“Us learning to live without him 24/7”

Exploring the experiences of parents of young people with profound and multiple learning disabilities at transition to adult services: A multi-perspectival and multi-modal phenomenological study

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Doctor of Philosophy

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Abstract

Young people with profound and multiple learning disabilities have increased life-expectancy, owing to improvements in healthcare, now often arriving at adulthood. They face multiple transitions from paediatric to adult health and social care services due to the complexity of their needs, whilst remaining reliant on their parents for care. Parents act as advocates and transition co-ordinators, facing new challenges as support moves from a family-centred model to symptom-led, medical model.

The work of this thesis aims to explore parents' experiences of their child's transition and the unaddressed issue of their own support needs at this time. This was achieved through a multi-perspectival and multi-modal phenomenological approach, employing relational mapping and research poetry. A committed research advisory group engaged with the project throughout.

A poetic synthesis of qualitative evidence illuminated parents' caring experiences during the transition years, exposing parental-child interdependence, difficulties sharing responsibilities with service providers and fear of the future. Template analysis adopting a phenomenological interpretative approach considered professionals' views of both transition and the parents' role. Differences in attitudes between professionals working closely with families and commissioners reflected differences in how parents are perceived. A secondary study from the template analysis considered professionals' experiences of working with families during Covid-19. In a study employing longitudinal Interpretative Phenomenological Analysis, parents of young people with PMLD shared their transition experiences, supported by relational mapping. The complexity of support for young people was contrasted with a lack of support for parents.

A change in parents' legal status induced uncertainty for the future. The parents' role as superseded marginalised carers was established through the application of Bronfenbrenner's Ecological Model (1979) and secondary analysis employing Twigg and Atkin's Typology of Caring (1994). Recommendations are provided for supporting parents through top-down systemic education and bottom-up interventions.

Keywords: Parent, Social-worker, Healthcare-professional, Qualitative, Phenomenology, Co-production, Poetry, Pictor, Reflexivity, PIMD.

Our children

Individual,
unique like all young people;
we want our children
just to be seen for all their
wonderfulness, uniqueness.

(Juliet)

I would like to dedicate this thesis
to all the young people with severe and profound learning disabilities
who have come into my life in the past 29 years,
to the children of the thesis
and to the "little angels".

Our world revolves around you.

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List of Abbreviations

CHCN	Complex Health Care Needs
CP	Cerebral Palsy
CQC	Care Quality Commission
EHCP	Education Health and Care Plan
GP	General Practitioner
HCP	Health care professional
LD	Learning Disability
MCA	Mental Capacity Act (2005)
NHS	National Health Service
OT	Occupational Therapist
PEG	Percutaneous Endoscopic Gastrostomy (tube)
PfA	Preparing for Adulthood
PHaR	Phenomenology of Health and Relationships
PIMD	Profound Intellectual and Multiple Disabilities
PMLD	Profound and Multiple Learning Disabilities
SALT	Speech and Language Therapist
SEND	Special Educational Needs and Disability
SLD	Severe Learning Disabilities
TRAG	Transition Research Advisory Group

List of poems

Chapter 1

Introduction

The work in this thesis focuses on parents' and professionals' experiences of the transition from children's to adults' services for young people with profound and multiple learning disabilities. In this chapter, I will define key terms and outline the rationale for the research. I will also introduce key concepts, including Bronfenbrenner's Ecological Model (1979) and Twigg and Atkin's Typology of Caring (1994), which will be employed throughout the thesis to explore parents' role in relation to their children's transition to adult services. Finally, I will outline the main research questions and framework of the thesis.

Introductory statements

The aim of this thesis is to contribute to the growing body of research about how parent-carers of young people with profound and multiple learning disabilities (PMLD) and complex health care needs (CHCN) experience the transition from paediatric services to adult health and social care. My particular focus is on the parent-carers' role within this process, looking beyond how they support and advocate for their children (Jacobs et al., 2020), to the impact of transition on them as individuals in their own right (Heath et al., 2017; Brown et al., 2018), in order to understand how parents could best be supported at this time (Beach et al., 2022).

There are increasing calls to include the views of young people themselves within transition planning (Jacobs et al., 2020) and within research (Grace et al., 2024). Recognising and including the individual needs and communication styles of young people with PMLD is a major focus of research (Simmons, 2020) and as a result parent-carers are sometimes labelled "proxies" (Nieuwenhuijse et al., 2024). I wholeheartedly recognise and support the importance of this research focusing on young people with PMLD. However, I feel it is important to clarify that this thesis does not concentrate on what the young person needs at transition, so much as what the parental role is at this time; thus shifting focus from the needs of the person being cared for, to the needs of the carer (Twigg & Atkin, 1994). This is important because research suggests parent-carers are in emotional turmoil at transition

(Brown et al., 2020) but their rights to assessment and support remain overlooked (Fernandez et al., 2020).

This thesis therefore considers what it means to care for a young person with PMLD and CHCN, as they approach adulthood; how professionals view the parental role during the transition years; how parent-carers and professionals work together; the variety and complexity of transitions one young person might encounter and how this impacts the parents. Finally, it also considers how parents might plan for their own futures, once their child reaches adulthood.

As a researcher, it is important for me to give good representation to those stories through qualitative methodology, thus allowing the participants to express their views, tell their own stories and explore their experiences. To ensure that my research was relevant to the PMLD population, I established a public involvement group to help guide my research. Their role grew as the project developed. At the outset, the group helped me develop creative research methods, which allowed the participants to explore their experiences, deciding and sharing what was important and relevant to them. Later, members of the group gave feedback on the findings and helped shape the recommendations. They have shared their wisdom and unique perspectives, working tirelessly and enthusiastically. This thesis is built on their contributions.

Origins of the thesis

I am the mother of a young man with severe learning disabilities (SLD) who has engaged with many elements of the special educational needs and disabilities (SEND) system, particularly within social care. Early in my parenting journey, I joined a local parent-carers' group who became a bedrock of support over the past 26 years. We learnt of the challenges and joys that are presented to families like ours. We met multiple professionals and service providers, who assessed our children, talked to us, and gave us varying degrees of support. During this time, opportunities arose to give feedback to service providers, and I soon found myself sitting on consultation boards, and writing reports.

In parallel, I started to study psychology, primarily because we had been in contact with many psychologists with our son, and I wanted to understand their methods of working and language. As part of my studies at Aston, I undertook two projects which explored the experiences of parents of disabled young people, in relation to service provision and healthcare. The current thesis builds on the skills I learnt in researching those topics.

The origins of this particular thesis lie in a previous, smaller project that I undertook on behalf of Shropshire Parent & Carers Council (PACC) in 2015, funded by Healthwatch Shropshire. Working with the Partnership Lead of PACC, Sarah Thomas, we developed a project which focused on the experiences of parent-carers of disabled children as multi-service users. The aims were to highlight the working relationships between parents and service providers, and to make recommendations to enhance partnership between the two groups. Our findings indicated that parent-carers accessed a wide range of services for their children, depending on the healthcare and learning disability needs of their child, and whilst many participants gave positive comments about service providers, many believed professionals generally lacked empathy. Sometimes parents felt that they were patronised, not understood or even not believed by professionals. Additionally, a key finding was that transitions between services in the young people's lives were experienced as stressful by both parents and young people (Slade & Thomas, 2016).

In particular, we found that the group of parents of young people with PMLD and CHCN accessed the highest number of services, sometimes in excess of twenty services at any given time, and therefore transitions were complex, poorly defined and time consuming. I developed a form of service mapping (using an online mind-mapping tool) to illustrate the differences in services accessed by the participating families.

That study then became the springboard for my PhD thesis proposal, with helpful feedback from the late Professor Helen Pattison and Professor Rachel Shaw.

Definition of terms

Defining PMLD

Profound and multiple learning disabilities (PMLD) is not a clinical diagnosis but rather a description of a group of disabilities, of which the defining feature is profound intellectual disabilities (Doukas et al., 2017). Additionally, people with PMLD have great difficulties in communication and rely on those who know them well to act as proxies and interpret their responses (Nieuwenhuijse et al., 2024). These young people also have physical disabilities which may affect movement and present a risk to body shape (Doukas et al., 2017); co-occurring complex medical needs, such as epilepsy and dysphasia, and are often susceptible to respiratory problems, which may result in life-threatening chronic chest infections (Proesmans et al., 2015). Children and young people often require extensive medical care, such as the frequent administration of medication, and support with daily care which is primarily carried out by parents (Seliner et al., 2016).

There is no worldwide agreement on the term PMLD. In Europe the presentation of these disabilities is referred to as profound intellectual and multiple disabilities (PIMD). Nakken and Vlaskamp, (2005) state that "*individuals with PIMD have two key defining characteristics (a) profound intellectual disability and (b) profound motor disability*" (p.85). Elsewhere in Europe the term "*polyhandicap*" is used, as particularly in France, the term "*profound*" is deemed "*pejorative*", whereas "*handicap*" is deemed acceptable, despite being considered offensive in other countries (Rousseau et al, 2023, p.2). This French term has been defined as "*a syndromic entity that includes progressive and fixed etiologies (sic), and refers to the definitive consequences of a disorder, anomaly or lesion occurring in a developing or immature brain*" (Rousseau et al., 2023, p.3). In the UK, the description of PMLD is less restrictive. The PMLD Link Standards (Doukas et al., 2017) state that "*causation may be ante- peri or post-natal and may include genetic disorders, brain damage as a result of infection and other acquired brain injuries*" (p.13).[1]

Why the definition matters

There is universal agreement that people with profound and multiple learning disabilities should be "*recognised for their uniqueness and specific qualities*" (Rousseau et al., 2023, p.3) and that a definition is necessary so that provision is made for appropriate care. However, Nakken and Vlaskamp (2005) state that it is important not just to view the needs of people with PMLD purely through the lens of the medical model and their perceived deficits, suggesting that this group of "*individuals... seem to have been forgotten in the discussion about citizenship and inclusion, probably due to the fact that they were seen purely as presenting medical problems and in need of non-inclusive care*" (p.84).Therefore, Bellamy et al. (2021) argue it is necessary for service planning to collate and categorize demographic health needs information to provide acceptable provision, whilst service delivery should be based around a person's individual needs, strengths and aspirations as well as medical deficits.

However, the often-cited, UK National Health Service (NHS) definition attempts to balance medical deficits with personal strengths but seems contradictory in its approach to communication and independence.

- "*A profound and multiple learning disability (PMLD) is when a person has a severe learning disability and other disabilities that significantly affect their ability to communicate and be independent.*

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[1] Owing to the differences of terminology across countries, and within the published literature, the terms "learning disability" and "intellectual disability" are used interchangeably throughout the thesis.

- *Someone with a profound and multiple learning disability might have difficulties seeing, hearing, speaking and moving. They may have complicated health and social care needs due to these or other conditions.*
- *People with a profound and multiple learning disability need support to help them with some areas of their life, such as eating, washing or personal care.*
- *Lots of people with a profound and multiple learning disability can still be involved in decisions about themselves, do things they enjoy and be independent.*
- *Some people who struggle with talking might be able to use other ways of communication, like sign language, Signalong, Makaton, or digital systems like picture exchange communication systems (PECS). (NHS, Jan 2022)".*

After reviewing literature on the term "profound and multiple learning disabilities" and drawing up a list of published definitions from grey and academic literature, Bellamy et al. (2010) consulted with focus groups to produce their own definition of PMLD, for use by the Joint Learning Disability Service (Sheffield). It is this definition that I have chosen to use within my thesis, over the NHS definition (NHS, Jan 2022), as it was co-produced by family members and professionals, and I feel it places relationships at the heart of that definition.

"People with profound and multiple learning disability (PMLD):

- *Have extremely delayed intellectual and social functioning*
- *May have limited ability to engage verbally, but respond to cues with their environment (e.g. familiar voice, touch, gestures)*
- *Often require those who are familiar with them to interpret their communication intent*
- *Frequently have an associated medical condition which may include neurological problems, and physical or sensory impairments*
- *They have the chance to engage and to achieve their optimum potential in a highly structured environment with constant support and an individualized relationship with a carer" (Bellamy et al., 2010, p.233).*

PMLD population

In 2009, Emerson estimated that there were approximately 16,000 adults with PMLD in England, which he predicted would increase by 1.8% each year (Emerson, 2009). Accordingly, we can estimate that the population in England in 2024 might be approximately 21,000, which is an increase of over 25% in 15 years. This number also equates to approximately 0.04% of the population.

Generally, people with learning disabilities have a shorter life expectancy and an increased chance of early death compared with the general population (Emerson & Hatton, 2011). However, with improvements in health care and assistive technologies, a shift in the health of young people with disabilities has occurred. More young people with complex health needs are now surviving into adulthood (Blum et al., 1993; Hagell et al., 2013; Fegran et al., 2014; Brown et al., 2019). Consequently, there is an increase in numbers of those young adults with PMLD and CHCN who are dependent on others to help and manage their care, unlike their non-disabled counterparts (such as those with Type 1 diabetes). Parents of these young people are consequently central to the management of their care and their transition to adult services (Brown, 2019). As a result, parents' and children's needs become interdependent (Jacobs et al., 2018).

Defining parent-carers

The Children and Families Act 2014 defines a 'parent-carer' as:

> *"A person aged 18 or over who provides or intends to provide care for a disabled child for whom the person has parental responsibility."* (Carers First, 2024)

It is therefore recognised that the role of parent-carers in this context carries responsibilities beyond normal parenting:

> *"When supporting a child with additional needs, there may be things they need support with that are related to a condition or disability, which form part of a caring role. Parent-carers balance the role of a parent with meeting their child's needs as a carer.*" (Carers First, 2024)

Recognition of this role within the legislation brought about a recognition of the need for support, which will be discussed further below.

Throughout this thesis, parents are assumed to be parent-carers, but both the terms parent-carers and parents are used interchangeably. I clarify the definition when referring to parents who are not carers.

Whilst acknowledging that parent-carers are actively involved in planning transitions for their children, it is useful to consider how parent-carers might be involved with service providers, and how they might be defined. In general care terms, Twigg and Atkin (1995) suggest that sometimes there is conflict between carers and service providers over the 'moral status' of the person being cared for. This concept is particularly relevant for young people with PMLD and CHCN at transition. "*The 'moral status'… is constructed by the interaction of two elements, mental competence and achieved adulthood*" (Twigg & Atkin, 1994, p.132) with professionals "*encouraging clients towards assuming independent adult persona*" (Twigg & Atkin, 1994, p.133). However, parent-carers of young people understand their children may fall short on both elements, and this in turn can lead to "*a major source of conflict between parent-carers and certain service providers*" (p.133).

Twigg and Atkin (1995) also state that carers occupy an "*uncertain and ambiguous position within service provision*" (p.7), existing in an "*off centre*" position being, "*rarely themselves the direct focus of an intervention, yet often significant in the determination of provision*" (p.7). Despite being infrequently referred-to within Psychology, Twigg and Atkin's Typology of Caring (1994) is regarded by commentators on caring, i.e. social care, "*as seminal in its field*" (Gant, 2018, p.95). I propose that its application to parent-carers during transition may help to explain their caring role.

Twigg and Atkin's Typology of Caring (1994)

Twigg and Atkin (1994) proposed four distinct models of caring in respect of the role of carers and the response of agencies. For clarity the care recipient is referred to throughout this summary as the young person, and the carer is assumed to be the parent.

- **Carers as *resources*,** where the carer is viewed as a "*free resource to be drawn upon*" (Gant, 2018, p.92) and is embedded in the notion of family. This model may involve carers who don't even recognise themselves as carers, who may see it as their role, in the case of children with disability. Given the expectations of care within the family, this form of "informal" care may be seen by professionals as "morally acceptable" (Manthorpe et al., 2003). The person in receipt of care is placed at the centre of this model, support by external agencies only becomes involved when informal support does not exist (Gant, 2018).
- **Carers as *co-workers*,** where agencies may work alongside carers. The model still places the person with care needs at the centre, but also highlights the well-being of the carer. Support is therefore "*threaded through*" (Gant, 2018, p.92) to support the carer to provide good quality care. Manthorpe et al.(2003) suggest that within this model, services may draw the carer into a worker role, by providing information and support (such as support groups), but the emphasis remains on a familial caring role. This model aligns with the notion of carer as expert (Gant, 2018).
- **Carers as *co-clients***, acknowledges that the person being cared for and the carer may have mutual or combined needs. Within this model, it is acknowledged that in meeting the carers' needs, carers are seen as "*legitimately equal in status*" (Manthorpe et al., 2003, p.481). Gant suggests that in respect of combined assessments outlined in the Care Act 2014, this model "*seems to be particularly relevant today*" (2018, p.93) for carers who face high demands. For example, respite, or short breaks, could be considered beneficial to both parent and recipient of care. The model also acknowledges that there may be some conflict between their own needs.

- ***The superseded carer***, when the carer is no longer needed owing to the increasing independence of the care recipient. Two routes may lead to the achievement of “superseded” status; firstly, by focusing on developing the independence of the young person, and additionally recognising the demands and restriction put on the carers’ lives. Secondly, this model considers the sustainability of the caring role, for example as parents get older and the physical aspects of caring for a young person with physical disabilities becomes challenging.

The significance of this typology means it is instrumental in explaining how carers are perceived by professionals, which in turn influences their responses to carers (Gant, 2018). Gant recommends the model, in the context of considering how carers might be viewed, to stakeholders working with carers (2018). Manthorpe et al. (2003) used the model to examine the understanding of stakeholders working with family carers of people with Alzheimer’s disease. The identification of carers as *co-clients* in need of respite was a significant finding, although stakeholders did not privilege carers’ needs above those of the person with dementia (Manthorpe et al., 2003, p.481). More recently, Marczak et al. (2021), employing the model, found that although carers’ needs are recognised under the Care Act (2014), services viewed carers as *resources,* thus diverting them from sources of support.

This model will be referred to throughout the thesis, to help explain findings in the studies.

Defining Transition

In its simplest form, “transition” might be described as the period when young people move on from school, leaving the support of children’s services, and moving into the adult world. Within the realms of health services, transition has been defined as:

> “*a purposeful, planned process that addresses the medical, psychosocial, and educational/vocational needs of adolescents and young people with chronic physical and medical conditions as they move from child-centred to adult-oriented healthcare systems*” (Department of Health, 2006, p.14).

The needs of young people with PMLD however, are recognised as presenting “*particular problems because often there is no equivalent adult service able or willing to take on their long-term health care and medical supervision*.” (Department of Health, 2006, p.13).

Effective transition is suggested to begin early, involving family, carers as well as the young people at the heart of the process. The starting point is usually around the age of 14 years or year 9, in the case of those with an Education Health and Care Plan (EHCP) or in receipt of Children's and Young People's Continuing Care (i.e. Health care funding). Transitions occur around the time of the child's 18th birthday, but may happen earlier, and may continue until they are 25 years old.

In broad terms, NICE guidelines (2016), state that transition support should be:

- Developmentally appropriate
- Strengths based, focusing on "*what is positive and possible for the young person*" rather than relying on "*predetermined*" options.
- Person-centred, treating the young person as a partner in the planning, implementation and review of their transition.

Within these contexts, the role of family is fully acknowledged, and their participation is anticipated. This person-centred, strength-based approach "*includes but is not limited to their family or carers"* (NICE, 2016).

Legislative background

Disability legislation

To appreciate the complexity of the current situation relating to young people with disabilities and transition to adult services, it is necessary to revisit the historic development of disability rights. In particular, it is important to remember that until as recently as the 1970s children with learning disabilities were often placed in long stay hospitals. Maureen Oswin, in her seminal book *The Empty Hours, A Study of the Week-end Life of Handicapped Children in Institutions,* stated:

> "*In 1968 there were 2,765 children with cerebral palsy in Special Schools for the Physically Handicapped and Delicate Children. Many others would be in hospitals for the physically ill, or hospitals for the subnormal, or in training centres, or at home" (Oswin, 1971, p7).*

The past thirty years has seen a major shift in legislation regarding both disability and carers' rights, from the introduction of the first Disability Discrimination Rights legislation[2] in 1995 (UK Govt, 1995), followed by 'Valuing People' (UK Govt, 2001) and 'Every Child Matters' (UK Govt, 2003). Valuing People (2001) laid out the strategy for improving services and increasing life chances for people with learning disabilities, whilst joint working and

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[2] The Disability Discrimination Act defined disability as "a physical or mental impairment which has substantial and long-term adverse effect on [the] ability to carry out normal day-to-day activities".

information sharing between services were also key commitments of Every Child Matters (2003). Additionally, the way social care was provided fundamentally changed. Direct payments for services users were introduced in 2000, so that service users had choice and control over the services they accessed. However, although they were introduced for parents of disabled children in 2000, it only became mandatory for local authorities to offer them from 2003, under the terms of the Health & Social Care Act (2003).

Building on these previous initiatives, the revised Disability Discrimination Act (DDA) (2005) was accompanied by "*Improving the life chances of disabled people*", a joint report from several government departments (UK Govt, 2005a). The report outlined four key strategies:

- to help disabled people achieve independent living,
- to improve support for families with young disabled children,
- to facilitate a smooth transition into adulthood, and
- to improve incentives for getting in and staying in employment (UK Govt, 2005, p.7).

Thus, the report promoted movement towards personalisation and self-advocacy. The then Labour Prime Minister, Tony Blair, stated in the foreword: "*By supporting disabled people to help themselves, a step change can be achieved in the participation and inclusion of disabled young people*" (p.5). Blair further stated that the report "*sets out an ambitious programme of action that will bring disabled people fully within the scope of the "opportunity society"* (UK Govt, 2005, p.5).

The DDA (2005) thus represented a shift within government modelling (reflected in the language used within these publications), from recognising that the disabled were discriminated against, to prompting them to take responsibility themselves to rectify this marginalisation. The Equality Act (2010) later put into law the principle that some disabled people required adjustments to access services, the community, or employment, and if those adjustments were not made, disabled people may face discrimination (Lacey, 2025).

The ideology embedded within these legislative measures did not necessarily translate into practice. In 2010, Professor Jim Mansell wrote in 'Raising our sights: services for adults with profound intellectual and multiple disabilities', a government commissioned report, that "*the major obstacles to wider implementation of policy for adults with profound intellectual and multiple disabilities are prejudice, discrimination and low expectations*" (Mansell, 2010, p.2). Mansell identified the development of person-centred services as key, whilst reflecting the difficulties parents faced:

> *"Families caring for a son or daughter with profound intellectual and multiple disabilities face an exceptionally heavy responsibility. Research by Mencap showed that, on average, 60% of parents of children and adults with profound intellectual and*

> *multiple disabilities spent more than ten hours per day on essential physical care. A third of these parents said their caring role was continuous and meant they were caring for their son or daughter 24 hours a day. 57% of parents were spending more than eight hours per day on therapeutic and educational activities. Parents were woken up, on average, three times a night by the need to care for their son or daughter." (Mansell, 2010, p.4)*

Reforms continued under the coalition Government of 2010. The Children and Families Act (2014, Section 19) introduced the establishment of Education Health and Care Plans (ECHP), which replaced the Statement of Education Needs. This statutory process brought Education, Health and Social Care together, to draw up individual plans, with a leading educational component, for young people with learning disabilities, who were eligible for support up to the age of 25.

Additionally, a national programme called Preparing for Adulthood (PfA) was developed by the Department of Education, after the introduction of the Children and Families Act (2014). The four main principles of Preparing for Adulthood are:

- employment,
- independent living,
- community,
- good health (NDTi, 2025).

These principles are now embedded in local authority approaches to transition, as part of their Special Educational Needs and Disability (SEND) guidance, (for example Shropshire County Council, 2023-25). Most recently, the Health and Care Act (2022) introduced the collaboration of NHS organisations, local authorities and third sector organisations into 42 regional Integrated Care Systems (ICS), to effect a more coordinated approach to planning and commissioning services (Lacey, 2025). This is argued to improve joined-up working practices at the transition of services.

Carers' rights and legislation

Parents' and carers' support and rights have also been recognised within legislation. In 2011, a budget of £11 million was allocated to *'Breaks for Carers of Disabled Children'*, an initiative brought in to allow parent-carers time for leisure, training and to spend time with their other children and household tasks, as well as providing positive experiences for the disabled children (UK Govt, 2011). However, ring-fencing for the funding of these breaks was later removed, with the money being reabsorbed by local councils into their social care budgets (Runswick-Cole & Ryan, 2019).

Additionally, The Care Act 2014 gave carers, in general, entitlement to a care assessment in their own right, distinct from the care needs of the person cared for. However, evidence suggests that post-2014, local authorities managed demand for help by steering carers away from statutory bodies towards voluntary bodies, such as support groups, and "*low-level preventative services for carers*" (Fernandez et al., 2020, p.3). Assessments were not taken up in the numbers expected before the legislation (Fernandez et al., 2020).

In summary, it is evident that, following the introduction of the Disability Discrimination Act (1995) there have been major shifts in policy, recognising the rights and needs of not only disabled people, but also their carers and family members. The principles of person-centred care became enshrined in law, particularly with the Care Act (2014). However, unofficial reports published by charities working with families (such as Mencap) and peer-reviewed literature suggest that transition processes were not always successful for young people and their families (Medforth & Huntingdon, 2015, Medforth et al., 2024).

Reflexive comment

When I first researched the legislation context, I was struck by how recent many of the developments are, particularly the Disability Discrimination Act (1995) and the Equality Act (2010), and how these may have impacted my family. My son was born only a year after the Disability Discrimination Act 1995, but I was quite ignorant of the legislation and the implications for us as a family. Information and access to the internet were not as readily available as they are today. Although we received support from both health and social care practitioners, they rarely explained what our legal rights were. There was a school of thought prevalent **amongst carers** before the introduction of the Care Act (2014) that they were deliberately kept in the dark. Looking back now I wonder whether that suspicion was true and if that approach was deliberately adopted: maybe it was because we were in an era of such rapid change that social workers too were getting to grips with a changing paradigm and newly established regulations.

Background literature

Transition literature

Following on from the legislation, which aimed to improve experiences for disabled people and their families, reports written by organisations such as the Care Quality Commission (CQC) and Mencap brought transition experiences to light. "*From the Pond to the Sea*", a report looking into children's transition to adult health services (CQC, 2014) stated that there was "*a significant shortfall between policy and practice*", and that "*the system is fragmented, confusing, sometimes frightening and desperately difficult to navigate*" (CQC, 2014, p.2). In a small scale pilot project, Medforth and Huntingdon (2015) identified themes of a lack of understanding around transition, variable plans and experiences, poor communication with young people left "*hanging*", as well as variance in how people were involved in the process, with parents and young people left feeling "*fearful*" and "*battle weary*"(p.10). Additionally, families indicated that they had lost services throughout the transition process. In conclusion, families stated they would like "*those in charge of commissioning services and making financial decisions to hear their stories and understand the challenges they face*" (Medforth & Huntingdon, 2015, p.10).

More recently, Medforth et al. (2024) revisited transition services for young people with disabilities, mental health and long-term conditions, noting a "*global interest in the topic*" (p.181). In their literature synthesis, the processes of transition (timing, preparation, barriers and facilitators, and outcomes) were identified as themes, along with personal factors such as aspirations, young people's rights, and advocacy. The authors highlight the intersectionality of disability, poverty, social inclusion, participation and self-determination for those with physical disabilities.

Peer reviewed published research focuses on transition for those with chronic somatic conditions, for example, diabetes, cancer, cystic fibrosis, or mental health issues. The Royal College of Nursing (2013) issued principles of good practice in arranging transitions for such service users, which states that service providers should examine the way transition services are delivered, whilst acknowledging that young service users will find "*significant differences in the expectations, style and culture of services*" (p.1). A qualitative meta-synthesis of 18 studies of young people's experiences of their transfer from paediatric to adult care showed that experiences were comparable across diagnoses, and feelings of not belonging and being redundant were reported (Fegran et al., 2014). Additionally, the study stressed the importance of young people taking responsibility for their care as they moved into adult services, and towards a less parent-led model of care.

These models are mainly built around transition for neurotypical young people who have an active role in the management of their condition and their transition from paediatric to adult services. The role of the parent-carer as the intermediary between their child and services needs to be examined to understand how they can affect outcomes for their children, but also how transition affects them. For example, the complexities for parents of interacting with the health care system around a child with cerebral palsy and complex health needs were highlighted by Hayles et al. (2015). Themes of navigating the system and a need to remain flexible whilst learning as they went along were found. The study also acknowledged that families needed to work in partnership with health care professionals (HCP), and that to work successfully, there was "*a need for mutual regard and respect*" (Hayles et al., 2015, p.1145). The authors suggest further research to explore the perspectives of healthcare workers and policy makers would add to theory of practice.

Models of transition practice

The lack of standardisation of transition practice models makes, not just transition itself, but research into it difficult. A systematic review of the impact of five transition interventions, from five different countries, found that the lack of clear definitions and methods of transfer presented methodological challenges (Chu, et al., 2015). This finding was also borne out by Nehring, et al. (2015), who suggested a need for clearer transition models and training for interdisciplinary providers. Longitudinal studies tracking the outcomes of young adult service users were suggested as an area for further research, as were a closer examination of the roles of supporting health care professionals such as physiotherapists, occupational therapists, practice nurses and dieticians.

Specific models suggested include utilising concepts in the World Health Organisation's International Classification of Functioning, Disability and Health (ICF) and its Child and Youth version (ICF-CY) framework (Nguyen & Gorter, 2013), which rules in elements across environmental, personal and physical domains (i.e. strengths-based), as opposed to ruling out possibilities, as the result of a medical diagnosis. In the UK, adherence to transition guidance implemented across a children's and an adult hospital resulted in increased patient satisfaction, but the "*optimal approach has yet to be identified*" (Shaw et al., 2013, p.668). Aldiss et al. (2015) developed a benchmark by which HCPs can evaluate the standard of the services they provide. In particular, the role of the GP was highlighted, including keeping the GP informed so they can help 'bridge the gap'. Transition models have also been developed and reviewed for young people moving from CAMHS to adult mental health services across eight European countries (MILESTONE, 2019).

I now turn to the application of Bronfenbrenner's Ecological Model within transition research.

Bronfenbrenner's Ecological Model and transition research

Bronfenbrenner's Ecological Model (1979) describes a system of multiple environments that surround an individual affecting their development (Wang et al., 2010). Rosa & Tudge (2013) highlight Bronfenbrenner's argument that there was a need for a model, within psychological research, which considered the contexts in which human beings lived. It has also been adopted as an effective tool for the study of public health because of its "*acceptance of complex and multi-layered connections*" (Lang & Rayner, 2012, p.3). Additionally, Eriksson et al.(2018) identified this method of considering the interactions between and within systems as producing the most useful recommendations for guiding policy and practice in public mental health research. As transition is seen as a life-course event, and therefore relates to the individual's development, the Ecological Model has been adopted by various researchers in this context (Wang et al., 2010; Small et al., 2013; Crotty, 2016; Jacobs et al., 2018; Jacobs et al., 2020; Fortune et al., 2023). Additionally, the model is suited to the study of the transition for young people with PMLD and CHCN, who by the nature of their disability will have multiple contacts across a number of health settings (Wang et al., 2010).

Bronfenbrenner developed the model (in the 1970s) to consider human development within an ecological context, arguing:

> *"The ecology of human development involves the scientific study of the progressive, mutual accommodation between an active, growing human being and the changing properties of the immediate settings in which the developing person lives, as this process is affected by relations between these settings, and by the larger context within which the settings are embedded" (Bronfenbrenner, 1979, cited by Rosa & Tudge, 2013)*

The initial model was conceptualised as having four interconnected systems, around the **Individual** who sits at the centre (Phase 1, 1973-79):

- First, the **Microsystem**, which include interactions with immediate influences, such as family and school in a young child's life.
- Second, the **Mesosystem**, defined as "*the relations among two or more microsystems in which the developing person actively participates*", and where activities occur across settings (Rosa & Tudge, 2013, p.246).
- Third, the **Exosystem**, within which the individual is not situated but which indirectly influences the individual for example, local authorities' provision of after school clubs.
- Fourth, the **Macrosystem** which embraces political, religious, legal and economic systems as well as cultural beliefs, such as communism or conservatism, which may influence the Exosystem.

See Fig. 1 below – this model has been adapted to include social care, as well as education, as it is relevant to the following discussions.

