syndrome (aged 15-30yo) completed a questionnaire survey; this time concerning transition planning. 74% of parents reported engaging in planning meetings with teachers prior to their young adults' transition from school. Within the same study, Leonard et al. (2016) surveyed parents of young adults with general intellectual disability in Queensland, Australia. For some findings, the researchers only provide combined figures representing both groups, hence it was not possible to ascertain more precise measures for young adults with Down Syndrome in these cases, however they offer a broad idea. 87% of all parents reported that they were involved in decision-making regarding next steps, whilst 60% of young adults were, and 38% of parents indicated that they would have liked to have been more involved in transition planning. This suggests room for development regarding person-centred planning of transitions, considering authentic involvement/empowerment of young adults and their parents. Parents of both cohorts identified provision of more information about financial assistance, the school transition programme, and the building of informal community-based supports as the most helpful strategies during transition, highlighting the importance of economic security, effective preparation, and inclusion in everyday community life for young adults with Down Syndrome and young adults with intellectual disability.

Regarding concerns/worries around transition issues generally, half of the parents of young adults with Down Syndrome reported that these impacted upon their daily life/wellbeing, where 34% also reported a wider impact on the daily life/wellbeing of their family. Parents of young adults with Down Syndrome reported worries specifically in the areas of future care, living arrangements, work/day activities, and access to social activities/friends; 83% were worried about work/day activities for their young adults when they had left school, where 59% reported experiencing worries frequently/very often; and 80% were worried about their young adults' access to social activities/friends, again with a significant proportion experiencing worries frequently/very often (51%). This implies that parents experience significant worry regarding the future daily occupation of their young adults, as well as their inclusion in social/community life. These worries appear to take their toll, on themselves and sometimes their wider family too.

Whilst the above quantitative studies paint a broad picture, the aim of such research tends to be to make generalisable claims which can be reductionist, particularly for multi-faceted/prolonged experiential phenomena. Even their generalisability is doubtful; the researchers studied large samples but those samples were recruited from the same database in three out of the four studies outlined above. Moreover, the quantitative findings only tell us so much, for example, one may acquire a sense of what young adults with Down Syndrome may be doing day-to-day post-school; of the skills/health status of those attaining what may be considered as traditional TIA outcomes like employment and independent living; or of potential environmental/systemic conditions that facilitate/hinder attainment of such outcomes. One could also obtain an idea of the potential impact of TIA upon their parents, for example, the proportion of parents who report that worries/concerns related to their young adults' TIA affect their daily life/wellbeing, or that of their family. However, open questions that lend themselves to detail, depth, and variety often remain untouched. For example:

- What is the TIA for young adults with Down Syndrome like?
  (What is the experiential component?).
- What are associated thoughts/feelings/perspectives?
  (That is, beyond ascertaining the proportion of parents who are worried and how often they experience those worries, what is behind their worries; what is it like to bear them; what other thoughts/feelings are implicated in the transition?).

Moreover, following on from such questions:
- Why/how?
- What does this mean?
- Could they elaborate?

Section One focuses on qualitative research which is argued to more holistically capture, attend to subtle aspects, and thereby do justice to, the intricacy of experience.

1.1. Practical independence: not an only or a must

Researchers tend to characterise TIA as a change of status amongst opposites, where ‘the protected life of a child’ is contrasted against ‘the autonomous…independent life of an adult’ (Dyke et al., 2013, p. 149; Leonard et al., 2016, p. 1370), and there is progression ‘from dependence to independence’ (Docherty & Reid, 2009, p. 458). TIA can also be depicted by adoption of adult roles regarding relationships, living arrangements, employment, and the general control one exerts over their life (Dyke et al., 2013). This subsequent elaboration seems to broaden the meaning of TIA, or at least uncovers further possibilities as to what it could look like. Nonetheless, preoccupation with conducting activities independently, or with attaining outcomes that are traditionally associated with adulthood status such as living out of the family home/gaining employment, seems to emerge from some studies. Indeed, gaining meaningful employment can be viewed as synonymous with successful transition (e.g., Leonard et al., 2016). Hartman et al. (2000) present a case study on a young adult with Down Syndrome, Jack (aged 18yo), investigating his TIA from his mother’s perspective. His mother considers Jack being able to live without his parents to be important, even if he would still require a full-time carer. Similarly, Peterson (2006), who offers a qualitative video essay and naturalistic inquiry exploring the perspectives of parents, siblings and young adults with Down Syndrome themselves (aged 19-42yo) on adulthood experiences, including insights from interviews with each party and observations of the young adults in natural contexts, found that parents were satisfied where their young adults were living independently/employed. Peterson (2006) appears to convey lack of employment/living independently as indicative of deficiencies in the adulthood status, along with parents becoming legal guardians for their young adults, and the dependence of these young adults on their parents to meet financial, self-care, and transport needs. This seems to be a narrow view of adulthood, especially when Peterson (2006) herself also found that involvement in social activities, satisfaction of the young adults in this realm, resilience in coping with familial changes, and satisfaction with their lives generally, to also be implicated in their adulthood experiences.

Whilst other authors highlight the importance of developing practical independence, they offer a more holistic picture. Docherty and Reid (2009) interviewed mothers of young adults with Down Syndrome (aged 19-29yo; average age of 23yo) who felt that TIA involved a mindset shift, relating to their young adults generating ideas, making decisions, delineating goals, and values, motivations, and responsibilities they began to assume; sometimes prompted by their parents. For example, one mother described encouraging her son to take a more active role in organising his social life, rather than just going out with his parents. Several authors highlight participation in, and gaining satisfaction from, social/community life: peer friendships [encompassing inclusion with typically-developing peers, e.g., college break times (Thomson et al., 1995), and going out for dinner (Wills et al., 2016)]; and enjoying a variety of interests, including social hobbies/activities, e.g., bowling, drama, skiing (Riesz, 2004; Thomson et al., 1995).

As well as engagement in social/leisure activities and peer relationships, it seems that personal growth; adapting to changes that are challenging initially; along with finding meaning and being content in one’s life are implicated in TIA. Peterson (2006, p. 137) discusses one woman who had transitioned to independent living but, rather than emphasise this phenomenon per sé, the element of significance was how she felt initial anxiety about novel experiences in her new home, yet preparation and subsequent achievement of positive outcomes boosted her confidence, inspiring ‘satisfaction and contentment’ in her living situation. Additionally, the young adults coped with familial changes even when these could be stressful, such as siblings moving away/progressing to the next stage of their lives, entailing less contact (Peterson, 2006). Thomson et al. (1995) present parent-reported case studies of two women with Down Syndrome; one of whom, Mandy, developed her self-confidence through attending an adult resource centre, via participating in activities like drama/Keep Fit classes. Mandy’s father explained that ‘her whole life…revolves around the centre’ (p. 333), suggesting that Mandy gained a sense of meaning/purpose through engagement in social/leisure activities. Whatever their living situation/employment status, Peterson (2006, pp. 136-137) found that her sample of young adults ‘appeared satisfied, secure…content’.

The above findings imply that TIA is broader than developing practical independence through employment, living situation or activities of daily living. Themes of peer relationships; feeling positive about one’s life; engagement in activities and finding meaning/purpose from these; and experiencing growth according to one’s individual circumstances, appear to feed into an adult life for young adults with Down Syndrome. Perhaps it would be useful to consider TIA more holistically, incorporating elements of emerging practical independence alongside aspects of positive psychology, specifically Seligman (2011)’s PERMA model of wellbeing (Positive Emotions; Engagement; Relationships; Meaning; Accomplishment), where each of these facets resonates from the discussion above.

Elevating practical independence when considering TIA for young adults with Down Syndrome may not only be reductionist; it could also create misinformed targets.

Researchers argue that independence does not equate to zero dependence; we live in an interdependent society, depending to some degree and in different contexts on family, friends, and wider systemic structures/resources (Detisch, 2007; Docherty & Reid, 2009). One could contrast an unemployed young adult with Down Syndrome with an employed typically-developing peer, arguing that the latter's employment renders them as independent, whereas the former is not. However, Peterson (2006) proposes that one view independence/dependence on a continuum, where people can be more independent in some areas of life than others. For example, the typically-developing peer may be employed whilst remaining in the family home. Hartman et al. (2000) argue that independence should be defined according to the individual rather than traditional adulthood status outcomes, where young adults are encouraged to progress on a journey tailored to them/their circumstances.

1.2. The role played by parents, what this is like, and the impact upon their lives

Literature on TIA for young adults with Down Syndrome concentrates heavily on their parents. From reviewing said literature, it seems plausible to propose that this focus is based on their pivotal role. Parents do much and assume great responsibility for their YP during the TIA and young adulthood years, whether rightly or wrongly given the amount they do; they experience worries and/or fears; as well as mixed feelings/positionings in their roles/beliefs around how they should be/act for their young adults; and these factors combined, along with simply having a young adult with Down Syndrome who is TIA, affect their lives considerably, as well as the family unit. These themes are discussed below.

1.2.1. What parents do and their perceived sense of responsibility

Parents commit a significant proportion of their time to planning/preparing for TIA, and supporting their young adults through it (Docherty & Reid, 2009; Dyke et al., 2013; Leonard et al., 2016; Riesz, 2004). This temporal dedication is equalled by their efforts which involve reading and research into services, which parents feel the onus is on them to do (Leonard et al., 2016; Riesz, 2004). Sourcing information, in the case of transition from paediatric to adult healthcare services for example, can be ‘overwhelm(ing)’ and ‘difficult’ (Peters et al., 2022, p. 1211).

Some parents describe still being very much depended upon by their young adults on a level similar to that when they were teenagers (Peterson, 2006), for example: financial dependence; self-care needs (food/clothing/health); their physical home; transportation; and support with employment (Peterson, 2006; Riesz, 2004). Parental involvement extends to orchestrating a fulfilling daily life for their young adults beyond practical arrangements, for example sourcing and/or organising volunteering/educational/recreational opportunities, checking first whether activities are suitable, creating weekly timetables (Docherty & Reid, 2009; Dyke et al., 2013), and hosting social activities (Wills et al., 2016). Scorgie and Wilgosh (2009) present a longitudinal case study of Chad, a young man with Down Syndrome whose mother was interviewed at various points of his life; her final interview was when he was 25yo. She aptly summaries parents’ efforts: ‘we just kind of created our own world for Chad’ (Scorgie & Wilgosh, 2009, p. 213). This level of involvement is necessary from the perspective of mothers in Docherty and Reid (2009); one mother explained that where their young adult has an interest, it is on her to ‘make it happen’ (p. 463). Wills et al. (2016) interviewed seven mothers of young adults with Down Syndrome, incorporating the method of qualitative ‘photo-voice’ which involved the mothers bringing photographs that represented aspects of their young adults’ lives, as stimulus for discussion; a mother shared that she is obliged to play the role of orchestrator, again to ensure things happen.

Notwithstanding the contribution of time/effort to finding, checking, and organising opportunities in pursuit of realising fulfilled lives for their young adults with Down Syndrome, the role of parents also seems to involve advocacy/pushing. This in relation to pushing themselves/their young adults out of their comfort zones, against hesitations, reservations, or long-established habits, to promote progression towards adulthood (Docherty & Reid, 2009), for example, the mother mentioned earlier who was trying to encourage her son to take a more proactive role in organising his social life. Reisz (2004), who offers an autobiographical narrative account of experiences with her daughter, Sarah (30yo), adopted a persistent attitude to nudging Sarah towards independent living, even when met with Sarah's resistance, from the standpoint of her perceived long-term potential/growth. Parents also feel the need to push regarding systemic provisions, such as seeking employment (Peterson, 2006), or when securing opportunities like those mentioned earlier when organising their young adults' daily calendar (Dyke et al., 2013). As part of a wider study, Dyke et al. (2013) interviewed seven mothers of young adults with Down Syndrome (19-27yo; average of 21yo); mothers reported needing to describe their young adults as very able to professionals, such that they could live the best adult life they could. In fact, Dyke et al. (2013) argue that 'The success of the transition process appear(s) to be associated with the level of the parent's advocacy' (p. 152); explored further in a subsequent section (1.3.2.).

1.2.2. Worries and/or fears

A palpable sense of worry/fear emerges from the literature on behalf of parents of young adults with Down Syndrome. Leonard et al. (2016), as part of their parent-report questionnaire study (please see Table 3), collected qualitative data. One parent described TIA as an 'extremely worrying period…(a) very grey area of life' (Leonard et al., 2016, p. 1375).

Parents' concerns around developing practical independence related to their young adults' safety, welfare, and perceived vulnerability in society/community, for example capability to manage money (Docherty & Reid, 2009; Thomson et al., 1995); safety in the workplace, including support/supervision and their commute (Leonard et al., 2016), even leading to decisions to cease employment where parents perceive their young adult to be unsafe (Peterson, 2006). Parents also worried about their young adults forming relationships with new professionals, and expectations placed upon them as they entered adulthood (Leonard et al., 2016). These concerns indicate a lack of felt safety on behalf of parents for their young adults with Down Syndrome in community/workplace contexts.

Parents expressed anxiety regarding their reduced influence/involvement in their young adults' lives and consequential unknowns, relating to transition to independent/supported living, or from the perspective of parents' own aging/mortality. Riesz (2004) shares a lengthy series of questions regarding Sarah moving out, including practical worries such as who would tend to her self-care needs, but also fears around whether she might encounter abuse in her new home, and/or whether she would be sad without her parents. Several authors demonstrate parents' worries emerging from the inevitability of their own aging/mortality, combined with uncertainty of who would assume their role, and what the futures of their young adults would look like without them (Detisch, 2007; Dyke et al., 2013; Leonard et al., 2016; Riesz, 2004; Thomson et al., 1995). Mothers in Dyke et al. (2013, p. 154) were actually 'hopeful they would outlive their son or daughter'. Even if this hope were only shared by a minority, the weight of anxiety shouldered by parents across several papers regarding the question 'What happens when I can't?', to the point where some parents may harbour this hope, suggests significant wider systemic deficiency. Whether this be support offered, parents' or young adults with Down Syndrome's satisfaction with said involvement, lack of parental trust, or a combination of these factors, it is an area that warrants further research and careful consideration by relevant professionals/systems. Where parents were comfortable about their young adult's future when they would no longer be able to play their role, this was attributed to having confidence in familial supports taking on the mantle, such as siblings/family friends (Peterson, 2006), rather than it being due to professional/community support.

Alongside worrying about no longer being able to support their young adults with Down Syndrome in the context of their own mortality, parents equally worried about becoming their only form of support during/following TIA. Parents express concern about their young adults leaving school which is characterised as safe/structured, and accompanying cessation of well-known routines (Dyke et al., 2013; Leonard et al., 2016; Riesz, 2004). Riesz (2004, p. 375) depicts anticipation of this transition as an 'impending loss of 18 years of school-based support', where school professionals knew Sarah well; her academic/social development were proactively promoted and formalised in legal documents; and there was contentment/security in the daily routine. Concerns around loss of school-based support were also related to impact upon parents' lives, where the school day provided respite, and parents needing to assume more responsibilities such as transporting their young adults to activities when they had gotten used to school transport (Dyke et al., 2013). Mothers in Dyke et al. (2013) worried about the impact on their ability to work, and highlight that loss of the school support network tends to co-occur with parents aging and loss of familial supports, such as siblings leaving home, which could be difficult where siblings assisted with practical arrangements like transport (Peterson, 2006). Parents' fear of losing school-system support could indicate considerable satisfaction in this area. However, it could also, or otherwise, signify a drop-off into the abyss, where parents feel alone in orchestrating, supporting/encouraging next steps, or at least that they are without/dissatisfied with wider systemic support, such that they seem to do most things themselves.

Parents are anxious about their young adults with Down Syndrome experiencing social isolation as they transition. They worry about how their young adults will feel when they see school friends progressing, perhaps going to college/marrying (Peterson, 2006);

one mother expressed anxiety around her young adult not experiencing inclusion in peer relationships and instead only having her day-to-day. Peterson (2006) challenges researchers who explain social isolation for young adults with Down Syndrome in the context of parents being inadvertently over-protective, arguing that it is difficult for parents to find socialising opportunities, and organise logistics like transport. Material explored in section 1.2.1. would support the latter explanation.

1.2.3. Mixed feelings/positionings

Parents occupy a middle space within their role, and their feelings towards TIA. Mothers in Docherty and Reid (2009) viewed themselves as both gatekeepers and facilitators on the journey towards their young adults developing independence. They wanted their young adults to be aware of the effects of their Down Syndrome, without this awareness blocking them from having dreams/goals. They wanted them to have a realistic outlook, for example, to consider their desire to live independently in the context of them depending upon adult support to ride the bus. Jack's mother in Hartman et al. (2000) wants him to become more independent, recognising independence to be his right, yet believes that his Down Syndrome will limit this. Mothers are conflicted when faced with paucity of accessible open employment options for their young adults with Down Syndrome, deciding to opt for supported workplaces instead to ensure consistency/safety, whilst feeling that these placements can lead to 'unmet potential' (Dyke et al., 2013, p. 159).

There is a sense of parental guilt/anxiety around pushing their young adults with Down Syndrome to strive for independence when they appear comfortable in their current circumstances. One mother depicted herself as being 'quite cruel' when suggesting to her young adult that they do something else whilst the parents went for a walk, rather than automatically joining them (Docherty & Reid, 2009, p. 462). Riesz (2004) describes ‘anxiously practi(sing)’ the conversation she and her husband would have with Sarah about her moving out, in anticipation of her resistance.

TIA seems to be a confusing period for parents. They may want to shield their young adults with Down Syndrome, or change the scope of their dreams/goals, whilst also desiring them to fly the nest and to have dreams/goals. Or/concurrently, they may nudge them to develop independence, whilst harbouring guilt around pushing them out of their comfort zone. Docherty and Reid (2009) argue that mothers’ values/beliefs relating to their young adults with Down Syndrome transitioning exist within a dynamic space; this dynamism may be a necessary response on behalf of mothers who are doing their best for their young adults in a society that may be lacking in inclusive practices.

Parents in Leonard et al. (2016) illustrate conflicting hopes and fears. Like worry around potential social isolation discussed earlier, parents are anxious that during TIA their young adults may lose old friends, struggle to be accepted by new colleagues in workplaces, and, where social contacts may reduce in transition, so too could their quality of life (Leonard et al., 2016). However, TIA is concurrently viewed with hope; that their young adults will make new friends in new work/social settings, be fulfilled in these networks, that they will be stimulated/challenged, potentially earn their own income, feel safe/secure, experience happy/rewarding lives, and embark upon lifelong learning/development; ‘like for everybody’ (Leonard et al., 2016, p. 1376). Detisch (2007) interviewed six young adults with Down Syndrome (16-23yo) and their families (including parents and siblings) and discovered optimism for the future of the young adults, despite difficulties inherent in the transition process itself. Additionally, Thomson et al. (1995) who present a parent-reported case study of a young woman with Down Syndrome, Anna, described that her parents were hopeful that she would gain employment someday; at the time she was attending college and volunteering in a nursery setting, experiencing success in both contexts, and her father shared ‘It seems that every time we say she’s not going to be able to do something, she does it.’ (p. 334).

1.2.4. The impact upon their lives

It appears that TIA and the experience of the young adulthood years exerts a substantial impact upon the lives of parents of young adults with Down Syndrome, including their practical circumstances, quality of life, and their life outlook. Regarding practical aspects, parents can experience financial, living and legal difficulties. Mothers describe having to move away from their community/extended family to find better opportunities for their young adults, or because they experience a lack of inclusion and consequentially social isolation (Wills et al., 2016). Some parents change their working arrangements to account for increased care responsibilities/family financial pressures (Leonard et al., 2016; Wills et al., 2016). Parents from the USA describe 'stressful' legal experiences, when applying for guardianship of their young adult aged 18yo/over, which involved an enduring, expensive process where they were scrutinised on their parenting skills (Peterson, 2006). This, after a lifetime of parenting their young adult.

The practical adaptations/requirements, and parents' role in and feelings towards TIA generally, can negatively affect their quality of life quite starkly. A mother in Dyke et al. (2013) expressed a limited quality of life which improved somewhat when her young adult moved into supported living but this was a 'hard decision' (p. 155). Even where young adults with Down Syndrome are in supported living, it can be a struggle for parents to be flexible/spontaneous in their own lives due to ongoing dependence, regarding their young adults' health, work/residential circumstances (Riesz, 2004). Furthermore, the notion of parents needing to make choices/decisions on behalf of their young adults, like encouraging them to move out, can take its toll, where they may become 'very tired and stressed' in fretting about whether they have made the 'right choices' (Leonard et al., 2016, p. 1375). General worries, pressures and practical changes associated with TIA can lead to deterioration in many aspects of parents' lives, for example: physical health; mental/emotional health [one parent disclosed their depression diagnosis (Leonard et al., 2016); and Riesz (2004) described for herself and her husband 'bouts of crying and inability to sleep, and (she) lost considerable weight' (p. 378) related to orchestration of Sarah's move, where they accessed counselling to prepare for/cope with Sarah's TIA generally]; work/life balance and financial pressures [a parent in Leonard et al. (2016) shared 'Our whole family has suffered. We are getting worse and worse off financially. We work and struggle' (p. 1376)]; marriage [Chad's mother reported that she and her husband divorced, explaining from her viewpoint that 'he can't recognize that this is a life-long issue' (p. 214); Riesz (2004) also reported periods of 'spousal conflict' (p. 379)]; and engagement in their own social/leisure activities (Leonard et al., 2016).

It is important to note that whilst TIA can prove to be a very challenging period, Peterson (2006)'s parents viewed raising their young adults with Down Syndrome and supporting them through transition to be rewarding, where siblings also emphasised positive aspects, for example, believing that their sibling with Down Syndrome had enriched their lives and made them better people. Scorgie and Wilgosh (2009) report that Chad's mother felt he had such a positive impact upon her life that he inspired her to further her own development, by way of further education, and she described experiencing enhanced empathy towards other parents. She characterises him as a 'teacher' (Scorgie & Wilgosh, 2009, p. 214). Siblings normalised their assistance with activities such as self-care and accompanying out and about as common aspects in sibling relationships between typically-developing individuals (Peterson, 2006), accepting these responsibilities (Detisch, 2007). It was parents rather than siblings who worried about them assuming responsibility (Docherty & Reid, 2009), fearing that it could be a 'potential burden' (Detisch, 2007, p. 159). Moreover, Peterson (2006) showed a sibling to involve their sibling young adult with Down Syndrome in a positive way when it came to their marriage, prioritising development of the relationship between them and the fiancé and including them in the excitement of wedding planning. Furthermore, even though another sibling worried about their sibling young adult with Down Syndrome adapting to them joining the AirForce, and the reduced contact, they were confident that they would be able to cope.

Notwithstanding positive aspects above, it is important to consider this sub-section in its entirety, recognising that parents may understandably see themselves as 'lifelong carer(s)' (Docherty & Reid, 2009). This is illustrated by their significant involvement; the great/enduring responsibility they uphold; difficult/character-testing decisions they feel obliged to make; adaptations they create; all the while experiencing 'emotional upheaval' (Riesz, 2004, p. 380) ignited by these elements and any secondary effects within TIA.

1.3. Experiences with systems

1.3.1. What's helpful?

Where families in Detisch (2007) identified post-school transition as positive, they emphasised the importance of teachers getting to know them, respecting their values/beliefs (acknowledging these even if every resultant wish could not be fulfilled), and working towards making the process as collaborative/inclusive as possible. Along this thread of developing relationships, parents' sense of trust in professionals also seems to aid transition. Peters et al. (2022) explored healthcare transition, interviewing twenty parents of young adults with Down Syndrome (aged 15-25yo) and six healthcare professionals [paediatricians and intellectual disability (ID) physicians; the latter take over from the former once the young adult with Down Syndrome turns 18yo]. Parents trusted the new ID physician, and felt more positive about the transition, where these professionals coordinated with paediatricians in preparation (and so were familiar with their young adult's medical history) and exhibited holistic interest in the young adult as an individual, creating a sense of 'comfort and safety' (Peters et al., 2022, p. 1212).

The value of preparation and treating young adults with Down Syndrome as individuals resonate in Leonard et al. (2016) and Riesz (2004). Leonard et al. (2016) show that parents find transition plans to be helpful. Riesz (2004) describes input from a service offered by their regional education agency entitled 'Next Steps' which provided timely, coordinated, collaborative, and tailored support for Sarah in preparation for, and during, her transition. This involved an initial course for parents where Riesz (2004) was invited to focus on Sarah's interests/skills, and envision her future, and what she may need to develop to get there. Consequentially, Riesz (2004, p. 376) attained an idea of what Sarah's day-to-day life could look like, and was signposted towards relevant 'vocational, respite, recreational, and residential services'. Sarah herself benefitted from a course whilst still at school which assessed her skills, identifying those she may need to develop for the workplace, and delivered a bespoke community work experience programme to hone those skills and offer a flavour of adult life, along with input from a speech clinician, specifically targeting her verbal/social development. Following this, Sarah obtained employment, and was successful in securing alternative employment when her original workplace closed.

Advanced/thorough preparation, coordination, tailoring, and the element of developing relationships/collaboration outlined above, are likely to positively affect TIA in a holistic fashion. This point is further illustrated in stories of what can be lacking/negative regarding interactions with systems in the transition process.

1.3.2. What's not so helpful?

Negative experiences which parents/families of young adults with Down Syndrome may undergo in their interaction with systems during TIA are aptly summarised by Chad's mother in Scorgie and Wilgosh (2009, p. 213): 'I find it much more difficult in the adult world than in the school world'. Experienced difficulties could partly contribute to parents' burden/worries, as explored earlier.

From the preceding and following discussion, there seems to be an inadequacy on behalf of wider systems when considering many of the roles parents feel forced to assume and/or to bear alone. Families interviewed by Detisch (2007, p. 206) experience various, even contradictory positions, such as adversarial: ‘advocate, fighter for services’; passive: ‘consumer of services’; or sole decision-maker/coordinator effecting their young adult’s day-to-day life, with little input from others: ‘key educational decision maker, ultimate transition coordinator’.

Regarding the adversarial position, a mother in Wills et al. (2016, p. 557) creates striking imagery in the ‘isolation’ that can be experienced during TIA, caused by ‘powerful institutions…in the disability sector’ which are depicted as the ‘enemy’, and the ‘betrayal’ felt by a disservice from schools. Even if it is not always quite a battle, Riesz (2004) describes herself being better equipped for negotiations with systems regarding Sarah’s TIA, due to prior experiences at earlier transition points. Moreover, parents may perceive that they are unpopular with systems where they do advocate, for example, a mother in Wills et al. (2016, p. 561) shares ‘they didn’t want parents like me’; instead, they wanted those who were ‘not going to be raising issues or questions’. Parents may feel they need to fight for services, whilst concurrently/otherwise bearing sole responsibility for making difficult decisions like limiting their young adults’ opportunities for safety reasons, or working towards long-term goals such as encouraging them to progress towards independent living, sometimes against their hesitations/initial resistance, as explored in section 1.2.

Neither decision-maker nor fighter positions are ideal; this also applies to the passive position. Families can see themselves as a ‘barrier’ in TIA when ‘they just give up’ due to perceiving that they are not respected, and their beliefs, attitudes/values not listened to/acknowledged, nor incorporated into transition plans or come to impact the transition process (Detisch, 2007, p. 207). Parents/families may experience disempowerment; a sense of ‘helplessness and hopelessness…discouragement’ (Detisch, 2007, p. 204) and lack of control (Wills et al., 2016). When one appreciates negatives/disadvantages associated with these roles, the value of collaboration between parents and systems is brought to bear.

Practices around TIA for young adults with Down Syndrome appear to convey a lack of person-centred planning. Families in Detisch (2007) believed that their young adults were not treated as individuals during creation of their Individual Education Plan (IEP), and unique interests/desires did not influence the type of work experiences offered. In some cases, families perceived stereotyped low expectations on behalf of teachers/schools, encouraging placements in more restrictive environments, a focus on disability rather than ability, and omission of the voices of the young adults themselves. Mothers in Wills et al. (2016) report that they and their young adults experienced not feeling valued/respected in the transition process. Families in Detisch (2007, p. 205) even experienced 'adversarial' attitudes from some teachers. Peters et al. (2022) found that healthcare transition can also exhibit a lack of patient-centeredness, where lack of continuity/detailed transfer between paediatricians and ID physicians means that parents may need to repeat themselves, which additionally slows re-building of parental trust across the professional transfer. Moreover, parents report that ID physicians may concentrate more exclusively on medical aspects, not asking holistic questions; something several had become accustomed to with paediatricians. Although, paediatricians shared that there is a lack of consistency in the transition process where it can commence when the young adult with Down Syndrome is anywhere between 14-17yo dependent upon their circumstances. Therefore, there is an absence of a transition protocol which could make the process more efficient. Furthermore, ID physicians explain that they do not have time to ask non-medical-related questions due to systemic pressures, even if their preference is to be patient-centred. Regardless of such constraints, it is important to highlight that the transition process is perceived by parents/families of young adults with Down Syndrome to be lacking in a person-centred/collaborative ethos.

Young adults with Down Syndrome may encounter a lack of inclusivity regarding community settings/contexts, for example, mothers in Wills et al. (2016, p. 558) report ad hoc activities in settings with a 'warehouse' type set-up, and Chad's mother describes him facing adult segregated settings and a lack of meaningful social interactions (Scorgie &

Wilgosh, 2009). Lack of inclusivity may be linked to inadequate transition preparation on behalf of systems (as suggested by ad hoc activities); it could also be related to insufficient authentic person-centred practice. Additionally, it is likely difficult to attain inclusion for young adults with Down Syndrome where they are already starting on the backfoot regarding systemic provisions. Mothers in Dyke et al. (2013) describe difficulties in securing funding, supported living placements, and day placements/employment options for their young adults; one mother revealed that she made their situation seem 'really really bad' to secure funding (Dyke et al., 2013, p. 154). Families in Detisch (2007) and Peterson (2006) describe insufficient employment opportunities. Where employment is obtained it tends to be insecure/very part-time, where onus is on mothers to 'fill up the rest of the week' (Dyke et al., 2013, p. 153); an aspect elaborated upon previously. Additionally, young adults with Down Syndrome do not always receive adequate training/supervision in their work roles; they may receive training on placements agreed by schools but once these programmes end, they may not retain their position since the decision resides with individual managers (Peterson, 2006). Moreover, their income may not be sufficient to achieve/maintain financial independence.

Wider systemic input may be left wanting in TIA for young adults with Down Syndrome, in terms of its nature and how it is orchestrated, but also regarding what is available to work with in the first place.

1.3.3. How could systems be more helpful?

Positive relationships/collaboration between parents/families of young adults with Down Syndrome and professionals are key. Families in Detisch (2007) feel that school staff should commit time/effort getting to know them and respect/acknowledge their beliefs, values/wishes even if desired provisions are not always available, and the transition process should be collaborative, as opposed to parents being left to it, feeling the need to fight, or being passive. Families felt that they and teachers could benefit from opportunities to learn collaborative skills (Detisch, 2007). Parents should be trusted/respected to assume a level of influence regarding funding for relevant programmes, since they know their young adults well (Scorgie & Wilgosh, 2009), and usually play an instrumental role in their lives.

Families share that development of trust in professionals relates to feeling heard (Detisch, 2007). Illustratively, parents in Peters et al. (2022, p. 1211) prefer a 'warm hand-off' in healthcare transition, where the paediatrician, ID physician, parents and young adults with Down Syndrome meet to share a holistic discussion as opposed to a 'cold hand-off' where there are separate meetings, and only a brief introduction to the new professional. The 'warm hand-off' means that parents do not retell their young adult's story, and feel their young adult is seen as an individual rather than represented by 'some data' (Peters et al., 2022, p. 1211). Moreover, the young adult's voice can be better elicited, thus the process is more patient-centred. Paediatricians also prefer warm hand-offs, however both parties recognise systemic constraints/barriers such as time, costs and, at times, hospital policies (Peters et al., 2022).

It is not just the nature of relationships between parents/professionals, and how they work together during transition; families in Peterson (2006) and Detisch (2007) emphasise the need for professionals to know young adults in an authentic way, such that systemic input is tailored. This applies to next-steps options, and level of support offered where this is not assumed, since families may differ (Detisch, 2007). Such tailoring and person-centred practice could also target parents'/families' hopes for inclusion for their young adults with Down Syndrome within their daily activities/social lives (Detisch, 2007; Scorgie & Wilgosh, 2009), which can offer the young adults a great sense of pleasure/satisfaction, although logistical facilitation could be improved were there better public transport options (Peterson, 2006). Preparation for TIA and activities aimed at community integration could also contribute towards inclusion. Hartman et al. (2000, p. 54) highlight the importance of 'independence-building activities' whilst young adults with Down Syndrome are still in school, focusing on life skills like money management/social skills. Moreover, Peterson (2006, p. 149) proposes the idea to conduct research with prospective/current employers of young adults with Down Syndrome, investigating positive aspects, any potential skill gaps, and what may be helpful foci in work experience/training programmes, which could lead to development of corporate policy, encouraging increased employment for young adults with Down Syndrome.

It would be helpful were parents to face a clear/consistent process, and be well-equipped with advanced/useful information, rather than navigating a hazy area and doing all the research themselves. Parents/families call for improved systemic connections, e.g., parental partnership with prospective employers (Detisch, 2007); a coordinated/joined-up approach between different systems/service providers (Hartman et al., 2000; Peters et al., 2022; Wills et al., 2016), where it may be helpful to appoint a coordinator who oversees the transition and liaises with all involved (Detisch, 2007; Wills et al., 2016); opportunities to connect with other parents (Wills et al., 2016); and enhanced clarity of roles/expectations around provision (Detisch, 2007), including for example, provision of brochures around what to expect in healthcare transition (Peters et al., 2022).

Leonard et al. (2016, p. 53) argue that ‘Considerable progress has been made in identifying strategies which could aid in…transition’, as outlined by earlier discussion of literature, but ‘widespread implementation…is lacking’. Notwithstanding positive experiences with systems, *Section One* thus far overwhelmingly indicates that parents are a linchpin to their young adults with Down Syndrome during TIA; a metaphor previously used by Timmons et al. (2004; in Dyke et al., 2013). This metaphor perhaps makes sense given the closeness of parents to their young adults, but one may ask themselves: is it an acceptable scenario when that linchpin is overloaded, or must withstand strong forces, as implied by the thematic exploration above?

1.4. Group Critique One

1.4.1. Strengths

Most of the papers reviewed in this section capture rich perspectives/experiences related to TIA for young adults with Down Syndrome, illustrated by the breadth/depth of the thematic exploration. Researchers were open to foci determined to a substantial degree by parents (e.g., Docherty & Reid, 2009; Wills et al., 2016), families, and, in some cases, young adults with Down Syndrome themselves (e.g., Detisch, 2007; Peterson, 2006), rendering an advantage over quantitative studies in that complexity could be better explored rather than reduced into categories, and potentially-unexpected findings were more likely to be elicited from open-ended interviews. For example, findings from mothers in Docherty and Reid (2009), and families in Peterson (2006) transcend traditional TIA outcomes like independent living/employment, offering insights into mindset shifts and personal growth. Open-ended qualitative approaches align with this researcher's SC epistemological stance, where researchers did not take the realities of parents, families or young adults with Down Syndrome for granted, which could be a risk with questions designed to obtain quantitative data which are often closed/specific, depending more so on researchers' a priori assumptions about phenomena under study. Moreover, there is enhanced appreciation for idiographic experience, rather than attempting to categorise, where Peterson (2006, p. 143) depicts this aptly: 'Each transition was approached in a unique manner by each family...There were many stories told by family members'.

Through recognising that researchers influence and are themselves influenced by participants, several authors kept reflexive notes/diaries (e.g., Docherty & Reid, 2009; Detisch, 2007; Peterson, 2006). Peterson (2006) notes her extensive involvement with young adults with Down Syndrome across her career, and how becoming acquainted with the particular young adults/families in her study during hours of research engagement affected her personally. Her thorough reflexive activity renders credibility to the findings since she attempts to recognise and separate out her own influence, therefore remaining close to what was offered by participants in her interpretation.

Another strength pertains to the variety of methods utilised, and their coherence with a qualitative, exploratory approach to explore experiences/meanings. Examples include naturalistic inquiry (Peterson, 2006), photo-voice (Wills et al., 2016), and longitudinal case study (Scorgie & Wilgosh, 2009); methods that are conducive to acknowledging TIA as a multi-faceted/prolonged process, rather than an event/change of status. Variety of method is viewed as a strength of the literature reviewed, not due to positivist notions of triangulation improving accuracy/validity, but because of the resulting richness/diversity inherent in the themes offered.

1.4.2. Limitations

A prominent limitation of the literature reviewed is the dearth of perspective from young adults with Down Syndrome themselves. Only two researchers accessed this perspective, and this was primarily within the context of family interviews (Detisch, 2007; Peterson, 2006). This demonstrates a strength in the apparent diversity of voices, however, it is not clear what the interview process entailed; did young adults with Down Syndrome speak for themselves; was it a co-construction; or did parents/family members speak on their behalf? Several researchers recognise the lack of perspective from young adults with Down Syndrome themselves as a limitation of their studies (e.g., Docherty & Reid, 2009; Dyke et al., 2013; Hartman et al., 2000; Peters et al., 2022). Hartman et al. (2000) maintain that parents can provide more of an outer perspective on the transition. However, if we consider the SC tenet that knowledge goes hand in hand with social action (Burr, 2015), one could argue that what may come to effect practice regarding TIA for young adults with Down Syndrome is mainly based on the voice of one actor; that is, parents [primarily mothers (e.g., Docherty & Reid, 2009; Dyke et al., 2013; Hartman et al., 2000; Riesz, 2004; Scorgie &

Wilgosh, 2009; Wills et al., 2016)]. What about the voice of the protagonist? This question is pertinent from an experiential perspective on TIA, but also an ethical standpoint, respecting young adults with Down Syndrome as agents whose perspectives matter.