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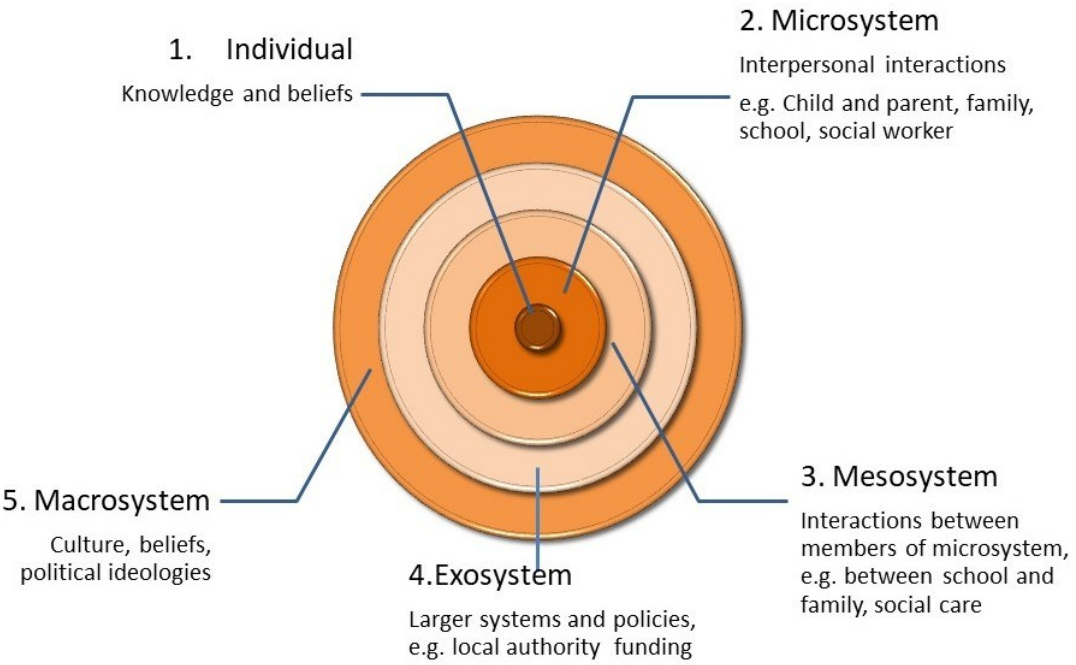

Fig. 1 Bronfenbrenner's Ecological model (Stage 1) adapted from Wang et al. (2010) and Jacobs et al. (2020).

Bronfenbrenner continued to develop and refine this model until death in 2005, concentrating not just on the systems that affect individual development, but also the influence of proximal processes, personal characteristics, context and historical time (Rosa & Tudge, 2013). In Phase 2 (1980-1993), he concentrated on the personal characteristics of the individual, proposing the Process-Person-Context model. He paid particular attention to the passage of time, and the effect that may have on the individual's development, suggesting the use of a 'chronosystem model'. Changes occurring across a lifetime may be as a result of external influences, such as going to school, or internal, e.g. physical or developmental changes. These experiences *"alter the existing relation between person and environment, thus creating a dynamic that may instigate developmental change"* (Rosa & Tudge, 2013, p.250).

Within the final stage of the model (Phase 3, 1993-2005) Bronfenbrenner focused on the proximal processes, relabelling the model the "bioecological model of human development". The significance of the proximal processes is the role played by the individual in the interaction between themselves and “*persons, objects and symbols within [their] immediate environment”* (Rosa & Tudge, 2012).

The model has been applied in different ways. Crotty (2016) argues for the model to be applied to transition planning for people with intellectual disabilities, stating “*all elements complement and expand development*” (p.37). Whereas Jacobs et al.(2018) adopted the Ecological Model as a framework for a synthesis of qualitative literature relating to the transition of young people with severe learning disabilities. An important finding of that synthesis was that the parents’ and children’s needs were interdependent, as parents acted as proxies and advocates for their children, because of their understanding of their child’s communication. Jacobs et al. (2020) then further embedded the Ecological Model in the design and analysis of a further study exploring the relationships and decision-making processes around young people with severe intellectual disabilities at transition. Significantly, they adapted the Ecological Model Stage 1 (1979), to include the Chronosystem. Initially, they argued transition represented a life stage but later revised the definition to represent the whole life course of young people with disabilities (Jacobs et al., 2020). This study further promoted the importance of interdependency, not just between parent and young person, but as a way of supporting decision-making and advocacy. The two-way interaction between stakeholders and families were also highlighted, with stakeholders being influenced by elements from the Exosystem, such as “*money*”, “*budgets*” and “*government*” (Jacobs et al., 2020, p.1079).

Jacobs et al.’s (2020) study, however, does not (nor was it intended to) explore the personal impact of the transition on the parents themselves as individuals. In designing this thesis, I decided to adopt Jacobs et al.’s (2020) definition of the model, placing the parent and young person as one interdependent entity at the centre, around which systems interact. I also decided to adopt their application of the Chronosystem. The significance of the Ecological model is that it exposes the interactions and influences around the transition process, highlighting strengths and weaknesses in an individual’s social network (Small et al., 2013).

The roles of parents

Parents and transition

Pilnick et al. (2011) suggest that research focused on the role of parent-carers at life transitions, as opposed to diagnosis, is important because this is a time that typically developing children would leave home and the parental role would diminish, or as discussed above, those with health needs take control of their own healthcare. Additionally, the "*normality*" that parents have endeavoured to construct around that school routine comes "*under threat*" (Pilnick et al., 2011, p.320). In reviewing qualitative studies relating to parental views and experiences, Heath, et al. (2017) found that parents are not only central to the success of their child's transition, but that they also require support throughout the process, undergoing their own transition.

Rapanaro et al. (2008) reported that while parents of young people with intellectual disabilities reported exhaustion, burnout and loss of freedom at their child's transition, they conversely found aspects of personal growth, new coping skills and the formation of new social networks, which were perceived as benefits of the challenges of transition. Furthermore, parent-carers have to negotiate the gap between 'letting go' and being over-protective, whilst letting others act in the young people's best interests, as well as allowing their children to negotiate risk (Almack, et al., 2009). Biswas et al. (2017) found parents of young people with severe intellectual disabilities worry and consider age appropriateness making comparisons with perceived norms, particularly around relationships and sexuality.

Parents are perceived as still being a key support; Biswas et al. (2018) suggest that understanding adulthood is not necessarily about young people with intellectual disabilities being able to make decisions independently, but about being supported to explore options. For example, health advocacy has been recognised as an important element for young people within transition (Okumura, et al., 2015), and particularly, for those with an intellectual disability, who are often disadvantaged with regards to healthcare, which Brolan et al. (2012) argue is a human rights issue. The lack of involvement of the young person in decision making about their future has been highlighted and explored by Jacobs et al. (2020), who suggest that "*the concept of interdependence might be more valuable than independence or dependence*" (p.1079).

There is a small but growing body of research relating specifically to the experiences of families of PMLD and factors influencing transition (Gauthier-Bordreault et al., 2017). Brown et al. (2019) found parents were acting as "*advocates in emotional turmoil*", and that a decrease in the provision of services following transition "*can affect parents' physical and mental health and consequently their ability to care*" (p.205). Brown et al. suggested that registered nurses, with relevant training, could provide support at this transition point (2020). A lack of understanding of the specific needs of the group makes transitions difficult, and it is suggested parents need material, informational, cognitive and emotional support (Gauthier Bordreault et al, 2017). These forms of support focus on helping the parent support the child, with only emotional support focusing on the parents' needs.

Parenting, being an expert and caring

Interactions with professionals have been perceived as problematic by parents, who would advocate for their children but did not like to highlight their own needs. At times parents felt they may be perceived as being selfish, in looking at their own needs as well as those of their children (Todd & Jones, 2003: Pilnick et al., 2011). These findings relate well to Twigg and Atkin's Typology of Caring (1994), which legitimises carers as having individual needs, which might be met with support.

Contrary to the aims of legislation, partnership is not easily achieved with differences of understanding joint-working and individual roles apparent. Conflict is a predominant discourse within the published literature around parenting a child with intellectual disabilities, and partnership is not experienced as such by parents. Rogers suggests that the "*sheer number of professionals involved in a child's life*" is disabling (Rogers, 2011, p.572). Parents at times feel criticised and blamed for their child's behaviour, particularly those with children who have autism spectrum disorder (ASD) (Rogers, 2011). Research draws on the Foucauldian concept of the 'medical gaze' with a shift of caring *in* the community to caring *by* the community, which in turn defines parents as needy and dependent when seeking support (Heaton, 1999). Parent-carers, or in particular, mothers, who are often the main carers within the published literature, are forced to present themselves as 'good mothers' (Knight, 2013), although the mothering role may vary from the parent as the expert in her child's care to that of an activist (Ryan & Runswick-Cole, 2008). Knight (2013) stresses that although the presentation of the mother as a 'good mother' may have changed over 40 years, "*her marginalised position has not altered significantly*" (p.671).

Two qualitative studies, which explore the professionals' view of parents of adult children with developmental disabilities (van Ingen, et al., 2008; van Ingen, et al., 2010) also identify conflict. The first study (van Ingen, et al., 2008) set out to examine the characteristics of those parents who were viewed by professionals as "*overinvolved*", which included parents described as having tunnel-vision, a need to be involved in every decision (as in the first stage of Twigg and Atkin's model, "*carers as resources*"), making decisions based on their own needs, and also having failed to process their own grief and anger. 'Healthy parents' were seen to be more emotionally independent and guided by facts rather than emotions, demonstrated flexibility and lived balanced and satisfied lives. These findings around healthy parenting and healthy involvement were reinforced in the second study (van Ingen, et al., 2010). However, it is possible that selective recruitment by professionals of those parents who they felt had attained a level of “*parental success*” produced an ideal view of what parenting a child with disabilities should look like from a professional point-of-view rather than the reality as felt by the parent, i.e. parents who conformed to the professionals’ expectations were held up as good examples of parenting. This conflict of views may also relate to the idea of the ‘moral status’ of the child, having competence and moving towards acquiring adult status (Twigg & Atkin, 1995) as discussed above. The parents who are “overinvolved” do not see their children owning such attributes.

While parents do not want to be seen to be tragic (Jarrett, et al., 2014), Green (2007), found that caring for a disabled child was acknowledged to be “*time consuming, expensive and physically exhausting*” (p.155), but concludes that previous research has emphasised the emotional distress but neglected to highlight the consequences of stigma and socio-structural constraints. Additionally, parents may be vulnerable (Thackeray & Eatough, 2015), because maintaining “*high levels of vigilance*” to protect their children, could induce “*feelings of intense anxiety*” (Thackeray & Eatough, 2015, p.272). Mothers’ emotional distress therefore arises from the practicalities and problems they face rather than the nature of the disability itself. Green (2007) suggests that their lives “*could be improved by consistent, effective and continuing assistance with the pragmatics of caregiving*” (p161).

Rationale for the thesis

In summary, there is a demonstrated gap in service provision (Brown et al., 2018), and a paucity of research around the experiences of transition, both of young people with intellectual disabilities and complex health needs and their parents’ own needs (Gauthier-Bordreault 2017). Caring for a child with learning disabilities is a complicated and demanding role, and parents require support to fulfil that role effectively (Rogers, 2011). Literature on caring for young people with disabilities focuses on diagnosis and less on caring for young adults (Thackeray et al., 2015).

Working with professionals is not always straightforward, as viewpoints diverge (Biswas et al., 2017). Existing literature suggests that there is scope for further research into the understanding and roles of professionals within the transition process (Hayles et al., 2015).

I, therefore, proposed to examine the experiences of parent-carers of young people with PMLD and CHCN leading up to, and within the transition process. It is necessary to consider the parents’ role in the process, and to explore, the nature of parental caregiving within the transition window. It is demonstrated in the published literature that parent-carers have rights to support, but that their needs are not being met. Given that there are demonstrable tensions around working in partnership, it is also proposed to examine the experiences and views of professionals who support families during transition. It is necessary to examine their understanding of the parents' role, as well as how they perceive the transition to adulthood.

Jacobs et al. (2020), demonstrated, using Bronfenbrenner's model, that there are multiple interactions between family, services, local and national policies and legislation. Therefore, I propose to build on these findings in a novel way. I intend to explore the experiences of the two groups in depth through interpretative methodology, examining findings through the application of caring theory (Twigg & Atkin, 1994). In this way, I hope to identify where parents own support needs lie and how they could be met.

Research questions

Outline of chapters

The following simplified model (see Fig. 2), adapted from Bronfenbrenner's Ecological model, is used here to illustrate the foci of the following chapters, outlining the specific questions addressed in each study.

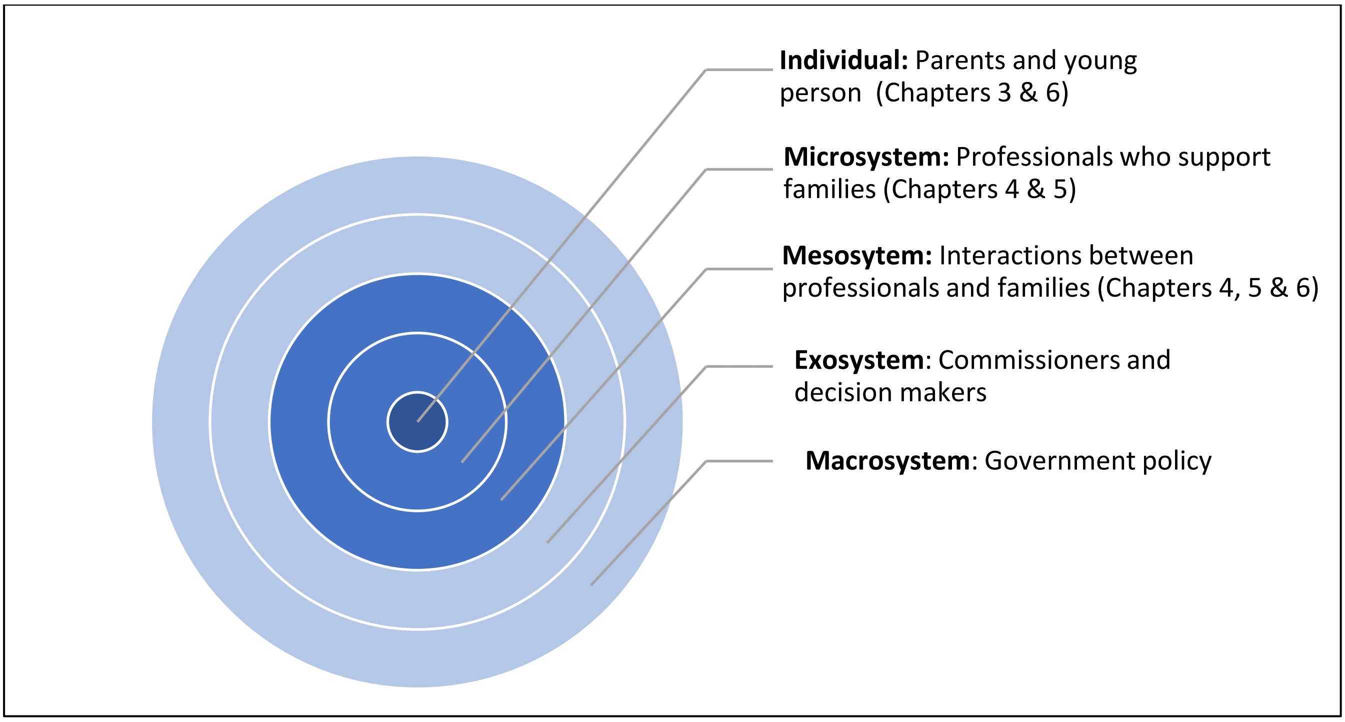

Fig. 2 The foci of the studies and their related chapters

Overarching research question:

What are the experiences of parent-carers of young people with profound and multiple learning disabilities and complex health care needs, and the professionals who work with them, at the transition from paediatric to adult services?

Aim: To identify unmet support needs for parent-carers of young people with PMLD and CHCN and make recommendations to service providers and families.

The following questions will be addressed in the individual chapters:

Chapter 3 – Poetic Synthesis

Question:
What are the caring experiences of parents of young people with PMLD and complex healthcare need aged 14-25?
Aim:

- To synthesise primary qualitative research exploring the lived care-giving experiences of parents of young people (aged 14-25 years) with PMLD and complex healthcare needs.

Chapter 4 – Professionals study

Question:
What are the beliefs and understandings held by professionals relating to transition working with the families of young people with profound and multiple learning disabilities and complex needs?

Aims: to explore how professionals view:

- Transition planning and processes
- The role of parents of young people with profound and multiple learning disabilities at this time
- Professionals' relationship with parents and their own role in supporting parents during transition.
- Additionally, to understand how identified barriers could be addressed and to make recommendations for support for parents.

Chapter 5 – Professionals working during the pandemic

Question:

What was the impact of Covid-19 on professionals who work with young people with PMLD and their families, at transition to adult health and social care services?

Aims:

- to understand in greater detail the working relationships between professionals and parents,
- to consider what was learnt as a result of the pandemic.

Chapter 6 - Parents' study

Question: What are the experiences of parent-carers of young people with severe and profound and multiple learning disabilities during the transition to adult services?

Aims:

- To explore parents' individual experiences of transition at key time points in the process
- To explore the support networks available to both child and parents, in order to identify parents' specific support needs.

Additionally, throughout the thesis I will also consider the question:

- How do my own experiences as a parent of a young man with Severe Learning Disabilities (SLD) affect my position within the research process and influence the direction of the research?

The following chapter (Chapter 2) will explore and outline the research paradigm and the methodological approaches and methods used to address these questions.

Chapter 2

Methodology

Introduction

In the previous chapter, I outlined the questions framing this research, which explore the experiences of both parents of young people with profound and multiple learning disabilities at their transition to adult services, as well as the professionals who work with them. This chapter presents an overview of the methodological approaches used in this thesis, which serve to address those questions. I consider the ontological and epistemological position, and the underlying philosophical beliefs of phenomenology. In particular, the epistemological influences on the methodology, and reasons for the use of creative methods. The establishment of a public involvement group for the project is also discussed, and their role in supporting development of the research methods. Following an outline of the methods employed in each study, the chapter closes with a discussion regarding engagement with the theoretical context.

Overarching Methodological Approach

As stated in the Introduction to this thesis, I arrived at this research topic through my own experiences as a parent of a disabled young man, as well as a researcher. Van Manen (2016) states:

> *"Phenomenological research does not start or proceed in a disembodied fashion. It is always a project of someone: a real person, who, in the context of particular individual, social and historical life circumstances, sets out to make sense of a certain aspect of human existence" (p.31*).

My previous research (Slade & Thomas, 2016) found that parents of children with PMLD and complex health care needs (CHCN) accessed a high number of services, and therefore transitions were complex, poorly defined and time consuming. I wanted to explore what it was about these experiences that made transitions so challenging, and possibly to uncover how support systems were working and where there was a deficit. To achieve these aims I opted to employ qualitative methodology, with an emphasis on exploring lived experiences. Frechette et al. (2020) argue that there is a significant difference between generic qualitative research, which rests on a constructivist paradigm and Interpretive (sic) Phenomenological research, which is "*set apart by anchoring its research tradition in a unique understanding of* ***being****"* (p.4). They highlight differences between the objective of the research such as practice and policy and "*uncovering the lived experience of individuals in being-with-others*" (Frechette et al., 2020, p.4).

The study of parenting a young person with intellectual disabilities at a time of transition within UK research is often treated within qualitative research by application of descriptive, rather than interpretative, methods (Brown et al., 2019; Jacobs et al., 2020). A notable example of phenomenological research is a study of mothers' experiences of parenting young adults with severe learning disabilities (Thackeray and Eatough, 2014). The in-depth interpretative analysis exposed that parents were fearful for the safety of their child, as well as being uncertain about the future. Individual incidents were examined to expose a hidden world where the child was vulnerable. Furthermore, the anxiety that parents felt in these circumstances led the authors to conclude that mothers were also vulnerable, suffering "*intense psychological distress*" (p.273). The research was able to capture and illuminate this emotional distress by using a phenomenological approach.

There is a body of Northern European research relating to intellectual disability, which explores parental experiences within the phenomenological paradigm. Published literature gives greater insight into the emotional life of parents around difficult life decisions such as moving a young person from home to residential care (Vandesande et al., 2024), and forward planning care for people with profound intellectual disabilities after their parent has died (Kruithof et al.2020). The following outline of methodology demonstrates how and why I have chosen to situate my research within this community of practice.

The research paradigm

Although I have stated my personal reasons for undertaking this research, it is important for validity to clarify the underpinning assumptions about the research paradigm. Creswell, et al. (2007) state:

> *"Researchers should begin their inquiry process with philosophical assumptions about the nature of reality (**ontology**), how they know what is known (**epistemology**), the inclusion of their values (**axiology**), the nature in which their research emerges (**methodology**), and their writing structures (**rhetorical**)" (p.238).*

A paradigm is "*a set of basic beliefs that provide principles for understanding the world and, hence, the basic principles underpinning research in the social sciences*" (Langridge,2007, p.3). The research paradigm adopted for this thesis is interpretivist. It aims to explore interpretations of the lifeworld of parent-carers which are both "*culturally derived and historically situated*" (Crotty, 1998, p.67), based within a phenomenological epistemology.

Ontology and Epistemology

The parents are not disabled themselves but live in a world that is dominated by their child's disability. Therefore, the reality of caring is mediated by their experiences of those children becoming adults, as well as the social, economic and political systems they encounter at that time. We assume that this is phenomenological ontology, as a way of being in the world. Addressing the epistemological question of "*how they know what is known*" (Creswell et al., 2007, p.238), the thesis is guided by the overarching epistemological framework of phenomenology, within which knowledge is uncovered by focusing on experience and narrative (Langdridge, 2007).

Phenomenology is "*the study of human existence and the way in which things are perceived as they appear to consciousness*" (Langdridge, 2007, p.10). It is a major philosophical movement of the 20th century, founded on the thinking of Husserl, Heidegger, Merleau-Ponty and Sartre (Smith et al., 2022). The basis of phenomenology lies in the thinking of Edmund Husserl whose "*focus was on people's perceptions of the world – or famously – their perception of 'things in their appearing*" (Langdridge, 2007, p.11). Phenomenology rejects the notions of dualism of mind and body, rather believing "*there is no separation between the world and the world that is experienced"* (Eatough and Tomkins, 2022, p.4).

Husserl's lifeworld (*Lebenswelt*) is an everyday world in which humans are directly immersed. As Langdridge states, it is "*the world as concretely lived*" and the foundation for phenomenological psychology investigation (Langdridge, 2007, p.23). In particular, Husserl was concerned with how humans make sense of their experiences within their lifeworld. He suggested that they should put aside their *natural attitude,* that is, their understanding of everyday, taken-for-granted experiences, and instead turn their gaze from everyday objects to their **perception** of those objects. Husserl introduced the concept of *bracketing*, of putting aside pre-understandings and concentrating on our perception of that world (Smith et al., 2022). This process is referred to as entering the phenomenological *attitude,* and engaging in the *epoque,* to reach to the essence of a phenomenon. Langdridge explains "*the aim of the epoque is to enable the researcher to describe the 'things themselves' and to set aside our natural attitude*" (Langdridge, 2007, p17). For a psychological researcher, Husserl's phenomenology can thus be seen to be an epistemological approach, of *how we know what we know*, considering individual psychological processes, such as consciousness and perception (Smith et al., 2022).

Martin Heidegger, who was Husserl's pupil, moved away from the focus on consciousness:

> *"The ontological question of existence itself, and with the practical activities and relationships which we are caught up in, and through which the world appears to us, and is made meaningful" (Smith et al., 2022, p.12).*

In Heidegger's philosophy, human beings are "*thrown into"* a world of relationships, language and objects (Smith et al., 2022). The human state of being-in-the-world is always perspectival, through being embodied, situated in time, space and relation to others (Eatough and Tomkins, 2022). Thus, Heidegger gives us a more contextualized phenomenology. He disputed Husserl's concept of the epoque, believing that it was not possible for people to bracket off their understanding of a given phenomenon. Langdridge (2007) explains:

> "*Our way of existing must be seen in its historical and cultural context and understood with due regard to the role of language – it must be interpreted and not simply described" (p.27*).

Following on from Heidegger, Merleau-Ponty concentrated on the embodied relationship between the individual and their world, primarily how the body shapes our experience of the world. Within the context of this research, Merleau-Ponty's approach has relevance not just to those with physical disabilities but also to those with intellectual disabilities and communication difficulties. These young people communicate in alternative ways, often through physical contact (Grace et al., 2024) and in this manner "*the body [is] no longer conceived as an object in the world, but as our means of communication with it*" (Merleau-Ponty cited Smith et al., 2022, p.14).

Social scientists have drawn upon these phenomenological concepts to develop methodologies for understanding questions about aspects of experience. For example, Brocki and Wearden (2006) argue that Interpretative Phenomenological Analysis is suited to the study of health psychology in a shift away from the medical model of illness

> *"Health psychologists have realised the importance of understanding patients' perceptions of and interpretation of their bodily experiences, and the meanings which they assign to them" (p.88).*

As a further example, Carel (2019) argues the case for a phenomenological approach to illness and well-being. She considers moving away from the medical model, to understand how people can endure long-term illness and still experience well-being within that framework. Thus, phenomenological investigation can elucidate hidden experiences and lead to shifts in understanding and practice.

An integrative approach to phenomenology

While the debate about differences between descriptive phenomenology (Husserl) and interpretative or hermeneutic phenomenology (Heidegger), is beyond the scope of this chapter, it is useful to consider Dahlberg & Dahlberg's (2019) summary of the two approaches:

"*Description, as well as scientific rigor*", are emphasised with reference to Husserlian philosophy, which requires the researcher to control their "*preunderstanding in order for phenomena's essences to be illuminated*" (Dahlberg & Dahlberg, 2019,p.1). In comparison, the Hermeneutic approach as demonstrated by Van Manen (2016) refers to Heideggerian philosophy, which emphasises interpretation. Researchers are encouraged to move beyond the data, and to bring their preunderstanding to the interpretation (Dahlberg & Dahlberg, 2019). The authors view this polarisation between the two approaches as "*destructive*" (p.2) and therefore propose a "*third way*" where theory or another external source of data is included in the analysis. They argue that the chosen theory should not silence the voices of the lifeworld but remain open to exploring "*the phenomenon and its meanings, the essential ones [descriptive] as well as the particulars, nuances [hermeneutic]*" (p.1).

In this thesis, I draw on key concepts which have their origins within the phenomenological writings of Husserl, Heidegger and Merleau-Ponty to frame my overall approach. Specifically, I draw on Heidegger's concept of "*being-in-world*" and engaging in the world through "*physically-grounded" (what is possible) and "intersubjectively-grounded" (what is meaningful) options* (Smith et al., 2009. p.17). My thesis will consider what is possible and meaningful for parent-carers as their children with PMLD move into adulthood.

To achieve this examination of experience, I employ two specific methods which have phenomenological roots, Template Analysis and Interpretative Phenomenological Analysis (IPA). Following Dahlberg and Dahlberg's (2019) suggestion that theory may help to uncover hidden social and historical structures, I apply theoretical models to the phenomenological findings, to study the interrelationships of individuals and statutory bodies, in connection with both practical and organisational issues as well as political agendas (methods and theoretical context are outlined further below).

Validity

Yardley (2000) argues that whilst quantitative methods within psychology are subject to established and widely acknowledged conventions and methods, the "*relative novelty*" (p.216) and variety of qualitative methods has made the evaluation of their validity problematic. In her seminal paper, Yardley (2000) lays out four characteristics against which the quality of qualitative research may be assessed:

- ***Sensitivity to context***
  Theoretical; relevant literature; empirical data; sociocultural setting; participants' perspectives; ethical issues.
- ***Commitment and rigour***
  In-depth engagement with topic; methodological competence/skill; thorough data collection; depth/breadth of analysis.
- ***Transparency and coherence***
  Clarity and power of description/argument; transparent methods and data presentation; fit between theory and method: reflexivity.
- ***Impact and importance***
  Theoretical (enriching understanding); socio-cultural; practical (for community, policy makers, health workers).

(*Reproduced from Yardley, 2000, p.219*)

Here I aim to demonstrate validity of my research design through consideration of these criteria. I establish *sensitivity to context*, by outlining my work with the public involvement group; I demonstrate *commitment and rigour* in my approach to using creative methodology; I demonstrate *transparency* by describing my methods of reflexivity and involvement in bracketing interviews. These three elements will be revisited, along with *impact and importance* in the quality assessment of the thesis in the Discussion (Chapter 7).

Underpinning Values of the research

Axiology is a "*term used to cover the philosophy of value*" (Hiles et al., 2008). Cresswell (2007) suggests the inclusion of the researcher's values to explain the adoption of one method over another is an important part of study design. Hiles et al. (2008) further state that "*axiology has relevance to the field of qualitative research inasmuch as it has a direct bearing on the ethical context of research, offers an important basis for making explicit the assumptions of different paradigms of research*" (Hiles et al., 2008, webpage). In this thesis, I adopted a reflexive stance to the planning and execution of the research, demonstrating that although I am a parent-carer with lived experience, I am keen to allow my experience to inform my research but not dominate the voices of my participants. For this reason, I undertook a series of bracketing interviews. I also established a transition research advisory group (TRAG), as I wanted the research to be inclusive and to ensure that methodological decisions were made based on different, but relevant perspectives and experiences.

Reflexivity

Bracketing interviews

Reflexivity and bracketing are essential parts of the hermeneutic cycle, allowing the researcher to contain preconceptions and examine them throughout the interpretative processes (Smith et al., 2009). Furthermore, reflexivity may be seen as a spectrum, as defined by Wolgar "*ranging from radical constitutive reflexivity to benign introspection*" (Shaw, 2010, p.234), with reflexivity being defined as "*an explicit evaluation of the self*".

The roots of reflexivity are firmly placed within Husserl's phenomenological philosophy, bracketing being part of the process of laying aside assumptions to access the real essence of a given phenomenon, the *epoche.* However, it is not necessarily the case that the researcher should be objective. Rather, *"good qualitative design seeks to understand the self in research … to unpack how subjectivity becomes relevant to producing certain knowledge*" (Lazard & McAvoy, 2017, p.4). In placing herself within the context of the research, and the participants' world, the researcher reveals her position which in turn helps to inform the reader "*to locate the researcher's suppositions and provide an intellectual context for any interpretations that follow*" (Pollio, et al., 2005, p.255).

Given my stance as a parent of a young man with disabilities, a 'bracketing' interview was suggested at the outset of the research by one of my supervisors, as a way of potentially understanding my own prior experiences and beliefs and putting them to one side, to be able to listen to the experiences of my participants, other parent-carers. However, in possessing fore knowledge of the phenomenon under scrutiny, that is caring, I felt that my position aligned more with Dahlberg's concept of "*bridling*" (Dahlberg et al., 2008, p.130). In this way, our pre-understanding not only acknowledges assumptions and personal beliefs, but also attends to a wider pre-understanding "*actively waiting for the phenomenon to show and display itself within the relationship with the researcher as a hunter of meanings*", we both look back at past assumptions and forward in an "*open and respectful attitude*" (Dahlberg et al., 2008, p.130).

The processes of a bracketing interview and the ensuing required reflexivity may also afford the researcher some self-protection, which is particularly important when working with emotionally challenging topics and potentially vulnerable participants. Rolls and Relf (2006) adopted a model where additional personal support was provided to the researcher. Their bracketing interviews are described as "*a supportive non-clinical, non-managerial relationship, where it was* ***the interface between the researcher as a person and the research data*** *that was explored*" (Rolls & Relf, 2006, p.292). In designing the bracketing process, I drew on this model. The interviews served as a sounding board, and a means by which I could reflect on my own sense-making and examine my own preconceptions.

In total, I participated in seven interviews across the course of the PhD research, with a variety of researchers, from the fields of disability, nursing and psychology. Five interviews were designated as "bracketing" interviews, three with researchers outside Aston University. Additionally, I talked twice to a fellow PhD student, early in the project (mid-2019) and then towards the end of data gathering (late-2023). I also drew on two interviews which I had given as a participant in external (to Aston) projects. These related to (a) being the parent of a person with learning disabilities who was shielding during Covid-19, and (b) to my involvement in the co-production of health and social care projects.

Initially, I intended to explore my experiences as a parent of a young person with learning disabilities, but the focus soon developed into reflections on my role as researcher as well. When considering the content of the interviews, a pattern of relationships started to emerge, within which I was positioned as both a Parent (and therefore sometimes service user) and as a Researcher, as demonstrated in Fig. 1.