One could argue that research ascertaining perspectives of parents/families is still valuable, and this researcher would agree. However, one cannot deny that investigating TIA for young adults with Down Syndrome is to explore a topic fundamentally about them. It is therefore important to highlight that only one out of the eleven authors detailed gaining consent from the young adults with Down Syndrome - Peterson (2006) who interviewed/observed the young adults themselves. Detisch (2007) reports 'families' signing consent forms, but one is unclear about whether explicit informed consent was obtained from the young adults. They most likely assented through participating in the family interviews, but this does not equate to being properly informed about the nature/purpose of the research, their participant rights, nor potential implications. Peterson (2006) offered an informed consent form to parents, family members and young adults with Down Syndrome but, where it was deemed appropriate that parents decide on behalf of their young adults, verbal assent was considered sufficient on behalf of the young adults. Peterson (2006) did not create an easy-access consent form for young adults with Down Syndrome who potentially could have given their informed consent via this means. Nevertheless, at least young adults with Down Syndrome in Detisch (2007) and Peterson (2006) were aware of, participated in, and assented in some form to the research about them. Whereas, it is unclear whether the young adults with Down Syndrome whom the nine other papers are about even knew about the research, let alone consented to it. This is an especially pertinent matter in the case of Riesz (2004) who offers a self-reflective piece about her daughter, Sarah's, TIA where; even if 'Sarah' is a pseudonym, anonymity is lost by relation to the author.

One marker of good qualitative research is coherence between the researcher's philosophical foundations (i.e., ontology/epistemology) on the one hand, and the nature of their aims, research questions (RQs), procedure, the type of data they collected and how they analysed them, the claims they make in their findings/discussion, and their self-evaluation of the study, on the other (Yardley, 2000). A clear coherence lends a level of trustworthiness and hence value to research. It is impossible to assess this aspect in eight out of the ten papers however [excluding Riesz (2004)'s self-reflective piece as this was not empirical research] since the researchers do not state an ontological/epistemological stance. Such philosophical foundations are integral to research process/write-up (Brown & Dueñas, 2019), yet those researchers have not offered them for readers' scrutiny. Interestingly, just as the authors of the two theses in the literature reviewed [that is, Detisch (2007) and Peterson (2006)] included young adults with Down Syndrome in their samples, they too offer details of their paradigms. One could wonder whether the rigour required for theses, or perhaps greater flexibility in wordcount, are contributory factors. If so, this suggests that outlining one's paradigm is not treated as a priority in the majority of research papers, which is disconcerting when the credibility/trustworthiness of findings in part depends on coherence within this.

A feature uniting papers reviewed, and the main reason why they were reviewed, is that the aim in most cases was to explore TIA for young adults with Down Syndrome (e.g., Detisch, 2007; Docherty & Reid, 2009; Peterson, 2006), utilising semi-structured interviews flexibly to be open to complexity, nuance/the unexpected, appreciating uniqueness of experience. Such a research goal seems incompatible with a positivist paradigm, where usually conditions are tightly controlled, there are attempts to homogenise/categorise, and the aim is to uncover a single 'truth'. Braun and Clarke (2022) denounce that the purpose of qualitative research is to fill gaps in knowledge, since this could imply there is one grand underlying truth waiting to be uncovered gradually, but surely, by research. They prefer the metaphor of an intricate tapestry, being continually augmented/increasing in complexity of patterning by research that enhances depth/nuance of understanding. It would seem that the design/findings of Peterson (2006)'s research are more aligned with Braun and Clarke

(2022)'s tapestry, yet they state 'The purpose of this study was to fill gaps in knowledge about adults (with Down Syndrome) and their families' (p. 155), seemingly confusing the research goal.

Positivist creep can also affect the research process. Member validation was conducted by several researchers, where themes were checked/corroborated by participants (Detisch, 2007; Docherty & Reid, 2009; Dyke et al., 2013; Peters et al., 2022; Peterson, 2006; Scorgie & Wilgosh, 2009). This is typically viewed as a strength in qualitative research, lending validity through the attempt to obtain a 'true representation of their experiences' (Docherty & Reid, 2009, p. 460). But where there are multiple realities and researchers necessarily influence participants, as proposed by Peterson (2006), can there be a single true representation? Riessman (1993; in Yardley, 2000) reserves a place for member validation but highlights the risk that the value of the researcher's interpretation could be 'eroded' (p. 221), were participants given too much control over the outcome. Regarding the preceding stage of data analysis, some researchers seem to feel urged to mould experience into neat/tidy boxes. Several describe using content analysis or cross-case analysis (Detisch, 2007; Dyke et al., 2013; Leonard et al., 2016; Peters et al., 2022), with emphasis on deriving commonality across experience (Detisch, 2007), and dividing it into 'mutually-exclusive' categories (Dyke et al., 2013, p. 152). Preoccupation with homogenising experience across participants and partitioning it into distinct categories is reminiscent of a 'filling the gaps' model, with the risk that one might dilute uniqueness/depth of experience.

Furthermore, positivist creep trickles into researchers' own study critiques. Several highlight limited generalisability of their research due to small/homogeneous samples (Detisch, 2007; Docherty & Reid, 2009), or use of the case study method (Hartman et al., 2000). This evaluative judgement is incoherent with the aim to explore a specific experience, which necessitates a fairly homogeneous sample (e.g., Smith et al., 2021). Indeed, Docherty and Reid (2009) state that their sample of mothers (all from central

Scotland, the same support group, sharing similar values) cannot represent the voices of all parents of young adults with Down Syndrome. Of course this is the case, the method of Interpretative Phenomenological Analysis (IPA) requires relatively homogeneous samples, and the commitment is towards eliciting/interpreting idiographic experience; not towards generalisation (Smith et al., 2021).

1.5. Meaning of quality of life and wellbeing to young adults with Down Syndrome

As the above group critique highlights, the voices of young adults with Down Syndrome seem to be missing or, where they are present, they may be diluted. The literature search for *Section One* did not return any papers pertaining to the perspectives of young adults with Down Syndrome on the experience of TIA, where this is the specific/explicit research focus. However, whilst two papers which were returned do not fit this criterion exactly, they explore something very related/relevant: the perspectives of young adults with Down Syndrome on their quality of life/wellbeing (Jevne et al., 2022; Scott et al., 2014). Considerations thus far include discussion of parents' experiences, thoughts, feelings, efforts, perceived responsibilities in TIA, and the impact upon their/families' lives; interactions between young adults with Down Syndrome, their parents/families and wider systems, including parents' views on systemic involvement; and what parents/researchers consider to be hoped outcomes of transition. The two studies reviewed below develop understanding through incorporation of the missing perspective; themes identified from them align with, build upon, or sometimes challenge themes explored above from studies which primarily access parents' perspectives. Whilst these studies do not answer the specific question of what TIA is like for young adults with Down Syndrome, they shine light on what their desired outcomes of transition might be and what may be needed to get there; that is, what is a good life according to young adults with Down Syndrome?

Jevne et al. (2022) conducted individual open-ended semi-structured interviews with eight young adults with Down Syndrome (aged 22yo), exploring their perspectives on quality of life/wellbeing. Scott et al. (2014) also conducted individual open-ended semi-structured interviews with twelve young adults with Down Syndrome (aged 18-29yo), but insights from these became stimuli that facilitated focus group discussions. The focus of this study was similar, exploring what makes a good life from the perspectives of young adults with Down Syndrome.

Regarding themes across the papers, it seems that having an active social life and meaningful friendships are prioritised when young adults with Down Syndrome consider what is good in their lives. Friendships were valued by the young adults in terms of evoking feelings of inclusion, acceptance, and development of self-esteem (Scott et al., 2014). Friendships were enjoyed in the context of leisure activities, whether these be informal within personal settings like watching Netflix; community-organised activities like sports (e.g., swimming, hiking groups), cultural/music activities like going to the theatre/music events (Jevne et al., 2022); or ‘going out with friends to the pub and movies’ (Scott et al., 2014, p. 1292). The thread appears to be young adults with Down Syndrome enjoying friendships external to the family, where the focus is on being together to share experiences. Enjoyment of intimate relationships amongst young adults with Down Syndrome in Scott et al. (2014) was depicted in this sense, and through displaying physical affection, e.g., ‘cuddles and kisses’ (p. 1292).

Peer relationships and having social hobbies/interests are correspondingly highlighted by parents as important factors in TIA (e.g., Riesz, 2004; Thomson et al., 1995; Wills et al., 2016). Although, families in Peterson (2006) worried about their young adults with Down Syndrome experiencing social isolation, especially where they see school friends progressing in ways they may not (e.g., marrying/further education). Moreover, parents in Thomson et al. (1995) and Wills et al. (2016) emphasise inclusion in the context of spending time with typically-developing peers. In contrast, it seems young adults with Down

Syndrome in Jevne et al. (2022) and Scott et al. (2014) felt they had fulfilling social lives/friendships, and these could be with individuals with ID (Jevne et al., 2022), not necessarily typically-developing peers. However, Jevne et al. (2022) report that the young adults tended to meet their friends in day centres/sheltered workplaces; settings which may not always provide such opportunities. For example, Chad’s mother described him encountering segregated settings when trying to access community activities, and a lack of meaningful interactions (Scorgie & Wilgosh, 2009), and mothers in Dyke et al. (2013) describe difficulties securing funding for supported living placements, and day placements/employment options; candidate environments for developing friendships. Even where such placements are secured and they adopt an inclusive ethos, young adults with Down Syndrome tend to be quite dependent on their parents to orchestrate/facilitate their social lives, as depicted by previous sections, and recognised by young adults with Down Syndrome themselves (Jevne et al., 2022). Therefore, whilst it is positive that young adults with Down Syndrome from the studies reviewed appear fulfilled in their social lives, it seems that parents still need to play a significant role in facilitating this.

Peterson (2006) depicted the young adults with Down Syndrome she observed/interviewed as ‘appear(ing)…content’ (pp. 136-137), regardless of their employment status/living arrangements. One could surmise from reviewing Jevne et al. (2022) and Scott et al. (2014)’s studies that the young adults interviewed were fulfilled/happy. However, it would not seem that they were content to not progress at some point; they described future dreams/aspirations, comprising personal development. Those in Jevne et al. (2022) desired to progress their careers; to obtain a job out of the day centre if they currently had one there, or gain employment if they were not yet in work. All the young adults in Scott et al. (2014) had ambitions to live independently, as did some young adults in Jevne et al. (2022). Furthermore, the importance of, and desire for, intimate relationships was a prominent theme in Scott et al. (2014), where some young adults had aspirations like marrying/starting a family. The topic of intimate relationships did not arise in exploration of

TIA experiences in the papers which primarily accessed parents'/families' perspectives. Through citing research about people with ID and sexuality by Cuskelly and Bryde (2004) and Evans et al. (2009), Scott et al. (2014, p. 1296) argue that parents may find this topic challenging, and could be resistant towards addressing it. Camire (2006) interviewed mothers and sisters of young adults with Down Syndrome about their views towards the young adults being involved in intimate relationships. Findings from this study challenge the idea that parents are simply resistant, illustrating supportive attitudes for the young adults to have a partner, yet hesitations/reservations around matters like safety, understanding/developmental level. Whatever the reasoning, there appears to be some level of discomfort on behalf of parents regarding their young adults with Down Syndrome engaging in intimate relationships, which may explain why it does not appear in the prior discussion. However, its relevance to a good life as a young adult is illustrated here, by young adults with Down Syndrome themselves (Scott et al., 2014), hence it warrants attention.

The importance of work was underlined by young adults with Down Syndrome as contributing to quality of life/wellbeing (Jevne et al., 2022). In Scott et al. (2014) work was characterised in terms of earning money to spend on items like jewellery/saving for a house; one young adult explained that she would like to be famous and make more money, rather than being 'stuck in a café' (p. 1295), perhaps suggesting that employment options and earning potential may be limited for young adults with Down Syndrome. Contrastingly, young adults in Jevne et al. (2022) did not mention financial aspects. They expressed very positive attitudes towards work, relating to interest; friendship/community participation; feeling like they had a purpose ['The others think I am so helpful and good' (Jevne et al., 2022, p. 845)]; feeling safe in their work context, knowing they had someone to ask for help; and being adequately prepared for tasks and the next stage of progression within their jobs, such that they could experience personal growth/achievement. Companionship, having a purpose, and personal growth/accomplishment resonated as important elements of TIA in the prior discussion of parents' perspectives (e.g., Peterson, 2006; Thomson et al.,1995). Therefore, it seems that the PERMA model (Seligman, 2011) aligns well with what is important in TIA, from both the perspectives of parents and those of young adults with Down Syndrome themselves. If work can provide such aspects, it is concerning that employment figures are generally low for young adults with Down Syndrome (Leonard et al., 2016; Thomson et al., 1995), and opportunities can be lacking/restrictive where young adults have lower self-care, community/communication skills (Foley et al., 2013), or certain health conditions (Pikora et al., 2014). It is also concerning that not all employment contexts feel safe for young adults with Down Syndrome, as expressed by some parents (Leonard et al., 2016; Peterson, 2006). Moreover, even where supported placements feel safe, they may not be contexts where young adults with Down Syndrome can develop/thrive, with lowered expectations/opportunities for challenge (Dyke et al., 2013). It seems having a job can be so beneficial to young adults with Down Syndrome, but professionals involved need to carefully think about how personal development is encouraged, whilst assuring young adults with Down Syndrome and their parents that their welfare will be adequately protected, and they will be sufficiently supported.

When considering support, it is important to adopt an individualised approach (Jevne et al., 2022). This is reinforced by literature on parents'/families' perspectives (e.g., Detisch, 2007; Hartman et al., 2000; Peterson, 2006; Riesz, 2004). Jevne et al. (2022) found that young adults with Down Syndrome differed in their thoughts about, and desires for, independent living. Moreover, they describe tailored support/encouragement experienced in their jobs, but also in their living situations which was not always provided by a person; it could be via use of smartphone technology to set reminders/organise their lives, e.g., calendar/travel apps. Use of smartphones also facilitated social contact. Some parents emphasise ongoing dependence of their young adults when they are in supported living (e.g., Riesz, 2004). Perhaps more advanced technology options today could enable young adults with Down Syndrome to be more independent in more aspects of their daily life, potentially reducing dependence on parents.

Young adults with Down Syndrome value autonomy/choice, for example, exerting self-control over food, clothing/activity options (Scott et al., 2014). It was important that this could be separate from parents, and one adult depicted it as being one's 'own boss' (p. 1294). Similarly, Docherty and Reid (2009) describe how mothers view TIA as a mindset shift for their young adults, where there is a notion of them having more of their own ideas and making more of their own decisions. However, it seems that young adults with Down Syndrome experience tensions where they feel their parents can be 'controlling' or that they are sometimes 'smothered' (Scott et al., 2014, p. 1292), and there is rhetoric of still in some ways being treated like a child, where one young adult stated that they 'hate being told what to do' (p. 1292). Jevne et al. (2022) accordingly found that some young adults wanted to live independently to be 'free and away from what they called "nagging parents"' (p. 846). One may propose from this that parents take a step back and unclip their young adults' wings. However, the picture is likely more complex/nuanced. Young adults with Down Syndrome recognise that their parents equally encourage development of their autonomy/independence, e.g., helping to prepare them for living independently or offering advice about intimate relationships (Scott et al., 2014). Moreover, some young adults illustrate dependence on their parents for transport regarding community activities (Jevne et al., 2022). The seemingly crucial/substantial parental involvement in the lives of young adults with Down Syndrome is brought to bear in studies exploring parents' perspectives. Significantly, parents' perspectives are aligned with those of young adults with Down Syndrome, since they too experience mixed positionings/feelings, concurrently upholding gatekeeper/facilitator roles (Docherty & Reid, 2009). Balancing between fostering independence and ensuring the welfare of young adults with Down Syndrome appears to be, at times, a precarious task for parents and, from reviewing studies on their perspectives, one where they primarily feel alone, lacking wider systemic support. Therefore, it seems that attention should be paid to the role of wider systems/contexts young adults with Down Syndrome encounter, to fully appreciate parents' mixed positionings, and think about how best to listen to the desire for autonomy from young adults with Down Syndrome, whilst ensuring they are still adequately supported/safeguarded.

1.6. Group Critique Two

1.6.1. Strengths

A significant strength of Jevne et al. (2022) and Scott et al. (2014)'s studies is that they explore how young adults with Down Syndrome themselves make sense of a good quality adult life, offering the voice of the protagonist which is distinctly lacking in literature on TIA experiences specifically. Moreover, like studies on TIA, these researchers adopted an open-ended qualitative methodology, flexibly eliciting/encouraging the young adults' choice of foci. Findings from both studies create holistic/nuanced pictures, as one might expect of the product of sense-making around what makes a good quality life.

Returning to a point made in *Group Critique One* about SC, where one conceives knowledge to go hand in hand with social action (Burr, 2015), these researchers prioritised gaining the voices of young adults with Down Syndrome, such that their perspectives can inform narratives about life as a young adult with Down Syndrome, and potential research/practice implications, rather than these only being based on parents'/professionals' views. Concurring with SC, Scott et al. (2014) conducted focus groups after the individual interviews, meaning insights from the former could inform the latter, where the resultant data were co-constructed by young adults with Down Syndrome. Mercer and Wegerif (2002) argue that group discussion outcome(s)/product(s) can equate to more than the sum of their parts, transcending what any one individual could offer. This suggests that co-constructions from the young adults with Down Syndrome lend greater richness to the tapestry [Braun and Clarke (2022)'s metaphor]. Additionally, Scott et al. (2014, p. 1291) cite Tietelman and Copolillo (2005) who propose that use of focus groups can facilitate voice elicitation, particularly for marginalised groups, such as those with ALN.

The researchers were transparent about the interview process; like several studies on TIA, they upheld a reflexive approach, recording reflections and keeping these separate from, or practising awareness of their influence on, data from the young adults. This transparency applied to procedural elements too. Scott et al. (2014) supply their semi-structured interview schedule (p. 1298) and outline how young adults with Down Syndrome were interviewed individually and resulting insights were recorded on posters that fuelled focus group discussions. Jevne et al. (2022) interviewed seven of the eight young adults with Down Syndrome with their parents present, but roles were contracted such that the young adults were the interviewees; parents only contributed where the young adults agreed to this, with the purpose of them facilitating expression rather than becoming their voice. Knowing how data were collected lends a certain trustworthiness to the researchers' interpretations (Yardley, 2000). This contrasts with Detisch (2007)'s study, who interviewed young adults with Down Syndrome along with their parents/families, but there is a lack of clarity about what this process looked like, potentially shrouding haziness around the origins of this researcher's interpretations.

1.6.2. Limitations

These studies fall prey to the same criticism directed towards papers on TIA, in that the researchers are not clear about their ontological/epistemological positionings. Again, this renders an inability to assess paradigmatic coherence, where attainment of such coherence would be a marker of good qualitative research (Yardley, 2000).

One could question Scott et al. (2014)'s interpretation around young adults with Down Syndrome experiencing tensions regarding their parents' concurrent facilitation and hinderance of developing independence. These researchers' interpretation concentrates on the hinderance aspect, and they explain this by referencing Docherty and Reid (2009), stating that the latter researchers found that parents' worries around safety may contribute. From reviewing this study themselves, the current researcher argues that this is a narrow depiction of Docherty and Reid (2009)'s findings, where they actually interpreted dynamicity in mothers' perspectives; movement between gatekeeper/facilitator roles, with an ultimate goal of encouraging their young adults to be more autonomous. Where one utilises a nuanced aspect of others' research to interpret their own findings, it is important that this aspect not be stripped of context, such that it could misconstrue the full picture.

A limitation identified by Scott et al. (2014) themselves was that only young adults with Down Syndrome whose speech could be understood in interviews participated in their study. Whilst this is not specified in Jevne et al. (2022), one may assume from their engagement in in-depth verbal interviews that this also applied to their sample. Therefore, despite commending these researchers for inclusion of young adults with Down Syndrome in research that is about them, one could simultaneously assert a certain exclusiveness, regarding young adults with Down Syndrome who may have speech needs that render them unable to orally contribute to such interviews/focus groups. Albeit this researcher's speculation on behalf of Jevne et al. (2022), it is a plausible possibility. Exploring parents' perspectives can be advantageous in that they can potentially speak for all young adults with Down Syndrome, no matter what their needs. However, one could also suggest that researchers employ more creative methods to produce improved equity in research environments for all young adults with Down Syndrome.

Scott et al. (2014) and Jevne et al. (2022) used qualitative coding techniques/content analysis to derive common themes across the young adults' contributions. If one were to adopt an experiential lens, it could be argued that individuality/richness of perspective is somewhat lost. When one is considering TIA and the meaning of a good life, the focus is on experience/meaning-making, which is perhaps better suited to a data analysis method like IPA.

Section Two: The Covid-19 Pandemic and People with Down Syndrome

This section provides an overview of research investigating the impact of C19P-related conditions on people with Down Syndrome. Please see Table 4 for description of the clinical status of people with Down Syndrome in relation to C19 infection; and Table 5 for a note about the literature reviewed.

Table 4: Clinical status of people with Down Syndrome in relation to C19 infection

People with Down Syndrome were identified as a high-risk population during the C19P since many within this demographic have medical co-morbidities implicated by C19 infection, are more likely to suffer exacerbated symptoms when infected, and tend to have a higher mortality than the typical population (Faundes et al., 2021; Illouz et al., 2021). In addition to potential anxieties arising from these medical vulnerabilities, people with Down Syndrome alongside the rest of the nation were required to adapt to pandemic-induced regulations/restrictions such as closure of workplaces, community groups, leisure facilities; measures like social distancing; and significant restrictions on daily life enforced by governmental lockdowns. People with Down Syndrome were classed as 'clinically extremely vulnerable' (Down Syndrome Act, 2022, s.10, UK Public General Acts, c. 18). Therefore, people with Down Syndrome likely experienced even further limited lifestyles due to the requirement to shield [defined by Jani et al. (2021, p. 1) as 'extended self-isolation']. Identification as a high-risk demographic in and of itself may have led to heightened fear/unease for people with Down Syndrome and their parents/carers. Indeed, in a questionnaire study surveying parents/carers of CYP with Down Syndrome (aged 2-25yo), conducted in the UK, 24% of CYP with Down Syndrome were reported as experiencing elevated levels of anxiety since the beginning of the C19P (Pagnamenta et al., 2023).

Table 5: Literature note

Literature searches on the Scopus and American Psychiatric Association PsycInfo databases combining variations of key terms relating to children, YP and adults; Down Syndrome; and the C19P, primarily returned research which focuses heavily on medical/biological aspects and clinical features which seems intuitive given the high-risk nature of this demographic. There is comparatively little research on the experiential component of the pandemic, from the perspectives of people with Down Syndrome and/or their families. Therefore, whereas *Section One* presents an in-depth thematic exploration and integration of literature, this section provides an overview of research investigating the impact of C19P-related conditions on people with Down Syndrome generally, with a brief group critique, as is befitting a scoping review (Munn et al., 2022). Moreover, in this research, the main phenomenon under study was TIA, as affected by the C19P. Particular attention is drawn to one study in this section, which is highly relevant to the RQs of the current author's study; that is, Vaccarino et al. (2022)'s research on adults with Down Syndrome in New Zealand.

2.1. Children and young people with Down Syndrome

Several studies highlight the impact C19P-related regulations/restrictions may have had upon the behaviour/functioning of CYP with Down Syndrome. Brugnaro et al. (2022) conducted a longitudinal questionnaire study surveying parents of CYP with Down Syndrome (aged 6-17yo) in Brazil, finding that physical distancing measures had mixed positive/negative associations with functioning; a positive correlation with involvement in home activities; and a negative correlation with parents' external social supports. Considering the former, young adults with Down Syndrome over the age of 18yo identify having an active social/leisure life; independence; and going out with friends outside of the family as important components of a good quality life (Jevne et al., 2021; Scott et al., 2014). This may lead one to wonder whether older young adults with Down Syndrome who were TIA during restrictions/lockdowns would have participated in family life in the same positive way or the impact this could have had on their wellbeing. Moreover, increased time spent with family coincided with reduced social supports for parents in Brugnaro et al. (2022) which may lead one to wonder about the impact on parents/carers of young adults with Down Syndrome, where it is conceivable that they may have become more involved in the lives of their young adults whilst concurrently receiving less support, especially given their substantial involvement under ordinary circumstances as explored in *Section One*.

Regarding external support for parents, Pagnamenta et al. (2023) additionally found that 60% of parents across the UK felt that they rarely/never received support they needed for their CYP (aged 2-25yo) during the C19P. Support that would have been desired was various, including around learning, speech/language, social skills, emotional status, and health/physical development, where parents reported deteriorations across many of these/related domains, with increased dependence on adults. Further to parent-reported deteriorations in functioning/wellbeing domains, a cross-sectional parent-report questionnaire study conducted in Italy found that CYP with Down Syndrome (aged 13-29yo) were less likely to engage in physical activity, and more likely to engage in sedentary activities like watching screens, both during and following C19P-related restrictions (Amatori et al., 2022), suggesting C19P-related conditions exerted a negative impact on the physical health/fitness of CYP with Down Syndrome. This seems compatible with research explored in *Section One*, which highlighted the importance of young adults with Down Syndrome participating in community life, including in the contexts of employment, and sport/leisure; where engagement in such contexts usually gives rise to more physically-active lifestyles.

2.2. Adults with Down Syndrome

Exclusively considering the adult population (for which research seems sparse), Villani et al. (2020) conducted a longitudinal study, assessing the impact of the first lockdown in Italy on the psychosocial, cognitive and functional wellbeing of adults with Down Syndrome (ADS) (aged 18+yo; mean age of 40yo), completing pre- and post- clinic-based assessments. The researchers triangulated measures, including trained assessors examining historical/current information about the adults, asking questions of close relatives (parents/siblings) or longstanding caregivers, and asking questions of the individuals themselves. This study too found significant deteriorations, e.g., increased social withdrawal and reduced engagement in instrumental activities of daily living. The researchers found a reduction in aggressive behaviour, however, they associated this with elevated depression symptoms such as withdrawal/anhedonia, which could have been triggered by social isolation. The reduced engagement in instrumental activities of daily living, along with increased prevalence of mental health aspects like withdrawal/anhedonia may be indicative of C19P-related restrictions/lockdowns dampening the motivation of adults with Down Syndrome to actively engage in day-to-day life, or to strive for personal growth. This is a noteworthy possibility, given the importance of these facets related to the PERMA model (Seligman, 2011) in TIA.

Hartley et al. (2022), like many of the other researchers, surveyed caregivers of adults with Down Syndrome (aged 22-66yo; mean age of 42yo) across the UK and USA in a longitudinal questionnaire study. Caregivers identified significant negative impacts of restrictions on the adults such as ceasing of employment, increased irritability/propensity to become easily angered, greater anxiousness, and increased likelihood of feeling sad/unhappy/depressed. The finding pertaining to caregivers reporting increased irritability/propensity to become easily angered on behalf of the adults seems to contrast against Villani et al. (2020)'s finding, regarding reduction in aggressive behaviour. This discrepancy could be attributed to difference in methods, or it could be indicative of a difference across regions. However, the increased likelihood of feeling sad/unhappy/depressed in Hartley et al. (2022) corresponds with the elevated depressive symptoms identified by Villani et al. (2020). Regardless, the main aspect to note here is that lockdowns/restrictions, across several countries, seemed to exert overall negative effects on adults with Down Syndrome. This appears to make sense when considering what constitutes a good quality of life from the perspectives of young adults with Down Syndrome in *Section One*, and therefore, what may have been missing/taken away during the C19P.

2.3. Group Critique Three

Whilst the above research provides a broad picture of the potential impact of C19P-related restrictions/lockdowns on young adults with Down Syndrome, the quest to quantify/categorise effects through questionnaire surveys and/or clinic-based measures is quite reductive. For example, they do not better one's understanding of the qualitative experience of the C19P, nor delve into unanswered questions of 'why'/'how' such quantitative effects were observed. Additionally, there is a dearth of research on young adults with Down Syndrome in the TIA phase where the researcher reviewed studies on those who were younger (e.g., Brugnaro et al., 2022), or older, e.g., the mean age of adults in Villani et al. (2020) was 40yo. Otherwise, CYP with Down Syndrome were grouped together, or younger adults were grouped with older adults, rendering it impossible to ascertain the C19P impact on young adults with Down Syndrome specifically. Most studies were also conducted in other countries, hence there is an argument to be made that research in this area specifically regarding people with Down Syndrome conducted in Wales/England is warranted. Another critique relates to the timing of the studies as, despite most of them being longitudinal, they tended to study the short-term impact of the first wave of lockdowns/restrictions. This may lead one to wonder about the longer-term experience which, at least in Wales/England, necessitated undergoing a prolonged period of restrictions tightening/easing, and what the experience may have been in the months encompassing adaptation to post-pandemic life. A further critique pertains to omission of perspectives of individuals with Down Syndrome themselves, where it again seems that researchers tend to recruit parents/carers.

2.4. Perspectives of adults with Down Syndrome

Vaccarino et al. (2022) conducted an in-depth qualitative study, interviewing adults with Down Syndrome (aged 18-41yo; average age of 27yo) in New Zealand, regarding their experiences of the C19P. This research was emancipatory in that adults with Down Syndrome themselves acted as co-researchers, designing interview questions for other adults who participated in the interviews. Adults with Down Syndrome described negative emotional experiences in relation to restrictions/lockdowns, including a prominent theme of missing friends outside the home, feeling ‘hopeless’, and several shared that they needed to move back with parents or that they felt ‘stuck at home’, where one adult stated ‘I lost my independence’ (p. 5). These findings make sense when interpreted in the context of literature on what is important for wellbeing for young adults with Down Syndrome (e.g., Scott et al., 2014). They also suggest that lockdowns/restrictions may have halted/constrained TIA or adult life in the eyes of adults with Down Syndrome. However, whilst parental self-report/clinic-based measure studies investigating the impact of C19P on people with Down Syndrome seem to present a largely negative picture, many adults with Down Syndrome in this study shared that, whilst pandemic life was hard, they coped well and made positive adaptations such as exercising at home and staying in touch with friends via use of technology. This study therefore highlights the complexity/nuance of experience and suggests that there is most likely much to be learnt from a phenomenological research approach. Nevertheless, this study too is not about young adults with Down Syndrome exclusively, which would be more relevant when contemplating TIA during the C19P.

Section Three: Rationale for Exploring Transition into Adulthood during the Covid-19 Pandemic for Young Adults with Down Syndrome

As demonstrated in *Section Two*, C19P-related conditions exerted a general negative impact on people with Down Syndrome, considering their autonomy/independence; various skills/functioning levels; restricted opportunities; reduced social engagement; physical/mental health; and, further to this, a paucity of external support for parents. Moreover, the 'clinically extremely vulnerable' status of people with Down Syndrome appeared to trigger anxious feelings in and of itself, and the requirement to shield likely led to more stringent C19P-related conditions and hence restricted lifestyles, which seems especially pertinent to young adults with Down Syndrome and their parents, in the pursuit of greater autonomy/freedom. Vaccarino et al. (2022) present stories of resilience/adaptability on behalf of adults with Down Syndrome, for example, positively coping during lockdowns by exercising at home and staying in touch with friends via use of technology. Although, from exploration of what parents do for their young adults with Down Syndrome and their role during/following TIA, it would be plausible to suggest that certain conditions/supports would have perhaps needed to have been in place for the above positive aspects to ensue and become protective factors, which one cannot assume would be the case for all adults with Down Syndrome. Moreover, these researchers did not exclusively study young adults with Down Syndrome in the TIA phase, when opportunities/relationships external to the home become even more important, as indicated by *Section One*, creating the case for studying this demographic undergoing this phase during the C19P. Furthermore, the C19P lasted for a prolonged period, with peaks/troughs regarding the varying tightening/easing of restrictions, and then a very gradual easing and adaptation to post-C19P life, especially for those required to shield. Considering TIA as a process rather than an event, occurring within the C19P context, there is cause for exploring the long-term impact of the C19P on TIA, in the years following the cessation of restrictions.

Thematic exploration of literature in *Section One*, on TIA and the meaning of quality of life/wellbeing to young adults with Down Syndrome, highlight the importance of developing autonomy (and not just in the sense of practical independence but also living life by one's own values/decisions, with some aspects separate from parents/family); experiencing inclusive social/community engagement; finding meaning/purpose in what one is doing, whether this be in employment/living/alternative contexts; and opportunities for personal growth/progression. All these aspects were likely impacted by C19P-related conditions, as is partially implied by discussion of literature in *Section Two*. Moreover, parents play a pivotal role in TIA in ordinary circumstances, upholding great responsibility, harbouring worries/fears, attempting to balance mixed feelings/positionings, whilst all the while their mental/physical/emotional investment and the transition generally significantly impact upon their own lives and that of the family unit. Furthermore, parents/families and researchers largely critique wider systems regarding their involvement/provision for young adults with Down Syndrome regarding TIA. Aspects that could be considered to result in positive interactions with wider systems in TIA such as advanced preparation, effective coordination of services, opportunities for supported community integration, genuine collaboration, and authentic person-centred practice, were likely limited, hindered, or even prevented during the C19P. The researcher believes it apt to return here to the linchpin metaphor (Timmons et al., 2004; in Dyke et al., 2013) for parents and ask: Was the weight carried alone, and did it become unbearable, under the incomprehensible force of the C19P?

Augmenting the topic of study rationale generated by combining *Section One* and *Section Two* literature strands, i.e., TIA for young adults with Down Syndrome during the C19P, the group critiques provide ideas regarding what could progress research process/design further, upholding qualities of papers reviewed whilst addressing limitations. Researchers could attempt the following: utilise an open-ended qualitative methodology to elicit/interpret in-depth experiences; practice a reflexive mindset throughout the research process, considering what it may mean for research, as well as being transparent about procedural elements; and be clear/coherent with their philosophical foundations from project conception to completion, ensuring these effect the research process, and following reflection/evaluation. The present researcher attempted to incorporate these aspects.

One may question why the present research accesses parents' perspectives, when the group critiques highlight the omitted voice of young adults with Down Syndrome. The Social Model of Disability (Barnes, 2019) reorients the focus on disability from defining what is impaired within the individual to identifying structures within society which place barriers on what said individual is able/expected to achieve. This model would recognise young adults with Down Syndrome as agents who should experience authentic inclusion within society, including in research. Nevertheless, such an approach also highlights the importance of learning from/empowering those closest to young adults with Down Syndrome, who play an instrumental role in promoting their inclusion/fulfilment in community/society. Exploration of TIA for young adults with Down Syndrome in *Section One* illustrates parents' pivotal role/involvement, and the impact of this on them/families. This, as under ordinary circumstances; C19P-related conditions produced extraordinary circumstances, which likely affected these dynamics. Moreover, parents hold a close yet outer perspective, regarding the C19P impact on their young adults; they may have observed/noticed aspects the young adults themselves had not. There is therefore rationale for exploring what the TIA for young adults with Down Syndrome was like during the C19P, from parents' perspectives.

On a practical note, due to the project's scope/timescale, it was not deemed possible to interview young adults with Down Syndrome regarding such an ethically-sensitive and in-depth area. However, the researcher gained the young adults' informed consent for their parents to be interviewed, in acknowledging that the research is fundamentally about them and their parents, hence rectifying previous researchers' potential oversight.

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PART TWO: The Empirical Paper

Wordcount: 12,225

Rationale

Qualitative research on TIA for young adults with Down Syndrome, and their perspectives on quality of life/wellbeing highlights the importance of opportunities to develop independence; experience increased autonomy; develop relationships external to the family, particularly peer relationships; and the prevalence/nature of societal engagement opportunities like participation in leisure/social activities and/or volunteering/employment. These factors were likely substantially affected by C19P-related conditions.

People with Down Syndrome were classified as clinically extremely vulnerable to C19 infection (Down Syndrome Act, 2022, s.10, UK Public General Acts, c. 18), resulting in more stringent preventative measures such as shielding (e.g., Faundes et al., 2021). Not only was it likely this entailed more restrictive lifestyles for people with Down Syndrome during the C19P than the general population, it also likely led to heightened anxieties for them and their parents/families (Pagnamenta et al., 2023). Research suggests that C19P-related conditions exerted a general negative impact on people with Down Syndrome, from parent/clinic perspectives (e.g., Hartley et al., 2022; Villani et al., 2020), and from the perspectives of adults with Down Syndrome themselves (e.g., Vaccarino et al., 2022).

The ALN Code for Wales (WG, 2021) and the SEND Code of Practice (Department for Education and Department for Health and Social Care, UK Government, 2015) apply to CYP aged 0-25years, placing responsibility on local authorities, EPs, relevant professionals in the post-16/post-18 sectors, and schools, in considering preparation for transition, relating to the authentic inclusion of, and provision for, young adults with ALN/SEN. EPs work systemically (e.g., Dowling & Osborne, 2003; Wagner, 2000) with parents/carers and professionals around CYP to facilitate holistic development and smooth transitions (WG, 2016, pp. 15-18). Hence, the demographic of young adults with Down Syndrome aged 18-25years is relevant to the practice of EPs, as is gaining parental perspectives/experiences. Since there is a well-informed case for research into the experiential component of TIA for young adults with Down Syndrome, as it occurred during the C19P [please see *Section Three (Part One)*], this project is justified from researcher and practitioner perspectives.