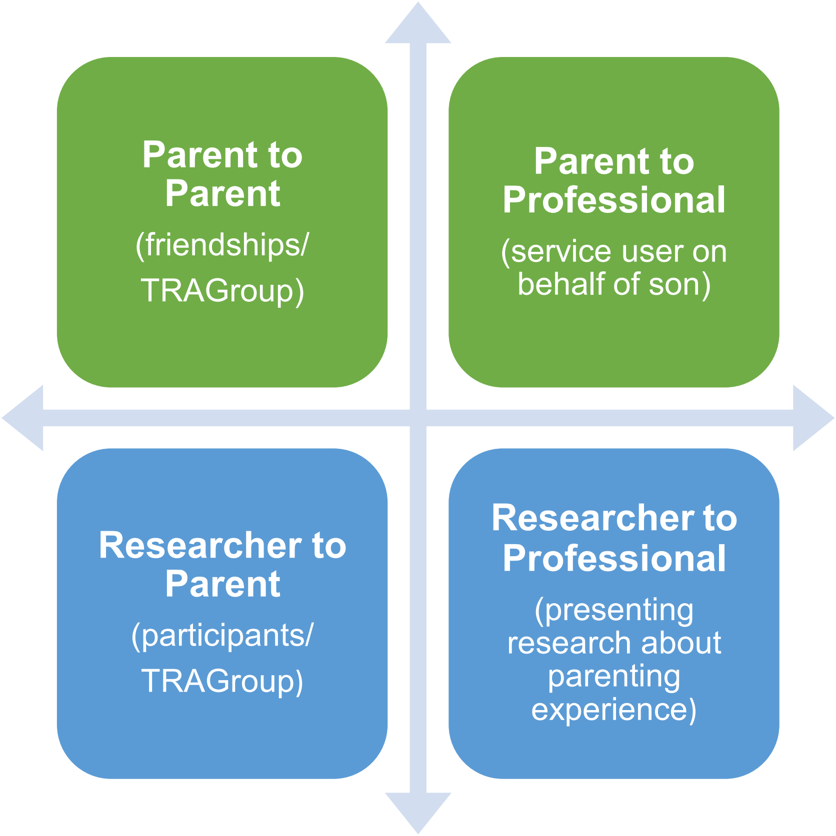

Fig. 1 Model of my relationships & personas as established in the analysis of the first bracketing interview

These personas were then explored further in relation to my encounters with participants during the research.

Whilst my experiences had led me to adopt certain views of caring for a disabled young person, I was keen to interrogate my own presuppositions to ensure they didn't take precedence over my participants' accounts. The bracketing interviews served this purpose. My reflexivity is presented within each chapter and relates my findings to individual bracketing interviews, as I explore my positionality as researcher and/or parent-carer.

An overview of this work is re-examined in the Discussion (Chapter 7).

Public involvement

Transition Research Advisory Group

From the outset, it was important that the research design should be guided by those with lived experience of the topic of study, who could bring first-hand understanding to the project. On a personal level, I also knew I needed support and guidance. My knowledge around the medical issues was limited, and consequently I was unfamiliar with care structures and the professionals with whom parents often interact. It therefore seemed imperative to consult with parent-carers and professionals who had cared for and worked with young people with PMLD to guide the research. This engagement with lived experience aligns with the phenomenological epistemology as it opens a window on to a group with specific needs, who might also be considered a hidden group, bringing their experiences to both the design and the findings, thus contributing to the conceptual coherence to the design.

Public engagement is an underlying principle of the National Institute for Health Research (NIHR), which actively seeks to involve patients and member of the public in the process of co-production. NIHR define public involvement in research as "*research carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them, and "it is an active partnership between patients, carers and members of the public with researchers that influences and shapes research*" (NIHR, 2024, webpage).[3]

Recruitment

A group of parents of young people with PMLD and professionals with experience in this field was established to contribute to discussions around design and management of the research, ethical considerations, research materials and findings and outcomes. These people were identified through my personal contacts and via snowballing through key members of the group. (Appendix 6)

We worked through three stages of the project together:

1. Recruitment (2018) of the group to include both parent-carers and professionals (although some members overlapped both groups) who were involved with young people with PMLD).
2. Consultation (2018) through initial meetings to discuss the definition of terms, ethics, recruitment and participant resources.
3. Collaboration (2018-2025) in small groups to test research methods, comments on data and findings, and subsequently make recommendations.

Eleven people contributed over the lifetime of the thesis, with a core of five members remaining active throughout the whole process.

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[3] As the project was started in 2018, I initially referred to the guidelines published by INVOLVE, a body set up by the NIHR in 1996 to encourage public engagement. INVOLVE guidelines were subsequently subsumed into the NIHR working guidelines on the principles of co-production (NIHR 2024).

Consultation

Meetings were initially held monthly, and subsequently quarterly. The establishment and administration of the group, as well as planning the contents of and setting up each meeting, took considerable time and preparation. It also had unforeseen cost implications for both members and researcher.

After consultation with members, it was decided to call the group the Transition Research Advisory Group (the TRAG), which reflected the major role the group adopted.

It was important to establish clear working guidelines with the group at the outset and define expectations (Isham et al., 2018). The TRAG members were given a job specification outlining what was expected of them and of me, as the researcher. They were also advised on their own right to withdraw from the project at any time. Feedback forms were filled in during the project.

Collaboration

The TRAG undertook a series of pilot exercises to trial the proposed visual methods. This proved to be an enjoyable and informative experience, both in terms of the stories they generated, and how the group found taking part in the activities. It was expected that with a tried and tested methodology, I would be better prepared for working with this participant group, understanding that sometimes parent may feel upset when discussing issues around caring for their children, therefore their feedback also fed into the Ethics applications.

Additionally, a pilot interview was undertaken with a member of the group, who had worked closely with parent-carers and young people with PMLD in her role as a social worker. The proposed interview schedule was trialled, in preparation for the professional's study.

The role of the group evolved over time, developing the design of the research, preparing for the NHS ethics proposal as well as making suggestions for sources of recruitment. In particular, the group contributed to the NHS ethics proposal in several ways; providing valuable background information, specifically helping prepare research materials, and also providing testimonials on the importance of participating in sensitive research. Latterly, they became involved in reviewing data and my analysis.

The contribution and importance of the group is referred to throughout this thesis.

Ethics

Ethical approval was sought from West Midlands South Birmingham Research Ethics Committee (REC ref 19/WM/0011.) Amendments were made during Covid-19 (2020) to allow for remote interviewing, and then more recently (2023) to include parents of young people with severe learning disabilities (Appendix 1)

Participants were sent the relevant participant information sheet and gave informed consent prior to interviews; they were reminded of their right to withdraw from the interview and the project at the start of the interview, without it affecting their rights, or affecting the care their child received. A distress protocol was devised in case a participant became upset (See Appendix 1).

The population of families with a child with PMLD is small and therefore anonymity was ensured not just by adopting pseudonyms but also changing locations and the names of schools and treatment centres. Participants were consulted on this. Furthermore, names were changed on the Pictor charts reproduced in Chapter 6.

Although the TRAG were not subject to the Ethics committee approvals, it was decided to prepare and use consent forms for the group, particularly around the ownership and reproduction of the visual data that they produced during the meetings.

Researcher wellbeing was also considered, a protocol was devised, and supervisors were available to talk to post interviews.

Research design

Guba and Lincoln (1994) pose the methodological question *“How can the enquirer (or would be knower) go about finding out whatever he or she believes can be known*?” (p.108). The adoption of a phenomenological ontology and epistemology as stated above leads towards a qualitative methodology, which is pluralistic in approach. The design is multi-perspectival across the studies and multi-modal both across and within the studies (Table 1).

Previous transition research has demonstrated that the parents’ world is dominated by their interactions with the professionals who work with their children, and those professionals who guide the systems (Brown et al., 2019; Jacobs et al., 2018). It was deemed appropriate to consider the accounts of “*other people*”, who belong to the parents’ “*lived world*” (Larkin, et al., 2019). By exploring the understanding and beliefs of those people who worked with young people with PMLD, the research design presented a more rigorous account of the context of transition processes and how they affected families. The aim of this pluralistic methodology was not to generate consensus, but to demonstrate how understandings and experiences relate to one another (Larkin et al., 2019). In this way, I hoped to reflect that "*experience is lived through a constellation of relations with others*" (Stainer, 2022).

A pluralistic approach was therefore adopted to consider two differing research questions with two populations, both involved in the transition process. An interpretative phenomenological exploration of parental experiences, and an interpretative template analysis of the beliefs and experiences of professionals who work with families during the transition processes. Additionally, I have employed several different methods, outlined below which endeavour to add depth to the analysis

Transition Research Advisory Group	**Chapter**	**Population**	**Research question**	**Methods/ Source**	**Data Collection**	**Data Analysis**	**Data Presentation**	Bracketing interviews
	Ch.3	**Parents** of young people 14-25	What are the caring experiences of parents of YP with PMLD within the transition window (14-25)	Qualitative Evidence Synthesis/ (Thomas & Harden, 2004)	Systematic literature search	Thematic analysis Line of argument (Noblit & Hare, 1988)	Poems synthesising voices	
	Ch. 4	**Professionals** working families at transition	What are the beliefs and understandings held by professionals relating to transition working with families of YP with PMLD	Template Analysis (Brooks et al., 2015)	Semi-structured interviews, in person and on-line	Thematic structure Interpretative examples	Individual narratives/vignettes as examples (Palmer et al., 2010)	
	Ch. 5	**Professionals** as above (same participants)	What is the impact of Covid-19 on professionals working with families of YP with PMLD	As Chapter 4	As Chapter 4	Themes developed during Template analysis Additional IPA (Smith et al., 2009)	Poetry representing single voices	
	Ch. 6	**Parents** of young people aged 17-21 in transition to adult services	How do parents of YP with PMLD experience the transition to adult services	IPA (Smith et al., 2009) Longitudinal IPA (Wanat et al., 2025)	Semi-structured interviews in person and online, with Pictor charts Email follow-up	IPA adopting longitudinal and line of argument approaches (Farr & Nizza, 2019; Larkin et al., 2019)	Poetry representing parents' descriptions of child's personality Reproduction of Pictor charts	

Table 1 shows the distinguishing methods contributing to each chapter

Study by Study Data Collection and Analysis plans

I will now outline the study plans by chapter before discussing the various methods employed in the studies. This discussion addresses "**why**" these methods have been adopted. Further details of "**how"** they were employed are outlined with the individual chapters.

- **Chapter 3** considers the question "What are the caring experiences of **parents** of young people with PMLD within the transition window (14 to 25 years old)?". This is a **qualitative evidence synthesis** of published research carried out according to the methods outlined by Thomas and Harden (2004). Papers were gathered through a systematic literature search, and data extracted according to inclusion criteria. Data were analysed thematically, whilst further analysis took place in the generation of **research poetry**. Here I attempted to uncover participants' lived experiences of caring through "*being-with-others*", by presenting the findings in the form of research poetry. Quality assessments were made of the included papers and the findings.

- **Chapter 4** considers the question "What are the beliefs and understandings held by **professionals** relating to transition-working with families of young people with PMLD?". Data collection was through **semi- structured interviews**, with professionals recruited across Education, Health and Social Care sectors as well as the Third Sector. Data were analysed using **Template Analysis,** according to the methods outlined by Brooks et al. (2015). Further analysis took place through the examination of **narrative vignettes** (Palmer et al., 2010). This account offers a thematic account of participants' beliefs informed by policy and practice, and yet hopes to be balanced by narrative vignettes which afford opportunities to disrupt the official discourse through interpretative examination.

- **Chapter 5** considers the question "What is the impact of Covid-19 on **professionals** working with families of young people with PMLD during their transition to adult services?". This study isolates and develops one theme from the Template Analysis, presented in Chapter 4. Data were further analysed through the application of **IPA** (Smith et al., 2022) to a subset of **interviews**. The positionality of participants in relation to parents was further examined through the scrutiny of language and stories. Further analysis took place through the generation of research poetry, which was used to highlight key incidents by adopting an interpretative phenomenological stance.

- **Chapter 6** considers the question “How do **parents** of young people with SLD and PMLD experience the transition to adult services?”. Five parents of young people at different stages of transition took part in a longitudinal study. Data collection was through individual **semi-structured interviews** supported by a relational mapping technique, **Pictor** (King et al., 2013), to undertake an “authentic” exploration of parents’ experiences. Data were analysed using **Interpretative Phenomenological Analysis** as defined by Smith et al. (2022). Adoption of this method aspired to reveal parents’ own transition within the context of their child’s arrival at adulthood. Further use of **poetry** aimed to highlight the young people with PMLD as individuals within the complex structures of transition.

- **Chapter 7** The Discussion chapter presents a synthesis of results from the previous chapters. It considers parents’ position in relation to others within Bronfenbrenner’s Ecological Model (1979), building on the work of Jacobs et al. (2020). This analysis is then further considered in light of Twigg and Atkin’s Typology of Caring (1994), to elucidate how parents are perceived as carers, and what implications this has for provision of support. Recommendations for practice and further investigations are made, as well as a review of the methodology used within the thesis.

To capture lived experiences of the participants, I have adopted analysis methods that align with a phenomenological approach. I opted to use Template Analysis, within the study of the professionals who work with the young people and their families, and Interpretative Phenomenological Analysis (IPA), with a longitudinal element, within the study of parents whose children are in the transition process. Template analysis differs from IPA, in that IPA concentrates on idiographic, case-by-case accounts, whereas Template Analysis focuses on a cross-case analysis.

Data gathering

Semi-structured interviews (Professionals and Parents’ study, Chapters 4, 5, & 6)

Data gathering was achieved through semi-structured interviews, supplemented in the parents’ study (Chapter 6) via use of a visual relational mapping method, the Pictor Technique.

Qualitative interviews are conversational in style, aiming to "*elicit concrete description and real-time sense making*" (Eatough & Tomkins, 2022), allowing the participant "*to tell their own stories, in their own words, in depth and detail*" (Smith et al., 2022). Although such interviews are labelled "semi- structured" in that they do not follow a rigid line of questioning, there is still a need for a schedule. However, Smith et al. (2022) suggest that within phenomenological research, the research question is addressed obliquely; the interviewer facilitates discussions, and the research question is answered later post interview through analysis.

Consequently, interview schedules for both the professionals and parents were drawn up in consultation with the TRAG and supervisory team. Whilst interview schedules were intended as a guide, they were devised on a three-stage model (Carter & Henderson, 2005). First, a general question for ease, such as "*how would you define profound and multiple learning disabilities?*" or "*what does your child enjoy doing?*". Second, a discussion about transition. At this point, the Pictor exercises were undertaken with the parents. In the final stage, "rounding off" questions, such as "*what support do you think parents need?*".

Although it was intended to undertake the interviews in person, because of Covid-19, most were conducted on-line using Zoom or Teams. Issues relating to this shift in working practice are discussed in the relevant chapters. Reflections on these processes are discussed in Chapters 4, 6 and 7.

Pictor Technique (Parents' study, Chapter 6)

Parent-carers have described how they repeatedly have to recount their child's story to professionals; they carry "*the burden of information sharing*" (Slade & Thomas, 2016, p11). This is both time-consuming and emotionally draining. Reiteration is particularly prevalent at transition when new professionals meet the families. Therefore, a further aim of the project was to explore methodologies that would enable parents to tell their stories with ease. At the outset of my PhD, the search was then to find a method that enabled participants to direct their own accounts of their children's care, but at the same time to allow me to focus their accounts beyond the descriptive timeline.

Pictor is a relational mapping method (King et al., 2014), developed from Hargreaves' social network method (1979) (Hardy, et al., 2012). Its theoretical background lies in personal construct theory (PCT), "*an approach that suggests that the meaning and interpretations that people attach to events affect their experiences of those event*s" (Hardy, et al., 2012, p.7). In this group it was important to highlight the relationships with service providers, their significance and the roles they fulfil in supporting both the young person and the parents.

The participant is given a large piece of paper and some arrow shaped Post It notes, asked to write the names of key people for a given scenario or network on those Post it notes, and then place them on the paper in relationship to the individual. The map/Pictor chart is then used as a prompt for discussion to explore those relationships, facets of communication and how the relationships facilitate care and support. Constructing a Pictor chart, therefore, encourages the participant to reflect on their experiences within this collaboration, moving away from narrating the medical chronology, to a wider, and more phenomenological discussion about the intersubjective nature of relationships. In this way, Pictor fits comfortably with phenomenological research.

Data Analysis

Template Analysis

Professionals who work with young people with PMLD and their families (Chapters 4 and 5).

Template Analysis is a form of thematic analysis with its roots in organisational and management research. Brooks et al. (2015) state that Template Analysis

> "*Emphasises the use of hierarchical coding but balances a relative high degree of structure in the process of analysing textual data with the flexibility to adapt it to the needs of a particular study" (p.203)*

The aim of the professionals' study was to explore the experiences of people who worked with families at transition. The group comprised of participants from Education, Health and Social Care as well as advocates, coming from different disciplines, and working within differing services within those disciplines. Template Analysis was considered appropriate because it gave the opportunity to explore the similarities between and across those groups, within the development of the template, while maintaining a focus on the underlying themes.

The analysis of data depends on development of a hierarchical coding template, drawn from an initial subset of data, usually interview transcripts. This template is then applied across the dataset being revised and refined at each round of analysis. A key feature of this process is the adoption of *a priori* themes within the initial coding template, based on, for example, research priorities, existing literature or policy. However, how the *a priori* themes are applied depends on the epistemological underpinnings of a particular study.

Brooks et al. (2015) state that "*Template Analysis is not inextricably bound to any one epistemology… a top-down realist approach testing a particular hypothesis would be expected to use "strong, well-defined a priori themes*" in analysis (p.205). Brooks (2015) compares this to a "*subtle realist*" approach, which acknowledges that whilst *"phenomena are independent of the researcher and knowable through the research process*" (p.215), the understanding that the researcher may be influenced by their own experiences and perspectives. In this case, the template would be developed from a bottom-up approach and *a priori* themes would be used more tentatively, where the researcher works in a more inductive manner (Brooks et al., 2015).

In reference to a specific study adopting an interpretative phenomenological stance, Brooks et al. (2015) describe how relevant findings from an earlier stage of the work were used to formulate pertinent *a priori* themes, to ensure analysis was based on participant experiences as related in their accounts. Within the context of the phenomenological epistemology of this thesis therefore, template analysis with an interpretative and phenomenological design is considered appropriate. Further details of the use of Template Analysis are discussed in Chapter 4.

Interpretative Phenomenological Analysis

Parents of young people with PMLD and CHCN during the transition to adult health and social care services (Chapter 6).

There are three strands to IPA. First, it has its roots in the philosophy of Husserl and Heidegger, as well as later phenomenologists such as Merleau-Ponty, in that it is concerned with "*exploring experience in its own terms*" (Smith et al., 2022, p.1). Second, the approach draws on Hermeneutics, the theory of interpretation. IPA thus focuses on close examination and interpretation of (primarily) textual data, to explore individual experiences and meaning making of those experiences. Third, IPA is an idiographic method of inquiry, committed to the particular experiences of individuals with a given context (Shaw, 2010; Smith et al., 2022).

Hermeneutics are central to Heidegger's thinking, that our access to the world we live in is through interpretation. Smith et al. (2022) explain:

> *"For Heidegger, phenomenology is concerned in part with examining something which may be latent, or disguised, as it emerges into the light. But it also interested in examining the manifest thing as it appears at the surface because this is integrally connected with the deeper latent form – which is both a part of, and a part from" (Smith et al., 2022, p.19).*

Within the context of the current study, I suggest that the experiences of parents caring for children with disabilities might be hidden or masked because society's focus would generally be on the needs of child. Therefore, to understand the hidden or latent parental experience, one must employ interpretative methods that not only consider those experiences but also the parents' understanding of those experiences. To access parents' *being-in-the world*, we may therefore employ the hermeneutic circle, where the part is seen in relation to the whole (Smith et al., 2009). Eatough and Tomkins (2022) explain the hermeneutic circle thus:

> *"It is an expansive and productive way of thinking about the constitutive relationships between things, steering us away from abstract 'either/or' thinking which strips human phenomena of contextual richness. The more circular our movements in interpretation, the larger the circle will become, embracing more contexts , more perspectives and more possibilities of understanding (Eatough and Tomkins, 2022, p.9).*

Furthermore, the researcher employs a 'double hermeneutic' in interpreting the sense-making of the participant. The process then comes iterative, as the researcher moves back and forth through the data, in their sense making of the described phenomena (Smith et al., 2009). Additionally, within the world of parenting a child with communication needs, a further level of interpretation takes place, where the parent interprets the communication of the child, and this transaction becomes central to the act of caring. The researcher is therefore exploring different levels of understanding and interpretation within the project.

The idiographic nature of IPA means that focus is on the individual accounts, drawing out similarities and differences between those accounts based within the phenomenon of interest, such as transition to adult services. Within this study I focus on a small group of parents who experience transition through their child. Furthermore, transition is, by definition, a temporal event, not only happening at a point in a young person's life, but also a process that should be planned for over a period of time (NICE, 2016). It is therefore appropriate to adopt a form of Longitudinal Interpretative Phenomenological Analysis (LIPA). Wanat et al. (2025) argue that LIPA is a "*powerful lens*" (p.2) for understanding the temporal processes of continuity and change with a person's life. LIPA can therefore be "*a source of significant insight*" exploring "*what grows and what diminishes*" to understand the particular experiences of the individual within the research context. The specifics of how LIPA was developed for and applied to this research are discussed further in Chapter 6.

Creative methods

Research poetry (Chapters 3,5,6) and the presentation of narrative vignettes (Chapter 4) were used within the data analysis and for presentation of results to further the interpretation across both groups of participants (Table 1).

Creswell, Hanson et al. (2007) suggest that the researcher should justify their choice of writing structures (*rhetoric*). Here, I justify and explain my use of my research poetry within the thesis, which brings the individual voices and experiences of the participants into the narrative of the findings. Whilst interpretation became an integral part of the reiterative process of developing and writing up the results, the concentration on the language used, as part of the phenomenological inquiry, lead to the development of this research poetry.

Research Poetry (Chapters 3,5 and 6)

Two conference experiences led me to incorporating poetry in this research. At the Phenomenology of Health and Relationships (PHaR) Conference (2019) Beth Moran presented "I am" poems drawn from interviews with social work students, and I was struck by the insight and emotion her poems conveyed. Subsequently, I attended BPS seminars which explored the use of creative and arts-based methods in applied psychological research (2019). I saw the possibility of presenting my findings in a more dynamic way than the traditional table of quotations; by presenting poems which could be read either quietly and reflectively as a solo activity, or dramatically out loud to an audience. Thus, I felt the narratives and reflections of participants would be received by a wider audience, in an "*ethical, caring and empathetic*" manner (Faulkner, 2020, p.39).

Research poetry, or 'Poetic Inquiry', has become increasingly important within health psychology. It is used as a tool for data generation, analysis and presentation of research results (Furman, 2006), using a variety of techniques. Faulkner states that "*poetry may be considered a 'special language' that researchers want to access*" (2020, p. 17) to further the understanding and impact of their work. As both qualitative research and poetry "*share understanding of living and what it is like 'to be there [by bringing] the richness of experience into language*" (Galvin & Todres, 2009, p.309), poetry may heighten and emphasise the findings of qualitative research. Additionally, as Brown (2018) comments, poetry may help the researcher to gain new perspectives and "*present findings that may otherwise go unnoticed*" (p107). Thus, there is a dichotomy of benefit for the researcher both in making people's experiences resonate more profoundly, but also in helping with meaning making within the research.

The resulting poetry can be described as "f*ound poems*", in that they were created from "*text discovered in a non-poetic setting… removed from its context and presented as a poem*" (Drury, cited by Faulkner, 2020, p.159). Exceptional use of language and imagery were highlighted, as well as elements of truth and surprise in the participants' narratives, and these were used as the building blocks for the poems. I then used Prendergast's Surrender and Catch approach to generating 'found' poems (Faulker, 2020). Prendergast's method suggests "*suspending any notion of what you expect to find – "the surrender" – and allowing "what happens [to] happen – the catch*" (Faulkner, 2020, p.162).

In phenomenological terms, the use of poetry can "*communicate human experiences in ways people can really feel and relate to*" (Galvin & Todres, 2009, p.309). Within the context of this thesis, poetry emphasised the meanings people attributed to their experiences by using poetic language derived from everyday speech. This was achieved within the chapters in several ways: poetry was used to synthesise voices of participants from previous studies (Chapter 3); to present emotional anecdotes and opinions in the context of working during Covid-19 (Chapter 4); and to present the parents' descriptions of their child's personality (Chapter 6). Each chapter gives further details about the development of the poetry.

Theoretical Context

Conceptual synthesis- dialoguing with theory

Within this thesis, I have considered both the findings of the professionals' studies and the interpretative phenomenological findings of the parents' study in the light of Bronfenbrenner's Ecological Model and Twigg & Atkin's (1994) Typology of Caring, to uncover what are the obscure social structures that influence the parental experience of transition. In this way, I applied theory to create a meaningful account of the examined phenomena.

Bronfenbrenner's Ecological Model

As discussed in the introduction, the experiential findings from professionals and parents in each chapter, are considered under the focus of the systems of the Ecological Model as adapted by Jacobs et al. 2020 (Fig. 2).

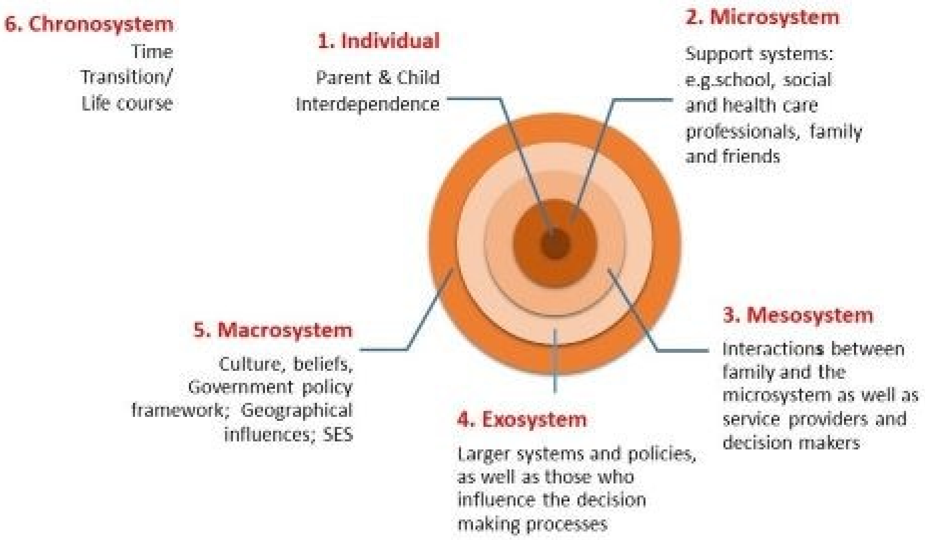

Fig. 2 Bronfenbrenner's Ecological Model (1979) including by Jacobs et al's (2018) adaptations

However, it is important to highlight a key difference within the design of this thesis and that of Jacobs et al. (2020).

Jacobs et al. (2020) built on the findings of their earlier systematic review (Jacobs et al., 2018), which found that parents and young people were interdependent, and so should be placed at the centre of the model. They also highlighted that parents view transition as a life event, consequently they adopted the Chronosystem to represent the life course. In their 2020 study, Jacobs et al. embedded the ecological approach through all stages of the design, particularly in data gathering by setting out their interview schedule according to Bronfenbrenner's hierarchy of systems. Additionally, they used the model in their analysis and presentation of results. In this way, their study is deductive by testing the established model (hypothesis) against the multi-perspectival view of transition processes for young people with PMLD.

Jacobs et al. (2020) demonstrated that the Ecological model could be used to identify gaps in planning for transition, as well as involving the young person in the process. Thus, their study highlighted certain aspects of the parents' experience. However, their research did not explain (nor was it intended to) how the parent's role as a **carer** was viewed by themselves or the services they interact with.

The studies presented within this thesis employ a variety of methods, underpinned by a phenomenological and interpretative epistemology, which are inductive in approach. The use of Bronfenbrenner's model therefore offers an integrated approach to analysis, as discussed above (Dahlberg and Dahlberg, 2019). Thus, I considered the findings of each chapter, post-analysis, in the light of this model, with particular reference to the interaction between the systems (Table 2).

Individual: *parent (with the child) since we are examining parental support needs around this process – have been shown to be interdependent*.
Microsystem: *individuals who support both the child (such as teachers) and parent-carers, (doctors, healthcare professionals, support workers*)
Mesosystem: *relationships with parents, also relationships with people who influence the decision making, (social workers, educational psychologists, assessing healthcare professionals)*
Exosystem: *people who influence the decision-making process, such as the commissioners*
Macrosystem: *cultural influences, such as ideology relating to disability, government guidelines/legislation, funding; global economics*
Chronosystem: *stage of life in relation to the situation: i.e. parent witnessing their vulnerable child becoming an adult; Approaching transition*

Table 2 Bronfenbrenner's Ecological Model 1979, adopted in this study, based on the findings of Jacobs et al. (2020)

Application of this model builds on previous research but brings a new perspective; by concentrating on the parent at the centre of model as a person in their own right. However, it will be demonstrated that this analysis alone does not explain the duality of needs of the parent-carer. Twigg (1993) states "***the duality of focus – the fact that we focus on the carer because of, and within context of the relationship with the cared-for person - has to be kept central***" (p.154). Therefore, parents' position within the transition process and their interaction with the professionals, as well as their child's needs, require further examination within a model that focuses on care systems. Consequently, within this thesis I decided to consider the identified interactions between Bronfenbrenner's systems in the light of Twigg and Atkin's Typology of Caring (1994). The aim of this secondary analysis is to understand how parents' caring role develops through the transition of their child to adult services, in conjunction with exploring their support systems and needs.

Summary

Within this thesis, I adopted an interpretative stance, which has its roots in phenomenology. By adopting this phenomenological epistemology, and through employing a multi-perspectival design which uses a number of creative methods, I illuminate the experiences of parents at this time of transition.

I add knowledge to the small body of published phenomenological work relating to parents of young people with PMLD (e.g. Kruithof et al., 2022; Vandesande et al., 2024). I also build on the established transition literature by adopting and developing Bronfenbrenner’s Ecological model in the analysis.

The next chapter considers the caring experiences of parents of young people with PMLD during the transition time frame (14 to 25 years old), by synthesising existing literature, to establish a context for the research.

Chapter 3

Care-giving experiences of parents of young people with PMLD and complex healthcare needs in the transition to adulthood years: a qualitative poetic synthesis

This chapter was published in Arts & Health online in November 2023 (Slade et al., 2023).

Introduction

This Chapter introduces the reader to the context of the thesis research question: caregiving experiences of parents of young people with profound and multiple learning disabilities and complex healthcare needs in the transition timeframe (14 to 25 years old).

As discussed in the Chapter 1, mainstream transition models conceive the parental role as incrementally decreasing with adolescent development. However, young people with PMLD remain dependent on caregivers, meaning parents necessarily retain responsibility for ongoing care and medical decision-making throughout adolescence and into adulthood (Jacobs et al., 2018). Healthcare transitions in general have been recognised as a time of great stress for parents (Heath et al., 2017), and, for those parenting a child with PMLD, that stress is often heightened by worry about future provision (Willingham-Storr, 2014).

While the challenges faced by new parents when their child is diagnosed with a profound disability are well-documented (Wong et al., 2017), less is known about the enduring elements of care required throughout transition to early adulthood. A recent review of parents’ knowledge of their child with PMLD found that parents fulfil key roles of expert in their child’s communication, wellbeing and pain, and advocate for their child’s needs (Kruithof et al., 2020). Despite this, previous reviews exploring adolescence and early adulthood of those with PMLD have focused on transitions from school to adult services (Jacobs et al., 2018) and the process of healthcare transitions, specifically implications for nursing (Brown et al., 2019) not on caring per se.

In addition, there are few qualitative evidence syntheses in this area. A review of reviews exploring healthcare transitions, but not including young people with PMLD, (Yassaee et al., 2019) found only four included solely qualitative reviews, focusing on the experiences of young people with chronic somatic conditions (Fegran et al., 2014), adolescents with autistic spectrum disorder (DePape & Lindsay, 2015), parents of young people with chronic illness

(Heath et al., 2017) and young people with attention deficit hyperactivity disorder (Price et al., 2018). No reviews have sought to understand the caring experiences of parents of young people with PMLD throughout transition to adulthood and adult services. Understanding parents' experiences in this context is important for identifying their (as well as their child's) support needs.

Question

What are the lived care-giving experiences of parent-carers of young people (aged 14 to 25) with profound and multiple learning disabilities?

Aim

- To synthesise primary qualitative research exploring the lived care-giving experiences of parents of young people (aged 14-25 years) with PMLD and complex healthcare needs.

Method

Pre-registration

A review protocol was pre-registered on the PROPSERO database (ID No: CRD42020187939) available via https://www.crd.york.ac.uk/prospero.

Research design

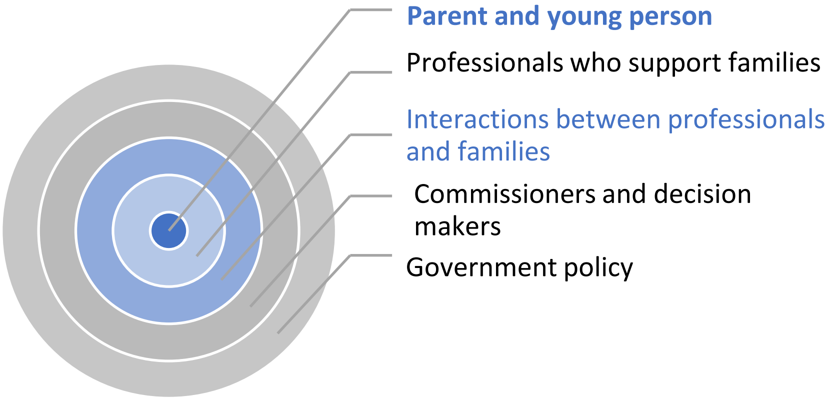

Fig. 1 Model showing the focus of the qualitative poetic synthesis

Inclusion criteria

Qualitative studies (stand alone or within mixed-designs where qualitative findings could be separated) were included if they reported care-giving experiences of parents of young people with PMLD and complex healthcare needs, within a transition window of 14 to 25 years (Care Act, 2014). To be comparable in terms of healthcare provision, studies had to be conducted within Organisation for Economic Co-operation and Development member countries, with a universal healthcare system (excluding USA and Mexico). Studies were included from 2005, when the influential Improving the Life Chances of Disabled People (UK Govt, 2005) report was published, up to April 2023. Only studies reported in English were included.

Exclusion

Paid carers, siblings, and young carers were excluded because they have different needs to those of parents. Also excluded were young people with intellectual disabilities without healthcare needs; young people with moderate learning disabilities; those with accidentally acquired disabilities. Studies examining diagnosis experiences and those examining parents' experiences of the death of a child with PMLD were also excluded.

Information sources and searches

Scopus, Web of Science Core Collection, Medline, SciELO, NICE Evidence database and Google Scholar from January 2005 to April 2023 were searched and alerts set up for Jisc Zetoc and Web of Science. References and citations of included papers were checked to identify further papers. A search strategy was developed using the Context, How, Issues, Population (CHIP) tool (Shaw, 2011) adapted for each database. Boolean operators were used to combine synonyms (OR) and key concepts (AND) including terms for the:

- **C**ontext: transitional care for young people with PMLD and complex healthcare needs;
- **H**ow: qualitative methods;
- **I**ssues: caregiving experiences;
- **P**opulation: parents of children with PLMD (Fig. 1).

Search strategy

1. Parent* 2. Mother 3. Father 4. Maternal 5. Paternal 6. Carer* 7. Caregiver 8. Guardian 9.Grandparent

10. 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9

11. Child* 12. Young person 13. Young adult 14. Teenage* 15. Adolscen*

16. 10 AND (11 OR 12 OR 13 OR 14 OR 15)

17. Profound-and-Multiple-Learning-Disabilities 18. Profound-and-Multiple-Learning-Difficulties 19. PMLD 20. Severe-learning-disabilit* [4]21. Intellectual-disabilit* 22. Developmental-disabilit* 23. Neurodevelopmental-disabilit* 24. Cerebral palsy 25. Microcephaly 26. chromosome-disorder

27. 16 AND (17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26)

28. Caregiving 29. Caring 30. Care 31. Transition to adult care

32. 27 AND (28 OR 29 OR 30 or 31)

33. Experience* 34 Interview* 35. Qualitative

36. 32 AND (33 OR 34 OR 35)

Study selection and data extraction

Duplicates were removed. Titles and abstracts, were screened, including papers for full text screening in cases of uncertainty. Selected full text articles were screened against the inclusion criteria, paying attention to level of disability, age, and whether parent-carer roles could be separated if presented as part of a mixed sample (e.g., other family members, paid carers). The data were extracted using a pre-designed study characteristics form (e.g., year, country, study design, recruitment, participant demographics). Following this, original author themes were extracted, and data split into first order (participants' quotations) and second order data (author's interpretations).

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[4] Severe learning disabilities were included in the search criteria as a catch-all term, as this term is commonly used within research to include both those with profound disabilities as well as those with severe learning disabilities. Data relating to parents of young people with PLMD and CHC was then extracted wherever possible.

Quality appraisal

The quality of the included studies was assessed using an adapted CASP checklist and checked by a member of the supervisory team. As suggested by Long et al. (2020), a "maybe" category was added to allow for more nuanced answers. Value of the research was scored on a scale of 1-5 (not valuable to very valuable). Discrepancies were discussed with a third member of the team. Findings of the synthesis were appraised post analysis using Confidence in Evidence from Reviews of Qualitative research (GRADE-CERQual) guidelines (Lewin et al., 2018 (Appendix 2)

Data synthesis

The extracted data was synthesised using an inductive thematic approach (Thomas & Harden, 2008), and during this process I constructed poems from extracts of the first order data to further explore and highlight key findings.

Thematic analysis

Included articles were allocated to three groups: parental experiences, healthcare studies, transition specific studies. Working with these sets, we synthesised data following Thomas & Harden (2008) guidelines. We coded data descriptively before combining codes to generate tentative themes. We then examined themes across the three groups, looking for similarities and differences. Themes were refined and agreed by all members of the review team and the TRAG. As data were so diverse, a line of argument approach (Noblit & Hare, 1988) was adopted in the final write-up to reflect the diversity and breadth of the caring experiences extracted.

Poetic synthesis

Writing original poetry is well established within healthcare science as an aid to patient care (Barak & Leichtentritt, 2017). Furman and Dill (2015) argue that the research poem "is a valuable means of condensing research data into its most elemental form" (p.44) while emphasising "understanding of living and what it is like 'to be there' [by bringing] the richness of experience into language" (Galvin & Todres, 2009, p.309). Ward (2011) argues that poetry brings participants' experiences to the reader, inviting them "into the research space" (p.356).

To generate the poetic synthesis, I adopted a method similar to Prendergast's *Surrender and Catch* process. Prendergast's method (based on phenomenological theory) suggests suspending preconceptions – *the surrender* – and allowing "what happens [to] happen" – *the* *catch* (Faulkner, 2020, p.162). After reviewing first order data to identify quotations that illustrated themes, I used original imagery and language to generate ‘found’ poems which resonated with my own experiences and emotional responses to the participants’ words. I then used a ‘free-verse’ approach to maintain participants’ narratives, enhancing *their* voice within the analysis. Finally, poems were given titles, adding a further interpretative dimension. Fidelity to original quotations was maintained throughout, except in the instance of standardising genders of the children to add cohesion to the poems, when blending the experiences of more than one parent.

Results

Demographic findings

Following removal of duplicates, searches yielded 3922 articles. 19 papers were included, referenced by number (see Table 1). Included studies were published between 2008-2021 and spanned eight countries (UK, Australia, Canada, Eire, Netherlands, Poland, South Korea, and Sweden). In most cases, parents of children with PMLD and complex healthcare needs (2, 5, 6, 9, 10, 11, 16, 18, 19) could be identified. In others, data were extracted specifically relating to parents of young people with PMLD, within the appropriate age group (1, 4, 7, 12 13, 14, 15, 17). Authors were contacted for clarification where required (3, 4, 8).

Fig. 2: PRISMA flow chart showing the screening process of papers included

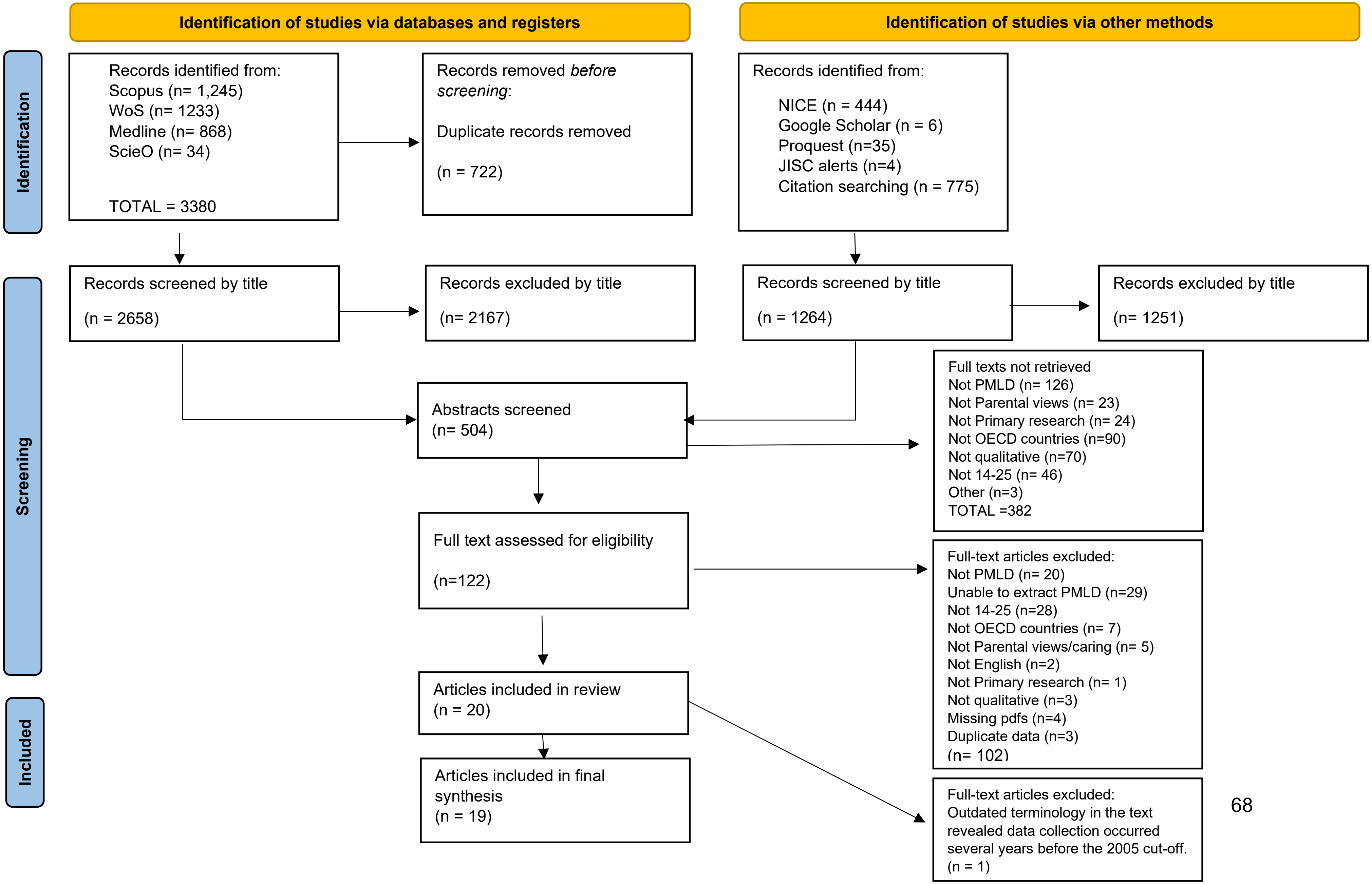

Table 1 Characteristics of included studies.

STUDY ID NO	LEAD AUTHOR YEAR/ COUNTRY	TOPIC	PMLD SPECIFIC	DIAGNOSES INCLUDED IN THE STUDY	METHODOLOGY	ADAPTED CASP QUALITY ASSESSMENT SCORE[5]
1	Bhopti, 2020 Australia	Family QoL, disability supports, parental occupations (Mixed Methods)	No	DS, ASD, CP, RGD	Mixed methods: Thematic Analysis	3
2	Bindels-de Heus, 2013 Netherlands	Parents experience of PMLD transition	Yes	PIMD, GMFCS IV & V	Mixed method: Content analysis	3
3	Brown, 2020 UK	Transition for young people with ID; family views	No	RGD, CP, ADS, ID	Thematic Analysis	5
4	Croot, 2012 UK	Caring strategy of Pakistani people in UK for severely disabled child	No	MLD, PMLD, ASD	Grounded Theory	5
5	Davey, 2015 Australia	Experiences of family social participation of parents with children with severe physical disabilities	Yes	Severe physical disabilities; GMFCS IV & V	Narrative summaries; Thematic Analysis	5
6	Davies, 2011 Canada	Parental perspectives of transition care for young people with neurological disorder	Yes	Complex chronic neurological condition and intellectual impairment	Constant Comparison	5
7	Davis, 2009 Australia	Impact of caring for a child with CP	No	CP, GMFCS 1-V	Grounded Theory	4
8	Doyle, 2020 Eire	Importance of parent-practitioner relationships giving medicine to young people with PMLD	Yes	SID & PID	Hermeneutic Phenomenological Interpretation	3
9	Gauthier-Boudreault, 2017 Canada	Parents' experiences of transition period for young people with PMLD	Yes	PID with & without physical impairment	Descriptive Interpretative	5

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[5] *How useful was this study 1- not very, 5 – very

10	Gibbs, 2008 UK	Experiences of adults with ID in hospital	No	SID & multiple physical disabilities	Grounded Theory	5
11	Griffith, 2011 UK	Mothers’ experiences of support services for children with rare genetic disorder	No	RGD – Angelman, Cornelia de Lange, Cri du Chat	Thematic Analysis	4
12	Lee, 2021, South Korea	How the oral health issues of young adults with severe IDD affect caregiver burden	No	Angelman, Autism, birth asphyxia, brain injury, CP, premature birth, urea cycle disorder	Thematic Analysis	5
13	Mitchell, 2012 UK	Decision-making for/with YP with complex needs	No	CMN, DMD, MID, RND, SID, RGC	Framework Approach	5
14	Oulton, 2009 UK	How parents of children with severe learning disabilities manage risks	No	DLD, PMLD, CP, Physical disabilities	Grounded Theory	5
15	Sim, 2021 Australia	The everyday activities of north-east and south-east Asian migrant mothers of children living with disabilities, living in Australia	No	Acquired brain injury, ASD, CHARGE syndrome, MID, Prader Willi Syndrome	Grounded Theory	4
16	Stahle-Oberge, 2009 Sweden	Parents’ experience of pain in children with CY & Multiple Disabilities	Yes	CP, multiple disabilities, non-verbal	Grounded Theory	5
17	Thackeray, 2015 UK	Maternal experience of parenting a young adult with DD	No	CP, ASD, SLD	IPA	5
18	Tomczyszyn, 2019 Poland	Problems of raising a child with ID (Poland)	No	DS, ASD, MID, SLD, non-ambulatory	Not reported	4
19	Young-Southward, 2017 UK	Health and wellbeing for young people with ID during transition	No	MID, PMLD	Thematic Analysis	4

Table 2 Participants included, according to reasons (A- Age; D- disability, P-participant profile)

STUDY ID NO	LEAD AUTHOR/ YEAR/COUNTRY	NO OF PARTICIPANTS & GENDER IN STUDY	NO OF PARTICIPANTS, & GENDER) WHOSE DATA WAS EXTRACTED	REASON FOR DATA EXTRACTION	AGE OF OFFSPRING IN STUDY	AGE OF OFFSPRING, RELATING TO EXTRACTED DATA	DIAGNOSES INCLUDED IN THE STUDY[6]
1	Bhopti, 2020 Australia	12 8F, 4M	3 2F, 1M	A/D	8-17	15	DS, ASD, CP, RGD
2	Bindels-de Heus, 2013 Netherlands	131 101F, 28M	131 101F,28M		16-26	16-26	PIMD, GMFCS IV & V
3	Brown, 2020 UK	10 9F, 1M	10 9F, 1M		16->30	n/a	RGD, CP, ADS, ID
4	Croot, 2012 UK	11 7F, 4M	2 1F, 1M	A/D	4-16	15-16	MLD, PMLD, ASD
5	Davey, 2015 Australia	10 10F	5 5F	A	14-17	14-17	Severe physical disabilities; GMFCS IV & V
6	Davies, Rennick, 2011 Canada	17 12F, 5M	17 12F, 5M		18-21	18-21	"Complex chronic neurological condition and intellectual impairment" - ambulatory and non-ambulatory
7	Davis, 2009 Australia	37 24F, 3M	8 n/a	A/D	3-18	13-18	CP, GMFCS 1-V
8	Doyle, 2020 Eire	15 15F	5 5F	A	2-18	14-18	SID & PID
9	Gauthier-Boudreault, 2017 Canada	14 12F, 2M	14 12F, 2M		18-26	18-26	PID with & without physical impairment
10	Gibbs, 2008 UK	25	9 8F, 1M	P	n/a (Adult)	n/a	SID & multiple physical disabilities

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[6] ASD = Autism Spectrum Disorder; CMN Complex Medical Needs; CP Cerebral Palsy; DMD= Duchenne Muscular Dystrophy; DS = Down Syndrome; GMFCS = Gross Motor Function Classification Scale; MLD, MID = Mild Intellectual Disability; PMLD or PIMD Profound and Multiple Learning disabilities, Profound Intellectual Learning Disabilities; RGD = Rare Genetic Disorder, RNC = Rare Neurological Condition; SID or SLD Severe Intellectual/Learning Disabilities.

11	Griffith, 2011 UK	8 8F	3 3F	A	24-44	24-25	RGD – Angelman, Cornelia de Lange, Cri du Chat
12	Lee, 2021 South Korea	14 14 F	9 9F	A/D	18-27	18-22	Angelman, Autism, birth asphyxia, brain injury, CP, premature birth, urea cycle disorder
13	Mitchell, 2012 UK	14 11F, 3M	5 4F, 1M	D	14-22	18-22	CMN, DMD, MID, RND, SID, RGC
14	Oulton, 2009 UK	20 18F, 2M	14 n/a	D	4-19	n/a	DLD, PMLD, CP, Physical disabilities
15	Sim, 2021 Australia	11 11F	2 2F	A/D	7-19	15-19	Acquired brain injury, ASD, CHARGE syndrome, MID, Prader Willi Syndrome
16	Stahle-Oberge, 2009 Sweden	13 6F, 7M	13 6F, 7M		13-20	13-20	CP, multiple disabilities, non-verbal
17	Thackeray, 2015 UK	3 3F	1 1F	D	19-28	24	CP, ASD, SLD
18	Tomczyszyn, 2019 Poland	4 4F	1 1F	D	11-22	22	DS, ASD, MID, SLD, non-ambulatory
19	Young-Southward, 2017 UK	40	9 7F, 2M	P/D	16-27	17-24	MID, PMLD

Participants

Data relating to 409 parents were reported across included studies; 278 parents participated in interviews and focus groups, and 131 participated in qualitative surveys. From this pool, data from 261 participants were extracted on age of child and disabilities. The reported overall ratio was 4:1 female to male, although gender was not reported in all studies. Young person gender was not available in eight studies, making it unreliable to report. Age range of offspring was 3-44 years, but only data from parents of young people aged 14-25 years were included. (Table 2).

Quality

Overall, quality of included papers was high, with 11 papers assessed as very valuable for answering the research question, five as valuable and three as quite valuable. No papers were excluded based on quality.

Thematic and poetic findings

Analysis generated three key themes: ***Interdependency; Sharing and shifting responsibility; An uncertain future.***(Table 3). See Appendix 2 for distribution of themes.

Findings are presented in the form of free-verse poems which formed part of the thematic synthesis.

Theme 1 **Interdependency**

- **Subtheme A:** **Retaining parental responsibility**
- *Poem 1: How is it possible to love a disabled child*
- **Subtheme B:** **Communication**
- *Poem 2: Pain*

Theme 2 **Sharing and shifting responsibility**

- **Subtheme C:** **Negotiated Care**
- *Poem 3: The Admissions Assessment*
- **Subtheme D:** **Sharing Expertise**
- *Poem 4: Experts by Experience*

Theme 3 **An uncertain future**

- **Subtheme E:** **(In)dependence**
- *Poem 5: Preparation for Adulthood*
- **Subtheme F:** **Fear of death**
- *Poem 6: A Mother's prayer*

Table 3 – Themes generated through the thematic synthesis

Theme 1: Interdependency

Subtheme A - Retaining parental responsibility

The included accounts revealed parents and their offspring as wholly interdependent. Parents had a dedicated commitment to, and expert knowledge of their child, and so assumed "*undelimited responsibility*" (14). "*Undelimited*" may be defined as dedicated and without boundaries, having the essence of something above and beyond that which would be considered 'normal'. The driving force behind this exceptional care was a need to protect the vulnerable young adult, often perceived by others as broken. Love was therefore coupled with the need to protect.

Poem 1

How is it possible to love a disabled child?

Looking on the outside of things
People think it's something
Dirty or Horrible?
That's the way people think.
The way I used to think
Before I had Nadeem.
Everyone used to pull their noses up
I felt I'd done something wrong,
Like he'd been cursed?

It's all a load of rubbish
What they say – people.
His brain is not functioning properly
And I've fallen in love with him like that.
I love him.
If I didn't love him I don't think
I would be able to care for him;
When he's hungry, I wouldn't feed him on time
Or make him his special foods;
I wouldn't bath him, wash him, change him
And make sure he's nice and clean.

When you have a child with special needs,
It's not that you won't love them
It's that you'll love them too much. (4,17)

Parents had to face their own beliefs, as well as discrimination from others, even moving to another country for greater acceptance (15). The mother in poem one, for example, described how she "*used to think*" of disability as something "*dirty or horrible*", possibly referring to a religious context, but also rooted in her child's double incontinence. She felt she was to blame. However, a shift in her understanding of the disability, "*his brain is not functioning properly*", reflected acceptance and adjustment to living with disability. Care given to the child demonstrated the mother's unconditional love (4), which was at times overwhelming (17). One mother said:

> *As parents you come to terms with your child's disability and accept it because if you don't, other people around them will not accept that disability as well.* (15)

This normalisation of disability made it hard to define how much labour was involved in looking after these young people, because parents often took it for granted, and assumed undelimited parental responsibility for their child's care:

> *When you've got a child that's as disabled as [daughter] is, your automatic reaction is to just take over. (13)*

Subtheme B - Communication

A key factor in parents' assumptions of responsibility was a belief that their child was unable to communicate effectively with others (17), or that others did not try to understand their child (11). It was an emotional challenge for parents "*The fact that he can't express what he's feeling…, well, as a parent, I'm extremely sensitive about it." (12).* Parents learned how to interpret their child's communication as they developed (16). This was often through limited language (17), the child's behaviours (9) or just through understanding facial expressions (16).

Poem 2

Pain

I ask the question:
"Does it hurt here?"
I touch the spot
No reaction
I carry on
Closer and closer
Then more reaction
I can see it
In her facial gestures
"What is it?"
"PAIN".
Her hip went out of joint
When I changed her
I took her leg
Her whole body shook

> *She grimaced*
> *It was the first time*
> *I experienced her pain* (16)

In poem 2, the parent becomes an investigator and interpreter, through word and action. They stated they "*experienced*" their child's pain, and thus became an extension of the child. Such deep understanding and interpretation are not inherent but learned from the child over time (16). Gradually, they also acquired an expert understanding of their child's needs and condition, so by the time their child reached adolescence, parents maintained a continuing role as primary advocate and decision-maker (2, 8, 10, 11, 12, 16), often acting as translator. Difficulties that professionals had in communicating with young people with disabilities highlighted parents' skill, and their vital role, as their child's mouthpiece. Communication was therefore, seen as key to the transition process. Some parents discussed when to include or exclude their child in decision-making, as they considered the young person lacked capacity to understand the complexity of life-choices (13).

Theme 2: Sharing and shifting responsibility

Sharing responsibility did not come easily. When parents recognised their child as having extraordinary needs, they often became hesitant about allowing others to support them (4, 14). Some mothers had an ambivalent attitude towards paid care, feeling guilty asking for help (4) or expecting highly qualified staff (4, 17). A lack of trust often arose from previous errors (4, 8,14,17). At the same time, however, families relied on healthcare professionals, because of the young person's high healthcare needs.

Subtheme C - Negotiated care

Sometimes parents felt healthcare staff were unhelpful:

> *A volunteer doctor was there, he was somewhat disrespectful, played fast and loose, I didn't want to go there again (12)*

Parents also worried that their adult child's difficulty in expressing themselves would make them vulnerable if left unattended in hospital (3, 10). They were afraid to leave their child's bedside, particularly when they were admitted to unfamiliar adult wards.

Parents reported they were often expected to stay by their offspring 24 hours a day in hospital, to administer feeds and personal care, although such care was not expected of paid support workers (10). This parent-child interdependence then led to a failure on behalf of healthcare staff to view young people and their parents as separate, and the child lost their identity as a person in their own right.

Poem 3
The Admissions Assessment

She doesn't speak,
can't move,
can't get anybody's attention
she could be just left there
if nobody's seeing to her.

The nurse came in,
"Let's fill in this form for her,
see if she's got any special needs"
She said.

"Feeding?"
"She can't feed herself,
can't give herself drinks"
I replied.
"You do that, don't you?"
She said.

"Incontinence pads -
you change her, don't you?"
she asked.
"Yes" I said.

The nurse asked the questions,
I answered,
We got to the bottom of the list.
"Well" she said
"she really doesn't have any special needs
because you do everything for her" (3,10)

Poem 3 highlights continued parental responsibility in an environment where they might be expected to share care. The problem thus became compounded, with parents feeling they could not leave their offspring unattended, and staff assuming parents would undertake caring roles.

When moving from familiar children's services to adult healthcare, parents used metaphors of battles and combats, having to '*fight'* (3, 10,11, 18) for their child. Sometimes they had to beg for their child to be taken into hospital (3,9,18), or were excluded from services owing to the severity of their child's disability (10, 14, 18). When healthcare professionals failed to take responsibility, the lack of support sometimes led parents to take risks. One mother weighed up risk of loss, bearing previous errors in mind:

> *...the biggest horror in my life is that my daughter may go into hospital …I have to admit I sometimes don't inform the GP because I know she might get taken away (10)*

In this case, and others, there were overtones of negligence (parents not asking for help; potential negligence in hospital) and fear of what might happen in both the short and long-term. Similarly with dental care, parents made decisions to avoid treatment, owing to dentists not understanding their child (12).

Subtheme D - Sharing Expertise

Parents frequently assumed a role that was above and beyond 'normal', such as administering medicines (14) and maintaining vigilance in situations when others might be in charge, such as assuming responsibility for writing out prescriptions (8) or having to explain how feed systems worked (3). So, although parents were seen as integral to their child's care, they were also perceived by as experts by experience:

Poem 4
Experts by Experience

We are experts
We are a resource
Listen to us, learn from us.
You've given us guidance,
Advice, help; now
Learn from us.

Often I think I'm ground-breaking -
I am concerned -
Have you never come across
An established trachie,
A PEG like that before?

Do you know about gastrostomies?
Syringes?
Do you know about flushing?
The wrong medication,
The wrong amount of bolus feeds
It wasn't necessary –
It was partly our fault,
We could have helped.

> *Am I listened to?*
> *I am helping.*
> *We wish to make decisions together*
> *we want to be taken seriously*
> *As parents, as experts.* (2, 3, 8, 10,14, 16)

Parental expertise was developed through caring for their child and working with medical professionals in paediatric services (2, 3). However, at transition to adult services, parents often felt they had more knowledge than the medical staff they encountered, who had sometimes never encountered the child's health technologies before (14). Parents demonstrated a deep understanding of their children's condition and found they could advise on things like medication, which often did not conform to standard doses (8).

In cases where parents had good relationships with healthcare professionals, they experienced a sense of shared responsibility and partnership (8), but when things did go wrong, parents felt they still carried responsibility: "*it was partly our fault/we could have helped"* (3). Parents were experts and were acknowledged as experts in their child's care by paediatric staff (2, 16), but in adult services, parents found themselves excluded from medical care and decision-making which was experienced as enormously frustrating. Ultimately, parents wanted partnership with professionals as their children entered adult services, but also to be supported by healthcare professionals at the point of transition:

> *We need guidance and advice in difficult decisions but make them ourselves (2).*

Theme 3: An uncertain future

Future timescales for people with PMLD remain uncertain throughout their lives. The unknown element of the child's lifespan was expressed by parents whose children had rare syndromes:

> *If you knew their lifespan you would know what to expect and which road you're going to go down. It's not fun living in the dark and that's what I've lived in for 30 years, not knowing what is the next stage (11)*

Parents lived with fear and knowledge that owing to their child's physical vulnerability, they could lose them at any time (14). It affected their own hopes and aspirations (5). Planning for the future was difficult and made harder by services being uncoordinated or unsupportive during the transition years.

Subtheme E - (In)dependence

Parents assumed an all-enveloping responsibility for their children up until the point of adulthood, the child's 18th birthday. Often, they believed this responsibility would not alter, owing to the young person's physical limitations and inability to take responsibility for their own lives. However, parents were faced with cessation of the familiar, supportive paediatric services and a transfer to adult services, in which their own role fundamentally changed. Parents had to adjust to new ways of working in partnership with services (3,9,19).

Poem 5
Preparation for Adulthood

Obviously, you have to move on
At some point.
She deserves to be doing her own thing.

You're not sure
who's your
First port of call
Moving towards a precipice
Not knowing
Will I have a parachute
Or not?
The real affection and
mutual respect gone
All of a sudden
Like somebody taking a rug
Just pulling it out-
It was scary
It was lonely
It was like where do I start?

Two sentences do not explain
Eighteen years of care
Doing my best for her
I'm not going to stop now
I won't be left hanging there
Hung out to dry.
The parachute appeared
At the last minute
I didn't even see it
It was a total blank:
I am going to be a carer
For the rest of my life
Facing that reality. (3,6,9)

Some parents wanted paediatric care, where they felt "*real affection and mutual respect*", to continue (1), whereas others recognised that their child was growing up and deserved a level of independence (19). There was also tension between the young person's right to independence, and an independence that was forced upon them because of their parents' ageing (1). Many parents felt that they would be carers for the rest of their lives (9, 19), expressing reticence to let their child go into full time care:

> *I mean we even spoke about if he gets really bad, we're going to give him up to the 'State'...God, it's horrible (1)*

The parent's vision of abandoning their child to institutional care was far removed from models of independent living. However, their choices were also influenced by practicalities of life, including the parent's need to work:

> *I don't want to place my daughter full-time or stop working yet (9)*

Parents also wanted to be involved in meaningful activities for themselves:

> *It's one's self worth and what you want out of life…I want to be able to do something...something worthwhile" (15)*

Another mother looked to regain her own future, saying "*I want my life back*" (11).

Subtheme F - Fear of death

Parents knew that their child was physically vulnerable, and with each hospital admission there was the overshadowing possibility of death, with terms such as "*life expectancy*" (2) used. Parents faced with the complex reality that either their child may pre-decease them, or that they may die first, thus abandoning their responsibilities, and leaving a vulnerable adult to be looked after by someone else.

Poem 6

A Mother's Prayer

What will happen
When we are no longer here?
I can't give Bethany to another
It is very difficult to say
"Take Bethany
I am going to die now".

I've seen the old mother
Sadly pass away
The disabled daughter

> *Cosseted all of her life*
> *Left, bereft.*
>
> *Do I have the right to disturb*
> *My son's life,*
> *To put the burden of*
> *Caring for his sister*
> *On his shoulders?*
> *I do not want that.*
>
> *I pray Bethany*
> *Has life-end before me. (14,17,18)*

In poem 6, the mother's wish that her daughter die before her seems shocking, not least because these parents have already gone beyond normal parenting to care for their children. Yet, uncertainty brings anxiety as she asks, "*what will happen if the parents are not around anymore – we wish we could stop worrying about it?"* (18). Tension thus existed between a mother confronting her own mortality and making plans for her child, when there was "*deep-seated mistrust*" in service providers (17).

This fear for the future was compounded by negative emotions associated with caring through the transition years, including bleakness (3, 10, 11); frustration (10); anxiety about the child's health and treatment (3, 9, 10, 13, 14); uncertainty (6, 11); fear (3, 9, 14, 17); and feelings of abandonment (3, 6, 9, 10). It was suggested that it is not only children who are vulnerable, but also parents: "*when the child suffered, so did the parent*" (16). But for some, there was just resignation:

> *She's going to come to a point where we're not going to be around. She can't rely on us to do everything all the time* (14).

Discussion

This review explored the lived care-giving experiences of parents of young people with PMLD and complex healthcare needs, during their transition to adulthood and adult health and social care services. Findings suggest that the experiences of this group are present in the literature, but rarely treated separately from those with other levels of physical disabilities) or learning disabilities. This highlights them as belonging to a hidden group, both in research and society, meaning they may be poorly understood even by professionals. As mentioned above, data was extracted from papers which also included those with differing levels of learning disability, as well as those young people with cerebral palsy who were diagnosed with different scores on the Gross Motor Function Classification Scale. The focus remained on parents of young people with PMLD and complex health care needs.

The poetic synthesis emphasised emotional aspects of these experiences, which span healthcare settings and countries. To understand further the impact of the relationship of parents to those professionals, and to explore their emotional responses, the themes were mapped onto Bronfenbrenner's Ecological Model (Fig. 3). Implications for the support available to parents explored using Twigg and Atkin’s Typology of Caring (1994) framework.