Purpose of the study

The aim was to explore how the C19P may have impacted TIA for young adults with Down Syndrome, considering both the short- and long-term. The researcher accessed the perspectives of parents of young adults with Down Syndrome aged 17[1]-25years at the beginning of the first lockdown (23rd March 2020).

The nature of the findings was not hypothesised, given the exploratory aim, and ethos of viewing participants as 'experts-by-experience' (Smith et al., 2021, p. 50). The goal was to inductively learn from parents, being open to complexity, novelty/the unexpected. Considerations/implications for EPs were devised from analysis of parents' experiences, perspectives/sense-making.

Research Questions

- How did the C19P impact the TIA for young adults with Down Syndrome, both at the time of the pandemic and in the longer-term?
- What were these experiences like for young adults with Down Syndrome and their parents, from the latter's perspective?

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[1] Whilst the TIA phase is considered to be the 18-25yo age range, the C19P was a prolonged period, hence the young adults who were 17yo at the start of the first lockdown still commenced, and progressed along, their journey towards adulthood during the C19P period. Experiences/perspectives of the parents of these young adults were therefore relevant to the study's aim and RQs. Moreover, the wider age range facilitated participant recruitment.

Ontology and Epistemology

Critical Realist Ontology

The researcher has elsewhere outlined their understanding of critical realism (CR) based upon Burr (2015)'s explanation which applies here:

'a critical realist perspective on ontology holds that an external reality exists, and humans can gain knowledge of it, but this knowledge relies on perception which is imbued/constrained by individual interpretation' (Davies, 2023, p. 219).

Critical realists acknowledge individuality of perspective, whilst maintaining that we can know something of a common reality.

Regarding this study, it was taken as fact that the C19P happened, and led to regulations/restrictions in Wales/England. It was assumed that young adults with Down Syndrome TIA during the age bracket of 18-25yo, where this transition is not an event but a multi-faceted, prolonged process. From reading literature on the impact of the C19P on young adults with Down Syndrome, as well as their TIA generally, it was hypothesised that the coincidence of the two experiences would have significantly affected both young adults with Down Syndrome and their parents. These factors combine to create the assumed reality uniting the participating parents; i.e., their young adults with Down Syndrome TIA during the C19P in Wales/England. What was appreciated in the open-ended qualitative methodology, was the individuality of parents' experiences/perspectives, and meaning/insights that could be gained from the researcher's interpretation.

Social Constructionist Epistemology

A SC stance on epistemology holds that what we know about the world is not just influenced by, but originates from, social processes/interactions (Burr, 2015; Crotty, 1998; Gergen, 2011). Knowledge differs between individuals/groups based on varying sociocultural/historical influences, hence one cannot take knowledge for granted, or apply it universally.

The researcher argues that what parents could know and share of their experiences of their young adults with Down Syndrome TIA during the C19P is borne from socially-constructed phenomena; that is, social interactions/processes between them and their young adults, within the family, and with wider systems, or conditions brought about by those systems. For example, during the C19P, people in Wales/England, including young adults with Down Syndrome and their parents, encountered or were subject to messages, restrictions/regulations, and lived the existence that ensued when playing out these aspects in family/social contexts, whether this was to stay at home, maintain a ‘bubble’, shield, keep a two-metre distance, go on one daily walk in the local area, wear a mask, adapt contact with people or access to things outside of one’s home to the virtual world, etc. Moreover, TIA is a socially-constructed transition/phase which is understood differently from distinct cultural/historical perspectives. It is also a phenomenon that grows in meaning for parents/their young adults with Down Syndrome through their own changing interactions, within the family context, as well as those with other systems such as young adults with Down Syndrome interacting with their peers, and parents with involved professionals/other parents.

The two together?

One may question whether a SC epistemology is coherent with a CR ontology in contrasting the inherently social origins of knowledge with the necessarily individual perception of reality. The researcher argues that the former does not preclude the latter. The researcher appreciates individuality of C19P experiences and the TIA process from the perspectives of parents of young adults with Down Syndrome, since, whilst their knowledge originates from socially-constructed phenomena, each parent and their young adult separately and together experience a unique set of interactions/processes, and each has their own prior knowledge, understandings, beliefs/attitudes, borne from their interactions with the social world. Therefore, they each have their unique perspective. Moreover, a SC stance on epistemology would hold that to have knowledge or an experience is to necessarily interact with something, and no matter the directedness of that interaction, that something could plausibly be a common external reality, as argued by Crotty (1998). Additionally, aligned with CR and SC stances, the present study aimed to offer an interpretation rather than produce a mirror image of parents' experiences, in recognising that the researcher's understanding is intrinsically scaffolded by their own sociocultural understandings/experiences, and hence unique lens.

Participants

A purposive, self-selecting sampling method was utilised to recruit three parents of young adults with Down Syndrome who were aged 17-25years at the beginning of the first lockdown (23rd March 2020), such that they were transitioning or had recently TIA during the C19P.

Please see Table 6 for characteristics of the participating parents and their young adults, and Appendix D for details of the recruitment process.

Table 6: Characteristics of the participating parents and their young adults

Please note, the parents and their young adults are assigned pseudonyms and characteristic information is minimal in the service of anonymity, given the relative size of the target population across Wales/England.

Parents

- Mothers (N = 3): Rosie, Olivia and Ruby.
- All self-identify as female.
- Between the ages of 39-80yo.
- All had the same occupation.
- Live in Wales/England.
- Family set up (for all three participants): mother, father, young adult with Down Syndrome and sibling. All the young adults ordinarily reside in the family home.

young adults

	Oscar (mother = Rosie)	Sienna (mother = Olivia)	Alfie (mother = Ruby)
Self-identified gender	Male	Female	Male
Age at the start of the first lockdown	21yo	17yo	17yo
Age at the time of interview	24yo	20yo	20yo

Procedure

The researcher conducted one-to-one semi-structured interviews with the mothers. All three were interviewed online from their homes, on Microsoft TEAMS. The interviews lasted between 60-70minutes, and were conducted in English. A self-created interview schedule was utilised which comprised open-ended questions designed to elicit parents' sense-making of their experiences in relation to their young adults' TIA during the C19P, as affected in the short- and longer-term. Question topics were based on themes relevant to TIA for young adults with Down Syndrome accrued in the LR [*Section One (Part One)*], for example, independence, relationships, community participation and mental health/wellbeing; and the effect possible changes during the C19P may have had on young adults with Down Syndrome and their parents. The guide was utilised flexibly, in line with the aim to inductively explore parents' perspectives/experiences through viewing them as 'experts-by-experience' (Smith et al., 2021, p. 50), such that they could determine their own foci and thus have an 'important stake in what (was) covered' (Smith et al., 2021, p. 4). The researcher probed further on the mothers' contributions, such that the discussion content was unique to each mother, concurring with the view that their and their young adults' experiences are idiographic. The interview schedule and a C19P-related timeline was shared with mothers prior to their interviews (please see Appendix E.iv), such that they could prepare mentally and, if they chose, through note-taking for recollecting their experiences. Please see Appendix E for ethical considerations and front-facing gatekeeper and participant documentation.

Methodology

The aim of this study was to conduct an in-depth exploration of parents' experiences of TIA for their young adults with Down Syndrome during the C19P, creating an open space in semi-structured interviews for parents to make sense of what happened. The unit of analysis was qualitative data from the mothers, where the researcher intended to investigate the phenomenological component, hence an intuitive choice of method was IPA (Smith et al., 2021). This method involves the researcher eliciting participants' experiences as they undergo a process of sense-making regarding a significant event, series of events or period in their lives. Whatever has happened awakens them from their everyday flow of experience to take more conscious notice of that thing/s, which hold/s particular significance/meaning (Smith et al., 2021). In this study, mothers were asked to make sense of a significant period in the lives of their young adults with Down Syndrome and themselves (i.e., TIA), as impacted by a significant phenomenon that affected most people in one way/another (i.e., the C19P).

The three main principles underlying IPA are phenomenology, idiography and hermeneutics (Smith et al., 2021). Regarding phenomenology, or the study of the act of experience (Smith et al., 2021, p. 4), mothers held an 'important stake in what (was) covered'. As outlined in the *Procedure* section, semi-structured interviews were conducted with a flexible stance to, on the one hand, provide a stimulus for parents to recollect over a three-year period and to focus their reflections on factors typically implicated in TIA for young adults with Down Syndrome (Please see Appendix E.iv) and, on the other hand, to actively encourage openness to complexity, nuance and the unexpected on behalf of the researcher.

Through eliciting/interpreting participants' experiences, IPA researchers uphold commitment to the particular, or the idiographic nature of experience (Smith et al., 2021). IPA appreciates individuality of participants' perspectives in line with CR, and the context-bound nature of knowledge, concurring with SC. The ethos of idiography applies to the particularity of perspective, hence why a fairly homogeneous sample of parents of young adults with Down Syndrome were interviewed to explore a specific, shared experience (their young adults with Down Syndrome TIA during the C19P). Conceiving that the mothers were similar in experiencing a combination of these socially-constructed phenomena (young adults with Down Syndrome TIA and C19P), is suggestive of a common reality existing, where their experience/knowledge of that reality may be relatable to one another, but are ultimately unique to them, concurring again with CR. The commitment to idiography also necessitates an in-depth, thorough approach to data analysis, hence why the individual voices of mothers are preserved in the *Findings* section, and divergence across mothers is demonstrated along with convergence. There is no attempt to average out/generalise experience.

Hermeneutics refers to the theory of interpretation (Smith et al., 2021). IPA relies on the researcher to apply their knowledge/experience when interpretating data, leading to richer meaning-making. Applying an IPA lens to this study, the researcher engaged in a double hermeneutic and, at times, a triple hermeneutic. Mothers made sense of their experiences of their young adults with Down Syndrome TIA during the C19P (first hermeneutic), and the researcher attempted to make sense of the mothers' interpretations (double hermeneutic); and mothers' made sense of how it was experienced by their young adults (involving a double hermeneutic), whilst the researcher then interpretated the mothers' interpretations (triple hermeneutic) (Smith et al., 2021).

As Smith et al. (2021) note, there is not one set way to conducting IPA. However, they provide guidance around immersing oneself in the data; exploratory noting; constructing experiential statements; searching for connections to arrive at personal experiential themes (PETs); consolidating/organising these PETs; continuing individual analysis of other cases; contemplating PETs across cases to develop group experiential themes (GETs); refining these; and writing up. Please see Appendix F for extracts that illustrate the data analysis process.

Findings

Interviews were analysed using IPA (Smith et al., 2021), within the framing of the RQs:

- How did the C19P impact the TIA for young adults with Down Syndrome, both at the time of the pandemic and in the longer-term?
- What were these experiences like for young adults with Down Syndrome and their parents from the latter's perspective?

The analysis is organised thematically rather than by RQ since the themes transcend both, i.e., the researcher could not interpret the C19P impact on TIA without detailing what this was like for young adults with Down Syndrome/their parents. The data were richly multi-faceted which could have led to the development of a plethora of GETs, hence the following analysis presents what the researcher considered to be most salient to the RQs. The GETs are:

- Autonomy – a kaleidoscope of forms
- Routine – a multi-edged sword
- Parents striking a precarious balance

Please see Figure 1 for the thematic map.

Figure 1: Thematic map

Autonomy - a kaleidoscope of forms

- The C19P snatched what was *theirs* and theirs *alone*
- Active agency to passive recipiency
- Dissonance – readiness to fly the nest yet forced to stay within it
- The virtual realm – offering another way

Routine - a multi-edged sword

- Oscar: variety and autonomy versus monotony and passivity
- Alfie: facilitation versus comfortable regression
- Sienna: facilitation versus ‘unmovable’ rituals

Parents striking a precarious balance

- ‘How how do you explain?’
- The impossible decision
- To nudge or not to nudge? Or somewhere in between…

Group Experiential Theme 1: Autonomy – a kaleidoscope of forms

The Covid-19 pandemic snatched what was *theirs* and theirs *alone*

Potential for the young adults to develop their autonomy and practice this quality, defined here in terms of self-government (Oxford Learner's Dictionary, 2024) and thus being the director of one's life and engaging in one's own activities, was undoubtedly hampered by C19P-related conditions. Their worlds abruptly/starkly diminished in scope, opportunity, challenge, and freedom; as Rosie and Olivia summarise for Oscar and Sienna:

'all his life almost stopped suddenly and all his activities…that was really difficult for him' (Rosie, p. 2).

'She was sad to miss out on her very hectic…oh Gosh, there was something nearly every day…all of that had to stop' (Olivia, p. 4).

Olivia's exclamation ('oh Gosh') captures the gravity of the lockdowns for Sienna; so many of her day-to-day activities came to a halt. Rosie goes further, stating that the stopping of Oscar's usual daily routine greatly restricted his life, and the adverb 'suddenly' conveys the rapidity of his world diminishing. Pre-C19P, Oscar enjoyed an active/colourful life, with his café job, skiing trips, swimming, spending time with friends; as did Sienna, with college, tennis, football, and spending time with 'her little social club' who shared her football passion (Olivia, p. 6). The mothers recognise that to lose these elements 'suddenly' for an indeterminate period was upsetting/challenging for Sienna and Oscar.

Despite the predictability, structure and minimal sensory/social demand of the lockdown routine seeming to befit Alfie's preferences during the C19P [Ruby explains this, especially the latter aspect, in the context of his Autism, as Alfie has diagnoses of Down Syndrome and Autism], he too missed hobbies such as football, swimming, and his activities that adapted to the virtual realm but were not suited to it such as his signing choir [internet delays meant the lyrics did not always match the signs, and he found this ‘quite frustrating’ (Ruby, p. 12)]. His missing these activities is conveyed through renewed appreciation post-C19P, which Ruby feels he realised on some level within himself:

‘…more keen to do stuff now compared to how he was before Covid. I don't know if that would be because he couldn't do it and he suddenly realised he did quite like doing it, could be, yeah’ (Ruby, p. 13).

This renewed appreciation manifests despite daily challenges for Alfie associated with being out and about in the unpredictable sensory/social world and the difficulties of becoming accustomed to it all again after the quiet predictability he enjoyed during lockdown. This suggests experiencing challenge/overcoming obstacles are important for Alfie, over and above pure enjoyment of his activities; such opportunities were vastly limited during the C19P.

Active agency to passive recipiency

Focusing on roles assumed by the young adults, Oscar transitioned from being autonomous/active, e.g., through his café job, socialising/travelling with skiing, to assuming a passive position during the lockdowns, where others made decisions on his behalf. Pre-C19P, Oscar had ‘his own life’; ‘something that we (as parents) don't have part of’ (Rosie, p. 26). In addition to enjoyment of social/leisure activities for himself alone, pre-C19P, Oscar actively made the most of adventurous opportunities, whilst illustrating relative independence, exemplified by Rosie’s description of his skiing travels:

‘he does go independently…he's been to France twice with them…three times to Bulgaria on his own’ (Rosie, p. 26).

Contrast the multi-colour nature in terms of opportunity, freedom and challenge inherent to such travels, his sports and his job, against the seemingly grey and restrictive hum-drum of 'the same thing every day' (Rosie, p. 10) when living at his grandparents in lockdown, which comprised a rather monotonous routine of short local walks, jigsaws, wordsearches, watching films/reading. Despite Oscar's grandparents' best efforts, Oscar was unstimulated; 'it was really boring…for him' (Rosie, p. 3), again highlighting the importance of challenge through its absence. The primarily sedentary activities suited to most grandparents differed starkly from actively getting out and about, seeing the world and developing his own life, which it appeared Oscar was doing in accordance with how most YP TIA, but the C19P temporarily, yet indeterminately, took this away from him. Note the juxtaposition of language where Oscar went from being the possessor in having 'his own life' (Rosie, p. 26), and use of the subjective personal pronoun in Rosie's utterance above where 'he does' things (Rosie, p. 26), and is the actor/subject of the activity, to him becoming the objective personal pronoun of the following utterances, where things were done to him:

- Start of the lockdown:

  'he was sent home…from work' (Rosie, p. 2).

- During the lockdown when parents decided it would be safer for Oscar to live with his grandparents since they were going to/from work:

  'we decided to move Oscar out of the house' (Rosie, p. 3).

- After the lockdown, the café consulted parents about whether Oscar could return to work:

  'they sort of asked us 'How do you feel about him?" (Rosie, p. 5).

This juxtaposition conveys Oscar's transition from being an active agent doing things in his own life, to almost re-adopting a childlike position through being subject to the decisions of others (his parents/employer) who were acting to keep him safe but, ultimately, this meant that Oscar became a passive recipient of others' directives, restricting his autonomy during the C19P. Moreover, this appeared to be sustained in some ways as restrictions eased, where his parents were consulted first regarding his return to work.

Alfie was also subject to decisions where his parents were acting to safeguard him, but the resulting conditions seemed to limit his autonomy. Pre-C19P, he would of his own volition help the Tesco delivery drivers bring the shopping into the home, and he travelled on the school taxi. During the C19P, due to Alfie's sensory-seeking habit of touching things and putting his fingers to his mouth, his parents decided it was safer to 'send him upstairs' (Ruby, p. 4) when the Tesco delivery arrived. Parents also returned to the prior arrangement of them being Alfie's school taxi, which Ruby felt 'was a step back for him' (Ruby, p. 4).

What was perhaps more striking for Alfie, however, was that conditions the family had to adapt to if they were to see grandparents, rendered him heavily reliant on his parents/sister for regulation in social interactions (which he can find challenging), when he had developed his own way of coping under ordinary circumstances. Alfie had a bedroom in each grandparents' house where, pre-C19P, 'he would take himself when it got too much' (Ruby, p. 5); hence an independent form of self-regulation. When the only way to see grandparents was visiting their gardens, Alfie fell back to being dependent on his parents/sister 'tag-teaming' to help him regulate in these interactions (Ruby, p. 8); something they were accustomed to doing when going out for other events/activities, but this appeared to be a regression in the context of interactions with grandparents. Like when Rosie described Oscar's transition, Ruby depicts Alfie assuming the subjective personal pronoun above, where he is in the driver seat of his regulation, whereas he became the shepherded objective personal pronoun during lockdown, where Ruby almost conjures imagery of parents needing to keep a child busy whilst the adults converse:

'So that would take a lot of…distracting by me or me taking him for a walk and then coming back and sitting back down' (Ruby, p. 5).

Dissonance – readiness to fly the nest yet forced to stay within it

C19P-related conditions not only practically restricted contexts/means for the young adults to be autonomous, it also created dissonance between the cocooned safety in which they found themselves encased and their emerging mindset shift as young adults, in the case of Sienna and Oscar:

‘Sienna was very much…wanting to pull away from…she loves us, but I think wanting to have her own time…she understood she couldn't go out, she understood why…I think she felt like it was a backwards step.’ (Olivia, p. 7).

‘I think his feeling…his own life, his independence away from us…Something that he knows about that we don't a bit…his control of it’ (Rosie, p. 26).

From the parental perspective, both young adults love their families and enjoyed spending time with them in lockdown (when Oscar was still living in the family home that is, although he also became closer to his grandma when living with his grandparents). However, quite naturally, each was enjoying more freedom and their own activities separate from family life pre-C19P. It seems just as they felt ready to fly the nest in certain respects, another larger nest (vis-à-vis, C19P-related restrictions) surrounded them, forcing them to retreat. Despite understanding this as a precautionary/exceptional measure, it made it no less jarring against their developing self-view in their readiness to transition.

Whilst Sienna and Oscar appeared to be quite self-directive in this realm, it seems that Ruby/her family more so encouraged Alfie to venture from the nest pre-C19P, carefully judging when to nudge him and when to hold back. For them, the C19P temporarily halted and thus slowed their endeavour to help Alfie develop his autonomy in a tailored way, i.e., for him to be able to go out with his Personal Assistant without a family member:

‘I think he probably might have been further along with that had there not been Covid…actually that definitely put the brakes on him doing stuff with other people.’ (Ruby, pp. 19-20).

There is a sense of the C19P slowing Alfie’s progress, even if this is more from the perspective of his family’s agenda, since that agenda is aimed at developing his autonomy/resilience in coping out and about, without relying on family members. Whereas, C19P-lockdowns enforced that he stay at home with his family, in the absence of those challenges.

The virtual realm – offering another way

Notwithstanding autonomy-hampering effects of the C19P, rapid evolution of the virtual realm for social interaction, education, and activities offered compensatory means for Alfie and Sienna to develop their autonomy, albeit in an altered form. In some ways, virtual social interaction was idyllic for Alfie; it is more structured/time-bound than in-person, with opportunities for him to break-off/regulate. He coped relatively well with virtual school, video calls with grandparents (as opposed to garden visits), and he even acquired a new hobby during lockdown – online dancing. Alfie could adapt to technological aspects as ‘He can use a screen quite well’ (Ruby, p. 3). However, more than this, it seemed to be the structure/clear sequence of virtual interaction, and Alfie knowing it would be for a certain period and then he could do something else:

- Video calls with grandparents:
  ‘he could talk to them for a bit and then go off and do stuff’ (Ruby, p. 7).

- Online dancing group:

  ‘That's meant he sees his friends, they all have a little chat to start with, then do the dancing’ (Ruby, p. 13).

Perhaps it is not only Alfie’s preference for structure and his need for regulation opportunities which renders virtual social interaction quite versatile/attractive to him. The online dancing group seemed better suited to Alfie than an in-person group would be, given removal of practical logistics. Ruby emphasises that car journeys to/from an in-person dancing group would be too tiring for Alfie, and that she would not have time to drive him either. Moreover, once Ruby has set the video call up, Alfie can participate ‘all by himself’ (p. 13), thus providing him with an autonomous outlet, contrasting from activities out and about where it seems he is more dependent on family.

Sienna was also enabled to develop her autonomy through virtual contexts, not in the sense of virtual social interaction being more structured/time-bound, as seemed to be important for Alfie, but in the sense of it providing opportunity to independently participate in an organised social group for young adults with Down Syndrome; hence chance to be with her peers (albeit in an altered form), and away from family:

‘that was so important because that was Sienna's bit of time to herself, away from us, with her own friends’ (Olivia, p. 5).

There is a renewed sense of Sienna being equipped through virtual social interaction to be autonomous in doing something for herself by herself; to engage in something that is her own. The C19P perhaps elevated recognition for the scope of the virtual world for Sienna and Alfie, offering them a different way to fly the nest and be with their peers. Moreover, their participation in these respective groups was sustained post-C19P.

Group Experiential Theme 2: Routine – a multi-edged sword

Oscar: variety and autonomy versus monotony and passivity

It was not only absence of his varied activities/seeing his friends which appeared to negatively affect Oscar during the C19P; he lost his routine, and with this, a way to be autonomous, cope, and find meaning/purpose in life:

‘he thrives on routine…Oscar learns a lot by rote and…copes well with routines and so those sort of things stopped’ (Rosie, p. 1).

When Oscar moved from the family home into his grandparents’, he followed their routine, including jigsaws, reading, etc. Rosie depicts this routine as relatively mundane: ‘the same thing every day, I suppose’ (Rosie, p. 10), contrasting against variety/colour offered by his own usual routine. These primarily sedentary activities may be commonplace/suited to Oscar’s grandparents’ generation, but perhaps not to a young adult eager to be active and try new things. This potentially contributed to Oscar’s feelings of ‘boredom’/his being unstimulated (Rosie, p. 16), as he repeatedly expressed to his family:

‘he’d just say he was fed up really’ (Rosie, p. 3).

Rosie worried about Oscar’s mental health/wellbeing during this period, which seemed to relate to Oscar not being able to be his own person in his own space (as he was used to in the family home); him missing being with his parents/sister; and him losing his autonomy-inspiring/colourful routine to becoming a passive follower of his grandparents’ schedule. Rosie perceived Oscar to be ‘quite low…almost depressed’ (Rosie, p. 3) when they visited. She evokes a sense of trudging along in a state of hopelessness:

‘it was all sort of dragging on. I think it does seem then, especially him, it seemed like there was no light at the end of the tunnel for it all’ (Rosie, p. 3).

The imagery of being in a never-ending tunnel, combined with a lasting temporal component ('dragging on'), implies that Oscar was stuck in, for him, a limiting, tedious routine. The enduring nature of routines can provide stability/surety, however, for Oscar, this quality seemed to serve as an ever-present reminder of the monotony determining his life during the C19P, without prospect of a change in sight, or the end of the tunnel.

Alfie: facilitation versus comfortable regression

Lockdown life seemed to suit Alfie, at least in the short-term. Despite him similarly missing out on his usual varied routine, e.g., in-person college, sports like swimming/football, activities like choir, seeing his peers within these contexts, Ruby does not highlight Alfie finding this upsetting/difficult as Olivia/Rosie do for Sienna/Oscar. The adjustment for Alfie was making sense of lockdown; subsequently, Alfie coped well. The strict stay-at-home lockdown provided clarity/predictability; elements he would not always experience under ordinary circumstances:

'when it was proper lockdown lockdown…it was very black and white. This is what happens' (Ruby, p. 5).

Alfie's routine of virtual college/activities removed challenges, primarily, through Ruby's eyes, in relation to coping with unpredictable sensory aspects, or the general unpredictability/proclivity for usual routines to change out and about in the world:

'he was probably more relaxed because it was just here, there wasn't anything unexpected going to happen [laughs]' (Ruby, p. 18).

'he kind of just had this routine…and it was quite controlled' (Ruby, p. 18).

Lockdown life appeared to be easier, where Alfie could follow his routine in a safe/controlled context. He was 'just at home' (Ruby, p. 18) with a family who accommodate his needs well, and where there would not be unexpected schedule changes/sudden sensorily-jarring noises:

'if we know we're gonna cough, we say 'I'm just gonna cough'…there's not really any dogs barking…there's no babies (crying)' (Ruby, p. 10).

One obtains a sense of Alfie's family being accustomed to 'Alfie-proofing' their behaviours; an accommodation Alfie would be vastly less likely to experience in other contexts. One can perhaps appreciate why Alfie was 'more relaxed' (Ruby, p. 18) at home in lockdown, when Ruby describes what it is ordinarily like for him out and about:

'when people cough, he does what I call a Billy Idol thing…funny lip curling…he can cope…the first time somebody does it…he literally jumps out of his skin…but if that continues…he hasn't run away for a long time, but…his fight or flight responses can be so high that he just has to go' (Ruby, p. 10).

This conjures imagery where one can almost viscerally imagine Alfie's stress in external settings, triggered by general unpredictability, but especially unexpected/prolonged loud noise (due to his auditory hypersensitivity). Alfie's vexation can be so encompassing that it precipitates his 'flight' response, and his aversion to the experience so strong that it visually manifests, hence Ruby's metaphor of Billy Idol's famous lip curl. Therefore, Alfie is continuously 'on…quite a high state of alert…when he's out' which, unsurprisingly, 'drains him quite a bit' (Ruby, p. 18). Thus, the external world seems to take its toll on Alfie, whether someone nearby has a coughing fit/not, as his automatic nervous system is merely on standby, constantly monitoring, with the caveat that even this monitoring would not prepare him for the unexpected. Despite these anxious/draining experiences, pre-C19P, Alfie had coping mechanisms, which he had to re-learn when adapting to post-lockdown life:

'that was the harder bit was actually for him going back out and being with other unpredictable people…remembering and learning those coping strategies again…and…emotionally how to deal with that' (Ruby, p. 18).

Ruby's use of the verb 'remembering' and qualification of the verb 'learning' with the adverb 'again' illustrates that Alfie had acquired coping mechanisms to manage the unpredictable external world, just as he had his own form of regulation during social interactions with his grandparents pre-C19P, where he would visit them in their houses, rather than their gardens. C19P-related conditions took away Alfie's regulatory technique on grandparent visits, but they equally removed the requirement for his other coping mechanisms. This may have been a reprieve for Alfie in the short-term but resulted in him being out-of-practice when lockdown ended. Transitioning from his state of home comfort with minimal challenge to 'just being back in…the hustle and bustle' (Ruby, p. 10) could have been akin to a student with exam anxiety honing their coping ability in the exam scenario over years, enjoying a prolonged break with an indeterminate end, before again being expected to enter and manage their emotions in an exam room, where previous coping mechanisms have been pruned due to lack of use.

The need to re-learn coping mechanisms suggests a regression for Alfie, where his family adopted a very gradual approach when re-introducing him to the external world. Alfie may have coped well with or, indeed, enjoyed the lockdown routine, but this routine was limiting; the essence of which is conveyed in the adverb 'it was *just* [2]at home' (Ruby, p. 18). Moreover, becoming accustomed to the lockdown routine/conditions also potentially associated with Alfie regressing due to its inherent paucity of challenge and dissimilarity to the external world.

Sienna: facilitation versus 'unmovable' rituals

Having a routine seemed to serve a protective function for Sienna during lockdown. It was something she could control in a context where she had very little control; offered her a

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[2] Italics here convey author's emphasis.

sense of meaning/purpose when activities that ordinarily provided this were taken away; and, similar to Alfie, it supplied reassuring clarity/calmness in a period of confusion/unease:

'I think it helped to make sense…of what was going on and…helped her…in her life, in her head…it made sense. There was some logic, if she did everything a certain way' (Olivia, p. 21).

One of Sienna's routines which began pre-C19P, but increased in intensity during the C19P, was folding clothes very neatly, Marie-Kondo-style. Olivia believed this was 'Sienna's way of winding down' (p. 10), which Olivia normalises:

'I think that's a lot of people do that, don't they? When they're anxious about something, they clean. The practical and positive thing that releases energy and something you do to distract yourself.' (Olivia, p. 20).

The rhetorical question with a taken-for-granted affirmative answer implies that Olivia thinks it was natural for Sienna to engage in certain routines (like clothes-folding) to affect something positively, when other outlets for such influence had vastly diminished, e.g., via in-person meet-ups with her friends, sports, etc., and, at a foundational level, just to have something to do.

Sienna's tidying routines were perceived as helpful to the family. Olivia even attributes her own organisational/cleaning skills in part to Sienna, who helps with chores and seems to aid Olivia keep on top of things:

'I'm so much better at housework for having Sienna grown up here' (Olivia, p. 26).

Sienna may therefore associate her tidying routine with being helpful to her family; and something she can take pride in, e.g., the aesthetic of her bedroom [like a 'show hotel' (Olivia, p. 20)] and inspiring her mother. Additionally, Sienna may see 'being tidy' as a quality of her personality:

'out of the four of us, Sienna's the tidy one' (Olivia, p. 9).

Olivia's description 'the tidy one' is characteristic. Elsewhere, Olivia depicts Sienna as 'the gregarious one' (Olivia, p. 1). Contexts for Sienna to express the latter quality were diminished during lockdown, hence Sienna may have fuelled her efforts into demonstrating the former quality, thus her intensified tidying routines.

Routines seemed to be important to/served a protective function for the whole family during lockdowns, again seemingly to have an itinerary, meaning/purpose, or as bluntly expressed by Olivia:

'we did a little timetable to stop ourselves from going mad' (Olivia, p. 2).

These routines enabled a slowing down of family life and replacement of usually busy routines, with those where the family could spend mindful quality time together:

'it made us closer as a family…instead of rushing from thing to thing, we would enjoy each other's company' (Olivia, p. 18).

Amongst playing boardgames, cooking and walks, the family enjoyed a nightly ritual of taking it in turns to choose a film/sit-com episode to watch together; a routine which has reduced in frequency after the C19P, but has nevertheless been sustained. Sienna directed the film night rota; she kept a diary, determining whose turn it was each time. Olivia described this as 'so good' (p. 3). This routine appeared to offer Sienna a sense of purpose, something in which to engage, and facilitate development of her autonomy in the sense of directing her family. Therefore, Sienna may have consciously/subconsciously felt that routines can do so much good; they can enable one to cope in very strange circumstances, following them can be a means of expressing an admirable part of your personality, and help others, and they can provide meaning/purpose.

Notwithstanding that routines can do these positive things (and likely more), and most probably did for Sienna during the C19P, Olivia felt her adherence to them following the C19P became too ritualised:

‘that addiction to the rou-, that…adhering to the routine was a little bit of a symptom of the pandemic…She became very erm, yeah, all about the routine and a bit unmovable’ (Olivia, p. 21).

It is almost like one of the most notable features about Sienna’s personality became her proclivity to strictly follow routines, to the extent that she became inflexible (‘unmovable’) in her prioritisation of them that was all-encompassing (‘all about the routine’). Olivia utilises clinical language: ‘addiction’ and ‘symptom’, implying that Sienna may have presented as glued to her routine in a way that could have negatively impacted her life/mental health. Olivia elaborates upon what this was/is like:

‘we just sort of explain these tiny little tweaks to the routine. And a year ago, she…wouldn't have had that at all, but now she is starting to understand that ‘Ok, we've got a routine, but…we can tweak the routine sometimes because we might have a later night or…’. I think she's starting to get her head round that and I think that's part of her mental health improving’ (Olivia, p. 21).

Whilst Olivia does not depict Sienna feeling low/depressed as Rosie does for Oscar, there is recognition here that Sienna’s mental health did somewhat take a hit, albeit in a different way; in Sienna’s case, anxiously/compulsively adhering to routines. The verb ‘improving’ implies that Sienna is on an upward trajectory in the longer-term period following the C19P, such that there was perhaps a dip during/shortly after the C19P. Olivia describes Sienna’s developing understanding (‘she’s starting to get her head round that’) in the sense of her accepting family members’ suggested tweaks to her routine, and her improving flexibility; comparing this to when Sienna followed her routine religiously, where no changes could be permitted.

In contrast to the earlier part of this section where Sienna’s routine-following was characterised positively, Olivia’s descriptions regarding the period following the C19P show how this activity perhaps tipped over into the negative end of the dimension. Olivia previously depicted Sienna's clothes-folding routine as calming, but it becomes something that compels her to stay up at night (where the disturbance can keep Olivia up too when they are away/staying at grandparents'). One may wonder about the potential sleep lost on behalf of Sienna/Olivia (and other family members who may hear Sienna up in the night). Moreover, Sienna's tidying routines can affect her punctuality:

'doesn't matter if you're…running late for college, Sienna will make the bed pristine…I can be red in the face at the bottom of the stairs 'Come on, Sienna! We need to leave!'. She will 'Ooh, hang on. I've got some dust, I just need to …'. [laughs].' (Olivia, p. 20).

This seems like a familiar, stressful experience for Olivia on weekday mornings following the C19P. Whilst it may be reminiscent of one encountered by many parents hurrying their CYP out the door for school/college, the reason for Sienna's lateness appears to be concerning. Sienna 'loves college' (Olivia, p. 11), yet her routines take precedence; she will be late and potentially miss things to see her routines through. Olivia laughs; applying humour may be Olivia's defence against succumbing to negative emotions that may arise around Sienna's routine-following such as worry, frustration/upset.

Perhaps the most significant impact of Sienna's routine-following was the distress she experienced when things did not go to plan. Olivia recounts a relatively recent experience (long-term since the C19P) when Sienna believed she was going out for brunch but Olivia was not intending to do this and did not know Sienna had this set idea in her mind. As time went on and it did not seem they were going, Sienna became increasingly distressed:

'All of a sudden I could hear shouting and I came up to her and said 'What's happening?' and she just kept shouting again and again 'I don't I don't understand, but I don't understand!', shouting…So…she was really annoyed, she couldn't tell me. She just kept shouting 'I'm confused!" (Olivia, p. 22).

Sienna was so dysregulated that she could not communicate what had upset her. Olivia creates a powerful scene here, where Sienna worked herself into a vexing state, and Olivia is trying to ascertain the trigger to help calm her, but Sienna is at a heightened point where all she can do is shout. Olivia explains that she was not sure from where Sienna had gotten the idea that they were going out for brunch, nonetheless she had the idea; it was in her routine and the thought of that not being realised caused Sienna much anguish. Eventually, through guesswork, Olivia ascertained the trigger. Olivia hypothesises why Sienna did not feel she could tell her the issue:

‘I think it was almost perhaps…she thought if she told me, then her fears would be realised, that I’d say ‘No, you're not going.’ [laughs]’ (Olivia, p. 22).

It seems Sienna may have suspected that Olivia was not intending for them to go out for brunch, but this caused her so much dissonance in diverging from what she had in her mind as the day’s routine, and not doing something she enjoyed, hence her repetitive expression of confusion/incomprehension. Olivia believes that her saying they were not going for brunch made the feared outcome real for Sienna; something she had tried to avoid. ‘fears’ is a strong word, suggesting it was very anxiety-inducing for Sienna to diverge from her routine/set plan in her mind. Again, Olivia laughs after recounting this experience. Later, she rhetorically asks:

‘who doesn't love a full…breakfast? [laughs].’ (Olivia, p. 23).

This is also followed by a laugh. It seems applying humour to the situation is one way Olivia copes with/makes sense of Sienna’s rigid routine-following; that, and normalising her behaviours like her cleaning habits, and her insisting on brunch. It appears to be Olivia’s way to process what was happening for Sienna and compartmentalise. However, despite this seemingly light attitude, it appears that Sienna’s adherence to routine triggered stressful, frustrating, upsetting, and sometimes even distressing/vexing experiences for both Sienna and Olivia, and perhaps the rest of the family too.

Group Experiential Theme 3: Parents striking a precarious balance

‘How how do you explain?’

Rosie and Olivia outline the seemingly ‘catch-22’ task of explaining C19P-related conditions/measures during the pandemic to Oscar and Sienna:

‘How how do you explain to him why he’s got to live somewhere else without making him…it's really tricky how to explain how, without making him anxious, how he's got to live somewhere else to avoid catching it, but you don't want him to be overanxious about it all either’ (Rosie, p. 5).