Application of Bronfenbrenner’s Ecological Model & Twigg and Atkin’s Typology of Caring (1994)

As discussed in chapter 1, Bronfenbrenner’s ecological model has been used to explore transition processes. The model suggests that young people and parents placed within the Individual level interact with member of the Mesosystem who provide direct support. Transition process are affected by external influences, such as policies and culture from the Exosystem and Macrosystem (Jacobs et al., 2020)

Twigg and Atkin’s typology (1994) defines carers as:

- *resources,* free and available sources of family support. Separate from statutory provision
- *co-workers,* working alongside or with professionals, in order to continue providing care
- *co-clients* equal in status with their needs being met, such as respite;
- *superseded carers* with independence for the young person achieved or inability to continue caring.) (Manthorpe et al., 2003)

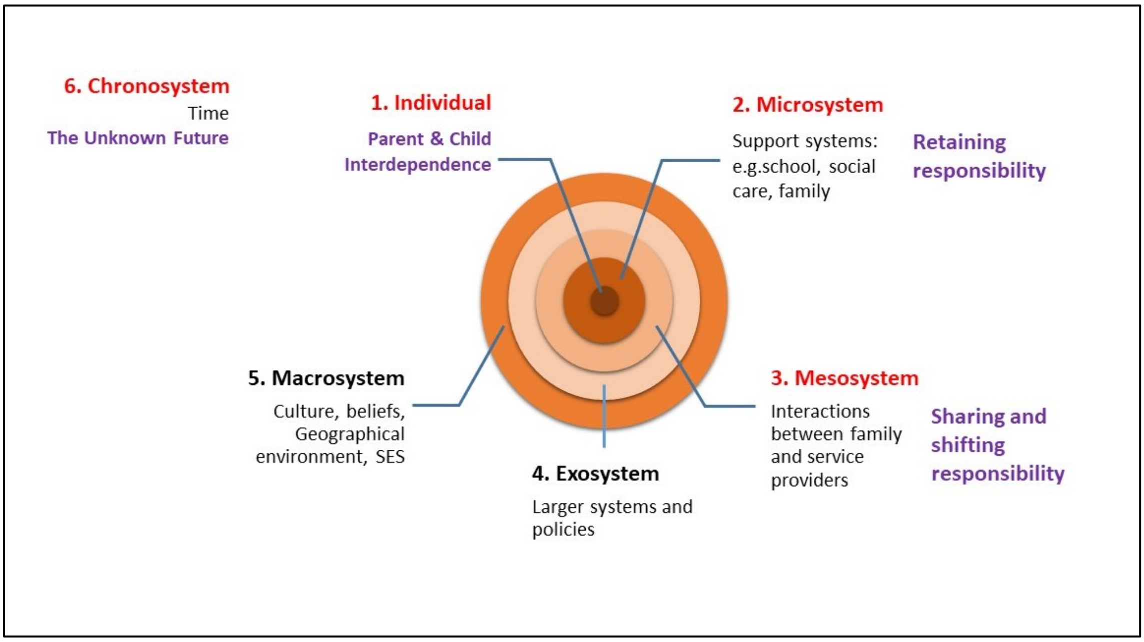

Fig. 3 Showing the themes and key findings mapped onto Bronfenbrenner's Ecological model
Key: red text highlights active areas of the model; purple text introduces key themes to the model

Individual – Parent & Child Interdependence

The poems highlighted the parental caring role as labour intensive and physically exhausting, eliciting a range of emotions, including frustration, fear and love. The theme of Parental and Child interdependence, therefore, becomes the key focus within the Individual and the Microsystem levels. As shown in the diagram, I placed the parent at the centre of Bronfenbrenner's model for two reasons. First, the focus of this research is parents in caring roles, and, as stated by Twigg (1993, p.154), "*the duality of focus – the fact that we focus on the carer because of and within context of the relationship with the cared-for person - has to be kept central*". Second, as stated by Jacobs et al. (2018), young people with PMLD have little influence over their environments, with family and school remaining their main social network, and there is interdependence between parent and young person.

Microsystem – Retaining Responsibility

The parents continued to retain responsibility for their child throughout young adulthood, despite the emotional cost, and this retention of responsibility suggests tension within the Microsystem, where other players, such education and healthcare professionals might be expected to appear. Although the level of responsibility is "*undelimited*" this may be seen as acceptable by professionals, as demonstrated in Poem 3. As informal carers, they may be seen as "*resources*" in the context of Twigg and Atkin's (1994) Typology of Caring. Furthermore, as Manthorpe (2003) suggests, this informal care may be seen by professionals as "*morally acceptable*" (p.481) because they *are* based with a family unit and *are* parents. The intense care element may not be recognised and external support is not provided whilst there is informal care.

However, whilst the poems highlight several adverse aspects of caring, parents also expressed love for their child and some positive aspects to quality of life. Thus, as Green (2007) suggests, caring for a severely disabled child is more nuanced than just burdensome. Parents may be tired and suffer financial constraints, but the emotional impact can also be positive.

Mesosystem – Sharing and shifting responsibility

Parents were shown to perform an "*intense parenting*" role (Woodgate et al., 2015), often acting as the child's voice, for example in medical situations. Within the Mesosystem, illuminated by Theme 2, Sharing and shifting responsibility, parents and professionals interact to achieve good outcomes for the child.

The poems emphasised parents' experiences of their exchanges with healthcare professionals as "*highly emotionally charged*" (Griffith & Hastings, 2014 p.416). Parental reluctance to share responsibility for their child's care partly developed from professional limitations in effective communication with young people with PMLD. Communication with, and for, their child was thus shown by parents to be central to their role as expert and advocate, having developed alternative communication strategies with their child based on "*tacit knowledge*" (Kruithof et al. 2020 p.1145). Parents' understanding of pain also placed an over-riding responsibility on them to act as interpreters for their child (Burkhard, 2013). Understanding how such knowledge can be shared is important, as these skills may be transferrable. Parents felt reassured when professionals took time to understand their child's method of communication and frustrated by a lack of interest and understanding (poem 3). However, within hospital settings, time was not always available for such learning.

With reference to the Caring Typology (Twigg & Atkin, 1994), we define this scenario as "*carers as co-workers*" where agencies may work alongside carers, the emphasis being on their role in supporting their child, whilst asking for help and information from professionals. However, in a reversal of the model, findings here suggested parents wanted to share their knowledge, and felt frustrated when this did not happen, as illustrated by Poem 4.

The Chronosystem – An uncertain future

The Chronosystem is defined as the impact of context on development, over time. *An Uncertain future*, which looks at both the immediate future as well as the distant unknown future towards death, thus maps onto this level of the model. In the transition to adult services, parents faced uncertainty and apprehension about service transfer, as well as fear for the future of their child's care. Jacobs et al. (2020) found that "*a life course perspective*" (p.1077) was adopted by parents, where parents framed future concerns within the context of diagnosis and life experiences. While parents had lived with the constant threat of their child's sudden death, the final poem also highlights fear for a future where the child outlives their parents. Kruithof et al. (2021) found parental concerns about not being there were not just related to caring and advocacy roles, but also to who would provide their child with love and physical touch, enabling them to thrive. Such concerns meant parents of young people with PMLD were afraid of dying before their child, sometimes expressing a wish that their child might die before them (Kruithof et al., 2021) and illustrated by Poem 6.

Within the context of Twigg and Atkin's (1994) framework, at the point of transition, parents move from the role of "*co-worker"* to the role of "*superseded carer*", without any reference to their own needs being acknowledged. Parents may therefore feel undervalued, and anxious about their own role. Twigg and Atkin (1994) suggest two reasons for this final stage of caring, first, either the person being cared for (young person) has reached independence, or second the caring role has become unsustainable. Whilst there are acknowledgments that some parents felt unable to continue in their caring roles within this dataset, there are other parents who felt they were excluded from decision-making because their child had become too old, reaching the 'age of independence', whilst not achieving that independence.

The role of advocate has been recognised as central to parents' identity (Ryan & Runswick-Cole, 2008). Yet, the current review suggests parents' identity is challenged during transition when they are excluded from decision-making. Preparing for adulthood was therefore shown to elicit anxiety for parents, both in terms of planning for the child, and in understanding their own role. In this synthesis, some parents embraced the idea of their child's independence, and having their own lives, where others felt they would remain carers forever. Jacobs et al. (2018) found the needs of parents and young people were highly interdependent, but it seems that by accepting this interdependence as the status quo, future outcomes for the child dictates the parents' role and identity.

The role of the TRAG

The Transition Research Advisory Group (TRAG) were consulted at three points:

- early stages of preparation, guiding the review parameters,
- at the point of study collation, providing feedback on a selection of identified papers,
- during data synthesis, reviewing thematic and poetic findings.

The groups' reflections about the poems are discussed within the Reflexivity section below, as are my thoughts on working with the TRAG.

Reflexivity

Both the bracketing interviews and discussions with the TRAG allowed me to reflect on my position both as researcher and parent. Throughout data analysis, it became clear that participants' voices resonated with my own experiences, despite the fact that my son does not have physical disabilities. The topics raised were discussed with the TRAG, and I found early in the PhD process that maintaining the line between researcher and parent was difficult to hold, but also added insight.

An example of this positioning happened within a discussion of the included papers. We discussed how a mother was offended when her child with PMLD was excluded from a family wedding (Croot et al., 2012). My response was mixed, remembering a time when we did not take my son to a friends' wedding because he was so disruptive. A TRAG member, whose daughter had PMLD, responded that her daughter had been a bridesmaid at one wedding, but also excluded from another to allow her parents to enjoy the day without caring responsibilities. On that occasion, the groom had organised a special day with her and the family at a later date to compensate. One of the bracketing interviewers (LT) expressed surprise at these examples of exclusion, and commented how my experience was able to throw light on this in a variety of ways, which she wouldn't have understood, without the lived experience.

The poems were 'found' within my emotional response to primary data, when I was undertaking the thematic synthesis. I wrote in my reflexivity notebook "*I suppose I'm finding some of this process a little difficult – it takes me back*". Certain phrases and anecdotes were too powerful to bury in a table of quotations, and I found building the poems helped me focus on key issues. The themes grew alongside the poems, and only Poem 4, *Experts by Experience,* was written retrospectively for the theme. I was encouraged to incorporate the poetry into the main body of the text by my supervisors.

The poems were discussed with the TRAG and some members commented that they did not reflect the "the joy" of parenting a child with disabilities. I wondered if my own experiences as a parent but also a researcher keen to address the issues had influenced the findings. I discussed this with the supervisory team and in response, we returned to the first order data and re-examined the analyses. This process confirmed emphasis on problems encountered by parents in the first order data, perhaps reflecting the original research questions set to identify issues. Alternatively, first order data may have been influenced by the parents who took part in those studies, wishing to express their concerns.

When I discussed this potential bias with the same bracketing interviewer, she responded:

> "*It is understanding these difficulties that people are experiencing are against our social structure in a way*".

So, we may argue that as researchers it is valid to focus on the difficulties the participants face. She concluded:

> "*You can't say [as a parent] that you know, you're very happy that your child's being fed through a PEG…. that's always going to be difficult isn't it? But actually in terms of you know, people valuing their children and loving them … that's there isn't it? all of that comes from that place of deep care and concern*".

It is witnessing of this deep care and concern that I feel drove me to this research topic in the first place.

Strengths and limitations

To my knowledge, this is the first review of parents' care-giving experiences of parenting a child with PMLD with complex healthcare needs during the transition to adulthood. Included studies were drawn from a range of countries, with data found to be predominantly 'very valuable' using the CASP criteria. Themes were assessed against the GRADE-CERQual guidelines (Lewin et al., 2018) with high confidence established (see Appendix 2).
Merging participants' voices to create poetry developed a line of argument which gave life to how caring was experienced by this hidden group. It is this methodological innovation which enables the experiential data to be presented in a powerful and emotionally resonating manner, which a standard qualitative evidence synthesis might not.

While searches identified a range of studies, qualitative research specifically exploring young people with PMLD and complex healthcare needs remains limited, with Australia and the Netherlands leading the field. Exclusion of US research (on grounds of healthcare systems) may have eliminated insightful experiences. A difficulty arose in trying to identify the level of disability of the young people within the studies, suggesting reporting terminology would benefit from standardisation. Additionally, given the limited research, it was difficult to highlight specific problems such as continence, as these issues are normalised by parents, and taboo in society.

Conclusions

This synthesis collates parents' experiences of caring, communication and future planning for their children with PMLD in the transition to adulthood years. Parents were reluctant to relinquish responsibility to professionals who may not be able to communicate effectively with their child. Parents' own sense of identity was also affected by marginalisation at the transfer to adult services. A key source of anxiety for parents was uncertainty regarding the future. Open conversations between parents and professionals about sharing responsibilities and decision-making, uncertainties and risks would reduce parental anxiety relating to lost knowledge when the young person leaves home, or the parent dies.

The following chapter turns to focus on the experiences of professionals who work with young people with PMLD and their families. In this next chapter, I explore how professionals understand the parents' role at transition. In doing so, I elucidate some of the tensions between professionals and parents revealed with this poetic synthesis.

Chapter 4

Multi-agency working with families of young people with PMLD at transition from paediatric to adult services: a template analysis:

Introduction

This chapter examines professionals' experiences and beliefs around transition for young people with profound and multiple learning disabilities and their parents. Chapter 1 established families of young people with profound and multiple learning disabilities (PMLD) and complex health care needs (CHCN) as a hidden group within society, but who have recently become the focus of research (Jacobs et al., 2019; Brown et al., 2020; Kruitof et al., 2021). Whilst mainstream transition research focuses on the growing independence of young people, and thus separating of parental responsibilities, the needs of this group of parents and young people remain interdependent (Jacobs et al., 2018).

The poetic synthesis (Chapter 3) confirmed this interdependence; demonstrating that parents are dedicated to their child, and act as advocates throughout their lives. Transition toward adulthood was identified as a particularly difficult time for parents, with a fear for the future expressed. Noting that transition research for young people with learning disabilities focuses on the parental viewpoint, Jacobs et al. (2018) identified that there is a need for enquiry into professionals' experiences of transition processes for this group.

I decided to build on Jacobs et al.'s (2018) and Jacobs et al.'s (2020) research, by gathering data from professionals to examine their beliefs and understandings of transition processes, including how they view the parental role. The focus shifts from meeting the needs of the young person, as discussed by Jacobs et al. (2020) to identifying the parents' own needs going forwards, as they adapt to new circumstances. Jacobs' et al. (2020) suggested that while national policies promoted person-centred care, local authorities struggled to meet these expectations, leaving families stuck. It is important to understand how the 'architecture' of transition affected the relationships between professionals and parents, which were shown to be strained in Chapter 3.

This first empirical chapter examines data gathered with individuals who work in the sectors of Health, Social Care, Education and Advocacy. Findings reveal the ideological underpinnings of transition and exploration of processes; how professionals build positive relationships with parents and where there are tensions; what the barriers are to successful transition, as identified by professionals. By examining these findings through the lens of Bronfenbrenner's Ecological Model (1979) and Twigg and Atkin's Typology of Caring (1994), I aim to achieve a greater understanding of how professionals view the parents' role at this time.

Research question

What are the beliefs and understandings held by professionals relating to transition working with the families of young people with profound and multiple learning disabilities and complex health care needs?

Aim

To explore how professionals view

- Transition planning and processes
- The role of parents of young people with profound and multiple learning disabilities at this time; and
- The professionals' relationship with parents and their own role in supporting parents during transition.
- Additionally, to understand how identified barriers could be addressed and to make recommendations for support for parents.

Methods

Research design

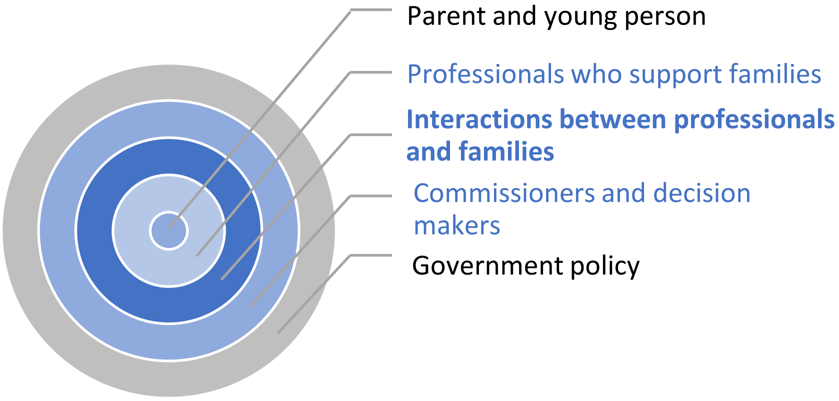

Fig. 1 Model showing the participant focus of the study

The current study builds on the findings of Jacobs et al. (2018) who noted that there was a lack a multiple stakeholders represented in research literature. I decided therefore, to adopt a multi-perspectival approach, drawing on professionals from Social and Health care, as well as Education and independent advocates (Fig. 1). Additionally, I aimed to recruit a cross section of stakeholders to reflect their employment status within each service, as reflected in Table 1.

Participants

Sixteen professionals working in the fields of Social Care, Health, Education and Third Sector (charity and advocacy) who worked with young people with PMLD, within the transition age group 14 to 25, and their families, were interviewed between October 2019 and January 2022.

Participants worked across seven authority areas, throughout the West and East Midlands, North and West Yorkshire. 15 female participants and one male participant, aged between 29 and 67 took part.

Age group / **Service**	**Children's services**	**Services that cross age group**	**Adult Services**
Social care	2 Social Workers (SC10, SC11)	1 Senior Social Worker, within transition team (SC01)	
Education	2 Educational Psychologists (ED9, ED16) 1 PMLD Teacher (ED17) 1 SEN Educational Commissioner (ED05)		
Health	1 Paediatrician (HCP7) 1 Paediatric Consultant (HCP15) 1 Learning Disability Nurse (HCP14)	1 General Practitioner (HCP12)	1 Occupational Therapist (HCP2) 1 LD nurse (HCP8)
Third Sector		1 Advocate (ADV4) 1 Advocate with nursing experience (ADV3) 1 Transition Advocate with nursing experience (ADV6)	

Table 1 – Participant profiles relating to the sectors in which they work

Recruitment

Recruitment was through identification of key people working within two Midlands health trusts and a local authority social care department. Further snowballing through their transition-related work contacts was undertaken to identify people who had specific experience with this hidden population. Contacts of the research team and the TRAG were also approached to take part.

Data collection

Data were collected through sixteen individual interviews, one joint interview (two co-workers) between October 2019 and January 2022. One participant was interviewed twice (SC01), pre-Pandemic and in early 2022. Interviews were held in person (3), via videocall (11) and via telephone calls (2). Interviews were audio recorded and anonymised during the transcription process. Interviews lasted between 39 minutes and 87 minutes.

An interview schedule was drawn up in consultation with the TRAG, to explore participants' understanding of PMLD, transition, and the parents' role within the process. The schedule was revised during Covid-19 to include questions about how transition procedures and their work in general had been affected by the pandemic, and what the challenges and benefits were of working at that time, (See Chapter 5)

Ethical approval was obtained from Aston University Research Ethics Committee, NHS South Birmingham and West Midlands REC, local NHS Trust and a hospital trust research ethics committees. Ethical approvals were revised during the pandemic to include changing methods of data gathering. Participants gave informed consent to take part.

Data Analysis

As the participant group represented the variety of people who may be expected to work with a young person with PMLD, the analysis adopted a multi-perspectival, and interpretivist approach to understand the different experiences within their working contexts.

The transcripts were read multiple times to ascertain an understanding of the key topics. Template analysis was undertaken according to the method laid out by Brooks et al. (2015) (Table 2).

1. Familiarisation of data	The whole data set was read and reread. Initial notes about each interview were taken, key observations were made and reflexivity was undertaken about personal experiences and assumptions
2. Preliminary coding with selected sample	A sub-set of four interviews were selected, with one from each sector, Health, Education, Social Care & Third Sector. These were coded in an abductive manner (Thompson, 2022), which considered the data in relation to a set of *a priori* themes, which were derived from 1.the initial read through 2. themes from the poetic synthesis
3. Cluster themes	Themes for each participant were mapped and evidenced, using mind-maps and line references, and then compared across the set of four interviews. Hierarchical relationships of themes were considered, and also mapped using mind maps and Post-It notes (see Appendix 3)
4. Define initial template	The initial template was defined according to the mapped themes, as it was felt there was a good cross-section of experiences .
5. Apply template to subsequent transcripts	It was also decided at this stage to code the remaining interviews in groups of four, and chronologically. The template was reviewed after each group of four and adjustments made at each review stage. The template was reviewed three times
6. Finalise template and apply to the whole set	The template was finalised (with minor alterations to the running order of the third template) after all the interviews were coded. The final template was then applied to the whole set. (See Appendix 3)

Table 2 Stages of Template Analysis (Brooks et al., 2015)

Themes from the poetic synthesis (Chapter 3), i.e*. parent-child interdependence, shifting responsibility, and fear of the future*, were included in an *a priori* framework. Commonalities of experience across the dataset were examined, and exceptions noted. The templates were discussed with the supervisory team at each reviewing stage. A theme development document was written (See Appendix 3).

Once the final template (Appendix 3) had been applied to each transcript, a table of quotations for each theme was constructed. Data were extracted from a spread of participants to evidence findings, and these quotations were considered while writing up. Writing up began as descriptive, then developed into a more interpretative approach by adopting some aspects of IPA analysis as defined by Palmer, et al. (2010), with consideration to the positionality, as well as the roles and relationships of the participants. Attention was given to the stakeholder context in which each participant worked (i.e. Social Care, Education etc); as well as ecological context of who had direct contact with the young person and the parent, and who worked at a remove. Further notes were made particularly relating to the convergence and conflict of ideas or experiences between participants. Stories relating to the parents' role in transition were also considered and presented here as vignettes, to examine professionals' opinions as well as parental experiences.

Results

Findings are presented as an overview of the participants, outlining their roles and experiences in disability. This is followed by thematic findings, addressing the research question.

Overview of participants

"*Depending on who you ask, the story about transition will be completely different*" (HCP12)

The participant sample included a wide range of professionals, who approached transition from different positions, for example in their discipline background, within the hierarchy of their own services, and within Children's or Adult services. Consequently, the relationships of the participants to parents and young people with PMLD were mapped (Fig. 2) to reflect the proximity or remoteness of the participants in relation to working with families.

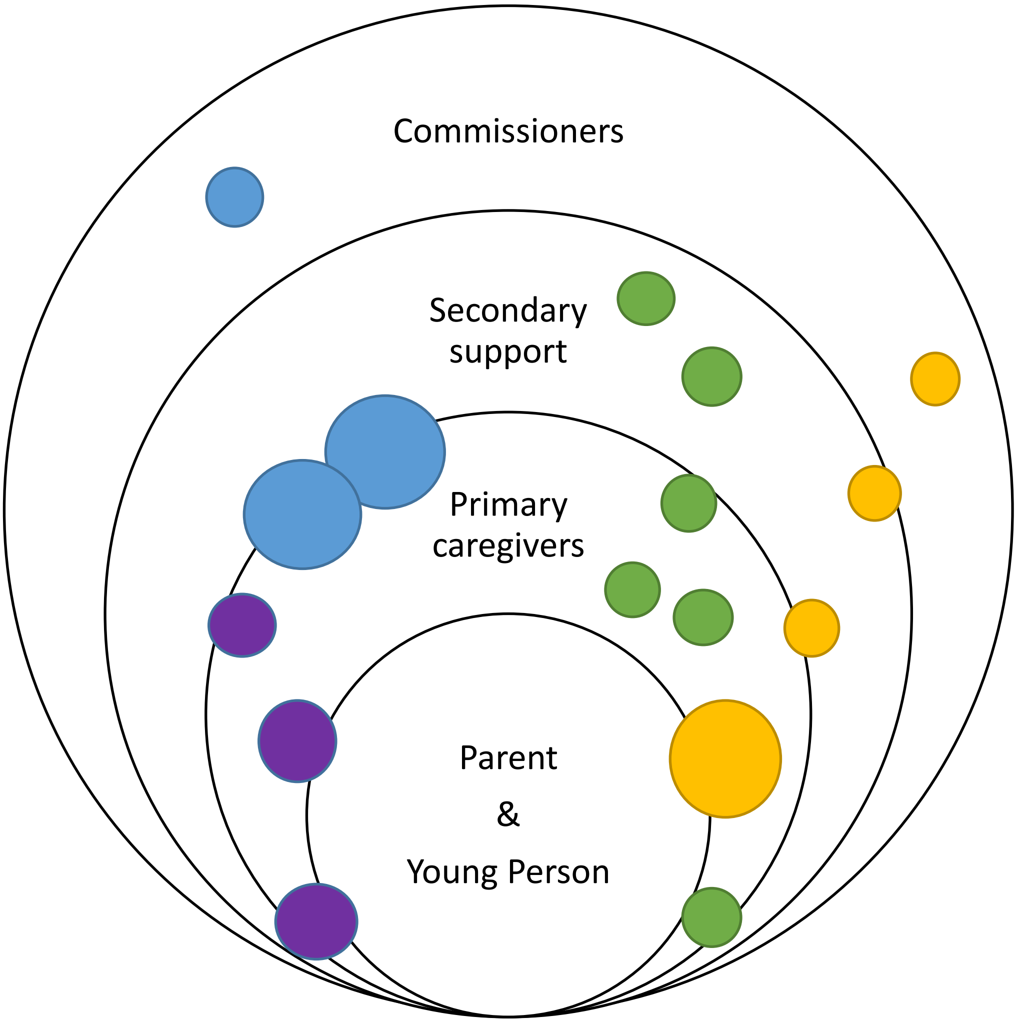

Fig. 2 Relational mapping of professionals and their roles

Key: *Yellow=Education, Green=Health, Blue=Social Care, Purple=Advocate; Size is an indication of time spent with parents & young people*

Primary caregivers – most contact directly with young person and family, answers to supervisory teams - teaching staff, support workers, nursing care (e.g. respite nurses and community nurses); with hands-on experience of young person/contact with parent; advocates; GP. consultant paediatrician.

Secondary support: assessing, advising on services, answerable to commissioners - Education, health, social care assessors, such adult OT, transition nurse; ed psych; social workers

Commissioners: overseeing transition and teams, advising secondary support some but limited direct contact with the young person and the family

As discussed in Chapters 1 and 3, there are multiple transitions for young people with PMLD and CHCN. Consequently, as the model suggests, numerous professionals are involved in their lives. One participant commented *“there’s no young person that takes a journey through transition who has some additional needs that only touches one service”* (SC01). However, despite the heterogeneity of the participant groups, there were commonalities in experiences and opinions. Participants were all experts in working with people with learning disabilities, although some were more involved with Autism and mental health issues than with complex needs. Three participants were also parents of children with learning disabilities.

Understanding Profound and Multiple Learning Disabilities

The level of engagement with young people with PMLD was not standard across the participant group, and consequently there was a variance in participants' understanding of PMLD. One participant commented

> *When you say PMLD and complex needs and it's not somebody who works within that area they don't fully appreciate the complexity of the complex needs* (ED17).

For example, a teacher, specialising in PMLD, regularly worked with seven young people in her class in a 'hands on' way, whereas an educational psychologist had less direct contact, working with the teaching staff, and undertook face-to-face assessments with a small pool of individuals once a year. A GP, on the other hand, reported having only one young person with PMLD on the practice register, but was the assigned practice learning disabilities expert.

Additionally, the sector in which participants worked influenced their concept of disability. An educational psychologist commented:

> *We generally come from quite a social model of disability ... where we don't really see that the it's the disability that's the problem it's how it's constructed and how it's dealt with and managed and supported that is where the difficulty lies* (ED9).

Whereas other participants describe disabilities in medical terms, relying on the medical model of deficiency. As one children's learning disability nurse commented

> *… We often aren't aware of those children because of the rare disease that they <u>have</u> their main focus is obviously their physical health and then their level of learning disability is then determined a bit later* (HCP14).

Thus, experiences and understanding of PMLD differed considerably. When asked how they defined PMLD, some participants gave definitions which aligned with NHS or NICE guidelines (2016):

> *Probably somebody who needs more 24 hour care…probably help with all sort of activities of daily living…erm domestic and erm personal activities of daily living that's <u>my</u> definition* (HCP2).

Although some participants found it difficult to isolate the PMLD group from other groups with "*learning difficulties*", it was apparent that care for this group was considered complex, in terms of numbers of professionals involved. They were also seen as part of a cohort of people with disabilities who may be massed together within specialist education provision.

The recognition of their learning disabilities may also be dependent on the services looking after them. For example, Education participants felt they understood the limits of young people's communication, describing them as "*sensory learners*" requiring a "*sensory curriculum"* (ED5). Thus, these young people are sensory beings, living in a world defined through their disabilities in both social and medical terms.

However, one social worker commented that within her team they tended not to use labels in the same way that Education might: "*we don't put people into categories as such it probably for me comes from their education review"* (SC10). Whereas her colleague had a clear definition, which included young people dependent on assistive technology:

> *who are PEG*[7] *fed who are wheelchair users who erm who have very severe learning disabilities …it's that sort of cohort* (SC11).

Therefore, the definition of PMLD might be understood as socially defined, to ease identification, aligning with the social model of disability. Alternatively, it might also be interpreted as a quasi-diagnosis which has a list of definable features, and fits with the medical model.

Young person as an adult

Considering transition and the future, some participants struggled with articulating the concept of the young person with PMLD as an adult. For example, one participant grasped to find the right word, or: *"where the peop...where the child where the young person"* (HCP09). Another stated "*you've got an oversized child essentially"* (HCP7). The difficulty in finding an adequate and fitting expression suggests an inability almost to see the young person as a recognisable individual with their own particular needs. Looking forward, one participant expressed a bleak outlook for these young people, reflecting her opinion of the supporting services:

> *So they have profound learning difficulties… and not going to benefit or going to adult services they're not going to be treated ever as an adult* (HCP14).
>
> .

Drivers for change:

Several participants highlighted the importance of being part of teams and gaining support by working with fellow team members. Transition teams were mentioned within sectors, working across children's and adult services; as well as interdisciplinary working, such as Education

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[7] Percutaneous endoscopic gastrostomy

and Social Care coming together. However, many participants believed that transition processes needed improving.

These participants described themselves as not just "*having enthusiasm*" but also "*passionat*e" about effecting change. Participants suggested that they owed a personal responsibility to those with disabilities and helping in the transition process; one participant with lived experience commented.

> *When I was a young parent we had hope that if we worked really hard we could make it better for the families after us in our slipstream* (ADV4).

Their efforts were often seen as a personal effort at the interface with various organisations. They worked at local, national and institutional levels, being members of "*working parties*", working on transition planning and training opportunities. Some were part of new transition teams within health and social care, suggesting that change was being driven not just from individual efforts within the system, but in a top-down approach.

However, effecting change was influenced by time, dedication and effort:

> *I haven't really got haven't really made huge changes in the world erm because it's very difficult to do it when … you don't have dedicated time* (HCP7).

In summary, with a rich variety of experience and employment, participants saw the young people to be child-like despite approaching adulthood. The thematic findings that follow, explore professionals' understandings of transition and the roles of both themselves, and the parents within the process.

Thematic findings

"I'm not entirely sure yet we are good enough at preparing young people and preparing young people's families for what the adult world looks like and how to negotiate it" **(SC01)**

The analysis illuminated a tension between the ideology and the practicalities of transition, between the sectors, as well as within individual services. Parents were acknowledged as being dedicated advocates for their children's needs. However, the person-centred focus on the young person's future sometimes marginalised the parental role.

The template analysis generated three themes: first, ***Ideological thinking versus processes*** which highlights the adoption of the Preparing for Adulthood model; second

Building relationships with parents, which explores the complexities of the professional-parent relationship; and third, ***Recognising the hidden issues*** which considers how professionals effectively support families, and the barriers faced by parents at this time. Narratives and vignettes are used to illustrate and explore these themes (Table 3) [8].

Theme 1

Ideological thinking versus processes:

"We want them to access the regular world rather than this small bubble"

- **Subtheme A:** **Ideological thinking**
- *Vignette 1: A good transition*
- **Subtheme B:** **Processes of transition**
- *Vignette 2: An extreme case*

Theme 2

Building relationships with parents:

"it takes a while to gather all these nuggets together"

- **Subtheme C:** **Understanding the parent**
- *Vignette 3: The mother as advocate*
- **Subtheme D:** **Working and planning with families**
- *Vignette 4: Parental expections*

Theme 3

Recognising the hidden issues:

"transition doesn't just affect the child... it's the whole family"

- **Subtheme F:** **Supporting families, alongside or behind them**
- *Vignette 5: You talk to the family*
- **Subtheme E:** **Facing Barriers**
- *Vignette 6: Giving up an EHC plan*

Table 3 - Table of themes generated within the Template Analysis

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[8] In this account, I have chosen to use the third person plural pronoun “they/them” for participants to avoid identification of the one male participant.

Theme 1: Ideological thinking versus Processes

"We want them to able to access regular things in the regular world rather than just things in this small bubble" (ED16)

As outlined in Chapter 1, The Preparing for Adulthood (PfA) framework has four objectives for young people at transition - independence, employment, being part of a community and healthy living – and this framework is used for goal setting for the future. However, some participants viewed transition as a process. Subtheme A (Ideological thinking) discusses how an ideological framework was adopted by participants in the fields of Social Care and Education, as well as the independent advocates. Subtheme B (Processes of transition) considers how participants from Healthcare concentrated on the processes by which young disabled were transferred to adult services. Participants who also worked closely with young people and their families, such as teaching staff and advocates also discussed these processes. Additionally, participants sometimes found that collaborative working between sectors did not always happen within those processes.

Subtheme A - Ideological thinking

> *You start of by thinking about the dream thinking about where you want to go thinking about your aspirations for that child or young person* (ED16).

The ideological standpoint considers what a good transition might look like. One participant, who supports both professionals and families in planning for Preparing for Adulthood, gave a highly aspirational account:

> *We're really trying to get people to think about "where do I want to live? When I leave home do I want to live right next door to Mum cos that's convenient or actually do I want to live next door to this service that provides that me a really good service? who do I want to live with?…. what does (county) look like for me and how do I want to start thinking about my aspirations and how am I going to build my life to give myself the best possible chance of maximum independence maximum meeting what I want to do …giving me a really happy healthy life* (SC01).

All the goals of PfA are included within this dialogue: independent living, employment "*what I want to do*", being part of a community and a "*healthy life*". Temporally based in the future, this is a vision of how people could plan their lives.

The participant does not solely present options, such as the "where, who and what" questions, they are cajoling, or even coercive, "*trying to get people to think"*. They imply a judgment of living at home as being "*convenient"* as opposed to being near a "*really good service*". The parent is, therefore, relegated to a convenient carer. Describing an abstract concept "*how do I want to start thinking about my aspirations"*, they challenge the perceptions of young people with PMLD, as people lacking the mental capacity to think in such abstract terms or communicate their wishes. The vision is "*maximum independence*", achieved through choice, self-fulfilment and self-efficacy.

However, achieving independence carries cost implications for service providers, as suggested by another participant:

> *for somebody with PMLD the impact is meant to be that there's less erm impact on adult services with them going forwards so the more independent they become the less impact there is and they have more erm I don't know they have more autonomy themselves the better* (ED5).

Independence in this account equates to "*less impact on adult services*", which means fewer man-hours involved in supporting someone. Less support is seen as desirable by a commissioner for financial reasons but is in direct contradiction to independence achieved by maximum support being put in place for independence for both young people and parents by providing respite (HCP14).

Part of the vision for the future, "*what I want to do*", includes how young people spend their time, and considers employment. A senior educational psychologist outlined their capabilities-based approach to planning

> *It's having those high aspirations …and in person-centred planning you focus on those skills you focus on their gifts on their capabilities on … thinking about well if they were to get some…employment if they were to get some kind of experience in like in a real world environment what would they be good at doing or what could they bring or … trying to think about where they might fit later in life and how we can make that happen* (ED16).

By suggesting young people might get some "*experience in like a real-world environment",* the speaker highlights that they live in the disabled world, and that there is a gap to be bridged between the two. This transition has to be focused on and thought about – *"where might they fit later in life?"*. While considering their *"capabilities*" and "*skills*", the focus remains on the individual and their achievements. However, their contribution is also to be considered, and in another account from an educational commissioner, Government agendas were acknowledged, with financial impact again being highlighted:

> *maybe the primary objective I suppose of the Government is to get more disabled young people into employment and contribute to the economy* (ED5).

Government policy is built around people with less profound disabilities (ADV3). Those with complex needs are still excluded, requiring the State to make expensive adjustments and provide expensive support. Additionally, wider ideologies, such as the Disability Rights movement, were implicated:

> *"and it's it's almost like they've skewed the Human Rights Act erm around disability and living erm er a fulfilled life around a small group of people erm but when it comes to actually making reasonable adjustments for people with more complex needs or complicated needs it's too expensive because they're not seen as potentially giving it back in terms of employment or independence they're still going to be seen as a drain on the state* (ADV3).

This participant's solution would be to "*flip the narrative*"[9], and to view these young people as employers, whose employees (support workers, nursing staff) are paying tax and therefore contributing to the economy.

Education was seen as the way of preparing these young people for such "employment", and the PfA framework was taken and adapted by participants who work in Education. For example, a senior educational psychologist considered the aspirational goals:

> *We have been trying to do kind of I think throughout the EHCP process more over the last kind of maybe four five six years thinking more about aspirations for children … and erm building in things around Preparation for Adulthood outcomes* (ED16).

Another educational psychologist uses the PfA categories as a framework for goal setting for achievable skills:

> *we'd be thinking a lot about independent living what sort of level of independence are they currently working at and displaying and what could they develop with a little bit more support and scaffolding* (ED9).

The PMLD teacher, however, worked from a bottom-up approach, fitting the young person's capabilities into the relevant framework grouping (ED17); for example, self-care and feeding, being allocated under Independent Living.

Additionally, using a life-planning tool such as MAP (ED9), aspirations might be mapped out but also fit the 'top down' model. In this way, the personal goals are brought in line with the Government agenda. The PfA framework also emphasises community belonging as part of the future vision, whereas historically, these young people would have been institutionalised.

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[9] Elly Chappel: https://www.youtube.com/watch?v=zH2SpBtl8wc

One participant recalled growing up near a long-stay hospital in the 1980s, where both young people and adults were contained, and segregated from society

> *These are big institutions in massive amounts of grounds…surrounded by rows of trees you know with the great long drives so that it was still very much out of sight* (ED17).[10]

Whilst being part of the community is important, inclusion is sometimes compromised by staffing limitations, and suitable accommodation (ADV3, ADV4, ADV6). There is also a dichotomy between "*the real world*" (ED16) and the disabled world. One advocate argued that, whilst it was an unpopular opinion, they believed that for young people with PMLD being with other people with disabilities was familiar and "*part of their life*" (ADV3). Alternatively, a conflicting opinion was given by an educator:

> *they're going to be in the real world that's …where they are going to live and we want them to able to access regular things in the regular world rather than just things in this small bubble* (ED16).

Vignette 1 outlines a case where the ideology has been adopted and has worked well for the young person and their family.

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[10] As described by Maureen Oswin (1973), "*The Empty Hours*"

Vignette 1 – A good transition

“A really personalised package”

ADV04: He is a young man with very complex impairments erm no formal system of communication although he communicates beautifully cerebral palsy some health needs ... he was in a special school in (city) then went off to a specialist residential college which he was happy with his family was happy with and then the idea was that he would move back into erm independent living in (city) er a beautiful new build erm and it was one of these trendy (city) er you know eco-friendly buildings
I: mmh fantastic
AVD04: it’s a lovely lovely place (provider’s name) housing erm and he moved back in there and his family had negotiated so a support provider (company name) have the contract for the main support with the house and there are four young people in the house each have their own erm kind of bed sitting room with their toilet and a room onto erm doors onto the garden and they’ve got a sitting room kitchen erm so there’s communal space but they’ve got their own private space and there are four young people in this house er three of them are full time supported by (company) but the young man that I’m involved with and working with has got a direct payment and has personal assistants from 8 o’clock in the morning until 4 in the afternoon erm then (company) do the kind of wraparound…and his family wanted that because they wanted him to be able to go out on his own they wanted a really personalised package and they didn’t want him to be stuck in the house with the other four say staffing was low (ADV04).

The narrator is an advocate who has worked closely with the family and the young person directly. They respect him, understanding that “*he communicates beautifully*”, and yet it is the family’s wishes on his behalf and consent that shaped his transition. The aim in telling this story is to illustrate that person-centred planning and the goals of Preparing for Adulthood can be brought together to achieve good outcomes. The “where”, “who” and “what” questions mentioned by SC01 are answered in this account.

He lives in a world of dependency and independence, having moved from the sheltered world of special provision (school and college) into “i*ndependent living*”. Within this world he also belongs to a community, but also has space for his own privacy.

They also reveal that in order to achieve maximum independence, the family fought for extra one-to-one support, through direct payments. The model of care sounded hopeful and idealistic, but her account also reveals the practicalities of supported living, in that staff shortages would curtail his independence. There is also an unresolved paradox in the account. The young man has extra support, to allow him to go out, as “*they didn’t want him to be stuck in the house with the other four”.* However, this independence does not necessarily bring "*autonomy*" as imagined by the previous participant (ED5), and that extra support might be considered a further "*drain on the state*". The Government's ideology was achieved through the family's vision and advocacy to obtain additional services.

Subtheme B – Processes

> *The difficulty is that children are transitioned in body parts which sounds horrendous…* (HCP14)

While the ideological view of PfA adopts a life-course paradigm, the processes of transition, discussed by the healthcare professionals, represent a point in time in the young person's life, which was not the same for all the services. For example, a consultant paediatrician commented that children are progressed to the local adult hospital at sixteen years old, because the children's hopsital *"is 99%full*", but they also reflected

> *if the hospital wasn't that full I think our hospital would consider keeping these children until 18 ...I think an adult hospital is easier can manage a sixteen-year-old they can't manage a sixteen-month-old* (HCP15).

There is some fluidity within healthcare, a community paediatrician revealed that they kept some of their clients beyond 18:

> *I'm going to keep them until they're 19 and then discharge ... maybe that's my fault I shouldn't be so ...cossetting erm but yeah certainly if they've got if they're in the schools we'd probably keep them on for longer* (HCP7).

School placements are available until the July of the young person's 19th birthday, and this transition is seen as decisive not just in life planning but also in terms of the termination of other provision that is accessed through school, such occupational therapy, speech and language therapy and physiotherapy. Social care transitions occur on the child's 18th birthday (SC10, SC11), which would apply to social care respite provision, but respite provided by a hospice might continue until the young person was 25 (ADV6).

Systematic differences between Children's and Adult services were noted. Within Health, the participants agreed that children's services are more supportive of the family, than adult services which is structured around a medical model.

> *Children's Services are are more embracing probably erm you know a lot more resources in it and … we know going to an adult ward you know it's full of old people you know shouting out and… it's not got butterflies on the wall and …carol singing and you know and nurses dressed as Noddy erm… and it's not one-to-one and they haven't got a hoist and …and that's the harsh you know*

> *yeah they have to say goodbye to their lovely paediatrician who they were on first name terms with and probably got their mobile numbers in their on their own phones* (ADV6).

In this account, a transition nurse appeals to the listeners' prior knowledge and senses: adult wards sound and look different, with a stark contrast between old people "*shouting out*" for attention, and carol singing on the children's wards. While the adult ward is a place of deficit, not just lacking sensory stimulation but also equipment, the parent is also faced with the "*harsh*" reality that they no longer have direct access to "*their lovely paediatrician*". The paediatrician is therefore seen as the parent's friend, as well than the child's doctor, whom the parent is forced to leave behind. In this respect, the needs of the child merge with the support needs of the parent.

Transition was recognised both historically and currently as a "*cliff edge*" by some participants (SC01, ADV4, HCP7). For example, participants highlighted that often there is a gap in services between the young person attaining adulthood and leaving school (SC11, HCP14, ED17), either in the handover to learning disability services or respite:

> *There was no community for support between eighteen and nineteen… so there's this massive gap that we try to change but but I think everyone has tried to change I don't quite understand it … erm so we couldn't refer to LD community support until six weeks prior to their nineteenth birthday because it is thought that those children would get all that support in the special schools?* (HCP14).

While this participant expressed they didn't "*understand it"*, other participants offered explanations for the cliff edge, such as the remaining impact from the Conservative government policy of Austerity and funding issues (ADV3, ADV4). It was felt that changes in government policy dating back years still impacted working procedures. One advocate discussed the impact of the loss of the New Labour government transition initiative[11] when funding was rescinded during Austerity:

> *we were able to facilitate that in in those projects there's no one there to facilitate it anymore and so people are much more in their silos I hear Health say how difficult it is to get Social Care erm to the table and in the educational work we've been doing we have found it really difficult to bring Health to the table erm or if you are working with Social Care to bring Education to the table so I think that is more difficult* (ADV4).

The fragmentation of services that they identify was discussed in other accounts. An educational psychologist discussed the problems with co-ordinating services when reviewing the ECH plans:

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[11] instigated under New Labour (DoH 2006)

> *and the idea of that is that it should be owned by Education Health and Care it should be sitting across all of them but for various reasons I think that has been one of the downfalls of the reforms*[12] *really that the idea was there to get all three services working together but practically that doesn't often … but those the four overarching aims of Preparation for Adulthood really should be covered by everybody in theory but it has been a real problem getting that rolled out I think it's not really truly embedded in yet* (ED9).

The participant additionally highlighted the problems of facilitating meetings where people come together physically (pre Covid-19). The availability of healthcare professionals is seen as problematic but is particularly relevant to individuals with PMLD, as their complex health care needs heavily influence future provision. A GP commented

> *think there still needs to be quite a lot of work sort of certainly involving GPs in the EHCP and cos GPs don't always get a copy of that so they're not always aware of exactly what's going on er…and they're not always asked to contribute to that either so that's also erm a bit of a shame and a missed opportunity considering the GP is likely to be the main I suppose we… tend to be the co-ordinator of medical care… we are the ones that make the referrals and try and link things and prevent fragmentation of care* (HCP12).

They highlight the role of the GP as a constant in the young person's care, who becomes the first port of call once the paediatrician has stepped back. They see their role as important in preventing the "*fragmentation of care".*

Fragmentation occurs in the shift from children's to adult health care services. One transition nurse commented that young people are transitioned "*in body parts*" (HCP14) as different aspects of the child's health are assigned to different specialists in adult services, thus losing a holistic overview. Another health care professional suggested that adult services would only see young people if there was a problem (HCP15), as opposed to at six monthly paediatric reviews. Consequently, there is a subtle shift in the definitions of need from maintained support to crisis response, and that change in definition alters the identification of who has needs and where those needs are met. Any future planning is dependent on identifying the need through assessments, which engage both parents and young people. Young people are required to meet set criteria, which again may differ from children's services, and be subject to restrictions: an occupational therapist commented "*we've tightened up the referral criteria"* (HCP2).

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[12] Children & Families Act, 2014

Whilst the ideological view of PfA might allow for creative solutions, this rigidity of organisational processes within services, particularly healthcare, do not necessarily make allowances for the vulnerability of young people with PMLD, as highlighted in Vignette 2.

Vignette 2 – An extreme case

Highlighting the issues

we have really difficult situations so we had a child for example he was severe neuro-degenerative condition and erm he was he weighed twelve kilos so that's the size of a one-two year old?...severe erm er learning difficulties in that sense I don't think he even smiled erm and so this child when he turned eighteen had to go to adult services there was no way we could keep him but can you but then we tried because we don't have an adult arm in our hospital but we tried …(said) could he just not be admitted to the children's hospital a children's ward and then you know the adults can still come in and you know do their ward round on the paediatric ward erm because it would have been you know imagine a twelve kilo child well er thing but anyway they they wouldn't they wouldn't do that so he had a twelve kilo child a twelve kilo very tiny chil..person had to go to the adult ward …I mean that's an extreme case but it does highlight the issues (HCP15).

This account, used by the participant to "*highlight the issues*", demonstrates how professionals recognise problems within the institutional and legal rules. The struggle to describe the young person at the centre of the story "*a twelve kilo child a twelve kilo very tiny chil..person"* highlights the conflict that the narrator has in identifying the young person as an adult, and the emphasis on the young person's weight furthermore highlights their extreme vulnerability in an adult world. There was recognition of the inappropriateness of sending such a vulnerable young person to an adult ward and solutions were sought. However, even paediatric consultants could not alter the system. In this instance, safeguarding rules to protect vulnerable children from adults seem to fail a vulnerable adult.

In this theme, transition in Education and Social Care is driven by a top-down ideology, which focuses on Human Rights. Vignette 1 illustrates how successful transitions can be made when the ideology is embedded and parents and professionals work together to achieve a vision of a good life. However, Healthcare still functions through a medical model, in which deficit is central to assessments and provision of future care and is processed based. Vignette 2 provides an example of how the rules and restrictions in place within the NHS do not allow for a person-centred approach to transition.

Participants also believed that the transition processes are also influenced by historic government policies, which can make planning difficult. The parent, as the young person's advocate, steps into this arena of conflicting ideas, where individual professionals are "*passionate*" about their clients and their work, but are sometimes frustrated by the systems:

> *So I'm not entirely sure yet we are good enough at … preparing young people's families for what the adult world looks like and how to negotiate it* (SC01).

Theme 2: Building relationships with parents

It takes a while to gather all these nuggets together and put them in your bowl of knowledge (ADV6)

As discussed earlier, the participants have a sound knowledge of young people with PMLD, but understanding parents' needs and responses are also important in order to support the families effectively. This theme explores this understanding of parents, and looks at how they work together in planning the future. Subtheme C considers that participants acknowledged parents as key holders of information about their child, having an important role to play in planning for the future. However, parents were also seen to be lacking information relating to transition. Subtheme D consider how professionals developed good relationships with parents, although they felt there was tension at times. Professionals also felt at times they needed to maintain professional distance (Subtheme D).

Subtheme C - Understanding the parent

> *Parents aren't a homogenous group you know like the individuals themselves (young people with PMLD) they are all individuals"* (ADV3)

Parents were perceived to be both experts and advocates, whilst simultaneously seeking information:

> *There's a certain er <u>tribe</u> of parents that you've seen who are very vocal who try and mobilise and get together often working in isolation but then they find another tribe that they can join with …and I've really noticed that at the …conferences there are lots of parents equally who are very very erm isolated… who don't have awareness that there's a world out there and feel that they're the only people who have a world like this and feel that nobody understands them er and then you have some parents who are juggling with a <u>bigger</u> family and it's very difficult to erm work to keep the other siblings happy … and feel very guilty and torn between the amount of time that their erm more disabled child takes up.* (ADV3).

This witness account refers to some parents as collective group, part of a tribe, who come together in the world of conferences, information gathering and networking opportunities. They are "*warrior mums*" . It also reflects the social setting of parents, not just as group members, but also as isolated individuals, in a world of their own, seeking information support from others, juggling caring with wider family duties. Containing closely observed behaviour as well as referring to tropes, the account therefore warns us not to make assumptions about parents. They may be experts in their own child but not necessarily in the systems that support them, and gaining relevant knowledge requires effort on their part. They are seekers of information during the transition process, looking for answers to questions such as: what will adult services look like (SC01, SC11), who will look after my child's medical condition (HCP7, HCP15), what happens when education comes to an end (ED5).

Acquiring information comes at considerable personal cost, but the parents who go above and beyond in this quest may achieve good outcomes. One advocate commented:

> *the families I know who are managing well and getting what they need and want for their sons and daughters or brothers and sisters are those that (..) are articulate can inform themselves they almost make it a life's cause.* (ADV4).

They illustrate this point by recounting the story of the young man who achieved a successful transition (Vignette 1). The success, defined in terms of his independence, was achieved by the persistence of his family. They reflect *"but that is only in place because <u>that family</u> fought for it they're very articulate they <u>know the system</u> they knew they could ask for <u>something</u> that wasn't being <u>offered</u>"* (ADV4). There is a sense that there are underlying factors here which lead to good outcomes, in terms of having the time and support to learn about the disabled young person's rights.

Participants also acknowledge that these challenges are confusing for parents:

> *you know a lot of things parents say they weren't expecting this they're not experts in navigating health and education and EHCPs and annual reviews and transitions they don't know what all of that means* (ED9).

This educational psychologist stressed that if parents are ill-informed and ill-prepared they may be daunted by the transition processes. Sometimes parents needed help and support from her in understanding: "*it's just supporting them through it explaining things as much as I can breaking it down".* On the other hand, another professional questioned whether parents should be expected to know everything relating to their child's disability:

> *the path of least resistance is absolutely the path (laughs) we'll never judge anybody for taking your young person's got to the end of the day and they are fed and watered and safe and they're in bed and they've had their basic needs met absolutely and how how are parents meant to have the specialist knowledge to understand that there's equipment out there* (SC01).

Whilst sounding empathetic, the participant's account places the parent in a caring role, meeting the child's basic physiological and safety needs, "*taking the path of least resistance*". It does not allow for parental aspirations. The account attempts to sound non-judgmental towards the parents, but it also raises an unanswered question regarding the responsibility of care – if the equipment is out there for the young person, who has the responsibility for ensuring the parents know about it? Parents therefore require support and information throughout their child's life regarding all aspects of care and decision-making, both on a practical level and aspiration level.

Professionals also acknowledge that the parents have a vital role to play in transferring their own particular knowledge of their offspring at transition (HCP8). They are emotionally invested in their child and the outcomes: "*families… are invested in it's their loved one it's their child"* (HCP2).

Sometimes this emotional investment makes parents demanding, which can be problematic for the professionals, especially in the context of who shouts "*the loudest*":

> *obviously I can't do it for all of them so that's a real ethical issue for me in that sense just because parents cry the loudest they get what they want and those who don't cry don't* (HCP15).

Parents are also understood to be holders of information about their child and how they can be supported, thus "*experts by experience*". Furthermore, they sometimes are seen to have superior knowledge to professional carers (HCP2). For example, a participant was trained by a mother to use her child's assistive technology, but they were later required to attend official training, because parental training was not considered valid. They commented:

> *they were amazed that I could do it straightaway and yet ... mum's training wasn't valid because she's not a trainer she's not a nurse but she's an expert by experience* (ADV3)

The parents are, therefore, seen to be in a liminal state between being the expert (in their child) and being uninformed (in transition processes) at a time of change. A small minority (ADV4) are well equipped to deal with the problems arising, by being "*articulate*", informing themselves whereby *"they almost make it a life's cause*". However, this is not a universal experience, the participant concluding "*not all of us can make it…can give our lives to it"* (ADV4), reflecting the level of time and dedication required to achieve good outcomes.

Professionals also sometimes marginalise parents at the point of transition, acknowledging their expertise, but criticising their rigidity in opinions:

> *also I think on the other side of that parents can be quite fixed in what they want and how they perceive things … and sometimes that works brilliantly and other times*

> *there are .. other agendas involved but ultimately it has to go back to that young person and what they want* (ED5).

The allusion to "*other agendas*" may suggest parents trying to express their own needs, which cannot be catered for within the framework, where, according to the Mental Capacity Act, the young person's needs are placed as central. Despite the parents' expertise and acquired knowledge, at this critical point everything reverts to legal status, as demonstrated in Vignette 3.

Vignette 3 - The mother as advocate

They would not let the mother into resus with him

he had a severe he has severe epilepsy and he had and he went into what's called status epilepticus … … and as a result he went into resus at A&E … not that they're expecting him to need resus .. that's just procedure … erm and as an adult you do not have a parent with you when you go into resus … and they would not let him mother into resus with him … he is so complex so she was left in the A&E waiting room knowing that he would have no idea what was going on and she couldn't be with him … because he was eighteen … because he was eighteen and she wasn't obviously she I mean she fought incredibly hard for her son but she didn't feel equipped at that point on her own in A&E to say "oi I'm going in there sorry I don't care what your rules say, my son needs advocating for and I'm going in"… which is what other parents have had to do but things like that the fact that A&E nursing staff would stick to such ridiculous rules for individuals who clearly developmentally are not adults … and respecting somebody's stage of development rather than just going by chronological age (ED17).

This is a parental account, repeated by a professional. The account suggests that the parent, who had previously been her child's advocate, was excluded when he reached adulthood, and the only way forward was by confrontation. This story is framed within a discussion about disability campaigning and vulnerable young people dying because of institutional ignorance of their needs, when parents have been excluded[13].

Both the parent and the young person within this vignette are, therefore, framed as being in a position of extreme vulnerability. The parent was an expert by experience, who suddenly found herself in a new position, being barred from accompanying her son and therefore unable to advocate on his behalf. She lacked the confidence to challenge the system and was unable to act as other parents in similar situations "*had to do*". Consequently, her status as an expert counts for nothing, because he son had acquired adult status.

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[13] Paula MacGowan and her son Oliver

Reflecting on the incident, the participant expresses outrage and a critical opinion of a cohort of individuals and the rules of an institution and system (hospital and NHS) who did not make what the participant considered be reasonable adjustments in the circumstances.

Subtheme D - Working and planning with families

> *There can be a tension and I don't mean that as a negative tension but there can be a kind of a tension between social worker and … parents* (SC10)

At the outset professionals need to understand the child and their needs. An advocate stresses that understanding the complexity of the young person and their needs requires time and patience:

> *to understand their nuances and and you know it's just like little little nuggets little nuggets it takes it takes a while to gather all these nuggets together and put them in your bowl of knowledge and use them effectively for the benefit of that young person* (ADV6).

This mining imagery highlights that such knowledge is not transparent or on the surface, but buried, therefore not casually acquired. In a three-stage process, the knowledge can be found, saved up and used to build something worthwhile. This is the foundation work required before planning begins. Professionals need to draw on the parents' knowledge and expertise but approach this information gathering sensitively. A social worker reflected:

> *obviously parents have got lots of information about their own child … but I think some of it we can gather can't we and then we can add to it by talking to parents so it's not an overload and we're not we're not asking them to repeat information that that's already there* (SC11).

The social worker is alluding to the fact that this cohort may have been in the system since they were young and records are available to draw for assessments. They want to avoid overburdening the parent by asking too many retrospective questions. The professionals are respectful, empowering and supportive, whilst maintaining professional distance at times. The accounts are also often presented as discourses of how they would like relationships to be, not just individually but as part of a profession.

> *I strive very hard to listen to the aspirations of of young people themselves and of their parents because professional voices can become dominant in a discourse about transition it can be very much about erm school staff or health staff that have dealt with this type of need before and so therefore we have a blueprint of of what they need …I I tried from my professional perspective to support them on that journey and not dictate not say it's this or that but to really*

> *go from a point of (.) of supporting them and empowering them as much as they can as I say I can't speak for the entire profession …* (ED9).

This participant presents herself as someone who is focused on both the young people and the parents, respectful of their aspirations. She is aware that prior knowledge on behalf of the professionals may lead to decision-making without proper consultation, so she is working against "*dominant" "professional voices".* By saying she "*strives*", she is working hard for the good of the people she interacts with. She is empowering by listening to individual aspirations against the group discourse about transition, reflecting potential conflict between the person and the institutional expectations – "*the blue print*". She also suggests that there is some discord with her peers *"I can't speak for the entire profession"* whilst possibly setting herself apart from others. She aligns herself with parents, which is a position which believes may not be the norm. Although it is an aspirational account of how professionals should approach working with parents, it also reflects some of the tensions.

Establishing such good working relationships with parents is seen as important. For some parents, who had been told their child wouldn't survive into adulthood, transition represents an unforeseen and unimagined future (ADV6) "*I'm talking about moving into adult services so it comes like a bit of a (..) a shock really …they never expected that"* (ADV6).
Additionally, it is recognised that relationships need to be well established before discussions about envisaged futures which might bring confrontation:

> *we don't want to be having a really difficult conversation with a family about saying "actually we don't think what you're suggesting is the right thing for your young person" ten minutes after we've met them we'd like to have a really robust relationship with that family before* (SC01).

This approach to the parent professional dyad is more pragmatic, and possibly based in experience, than the "*Vygotstkian approach"* outlined by an educational psychologist:

> *with a bit of scaffolding what does come next and and to listen to the parents very much "we'll work with you closely looking about this is your child you are the expert here we're not the expert no-one is the expert you are how can we work with you to to help you get what you want for your child and what are the most important things* (ED9).

She goes on to describe her role as that of a "*dream catcher*" (ED9) helping the parents to express their aspirations.

The professional accounts suggest that is a power dynamic between the parent and the professional, which represents an imbalance of power. As demonstrated the professionals hold the information about transition, while commissioners oversee budgets. Sometimes parents are sometimes perceived as being "*scared*" (ADV6), uncertain of themselves (ED9) or even angry (SC10). A social worker describes this as "*a tension*":

> *I do sometimes feel that while we kind of (..) there can be a tension and I don't mean that as a negative tension but there can be a kind of a tension between social worker and adult parents throughout the young person's [life] particularly if they're within the team for a long period of time so there can be a tension between them but I do think then once it gets closer to that 18 that parents start to get a bit more anxious about losing us as such* (SC10).

In this case they see the tension as parents fearing the loss of a familiar face and source of support. This tension may also be a result of the professional distancing themselves from the parent in several ways and for a variety of reasons. For example, teachers were seen to be "*protective of parents*" when withholding information, in the context of child's behaviour at school (ED17) to avoid causing parents' emotional distress. Advocates were "*canny*" with their time due to lack of funding, and a fear of letting parents down:

> *if someone comes to me with a story I'll feel like "oh what can we do, how can we help" but we do have to be very careful so sometimes cos we could spend all our time doing this and there is no funding and then we would let people down* (ADV4).

The establishment of boundaries could therefore be seen to be problematic for the participants. Professionals withdrew for reasons of self-protection when giving too much time to help: one nurse stated: "*I probably wasn't the right person in that way because I'm not very good at switching off"* (HCP14). Other participants represent themselves as resilient in stressful situations. In a discussion about parents "*shouting for things*", the social worker suggested that it was part of their role:

> *well I mean I think obviously because we do everything we do child protection we do erm court work we do erm everything we get parents shouting at us for different reasons a lot of the time erm and I suppose it can feel different depending on what you're being …shouted at about* (SC10).

This sense of professional vulnerability and the need for self-protection was particularly apparent in the data relating to working during Covid-19 and will be discussed further in the next chapter.

Throughout the dataset, importance of the young person's contribution was not overlooked, and it is largely prioritised by professionals, over the parents' needs. Parents, as well as school staff, help their children express their wishes (for example in Vignette 1). However, some participants suggested that parents put their own interpretations and needs first:

> *that closed closedness to the way of looking at creating solutions to give people the life they want and again how do parents allow that individual to be part of that conversation because some parents are overprotective in a way that*

> *conversations don't happen and they put their version of what they would like to happen* (ADV3).

Parental expectations are acknowledged, but there was an indication that they cannot just be expressed and met (ADV3, HCP8, HCP15). As previously discussed parents were encouraged to be aspirational, but there was some ambivalence between parents being allowed to say what they would like for their son or daughter, and listened to in those discussions (SC01, ED5, HCP8, HCP12). Consequently, it was stressed that setting expectations by keeping the parent informed is a good start to the transition process. A consultant paediatrician commented:

> *you know <u>setting the expectations</u> right from the start it's usually…helps you know …if you're expecting a replication of what happens in Paediatrics in the Adult world you're going to be really disappointed and it's not all bad I mean I have transitioned patients really successfully so it's not all bad* (HCP15).

A potential dichotomy of expectations either being too high because they have received good care in paediatric health (HCP15) and social care, or alternatively low because they have heard bad things about adult services (SC01) was identified. Parents, therefore, need to be informed of their choices, and need support in understanding processes and possibilities. A social worker commented "*we know what a good transition should look like and at the heart of it is choice and you can't make choices unless you know what you are choosing from"* (SC01).

Within the planning process, parents can be seen as "*clinging onto education*" (SC01) (such as a place at a residential college) because it is familiar. However, there was an acknowledgement that the alternative option of aspirational planning may be seen as something "*fluffier*" and more abstract (SC01) which is therefore more difficult for parents to consider (such as an as-yet uncommissioned residential setting). However, sometimes it is just very simple acts that parents are looking for in forward planning which may make a difference to their lives, and the quality of their child's life going forward, as demonstrated by Vignette 4.

Vignette 4 - Parental expectations

If that's the important issue to you

I can sort of say "well I wonder how we can work towards what what this parent was saying that they'd like their young person to be able to drink from an open cup erm that's something that would be really important to them and at the moment they're able to access a straw or something you know that's oh quite important to this parent so that they can take them out and enjoy the pub back in the days and be able to have those drinks without taking special cups and things like that so how can we do that" and that's what I think we often try to do is that bringing in the parent point as much as we can and empowering that parent to say it in the first place I remember one parent saying "oh that feels really silly (.) it feels like that's not important" and I was saying "but if that's the important issue to you" (ED9).

The story suggests that even in a simple request, that her *"young person"* is taught to drink from an open cup reveals the extent of the young person's disability. Critically, parent lacks confidence, *"oh that feels really silly",* to ask for this seemingly menial task to be mastered. The consequences for her, however, are transformative. It would mean she could join "*the real world"* (as discussed in Theme 1) instead of remaining in the disabled world, as embodied by special cups. For example, looking forward, the whole family could possibly enjoy community activities without taking specialist equipment with them, which in turn could improve quality of life for both the young person and their family. Knowledge of the fine details of their child's life are central to planning the future.