*‘It's a difficult one…when you've got someone with a learning disability to teach them…hand washing and social distancing is if you put fear into someone, ooh they're gonna do it…But you don't want to put fear into people…So it's really **hard**[3], isn't it?’ (Olivia, p. 17).*

Both mothers pose a question; Rosie, it appears, in the sense of believing there not to be an answer to the conundrum, and Olivia in terms of highlighting the difficulty, along with her prosodic emphasis on the adjective ‘hard’. Rosie had to explain to Oscar why she and Oscar’s father made a safeguarding decision that impacted his life significantly; to move him out of the family home and into his grandparents’. They needed to justify this to him (when he wanted to be at home), whilst protecting him from becoming ‘overanxious’, in knowing that the thought of being unwell makes him uneasy under ordinary circumstances [‘He hates being unwell’ (Rosie, p. 9)]. Rosie’s utterance breaks up several times and she repeats the interrogative pronoun ‘how’, conveying the gravitas of emotion mixed into this, and her appearing to feel at a loss when trying to strike a balance that felt optimal, when perhaps there was not such a one. Olivia also portrays the challenge inherent in the explanation, yet

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[3] Bold font here represents the participant’s prosodic emphasis.

perhaps with not quite the emotion as she was explaining the importance of universal measures like hand-washing and social-distancing, rather than justifying a decision to move Sienna out of the house. However, it was still a feat of a task to explain why these regulations were not a ‘faff’ (Olivia, p. 17) but a necessary safeguarding measure, where Olivia appeals to a moral conundrum. She wanted Sienna to perceive the measures seriously and thus adhere to them, hence it was important to express the solemnity of the risk, whilst battling with another perspective within herself which questioned whether she should intentionally make Sienna feel afraid.

Attempting to understand their young adults’ vulnerability and the severity of the C19 risk was difficult in and of itself for Rosie and Olivia, not in the least because they had no prior similar experience to reference like everyone else [‘We've never been through anything quite like that’ (Rosie, p. 17)]; but because governmental advice for adults with Down Syndrome was changeable, due to newly-emerging research:

‘sometimes it wasn't clear advice…It was a little bit…changeable…you think…why has that suddenly changed?’ (Rosie, p. 17).

Rosie is referring to the change in status of young adults with Down Syndrome, from clinically vulnerable to clinically extremely vulnerable, which prompted the decision to move Oscar into his grandparents’. Olivia was aware of Sienna’s clinical status as an adult with Down Syndrome, but thought the advice more so applied to adults with Down Syndrome who have additional health risks, such as age/weight; therefore, she felt a level of calm for Sienna, as long as she stayed fit/healthy. However, she later became aware of research which suggested a genetic element implicated in the elevated risk, which ‘shocked’ her (Olivia, p. 17). It was likely even more difficult for the mothers to navigate for their young adults, when the advice was not definitive and the reason behind adults with Down Syndrome being at a greater risk still relatively not understood by those they were relying on for guidance.

Making sense of their young adults' clinical vulnerability and therefore the safeguarding measures they should take was compounded for Rosie and Olivia through encountering evidence which seemingly contradicted their young adults' status. Oscar and Sienna each contracted C19 once; Oscar seemed to have strong immunity since he did not catch it when living in the family home, when his parents caught it several times. When Oscar eventually caught it, his parents had suffered with it 'worse than him' (Rosie, p. 15) and they then caught it off him, even though he had not caught it off them and this would be yet another time they contracted it. Similarly, for Sienna, C19 infection 'wasn't a picnic…but…she was fine' (Olivia, p. 16). Olivia compares it to a chest infection Sienna had that same year, which was 'worse' (p. 16). What the mothers experienced here with their young adults did not align with the advice/guidance, and the general ambiance of unease during the C19P, which likely caused them dissonance. Rosie conveys her bewilderment and apparent disbelief in the guidance:

'trying to make sense of it all in your own head…he'd come back from Bulgaria…on the 21st of March…and then we went into lockdown on the 23rd. Well, it was just so close, and yet he'd been in the middle of a busy airport and not caught it' (Rosie, p. 17).

How can one see logic in the above, given the tight timeframes, and the context Oscar had been in, which differed starkly from the lockdown bubble, and could have feasibly been a breeding ground for infection? Rosie struggles to make sense of it, and it seems this caused her significant dissonance given her and her husband's safeguarding decision to move Oscar out of the family home, as explored in the next sub-theme.

It was a feat to make sense of/explain to their young adults, yet Olivia and Rosie also convey the need to strike a balance when contemplating how to move forward. Both mothers seem resilient and realistically optimistic in their mindsets, foreseeing a future where C19 is not an all-encompassing phenomenon, but something they learn to live with, like other illness risks:

‘I think we're looking ahead…I'm hoping sort of Covid’s gonna be a bit more like flu…peaks and then goes’ (Rosie, pp. 7-8).

‘resigned to the fact, well, you're never gonna be able to avoid it; can't never go out…it was a case of just trying to keep as fit as possible’ (Olivia, p. 17).

This resoluteness implies that the mothers concluded that C19 may present a risk to their young adults, but not a risk so great that it accrues the power to significantly restrict/alter their lifestyles, for an ever-lasting period.

The mothers commend and seek to inspire similar resilience in how their young adults approach life. Olivia is pleased by Sienna’s bravery:

‘I don't think she was ever terrified of it, which is a really good thing, isn't it?’ (Olivia, p. 16).

It appears Olivia seeks recognition with her ending question; recognition that, despite Sienna understanding the risk, she carried on with life, not becoming too fearful. Rosie describes adopting a transparent approach with Oscar:

‘I…try not to hide…things from him because he's got to learn to cope in difficult situations cause you never know what's round the corner, do you?’ (Rosie, p. 18).

Whilst there seems to be a confidence in their resilience, the small questions at the end of Olivia’s and Rosie’s utterances appear to seek clarification/validation. Perhaps even if they do believe in this approach, there is still a hesitancy since they likely continuously contemplate whether they are doing the right thing for their young adults as their mothers, such that the balance is ever a precarious one to strike.

The impossible decision

Questioning whether one is doing the right thing very much applies to Rosie's mental turmoil regarding the safeguarding decision to move Oscar out of the family home and into his grandparents'. This decision was borne from his parents going to/from work, Oscar's clinical status becoming 'extremely vulnerable' due to him having Down Syndrome but also considering his heart condition, and an unpicking of the guidance that led his parents to believe it was safer for Oscar to live at his grandparents' until he had been vaccinated. Rosie repeatedly summarises this decision and the resulting conditions as 'really hard' (p. 3; p. 5; p. 6; p. 16; p. 17). She and her husband were trying to keep Oscar as safe as possible, given the severity of risk portrayed by the advice and the general ambiance of the C19P. However, Rosie questioned their decision, and experienced much dissonance:

'you do feel guilty as if…or sort of you have mixed feelings about whether you're doing the right thing' (Rosie, p. 17).

Rosie's 'mixed feelings' seemed to arise from several factors, including questions she had around Oscar's vulnerability and hence the justifiability of their decision; the fact that he wanted to come home; concerns regarding deterioration in his physical health due to his contrastingly-sendentary lifestyle at his grandparents' compared to his usual life pre-C19P, and his altered diet. Regarding the latter, Rosie expresses the irony of it all:

'he became less healthy from being…isolated [laughs]' (Rosie, p. 5).

It seems all she can do is laugh here to cope with the fact that, in a 'catch-22' way, Oscar's physical health took a dip when isolated; the very thing this manoeuvre was designed to safeguard.

Perhaps the most significant impact of the move, which caused Rosie much strife, was the seemingly profound negative effect on Oscar's mental health/wellbeing. Rosie conjures poignant imagery in her description of visiting Oscar at his grandparents':

‘We used to go over there and stand outside sort of at a distance. And I remember sort of him looking as if he was gonna cry. And he’d never, he was never like that. And I thought oh he looks quite low and depress-, almost depressed…I thought oh he doesn't look, he's unhappy really, he was’ (Rosie, p. 3).

The breaking up of Rosie’s speech conveys the strength of feeling in her recounting of this experience. Her physical distance seems to segway into a metaphorical distance; her powerlessness in this situation. Her son appeared to be in a dark, hopeless place, which seemed even more concerning in its contrast to his everyday countenance, and it appearing to be the case that he had not experienced such a mental state before:

‘it's the first time I've been really worried about him…mentally…he's always really happy and sort of gets on with life and quite laid back’ (Rosie, p. 3).

Yet Rosie was powerless to effect change, in upholding the decision to prioritise his clinical health. As a parent, not being able to make it better for your offspring, even if they are a young adult, this was likely an unbearable position for Rosie, and an aversive responsibility to own. This appears to be the case when Rosie seems to compartmentalise the decision through absolving her and her husband of knowledge/understanding [‘we’re not experts’ (p. 5)], and instead appealing to ‘the experts’ (p. 5); the description she attributes to those supplying advice/guidance. She depicts it as ‘passing the book [laughs]’ (p. 17). This metaphor almost conveys Rosie physically relieving herself of the burden. The laugh seems to minimise the gravitas of emotion here, perhaps to also conceal Rosie’s discomfort in not feeling strong enough to carry the mantle. However, despite her attempts to mentally justify and place responsibility on another, Rosie and her husband ultimately had to make the decision, and thus struck a balance, even if that balance did not seem right as they lived through it and Rosie looks back on it. This is implied by Rosie’s definitive utterance:

‘we can’t we can’t stop everything again’ (Rosie, p. 22).

After their experience, something similar cannot happen again in Rosie's mind. She is referring to the halting of activities during the C19P, but the sentiment also seems to apply to their safeguarding decision. Rosie does not outwardly express that she regretted this decision, however, perhaps conscious regret would be too much to bear and permit the guilt she felt to overflow. What this utterance suggests is that Rosie really could not do it again; the impossibility of the decision a second time around could not be overcome.

To nudge or not to nudge? Or somewhere in between…

Ruby and Olivia needed to strike a balance when helping Alfie and Sienna adapt to life post-C19P. For Alfie, it was coaxing him out and about again without becoming too distressed, and assisting him when re-learning his coping mechanisms for the busy/unpredictable sensory/social world, following his retreat into his comfort zone during lockdown. For Sienna, it was gently loosening ties to her routines; strong in their influence following the lifeline they provided during lockdown. In both cases, a push at the deep end or even just moving too quickly could have been catastrophic. Rather, efforts had to be deliberate, gradual, patient and sustained, and seemed to be endeavours shared by the family units as whole, which Ruby aptly characterises as 'hard work' (p. 11). She summarises the task of nudging Alfie out and about:

'So how was the best way of doing it so that we weren't too stressed out, he wasn't too stressed out, but that we were pushing him back into society kind of thing and getting him used to doing that' (Ruby, p. 11).

This appeared to be an expert balance, which required much mental investment/preparation on Ruby's part:

'I'm already three steps ahead of, all the time, of what might happen' (Ruby, p. 11).

The approach necessitated fine attunement to Alfie's thoughts, feelings/needs, which the family are accustomed to, however, during this period they were on 'higher alert' (Ruby, p. 10), perhaps ironically, just like Alfie. Thus, the balance was two-fold: encouraging Alfie's progress, his ability to cope with/his resilience in the external world, whilst ensuring this did not become too 'anxiety-inducing' for him (Ruby, p. 11), after experiencing the quiet ease of lockdown; and the balance for the family, which is borne from the mental/physical taxation when attempting to strike the former balance for Alfie; something that is 'stressy' for themselves (Ruby, p. 11). Ruby transparently admits: 'I could stay at home' (p. 11) with the insinuation that this would be easier. However, she/the family are strong in their resolve, where she recognises that to stay at home is 'not helping him' (p. 11). Moreover, she depicts their 'tag teaming' (pp. 6-7) when helping Alfie to regulate out and about as 'not too bad' (p. 7), demonstrating their resilient mindsets and dedication towards striking that balance for Alfie.

Olivia reveals a change in how her/the family responded to Sienna's rigid routine-following. She admits that they previously opted for 'a quiet life' (p. 22), succumbing to the power of Sienna's adherence, for example, by just making her a small sandwich after she had already had brunch just so that she could 'tick…off' lunch (p. 22). Olivia's description of the distress experienced by Sienna when her routine fell apart in *GET 2: Routine* affords an air of understanding to this response; that is, the family tried to avoid Sienna becoming so vexed. However, similar to Ruby, Olivia recognises that what may be in Sienna's short-term interests could lead to her long-term downfall, through becoming so glued to her routines that this exerts a significant negative impact on her own/her family's lives. Hence, initially the family may have resignedly thought:

'it's ***Sienna***[4]*…what can you expect?' (Olivia, p. 22).*

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[4] Bold font here represents the participant's prosodic emphasis.

This appears to convey low expectations about Sienna's ability to dissociate herself from her routines; low expectations which are quite disparate from how Olivia otherwise depicts Sienna. Whereas this was the motif, the family shifted their mindset to believe that these low expectations and resultant actions were a 'disservice' (Olivia, p. 22) to Sienna's potential to change. Therefore, they changed their tack to rather 'empower…Sienna' (Olivia, p. 22), gently presenting ways to diverge from the routine which would make sense and be manageable, before enabling her to decide. Olivia is positive about this approach, and describes Sienna being more flexible at times, although, like Ruby/her family, they need to strike a precarious balance to know when to nudge Sienna and when to hold back. At times, it is better to hold back:

'if it's to the point where she's really upset…then that's it…we'll go with the flow' (Olivia, p. 22).

Olivia's metaphor offers an indication as to the efforts directed towards coaxing Sienna out of her routines; it is to go against the current, yet in creative ways where an off-stream outlet is carefully manufactured, and the river lightly drawn to another direction. To let the river flow as it is would be the easiest option, but a long-term unkindness in foreseeing the limited destination [where Sienna remains 'all about the routine' (Olivia, p. 21)]. To place a jarring barrier which completely halts the flow would lead to a build-up of pressure (and thus, overwhelming distress for Sienna). To offer the alternative off-stream outlet enables Sienna to decide and gradually become more flexible, which is the balance her family attempted to strike with their persistent/dedicated efforts.

Discussion

Please see Table 7 for theme summaries. Discussion of each theme is presented following this, highlighting practice/research relevance.

Table 7: Theme summaries

GET 1: Autonomy – a kaleidoscope of forms

Perhaps C19P-related conditions both facilitated and hindered development of the young adults' autonomy. It was facilitated in the sense of opening up the virtual world where Sienna and Alfie could be more independent when participating in activities, and for them to have something that was their own, separate from family life. On the other hand, they all faced boundaries that restricted their lives, which appeared to be especially upsetting/difficult for Sienna and Oscar; it snatched away so much that was *theirs* and theirs *alone*. Perhaps not to the same extent, Alfie also missed his usual activities even if they could be challenging, as implied by his renewed appreciation post-C19P. The limiting C19P-conditions which diminished their worlds conflicted with Sienna's/Oscar's emerging self-directive mindsets and eagerness to fly the nest, and additionally clashed against Alfie's family's efforts to encourage next steps on the tailored journey towards developing his autonomy. Related to this clash, Alfie and Oscar were subject to significant safeguarding decisions, which rendered an increased dependence on behalf of Alfie upon his family; a dependence perceived as a regression, and placed Oscar in a passive position, where the loss of agency/challenge seemed to exert a negative impact on his mental health.

GET 2 – Routine: a multi-edged sword

Routine can be defined as 'a usual or fixed way of doing things' (Cambridge Dictionary, 2024). From interpreting the mothers' accounts of their young adults' experiences during and following the C19P, one would need much more than this simple definition to understand what a routine can mean; how it can, on one hand, facilitate/offer, but on the other, ensnare/limit. Having a routine seems important for the young adults; for reasons including enabling learning, ability to cope with, make sense of, and developing a sense of self-directedness in their lives. Sienna/Alfie had alternative/compensatory routines during the C19P which seemed to serve a protective function, enabling them to cope relatively well during lockdown. They provided meaning, purpose, a sense of control, and a stable structure in an unprecedented/confusing time. However, concerning other sides of the sword, routines could be limiting or exert negative effects when they drummed a sense of mundanity into Oscar's life, offered a reassuring retreat for Alfie into his comfort zone, or else, became a strict agenda from which Sienna could not diverge, where the effects of the latter two only really became apparent in the long-term, adapting to post-C19P life.

GET 3: Parents striking a precarious balance

Parenting the young adults during and following the C19P seemed to involve multiple and complex balancing acts that required much mental/physical investment, and seemed quite exhausting. Rosie and Olivia struggled with the feat of explaining C19 to Oscar and

Sienna, and their serious clinical vulnerability, whilst safeguarding them from becoming very afeared. This, whilst trying to make sense of it in their own minds in the face of changeable conditions/advice, and seemingly contradictory evidence regarding their young adults' vulnerability. Additionally, the C19P-related conditions somewhat conflicted with their own stoic mindsets, focused on getting on with life. Rosie battled mentally and emotionally with her and her husband's safeguarding decision to move Oscar out of the family home. Finally, but not exhaustively, Ruby and Olivia walked a tightrope when helping Alfie and Sienna adapt to post-C19P life. Ruby/her family assisted Alfie to develop his resilience such that he could cope again in the external world, and Olivia/her family coaxed Sienna's flexibility and ability to let go of/modify her routines. Both parents/families worked on these endeavours whilst trying to ensure neither young adult became too distressed, nor the families too stressed, yet retaining focus on Alfie's/Sienna's long-term growth and fulfilment as young adults.

Autonomy – a kaleidoscope of forms

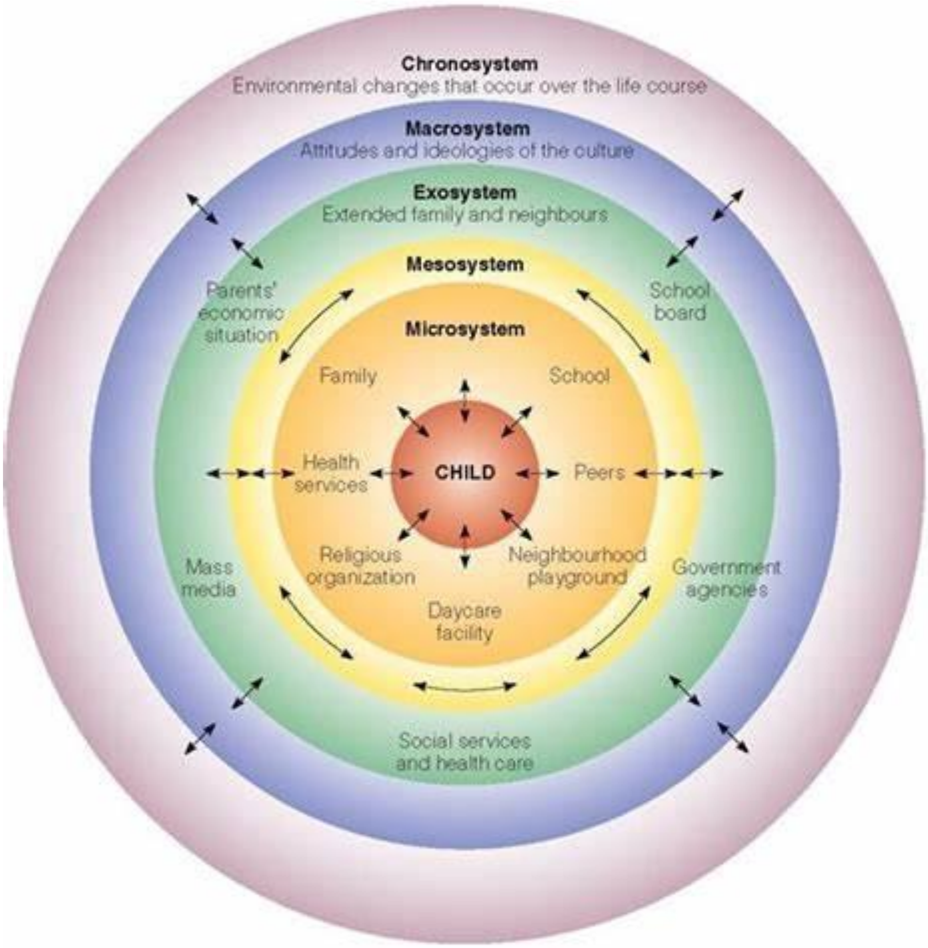
Life during the C19P opened up a kaleidoscope of forms for what autonomy could mean and how it could manifest for the young adults. The construct applied to possession of/engagement in one's own activities/routine where one can experience enjoyment, challenge, and growth, as separate from family life; a mindset shift; and emergence of a perhaps unconventional configuration in the virtual realm; as well as the more traditional conception of the roles relating to self-directedness or contrastingly being subject to/dependent upon the directives of others. This coheres with the first theme of the LR in *Section One (Part One)*, which offers a more holistic, nuanced understanding of TIA for young adults with Down Syndrome, bringing into question the outcome-based outlook which seems to solely focus on practical independence (like employment/independent living) in a rather reductionist manner. As suggested by the LR, autonomy seemed to relate closely to the PERMA model (Seligman, 2011), e.g., *engaging* in one's own activities in one's own space with one's own peers, indicating the importance of certain *relationships* (whether this be in-person or online); encountering/overcoming personal challenges, thus experiencing growth/*accomplishment*; experiencing *enjoyment* in and gaining *meaning* from those things.

Thinking about TIA for young adults with Down Syndrome in relation to the PERMA model appears to capture the phenomenon more holistically. Moreover, these findings imply that the construct of autonomy may permeate these elements. Seligman (2018) notes that researchers have identified many more potential candidate contributors to wellbeing than the five he expounds, for example, the sense of responsibility one assumes in their life could be considered which links to autonomy and Docherty and Reid (2009)'s conception of mindset shifts. However, the five elements Seligman (2011) settled upon he argues to be distinct elements, yet related, e.g., someone who finds flow/engagement in their career is likely to also experience accomplishment in this realm; and strongly correlated to a comprehensive independent measure of subjective wellbeing [as reported by Goodman et al. (2017; in Seligman, 2018)]. Moreover, the PERMA model offers a parsimonious theory of wellbeing, and it can be applied pragmatically, focusing on each aspect to promote happiness/wellbeing (Seligman, 2018).

This researcher does not have theoretical/empirical justification to suggest that the PERMA model be augmented by autonomy. However, practitioners in post-18/young adulthood sectors should consider the importance of developing autonomy for young adults with Down Syndrome, whether this is driven by them or their parents/families initially, and the different forms in which it can manifest, tailoring activities and progression to individuals [similar to tailoring the meaning of independence as proposed by Hartman et al. (2000)]. Within this, it is paramount to practice in an authentic person-centred way, eliciting the voices of young adults with Down Syndrome to contemplate what autonomy and a fulfilled adult life would look like to them.

To a significant extent, the C19P clashed with the developing autonomy of the young adults. Framing this in the context of Bronfenbrenner's Ecological Systems Theory (1977) (please see Figure 2 for an annotated visual representation in relation to this study), just as the young adults were preparing to fly the familial microsystemic nest, or had seemingly already flown it in some ways (regarding following their own routines/engaging in their own activities, separate from family life; the more self-directed roles they had assumed; and their emerging mindset shifts), they were encased in a chronosystemic/macrosystemic cage. The latter part of the metaphor is in relation to the environmental and legislative C19P-related conditions, constricting/diminishing the scope, freedom, opportunity, challenge, and self-directedness in their lives as young adults. Bronfenbrenner and Morris (2006) developed the original systemic theory, offering the Person Process Context Time (PPCT) model. The metaphor outlined above could also be framed within the context of the PPCT model. Considering this author’s understanding of the theorists’ depiction of ‘process’ outlined elsewhere, that is: ‘CYP engage in complex, reciprocal interactions with others/artefacts within systemic contexts as they develop’ (Davies, 2023, p. 220), one could appreciate how time and/or environmental related or chronosystemic changes such as those brought about by the C19P perhaps hindered, constrained or even prevented processes in which the young adults would have ordinarily engaged as they transitioned. This appears to be implied in the sub-themes: The *C19P snatched what was theirs and theirs alone*; *Active agency to passive recipiency*; and *Dissonance: readiness to fly the nest, yet forced to stay within it*.

Figure 2: Visual representation of Bronfenbrenner's Ecological Systems Theory (1977), offered with definitions of each system, and applied to the young adults with Down Syndrome



- There are bidirectional influences/effects across the systems, illustrated in the diagram as double-headed arrows.
- The *person* or young adult with Down Syndrome concerned is at the centre, with their own individual characteristics such as age, gender, personality attributes. These come into play in interactions with / processes between systems. For example, the young adults' ages placing them in the TIA phase of their lives; their various personalities determining their engagement in family/community life; and their interactions with, and affecting, people in the microsystems around them such as their parents and friends, as well as being affected by them.
- The *microsystem* entails systems that come into direct contact with the young adult, such as family, school, peers, neighbours, people in community/social groups. For example, the young adults' parents/families; school/college for Alfie and Sienna; colleagues/customers in Oscar's workplace; peers in various social/leisure activities in the community.
- The *mesosystem* comprises interactions between microsystems, e.g., conversations between Oscar's parents and employer.
- The *exosystem* refers to systems that indirectly influence and are indirectly influenced by the young adult, resulting from direct interactions with their

microsystems, e.g., the parents' workplaces; parents interacting with medical professionals regarding their young adults.
- The *macrosystem* concerns the prevailing cultural and legislative context. The C19P led to a significant governmental response which imposed significant alterations such that life appeared quite different from the young adults' and their parents' ordinary lives.
- The *chronosystem* refers to environmental changes over time. For example, the emergence of the C19P.

The emphasis during the C19P, particularly for those classed as clinically extremely vulnerable like young adults with Down Syndrome, was medical safeguarding. This is understandable, especially given the unprecedentedness/scale of the C19 threat. Notwithstanding the risk, this study highlights the importance of contexts and processes for developing/practicing autonomy for young adults with Down Syndrome. Where substantial safeguarding measures are to be enforced/advised again, relevant practitioners should work to promote the development of autonomy via alternative creative ways, working collaboratively with parents/families and young adults with Down Syndrome themselves. Navarro and Tudge (2022) propose an adaptation to Bronfenbrenner's (1977) original theory, recognising that contemporary development comprises processes/interactions with various systems through physical and virtual means. Therefore, practitioners could exploit the virtual realm as another platform to explore the development of autonomy, in addition to in-person contexts, which could also aid parents concerning the reduced dependence on them to travel to/from such activities. This is not to say the virtual realm is a replacement, but a further avenue to explore, as seemed to benefit Sienna and Alfie. Future research specifically exploring the meaning/experience of autonomy for young adults with Down Syndrome could develop societal understanding of this construct, and create avenues to traverse with the young adults in practice.

Routine – a multi-edged sword

The name of this theme originated from contemplation of how routines can simultaneously offer/take away; facilitate/limit growth; and bolster resilience/become an all-encompassing ritual a person must do; hence a double-edged sword manifesting uniquely for the young adults.

Having a daily routine is predominantly considered in a positive light, promoting good mental health (e.g., charities like Mind, 2018); and it was elevated as a resiliency buffer against C19P-related conditions, where the World Health Organisation (2020) recommended forming and sticking to engaging/healthy routines. It seems routines were instrumental to the young adults, facilitating learning, ability to cope, enjoyment, relationships and developing autonomy in life. Creation of new routines during the C19P and adhering to these appeared to help Sienna and Alfie through it. These findings are aligned to prevailing thinking around routines. However, this study also reveals perhaps lesser-recognised darker sides to routines, or at least how one may approach them. For example, passive apathy that can arise when it is not one's own routine and the activities are not matched to their age/interests; the difficulties associated with adapting to a prior, more challenging routine, when one has undergone a prolonged period following a comfortable yet potentially regressive routine; and the challenge of letting go of a routine that seemed to act as a lifeline, when that has become how one makes sense of the world and their life.

This researcher is not denying the importance of routines, and their potential to bolster resilience/promote wellbeing, especially during strange periods like the C19P. However, their specific suitability to young adults with Down Syndrome, given a holistic PERMA-based outlook (e.g., enjoyment, engagement, potential to develop relationships, meaning to the young adults, and opportunity for challenge/progression), as well as consideration of their long-term impact, should be factored into practitioners' guidance. Flexibility around routines should be equally promoted, as a quality to practice/develop, for the benefit of young adults and those around them. Where routines can become a mundane schedule, a limiting comfort zone, or preoccupation with them become a strict adherence, relevant practitioners could consider the use of therapeutic approaches to inspire colour/variety, gentle challenge, and coax flexibility, empowering/supporting young adults with Down Syndrome and those around them to work towards positive change. Any such approach would need to be tailored to the needs/interests of specific young adults. Moreover, practitioners generally should be mindful of the possible temptation to jump onto routines as a mental health protective factor. As with most things in life, routine as something generic or afforded too much weight could be unhelpful, or even detrimental, especially in the long-term. Rather, practitioners should aid young adults with Down Syndrome and their parents/families, regarding creation of tailored, adaptable and flexible routines, capturing lighter sides of the sword, whilst guarding against potential pitfalls.

Parents striking a precarious balance

As demonstrated by the LR in *Section One (Part One)*, the parents in this study commit substantial mental/emotional/physical investment into their young adults, in varying ways. It is probable that this theme only captures a fraction of this. What was salient for these parents, was the balances they attempted to strike. These related to Rosie/Olivia explaining Oscar's/Sienna's vulnerability to them, and the necessity of safeguarding measures, whilst ensuring they did not become too scared, within a confusing/changeable landscape for themselves; Rosie/Oscar's father making a 'catch-22' decision to safeguard Oscar by moving him out, yet battling with the mental/emotional turmoil of bearing witness to his mental state; and Ruby/Olivia nudging Alfie's/Sienna's progression post-C19P, walking a tightrope between promoting their growth/resilience and ensuring they could cope with each nudge, whilst making this endeavour manageable for the parents/families. This theme coheres with, and perhaps provides further insight regarding, findings of studies discussed in the LR [*Section One (Part One)*], particularly pertaining to the exploration of parents experiencing mixed feelings/positionings.

Despite the three parents seeming to stay abreast with, and utilise, the guidance, it seems they/family members took on a heavy mantle, striking these precarious balances for their young adults, with little input from wider systems, especially in Oscar's case, who had left education. Sienna and Alfie benefitted from use of the virtual realm for adaptation of activities or discovery of new ones, hence receiving input from social/community groups in addition to more formal systemic provisions like college. However, parents/families appeared to be primarily alone in striking balances for their young adults. Returning to the linchpin metaphor in *Section One (Part One)* (Timmons et al., 2004; in Dyke et al., 2013), was this perhaps too much pressure, during/following the C19P, in the absence of adequate reinforcement? There is an element of the parents stoically carrying on, but their sense-making of these experiences and their associated thoughts/feelings would indicate an unacceptable load for anyone to bear.

Regarding implications, one should consider not only the explanations parents mastered nor decisions they made during the C19P, but the precarious, arduous balances they tend to strike generally as their young adults with Down Syndrome TIA, such as finding that optimal nudge/being both gatekeepers and facilitators (Docherty & Reid, 2009). Parents should be offered professional support in this realm beyond school, not only with provision of information about different options/respite provision, but timely, regular, and practical input/check-ins, with the additional proffer of compassionate support, such as in the form of active listening/provision of parent support groups. As illustrated in the LR in *Section One (Part One)*, the formation of positive, collaborative relationships; effective preparation/coordination; and getting to know young adults, their parents/families, is key to this support. This input necessitates commitment of professional time/effort, and developing current ways of working, which is recognisably difficult given systemic constraints like funding/recruitment/availability of contexts. However, promotion of the positive development of young adults with ALN, with a specific focus on TIA, is written into the ALN and SEND codes; thus, it is a legislative duty for practitioners in the post-18/young adulthood sectors. Professionals may need to strike various balances in their roles, but it is apt that they share this responsibility, rather than parents being over-burdened.

Considerations/implications for educational psychologists

Please see Table 8 for considerations/implications for EPs across different realms of the role.

Table 8: Considerations/implications for educational psychologists	
Eliciting voice – What is autonomy? *Ideas from personal construct psychology*	EPs could adopt a personal construct psychology approach (Kelly, 1995; in Burr, 2015) to explore the meaning/s of autonomy to young adults with Down Syndrome and their parents/carers, evoking their constructions; contemplating possible manifestations [for example, considering the sub-themes such as role, having one's own life separate from family life, mindset shifts, different contexts (e.g., the virtual realm)]; and opening up a creative space to explore how they might wish to develop/practice this quality. Originating from a SC lens, EPs could facilitate transparent, yet safe discussions between young adults with Down Syndrome, their parents/carers and practitioners, working to arrive at co-constructions which could inform next steps, with which the young adult and each stakeholder are satisfied, and there is a clear thread depicting the voice of the young adult, in line with person-centred practice. The above involvement could be in the context of several EP-facilitated sessions, where the EP perhaps meets individually with the young adult, their parent/carer, and relevant practitioners; before conducting a joint consultation. Alternatively, the EP could meet with the three parties from the outset, deeming it a useful exercise for each to observe the active sense-making of the others, e.g., observing how the young adult approaches the discussion may lead to further insights. Exploration of the autonomy construct could be facilitated in the context of person-centred planning / review meetings too. Helpful tools could include the Salmon Line (Salmon, 1998; in Beaver, 2011), where a sense of the meaning/s of autonomy emerges through elicitation of the construct's opposite, as conceived by the person being asked. The person is encouraged to envision a scale between the two, placing themselves and significant others in their life on it, contemplating any desired change, the direction of said change, and what/who could help facilitate that change. It is a solution-focused technique which also utilises ideas from how similar change has been achieved previously, to consider what could be applied to the present situation. The Ideal Self (Moran, 2001) could also be a helpful tool; an activity which would encourage the young adult to envision the person they would be and what life would look like from different aspects, in non-ideal and ideal scenarios, with usually a scaling between, to formulate ideas to facilitate change. These are engaging, visual activities which aid exploration of CYP's constructs

	and elicitation of their voice. EPs could use their well-suited skillset to sensitively adapt such tools to the learning needs/preferences of the young adults. What might be additionally helpful in this arena could be if EPs were to develop a new tool, closely based upon another currently widely used within the EP community. Inspired by personal construct psychology principles, Timney and Cohman (2020) offer the Children's Exploratory Drawings (CEDs), and indicate an intention to develop a similar resource for the post-16 age range. Perhaps such a resource could be developed for young adults with ALN who are 18-25yo, specifically considering TIA, and life as a young adult. The CEDs are pictorial stimuli representing different school-based contexts CYP may encounter; the characters are presented as stick figures, inviting CYP to impose their own interpretation/story (Timney & Cohman, 2020). The aim is to elicit the voices of CYP and how/what they think about school, in a creative/engaging way aimed at inspiring their contributions. Perhaps a comprehensive review of literature on TIA for young adults with ALN, including those with Down Syndrome, could be conducted, building upon the integrative review offered in this paper. Themes derived from this secondary research, as well as further primary research with young adults themselves and those closest to them, along with practitioners, holistically investigating salient aspects in transition, possible contexts, and future goals/ambitions, could lead to the development of a CEDs-style resource for young adults with ALN; used in preparation for/during their TIA. Stimuli could depict scenarios around family life, educational/occupational options, social/leisure life, relationships, online activities, daily living, and dreams/goals; where this list is suggestive, not exhaustive, as the stimuli would be determined by research findings. Conversations between the EP and young adult around these (where the EP utilises their rapport-building and investigative skills), could be a creative way to elicit the young adult's voice, which EPs could then share with parents/carers and relevant practitioners. This could help to tailor any transition plans / input going forward, where tailored, person-centred plans/opportunities were identified as possible facilitators of the transition process in the LR [*Section One (Part One)*]. Interwoven in the above approaches could be consideration of what development and progress towards goals could look like under widespread/substantial environmental change; for example, if something like the C19P were to happen again. It may be an idea to consider possible contingency plans (such as adaptation to the virtual realm, or roles young adults could assume within their family set-ups in lockdown-style scenarios), or at least for relevant practitioners to agree to formally revisit plans, should such circumstances arise.
Coordinating systems *Multi-agency working with a focus on holistic development*	EPs transcend systems around CYP (WG, 2016). They are therefore well-positioned to research/learn about the current roles/involvement of each pertaining to young adults with Down Syndrome (i.e., practitioners in the post-18 and young adulthood sectors), for example, education (in the context of further education and preparing for transition from school/college); social services (community participation, social/leisure activities, and opportunities for work/volunteering); housing (considering living arrangements); third-sector organisations who can provide many and varied services/provisions to the young adults and their parents/families. From a SC lens, knowledge is specific to sociocultural and historical contexts (Burr, 2015) so the above is likely to be specific to the local area in which an EP practices.