In this theme, the parents are seen as both seeking information about transition whilst being experts in their children's needs. When transition approaches, their identity as experts by experience is challenged when they are sometimes excluded in both the information-sharing process and decision-making. Vignette 3 demonstrates this parental exclusion, and further develops the image of a vulnerable child in an adult world introduced in Vignette 2. The importance of role of advocate is highlighted in Vignette 4, which explores the importance of sharing minor details to achieve a good quality of life for both the young person and their families.

Professionals engage with parents, but at times have to maintain their distance for professional and personal reasons. The participants acknowledge the shortcomings of the system and resulting parental vulnerability, as the transition process has an emotional impact on parents:

> *they've lost their security blanket and you know you've got the impact of moving from children's to adults'* (ED5).

Theme 3: Recognising the hidden issues

Transition doesn't just affect the child... it's the whole family (HCP14)

As demonstrated, transition to adult services is not just the practical transfer of service but is affected by ideological viewpoints and working relationships. Furthermore, professionals acknowledged barriers to good transitions, which ranged from individual difficulties to contextual issues. The latter ranged from political agendas (ADV4, ED5) such as Austerity or the emphasis on other current agendas such as racial equality; the geography and demographics of a given region, with a difference in services between urban and rural areas (SC01, HCP7, HCP14) as well as local politics (ADV3) . The availability of care in certain areas, the budgets allocated at government and council level, as well as political models were all identified as being contributory factors to services being restricted.

Whilst mentioning those wider barriers, participants focused on how future planning was influenced by individual circumstances. This theme, therefore, explores some of the hidden issues professionals identify and how they work with the families for the better outcomes. Subtheme E considers how professionals place themselves alongside parents. Subtheme F continues to identify some barriers that parents face, such as understanding the Mental Capacity Act and the financial implications of their child’s transition, which may affect their relationships with professionals as well as their decision-making.

The professionals’ recommendations for parental support will then be explored.

Subtheme E - Supporting families, alongside or behind them

> *The sort of not feeling isolated and alone I think that would be my concern for parents* (HCP02)

Meeting the young person and the parents face-to-face was recognised as having great value for meaningful assessment and support, and that being with the child is important in order to understand their “*clinical needs*”, communication styles and “*what sort of things they like*” in order to draw up appropriate plans. One social worker said they would be *“shocked”* to learn people weren’t seen in person (SC10), whereas another reported that some people were not seen face-to-face during the pandemic (SC01). One healthcare professional emphasised that seeing the child might help them demonstrate their needs, and therefore help the professional to judge whether parental requests were reasonable in light of the young person's disabilities

> *HCP15: a child with CP [*Cerebral palsy *] could be a child in a wheelchair but could also be a child who has a very mild weakness down one side er and so sometimes if they have met the patient before they will actually have a better picture of what you know what they're dealing with*
> *I: yeah and what the baseline is*
> *HCP15: yeah and also you know of course you know a child in a wheelchair should have antibiotics whereas a child that's running around doesn't necessarily need to have an antibiotic the minute they have a cold* (HCP15).

The support professionals give to parents during this process, whether that in the form of information sharing, practical, planning or emotional, is seen as key to the professional-parent relationship. Information support included tools for parents giving an outline of procedures and what to expect, such as a transition guide with local knowledge (ED17, HCP2) or more general guidelines, such as those recommended by a paediatrician (ED9). Procedures to help ease the sharing information, such as using hospital passports, data sharing software in hospitals such as RIO, and one-page profiles containing the main information on the young person's health statistics and needs, were all mentioned as important aids to smooth transitions (HCP2, HCP12, HCP14). Practical support might be a doctor chasing a prescription for a mother (HCP12), or an advocate and expert in PMLD needs helping to recruit and train support staff for the family in a new package of support (ADV4). One authority organised an annual transition event for parents of the local special needs children (SC01, HCP2).

Working with other professionals as part of a team can also help give parents the right information and support (HCP2). Furthermore, there is a sense of professionals wanting to join parents, not just for assessment or information sharing purposes, but joining them both physically and empathetically in their world, while those assessments are taking place:

> *it's because my role is is an advocate and to support them and and I wish I was sitting next to them you know reach out a bit more erm because you know for parents to go through Continuing Healthcare meetings hideous hideous they are the most cruel brutal processes that a parent … imaginable* (ADV6).

The importance for the professional of being able to listen to the parent was explored throughout the dataset. An advocate suggests professionals need to listen to the emotional content of a parent's story (ADV3); the consultant paediatric specialist felt they were giving parents "*space to think outside the box*" and explore their ideas, while motivating them (HCP15).

Conversely, an educational psychologist reported seeing parents "*not say a word*" at important review meeting (ED9); whereas a social worker felt that parents sometimes felt they were not being heard, particularly by Adult services who concentrate on the "*best interests of the young person not what the parent thinks*" (SC10). The professionals understand the emotional impact uncertainty has on the parents.

> *I think you can pick up on parents' stress and anxiety... and ... it's about trying to break it down... in understanding what are those concerns* (SC11).

An advocate suggested that parents need "*someone behind them or alongside them*" although a paediatrician commented with some resignation that

> *You can't make it better and sometimes all you can do is listen...it's different for each family because it's different what...they need and some let you in more than others* (HCP14).

However, professionals listen to parents responding appropriately by signposting to other services, and felt practical support also has the impact of emotional support, as demonstrated in Vignette 5.

Vignette 5

Supporting families

"You talk to the family"

one of the families in particular that I erm met for the transition erm we had like a meeting where we sort of go through some paperwork to see what the needs are going to be erm obviously if the person come along as well so I met her so that was really useful sort of thing …and then erm you talk to the family and what what they're currently receiving and what they might get in the future which I think can cause sort of fear confusion to people and but also it enables you to understand more about the person. I mean the one person I'm thinking of had got sort of erm her epilepsy was sort of quite uncontrolled and she got like erm basically the family had got something where they could just present to hospital and they could go into the Children's Department and I actually worked with a with the physical health team after she'd come into the team from an adult perspective and that's not offered in Adult Services so trying to sort of put other things in place and reassure and make sure that she's been reviewed by the relevant people (HCP8).

The vignette reveals the professional going above and beyond her job remit, helping in response to parental "*fear confusion*". Her account explores the multifaceted nature of an assessment: filling in paperwork; considering both current and future provision; understanding medical condition of the young person; making plans and preparing pathways; as well as well taking the emotional state of parents into consideration. Understanding the fear and confusion of parents losing familiar services was key to planning ahead with adult services. They were the interface between the established services as experienced by the family, and the new services "*and I actually worked… with the physical health team"* working across teams within adult healthcare. The word "*actually*" used for emphasis suggests that this may not be standard practice.

The importance of the face-to-face meeting in particularly stressed in her account, when they go on to say:

> *as a nurse I think you know face-to-face assessment is absolutely vital in so many ways cos like I said sometimes you don't necessarily you're reliant on other people's information and it's not always what you see doesn't add up to what people are saying* (HCP8).

Transition is nevertheless recognised as a "*difficult time*". One LD nurse commented:

> *I think 80 90 % of my Mums and the majority were single mums erm were on anti-depressants you know this we* have *to look at a family when you look at transition it doesn't just affect the child you know it's the whole family* (HCP14*).*

The effects of the stress of the transition reinforced the importance of professionals meeting both parents and young people face-to-face, to gather information, for better understanding, and to give practical and emotion support.

Subtheme F - Facing barriers

> *Transition is a hugely difficult time for parents* (HCP12)

As discussed in Chapter 3, and in the previous theme of this chapter, parents are advocates for their children. However, the professionals sometimes had differing views about parental advocacy and felt that parents did not always act in the best interests of their child. Two reasons for this behaviour were suggested: firstly, a lack of understanding of the Mental Capacity Act, and secondly, the hidden issue of the financial impact of transition on some families.

People who work closely with the families understand the parents' reluctance to let their young person leave home (HCP2, SC11, HCP14). However, commissioners stress that future care should be the young person's choice, even though those decisions will be made within the guiding principles of the Mental Capacity Act, by a team of people at a Best Interests meeting (ADV3). Understanding their new role in the transition decision-making process was described as problematic for parents:

> *often a problem with transition time again is that erm parents are not aware because they still see their son or daughter as the person they have been caring for in erm a younger version of themselves without the rights that they start to enjoy when you come of age at transition time and it's hard even though you might have Power of Attorney to know that all that's giving you is a place at the table in a best interest decision-maker … several parents that I have worked with think that gives them the choice to overrule everybody and "this is what's going to happen because I've said so" and they don't understand what Power of Attorney means, they don't understand what Mental Capacity means or Best Interest Decision-making process means and again they feel quite threatened by the number of people that have come to a best interests decision meeting* (ADV3).

Parents are again seen to be in a liminal state, between a world where they were responsible for decisions around the care for their child and a world where their child is considered as an adult with "rights". The decisions about living arrangements and health have to be made within a new context, where the parental position shifts from that of sole decision-maker to just having "*a place at the table in a best interest*" meeting. Additionally, parents may be unaware of this loss of control of the decision-making process, still regarding their offspring as a child, because they still require the same level of care, and lacking the mental capacity to make those decisions for themselves. Parents are therefore vulnerable and may feel threatened by processes of law and other individuals involved in the decision-making process. A social worker also emphasises this shift:

> *that's a massive change going through that and understanding the legal process around that and how decisions are made erm after that point* (SC11).

Professionals acknowledge that parents arrive "*at the table*" unprepared and uninformed about mental capacity. Two professionals suggested that training in Mental Capacity Act would help parents at this stage (SC01, ED9), while other suggested improved advocacy provision would be supportive (ADV6). They felt parents should be prepared for this shift from when their children were young but acknowledged that parents of young children are often not ready to learn about the future, while they are busy dealing with the present (ED9). Some professionals concurred with this position, recognising that for young people with PMLD in particular the future is not assured (ADV6).

The fourth guiding principle of the Mental Capacity Act is to act in "the best interests" of the person who lack capacity. Within the dataset, there are hints that parents do not always act in the best interests of their child, and this is interpreted to be the result of financial pressures. The benefits that young people are entitled to may subsidise family budgets, and a move to independent living means families lose this income.

> *AD6: Erm I think one of the biggest challenges is finance? … because I think one of the barriers one of the difficulties for movement after school residential placement is financial a lot of families can't afford to lose the money that comes with the child*
> *I: and that's because they're getting benefits but when they go into supported living or [residential] college they lose those benefits that's?*
> *AD6: yeah and that's understandable because most of these families have given up their careers and their work to look after the child* (ADV6).

Furthermore, this may lead families to press for higher/further education, as benefits continue while child is in education: "*sometimes it can be a perverse incentive to continue on you know in education where it might not be in the best interests of that young person"* (ED5*).* The decision for further education for this cohort also rests on the Education Health and Care Plan. Parents cannot just decide to send their child to college. The process requires an educational need to be identified, and funding agreed. What is in the best interests of the young person will be considered, and it is then that parents are confronted by their limited role in the decision-making process. Their own circumstances are not considered within this process, and consequently their motives for requesting further education may be questioned. Whilst the impact of parenting a child with disabilities on career prospects and family finances is empathetically acknowledged by the first participant, the lack of public acknowledgement of this financial cliff edge for some families leaves their motives in requesting further education open to suspicion: "*parents can't afford to lose the money*" (ED5).

Sometimes, it is an acknowledgement that the parents just can't manage to care for their child, which points them towards requesting further education, which might feel more familiar than supported living accommodation (SC01). However, the pathway is not always clear.

Vignette 6

Giving up an EHC plan

"she can't manage this child anymore"

I was at a meeting a few weeks ago to do an annual review for an 18 year old child who's leaving in the summer yeah and lives in (town) at the meeting they said to Mum erm "so we'll send you the Education Health Care Plan because she doesn't need it anymore and you'll sign to that effect" right I didn't say anything in the meeting because I didn't want to. Anyway this this mum's desire for many years she can't manage this child any more she's just yeah getting older and they're really really struggling and she always wanted this child to go to (college) on a residential placement now this has always been the plan the school's always supported this and the over the last 18 months this has been creeping in (county) and they said to this mum yeah "she's got no educational needs" now she has her communication is developing more and more yeah and I see that as education and the social worker at

> *the meeting and the person from the LEA said that they would they would provide daycare facilities for this child in these fictitious daycare facilities that exist and if they do exist they're full of old people and that they would find somewhere for her to live in the community in supported living yeah ... now I know that to find supported living in the community takes years (to find)…appropriate roommates* (ADV6).

The narrative presents the parent, and the young person, as without agency within the decision process, but is told by an advocate. The parent has historically expressed a wish for the young person to move to residential college, because she is no longer able to care at home, she is "*really, really struggling*" as she gets older. Education does not see that there is an educational need, and therefore possibly the suggested move is not in the best interests of the young person. The narrative also suggests that decision-making has been left until it is too late to meet the young person's needs adequately. Consequently, the lack of an identified placement illustrates the "c*liff edge*". The narrator as an advocate, adopted a position alongside the parent in this potential conflict, advising her not to agree to the proposal – her account suggests disagreement, anger, suspicion and disbelief in the proposed solutions. It also reveals that the mother's own situation is not supported.

This theme explored the hidden aspects of working with parents. The importance of meeting with families face-to-face, in order to understand the needs of the young person as well as the needs of the parents was stressed. This finding builds on the establishment of robust working relationships in the run-up to transition mentioned in Theme 2 (Subtheme D). Vignette 5 illustrates not just positive working practices, but also the complexity of support families require. Professionals identified the change in the parental role when the child becomes an adult, and frequent lack of understanding of the Mental Capacity Act, as particularly challenging for parents. Often parents face difficulties, such as physical exhaustion, and transitions are not smooth when there is a fragmentation of services (Vignette 6). The financial implications of transitions on the parents' situation can sometimes make parents fixed in the aspirations for their child.

Summary of thematic findings

Transition is viewed as an ideological pathway to adulthood and independence by commissioners, whilst the professionals who work closely with young people and their parents are more focused on the processes. Professionals acknowledge that parents have a vital role as the holders of knowledge and advocates for their child, but that this role is compromised when their child reaches adulthood. A lack of understanding of the Mental

Capacity Act and financial pressure add extra stress at this time for parents. The lack of co-ordination between services can cause problems, but good outcomes can be achieved by attention to detail and careful planning involving everyone. The recommendations were acknowledged that parents have to make major decisions in constrained circumstances:

> *it's not just preparing our young people for adulthood it's preparing our families the families for that young person's adulthood is this is (...) we're often putting an awful lot of responsibility onto our families with making choices and understanding what's going on and asking some quite big questions* (SC01).

Whilst the systems may be helping parents to prepare for their child's future, there is little acknowledgment of their parents' own future needs.

Participants' recommendations

When asked for recommendations for support focused on parents (as opposed to the young people), most participants expressed a sense of uncertainty. The recommendations for further support were diverse, and mostly informed by the participants' immediate working environments and their areas of expertise. They focused on the fragmented nature of the services, such as the gaps in joined up working and in providing the correct information to parents.

The role of keyworkers, as suggested by NICE guidelines (2016), was discussed in a theoretical way by participants in in Health and Education. This role was identified as "*someone whose job it is to know all the post19 provision*" and *"whose job it is to work with families for those two years"*. However, the job was seen to be time-demanding. One participant said: *"I couldn't be a key worker for somebody I haven't got time to do it justice"* (HCP7), while another added "*they need a team of keyworkers"* (HCP14). Advocates felt that parents, as well as the disabled person, should have the right to advocacy (ADV3, ADV4, ADV6) stressing their independence from statutory organisations being a key benefit: *"I can question and I can challenge"* (ADV6).

However, external support for families from parent and carer forums, was seen to be compromised due to their sources of funding, "*they have contracts with local authority so there's been a compromise there*" (ADV4). The role of parent-carer forums will be discussed further in Chapters 6 and 7.

Link organisations such as Connexions (ED5, HCP14) and Brokerage (ADV3) were perceived as having key roles in helping parents identify suitable services for their children, but these services were available in some authorities and not others. In the absence of transition social workers in one authority, Education filled a gap:

> *as with a lot of other things that have fallen by the wayside due to reduced resources schools are trying to pick it up* (ED17).

Mention of direct support for parents, such as the provision of respite for families whose offspring remained at home, was largely absent from the dataset. Respite was suggested as something important to families, "*kind of a huge thing for people"* (HCP2), and as a service offered by a hospice (ADV6). However, it was also acknowledged that this service does not often continue beyond children's services.

In health, there were conflicting views of the pivotal role of the GP as the replacement for the paediatrician as the co-ordinator of future healthcare. Specifically, one participant expressed uncertainty about how much involvement the GP has, and how much nursing expertise the Learning Disability Team might have (HCP15). The needs of both the parent and the young person therefore seem to fall into a gap between services.

Discussion

This study aimed to explore the professionals' understanding of transition, how they view the role of parents of young people with profound and multiple learning disabilities at this life stage; and also how they understand their role in supporting parents during transition.

Findings suggest that the ideology of transition, based on the person-centred social model of disability, permeates transition planning. Transition processes are influenced by a number of factors on a personal level, such as family circumstances, organisational level, such as co-working within teams, and a policy level, such as funding restrictions. Professionals show understanding and empathy for families and offer practical support to parents, but sometimes are suspicious of parental motives.

When being interviewed, the professionals, except the advocates, adopted an 'official' discourse. Much of the transition work involves interdisciplinary collaboration, and it has been noted by King et al. (2013) that when interviewed about their collaborative work, health and social care staff will often present an "*ideal version*". In this study, it was interesting therefore to examine this ideal, in comparison to the actual processes. The vignettes have been used in this analysis to elucidate specific issues relating to the young person and parents' positions within the transition process. These vignettes, therefore, present a less idealised account of specific events.

The findings are examined through the application of Bronfenbrenner's model, with particular emphasis on the Individual, (Theme 2), the Mesosystem (Themes 1, 2, & 3) and the

Exosystem (Themes 1 & 3). The analysis builds on the work of Jacobs et al. (2020), which will be discussed in Chapter 7 (Fig. 3).

Identified factors which affect the parents' position within the process and the parent-professional relationship were considered in the light of Twigg and Atkin's Typology of Caring (1994). The recommendations for support for parents were also considered under this lens.

Application of Bronfenbrenner's Ecological Model and Twigg and Atkin's Typology of Caring (1994)

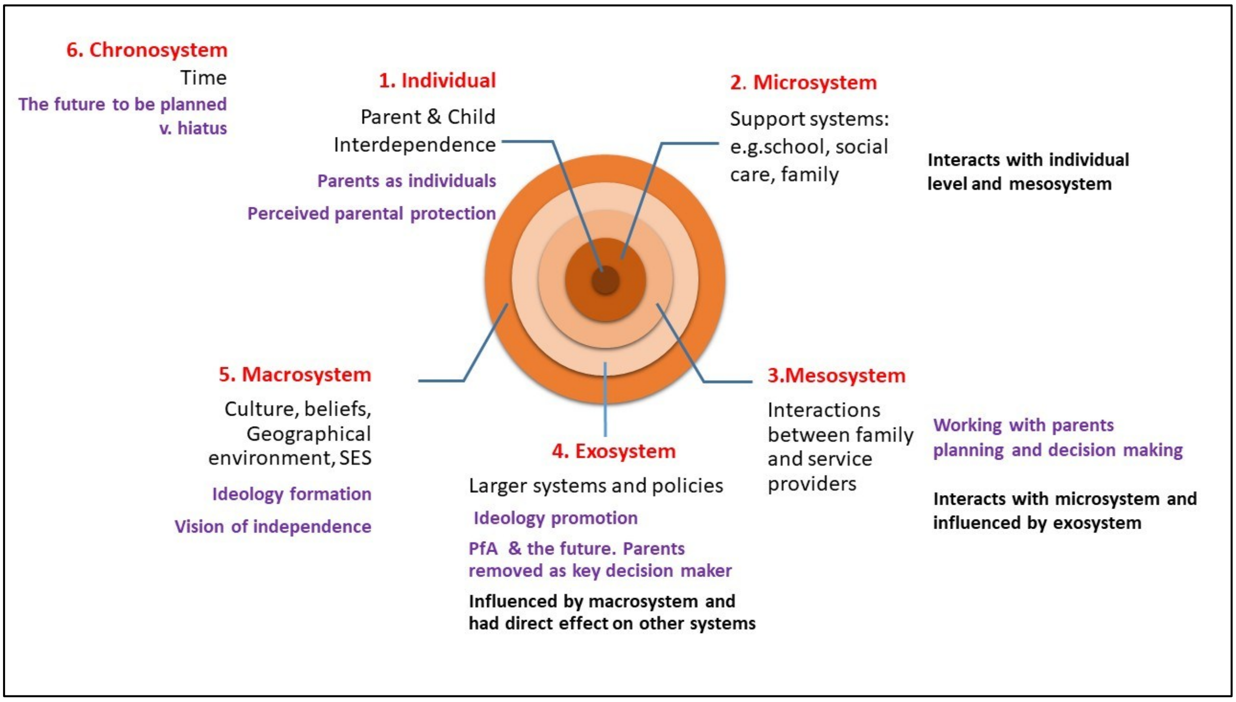

Fig. 3: Showing the themes and key findings mapped onto Bronfenbrenner's Ecological model

Twigg and Atkin's typology (1994) defines carers as:

- *resources*, free and available sources of family support. Separate from statutory provision
- *co-workers*, working alongside or with professionals, in order to continue providing care
- *co-clients* equal in status with their needs being met, such as respite
- *superseded carers* with independence for the young person achieved, or inability to continue caring. (Manthorpe et al., 2003)

Individual: (*the parent and their child)*

Contrary to the findings of the previous study, the parent-child interdependence is not always recognised within these accounts. The professionals see the young person as the focus of the transition, and therefore is placed more traditionally at the centre of the model. This is demonstrated in discussions relating to person-centred planning throughout the child's life and the needs identified in the EHCP (ED9, ED16). However, the young person was also seen as child, as in Vignette 2, which presents a tension between how the young person is viewed and the aims of PfA.

The parent was seen as separate from the young person but was acknowledged as protective of the young person (HCP2, ADV3, ADV4), the holder of knowledge about the child and an advocate for their child's needs (Vignette 4). I argue that within this study the parent is seen by professionals as wrapping themselves around the child and acting as a barrier or interface between themselves and the people who are there to support them, almost like a nutshell. Their protection and care has allowed the child to develop.

Within the Twigg amd Atkin's typology at this point parents may be seen as *resources* or *co-workers*. Keeping the "*duality of focus*", that is the needs of both the young person and the parent, reveals some conflict. Parents who are believed to be acting in their own interests, and in effect putting themselves at the centre of the model, are met with sympathy or suspicion (ADV6, ADV4).

Microsystem:

(individuals who support both the child, such as teachers, doctors, healthcare professionals, support workers. the people who work closely with family)

The Microsystem for a young person with PMLD and their families is complex (SC01, HCP12). The recruitment shows that many people from many different areas work with the young person, and each service produced more than one person with expertise. Health care professionals are particularly important to young people with PMLD, and also represent multiple transitions across services, such as speech and language therapy, neurology, occupational therapy for example (SC11).

However, with the move to adulthood and losing the main decision-making role, the parent becomes one of member of the transition team and may also therefore be seen as part of the Microsystem, earning *co-worker* status in the Twigg and Atkin's typology. Occasionally, parents receive support from these individuals and networks, as a person in their own right.

The data also suggests that advocates sit beside parents (ADV3, ADV4, ADV6) both literally, and emotionally, within the Microsystem. This positioning suggests the parent is sometimes promoted from being a *co-worker* to a *co-client* (Twigg and Atkin's framework).

Mesosystem:

(*relationships with parents, also relationships with people who influence the decision-making, social workers, educational psychologists, assessing healthcare professionals)*

The Mesosystem is the pivotal point where the 'process' people (Theme 1), from the Microsystem, meet to plan and facilitate transitions. Additionally, there is considerable influence from the policies and influences from Government and society (Macrosystem), passed down through the commissioners (Exosystem). In particular, parents learn through their interactions with professionals, such as social workers and doctors, that they no longer have the right to decide the future, and their fundamental position alters (ADV3, SC10, HCP12), as shown in Vignette 3 and Vignette 5.

The accounts report examples of positive support for the family in terms of meetings and information sharing. Although the young person remains the focus, parents are involved in forward planning as demonstrated in Vignette 1 and Vignette 6. Vignette 6 demonstrates how a LD nurse prepared a family for the move to adult epilepsy services and help prepare both the family and services. This type of "*practical*" transition was identified by Jacobs et al. (2020, p.1069) with good communication and sharing of practice. However, within this dataset tensions were reported across all sectors, as demonstrated by the lack of consistency within the organisational systems.

There was an identified lack of consistency in practical handovers (SC01, HCP12, ED17); an admission that professionals themselves do not know who they are handing young people over to, particularly in healthcare (HCP7, HCP15) and acknowledgement from a senior social worker that services were "*not good enough*" at preparing families for transition. The recommendations of the participants demonstrate that there is a need for more co-ordination between services and identified "keyworkers", as suggested by NICE guidelines (2016). These recommendations will be discussed further in Chapter 7.

At this stage, parents are identified as a "*co-worker*" in the Twigg and Atkin's typology. This model still places the young person with care needs at the centre, but also highlights the well-being of the carer. Support, such as information, is "*threaded through*" (Gant, 2018, p.92), to help the carer to provide good quality care. However, within the transition process, parents are left unsupported if stakeholders are unable to provide the correct information, and their role as "*co-worker*" is compromised.

Theme 2 also demonstrated that the professionals show empathy, recognising the both the physical and emotional impact of caring. Furthermore, they recognise the parents' fear of transition (ADV3), as they experience their own difficulties at times in navigating the processes (ED9). This element of empathy will be explored more in the next chapter. However, there was little evidence of these professionals providing support in terms of caring for the carers and recognising their own transition as something that could be positive and planned in parallel with their child's transition.

Parents therefore shift from the *co-worker* status outlined above to "*superseded carers*". However, the Twigg and Atkin's (1994) typology only allows for a carer who steps back because the young person has achieved independence, or because they no longer cope. Parents of young people with learning disabilities generally often have to step back because of the legislation and attitudes of commissioners and managers, and not through their own choice. The superseded carer role is therefore symptomatic of the "*cliff edge*" of transition.

Exosystem:

(people who influence the decision-making process, such as the commissioners)

There was a clear difference in the discourses of the people who oversee the decision-making process (SC01, ED5, ED16) as opposed to the members of the Microsystem, who work directly with families. Their vision of transition was more ideological in approach, driven by the four tenets of Preparing for Adulthood. Independence was seen to be the main goal of transition, with little acknowledgement of the interdependency of the child and parent, and it was the commissioners' role to promote that concept. Jacobs et al. (2020) also found "*differences in conceptualisation of independence as an absence of support, compared with a more relational understanding that valued consistent and supportive relationships in young people's lives*" (p. 1077). Whilst the commissioners acknowledged the importance of the parents in planning their children's future in this study, there was little emphasis on how those relationships might be maintained going forward. It was suggested that the young person chose between a "*really good service*" or living at home (SC01).

This representation also places the parent as the *superseded carer*, as discussed above.

Macrosystem:

(cultural influences, such as ideology relating to disability, government guidelines/legislation, funding; global economics).

The social model of disability and the person-centred agenda is reflected with the influence of the ideology of PfA, and its four central goals (Theme 1). The PfA agenda affected the way participants discussed both planning as well as working with the young person, who was placed at the centre of the model. (SC01, ED9, ED16, ED17). These participants came from in Education and Social Care and advocates (ADV3, ADV4), and the ideology was embedded in the commissioners' aspirations (Exosystem) as well as some people working in Social Care and Education with the families (the Mesosystem).

However, Government policies around funding, such as the Austerity programme, impacted the delivery of services and also had an impact on available funding for available places and training (ADV3). Policies were also seen to influence the way commissioners talked about the goals. Independence was promoted to avoid young people being a "*drain on the state*" (ADV3, ED5). There was an incompatibility, therefore, between the ideals of service delivery and the realities of Government budgeting, which impacted outcomes for the young person. Only the most dedicated and well informed, parents were able to influence their children's outcomes (ADV3, ADV4). Jacobs et al. (2020) also found that there was an inconsistency between the values of delivery service and the reality of cuts to services offered to families.

The positive outcome, where the ideology and processes come together, in Vignette 1 is in contrast with the unresolved issues in Vignette 6. In the former, parents are seen to be onboard with a person-centred ideology and work hard to achieve that level of care for their son. In the latter, the narrator's scepticism about "*imaginary*" services suggests a dichotomy between the ideology and the reality, in which the parent is left to make the "*choices*" and ask the "*big questions"* (SC01) but lacks the agency to make the final decisions.

Chronosystem:

(*stage of life in relation to the situation: i.e. parent witnessing their vulnerable child becoming an adult)*

As discussed in Theme 2, there was recognition that parents may not expect their children to live into adulthood. Therefore, they sometimes arrive at transition unprepared emotionally (ADV6). While the planning procedures should prepare them for this shift, the problems with the processes often induce anxiety and strain in working relationships (SC10). Parents are faced with their own situations, as illustrated by the discussion around their financial needs (ADV6), as well as their role going forward in their child's life. While life planning tools were used in one authority to support transitions for young people, there is no discussion about how parents could be supported to plan their own lives.

Acknowledgement of these issues and support going forward would help move the parent from co-worker status to *co-client* in the Twigg and Atkin's (1994) model. Throughout this discussion, the parent is represented as moving from a *resource* to *co-worker*, and then to a *superseded carer*, with little acknowledgement of their own needs.

Role of the TRAG

In the initial planning of the research, the Transition Research Advisory Group (TRAG) discussed their own experiences, which was useful for contextual understanding. One member also asked "*What does a good transition look like?"* This question prompted me to consider the framing of this study, so we can understand what the goals are, not just concentrate on the problems.

The TRAG were consulted in all stages of the study, advising on the interview schedule, making recruitment suggestions, reading and commenting on the transcripts, and making recommendations relating to professional/parent support. In particular, one member felt strongly that face-to-face assessments of the young person are essential for planning, as knowing that someone had seen their child, gave her reassurance that they recognised the extend of the young person's disabilities.

Reflexivity

I feel my self-belief in myself as a researcher developed throughout the interview stage of this study. I grew in confidence as my understanding of the systems at play increased. At the outset of my research, my comprehension of transition processes was influenced by my experiences as a mother of a young man with SLD at a particular point in time. My son left school and moved across to a residential placement in 2016, when the impact of the Children & Families Act (2014) was first being felt with the introduction of the new EHC plans. As parents we didn't feel we had much agency. However, he was allocated a wonderful advocate through Coram Voice and a proactive social worker, and his outcome was a positive one.

Consequently, I approached the topic of transition with a mixed knowledge and experience. I knew that laws existed but didn't necessarily understand them. I felt this ignorance of the workings of the EHCP process keenly and raised it with my first bracketing interviewer. I commented

> *I don't feel prepared enough to talk to professionals because I still need to get to grips with you know all those various little bits of legislation like the Children's Act and you know I just need to really know that … so when they start talking about it I know what they are talking about (2018).*

She responded

> *you don't have to be an expert because you are able to ask the naïve question ...it's about unpicking that a little bit and just suggesting that there may be a bit of a hangover from your interactions with professionals as a service user ...but actually you are going there with a different relationship this time you are going as a researcher who happens to have had some experience personally.*

Consequently, I have attempted to carry the two positions of the service user versus a researcher (with some personal experience) in my mind, bridling those experiences in order to hear the professionals' viewpoints. I learnt along the way; once a participant asked if what they had said had been useful and I admitted *"really useful actually because it is also a learning curve for me".*

Additionally, I learnt about the transition experiences of members of the TRAG, who were parents of young people with PMLD. So, although I was nervous of inadvertently bringing my own experiences into discussions, I was more conscious of sometimes presenting an opinion or experience shared by members of the TRAG. In another bracketing interview I commented that I felt at times I needed to state my experience to give weight to the discussion, rather than just being the naive researcher. In my final bracketing interview I explained:

> *it was like I needed to prove that I'd got some expertise or I'd, you know, some experience that I then had to bring to the table to say ... to further the conversation (2023).*

Initially, I believed this comment reflected a sense of insecurity within the researcher-professional dynamic. Having historically been in the position of requesting help from social workers and experiencing the imbalance of power of the parent-social worker relationship, at times I may have felt the need to prove myself. However, halfway through the interview process I noted in my diary

> *I feel I'm being a bit too opinionated at times – I bring my own experiences to the table a bit – to explain my questions maybe. What I am finding is that professionals have a very defined, removed way of talking about stuff, but when I chip in with "well as a mum" or "my experience is this" they tend to open up a bit (2021).*

I believe I was able to reflect on long past experiences in a measured way, and I hope this bridling has informed by interpretation of the data. I feel that I moved from an ill-informed parent, albeit with personal experience, to a more reflective researcher.