	Forging connections across systems may be the first port of call. This stage should not be omitted/rushed as practitioners getting to know and understand the roles of practitioners in other contexts is important for effective multi-agency working, as is the development of positive, proactive professional relationships. EPs could facilitate such introductory meeting spaces. The takeaways from the LR [*Section One (Part One)*] regarding systemic involvement include the development of positive relationships; a collaborative and person-centred ethos; and coordinated, timely input. EPs could share these insights with the relevant systems, as well as the finding relating to *Parents striking a precarious balance* from the present research, and work with them to contemplate how they are currently interacting with young adults and their parents/carers, and what may help to develop this such that support is well-coordinated and there is a shared understanding of respective roles. Activity Theory (Leadbetter et al., 2008) may be a helpful tool in this arena. This framework encourages explicit/thorough exploration of what may be going on in system/s relating to a specific activity/phenomenon, e.g., in this case, facilitating TIA for young adults with Down Syndrome, including relevant roles, division of responsibilities, characteristics of parties involved, and conditions/boundaries within which this is all happening. Use of this tool may elucidate who is involved, how they relate, and facilitatory/hampering processes which subsequently may encourage sharing the load of various balancing acts, providing practical and/or emotional support to parents/carers within this. As part of this coordination of roles/input, EPs could encourage relevant systems to consider additional balances parents may have to strike in contexts of widespread/substantial change like the C19P, and the balances that they already strike which may become more complicated during such changes. Practitioners should then consider possible alternative means to provide support (e.g., virtually), and adopt a collaborative approach with parents to explore what input/involvement would be most helpful to them and their young adults.
Training/consultation with practitioners *Ideas from positive psychology, Self-Determination Theory, and coping/resiliency*	EPs could play a role in training/consultation with practitioners working within post-18 / young adulthood sectors (including educational professionals but also other systems mentioned above) regarding preparation for and support during TIA for young adults with ALN, including young adults with Down Syndrome. Such training could inspire active contribution from practitioners to explore transition, really opening up the focus beyond measures of practical independence like employment/independent living (although whilst also considering these). EPs could adopt approaches such as Wagner (2000)'s approach to consultation, which is aimed at empowering stakeholders to come up with their own ideas, through use of curious questions, for example. This, in contrast to EPs telling other practitioners what to do. Where practitioners devise their own ideas, they are more likely to see a perceived utility in applying knowledge/skills/understanding gained to their practice; an aspect integral to implementation/transfer, according to Chidley and Stringer (2000). EPs may consider sharing theories to develop practitioner understanding such as the PERMA model (Seligman, 2011), encouraging practitioners to contemplate how each avenue could be explored with young adults and their parents, with consideration of coordination across systems as outlined in the above consideration/implication. Ryan and Deci (2000)'s Self-Determination Theory may also be helpful; within which autonomy is an element, alongside competence and relatedness. As explored in the *Discussion (Part Two)*, autonomy can be related to the PERMA model; so too can competence and relatedness, e.g., experiencing accomplishment may enhance feelings of competence, and sense of relatedness involves engagement in

	relationships. EPs are well-positioned to exploit and utilise links across theories to help practitioners think creatively and holistically about TIA. Moreover, EPs could consider offering training on the BASIC-Ph model of resiliency and coping; the elements are: Belief, Affect, Social, Imaginative, Cognitive, Physiological (Lahad, 2017). This may widen practitioners' focus on ways to promote resilience/wellbeing in young adults with Down Syndrome, where the BASIC-Ph model postulates six possible avenues, listed above. Considering the theme of *Routine – a multi-edged sword* interpreted from the mothers' experiences in this study (which could be conceptualised as a cognitive way of coping, through imposing and keeping to a daily structure), perhaps EPs could encourage practitioners to guide young adults with Down Syndrome and their parents/carers to use the BASIC-Ph model holistically and in a flexible manner. This, in the sense of utilising multiple avenues, and being wary of becoming too focused on any one outlet, aiding development of the young adults' understanding that a balanced approach is healthy. It is not just the content of transition discussions whereupon EPs can offer a useful lens, they can also offer guidance regarding how practitioners approach their work with young adults with Down Syndrome and their parents/families. The LR [*Section One (Part One)*] highlights the importance of collaboration, development of authentic relationships, and person-centeredness in the transition process for young adults with Down Syndrome and their parents/families. EPs could offer insights regarding building rapport and collaborative skills. They could also share solution-focused principles where, for example, young adults/their parents are encouraged to contemplate what has worked well in previous transitions, what they valued, and what could be developed, which could inform the TIA process; a suggestion from Park and Mortell (2020) who investigated the transition experiences of Autistic young adults.

Strengths and limitations

Please see Table 9 for the researcher's breakdown of the study's strengths/limitations. Please also see Appendix G for an illustration of how this study met Yardley (2000)'s criteria for trustworthy qualitative research, from this researcher's perspective.

Table 9: Strengths and limitations

Strengths	Limitations
Methodology/method: Adopting IPA principles (Smith et al., 2021) from research conception through to design, data collection and ultimately analysis, firstly enabled elicitation of mothers' in-depth experiences and sense-making of life during the C19P, for themselves and their young adults; and secondly, equipped and liberated the researcher to really immerse themselves in the data, contemplating the meaning that could be derived. This led to an interpretation which captured the richness/nuance of the experience, where the GETs unite the participants, yet manifest idiographically in each case. Choice of methodology/method is listed as a strength since the resultant offering seems more holistic and attributable to participants than what may be provided by quantitative questionnaire studies. This, in the sense of such studies usually measuring specific elements determined a priori by researchers, for example, reporting on levels of sedentary behaviour during the C19P (e.g., Amatori et al., 2022), or the percentage of parents who find themselves worrying about their young adults' TIA frequently/very often (e.g., Leonard et al., 2016). As argued in Table 3 of *Section One (Part One)*, qualitative studies have the potential to tell us more/delve deeper into the whys/hows. Moreover, use of IPA specifically justified a focus on the idiographic, where the experiences of the mothers and their sense-making could converge and diverge. Some of the qualitative studies reviewed in the LR in *Section One (Part One)* attempted to derive commonality, which perhaps lost something in terms of the particular, as explored in *Group Critique One*.	**Perspective:** Like the researcher's critique of most studies reviewed in *Section One* and *Section Two* of the LR *(Part One)*, the present study did not access the perspectives of young adults with Down Syndrome themselves. Originating from a SC epistemology, knowledge is perceived to go hand in hand with social action (Burr, 2015), hence one needs to consider what might be being done when the voices of young adults with Down Syndrome remain relatively silent in research conducted about them, which will most likely come to effect related societal narratives/perceptions, and practice. Considering the Social Model of Disability (Barnes, 2019), it is important that their voices come to affect the research field. Unfortunately, given the scope of this thesis, the researcher was not able to gain the voices of young adults with Down Syndrome (as reflected upon in *Part Three*). However, parents are key contributors to TIA, as indicated by the LR in *Section One (Part One)*. Their voices are also important given the Social Model of Disability (Barnes, 2019), as argued in *Section Three (Part One)*. There was hence strong rationale for eliciting and exploring their perspectives on TIA for their young adults during the C19P. Moreover, these findings perhaps provide a foundation for future research, where the themes interpreted could inform the conception/design of an empirical study exploring the perspectives/experiences of young adults with Down Syndrome themselves.

Temporal focus: This study holistically explored the experience of TIA during the C19P, and the long-term impact. This is a strength in considering TIA to be a prolonged process rather than an event, and from a position of wondering regarding the long-term effects of the pandemic, given that many of the studies reviewed in *Section Two (Part One)*, despite having longitudinal designs, only really investigated the immediate aftermath. Were the researcher to have only studied the short-term impact of the C19P on TIA for the young adults, certain nuances may not have been elicited and potentially whole themes may have not been generated, for example, considering how other sides of the routine sword only really became apparent in the long-term following the C19P for Sienna and Alfie. Moreover, the time between the end of C19P-related restrictions/regulations and the interviews most likely aided the process of the mothers' reflections and sense-making.	**Sample:** As befitting IPA, the researcher managed to recruit a fairly homogeneous sample for the purposes of exploring a particular experience (Smith et al., 2021). In fact, this sample was arguably too homogeneous: the three parents were all mothers who were Caucasian and had the same occupation (not shared here due to anonymity purposes). This critique does not originate from a positivist notion of representativeness/generalisation, but from a concern arising from the potential omission of certain voices. Returning to the thread of knowledge going hand in hand with social action (Burr, 2015), it is a limitation of this research and most of the studies reviewed in *Section One (Part One)* that the voices of fathers are not accessed. The researcher attempted to reach out widely during the recruitment stage, contacting many organisations, community/social groups, schools/colleges, and encouraged snowballing of the advertisement. They also created a video introducing themselves and the research, in an accessible and approachable way. However, with hindsight, the researcher would have thought more about the timing and method of recruitment. Recruitment primarily took place during school summer holidays; gatekeeper organisations may have had reduced staffing during this period and most likely had reduced contact with the target population of parents of young adults with Down Syndrome during this time. The researcher offered to attend groups/organised activities to introduce themselves and the research opportunity in person, however, perhaps they could have given more thought to what this could have looked like, providing a more transparent and detailed offer to gatekeepers. Moreover, if the researcher were to access parental perspectives again, they would emphasise in the study advertisement an eagerness to recruit both mothers and fathers.
Procedure: All three interviews were conducted online. The mothers covered a wide geographical area across Wales and England; all a significant distance from the researcher. Offering the option to administer interviews online enabled their participation in a convenient, accessible, and comfortable way (i.e., they were able to do the interviews in their homes). In fact, the	**Skillset as a research interviewer:** The researcher attempted to actively listen to mothers sharing their and their young adults' experiences, really trying to access their sense-making and their choice of foci, in upholding the IPA principle of recognising the participants as 'experts-by-experience' (Smith et al., 2021, p. 50). However, upon reflection, at times, the researcher may have used the interview schedule like a safety crutch,

researcher may not have been able to recruit any participants in the timeframe had the virtual mode not been an available option.	continuously returning to it in their mind. This is not to say it was not utilised flexibly according to a semi-structured, open-ended design. The researcher probed into the mothers' experiences, and did not ask all the questions on the schedule, if it was judged at the time that these were not relevant/salient, based on actively listening to the mothers' accounts. However, upon data analysis, the researcher feels at times during the interviews they could have probed further, or more often/for longer segments followed the mothers' foci, diverging more from the interview schedule to enhance fidelity to the process regarding inductive exploration, and IPA generally. Having said this, the researcher invited the mothers to make notes prior to their interview, with the prompt of a C19P timeline to help recollect their experiences (please see Appendix E.iv). The mothers seemed satisfied that they had shared what they deemed to be most salient for themselves and their young adults. On the note of the researcher's interviewing skills, these are likely to improve over time with further experience and reflection upon the process. As Smith et al. (2021) would propose, one can become an expert through experience. Nevertheless, given this was the researcher's first time using IPA, and only their second time interviewing participants using a qualitative methodology, they were flexible in their interviewing approach (and use of the schedule), and honed in on eliciting and following the mothers' foci, along with seeking elaboration to learn more about their and their young adults' experiences.
Contribution: As far as the researcher is aware, this study is unique in its combined focus/design, augmenting the research tapestry regarding TIA for young adults with Down Syndrome [to borrow Braun and Clarke (2022)'s metaphor]. The *Discussion* and Table 8 (considerations/implications for EPs) demonstrate its value in terms of developing understanding and ideas for practice.	

Conclusion

One parent characterised the C19P experience as ‘a mixed time really…’. This quotation entitles the research since it encapsulates an essence common to the three themes. The impact of the C19P on the young adults and their mothers as the former transitioned, and salient aspects that came to the fore, give rise to a particularly nuanced picture. This picture is not ‘black and white’ as strict lockdown life was to one of the young adults, nor ‘grey’ in the sense of vagueness/unknowns around TIA captured by the LR. Rather, from delving into the experiences shared, one can appreciate variety/colour, and the offer of multiple, interweaving avenues of exploration/insight, which the researcher tried to interpret and proffer to readers.

From a study unique in its combined focus/design, the themes of autonomy, routine and parents striking a balance are of researcher/practitioner relevance regarding provision, support, and the active promotion of positive development/wellbeing for young adults with Down Syndrome as they TIA, where specific implications for EPs are highlighted. It is hoped that insights gained from the mothers could inspire facilitation of inclusive practices for young adults with Down Syndrome as they transition, learning from a period of significant adaptation for society at large (i.e., the C19P), which could lessen any negative impacts of such significant changes in the future, or update practices with regards to the current worlds of young adults with Down Syndrome, their parents/carers and families.

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PART THREE: Critical Appraisal

Wordcount: 7825

Overview

My research explored the experience of TIA during the C19P for young adults with Down Syndrome, from their mothers' perspectives. The LR in *Section One (Part One)* illustrates TIA for young adults with Down Syndrome as a multi-faceted and prolonged process. Within the transition period, implicated factors interact and, whilst some elements seem to be common across young adults with Down Syndrome, it is ultimately a bespoke experience when viewed holistically. What is striking in the literature is the pivotal role played by parents in the transition; their practical/psychological investment, where stories of warmth, resilience, progress, accomplishment and hope emerge, but these come alongside tensions, a seemingly general dissatisfaction with wider systems, and a potentially concerning impact upon their own lives. Positively, from studies reviewed, young adults with Down Syndrome themselves perceive that they have good lives, with a sidenote of experiencing the flipside of the coin when it comes to some of the tensions emanating from the parental perspective. A thread uniting these strands is demonstration of the importance of opportunities outside of the family home; contexts/circumstances for young adults with Down Syndrome to develop and thrive as framed well by a PERMA perspective (Seligman, 2011); that is, for them to participate in and develop *relationships* external to the family microsystem, for them to *engage* in their interests within community settings, for them to find purpose/*meaning* in their adult lives beyond their familial role, and for them to experience personal growth/*accomplishment*, whether this be according to traditional adulthood outcomes like developing their practical independence through employment/living arrangements, and/or progressing in other domains, such as becoming more confident in a community leisure group.

As argued in *Section Three (Part One)*, integrating literature on TIA for young adults with Down Syndrome and the experience of the C19P for people with Down Syndrome generally, exposes a juxtaposition. One could argue that C19P-related conditions were incongruous with TIA for any individual, but I argued that this was particularly complex in the case of young adults with Down Syndrome, where there are many complexities inherent in their TIA generally, and they were identified as clinically extremely vulnerable; a status which brought about its own practical/psychological implications. Considering the heightened juxtaposition, I was curious: what did TIA for young adults with Down Syndrome look like during the C19P? Moreover, like TIA, the C19P was prolonged and multi-faceted. If the transition experience exerts enduring impacts on their life as a young adult, perhaps the C19P had its residual effects. Therefore, I was interested in any long-term impact since the C19P; an aspect currently under-explored in the literature.

This was an inductive study, where I attempted to elicit the mothers' experiences and their sense-making of those experiences, in the absence of a priori directions/hypotheses. Viewing the mothers as 'experts-by-experience' (Smith et al., 2021, p. 50), I wanted to evoke their phenomenology, remaining open to whatever this would be. Hence, I created a space and fostered conditions to encourage this to come forth through utilising individual open-ended, semi-structured interviews. I was concerned with the particular in each interview so there was no attempt to generalise a universal experience across mothers, in conceiving that such a nomothetic claim would not exist. IPA (Smith et al., 2021) aligned with all aspects of my project, from the philosophical foundations to my aim to explore experience, through to the manner in which I conducted the study. I did not need to mould my research to slot into the requirements for IPA; it was a natural fit. The interpretation I offered of the mothers' qualitative data, albeit with the attempt to bracket off from my significant personal influences (Smith et al., 2021), was ultimately a product of rich interaction between their perspectives and my sense-making; a process enhanced by my knowledge/skills as a researcher and a practitioner. This led to considered reflections about EP practice, from an authentic and transparent place. Adopting Braun and Clarke (2022)'s metaphor, my goal here was not to fill a gap, nor to claim an absolute truth, but to learn something, and to offer something insightful to readers; something that augments the research tapestry around TIA for young adults with Down Syndrome. Most importantly, my goals were to elicit and learn from the voices of one of the closest microsystems to young adults with Down Syndrome (their parents); to enhance practitioners' (including my own) and wider systemic understandings about what TIA could look like within a significantly-altered chronosystemic/macrosystemic context; and to offer valuable lessons were a significant change on this level to happen again, as well as generally regarding TIA for young adults with Down Syndrome.

Please note, this account is written from the first-person perspective to align with its reflexive ethos; that is, the activity of turning my reflective gaze onto myself as a researcher.

Bracketing off my inspiration

The idea of bracketing off originates from Husserl (1927; in Smith et al., 2021, p. 12) who proposes that to access/study the act of experiencing (or the conscious element of experiencing), one must become aware of their own taken-for-granted ways of perceiving and, in a metaphorical sense, put these aside to arrive at the essence of the experience itself. When applied in the context of IPA, one is attempting to become reflexively aware of their own fore-structures, and to put these aside to attain a level of 'experience close(ness)' to participants' data (Smith et al., 2021, p. 28), or, in other words, to draw out their phenomenology, rather than moulding this to fit into the researcher's own pre-conceived notions, or taken-for-granted ways of experiencing. According to CR, one can never fully set aside/bracket off their unique way of perceiving/experiencing, which will inevitably in some part imbue interpretation. However, within IPA, the researcher is encouraged to adopt a reflexive position; a transparency about their own influences, and how they themselves impact the research process. The aim is to remain mindful of what you as the researcher are bringing to the interpretation of participants' data and to, as much as possible, separate your 'stuff' from their 'stuff'. This was a continual reflective endeavour for me from creating the semi-structured interview schedule, to formulating in-the-moment questions in the interviews, and throughout the data analysis process. This is because I have a sister with Down Syndrome who TIA during the C19P.

I have my sister to thank for the seed of this research. During the C19P I was in the everyday mode of taken-for-granted experience. It was only in the months following the end of rules/regulations/restrictions and a gradual return to ‘normality’ for my parents and myself that I started to reflect on what life was like for my sister at that point post-C19P, what it was like at various points during it, and what it was like back when C19 did not exist. It hit me that she, like I, was in the TIA phase of her life at the start of the first lockdown (she was 23yo, and I was 22yo), yet our experiences were very different. Yes, our experiences would have most likely been pretty different had the C19P not happened, but there was something significant about the impact of the C19P.

I became curious about what it was like for other young adults with Down Syndrome to TIA during the C19P. I wanted to learn from their parents’ perspectives; on a personal level, enhancing my own and my parents’ knowledge/understanding and, on a societal level, to offer a piece of research that could be worthwhile to young adults with Down Syndrome and their parents/carers/families more widely, and to practitioners who may support them in their transition. This made sense as the topic for the biggest research project I will probably ever do in my life; an area about which I am fiercely passionate, and to which I am closely attached. It also made sense from a practitioner lens. EPs may work with young adults with Down Syndrome up to the age of 25yo, and/or with stakeholders/systems around them. Even if I never have this honour, it would be a privilege to inform the research tapestry upon which the involved EP may base their practice.

My goals above were all well and good, but I had to be reflexive throughout the research process to achieve them; that is, to elicit and inductively explore the experiences/perspectives of the mothers in my sample, rather than falling prey to the temptation to make sense of their young adults’ experiences within the context of my sister’s experience, and the mothers’ thoughts/feelings according to mine and my parents’.

Therefore, I carefully designed questions in my semi-structured interview schedule after consulting themes I interpreted from the literature, rather than basing these on what I thought to be salient aspects from my sister's transition. I could do this with relative ease with ample consideration time, however, this was harder to do on-the-fly in the actual interviews. I designed my study such that I could flexibly ask ad-hoc questions, to delve deeper into the mothers' experiences. Although, at times I found myself identifying parallels with my sister's experience, or sympathising perhaps too much with the mothers' perspectives, meaning that there was a risk that my own 'stuff' could get in the way of eliciting their 'stuff'. Therefore, despite not saying much myself in the interviews, which is usual for researchers in IPA (Smith et al., 2021), my mind was in a constant state of high alert, actively listening to the mothers, whilst appraising each question that came to me – would this question lead them down a certain path? Was I trying to find out something specific? Was I trying to draw out a feeling with which I identified? I mentally dismissed such questions, and really focused on what the mothers were saying and how they were saying it – what was significant for *them* and *their young adults with Down Syndrome* here? Did I need to find out more? Could I encourage them to make further sense out of *their* experiences? At points this could be a taxing process, especially when I heard something that resonated with me. However, from close analysis of the transcripts and my own utterances within them, I believe my on-the-go reflexivity enabled me to stay true to the principles of IPA, and to 'bracket off' my own 'stuff' during the data collection stage.

Concurring with IPA, one aim was to stay 'experience close' to the mothers' accounts (Smith et al., 2021, p. 28) throughout the data analysis process, such that my interpretation was steeped in their phenomenology. I adopted a thorough and gradual approach in my exploratory noting, highlighting anything that could be significant even if at a quick glance these aspects would not have stood out to me. I listened to the recordings several times, paying close attention to the mothers' voices and prosodical elements, retaining their sense of character and the characters of their young adults expressed through their utterances.

This assisted my focus on the idiographic (or the particular) element of IPA (Smith et al., 2021); they were each individuals in their own right despite the homogeneity uniting them, and commonalities with my sister. Following on from this, my experiential statements were derived from the exploratory notes and they were clustered and revised, involving much contemplation/consideration. This was to ensure that the PETs for each transcript, whilst set apart from their data in terms of the researcher interpretation offered, were fundamentally reflective of the mothers' experiences, and what came through as particularly salient for them when making sense of their young adults' TIA during the C19P. I mentally checked these against what I would imagine could be themes reflective of my sister's and my parents' experiences, and I could personally conclude from this exercise that I had not tried to interpret the data in light of my sister.

Additionally relating to the principles of reflexivity and bracketing off in IPA concerns the process of appraising my initial generation of GETs. Originally, I created a GET around resilience with sub-themes of 'mindset', 'being with', and 'adaptation to life post-C19P' (please see Appendix F). The first, 'mindset', arose from exploration of Sienna's optimism and stoic self-description, as well as Oscar's ability to close a door on the darkness of lockdown life, positively anticipating returning to his family home and his pre-C19P colourful routine. The second, 'being with', highlighted the importance of quality time and shared experiences with family/friends, as signified through its presence and absence and, where it was present, its acting as a protective factor. The third, 'adaptation to life post-C19P', detailed progression for all three young adults, in the sense of building their lives after the pandemic, whether this was resuming pre-C19P routines/activities, starting new activities/chapters, sustaining hobbies discovered during the lockdowns, or becoming more open to change even when this was challenging or caused dissonance. It was as I was writing up this third sub-theme that I questioned what the GET in its entirety was trying to say. Turning a critical lens upon myself, I admitted that the third sub-theme was purely descriptive, where the aim of the write-up here was almost trying to evidence resilience on behalf of the young adults. I then scrutinised the other two sub-themes, realising that optimistic/anticipatory mindsets were present in Sienna's and Oscar's experiences, as was the construct of 'being with' across the three young adults. However, the essence of each of these sub-themes was not necessarily about resilience; I had somewhat contrived this link to build up my GET. This could then warrant my evidencing the young adults getting through the C19P, emerging positively the other side and, even where there were residual effects, for example, the lasting hampering effect regarding Alfie's autonomy when out and about, and Sienna's still-present tenacious grip on her routines, demonstration of the young adults gradually progressing, developing their understanding/skills, and overcoming challenges.

Stepping back and contemplating my analysis in its entirety, and discussion in supervision, made me realise that I was trying to say something about the young adults here, to somehow prove a form of resilience. My sister may have permeated my thoughts subconsciously here where I have always defied any low expectations we encountered, and wanted to show people just what she could do. And I did think she was resilient during and following the C19P. However, whether the young adults whose mothers I interviewed were resilient or not (and my personal opinion is that they were), this was not for me to claim/prove. This was not the purpose of my research, nor would such a positivist notion cohere with my philosophical foundations. My role as researcher was to bring out the sense-making of the mothers, regarding their young adults' experiences and their own. That is, what was significantly resonating from the interviews within the framing of my RQs? This enabled me to further develop and collapse some themes such that I arrived at my three GETs: *Autonomy: a kaleidoscope of forms*; *Routine: a multi-edged sword*; and *Parents striking a precarious balance*.

Delving deeper into ontology and epistemology

Supervision really challenged the security and depth of my understanding regarding my philosophical foundations. A CR ontology [as depicted by Burr (2015) and Fletcher (2017)] combined with a SC epistemology [as depicted by Burr (2015)] makes sense to me; it is a paradigmatic approach I have adopted previously in research, and one I like to think I uphold in my practitioner role.

Regarding my practice, I believe that CYP, their parents/carers, relevant stakeholders, and I as the trainee educational psychologist (TEP) access a common reality of the situation in which I find myself involved, yet each perspective is unique. Despite the uniqueness of these perspectives, each has a socially-constructed nature. That is, each perspective consists of a unique set of constructions conceived by social processes/interactions, such that each person's knowledge/experiences are historically, culturally and socially-bound, and cannot be assumed/taken for granted. Moreover, knowledge goes hand in hand with social action, which is to say that knowledge and what is constructed between people, along with narratives that are created and the language we use, exert effects on people's lives. When I facilitate change as a TEP, I co-construct ways forward through interacting with CYP and/or those around them, and the subsequent interactions between them can bring about further change. From appraising the outcomes of my involvement (i.e., the changed common reality for the CYP and those around them upon which we all in some way converge), it is not possible to separate what we each did as one might disassemble a jigsaw. Rather, the input of each party is interwoven such that one could no more tease each influence apart than one could transform a cake back into its constituent ingredients.

I rather intuitively applied CR and SC to my thesis research, initially not giving sufficient thought as to their coherence with an IPA methodology, as I discovered in supervision where I was challenged to defend my positioning. My supervisor explained that a relativist ontology and a constructivist epistemology would be the archetypal approach to adopt when utilising IPA, as the focus is on participant's particular realities, their particular experiences, and on how they, as individuals, make sense of and hence construct those experiences. Within IPA, there is no attempt to discover a truth, or a singular reality common to all participants, nor to make nomothetic claims/generalise experiences. A commitment to how they, as individuals, construe their reality, and to the idiopathic nature of their experiences, is retained throughout such that their individual voices can resonate through the interpretation (Smith et al., 2021). There seems to be a philosophical coherence here yet, whilst I appreciate that such an approach could fit well with IPA, I make the case that, when reasoned and articulated properly, the approach I adopted is also coherent with IPA.

My supervisor encouraged me to read further into ontology/epistemology; a suggestion I admittedly found frustrating at first since I was anxious to 'get on with it' as it were. Nevertheless, I recognised that a reflective pause was necessary since my choice of ontology/epistemology would ultimately affect all aspects of the research. I needed to have coherence and, if I did already have an instinctive sense of that coherence, this needed deeper thought/clarification, as deserving a doctoral thesis, and a marker of good qualitative research (Yardley, 2000). I therefore read into SC [Crotty (1998)'s chapter], which developed my understanding, and enabled me to explain the coherence between SC as an epistemology, and an ontology that would not denounce realism (hence the fit with CR), as well as the nature of SC being compatible with the ethos of IPA. Moreover, I read Oxley (2016)'s defence of CR within the context of IPA.

I do not repeat the content from *Part Two* here, but I attempt to explain my reasoned and clarified coherence; that is, the coherence between SC and IPA; SC and CR; and CR and IPA.

Social Constructionism and Interpretative Phenomenological Analysis

According to Crotty (1998), SC is ultimately a meaning-making process; the product of which is knowledge which has social, cultural, and historical origins. Every creation of meaning necessitates interaction of some sort, and social processes are inherent within this. A surface-level understanding of the word ‘social’ may evoke an image of a person interacting with other people, and one may agree that social construct/s could be created in this type of interaction. What is potentially less overt is the socially-constructed nature of knowledge arising from interactions with artifacts/objects. For example, adopting Crotty (1998)’s example of a chair, what one knows of a chair is yes based on numerous physical perceptions of chairs, but their construct of a chair is also fed by language (the name ‘chair’ itself, or the translation in any other language), their communications with others which featured a chair, how they have seen others interact with chairs, what they may have read about chairs, etc. The chair construct is steeped in social processes. Even if a person has seen what we would know as a chair, their chair construct would not exist or else would be considerably altered if their language had no word for ‘chair’ and who, as such, has never referred to one in communication, nor seen someone interact with one in the way we would. One could argue here that a chair is an artificial object, manufactured by society for society. However, knowledge of natural phenomena is similarly socially-constructed. Again adopting Crotty’s (1998)’s example, one’s construct of a tree will be based on the language used to describe trees, including the name itself, how trees are viewed and treated by different social groups of which one is a member, e.g., one may be part of a community who consider trees to be integral to their home; one may be a resident of a tidy street where trees serve as a decorative boundary; one may be a conservationist, desperately trying to plant as many trees as possible to buffer the effects of climate change; or one may be a director of an infrastructure company who views trees as a nuisance in need of curbing. One’s tree construct is made up of previous interactions they have experienced within social contexts, and it can be shaped/changed by future interactions. Even an internal feeling within one's self; what one knows of this and how they make sense of it, e.g., words, images and meanings they attribute to it, are based on social processes/interactions experienced previously, and those they may be experiencing at the time, such that they can conclude that they are feeling sad, happy, angry, jealous; whether the trigger for this experienced emotion was another person or not. Moreover, they may re-interpret this emotional experience in light of future social interactions/processes. To summarise, from this perspective, knowledge is constructed through interaction, where there is an intrinsically social element to this interaction, whatever the context.

When someone has an experience, this must be of something, whether this 'something' is concrete, abstract, and/or a mixture. Like for the construction of meaning, the act of experiencing is necessarily an interaction between the person having the experience and the phenomenon/phenomena. That phenomenon/phenomena are perceived as meaningful to the person due to related social processes/interactions they have experienced previously (and therefore have knowledge of), and due to the social context within which this phenomenon has emerged. I argued that how mothers made sense of the experience of their young adults with Down Syndrome TIA during the C19P was based upon their prior socially-constructed ideas about this transition; e.g., their interactions with their own parents and peers/other systems when growing up; the interactions between themselves and their young adults thus far in their lives, as well as those with close, related systems; their interactions currently with their young adults as they transition; and all within the social context that was brought about by the C19P (ideas/meanings attributed to which again being steeped in social processes). Herein lies coherence between SC and IPA. Moreover, use of IPA requires fairly homogeneous samples, proposing that there is something significant about a specific phenomenology for this particular social group (Smith et al., 2021), which is compatible with the notion that knowledge/sense-making is historically, culturally and/or socially-bound. My mothers could all report on a specific type of experience relating to themselves being parents of young adults with Down Syndrome who were TIA during the C19P.

One could argue that constructivism might better match the idiographic commitment of IPA; the particularity of perspective, and the participant as an individual actively making sense of their experiences. I would agree that sense-making is particular and unique to each of my mothers, but, just as I proposed when discussing how I approach my practice earlier, the act of experiencing and making sense of experiences is still steeped in social processes/interactions. The phenomenology as a product is unique to each mother but it is constructed via social means. One may contend that constructions have social origins, but that the process of meaning-making involves individuals deriving something from objects directly, and that this is combined with social interpretations of those objects; as a social constructivist may propose (Kim, 2001). However, if direct meaning gained from the object alone is *combined* with social interpretation, this implies that they could be teased apart and the social aspect could be removed. Whereas, a social constructionist view would assert that the social aspect is necessarily integral to the creation of meaning (Kim, 2001). What meaning could one gain from a tree devoid of social constructions? It is hard to fathom that it would *mean* anything. Moreover, if any sort of direct meaning from the tree itself does exist, but it is always combined with social interpretation to become what one perceives/experiences, is not making claims about the ‘direct meaning’ element a redundant activity?

When considering my study, I argue that the mothers’ knowledge, and how they experienced their young adults TIA during the C19P, along with the sense they could make of those experiences, necessarily originated from their pre-existing social constructions and the social processes/interactions mentioned earlier. Even if there were any sort of direct meaning that could be gained by mothers from these phenomena, in my study they were reflecting upon and making sense of those experiences through language, in response to my questions and the interactions between us. Therefore, the data that were produced could not help but have a social element to their origins; the mere activity of interaction within the interview context would have created social constructs which interacted with my and their social constructs, and determined the product that came out of the interviews. The choice of social *constructionism* rather than social *constructivism* was deliberate – the 'social' cannot be taken out of the construct; it is embodied within the construct, or the construct is borne out of the 'social'.

Social Constructionism and Critical Realism

Thus, a SC epistemology concurs with an IPA methodology. What about my CR ontology? One may sensibly propose that SC is compatible with relativism since the focus is on how people make sense of phenomena. Within SC, this sense-making is what is of interest rather than any attempt to access the phenomena as they might exist in an external reality in and of themselves. According to this perspective, such an attempt is futile from our human lens as interactions between social constructs are inherent to the process of meaning-making, and hence the creation of knowledge. In Crotty (1998, p. 64)'s words: 'What is said to be 'the way things are' is really just 'the sense we make of them''. Therefore, a social constructionist would not lay claim to a single truth but multiple truths; this view of multiplicity seems compatible with relativism.

However, Crotty (1998) argues that SC could fit with relativism or realism. SC as an epistemology is not asserting a set stance on ontology. Indeed, the phenomena one interacts with, or experiences, could be situated within an external reality; a singular reality that is common to us all. Crotty (1998) conceives constructionism in the sense of interaction which is coherent with the proposal that there is an external reality, i.e., one of the interactants. He quotes Fish (1996; in Crotty, 1998) who illustrates that just because something is a social construct, does not mean it is not situated within reality. Fish (1996; in Crotty, 1998, pp. 63-64) provides the example of baseball, arguing that elements to the game such as ‘strikes’ and ‘balls’ and the game itself exist on the basis of rules (borne from social interactions/processes), however this does not mean that the game is exempt from being ‘real’, and it creates very real effects such as its constituent workforce, following and profits/losses, right down to the individual fan who devotes a large amount of their leisure time/energy to the sport. Therefore, whilst constructionism is also coherent with a relativist perspective on ontology in terms of only being concerned with how people make sense of reality, one can still retain that focus and concurrently recognise that reality as possessing an external validity, even if it is not directly accessible. Thus, the researcher aimed to access parents’ socially-constructed sense-making of their experience of the C19P in relation to their young adults with Down Syndrome TIA, assuming they shared some element/s of a common reality whilst coincidentally experiencing, and being able to offer, their individual substantiations of it.

Whilst I am proposing that SC coheres with CR, if one were to consider realism in its pure unadulterated form, I would argue that this perhaps is not cogent with SC. The goal of realists is to get to the essence of phenomena as situated within external reality; to control/remove all the human aspects of sense-making, viewed as biases; to access phenomena as much as possible in their pure objective form. This seems to be saying that we can in fact access ‘the way things are’, as separated from ‘the way we make sense of them’, which seems incompatible with SC. CR on the other hand, which recognises that we cannot directly access reality, and so our perspectives, experiences and knowledge differ, but we ultimately converge on some form of a common reality, I believe to cohere with SC. Yes, each individual’s perspective is unique, but that is because their phenomenology consists of a particular total set of interactions with socially-constructed phenomena. My experience of the sun setting may be very different from yours, but each of our phenomenologies are borne out of the social processes/interactions which each of us has experienced in relation to sunsets. Therefore, CR acknowledges the sense-making element of experience, and one could adopt a SC lens on this sense-making. The realist aspect comes in the sense that the sun still sets for us both, and neither of us questions this, taking it to be fact.

Crotty (1998) is careful to highlight that relativism is not idealism; the view that what exists is confined to ideas in the mind. Whilst relativists do not deny something existing external to the mind, they do not make claims about an external reality. I feel it would have been incoherent for me to do this when the conception of my study depends on assumptions I made about a common external reality, i.e., that the C19P happened and impacted people’s lives in one way or another; that young adults with Down Syndrome TIA during the 18-25yo chronological phase of their lives; that my sample of mothers had in common a particular experience which was why they were recruited for the study.

Critical Realism and Interpretative Phenomenological Analysis

Oxley (2016) explains the compatibility between a CR ontology and the IPA method. IPA researchers are concerned with how participants make sense of their experiences, recognising that the interpretations they offer are not direct representations of reality; rather, they are permeated with the individuality of their lenses. As Oxley (2016, p. 58) states, critical realists would accept that this ‘filtration is taking place’. Furthermore, IPA researchers highlight that they engage in a ‘double hermeneutic’ (Smith et al., 2021) when interpreting participants’ data; the researcher’s sense-making does not directly reflect the participant’s interpretation, as subjectivity always enters the process of meaning-making, again coherent with CR. Moreover, in accordance with IPA, I interviewed parents who I took to have shared a specific experience; that is, to have accessed a somewhat common reality, as a critical realist would argue. Each mother’s sense-making of that reality may be individual, yet it would originate and be situated within the social processes, interactions, and contexts in which they were each engaged, hence the additional coherence with SC.

The researcher did not impose or assume specific hypotheses about what the mothers' experiences were like but sought to explore these in an inductive fashion. The aim was not to derive nor generalise a universal experience of the C19P and its impact on the TIA on behalf of all parents of young adults with Down Syndrome, in originating from the perspective that such a nomothetic claim would not exist. Rather, the goal was to elicit the voices of a small number of parents of young adults with Down Syndrome on their and their young adults' experiences, and to learn from interpretating these voices. This interpretation was inextricably a product of interaction between the mothers' experienced realities with their young adults and the researcher's own way of perceiving/experiencing. Yet, albeit imbued, the interpretation was still connected to the mothers' phenomenology. The interpretation is therefore also connected to external reality, since the mothers' phenomenology is a product of interaction between their unique way of perceiving/experiencing phenomena, and the phenomena themselves. Thus, the external reality is a necessary contributor in the conception of the experience under study (Oxley, 2016).

Personal Reflection

Delving deeper into ontology and epistemology could lead one down many winding paths, and one could easily get trapped in philosophical loopholes. My understanding of these concepts is still in the emerging stages, such that someone with a more mature philosophical understanding could argue against my positioning. What I can say is that I have contemplated my arguments and I see coherence, even if this coherence could be considered rudimentary. Moreover, I have been transparent about my positioning, explaining thoroughly, therefore readers can appraise my study with the knowledge of where I was coming from, and what I was trying to achieve.

Participants

Tensions around whose voice

I critiqued studies in my LR *(Part One)* for not accessing voices of young adults with Down Syndrome themselves. One could then reasonably expect my study to address this limitation. I explain in my *Section Three (Part One)* why I interviewed parents instead of young adults with Down Syndrome and, yes, that reasoning did inform/justify this decision in an academic/practitioner sense. However, I was also influenced by significant reflection pertaining to ethics, which is only detailed briefly in *Section Three (Part Three)*, hence I elaborate here.

I knew that the research project I completed in the second year of my doctorate would be quite quickly/easily approved by the university's Research and Ethics board. I was interviewing professionals about a topic that was neither sensitive nor personal. However, from discussions with other TEPs I learnt vicariously that the ethics approval process could be uncomfortably lengthy and present various obstacles, when the proposal is to study a sensitive/personal topic from the perspectives of participants who would be classed as vulnerable. Nevertheless, in originating from a Social Model of Disability (Barnes, 2019) viewpoint, and being a strong advocate of person-centred practice as a practitioner, I originally wanted to interview young adults with Down Syndrome about their experience of TIA during the C19P, believing that they can speak for themselves rather than relying on others to speak for/about them, and that their views should be actively elicited and come to impact practice.

My supervisor agreed with the axiology (Brown and Dueñas, 2019) underpinning my proposal; that is, my values regarding research/practice which led to the idea. However, we had a frank discussion about the ethics approval process, considering the attention I could afford to dedicate to my thesis whilst also fulfilling my placement training requirements. I was intending to interview young adults with Down Syndrome, who would be considered as a vulnerable group from an ethics perspective, about a very personal/sensitive topic (i.e., their experience of TIA during the C19P). It was almost certain that I would experience what my colleagues had regarding the ethics approval process. I have come to realise that completing an EP doctorate is a balancing act, with tight time demands. Moreover, it is not just the time aspect, it is the differing mindsets and headspace one needs for research versus practice; the difference between these and the need to continuously switch between the two requires a great deal of mental effort/energy and would task any person's executive functions. Did I feel confident/comfortable enough to embark upon an ethics approval process that would necessarily be lengthy, and potentially quite difficult? Were I to attain approval, would I then have enough time to complete the project, in the sense of the 'enough time' with which I could personally manage, whilst looking after my own wellbeing? After considerable reflection, I recognised that my thesis at this time perhaps was not the research project to gain the voices of young adults with Down Syndrome themselves on this topic.

Furthermore, my supervisor and I contemplated whether, even if there were a loosening of practical constraints, would not an initial research project in this area (studying the combined experience of TIA during the C19P for young adults with Down Syndrome) be better suited to gaining parents' perspectives? This is a very sensitive/personal topic to parents too, but it is perhaps less of an exposing position for them than it is for young adults with Down Syndrome to reflect more deeply on themselves. As argued in my *Section Three (Part One),* parents hold a close, yet outer perspective. Perhaps it was appropriate from an ethical stance that a study accessing parents' voices laid the groundwork or sewed the initial tapestry as it were for this topic. The insights gained could suggest where future researchers may wish to focus or tread carefully, were they to embark upon a research project accessing the perspectives of young adults with Down Syndrome themselves, in such a way that could give voice to aspects that were phenomenologically-significant for them, and that could more effectively minimise potential risk of psychological harm.

Notwithstanding my comprehensive reasoning for interviewing parents rather than young adults with Down Syndrome themselves, my experience as a researcher here led me to reflect on the ethical approval process, in the case of tightly-constrained theses undertaken on doctorates like the EP doctorate. Should practical constraints really be a contributory factor to the decision regarding who will be one's participants? Perhaps not, and I know some TEPs who have impressively managed to study very sensitive/personal topics from the perspectives of participants who would be classed as vulnerable. But I also know something of their experiences, and how the thesis can encroach upon every element of one's life around placement, jeopardising work/life balance. This means one's own wellbeing and aspects of their personal life could be at risk, and I believe it is hypocritical to propose that TEPs should just 'get on with it' when we are entering a profession which strongly advocates wellbeing for CYP and stakeholders. Moreover, according to our own proficiency guidelines, we have a duty towards fostering our own wellbeing [*Standards of Conduct, Performance and Ethics (SoP 6.3)*, Health and Care Professions Council, 2024]. Therefore, this makes me wonder and perhaps somewhat concerned regarding the possibility that worthwhile research with vulnerable groups about important, yet sensitive/personal topics may not happen, in the case of the EP doctoral thesis. We as developing EPs are well-placed to identify vulnerable groups for research regarding areas of practice that warrant an enhanced evidence base. Our role as practitioners can inform our research ideas in this way. Yet, whilst we may conceive worthwhile ideas for research projects, we may not come to conduct them because we must balance this research commitment with the demands of our practice; the thing that probably ironically gave us the idea in the first place.

Recruitment challenges

Even if I did not recruit young adults with Down Syndrome themselves, recruiting parents of young adults with Down Syndrome to be interviewed regarding this sensitive/personal topic presented its own challenges. I was initially looking for parents of young adults with Down Syndrome (aged 18-25yo at the start of the first lockdown), only in Wales. This particular population is small anyway, let alone the number of parents who could and would like to participate in my study. I contacted all the systemic organisations I could think of across Wales, including specific sectors of local authorities, further education colleges, community/leisure groups, and third-sector charities. It was a painstakingly repetitive process, emailing and calling every day; attempts often met with voicemail messages or a lack of response, or ‘out of office’ email replies since I started participant recruitment not long before the school summer holidays. When contact was achieved, many organisers apologetically informed me that their services were not accessed by my demographic, and some were less apologetic and/or irritated by the interruption of my call into their busy schedule. Honestly, I was starting to irritate myself at this point.

A significant proportion of my contact attempts were met with kindness, interest, and a willingness to help, even if the chances of the input leading to participants were remote. These experiences lightened what felt like a never-ending process, and these organisers’ interest in my study renewed my own enthusiasm for it. Eventually I arrived at a point where I was satisfied with the advertisement of my study, where several organisations had made significant efforts, for which I will be eternally grateful. But then came the wait. I think I expected that, once my message was out there, the expression-of-interest emails would flood my inbox, where I would need to stick to my maximum sample size declared to the ethics board. As one might imagine given the challenge of finding appropriate gatekeeper organisations who could/were willing to advertise my study with the identified demographic, and now, with hindsight, I can appreciate that it would be a very small number of parents who could/were willing to share their experiences on such a sensitive/personal topic; my expectation didn't come to pass. Instead, I waited. What was in fact only a few weeks felt like months when I was eager to do my research, and worried about how much time I had to do it. Would it not be ideal to recruit and interview all my participants prior to starting my final year? My supervisor helped me stay patient here; to remain hopeful that parents would come forward but this would take time and may occur after the summer holidays, since they themselves were probably busy during this period.

I did sit with it, in this uncertain and uncomfortable space. Eventually though I decided (with my supervisor's approval) to expand my search, including the age range of young adults with Down Syndrome (17-25yo at the start of the first lockdown, in thinking that organisations geared more towards CYP could help me here, not only organisations geared more towards adults), and including England as well as Wales. This expansion was still consistent with my rationale and would considerably increase the population pool. I still had to wait, but eventually I got my three mothers, from across Wales/England, and two of them had young adults who were 17yo at the start of the first lockdown. I therefore felt justified in expanding my participant search and could get on with my research.

Contribution to knowledge

Less is more

My initial analysis comprised five rather than three GETs, and it was a struggle to arrive at this point after much contemplation/consideration of the PETs. I knew that I had too many considering my goal to offer a coherent and accessible narrative, where I was liberated to go into depth on each GET. Supervision discussions prompted me to assume a meta-perspective upon my analysis. The analysis as it was with too many winding paths was in danger of blurring/clouding what could be taken from my research. Moreover, parts of my write-up had a primarily descriptive air. I re-visited the IPA principles (Smith et al., 2021) to realise that my job as researcher was not to simply *describe* the mothers' experiences, but to *interpret* them.

Therefore, I interrogated my themes, leading to the further realisation that my own 'stuff' had perhaps come to influence one of the original GETs (Resilience), as reflected upon earlier. However, I also discovered a discomfort within myself around synthesising the analysis and choosing the most salient GETs. This was around a question that kept surfacing in my mind: Are these GETs what the mothers would choose? Further supervision discussions inspired me to reconstruct my purpose here. I had undertaken the interpretative work as the researcher, where there was value in my interpretation. This, in the context of understandings I had gained from the literature; the context of the research conception/design and researcher skills I have acquired conducting previous projects; and my offer to those involved in TIA for young adults with ALN, specifically EPs, in my developing knowledge of the role and how it could evolve, as I progress on my TEP journey. I needed to trust myself as the researcher, where I had stayed true to the principles of IPA. My interpretation was steeped in the mothers' phenomenology, but it was for me to create, revise, and decide upon the final GETs.

The offer from interpreting experience

My study reinforces the tenet of SC which warns against 'taking knowledge for granted' (Burr, 2015), where I maintained an openness to the unexpected and nuance from the mothers' accounts, enabling generation and in-depth exploration of my three themes:

Autonomy – a kaleidoscope of forms; *Routine – a multi-edged sword*; and *Parents striking a precarious balance*. This, rather than assuming anything about their experiences, imposing preconceived notions, or trying to reduce/categorise. The themes perhaps even challenge or prompt one to re-examine some preconceived notions that, when taken blindly/in a reductionist manner, may lead to missed opportunities, or even unhelpful/detrimental effects. For example, were one to elevate the importance of routines, viewing only the good they can do, one may miss their potential to demotivate, limit and/or even become a binding schedule. Moreover, if one were to predicate practical independence in discussions of autonomy, one may miss more nuanced, perhaps less-observable, but no less meaningful/important, aspects such as having one's own life separate from family life, the nature of the role one assumes within this, and mindset shifts. Hence, the possibility to inspire the development of autonomy in creative ways (such as during the C19P) may also be missed, for example, considering the potential of the virtual realm. Such elements were captured through inductive exploration and close interpretation of idiographic experience in my study.

Furthermore, the instrumental role of parents is highlighted in TIA for young adults with Down Syndrome, along with an emphasised need for wider systems to share the load, and to offer support to parents when striking balances for their young adults. Potential considerations for practitioners generally who may be involved with young adults with Down Syndrome, as well as possible implications specifically for EPs, are provided in the *Discussion (Part Two)*.

The offer here is by no means a complete product. Returning to Braun and Clarke (2022)'s metaphor, my findings augment the researcher/practitioner tapestry regarding TIA for young adults with Down Syndrome, considering insights gained from study of this phenomenon during/following the C19P. I would invite future research to build upon this, whether this be adding colour, a new pattern, existing pattern continuation, or completely novel sections; in the endeavour to continually develop researcher/practitioner fields for young adults with Down Syndrome and their parents/families.

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Appendices

Appendix A: Literature review strategy for Section One (Part One)

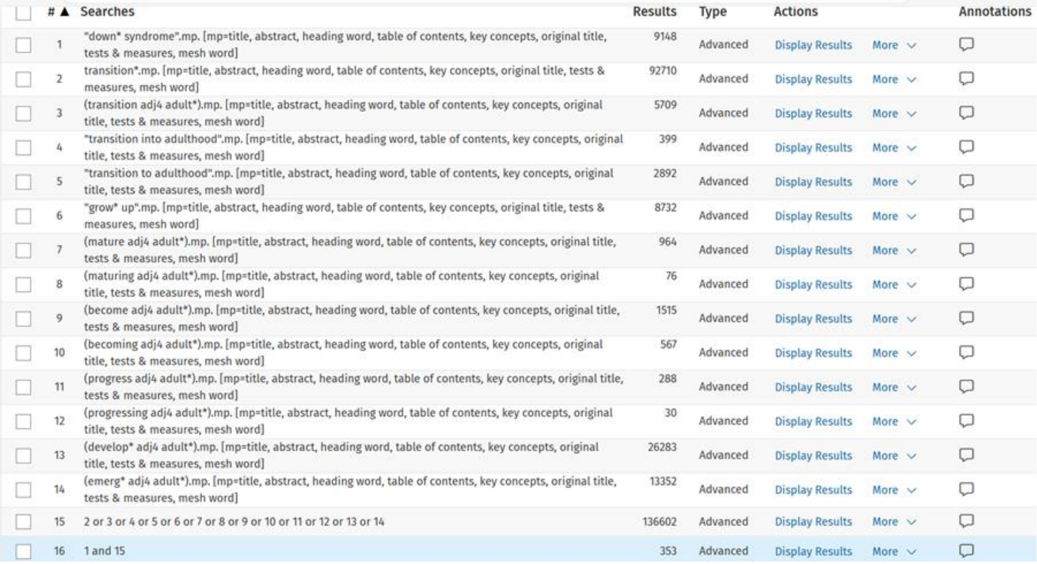
Conducting an integrative rather than a systematic/semi-systematic LR does not preclude adopting a transparent/reasoned approach. The researcher utilised the PRISMA checklist guidance (Page et al., 2020) for *Section One* (as TIA was the main phenomenon under study, as affected by the C19P), although this guidance was not followed prescriptively. Aligned with Braun and Clarke (2022)'s ethos, the aim was not to identify all research relating to TIA for young adults with Down Syndrome and proclaim the resulting review to be a thorough summary; rather, the discussion offered delves into depth regarding a handful of qualitative studies accessing the experiential component of TIA for young adults with Down Syndrome, laying foundations for the rationale of the present research. Nevertheless, to lend transparency and trustworthiness to the LR strategy, please see below for a description of the process followed; Figure 3 for screenshots of searches on the databases for the search terms; Table 10 for the final inclusion/exclusion criteria; and Appendix B for a breakdown of the papers reviewed in *Section One*.

Process

The researcher devised initial inclusion/exclusion criteria deemed to be focused/relevant to the scope of the LR topic. Search terms were created based on variations of the key terms and inputted into two reputable/relevant databases: American Psychiatric Association PsycINFO and Scopus, using the combining AND/OR and other relevant functions in each database (please see Figure 3). The returned literature was initially appraised, sifting out obviously irrelevant papers based on their titles. The researcher then considered the papers more methodically, and developed the inclusion/exclusion criteria based on this appraisal of the available literature. The researcher re-appraised the studies, contemplating their abstracts and sometimes their introduction/participant sections, according to the revised inclusion/exclusion criteria (please see Table 10). This led to the researcher arriving at a bank of thirteen studies, which are subject to thematic exploration and integration in *Section One*, and descriptive summaries of each paper appear in Appendix B.

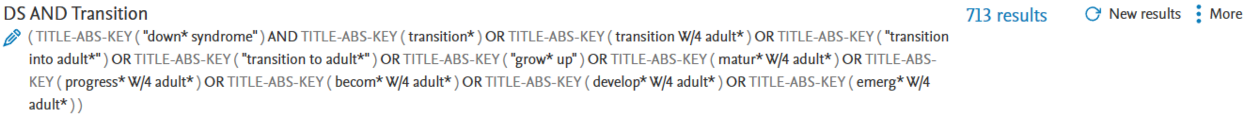
Figure 3: Literature searches and search terms on the two databases for Section One (Part One)

APA PsycINFO:



☐	# ▲	Searches	Results	Type	Actions		Annotations
☐	1	"down* syndrome".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]	9148	Advanced	Display Results	More	
☐	2	transition*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]	92710	Advanced	Display Results	More	
☐	3	(transition adj4 adult*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]	5709	Advanced	Display Results	More	
☐	4	"transition into adulthood".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]	399	Advanced	Display Results	More	
☐	5	"transition to adulthood".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]	2892	Advanced	Display Results	More	
☐	6	"grow* up".mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]	8732	Advanced	Display Results	More	
☐	7	(mature adj4 adult*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]	964	Advanced	Display Results	More	
☐	8	(maturing adj4 adult*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]	76	Advanced	Display Results	More	
☐	9	(become adj4 adult*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]	1515	Advanced	Display Results	More	
☐	10	(becoming adj4 adult*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]	567	Advanced	Display Results	More	
☐	11	(progress adj4 adult*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]	288	Advanced	Display Results	More	
☐	12	(progressing adj4 adult*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]	30	Advanced	Display Results	More	
☐	13	(develop* adj4 adult*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]	26283	Advanced	Display Results	More	
☐	14	(emerg* adj4 adult*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures, mesh word]	13352	Advanced	Display Results	More	
☐	15	2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14	136602	Advanced	Display Results	More	
☐	16	1 and 15	353	Advanced	Display Results	More	

Scopus:



DS AND Transition

(TITLE-ABS-KEY ("down* syndrome") AND TITLE-ABS-KEY (transition*) OR TITLE-ABS-KEY (transition W/4 adult*) OR TITLE-ABS-KEY ("transition into adult*") OR TITLE-ABS-KEY ("transition to adult*") OR TITLE-ABS-KEY ("grow* up") OR TITLE-ABS-KEY (matur* W/4 adult*) OR TITLE-ABS-KEY (progress* W/4 adult*) OR TITLE-ABS-KEY (becom* W/4 adult*) OR TITLE-ABS-KEY (develop* W/4 adult*) OR TITLE-ABS-KEY (emerg* W/4 adult*))

713 results

Table 10: Inclusion and exclusion criteria for Section One (Part One)

	Inclusion Criteria	**Exclusion Criteria**
Type of literature	• Empirical research articles. • Reflective pieces; could be anecdotal experiences. • Unpublished theses.	• Book/film reviews. • Film documentaries. • Fictional stories. • Books, book chapters and review articles that are more like a textbook-style approach, or collation of information. • Whole books on personal experiences (considering the scope of the LR).
Methodology	• Qualitative. • Qualitative component of mixed-methods studies.	• Quantitative.
About - who	• YP with Down Syndrome and young adults with Down Syndrome. The researcher was not strict on age range as the	• Individuals with ALN or intellectual/developmental conditions other than Down Syndrome. This includes studies

	literature comprised varied methods/designs, including longitudinal, retrospective / prospective angles. Broadly, the research reviewed concerns people with Down Syndrome in/just before/just after the TIA phase of 18-25yo. • YP with Down Syndrome and young adults with Down Syndrome with other co-morbid conditions.	where the sample may comprise a group of young adults with Down Syndrome, but they have been grouped together with young adults with other conditions, where readers cannot ascertain findings specific to the target demographic.

About - what	• TIA, including transition regarding:
	  ○ Leaving school.
	  ○ Child to adult services.
	  ○ Generally entering the adult world.
	• Meaning of an adult life / quality of life to young adults with Down Syndrome (considering their perspectives on their lives).
		• Studies on specific medical / physiological aspects (specific clinical lens), including level and type of healthcare usage / health status.
		• Studies on specific cognitive or physical skills or conditions, and not really about the experience of transition, or transition outcomes, e.g., measures of sleep, sensory needs, reading, executive functioning, memory, specific measures of intelligence, levels of exercise/physical activity.
		• Studies related to bereavement.
		• Studies related to Dementia.
		• The impact of a specific programme, e.g., an apprenticeship programme; weight-loss or exercise-regime programme; education intervention; individualised support programme (where the success of the investigated programme is based on outcome measures not offering insights regarding TIA per sé).
		• Teaching young adults with Down Syndrome about something related to adulthood in the form of a guide, e.g., sexuality.
		• Clinical practice guidelines.

Perspectives / participant group	• Young adults with Down Syndrome. • Parents/carers / close family members, e.g., siblings. • Professionals who may support young adults with Down Syndrome in their adult life.	• Research that only focused on measures related to caregivers such as their wellbeing; not really about the target demographic and their TIA.
Timeframe	• 1980-present day. Considering the legislative rights for CYP with SEN introduced in the Education Act 1981 (UK General Public Acts, c. 60).	• Studies before 1980.

Appendix B: Summary table of qualitative research reviewed in Section One (Part One)

Please note, relevant extracts are directly taken from the studies, as each entry provides a descriptive summary. On this basis, quotation marks for the authors' prose have not been added, however, they have been used for participant quotations or key phrases. The studies are presented in alphabetical order.

Author	Year	Country	Aim/s	Participants	Methodology and Research Design	Findings applicable to the focus of this research
Detisch, E.	2007	USA	To explore the perspectives/experiences of transition-aged students and their families regarding transition; and their perceptions pertaining to how their family attitudes, beliefs and values affected their involvement in the transition process.	6 young adults with Down Syndrome (aged 16-23yo) and their families (including parents and siblings).	Qualitative naturalistic methodology. Cultural interviewing (Rubin & Rubin, 1995) – in-depth semi-structured family interviews. Data interpreted in the context of family systems theory.	All families attributed great importance to community supports in relation to decision-making, e.g., case workers, early intervention services, etc. Three of the families reported committing a lot of time doing their own reading and research. Some of the families found Down Syndrome support groups to be helpful, particularly those with a strong desire for inclusion in school/the wider community. However, two families ceased affiliation with their support group; reasons included perception of militancy / lack of flexibility. Siblings and extended family members were cited as significant supports and influences. Parents were concerned about the potential burden that their young adult would be to their sibling and worried about who would look after them when they no longer could. Families reported that siblings felt guilty as they moved through the developmental milestones for their age, e.g., going to Prom, college, moving away. Transition interpreted as a lifelong process. Transition experiences mixed; both positive and negative. Negative feelings/thoughts/experiences were reported more often and included helplessness, hopelessness, fearing transition and finding it stressful, discouragement, frustration, being unclear about whose responsibility transition was, low teacher expectations, lack of tailoring of IEPs, lack of post-school opportunities. Teachers made a big difference to transition perceptions/experiences, either positively or negatively. Positives included a focus on inclusion, collaborative ethos, getting to know

						the young adult and family well. Negatives included teachers who didn’t work towards inclusion, focused on stereotypes, pushed towards more restrictive environments. Families sometimes noted school staff who were adversarial to work with. Overall, families didn’t feel that they were encouraged to actively participate in the transition process. They felt the most important factor for this to happen was the development of a meaningful relationship with the teacher and working together collaboratively. Families tended to feel that what was important to them was not known by the school or, if known, not acknowledged/incorporated into the transition plan. Sometimes families themselves feel like they are a barrier when they feel defeated or become ‘tired of fighting’. Families felt it was important for school staff to acknowledge their desires even if these couldn’t always be met. Families seem to want more ownership in the transition process. There seemed to be many and varied roles that families took on in transition, including ‘key educational decision maker’, ‘fighter for services’, ‘consumer of services’, ‘IEP participant’, ‘provider of transition services’, ‘link for self-determination’, ‘ultimate transition coordinator’, ‘strategist’, etc. There seemed to be a lack of person-centred planning where families felt that their young adult’s interests/desires didn’t influence the type of work experiences they were offered; these were generic. Families felt that the transition process would be better if professionals were to form meaningful relationships with them and their young adult, taking the time to get to know them, and working collaboratively. They believed that perhaps parents and teachers could benefit from learning collaborative skills. Provision of information is also important and awareness of options; perhaps a liaison person from high school to next steps would be helpful. Moreover, IEPs should be strengths-based and transition plans individualised. Despite difficult experiences, overall, the families were hopeful for the future.
Docherty, J., and Reid, K.	2009	Scotland	To explore the values, beliefs and experiences of mothers of young	8 mothers of young adults with Down	Qualitative methodology; IPA (Smith & Osborn)	‘What’s the next stage?’: mothers felt the need to prepare early for the next stage as it takes time to organise; notion of pushing themselves and their young adults towards independence goals;

			adults with Down Syndrome as they journeyed from dependence to independence; and the meanings the mothers attributed to those experiences.	Syndrome (aged 19-29yo; average age of 23yo; all had left school).	data analysis method. In-depth semi-structured individual interviews.	mothers wanting their young adults to be realistic about these goals; mothers' awareness of their young adults' developmental needs. 'Defining and shaping adulthood': Trying to help young adults to understand the concept of adulthood, encouraging them to lead their own lives. The mothers wanted the young adults to be aware of their Down Syndrome without this preventing dreams/goals. 'Gatekeeping and facilitating on the path to adulthood': mothers needing to 'make things happen' – they facilitate a lot for their young adults, e.g., checking activities out, forming timetables, running groups themselves. 'Self-reliance and independence as a value, goal and cultural norm': mothers wanting their young adults to strive for independence; reflections upon their own role within this. Siblings play a crucial role but the mothers don't want them to take over responsibility. Mothers in a dynamic space, concerning their roles, beliefs and values in interaction with their young adults and wider systems as they TIA, pursuing autonomy for their young adults. Considering mindset shifts, e.g., goals, values, beliefs and responsibilities; not just elements of practical independence. Moreover, independence and dependence are not dichotomous.
Dyke, P., et al.	2013	Western Australia	To investigate the experiences of mothers as their young adults with ID TIA. Compared experiences between two groups.	7 mothers of young adults with Down Syndrome (aged 19-27yo) and 11 mothers of young adults with Rett Syndrome (aged 19-33yo).	Qualitative component as part of a wider study. Semi-structured interviews.	*The present researcher just focused on findings related to the mothers of the young adults with Down Syndrome, in line with the focus of the LR.* Success of the transition process seemed to be related to parent's advocacy. Provision of information regarding options and choice could be limited. Mothers needing to organise daily/weekly occupation for their young adults; difficulty securing placements and funding (sometimes had to make the situation appear bad in order to get such funding); employment tending to be insecure or very part-time; a lot of time spent waiting or advocating or organising. Seemed to be a difficult and lengthy pathway before settled into adult roles.

						The young adults tended to not be involved in the decision-making during transition, but mothers tried to accommodate their preferences/interests. Several mothers worried about what would happen regarding their young adult in the context of their own mortality, where some hoped they would outlive them for this reason. Majority of mothers thought that their young adult had a good/great quality of life but some reported a limited quality of life for themselves which sometimes improved when their young adult moved out, yet this was a ‘hard decision’. Mothers felt the loss of school-based support, alongside more informal supports as their young adults transitioned. Worried about the impact on their ability to work. Some mothers moved to access opportunities for their young adults. Sometimes mothers decided to opt for a supported workplace for their young adults in the interests of consistency and safety but this could arise to ‘unmet potential’.
Hartman, A., et al.	2000	USA	To examine the service and support needs of adolescents with special health care needs who are TIA.	Interviewed 3 parents but this researcher’s focus was on one of the participants – Jane, the mother of Jack, an 18yo man with Down Syndrome.	Multiple qualitative case study methodology relying on life history – longitudinal perspective. Interviews.	Lots of time, resources and energy committed by Jane towards ensuring that Jack had access to appropriate services throughout his life. Sometimes the potential to develop independence seemed bleak, however, both Jane and Jack desired independence for him, perceiving it to be his right. Independence to Jane would look like Jack living without parents yet with a full-time carer; considered selling the family home to Jack so that he would be safe and familiar in this environment whilst her and her husband moved somewhere else. Jane highlighted the importance of independence-building opportunities for Jack’s future independence and confidence, e.g., opportunities in school, money management, socialisation.
Peterson, M.	2006	USA	To explore and describe the experiences and concerns of young adults with Down Syndrome and their families,	7 young adults with Down Syndrome (aged 19-42yo) and their	Qualitative study using a naturalistic inquiry methodology, involving	Seven types of transition identified: independent living, employment and financial security, changes in family composition, legalities for the young adult, support, social interaction and a movement from shock to acceptance and love.

			including everyday experiences, concerns for future health and financial wellbeing, and to identify what people and resources can best attend to these concerns.	families (including parents and siblings).	interviews and observations in natural settings. A video essay was also produced.	Varying experiences regarding employment; some in competitive employment, some in sheltered workshops, others developing job skills or not currently seeking employment but consideration for the future. Sometimes jobs were ceased due to safety/transport considerations. Families reported insufficient employment opportunities; inadequate supervision/training; and the issue of their young adults participating in extended programmes aimed towards employment but then individual store managers not deciding to recruit them. Moreover, receiving Medicaid benefits restricts the amount a young adult with Down Syndrome can earn and still receive coverage. Parents recognised at somepoint they would no longer be able to care for their young adult, but felt assured in knowing a confident sibling could, or a close family friend could make decisions on their behalf. Not many concerns regarding health, compared to when they were children. Parents worried about potential social isolation for their young adults, e.g., lack of opportunities or mainstream peers moving on with their lives. Parents needed to consider the future financial needs of their young adults. Parents reported the rewards of raising their young adults with Down Syndrome. Siblings also reported that the young adults had enriched their lives or made them better people and tended to accept certain responsibilities. They accepted that ultimate responsibility would eventually be theirs. Siblings worried about how the young adults would manage changes in family composition/transitions in their own lives like marriage/moving out but were positive that they could cope, and they positively participated in such transitions, e.g., excitement in getting to know fiancé and involvement in wedding plans. Young adults with Down Syndrome perceived their families to be very important to them and reported being satisfied with their lives, not reporting any concerns about the future. They seemed content in their lives, whatever their situation, including satisfaction with their social connections and leisure activities. Families highlighted

						the importance of opportunities for social interaction for their young adults, and participation in community/leisure activities such as sports/volunteering. When presented with opportunities to develop their practical independence such as moving out of the family home, the young adults rose to the challenge and even if such experiences were anxiety-inducing initially, they experienced increased confidence and contentment as they achieved outcomes. Families perceived independent living and employment for their young adults very favourably. Parents who opted to pursue legal guardianship for their young adults described the process as stressful, experientially and financially. After a lifetime of raising their young adults, they almost had to prove the adequacy of their parenting skills to court systems. Parents seek variable levels of support in TIA. Young adults demonstrated ongoing dependence on their families, e.g., for self-care and financial aspects.
Wills, R., et al.	2016	New Zealand	To explore the experiences of mothers of young adults with Down Syndrome regarding their young adult's transition from schooling to adult life.	7 mothers of young adults with Down Syndrome.	Qualitative methodology. Interviews using the method of 'photo-voice' where the mothers brought photographs of their young adults' daily lives to act as stimuli for discussion.	There is a need for integration across support services in transition, where parents and young adults can experience a lack of clarity/cohesion. Some parents feeling they needed to do things themselves. There was a theme around parents and young adults not feeling valued/respected; having a lack of control/experiencing a lack of inclusion within the community. Advocacy for inclusion could feel like a battle, where one parent described feeling like services didn't want parents like her who would raise issues/questions. Parents keenly felt the importance of inclusion for their young adults with peers, including typically-developing peers, whilst acknowledging that they would still hold a great deal of responsibility in their lives. Seems to be a discrepancy between legislation and reality of services/provisions, e.g., parents having to facilitate their young

						adults' social lives; ad-hoc activities in 'warehouse' type set-ups; again, experiencing a lack of authentic inclusion. Parents highlighted the importance of support from other parents beyond sharing medical advice, in terms of being able to properly empathise. Parents felt the loss of school-based support/structure, where some had to give up work once school had finished in becoming their young adult's carer, which affected family income. Parents described moving away from their home communities, either due to experiencing a lack of inclusion where they were, or to access opportunities for their young adults, which involved moving away from extended family.
Scorgie, K., and Wilgosh, L.	2009	Canada	To explore parental perspectives of different transition points longitudinally, including TIA, in support of a cyclical model of life management and coping (Scorgie et al., 2004).	One mother of a young adult with Down Syndrome (Diane, mother of Chad, who was 25yo at the time of the final interview).	Qualitative re-examination of a previous longitudinal case study (Scorgie & Wilgosh, 2008); one case study was chosen due to the authors proposing that this one typified themes of the others. 3 interviews: 2 when Chad was 15yo and one 10yrs later, when he was 25yo – *this latter interview was focused upon in this LR.*	A theme across the three interviews was Diane's rhetoric that Chad should not experience isolation due to his Down Syndrome. Chad inspired Diane in many ways and she characterises him as her 'teacher'. For example, she started work as an advocate for people with disabilities after advocating for Chad all his life, and also embarked upon a degree. Even though there were difficulties across Chad's school experience (e.g., in relation to advocating for his inclusion), Diane felt it was much more difficult in the adult world, where the onus was primarily on her and Chad's father: 'we just kind of created our own world for Chad'. Diane and Chad encountered segregated settings in the adult world with a lack of meaningful social interactions, which saddened Diane. Diane shares the impact upon her marriage with Chad's father as caring responsibilities continued into his TIA. Diane felt guilty when she became physically ill and didn't have the energy to do as much in Chad's life, but was also feeling the limitations of her efforts. Diane was both hopeful and uncertain about the future, believing that society needed to improve regarding authentic inclusion and valuing of people with disabilities.

						The findings indicate that families would benefit from a cyclical model of support, especially considering points of transition like TIA, rather than a more linear form of support where it might reduce as the YP grows up.
Riesz, E. D.	2004	USA	/	A qualitative self-reflective narrative offered by a mother of a young adult with Down Syndrome, Sarah. Sarah was 30yo at the time of writing.	A personal retrospective reflection offered by a mother of a young adult with Down Syndrome, reflecting upon 3 transition points: the birth of her daughter, her high school graduation and her move away from home. *The latter two were focused upon in the LR.*	Riesz describes revisiting feelings experienced at birth during later transition points (e.g., high school graduation and moving out), which include loss, mourning, chronic grief, contemplating difficult questions about Sarah's future as well as her own. Riesz doesn't feel that friends/professionals always recognise parents' struggles at times of transition like TIA; not just at birth. Coming to understand one's circumstances enables meaning-making and purposeful action, as well as hope to emerge. Telling the story to others is a helpful process. High school graduation at 21yo: Riesz found herself comparing to the experiences of other parents and feeling a renewed sense of loss. She was proud of Sarah for her own achievements but compared to her peers where there was much anticipation for the future, whereas, for Sarah, next up was transition planning. Dreaded loss of school-based support – professionals who knew Sarah well, the routine of the school bus, protected/legalised recognition and provision in her IEP. Riesz details Sarah's fulfilled life and her skills, e.g., budgeting, cooking, part-time work in a discount store, varied interests and activities, independent use of public transportation. Felt she had made much progress in school. Questions about the future: Where would Sarah live? What would happen? Who would care for her when Riesz and her father died? Next Steps course which Sarah had participated in for 2yrs prior to her graduation was very helpful in planning/imagining the future – both Sarah and her parents got involved. Effective collaboration across different systems of professionals. Sarah acquired a job and was able to obtain another when the previous store shut down (the skills she had learnt). Sarah had expressed a desire to work and achieved this. Moving to a new home at 30yo: Riesz describes her and her husband anxiously practising the conversation around broaching Sarah moving out and into

						supported living and persisting even though she was initially resistant, e.g., Riesz would even sleep on her new bedroom floor to help her settle. They were worried about the unknowns around it all, e.g., her health, concerns regarding whether she would experience abuse, whether she would be sad without her parents, how they would feel when she was no longer living with them. The transition process was lengthy; felt like the options were unclear. The stress of arranging supported living for Sarah took its mental/emotional toll on her parents and their marriage, and they accessed counselling in relation to the transition. Felt a lack of understanding from other parents in relation to their decision to help Sarah move out. Eventually settled into her new house – her routines and activities were similar to when she was living with parents; still had regular contact with parents. Parents still couldn't be very flexible/spontaneous in their personal lives due to ongoing involvement in Sarah's life. Further reflections: Seeking help from 'experts' (professionals) and 'experienced' (other parents, educators) helped them through the process. Within transition there is a need for parents to search for information, make difficult decisions, and cope with emotional upheaval, whilst worrying about the uncertainty of the future. By TIA, parents have already learnt coping skills due to years of raising their young adults and experiences with systems.
Peters, V. J., et al.	2022	Netherlands	To explore the experiences, concerns and needs of parents of CYP with Down Syndrome and professionals regarding healthcare transition (paediatric to adult healthcare services).	20 parents of CYP with Down Syndrome (aged 15-25yo) and 6 healthcare professionals (3 paediatricians and 3 ID physicians).	Qualitative methodology. Semi-structured open-ended interviews.	Parents and professionals both have concerns during each stage of transition: preparation, transfer and integration; particularly, communication, continuity of care and rebuilding trust (across the transfer). Regarding preparation, this sometimes feels ad hoc between the paediatrician and the ID physician, resulting in ineffective preparation. Lack of consistency – paediatricians say the process could start at 14yo or 17yo depending on the individual and their circumstances which means there is a lack of a transition protocol. Parents feel that families have varied experiences.

						Parents feel there is a lack of communication and not enough information where they need to find it themselves which can be difficult/overwhelming. Paediatricians say they don't have readily-available/accessible information to give. Parents and professionals identify 3 types of transition approach: warm hand-off, cold hand-off and general hand-off. The warm hand-off involves parents, young adults, their parents, the paediatrician and ID physician meeting together which feels more holistic and patient-centred, and also aids developing trust in the new professional where parents don't have to retell their young adult's story; the cold hand-off involves the ID physician being introduced briefly but not properly meeting with the paediatrician and young adult and their parent together, where the first meeting between the ID physician and the young adult and parent is after the transition; the general hand-off just involves a transfer of documentation. Both parents and professionals prefer and see value in warm hand-offs but there are systemic constraints such as time, planning and cost which sometimes prevent them from happening. The importance of effective coordination in transition was highlighted. Developing trust in the new professional was aided where they took a genuine interest in the young adult beyond medical aspects and focused on creating 'comfort and safety'. Continuity of care was highlighted to be important by parents and professionals. Paediatricians feel it would help to have a designated healthcare transition coordinator. Parents didn't question the skills of the ID physicians but tended to feel that the paediatricians took a more holistic approach, enquiring about wellbeing, not just medical aspects. ID physicians report being time-pressured and, due to a lack of coordination in the transition process and needing to repeat checks, there is then less time for a holistic approach.
Thomson, G. O., et al.	1995	Scotland	To explore transition pathways and quality of life outcomes for young adults with Down	35 young adults with Down Syndrome	Mixed-methods design. *In Section One of the LR the*	Mandy and Anna enjoyed opportunities for social/community engagement, e.g., sports, activities in a community centre, college. Mandy's self-confidence grew and she gained a lot of meaning in

			Syndrome, given developments in inclusive legislation.	studied longitudinally from 1987-93 as part of a mixed-methods study from when they were 16-22yo (investigating pathway after school and into TIA). 2 case studies: Mandy and Anna, including descriptions of their experiences and parents' perspectives.	*researcher references the qualitative case studies of 2 young women with Down Syndrome, in line with their focus.*	her life from the centre, where her father explained: 'her whole life…revolves around the centre'. Anna experienced inclusion in college, e.g., spending break times with other students. Both sets of parents worried about their daughters regarding them managing their own money, along with worries around future employment. Anna's parents felt optimistic in reflecting on how she continues to impress them with her achievements, e.g., going onto further education. Mandy's parents worried about her regarding when they could no longer care for her.
Leonard, H., et al.	2016	Australia	To explore transition planning to examine whether legislative changes are reflected in reality. Moreover, what is the effect on parent and whole family wellbeing?	Parents of 190 young adults with Down Syndrome (aged 15-30yo) (Western Australia) and 150 young adults with ID of any cause (Queensland). *This researcher concentrated on the former cohort, although some findings were presented for the groups collectively.*	Mixed-methods parent-report questionnaire survey; the focus in *Section One* and this summary is on the qualitative findings. Please see Table 3 in *Section One* for some of the quantitative findings.	Parents reported worries about leaving behind school-based routines/structures and their young adults adapting to new ones; forming relationships with new professionals and encountering new expectations as they transitioned. Some parents felt positively about transition, viewing it as a usual part of growing up and felt that transition planning was helpful and even though adapting to new occupational options was challenging for their young adults, this was less of a concern as initially anticipated. Parents spend a lot of time planning during their young adults' transition. Some felt that it is an 'extremely worrying period' or a 'very grey area of life', where the onus is on parents to do the research and become aware of services. It can be very tiring and stressful, e.g., parents can experience stress when thinking about whether they've made the right choices. They also reported feeling worried about unknowns, e.g., whether their young adult would get a job, whether they'd be supervised/supported, feel safe, what transport would be like. However, they also valued the rewards an adult life could bring to their young adult.

						Parents reported both hopes and fears: some were hopeful about their young adults entering new settings with the chance to develop new friendships, for engagement and challenge; others worried whether their young adults would be accepted by new colleagues and about a potential loss of social connections from school. They were also concerned that their young adults may encounter abuse and/or not find their new activities fulfilling. The stress, worry/pressure felt by parents during TIA impacted upon their own emotional/mental/physical health and wellbeing, e.g., stressing over whether they had made the right decision for their young adult. This could also affect familial relationships and dynamics. The financial pressures meant some parents needed to work more which put a strain on family and social life. Stresses could also affect parental marriages and one parent spoke of their depression diagnosis. Parents also worried about what would happen to their young adult when they were no longer able to care for them.
Jevne, K. W., et al.	2022	Norway	To explore the thoughts of emerging adults with Down Syndrome on quality of life and subjective wellbeing.	8 young adults with Down Syndrome (aged 22yo).	Qualitative methodology. Individual, open-ended semi-structured interviews.	The young adults who worked showed pride and enjoyment in their work and gained meaning from it, e.g., in feeling like they were helping others. Work was important to the young adults for several reasons including learning, developing skills, friendships, and community participation. The young adults needed to feel safe and be prepared for tasks in order to develop their mastery, e.g., use of support strategies like lists and knowing who to ask for help. Mastery seemed to be about interest, capability and careful preparation for tasks rather than type of work setting or money for these young adults. The young adults shared aspirations to move on to other jobs (e.g., out of the daycare centre if working there or for those not in work, to obtain work at somepoint). Financial aspects were not mentioned. Young adults highlighted the importance of having an active and social leisure life comprising both organised (e.g., sports and community/cultural activities, e.g., going to the theatre) and informal activities (e.g., watching Netflix with friends). The young adults were mainly friends with young adults with ID, whom they met in daycare centres/sheltered workplaces. Contact with friends via virtual means was important, as was spending time with siblings. Young adults recognised their parents' help/involvement when it

						came to their transport to/from or participation in organised activities, or the help of a personal assistant. Some enjoyed the independence of independent living where they could use technology to assist them, e.g., setting reminders/travelling apps; and staying in touch with their families. Some were excited about the prospect of moving out and getting away from what they called their ‘nagging parents’. Some young adults did not express the desire to move out of the family home, feeling they needed help with self-care, or worrying about who they could ask if they needed help.
Scott, M., et al.	2014	Western Australia	To explore the perspectives of young adults with Down Syndrome on what makes a ‘good life’, and to identify barriers and facilitators to participation.	12 young adults with Down Syndrome (aged 18-29yo).	Qualitative methodology with a two-stage design: individual semi-structured open-ended interviews; insights from which were used as insights for exploration in the focus group discussions.	There was a general consensus amongst the young adults that they felt that they had a ‘good life’. Young adults highlighted the importance of meaningful relationships with family, friends, and intimate partners; a pivotal element was spending time together, and physical affection in the case of intimate relationships. Young adults also saw it in the sense of the status of being a girlfriend/boyfriend. Some of the young adults had future aspirations for marriage/starting a family. Young adults felt that their parents both supported and sometimes experienced tensions with their parents regarding the development of their independence and/or autonomy. For example, parents provided positive and secure environments and gave advice, e.g., in relation to intimate relationships and taught skills like cooking and shopping. On the other hand, young adults sometimes felt that their parents imposed too many rules upon them, and they could experience feeling ‘smothered’ by their families. Friendships were pivotal and highly valued by the young adults in developing their sense of inclusion, acceptance and self-esteem. The young adults were enthusiastic about their friendships and enjoyed spending time and participating in activities with their friends. Some of the young adults considered further education to be important / practical within their circumstances, e.g., vocational courses. The young adults wanted to develop their autonomy, e.g., making their own decisions regarding food, clothing, etc., and being less

						dependent on their parents. For example, one young adult stated 'A good life is being my own boss and living by my own rules'. All the young adults shared the aspiration to live independently someday, whilst only two had achieved this. The young adults who worked described wanting to save their money and/or spend it on items like jewellery. There was a sense of being limited in terms of employment opportunities, e.g., one young adult described wanting to be famous but being 'stuck in a café'. Some young adults expressed the desire to want to learn to drive and hence not depend on their parents for transport to/from organised activities. Overall, the young adults were excited about their futures and had hopes/dreams. They perceived achieving these as being inherently important to having a 'good life'.

Appendix C: Description of group critiques applied to the literature review (Part One)

The studies reviewed in *Section One* and *Section Two* (*Part One*) are subject to appraisal in the form of group critiques, in keeping with the integrative nature of the LR (Snyder, 2019; Torraco, 2005). Baumeister and Leary (1997) commend group critiques for enabling an evaluative oversight across studies. The group critiques are intended to provide readers with a sense of the strengths and limitations across the body of literature discussed in one summary, rather than supply individual tenets dotted throughout which could be lost in the thematic exploration, and may not be as meaningful alone than when considered together. The critiques originate primarily from the researcher's own consideration which is based on their developing knowledge and understanding of research gained across their academic career. However, they are also informed and augmented by Yardley (2000)'s evaluative framework for qualitative research. The evaluative lens therefore pays heed to what could be considered as good qualitative research practice generally, yet it is also coherent with the researcher's own philosophical positioning (please see the *Ontology* and *Epistemology* sections in *Part Two*).

Appendix D: Recruitment process (Part Two)

The parents and their young adults with Down Syndrome lived in Wales/England and had resided in either of these two countries from the start of the first lockdown until the time of their interviews. Participant recruitment was restricted to Wales and England in terms of the similar conditions brought about by the C19P in these two countries, and when considering implications for EP practice as applied to the Welsh/English contexts, i.e., the ALN Code for Wales (2021) and the SEND Code of Practice (2015) which include commitments towards TIA through applying to YP identified as having ALN or SEN up to the age of 25yo. This geographical delineation also factored in travel feasibility as the researcher is local to North Wales, and participants had the option of in-person or online interviews.

The researcher contacted numerous and varied organisations that could be relevant to young adults with Down Syndrome and/or their parents/carers, including post-16/post-18 educational settings; community/support groups for young adults with Down Syndrome/their parents; leisure, sports/social clubs; various social media groups; local authority education/family/disability services; and third-sector organisations. Contact was established with the gatekeeper organisations via email or telephone, where the researcher described the study and provided supplementary/supporting information in a formal letter (please see Appendix E.vi). The researcher also sent a short video, introducing themselves and the study, and flyers in both Welsh and English (please see Appendix E.vii, and Appendix E.viii for the flyers and video link). Consenting organisations were requested to share the flyers and video with parents directly, or with related organisations who could disseminate to parents, and these contained the researcher's email address. Prospective participants expressed their interest via emailing the researcher. The researcher sent a reply email to each prospective participant with further information about the study [including potential interview questions (please see Appendix E.iv), an information sheet for themselves, and an accessible information sheet for their young adults with Down Syndrome (please see Appendix E.ii)], and detailed consent forms both for themselves and their young adults with Down Syndrome (please see Appendix E.iii). Hence informed consent was obtained from parents and their young adults with Down Syndrome to ensure that the latter consented to their parents engaging in an interview that would primarily be about them. The researcher offered to have a phone/video call with parents and their young adults with Down Syndrome to explain the study prior to them signing the consent forms but this offer was not taken up by any of the parents. Once parents completed and returned signed consent forms for themselves and their young adults with Down Syndrome, an interview was arranged.

Appendix E: Ethical considerations and front-facing documentation

Appendix E.i: Ethical considerations

This project was approved by Cardiff University's Research and Ethics Committee. The mothers were recruited indirectly via gatekeeper organisations such as schools/colleges, local authority organisations, social/community groups and third-sector organisations, and their participation was completely voluntary through self-selection. Self-selecting parents/carers emailed the researcher who then sent the detailed information sheets (Appendix E.ii) and consent forms (Appendix E.iii) for themselves and their young adults, and the interview prompt sheet (Appendix E.iv). The interview prompt sheet contributed towards honouring the ethical principle of informed consent, as the mothers would know something about what to expect, whilst being aware that the interview flow would also follow their direction. Together, these documents transparently delineated the purpose of the research, what would be expected of parents/carers in the interviews, how their data would be stored, and their right to withdrawal. It was required that young adults with Down Syndrome read their own accessible information sheet (Appendix E.ii) and read and sign their own consent form (Appendix E.iii). Hence the researcher ensured they obtained informed consent from parents and the young adults. The mothers who signed the consent form, and whose young adults with Down Syndrome signed their consent forms, and progressed to arranging an interview, were invited to contact the researcher prior to the interview if they had any queries, and were given opportunities at the start and end of the interview to ask questions or share feedback. They were also welcomed to contact the researcher after the interview if they wished to withdraw their data or if they had any questions, which none of the mothers did.

Please also see the letter/email to the gatekeeper organisations (Appendix E.vi) and the study advertisement flyers (English and Welsh) (Appendix E.vii), and video (Appendix E.viii), where the researcher introduced themselves and the research. The researcher offered participation through the medium of Welsh, however, the mothers recruited chose to participate through the medium of English.

Smith et al. (2021) emphasise the importance of researcher qualities in IPA such as flexibility, sensitivity and empathy. IPA involves studying experiences of significance to participants that may induce strong feelings. This study is no exception based on the focus of parents' young adults with Down Syndrome TIA during the C19P. It was therefore paramount to elicit their experiences from a position of curiosity and empathy. The researcher has been developing such skills over the course of the doctorate via working with CYP who present with a variety of needs, and various stakeholders including their parents/carers, as well as relevant experiences prior to the doctorate. Moreover, the researcher specifically prepared for the possibility that parents may experience psychological distress whilst sharing their personal experiences [Please see the Research Interview Graduated Distress Protocol adapted from Druacker et al. (2009; in Haigh & Witham, 2015) in Appendix E.ix], and the possibility that any safeguarding issues arose; possibilities that didn't come to bear. The mothers were also properly debriefed verbally at the end of their interviews, and they were sent a debrief form (Appendix E.v).

The mothers and the young adults with Down Syndrome were assured of data storage and anonymisation processes in the information sheets and consent forms; mothers were additionally reminded after their interviews in the debrief form (Appendix E.v). All the names that appear in the *Findings* section are pseudonyms and any identifiable information was changed/removed, e.g., residential locations, names of clubs/support groups, etc.

Appendix E.ii: Information sheets for parents and their young adults

Information sheet for Parents/Carers of Young Adults with Down Syndrome

How did the Covid-19 pandemic impact the transition into adulthood for young adults with Down Syndrome? Experiences of parents/carers.

I would like to invite you to participate in my study. **Please read the information below before deciding whether you would like to participate. Please also read the documents provided for your young adult, and ask them to read these**, supporting them where necessary.

1. What is the purpose of the study?

The purpose of this study is to explore how the Covid-19 pandemic may have impacted the transition into adulthood for young adults with Down Syndrome, considering both the period of the pandemic and in the longer-term. This will involve a **one to one interview with myself lasting up to one hour**.

2. Why have I been invited?

You have been asked to participate as you are a parent/carer of a young adult with Down Syndrome who was aged 17-25years at the start of the first lockdown (23rd March 2020), and so they would be 20-29years now.

3. Do I have to take part?

Your participation is completely voluntary and you can withdraw at any time. If you would like to withdraw before the interview, please email me. If you would like to withdraw during the interview, we will stop immediately and the data will be destroyed. If you would like to withdraw your data after the interview, **please email me within one week** of your interview and your responses will be destroyed. After this, the data will be anonymised and it will not be possible to identify your data in order to remove it from the research.

4. What will I have to do?

In my email there should be the following attachments for yourself: this **Information Sheet**; the **Consent Form**; and the **Interview Prompt Sheet**. I have also attached an **Information Sheet** and **Consent Form** for your young adult.

If you would like to take part in my study please complete the following steps:

- Read the **Information Sheet**, the **Interview Prompt Sheet**, and the **Consent Form for parents/carers**.
- If you are happy with the terms stated, please complete and sign the **Consent Form**.
- Please ask your young adult to read the **Information Sheet** and **Consent Form for young adults**, supporting them where necessary. I am happy to have a call with you both to offer further explanation; if you would like this, please send me an email.
- If your young adult is happy with the terms stated, please could they complete and sign the **Consent Form**.
- Please send me the signed **Consent Forms (one for yourself and one for your young adult)**.
- We can then arrange an interview time and date.

Interviews will take place in person at a location convenient to you or online on Microsoft TEAMS. This will depend on your preference or the distance between us. As this study involves you recollecting experiences across a three-year period, I have provided a Covid-19 timeline as a prompt, and space for notes. Please feel free to write any notes that you think would be helpful for you in the interview. Please note that this is not compulsory, but **I would invite you to familiarise yourself with the prompt sheet before our interview**. I will ask you the questions on the prompt sheet and may ask you to elaborate on your answers or follow-up questions.

You will be able to pass interview questions and you do not need to share an experience if you think it would make you or your young adult feel uncomfortable. You may want to have a conversation with your young adult before your interview about things they would like you to share or not share, but this is not compulsory.

5. Will my taking part in the study be kept confidential?

Please note that you will be identified by a randomised participant code (and not by name) and any data will be stored confidentially on a password-protected computer. The interview will be audio recorded for transcription. This audio recording will be stored in my password-protected electronic university files and the recording will remain untouched for one week following your interview, to allow you to withdraw your data if you wish. After this I will start transcription and data analysis. The audio recording will be stored for no more than two months after your interview to allow time for transcription. After I have analysed the data, audio recordings will be destroyed, and transcriptions will be anonymised by removing the participant codes. Any names including yours and your young adult’s will be changed, and any personal information will be removed. Quotations or themes that are used in the write-up will be completely anonymous.

6. What will happen to the results of the research study?

The findings will be written up for my thesis, which may be published at a later stage. I plan to share findings with the organisation who advertised my study to you so that they can share them with yourself and others. You can contact me should you wish to discuss the findings or if you have any questions/comments about the study. Your participation in this research will not affect your relationship with the organisation, or any member of it, in any way.

This study will be unique in its orientation on the short-term and long-term impact of the Covid-19 pandemic on the transition into adulthood for young adults with Down Syndrome. Your insights could be helpful to educational psychologists, and wider systems of professionals supporting young adults with Down Syndrome, as well as to young adults with Down Syndrome themselves, and other parents/carers.

7. Where could I find advice/support for myself or my young adult following the interview?

If you would like support for yourself or your young adult, please consider getting in touch with the following charities/organisations:

- The Down's Syndrome Association:
  - Website: https://www.downs-syndrome.org.uk/
  - Email address: info@downs-syndrome.org.uk
  - Helpline number: 03331212300 (10am-4pm)
- Mencap:
  - Website: https://www.mencap.org.uk/advice-and-support/our-services/learning-disability-helpline
  - Helpline numbers: 08088000300 (Wales); 08088081111 (England) – Monday - Friday

- Mind:
  - Website: https://www.mind.org.uk/
  - Email address: info@mind.org.uk
  - Helpline number: 03001233393 (9am-6pm; Monday to Friday, except bank holidays).

- If you need urgent advice:
  - Crisis coping tools: https://www.mind.org.uk/need-urgent-help/
    Contact NHS 111 if you live in England or NHS 111 Wales if you live in Wales.
    https://www.mind.org.uk/information-support/guides-to-support-and-services/crisis-services/getting-help-in-a-crisis/

8. What if there is a problem?

If you have any questions relating to the research, please contact me on the email address below. I have also provided contact details for my research supervisor, [anonymised].

Contact Details [anonymised]:

Any complaints may be made to:

Secretary of the Ethics Committee
School of Psychology
Cardiff University
Tower Building
Park Place
Cardiff
CF10 3AT
Tel: 029 2087 0707
Email: psychethics@cardiff.ac.uk

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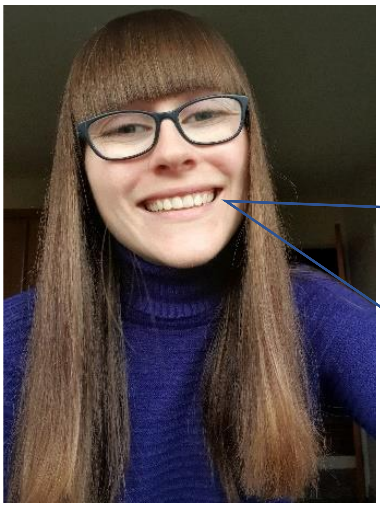
Information sheet for Young Adults with Down Syndrome

How did the Covid-19 pandemic impact the change into adulthood for young adults with Down Syndrome?
Experiences of parents/carers.



- My name is Eleri.
- I want to invite your parent/carer to take part in my research.
- I'm exploring how Covid-19 may have affected you and your parent/carer, as you became an adult.
- **Please read the information below if you want your parent/carer to take part**.

To help you understand this information you could:

- Ask your parent/carer or another person you trust to go through it with you.
- Watch my video - Research Video Clip.mp4

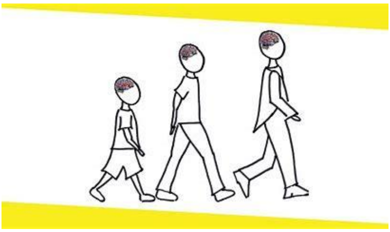
- Arrange a phone call or video call with me and your parent/carer.

1. What is the study?

I want to explore how the Covid-19 pandemic may have affected you and your parent/carer, as you became an adult.

I would like to interview your parent/carer.

2. Why has my parent/carer been invited?



You became an adult during the Covid-19 pandemic.

You were between **17-25 years old at the start of the first lockdown (23rd March 2020)**.

So you are between **20-29 years old now**.

3. Does my parent/carer have to take part?

No. They will only take part **if they want to** and you want them to.

They can only take part if you consent (agree) to this. You do not need to consent, it's completely **your choice**.

They can stop taking part before or during their interview and they don't need to say why.

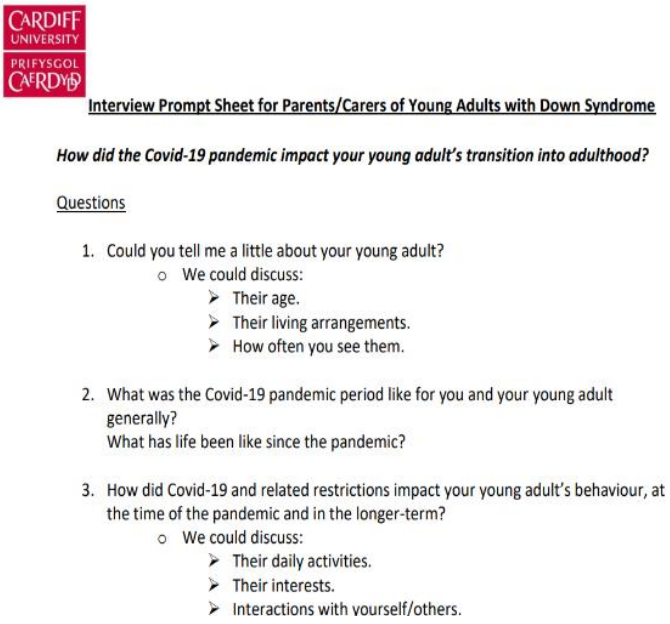
They can take away their information from the study **up to one week after their interview**.

4. What will my parent/carer do?

They will take part in a **one-to-one interview with myself lasting up to one hour**.

This can be **in-person or online** depending on their choice and the distance between us, and at a date and time chosen by them.

Please see the **Interview Prompt Sheet** which shows the questions I plan to ask your parent/carer, and I may ask other questions to find out more about what they say.

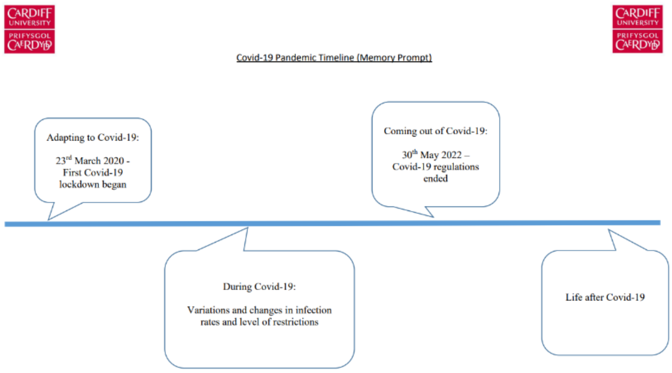


Interview Prompt Sheet for Parents/Carers of Young Adults with Down Syndrome

How did the Covid-19 pandemic impact your young adult's transition into adulthood?

Questions

1. Could you tell me a little about your young adult?
    - We could discuss:
        - Their age.
        - Their living arrangements.
        - How often you see them.
2. What was the Covid-19 pandemic period like for you and your young adult generally?
   What has life been like since the pandemic?
3. How did Covid-19 and related restrictions impact your young adult's behaviour, at the time of the pandemic and in the longer-term?
    - We could discuss:
        - Their daily activities.
        - Their interests.
        - Interactions with yourself/others.



The **Interview Prompt Sheet** also has a **Covid-19 timeline** to help your parent/carer remember your experiences.

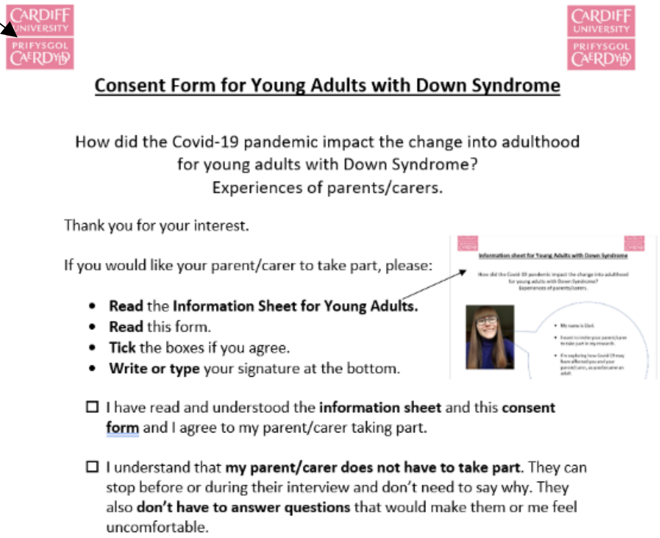
Your parent/carer does not have to answer questions if they think this would make you or them feel uncomfortable.

You could have a conversation with your parent/carer before their interview about things you would like them to share or not share, but **you do not have to do this**.

The interview will be **voice recorded** so that I can remember what they say.

5. What will I do?

If you are happy for your parent/carer to take part, please read, fill in and sign the **Consent Form for Young Adults with Down Syndrome**.



Consent Form for Young Adults with Down Syndrome

How did the Covid-19 pandemic impact the change into adulthood
for young adults with Down Syndrome?
Experiences of parents/carers.

Thank you for your interest.

If you would like your parent/carer to take part, please:

- **Read** the **Information Sheet for Young Adults.**
- **Read** this form.
- **Tick** the boxes if you agree.
- **Write or type** your signature at the bottom.

☐ I have read and understood the **information sheet** and this **consent form** and I agree to my parent/carer taking part.

☐ I understand that **my parent/carer does not have to take part**. They can stop before or during their interview and don't need to say why. They also **don't have to answer questions** that would make them or me feel uncomfortable.

You can ask your parent/carer to help you with this.

You both could also get in touch with me if you have any questions.

6. Will our information be kept confidential (private)?

Yes.

Information will be stored securely on my **password-protected** computer.

Only me and my supervisor can see it.

The voice recording of your parent/carer's interview will be stored for **no more than two months** after their interview.

After I have made sense of the interview, **the recording will be destroyed**.

The **transcription** (a written version of the interview) will be **anonymised**.

This means **no one will know the interview was about you or your parent/carer**.

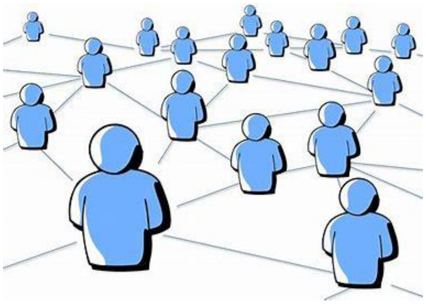
7. What will happen to the results of the research?

The findings will be written up for my thesis, which is a large research project that might be published (so more people can see it) at a later stage.

I plan to share findings with the organisation who advertised my study to your parent/carer so that they can share them with yourself and others.

You and your parent/carer can contact me if you want to talk about the findings or have any questions.

Your parent/carer taking part in this research will not affect your relationship with the organisation, or any member of it, in any way.



What your parent/carer shares with me could be helpful to you both, other young adults with Down Syndrome, and other parents/carers.

The findings could also be helpful to educational psychologists, and other people supporting young adults with Down Syndrome.

8. Where could I find advice/support for myself or my parent/carer?

If you would like support for yourself or your parent/carer, please speak to your parent/carer and consider contacting the following charities/organisations:

- **The Down's Syndrome Association:**
    - Website: https://www.downs-syndrome.org.uk/
    - Email address: info@downs-syndrome.org.uk
    - Helpline number: 03331212300 (10am-4pm)

- **Mencap:**
    - Website: https://www.mencap.org.uk/advice-and-support/our-services/learning-disability-helpline
        - Helpline numbers: 08088000300 (Wales); 08088081111 (England) – Monday - Friday

- **Mind:**
    - Website: https://www.mind.org.uk/
    - Email address: info@mind.org.uk
    - Helpline number: 03001233393 (9am-6pm; Monday to Friday, except bank holidays).

- **If you need urgent advice:**
    - Crisis coping tools: https://www.mind.org.uk/need-urgent-help/
    - Contact NHS 111 if you live in England or NHS 111 Wales if you live in Wales. https://www.mind.org.uk/information-support/guides-to-support-and-services/crisis-services/getting-help-in-a-crisis/

9. What if there is a problem?

If you or your parent/carer have any questions, please contact me on the **email address below.**

There is also the email address for **my supervisor, [anonymised]** (the person who guides me with this research).

Contact Details:

- [anonymised]

Any complaints may be made to:

Secretary of the Ethics Committee
School of Psychology
Cardiff University
Tower Building
Park Place
Cardiff
CF10 3AT
Tel: 029 2087 0707
Email: psychethics@cardiff.ac.uk

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Appendix E.iii: Consent forms for parents and their young adults

Participant Consent Form for Parents/Carers of Young Adults with Down Syndrome

How did the Covid-19 pandemic impact the transition into adulthood for young adults with Down Syndrome? Experiences of parents/carers.

I would like to thank you for your interest in this research. If you would like to continue and participate in the interview process, please read this **Consent Form** and indicate below whether you are comfortable with the terms stated. Please remember, **participation is voluntary and there are no repercussions for declining at any stage**.

- ☐ I have been informed of the nature, format and aim of this study and I consent to taking part.
- ☐ My young adult consents to me taking part and has read the information sheet and consent form for young adults, as well as completed and signed the consent form.
- ☐ I understand that my participation is voluntary and that I have the right to withdraw before or during the interview and that I do not need to give a reason for this. I also understand that I can pass interview questions or not share an experience if this would make me or my young adult feel uncomfortable.
- ☐ I understand that I can withdraw my data from the study at any point within one week of the date of the interview. I understand that after this my anonymised interview data may be used as part of the findings of the research, and as such would be unretractable.
- ☐ I understand that my interview audio recording will be stored securely and confidentially on a password-protected computer. This recording will be kept for no more than two months to allow time for transcription. After transcription, the audio recording will be destroyed. The participant code will be removed from the transcription.
- ☐ I understand that the conversation from my interview including quotations may be used in the discussion and write-up of this study, but that these will be anonymised (for example, any names will be changed and personal/identifiable information will be removed). Therefore, the research data in the write-up and possible future publication will be fully anonymous.
- ☐ I have had the opportunity to ask any questions I may have about the research, and I know who I can contact if I have any further questions, concerns, or comments.

Signature: ____

Date: ____

Participant code (to be assigned by the researcher): _________________________________

For queries relating to the research, please contact the researcher via the below email address:
[anonymised]

Research Supervisor contact details:

[anonymised]

Any complaints may be made to:

Secretary of the Ethics Committee
School of Psychology
Cardiff University
Tower Building
Park Place
Cardiff
CF10 3AT
Tel: 029 2087 0707
Email: psychethics@cardiff.ac.uk

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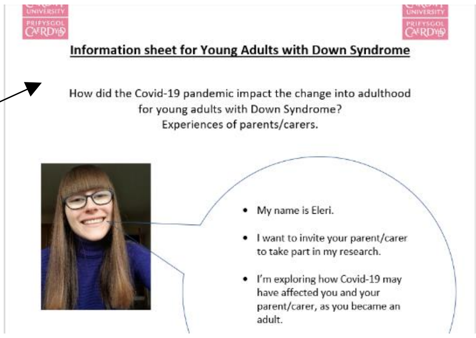
Consent Form for Young Adults with Down Syndrome

How did the Covid-19 pandemic impact the change into adulthood
for young adults with Down Syndrome?
Experiences of parents/carers.

Thank you for your interest.

If you would like your parent/carer to take part, please:

- **Read** the **Information Sheet for Young Adults.**
- **Read** this form.
- **Tick** the boxes if you agree.
- **Write or type** your signature at the bottom.



Information sheet for Young Adults with Down Syndrome

How did the Covid-19 pandemic impact the change into adulthood
for young adults with Down Syndrome?
Experiences of parents/carers.

- My name is Eleri.
- I want to invite your parent/carer to take part in my research.
- I'm exploring how Covid-19 may have affected you and your parent/carer, as you became an adult.

To help you understand this information you could:

- Ask your parent/carer or another person you trust to go through it with you.
- Arrange a phone call or video call with me and your parent/carer.

If you agree, please tick each box

☐ I have read and understood the **information sheet** and this **consent form**.

☐ **I agree** to my parent/carer taking part.

☐ I understand that **my parent/carer does not have to take part**.

They can stop before or during their interview and don’t need to say why.

They also **don’t have to answer questions** that would make them or me feel uncomfortable.

☐ I understand that my parent/carer can remove their information from the study **up to one week after their interview**.

After this week what they say will be used in the research.

This will be **anonymous (so no one will know it’s about you or your parent/carer)**.

☐ I understand that the interview voice recording will be stored securely on a **password-protected** computer.

No one will hear this except Eleri and Eleri’s supervisor.

This recording will be kept for **no more than two months** to allow time for writing up. **After writing up, the recording will be destroyed**.

☐ I understand that what my parent/carer says in their interview may be used in the discussion and write-up of this study.

This will be **anonymised (no identifiable information so no one will know it is about you or your parent/carer)**.

☐ I have had the chance to ask any questions I have about the research.

☐ I know who I can contact if I have any questions, worries, or comments.

Signature:

____

Date:

____

For questions about the research, please email the researcher:
[anonymised]

Research Supervisor contact details:
[anonymised]

Any complaints may be made to:

Secretary of the Ethics Committee
School of Psychology
Cardiff University
Tower Building
Park Place
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Appendix E.iv: Interview prompt sheet

Interview Prompt Sheet for Parents/Carers of Young Adults with Down Syndrome

How did the Covid-19 pandemic impact your young adult's transition into adulthood?

Questions

1. Could you tell me a little about your young adult?
    - We could discuss:
        - Their age.
        - Their living arrangements.
        - How often you see them.

2. What was the Covid-19 pandemic period like for you and your young adult generally?
   What has life been like since the pandemic?

3. How did Covid-19 and related restrictions impact your young adult's behaviour, at the time of the pandemic and in the longer-term?
    - We could discuss:
        - Their daily activities.
        - Their interests.
        - Interactions with yourself/others.
        - Adapting to new routines.
        - What possible changes were like for you and them.

4. How did Covid-19 and related restrictions impact their independence, at the time of the pandemic and in the longer-term?
    - We could discuss:
        - Engagement in independent activities, e.g., going out, travelling independently.
        - Living independently.
        - Self-care; chores.
        - Following their own agenda.
        - What possible changes were like for you and them.

5. How did Covid-19 and related restrictions impact their relationships, at the time of the pandemic and in the longer-term?
    - We could discuss:
        - Your relationship with them.
        - Other family relationships.
        - Social friendships or connections outside the family.
        - Intimate or romantic relationships.
        - Community relationships, e.g., volunteering, employment.
        - What possible changes were like for you and them.

6. How did Covid-19 and related restrictions impact their community participation, at the time of the pandemic and in the longer-term?
    - We could discuss:
        - Leisure or sport activities.
        - Employment or volunteering.
        - Further education.
        - Groups or clubs.
        - What possible changes were like for you and them.

7. How did Covid-19 and related restrictions impact their physical health, at the time of the pandemic and in the longer-term?
    - We could discuss:
        - Eating or exercise.
        - Sleep.
        - Medical aspects.
        - What possible changes were like for you and them.

8. How did Covid-19 and related restrictions impact their mental health and wellbeing, at the time of the pandemic and in the longer-term?
    - We could discuss:
        - What possible changes were like for you and them.

9. How did Covid-19 and related restrictions impact their future aspirations, at the time of the pandemic and in the longer-term?
    - We could discuss:
        - Employment / volunteering.
        - Further education.
        - Social connections or family life.
        - Future dreams, e.g., holidays or experiences.
        - What possible changes were like for you and them.

10. Is there anything else you would like to say about how Covid-19 impacted your young adult’s transition into adulthood?

Covid-19 Pandemic Timeline (Memory Prompt)

Adapting to Covid-19:

23rd March 2020 -

First Covid-19

During Covid-19:

Variations and changes in infection rates and level of restrictions

Coming out of Covid-19:

30th May 2022 –

Covid-19 regulations ended

Life after Covid-19

Space for Notes (Optional)

Appendix E.v: Debrief form

Debrief Form for Parents/Carers of Young Adults with Down Syndrome

How did the Covid-19 pandemic impact the transition into adulthood for young adults with Down Syndrome? Experiences of parents/carers.

Thank you very much for taking part in my research. Your time and contribution have been greatly appreciated.

What was the purpose of the study?

I am interested in accessing parent/carers' experiences so that more can be learnt about the transition into adulthood for young adults with Down Syndrome during the Covid-19 period, considering what it was like at the time of the pandemic and what is has been like in the longer-term. Your insights could be helpful to educational psychologists, and wider systems of professionals supporting young adults with Down Syndrome, as well as to young adults with Down Syndrome themselves, and other parents/carers.

What will happen to my information?

The information collected will be stored confidentially and securely on my password-protected computer. The audio recording will be stored in my password-protected electronic university files and the recording will remain untouched for one week to allow you to withdraw your data if you wish. After this I will start transcription and data analysis. Information will only be shared with my research supervisor (please see email address below).

The audio recording will be stored for no more than two months after your interview to allow time for transcription. After I have analysed the data, audio recordings will be destroyed, and transcriptions will be anonymised by removing the participant codes. Any names including yours and your young adult's will be changed, and any personal information will be removed. Findings that appear in my thesis write-up which may be published at a later stage, and shared with the organisation who advertised my study, will be completely anonymous.

Should you feel you no longer want your interview to be part of this research, please contact me (please see email address below) within one week of the date and time of your interview. If you have any questions relating to the research, please contact me or my supervisor.

If you would like **advice/support for yourself or your young adult**, please consider getting in touch with the following charities/organisations:

- The Down's Syndrome Association:
    - Website: https://www.downs-syndrome.org.uk/
    - Email address: info@downs-syndrome.org.uk
    - Helpline number: 03331212300 (10am-4pm)

- Mencap:
  - Website: https://www.mencap.org.uk/advice-and-support/our-services/learning-disability-helpline
  - Helpline numbers: 08088000300 (Wales); 08088081111 (England) – Monday - Friday

- Mind:
  - Website: https://www.mind.org.uk/
  - Email address: info@mind.org.uk
  - Helpline number: 03001233393 (9am-6pm; Monday to Friday, except bank holidays).

- If you need urgent advice:
  - Crisis coping tools: https://www.mind.org.uk/need-urgent-help/
  - Contact NHS 111 if you live in England or NHS 111 Wales if you live in Wales. https://www.mind.org.uk/information-support/guides-to-support-and-services/crisis-services/getting-help-in-a-crisis/

Thank you again for your time. I hope that you enjoyed your participation.

For queries relating to the research, please contact the researcher via the below email address:
[anonymised]

Research Supervisor contact details:
[anonymised]

Any complaints may be made to:

Secretary of the Ethics Committee
School of Psychology
Cardiff University
Tower Building
Park Place
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Appendix E.vi: Letter to gatekeeper organisations

To whom it may concern,

I am a Cardiff University trainee Educational Psychology student based in North Wales. For my thesis, I would like to explore how the Covid-19 pandemic may have impacted the transition into adulthood for young adults with Down Syndrome from the perspectives of parents/carers.

I would like to gain the voices of parents/carers of young adults with Down Syndrome who were in the process of, or had recently transitioned into adulthood during the Covid-19 pandemic, and so were in the age bracket of 17-25years at the start of the first lockdown (23rd March 2020) and so they would be 20-29years now. It is hoped that the insights of these parents/carers will be helpful to educational psychologists, and wider systems supporting young adults with Down Syndrome such as yourselves, as well as to young adults with Down Syndrome, and their parents/carers.

I am writing to enquire whether you would be willing to advertise this study on my behalf to parents/carers of young adults with Down Syndrome accessing your organisation? Please would it be possible for you to share the attached flyers and video with parents/carers? If possible within your remit and depending upon the distance between us, I would be happy to attend the beginning or end of a meeting/session to introduce myself, the study and share the flyers directly with parents/carers. Alternatively, if you or another professional member of the organisation could share the flyers and video with parents/carers, this would more than suffice.

The study will involve parents/carers taking part in a face-to-face one-to-one interview with myself lasting up to one hour, either in-person or online depending on their preference or the distance between us. For those parents/carers who are Welsh speakers and would prefer to do their interview in Welsh, this option is available as I am a Welsh speaker. Therefore, I have attached both English and Welsh language versions of the flyer.

Many thanks / diolch yn fawr in advance for your consideration of this project. Please let me know if you require further information. You are also welcome to contact my research supervisor on the contact details provided below.

Kind regards / cofion cynnes,
Eleri Davies, Researcher & Trainee Educational Psychologist [anonymised]

Research Supervisor
[anonymised]

Any complaints may be made to:

Secretary of the Ethics Committee
School of Psychology
Cardiff University
Tower Building
Park Place
Cardiff
CF10 3AT
Tel: 029 2087 0707
Email: psychethics@cardiff.ac.uk

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Appendix E.vii: Study advertisement flyers (English and Welsh)

PARENT/CARER RESEARCH OPPORTUNITY

I am a Trainee Educational Psychologist studying at Cardiff University. I am looking for parents/carers of young adults with Down Syndrome across Wales and England to take part in my thesis research. The study will explore how the Covid-19 pandemic may have impacted the transition into adulthood for young adults with Down Syndrome, from the perspectives of parents/carers.

If you are a parent/carer of a young adult with Down Syndrome who was aged 17-25 years old at the beginning of the first lockdown (23rd March 2020) (so they would be 20-29years now) and would like to share your experiences, I would be eager to gain your insights.

If you would like to take part, you will be asked to join a semi-structured interview with myself which will last up to one hour. This will be at a time that is convenient for you and the session can be held in person or over Microsoft TEAMS, depending upon your preference or the distance between us. Interviews can be conducted in Welsh if this is preferred.

If you are interested in taking part in this study, **please send me an email (please see email address below).** I will then send further information about the study and a consent form.

Thank you very much / diolch yn fawr for your consideration.

Best wishes,

Eleri

Contact Details:

- Eleri Davies, Researcher & Trainee Educational Psychologist: [anonymised]

CYFLE YMCHWIL AR GYFER RHIANT/GOFALWR

Rydw i'n seicolegydd addysg dan hyfforddiant sy'n astudio ym Mhrifysgol Caerdydd. Rydw i'n chwilio am rieni/gofalwyr oedolion ifanc hefo Down Syndrome ar draws Cymru a Lloegr i gyfrannu at fy ymchwil doethuriaeth. Bydd yr astudiaeth yn dysgu am effaith bosib y pandemig Covid-19 ar gyfnod pontio i fewn i oedolion ar gyfer oedolion ifanc hefo Down Syndrome, o safbwyntiau rhieni/gofalwyr.

Pe baech chi yn riant neu yn ofalwr oedolyn ifanc hefo Down Syndrome oedd yn 17-25oed ar gychwyn y cyfnod clo cyntaf (23ain mis Mawrth 2020) (felly buasen nhw'n 20-29oed rwan) ac yn fodlon rannu eich profiadau, buaswn i'n awyddus i glywed eich meddyliau.

Pe baech chi'n hoffi gwirfoddoli, byddech chi'n gwahoddiad i ymuno â chyfweliad lled-strwythuredig hefo fi, a fydd yn parau am hyd at un awr. Trefnid cyfweliad ar dyddiad ac amser cyfleus i chi mewn person neu dros Microsoft TEAMS, yn ôl eich dymuniad a'r pellter rhyngddon ni. Gall y cyfweliad cael ei gynnal trwy gyfrwng y Saesneg neu'r Gymraeg yn ôl eich dymuniad.

Os oes gennych chi ddiddordeb mewn cymryd rhan yn yr astudiaeth, **anfonwch e-bost i mi os gwelwch yn dda** (**gwelir cyfeiriad e-bost isod**). Ar ôl derbyn eich e-bost byddaf yn anfon mwy o wybodaeth am yr ymchwil yn ogystal â'r ffurflen caniatâd.

Diolch yn fawr am eich ystyriaeth.

Cofion cynnes,

Eleri

Manylion Cyswllt:

Eleri Davies, Ymchwilydd a Seicolegydd Addysg dan hyfforddiant: [anonymised]

Appendix E.viii: Study advertisement video link

Research Video Clip.mp4

Appendix E.ix: Research Interview Graduated Distress Protocol

The Research Interview Graduated Distress Protocol
Adapted from Draucker et al. (2009; in Haigh & Witham, 2015)

1.) If a participant’s distress reflects an emotional response reflective of what would be expected in an interview about their young adult’s transition into adulthood and Covid-19 pandemic experiences, offer support and extend the opportunity to: (a) stop the interview; (b) regroup; (c) continue.

2.) If a participant’s distress reflects acute emotional distress or a safety concern beyond what would be expected in an interview of this type but they are **NOT** in imminent danger, take the following actions:

   a.) Stop the interview immediately, explaining to the participant that the best course of action is to discontinue.

   b.) Offer support in the moment, utilising active listening and empathetic skills.

   c.) If, after time and space sitting with the participant, they feel their distress was not indicative of an immediate or high-level concern for their young adult encourage them to visit the Down Syndrome Association (https://www.downs-syndrome.org.uk/) and Mencap Cymru websites (https://wales.mencap.org.uk/), providing them with the website addresses so that they can seek information/resources. Signpost them to the helpline numbers on these websites.

   d.) If, after this period of reflection, it appears that their distress was indicative of an immediate or high-level concern advise the participant to contact the Down Syndrome Association (03331212300) or Wales Learning Disability (08088000300) helplines, providing them with these phone numbers.

   e.) In addition to the above, provide the participant with a mental health helpline number such as Mind (03001233393). Encourage the participant to call this number if they experience continued or heightened distress in the hours/days following the interview.

   f.) If they have an urgent concern, the researcher will signpost them to the crisis coping tools on the Mind website (https://www.mind.org.uk/need-urgent-help/) or to contact NHS 111 or NHS Direct (08454647).

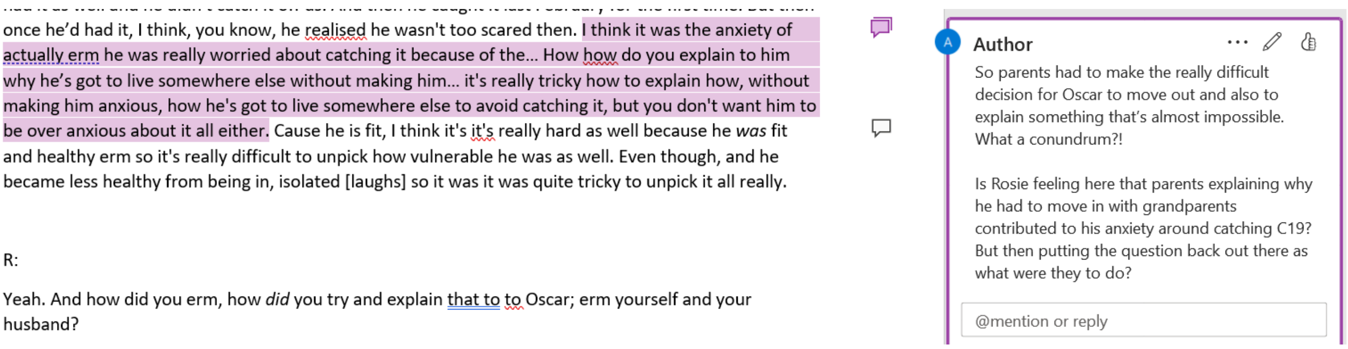
NB: Signposting information also appears on the Information Sheet and Debrief Form.

Appendix F: Illustrative extracts of the data analysis process

Development of the GET ‘Parents striking a precarious balance’

Exploratory Noting

Rosie and Oscar:



once he’d had it, I think, you know, he realised he wasn't too scared then. I think it was the anxiety of actually erm he was really worried about catching it because of the... How how do you explain to him why he’s got to live somewhere else without making him... it's really tricky how to explain how, without making him anxious, how he's got to live somewhere else to avoid catching it, but you don't want him to be over anxious about it all either. Cause he is fit, I think it's it's really hard as well because he *was* fit and healthy erm so it's really difficult to unpick how vulnerable he was as well. Even though, and he became less healthy from being in, isolated [laughs] so it was it was quite tricky to unpick it all really.

R:

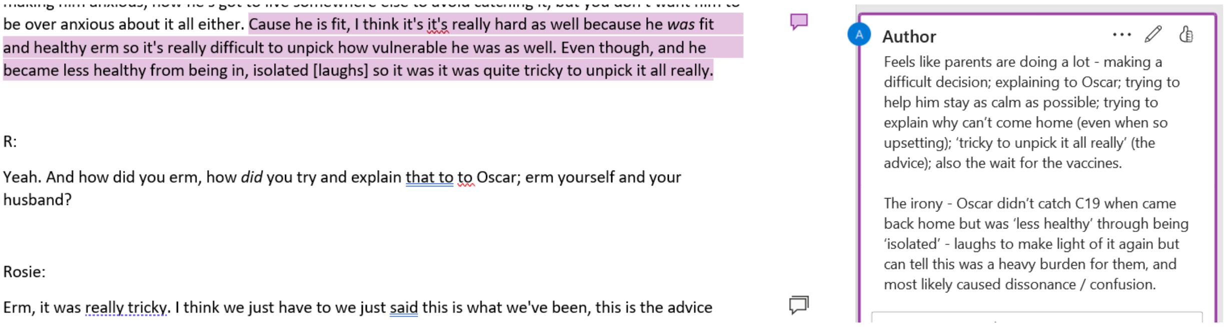
Yeah. And how did you erm, how *did* you try and explain that to to Oscar; erm yourself and your husband?

Author

So parents had to make the really difficult decision for Oscar to move out and also to explain something that’s almost impossible. What a conundrum?!

Is Rosie feeling here that parents explaining why he had to move in with grandparents contributed to his anxiety around catching C19? But then putting the question back out there as what were they to do?

@mention or reply



be over anxious about it all either. Cause he is fit, I think it's it's really hard as well because he *was* fit and healthy erm so it's really difficult to unpick how vulnerable he was as well. Even though, and he became less healthy from being in, isolated [laughs] so it was it was quite tricky to unpick it all really.

R:

Yeah. And how did you erm, how *did* you try and explain that to to Oscar; erm yourself and your husband?

Rosie:

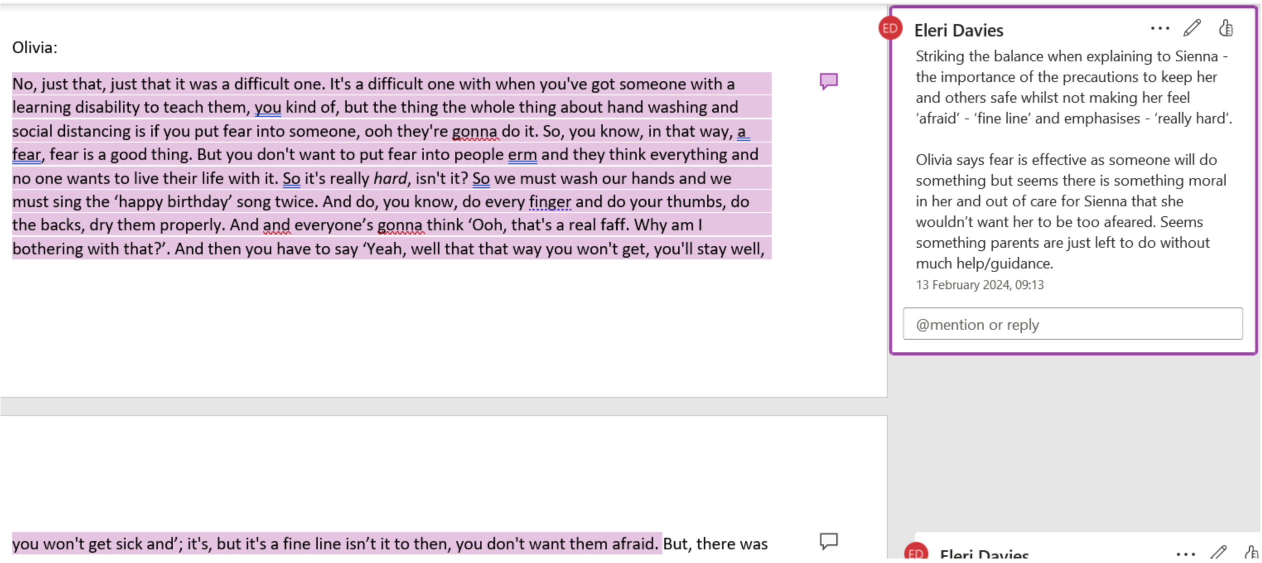
Erm, it was really tricky. I think we just have to we just said this is what we've been, this is the advice

Author

Feels like parents are doing a lot - making a difficult decision; explaining to Oscar; trying to help him stay as calm as possible; trying to explain why can’t come home (even when so upsetting); ‘tricky to unpick it all really’ (the advice); also the wait for the vaccines.

The irony - Oscar didn’t catch C19 when came back home but was ‘less healthy’ through being ‘isolated’ - laughs to make light of it again but can tell this was a heavy burden for them, and most likely caused dissonance / confusion.

Olivia and Sienna:



Olivia:

No, just that, just that it was a difficult one. It's a difficult one with when you've got someone with a learning disability to teach them, you kind of, but the thing the whole thing about hand washing and social distancing is if you put fear into someone, ooh they're gonna do it. So, you know, in that way, a fear, fear is a good thing. But you don't want to put fear into people erm and they think everything and no one wants to live their life with it. So it's really *hard*, isn't it? So we must wash our hands and we must sing the ‘happy birthday’ song twice. And do, you know, do every finger and do your thumbs, do the backs, dry them properly. And and everyone’s gonna think ‘Ooh, that's a real faff. Why am I bothering with that?’. And then you have to say ‘Yeah, well that that way you won't get, you'll stay well,

you won't get sick and’; it's, but it's a fine line isn’t it to then, you don't want them afraid. But, there was

Eleri Davies

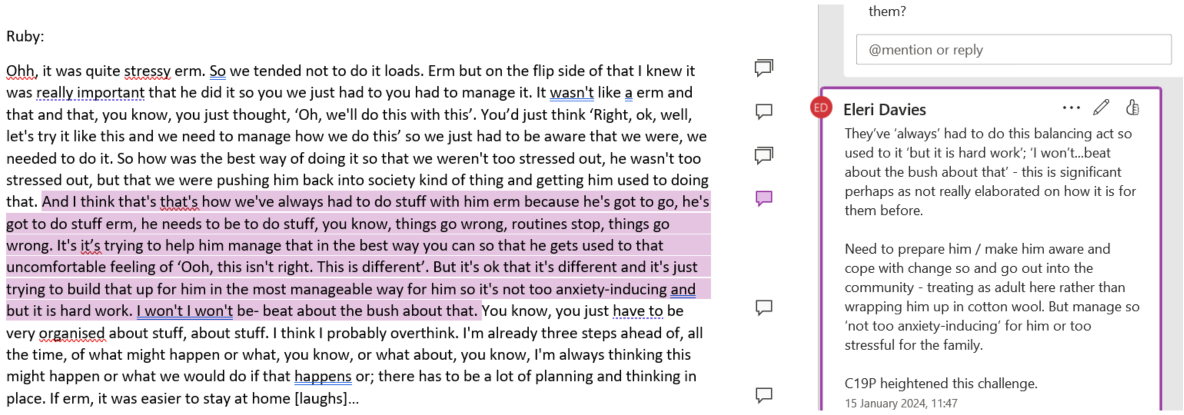
Striking the balance when explaining to Sienna - the importance of the precautions to keep her and others safe whilst not making her feel ‘afraid’ - ‘fine line’ and emphasises - ‘really hard’.

Olivia says fear is effective as someone will do something but seems there is something moral in her and out of care for Sienna that she wouldn’t want her to be too afeared. Seems something parents are just left to do without much help/guidance.

13 February 2024, 09:13

@mention or reply

Ruby and Alfie:



Ruby:

Ohh, it was quite stressy erm. So we tended not to do it loads. Erm but on the flip side of that I knew it was really important that he did it so you we just had to you had to manage it. It wasn't like a erm and that and that, you know, you just thought, 'Oh, we'll do this with this'. You'd just think 'Right, ok, well, let's try it like this and we need to manage how we do this' so we just had to be aware that we were, we needed to do it. So how was the best way of doing it so that we weren't too stressed out, he wasn't too stressed out, but that we were pushing him back into society kind of thing and getting him used to doing that. And I think that's that's how we've always had to do stuff with him erm because he's got to go, he's got to do stuff erm, he needs to be to do stuff, you know, things go wrong, routines stop, things go wrong. It's it's trying to help him manage that in the best way you can so that he gets used to that uncomfortable feeling of 'Ooh, this isn't right. This is different'. But it's ok that it's different and it's just trying to build that up for him in the most manageable way for him so it's not too anxiety-inducing and but it is hard work. I won't I won't be- beat about the bush about that. You know, you just have to be very organised about stuff, about stuff. I think I probably overthink. I'm already three steps ahead of, all the time, of what might happen or what, you know, or what about, you know, I'm always thinking this might happen or what we would do if that happens or; there has to be a lot of planning and thinking in place. If erm, it was easier to stay at home [laughs]...

them?

@mention or reply

Eleri Davies

They've 'always' had to do this balancing act so used to it 'but it is hard work'; 'I won't...beat about the bush about that' - this is significant perhaps as not really elaborated on how it is for them before.

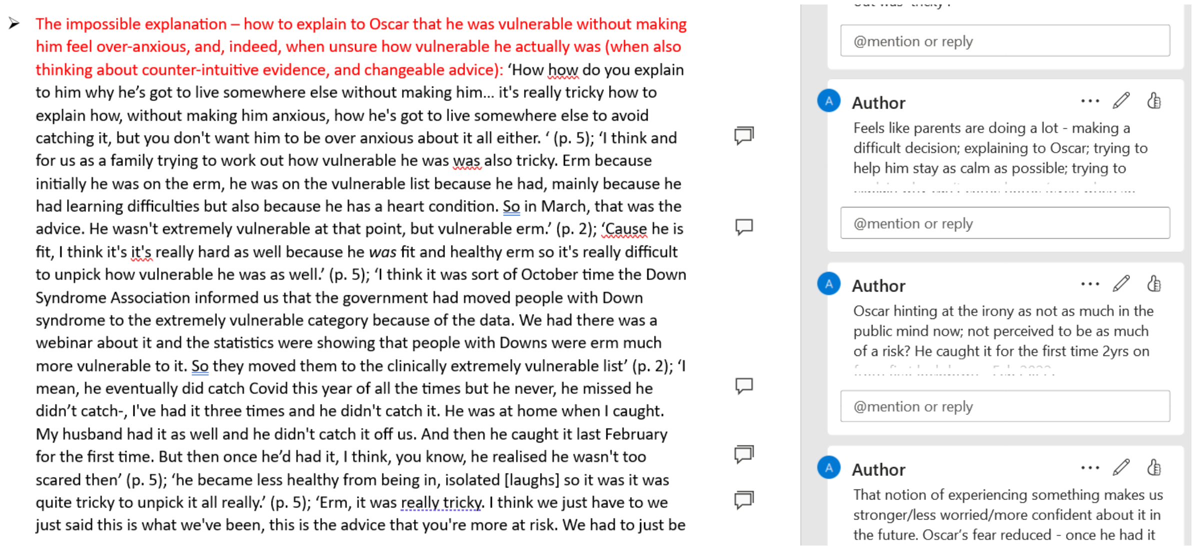
Need to prepare him / make him aware and cope with change so and go out into the community - treating as adult here rather than wrapping him up in cotton wool. But manage so 'not too anxiety-inducing' for him or too stressful for the family.

C19P heightened this challenge.

15 January 2024, 11:47

Experiential Statements

Rosie and Oscar:



- The impossible explanation – how to explain to Oscar that he was vulnerable without making him feel over-anxious, and, indeed, when unsure how vulnerable he actually was (when also thinking about counter-intuitive evidence, and changeable advice): 'How how do you explain to him why he's got to live somewhere else without making him... it's really tricky how to explain how, without making him anxious, how he's got to live somewhere else to avoid catching it, but you don't want him to be over anxious about it all either. ' (p. 5); 'I think and for us as a family trying to work out how vulnerable he was was also tricky. Erm because initially he was on the erm, he was on the vulnerable list because he had, mainly because he had learning difficulties but also because he has a heart condition. So in March, that was the advice. He wasn't extremely vulnerable at that point, but vulnerable erm.' (p. 2); 'Cause he is fit, I think it's it's really hard as well because he *was* fit and healthy erm so it's really difficult to unpick how vulnerable he was as well.' (p. 5); 'I think it was sort of October time the Down Syndrome Association informed us that the government had moved people with Down syndrome to the extremely vulnerable category because of the data. We had there was a webinar about it and the statistics were showing that people with Downs were erm much more vulnerable to it. So they moved them to the clinically extremely vulnerable list' (p. 2); 'I mean, he eventually did catch Covid this year of all the times but he never, he missed he didn't catch-, I've had it three times and he didn't catch it. He was at home when I caught. My husband had it as well and he didn't catch it off us. And then he caught it last February for the first time. But then once he'd had it, I think, you know, he realised he wasn't too scared then' (p. 5); 'he became less healthy from being in, isolated [laughs] so it was it was quite tricky to unpick it all really.' (p. 5); 'Erm, it was really tricky. I think we just have to we just said this is what we've been, this is the advice that you're more at risk. We had to just be

@mention or reply

Author

Feels like parents are doing a lot - making a difficult decision; explaining to Oscar; trying to help him stay as calm as possible; trying to

@mention or reply

Author

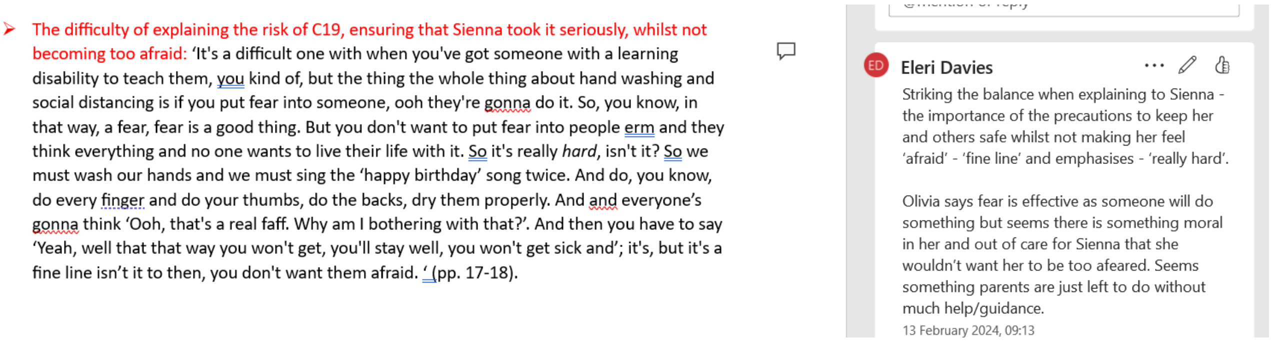
Oscar hinting at the irony as not as much in the public mind now; not perceived to be as much of a risk? He caught it for the first time 2yrs on

@mention or reply

Author

That notion of experiencing something makes us stronger/less worried/more confident about it in the future. Oscar's fear reduced - once he had it

Olivia and Sienna:



- The difficulty of explaining the risk of C19, ensuring that Sienna took it seriously, whilst not becoming too afraid: 'It's a difficult one with when you've got someone with a learning disability to teach them, you kind of, but the thing the whole thing about hand washing and social distancing is if you put fear into someone, ooh they're gonna do it. So, you know, in that way, a fear, fear is a good thing. But you don't want to put fear into people erm and they think everything and no one wants to live their life with it. So it's really *hard*, isn't it? So we must wash our hands and we must sing the 'happy birthday' song twice. And do, you know, do every finger and do your thumbs, do the backs, dry them properly. And and everyone's gonna think 'Ooh, that's a real faff. Why am I bothering with that?'. And then you have to say 'Yeah, well that that way you won't get, you'll stay well, you won't get sick and'; it's, but it's a fine line isn't it to then, you don't want them afraid. ' (pp. 17-18).

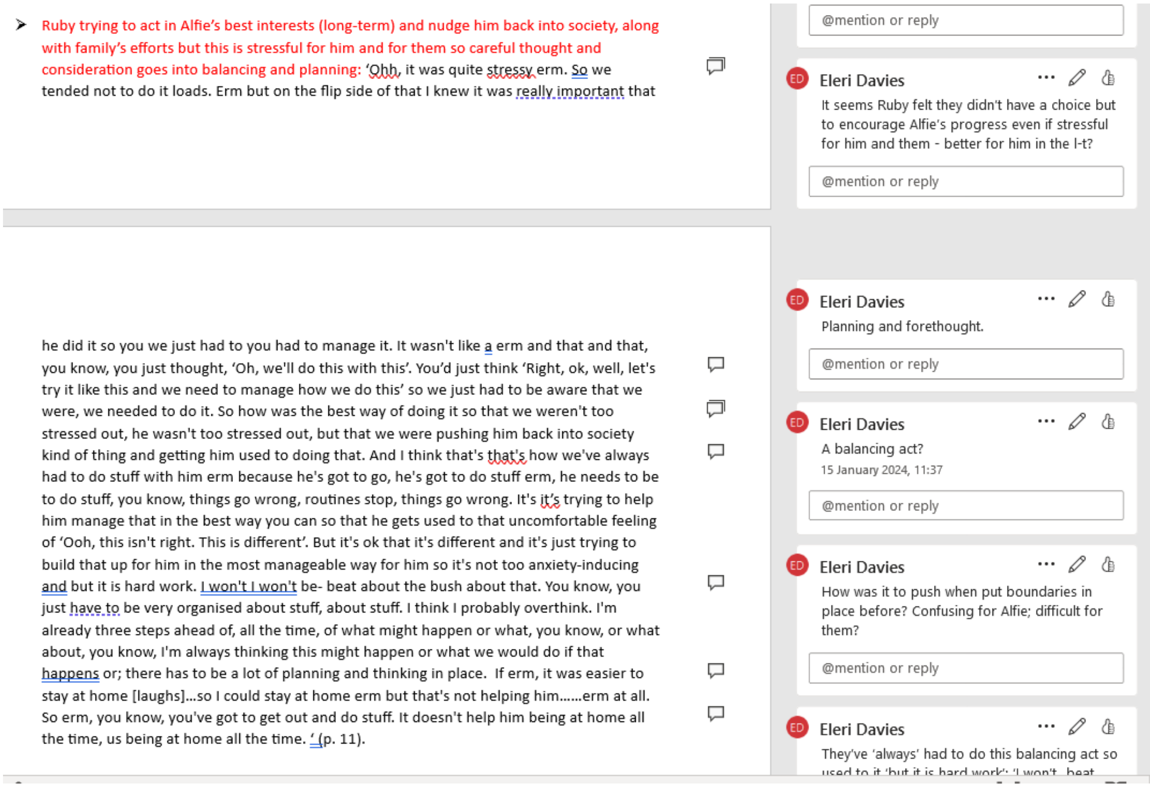
Eleri Davies

Striking the balance when explaining to Sienna - the importance of the precautions to keep her and others safe whilst not making her feel 'afraid' - 'fine line' and emphasises - 'really hard'.

Olivia says fear is effective as someone will do something but seems there is something moral in her and out of care for Sienna that she wouldn't want her to be too afeared. Seems something parents are just left to do without much help/guidance.

13 February 2024, 09:13

Ruby and Alfie:



- Ruby trying to act in Alfie's best interests (long-term) and nudge him back into society, along with family's efforts but this is stressful for him and for them so careful thought and consideration goes into balancing and planning: 'Ohh, it was quite stressy erm. So we tended not to do it loads. Erm but on the flip side of that I knew it was really important that

he did it so you we just had to you had to manage it. It wasn't like a erm and that and that, you know, you just thought, 'Oh, we'll do this with this'. You'd just think 'Right, ok, well, let's try it like this and we need to manage how we do this' so we just had to be aware that we were, we needed to do it. So how was the best way of doing it so that we weren't too stressed out, he wasn't too stressed out, but that we were pushing him back into society kind of thing and getting him used to doing that. And I think that's that's how we've always had to do stuff with him erm because he's got to go, he's got to do stuff erm, he needs to be to do stuff, you know, things go wrong, routines stop, things go wrong. It's it's trying to help him manage that in the best way you can so that he gets used to that uncomfortable feeling of 'Ooh, this isn't right. This is different'. But it's ok that it's different and it's just trying to build that up for him in the most manageable way for him so it's not too anxiety-inducing and but it is hard work. I won't I won't be- beat about the bush about that. You know, you just have to be very organised about stuff, about stuff. I think I probably overthink. I'm already three steps ahead of, all the time, of what might happen or what, you know, or what about, you know, I'm always thinking this might happen or what we would do if that happens or; there has to be a lot of planning and thinking in place. If erm, it was easier to stay at home [laughs]...so I could stay at home erm but that's not helping him......erm at all. So erm, you know, you've got to get out and do stuff. It doesn't help him being at home all the time, us being at home all the time. ' (p. 11).

Eleri Davies

It seems Ruby felt they didn't have a choice but to encourage Alfie's progress even if stressful for him and them - better for him in the l-t?

Eleri Davies

Planning and forethought.

Eleri Davies

A balancing act?

15 January 2024, 11:37

Eleri Davies

How was it to push when put boundaries in place before? Confusing for Alfie; difficult for them?

Eleri Davies

They've 'always' had to do this balancing act so used to it 'but it is hard work': 'I won't beat

Personal Experiential Themes (PETs)

Rosie and Oscar:

PET 3: The impossibility of decisions/explanations - Parents making an impossible decision for Oscar to move out of the family home, and the impossible task of making sense of what was going on, for themselves and for him; 'how how do you explain?'.

Olivia and Sienna:

PET 4: Olivia attempted to strike several balances with the help of her family, regarding TIA generally and those which were brought about by C19P-related conditions (such as explaining the pandemic to Sienna), and impacted Sienna in the long-term (e.g., her adherence to routines).

Ruby and Alfie:

PET 4: Parents striking a balance – pushing Alfie to be able to cope, being exposed to the world, yet, in a way he could manage which C19P potentially regressed / complicated. Pushing him and themselves (hard work for the family and Alfie). Knowing when to push v. when to hold back v. doing a bit of both.

Detailed consideration and contemplation of each PET, and returning to the transcripts/exploratory notes/experiential statements and illustrative quotations, enabled the researcher to interpret convergence towards development of the GET: Parents striking a precarious balance. Yet, idiographic manifestations were captured in the sub-themes.

Original thematic map

Autonomy: a multi-faceted phenomenon

- The C19P took away what was *theirs* and theirs *alone*
- Active agency to passive recipiency
- Dissonance – readiness to fly the nest but forced to stay within it
- The virtual realm – an alternative independence

Developing awareness

- The risk of C19: sensible caution or hypervigilance?
- Self-awareness
- Empathy and difference
- The fragility of life's circumstances

Routine: a kaleidoscope of meanings

- Oscar: variety and autonomy versus monotony and passivity
- Alfie: facilitation versus regression into his comfort zone
- Sienna: facilitation versus 'unmovable' rituals

Parents striking a precarious balance

- 'How how do you explain?'
- The impossible decision
- To nudge or not to nudge? Or somewhere in between…

Resilience

- Mindset
- Being with
- Adapting to life post-C19P

Analysis refinement through returning to the transcripts and the RQs led to the collapsing of two GETs: Awareness and Resilience; some of this process/consideration receives further exploration/reflection in *Part Three*.

Appendix G: Application of Yardley (2000)'s criteria for good qualitative research to the present study

	Application of criterion to the present study
Sensitivity to context	• The LR exploring TIA for young adults with Down Syndrome in *Section One (Part One)* went beyond descriptives to offer a thematic integration of previous studies, utilising available literature to deepen understandings of the topic, rather than simply retelling what's out there; thus, evidencing an enhanced sensitivity to context with a thematic oversight of relevant research. • A study of the literature regarding TIA for young adults with Down Syndrome, and a scoping review of literature regarding people with Down Syndrome and the impact of the C19P, as well as personal experience of the C19P living with a sister who is a young adult with Down Syndrome, equipped the researcher with a detailed awareness of factors that may have clashed during the C19P for young adults with Down Syndrome TIA, which fed into the rationale for the present study. • Whilst the above knowledge helped the researcher conceive and design the present study, use of the IPA method entailed an inductive focus, eliciting the experiences of mothers of young adults with Down Syndrome in the present research, with a commitment towards staying close to the data in interpretation, where the researcher frequently revisited the original transcripts in theme generation, and worked to reflexively 'bracket off' their own influences (reflected upon in *Part Three*), to ensure sensitivity to the data. • The relationship between researcher and participants must be considered, and any influence/s reflected upon and highlighted. The researcher was careful not to mention they had a sister with Down Syndrome unless the mothers asked. Originally, they intended to disclose this for the purposes of building rapport and helping the mothers to feel safe in sharing their experiences. However, they decided to create a safe interview space via using their skills developed over the course of the doctorate (in practitioner and researcher contexts), and did not mention their sister so that the discussions focused on the mothers' young adults, such that researcher and participant experiences did not become enmeshed together.
Commitment and rigour	• The researcher completed an in-depth integrative LR, exploring TIA for young adults with Down Syndrome, thoroughly appraising studies reviewed such that they could organise concepts according to their own interpretation from contemplating them together as a unit. Moreover, there is a sense of wholeness to the evaluations of the literature which are presented in group critiques. • The researcher engaged in deep contemplation of the topic when reading for and writing the LR, but additionally in the sense of data analysis. This took time, where the researcher fully immersed themselves in the data, flexibly moving between and returning to different stages of the IPA process to ensure adherence to the principles and bracketing-off of their own influences.

	• The researcher produced a comprehensive, in-depth analysis. The researcher tried to be thorough and in so doing originally had too many themes for a synthesised, accessible analysis. Refinement of the themes required further immersion and revisiting the RQs, thus upholding rigour to the purpose of the study and the process of IPA; that is, interpreting the mothers' phenomenology, rather than descriptively summarising all aspects of note.
Transparency and coherence	• The researcher has openly and clearly explained the processes undertaken to arrive at the products offered in this thesis research. The approaches to each LR in *Section One* and *Section Two (Part One)* are explained and justified; with transparency of process illustrated for *Section One* in Appendices A and B. Moreover, there is transparency regarding the data analysis process, where the researcher provides illustrative extracts in Appendix F. • Staying true to IPA, and qualitative methodologies generally, the researcher was reflexive throughout the process, from conception to completion, and key reflections appear in *Part Three*. • As outlined in *Group Critique One*, researchers should demonstrate coherence in their studies, with cogency between philosophical foundations and research design, right through to the claims made in findings/discussion and evaluation of their research. The threads of CR and SC run through the RQs, cohere with the qualitative methodology and IPA data analysis method, and insights offered are bound to the participants' idiographic experiences; there is no attempt to homogenise or generalise. Moreover, the strengths/limitations are applicable to the philosophical foundations, rather than allowing positivist creep to cloud the researcher's self-evaluative lens, making the resultant appraisal more meaningful.
Impact and importance	• According to the awareness of this researcher, this study was unique in its combined focus/design and sheds light on TIA for young adults with Down Syndrome from an interesting and helpful angle, i.e., TIA during the C19P. This not only provides insights to practitioners in the post-18/young adulthood sectors on TIA generally for young adults with Down Syndrome, but also in the context of widespread/substantial societal and environmental change. Therefore, practitioners can learn from this study what may be helpful to consider should something on the scale of the C19P happen again. • The themes generated offer a nuanced/complex picture, hopefully developing understandings of what to consider regarding TIA for young adults with Down Syndrome, rather than relying on preconceived notions, or potentially reductionist outcome-based measures. • Specific implications for EPs are offered, illustrating practical utility to the profession regarding the demographic of young adults with Down Syndrome, where insights gained could also be transferred/adapted to young adults with ALN more generally. Moreover, EPs work systemically such that their use of insights from this research could positively impact upon young adults with Down Syndrome and their parents/families, but also other practitioners, widening the practical impact of the research.