Strengths and limitations

A strength of this study is the diversity of the participants. Jacobs (2018) commented that existing transition research relating to young people with PMLD at transition was largely based on the experiences of parents. It was therefore decided when designing this thesis that the opinions and experiences of professionals should be examined. This diversity allowed exploration of similarities and differences within and across four sectors. Recruitment was to some extent hindered by Covid-19, as staff had been seconded to frontline services, but, over time people volunteered to take part. However, few people who worked solely in Adult services came forward. The participant sample largely consisted of people who understood transition issues and were "*passionate*" about improving services. The sample did not include those stakeholders who support young people, either in children's or adult services, who do not have an interest in transition. They make up a large proportion of service providers families interact with and will be introduced and discussed in Chapter 6.

Despite the recruitment approaches to learning disability-specific further education establishments and adult social workers none participated. I believe this reflects that transition is viewed as a handing over process, and therefore health and social care professionals in the Adult sector may not be involved with the young person until there is a problem. I believe the failure to recruit anyone from further education was related to pandemic restrictions.

Furthermore, some key roles, such as a community nurse and a speech and language therapist were not represented within the data set. These people were stressed as key by member of the TRAG.

Conclusions

This chapter explores the beliefs and understandings of professionals who work with families of young people with PMLD and CHCN at their transition to adult services. The diversity of professionals within the services and across the four sectors revealed that there is a difference in approaches to transition, varying from the highly aspirational to the more practical aspects of care. Transition is therefore seen in some areas as a handover process, whereas in others it is planning for the life ahead as an adult. Parents are understood to be vulnerable at this time as they shift from the key decision-makers in their child's life to a member of a team who make Best Interests decisions for the young person. In some cases, their motives wanting what they might perceive as the best for their child were questioned by the professionals, and it was suggested that there was a tension in co-working.

Within the context of the Bronfenbrenner model, there was considerable interaction between the systems, as working practices were influenced by government agendas, which in turn affected relationships between parents and professionals. Within the context of Twigg and Atkin's Typology of Caring (1994), professionals see parents as *co-workers* during the run up to transition, but they are regarded s*uperseded carers* when the child reaches adulthood, despite their caring role continuing. They are therefore often isolated by the systems who support their child.

This analysis represents the beliefs and understandings found in the factual and practical accounts within the dataset. Participants were reluctant at times to discuss and reflect on the support needs of parents as individuals. Ross et al. (2005) suggest that only when things go wrong within relationships do professionals reflect, rather resorting to the established narrative of everyday working. As all these interviews, except one, took place during the Covid-19 pandemic, when normal working practices were suspended, the professionals reflected on those experiences during their interviews. There was a shift from the factual to a more reflective approach. These Covid-19 related findings were subjected to secondary analysis, which forms the next chapter.

Chapter 5

Exploring the impact of Covid-19 on professionals working with families with young people PMLD in the transition window

Introduction

As demonstrated in the previous chapter, professionals dedicate time and energy in developing good working relationships with parents and young people with profound and multiple learning disabilities across the lifespan and at transition. In particular, transition has been shown to present many challenges in terms of these relationships (Chapters 3 & 4) and generates a shift in the identity of parents. In 2020, with the global spread of Covid-19 and the resultant lockdowns (Fig.1), these issues were polarised. As the pandemic evolved, this research project was adapted to include a focus on the impact of Covid-19 on the lives of those professionals working with young people with PMLD and their families. This chapter is a secondary exploration of the template analysis findings and considers what the dataset revealed about the impact of Covid-19 on transition practices.

The situation for young people with PMLD was at times unclear. This group was recognised as being extremely vulnerable to Covid because of their susceptibility to chest infections, however they were not specifically included in the Shielding[14] Patient List, (Ministries of Housing, Communities and Local Government, 2020). Additionally, the lockdown rules were ever changing and sometimes confusing (see Fig. 1) leaving families to make their own decisions around self-isolation. As services were withdrawn, the impact on carers was substantial, with unmet needs for emotional, social, practical and financial support being heightened by the imposed restrictions (Onwumere et al., 2021). An All Party Parliamentary Group examining the impact of Covid-19 on education transitions found that the “the needs and experiences of young people and their families [were] wide-ranging, emotional and often desperate” (APPG, 2021 p.3). The impact on the people who worked with these families was also felt particularly in Health and Social care (Owens et al, 2024).

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[14] Shielding is a measure to protect people identified by the NHS who are medically extremely vulnerable to COVID-19 by minimising all interaction between these people and others until the end of June. (Ministeries of Housing, Communities & Local Government, 2020)

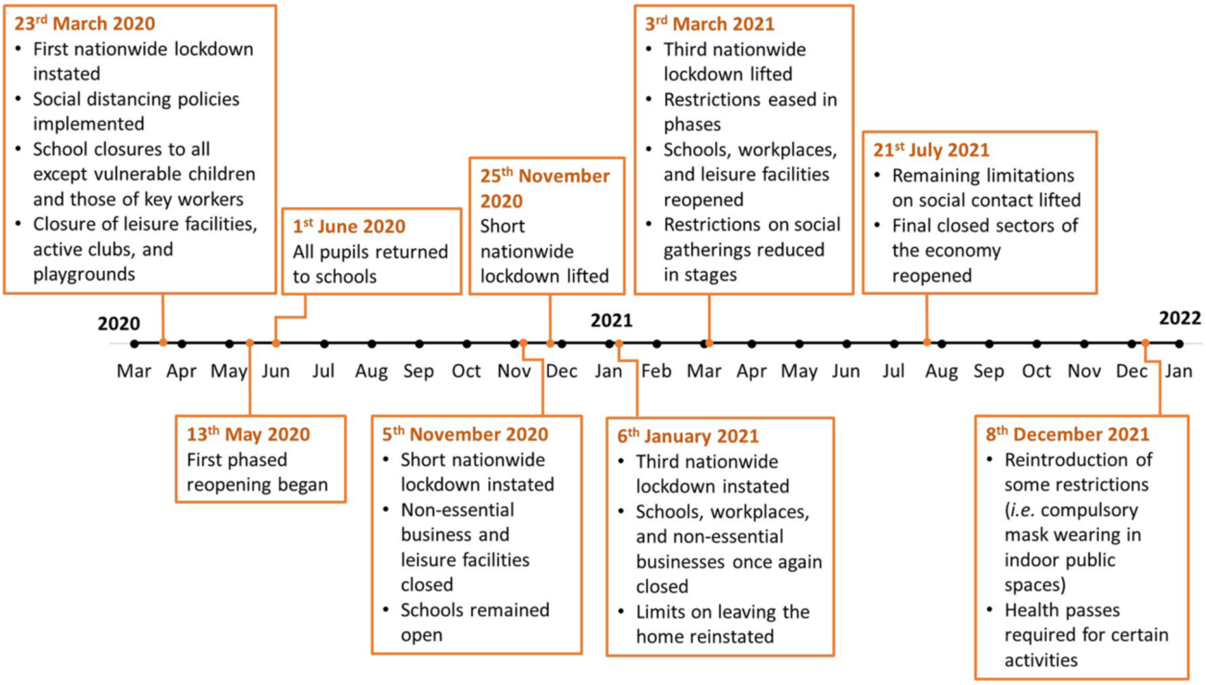

Fig. 1 Timeline of UK Government coronavirus lockdowns and measures (March 2020 to December 2021) (reproduced from Walker et al., 2022 used under CC BY 4.0, doi:10.1186/s12966-022-01356-3)

This study therefore considers what the dataset revealed about the impact of Covid-19 on transition practices

Research Question

What was the impact of Covid-19 on professionals, who work with young people with profound and multiple learning disabilities (PMLD) and their families, at transition to adult health and social care services.

Aim

To understand the working relationships between professionals and parents, and consider what was learnt as a result of the pandemic.

Covid terminology: Both “Covid-19” and “Covid” are used in this chapter. The term Covid-19 is used to refer to the pandemic, to give the phenomenon a timeframe reference, being between March 2020 at the time of the first lockdown and Spring 2022 when restrictions ended. The term “Covid” is used in reference to the illness, or someone suffering the symptoms. It is also used in quotations according to the participants’ original words.

Methods

Research Design

The research design evolved throughout the pandemic, in response to delays in recruitment due to the (in)accessibility of participants. It was decided during the development of the previous chapter to present the Covid-19 work as a separate study with a shift in focus to more experiential accounts. This study is a secondary analysis of the template analysis, as it became apparent that a group of interviews was particularly rich in experiential detail, and these became the focus of further interpretative analysis.

As discussed in Chapter 4, a cross section of professionals, who work in the sectors of Health, Social Care, Education and advocacy, were recruited in order to reflect the variety of approaches and beliefs around transition working (Fig.2).

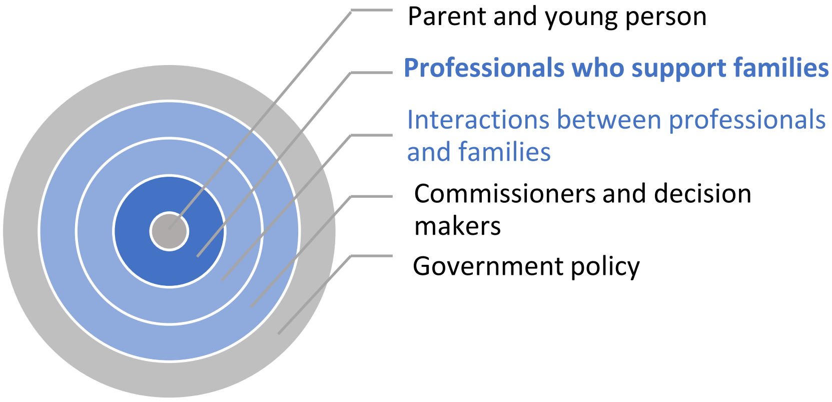

Fig. 2 – Model showing the participant focus of the study

Ethical approval was obtained from West Midlands and South Birmingham Research Ethics Committee for amendments to the original interview schedule, as well as data gathering through online recruitment and interviewing, in May 2020.

Participants

The participant group remains the same, as outlined in Chapter 4. All participants gave informed consent to take part.

Data Collection

In response to Covid-19, additional questions for the semi-structured interviews were developed, with input from the supervisory team. The three participants who had been interviewed before Covid-19 were invited to submit comments on these questions via email, two people responded in 2020, the third agreed to be interviewed for a second time in January 2022. Questions included:

- In your opinion, what has been the biggest impact of Covid-19 on families caring for a young person with PMLD?
- How do you feel these factors will affect transitions for young people and their families?
- What has been the biggest impact of Covid-19 on your working relationship with those families?
- Have there been any unanticipated advantages to the way things have adapted during the pandemic?

Data and analysis

All the data gathered was included in the initial template analysis and a theme examining Covid-19 working was developed as part of that process. Template analysis was carried out according to the six stages outlined by Brooks, et al. (2015) (see previous chapter). The resulting templates were discussed with the Supervisory team at each reviewing stage. (See Appendix 4 for final template, themes and quotations).

As outlined in the previous chapter, further interpretative analysis was developed in the writing up process. In particular, data was extracted from the table of quotations and two interpretative processes were employed. Firstly, by adopting some aspects of IPA analysis as defined by Palmer et al. (2010) the analysis moved from description to give a deeper interpretation of the data. In particular, the positionality of the participants in relationship to their clients was examined, considering the organisational changes imposed by Covid-19 restrictions. Stories and the language employed were examined. Four whole interviews from the set were particularly focused on working within the pandemic (SC01B, ADV04, HCP14, ED17) as were sections of two other interviews (ADV06, HCP12), and it was decided that these were an acceptable representation of the sectors that participants worked in. Secondly, aspects of these accounts were developed into research poetry, using methods similar to those employed in the poetic synthesis. These Covid-19 related poems were drawn from individual accounts, whereas the poems in Chapter 3 drew on aspects of experience from more than one participant. The poems are written mainly in the form of “I” and “we” statements to emphasise of the participants’ physical and emotional states within the context of the pandemic (Toye et al., 2020) (Table 1). (See Appendix 4)

Identification of themes	Themes were identified during the template analysis, and follow up interpretative phenomenological analysis
"Surrender"	KS engaged in reflexive examination of own preconceptions of being a parent of a young person with LD, who was living in a carehome, during the pandemic
Extraction of data from papers	Verbatim quotations from participants were extracted and presented in chart form according to the identified themes
"The catch"	Verbatim quotations were examined for use of imagery, language and emotional content
Creating "found" poetry	Selected narratives and imagery, using original vocabulary, were edited and blended with KS's interpretations to produce free verse as well as experimenting with structured formats Emphasis was put on creating "I" and "We" poems to represent the witness accounts
Titles	Further layer of interpretation within creation of titles

Table 1 – The process adopted to create research poems

Results

Context of Covid-19

Covid-19 was a universal experience: no-one was unaffected. Thirteen of the participants worked within the sectors of Education, Health and Social Care and therefore were "key workers" during the pandemic. Not only were their clients' lives disrupted by Covid-19 but their own working procedures and environments were significantly altered. Most participants started working from home, either full time or splitting time according to need and circumstances. Consequently, within the context of transitions to adulthood, there was a hiatus in services. The professionals were hindered by the Government-imposed Covid-19 restrictions, and felt circumstances were beyond their control.

In relation to transition, participants reported disruption to working practices across all four sectors. Health care services, such as paediatric clinics, and speech and language interventions, were stopped, as staff were redeployed within the NHS. In Social care, social workers were sometimes unable to meet families, which in *"pre-Covid…would never in a million years have happened*" (SC01B).

The context of working in Covid-19 is considered first before focusing on the particular impact on transition processes.

Poem 1

We need to leave (a) space

We are in a tsunami
I feel there's a bit of a gap
We are being crashed but
I'm just carrying on

I feel there's a gap so
I position myself with people working for change
I'm just carrying on as
I feel a responsibility to use my voice

I position myself with others working for change
I have to hope that change is positive
I feel a responsibility to use my experience
We have to find ways

I hope that change is positive
We need everyone to support each other
We have to find ways then
We can do no more

We need to support each other
We are being crashed
We can do no more
We are in a tsunami[15] (ADV04)

This poem is drawn from the account of a participant who was interviewed in June 2020. She felt that the disruption, which she compares to a tsunami, was affording some opportunities for change, and she wanted to align herself with others who could affect that change. She felt she had a personal "*responsibility*" to improve care for young people with disabilities. The imagery of Covid-19 being a tsunami was striking at the time of the interview, but has subsequently been used as a popular image in personal accounts, news reporting and academic journals to describe a variety of aspects of the pandemic, such as increased mental health issues, suicides; as well as the number of cases of Covid (Shevlin et al., 2021; Kavukcu et al.,2021; Lledo et al., 2022). In this account the speaker uses the

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[15] The poem uses the form of a Pantoum, a 15th century form of poetry from Malaysia, imported to France allegedly by Victor Hugo in about 1830 (Fry, 2007).

image of the tsunami as something more abstract, suggesting society being torn apart, but also thrown together, and adding that "*a bit of a gap*" leaves room for new beginnings. Lines from the poem are used to define the following themes.

Thematic findings

The poem introduces three themes exploring the professionals' roles working with families: Theme 1, ***Being in it together- "we need everyone to support each other",*** considers how the professionals are working with and removed from the parents with particular focus on what happened when they engaged with families. Theme 2, ***Professional dedication – "I'm just carrying on"*** considers how much professionals give in extraordinary circumstances to support families, working with creative initiative. Additionally, the future is considered in light of what the professionals have learnt through Covid-19. Theme 3, ***Personal impact: "We are being crashed",*** explores the personal impact of Covid-19 on the professionals, both in their home lives and in their work lives, expressing fear and frustration (Table 2).

Theme 1 — ***Being in it together -***
"We need everyone to support each other"

- ***Subtheme A:*** ***From the outside***
  - *Poem 2: Tears*
- ***Subtheme B:*** ***Engagement***
  - *Poem 3: Witness*

Theme 2 — ***Professional dedication***
"I'm just carrying on"

- ***Subtheme C:*** ***Giving more***
  - *Poem 4: Building a future*
- ***Subtheme D:*** ***Creative solutions***
  - *Poem 5: Red, Amber, green*

Theme 3 — ***Personal impact -***
"We are being crashed"

- ***Subtheme E:*** ***Frustrated***
  - *Poem 6: A slap in the face*
- ***Subtheme F:*** ***Family/work crossover***
  - *Poem 7: They wanted me to work from home*

Table 2 – A table of themes generated through Template Analysis and IPA exploration

Theme 1: Being in it together

We need everyone to support each other

A participant interviewed in June 2020 commented on the used in Government briefings:

> *we've we're are still talking about different groups you know disabled people non-disabled people and shielded people and non-shielded people and it's like we're in this together* (ADV04).

From her stance as a disability rights campaigner, she wanted equal rights. Everyone was "*in this together*" in that everyone was experiencing the pandemic, but there were still divisions. Subtheme A considers how participants' accounts discussed looking in from the outside at parents and families as well as being with them. The resulting divisions and adjustments affected transition processes. Subtheme B considers the professionals' response to the parents' isolation.

Subtheme A - From the outside

From the first lockdown, families who are often isolated within their everyday lives, were further isolated from the people who provided support. Contact was maintained remotely, but personal stories still filtered through; often these stories were not necessarily about care needs and parents demanding support, but showed the true impact of the situation. The participants witnessed acts of selflessness as well as fear.

In the next poem, the participant reflects on a mother's story. The mother went shopping during the food shortages in March 2020 to get a specific brand of sausages for her child, who was on a self-restricted diet. On finding there were only two packets available, she took one, leaving the other. She told the social worker:

> *It was amazing I couldn't believe I'd found them she said but I only bought one packet because there might be another family like me that needed them* (SC01B).

Poem 2

Tears

She made me cry
I think about her every so often
When I am thinking
"it's a bit tough".

You see acts of kindness
from our families
People have still got that
in them
The way they pull together
with each other
Being absolutely amazing.

So forgiving of the system
So understanding
That's what makes it
Heart rending. (SC01B)

The poem reflects the social worker's admiration for the parent's regard for others, and in a reverse of the norm where parents look to social workers for support, she drew courage from the account. She also reflects more widely on parents working together for mutual support recognising that those who are often the most vulnerable and in need of support made the greatest sacrifices. Her expression of the situation being "*heart rending*" suggests a tension that she feels, being part of "*the system*", which is also constrained by the Government rules, and perhaps personal guilt, in that she has to restrict access to support these families.

This raised level of emotional awareness and helplessness was evident throughout the participants' accounts of working during the pandemic and is in contrast with the more ideological and practical accounts of transition discussed in the previous chapter. When asked what they thought was the biggest impact Covid-19 had had on families, participants often replied on the theme of fear. Professionals believed that parents were afraid of both the physical risk Covid-19 presented, but also the outcomes in the future as a result of the disruption to services. The professionals not only recognised the risk Covid-19 posed to young people with disabilities, but also acknowledged the physical and emotional stress families faced. Parents were described as "*frightened*" (ADV06); considering questions such as "*what if the carer gets ill ...who's going to care for the young person what what sort of back-up's in place there?*" (HCP07) concerned not just for the health of a vulnerable young person, but also their own health and the knock-on effects of illness impacting their ability to care; and within the wider context that "*everyone was scared anyway"* (HCP14).

Isolation was imposed by both Government restrictions and put into place by parents and care providers interpreting guidelines. Parents often acted as gatekeepers, as they considered:

> *how do they keep their young person safe now that's it this awful what I hear from people is they're weighing up the risk of … physical health against mental health and erm what do we prioritise and how do we prioritise that?* (ADV04).

Consequently, both Social Care and Education reported that working with families was at times "*very difficult".* Families sometimes wouldn't let people come into their homes, citing they had a *"vulnerable"* or shielding young person at home. When children weren't sent into school, Education professionals felt they were failing at times in their *"statutory duty".* This parental withdrawal made it "*very tricky*" in a practical way for social care assessments to go ahead, whilst there was also an impact on the social interaction of the young person, and family members.

> *ED: very tricky where families are just totally isolating so you know the social impact of that is a massive err you know erm part of that they lose the social interaction the social skills*
> *I: yeah... the young people or the parents or both?*
> *ED: it could be both actually but predominantly the young people but yeah parents as well* (ED05).

The concern of this participant was not just the knock-on effect of social interaction with learning disabled young people, but how parents would re-engage with the system post pandemic.

Subtheme B - Engagement

Participants recognised that they needed to respond appropriately to the risks presented by isolation:

> *it was important to act in people's best interests because the mortality rate for people with learning disabilities was so high …I think … it was six times higher for someone with a learning disability than for someone without which just seemed completely unfathomable to me* (HCP12).

Physical vulnerability was seen in both family and group homes for people with learning disabilities who had to shield. Adjustments were made accordingly, with meetings held outside in gardens or school playgrounds, or restricted numbers of visits each day, in order to reduce contact. Participants witnessed fear and stigma experienced by families, as well as the impact of the withdrawal of services.

Poem 3
Witness

I hear all kinds of things
I hear parents talk of a greater fear for the future
I've heard stories from families during lockdown
They are feeling kind of stigmatised
We had families say
"I can't cope with them at home"
Families need people
They've lost their security blanket
I really feel for the young people (ADV04)

The poem describes the parental inner life as witnessed by the professionals. Parents were afraid for the future of their children; they felt stigmatised because of comments made when they went out; they were exhausted by caring with no support. The analogy of support being "*a security blanket*" is a rare metaphor within these accounts, and the outlook for the future is bleak: one participant stated *"I think our present situation is going to make transition trickier" (ADV04).*

Whilst the isolation was part of safeguarding within the whole Covid-19 context for the general public, there was also concern for the parents. One participant commented:

> *the it's the parents that's at risk because they're trying to support their young person at home who previously would've had a lot of support in erm you know positive behaviour support or they just wouldn't physically been at home for that amount of time and the parents wouldn't have had to be dealing with it but it's actually safeguarding the parent that we've been dealing with because that young person is a risk to the parent* (SC01B).

Again, Covid-19 seemed to reverse the normal order of things, and parental vulnerability was acknowledged. It was recognised that the lack of *"respite*" in various forms, whether that was not being able to send children into school, the closure of a children's hospice, or the closure of social care respite facilities had a "*massive*" impact on parents. The articulation of concern also reflects an element of uncertainty about the truth, around the parents' ability to cope:

> *people became even more isolated than they were already and that was always a huge worry to us a really big worry about the people that had gone quiet when they're saying they're okay are they really okay* (SC01B).

This participants' worry reflects not just an awareness of professional responsibility, but also genuine concern for parents. It also reflects doubt in the participants' minds, both in the parents' judgment that they are "okay", and their reasons for saying that, but also self doubt in the social workers' own judgment to believe that parents are telling the truth. Issues around safeguarding vulnerable people, which are fundamental to the social workers' role, were extended beyond the young person to the entire family.

Within the context of transition, Covid-19 restrictions meant that families were unable to visit potential future settings, and plan for the future. Educational psychologists, who would also be involved in planning, were unable to meet children for assessments due to Covid-19 restrictions. Transition preparations, such as familiarisation and handover visits, which normally would have been carried out in school were also interrupted:

> *we didn't have er the post-19 provision staff coming in for visits erm so a lot of the stuff that would normally happen didn't happen* (ED17).

Throughout these restrictions, legislation was still in place, and participants sometimes felt their working practice was compromised by both Covid-19 and that legislation:

> *had someone referred to me with really significant needs that I haven't been able to lay eyes on yet I still had to write my report within the statutory deadlines* (ED09).

The restrictions on meeting in person and missing information led to time delays for transition planning:

> *decisions being like whether to get an Education Health Care Plan or decisions about transition … seem to be taking longer because of bits of information that are missing and it's just hard to get access to the young person* (SC10, 2021).

Additionally, it was not just the assessments that were affected but significant rites of passage. Each summer, schools hold leavers' assemblies to mark the graduation to adult life; the leavers' assemblies have personal significance for staff as well as families and young people. One teacher described how they marked the end of school life for two pupils:

> *I had two leavers in my class in in July 2020 erm we had our leavers' assembly in a massive ring two metres socially distanced in the car park... (laughs) erm with all the staff in full PPE erm that that's the sort of surreal thing this is the sort of thing that you end up telling your grandchildren (laughs) ...in forty years' time isn't it* (ED17, 2022*).*

The use of Covid-19 terminology - *"two metres socially distanced*" and "*full PPE*" embeds the account in the Covid-19 timeframe. A leavers' assembly held in a car park would appear "*surreal*" in any other circumstances and is further emphasised by her reflection that it is something she would remember for decades and share with future generations. This reflection also hints at her optimism that life would return to normal.

Theme 2: Professional dedication

I'm just carrying on

Professionals, as key workers, were required to continue working, whether that was in situ or at home. Subtheme C considers how professionals just "*carried on*" despite the circumstances. Subtheme D examines the creativity in problem solving adopted by professionals, who took control of situations owing to lack of clear guidance.

Subtheme C -Giving more

Poem 4

Building a future

We decided we were gonna go out
just the two of us
Vaccinate our carehomes
our people with a learning disability

We did prioritize them
We did feel they were
Clinically extremely vulnerable

I was the person
That did the consent
Gave the vaccination

We felt that was very very
Important and worthwhile
It felt amazing to go in

A lot of those people have not left
Their care homes for almost a year.
They were shielding other people. (HCP12)

The poem describes how one GP and their partner went into the local community to administer the vaccine, although at that point there were still categories of vaccine eligibility, which some of the clients did not necessarily fall into. The decision to act on their behalf, to guide people through best interests decisions, when they were unable to give informed consent, was just one example of a professional having to make a decision beyond their typical professional remit. The doctor commented:

> *do you know what it was hugely emotional it was a massively emotional day and you know I had to you know it was on occasions quite difficult to give people vaccinations because they couldn't consent but for me to give it in their best interests and make sure that they were protected erm and mean that they could go out again and see people and have you know a relatively normal life was was so important* (HCP12).

This example is typical of the professionals' dedication to their clients and their welfare. However, within transition there were conflicting approaches. Whilst paediatricians were able to hold on to and support their young people for longer, when adult services were not available, Education and Social Care were adamant that young people continue to move on, due to statutory guidelines. In the context of social care, the end result was *"the backlog is so massive the demand for…all services is massively outstripping supply"* (SC01B).

In face of these disruptions and restrictions, participants carried on whilst adapting their working practices; for example one social worker commented:

> *I don't know if it's held anything up you know we still carry on and do all the things we need to do and erm we you know we would still have the same meetings erm albeit through Teams* (SC11).

Subtheme D - Creative solutions

Sometimes people found new and creative solutions within the guidelines, from the small details to overarching working practices. Several participants discussed the adjustments required when wearing masks to help young people understand, such as waving at the window before a face-to-face meeting. Sometimes people bent the rules. For example, early in the pandemic, an advocate rang a Government helpline and initially lied about a paid carer potentially having Covid in order to acquire a test, so that they could work with a vulnerable young person. Once the advocate got through to talk to someone, they explained the situation and were given the test. The advocate felt that this was acceptable and the right thing to do. Another participant drove 80 miles one day to obtain a test.

Throughout the accounts, there was recognition of the emotional impact on the professional, in that adjustments made things "*difficult*", but there was also a sense of achievement in being able to help families in these circumstances. Their dedication reflects their genuine concern and wish to help a vulnerable population.

However, sometimes they ignored the advice they were given:

Poem 5

Red, amber, green

I joined the Adult Team but
I kept my children
My working hours were just –
I don't know – they were not good.

We were told to halt assessment but
Covid wasn't going any where
We started again

> *We didn't have any direction.*
>
> *We said "unless someone tells me*
> *I can't do this then*
> *I'm just carrying on*
> *As normal".*
>
> *We started new referrals but*
> *No-one was verifying them*
> *"If we don't do it now"*
> *We knew we would be inundated*
>
> *We wrote them anyway*
> *It soon just became*
> *Part of normal life*
> *We just got used to it really.* (HCP14)

The participant talks about the assessment process, and how she continued working in order to avoid a potential backlog further down the line. These decisions were made within her team despite other official bodies stopping assessments and safeguarding visits, so it is clear professionals took responsibility for both their clients and their workflow. They also devised their own safeguarding assessment tools to triage the clients' needs, using a traffic light system of red, amber and green. Within the context of transition, another health care participant discussed the inadequacy of the available transition assessment tools, and their relevance to the PMLD community, suggesting adaptations, (ED07), whilst another participant discussed the creativity required in future planning both before and during the pandemic (ADV04). Therefore, participants were used to adapting to their clients' needs and working outside established guidelines. During Covid-19, when Government advice was not always clear, the need for people to find their own solutions increased:

> *so I'll be honest we did our own sort of risk assessments and things because we didn't have any directions* (HCP14).

Looking ahead, professionals felt that there were practical things learnt from working within the pandemic. In terms of practicalities, working from home presenting both positives and negatives:

> *I think people have found ways of working differently erm I think we are this is a pro and also a negative so we're in terms of capacity we're able to do more if you're just from home...in terms of the meetings you know you haven't got the commute and you haven't got those sorts of things but then the negative to that is <u>your day is so much longer</u> because you don't get the breaks in between (*ED09).

Whilst participants mentioned that they had become used to the ups and downs of working online (such as poor connections and interruptions by delivery drivers and pets), some acknowledged they weren’t altogether comfortable with technology generally and remote working, either by phone or even via phone calls. This admission of lack of technical expertise reveals a possible vulnerability in their role, maybe due to a lack of training, which the circumstances had placed them in. However, one participant commented on how remote working had improved communication within her team (HCP02), and another mentioned that she was able to discuss problems easily with colleagues, if they were available online via MS Teams (HCP08).

In relation to transition, they considered there were benefits, in terms of getting people together for meetings, and improving connections with other services, such as Health, who historically had not been able to find the time to attend transition meetings because of conflicting commitments.

Participants commented that online meetings were a good alternative for parents who were unable to attend meetings, especially when people were shielding. One participant discussed improvements in transition processes, introducing parents to the Adult team:

> *often we would set up a clinic and then at the last minute the Adult team would say “oh we can’t come after all” and so these patients would turn up and you know the Adult team wasn’t actually there so that’s a bit of a waste of a transition so what we did during Covid is … we did video clinic …and that worked really well actually I don’t think we’ll move back to face-to-face for the transition clinic … because we’re not on the same site [as the Adult team].* (HCP15).

The importance of time savings, and to a less extent the ecological benefits, of not travelling, was stressed by participants. One transition-focused advocate commented she was able to attend three reviews in one day, whereas previously she would have had to choose which one to attend, reflecting the pre-existing pressures that professionals faced before Covid-19. Education suggested that online meetings would also be beneficial for working parents as the time savings would be considerable

> *I had a parent who was a manager for (supermarket) it’s a lot easier to attend a meeting if it means ducking into the office for half an hour …rather than driving to the local medical centre and sitting down with people around a table* (ED17).

For parents with other children, not having to organise childcare in order to attend clinics in-person, was also cited as a benefit of online meetings. These time savings were therefore beneficial for both parents and professionals alike, and would give rise to greater accessibility and availability of appointments.

Participants felt that the parents were mainly happy to embrace the technology, although one participant mentioned that not everyone was comfortable with the technology and in some rural areas there was poor connectivity.

However, one participant commented:

> *I've only had one meeting where I've had to go to the house and we sat in the garden and social distanced because they … didn't want to do any I.T. [information technology]* (ED05).

Theme 3: Personal impact

We are being crashed

Subtheme E – Frustrated

Throughout the dataset, professionals expressed a sense of personal frustration in the context of the pandemic. This feeling may have been evoked through personal circumstances, such as professionals having to shield themselves because of health issues, which normally wouldn't have prevented them working, or through being "pinged" by the track-and-trace initiative in the summer of 2021.

Additionally, the necessity of working within the restrictions, proved frustrating: an educational psychologist commented on keeping their distance from children within a school (ED16). A social worker described not being able to work in a way that they were familiar with, such as getting down to play with a child on the floor; she stated:

> *"it felt like doing your job with one arm tied behind your back for a lot of Covid I think you know a lot of your resources and skill were taken away"* (SC01B, 2022).

This sense of restricted practice was particularly prevalent, and professionals felt this in a personal way:

> *it has made a lot of us feel erm (.) like we just don't have very much we can offer them? ...anymore that that feels quite quite sad when I think we are usually a service that is right in there of "what can we do how can we help?"* (ED09).

The emotional impact underlies their work, so that it was not just that they felt like "*one arm was tied*" but that it was *"really unpleasant to see people struggling"* and *" it's it's really uncomfortable to see families not doing well" (SC01B).* There was a sense that they were doing as much as they could but felt they were failing people.

Furthermore, frustration was expressed when they their efforts were unrecognised and unappreciated within the wider community.

Poem 6
A slap in the face

I was able to go in
  and do a handover
  the first week of August
Plonking my daughter
  in their office
  with her iPad
I handed over the memory sticks
Sorted them out

We stayed open
We made places available
  for vulnerable students
We just stayed open
  through half term
  through the Easter holidays

It feels like a bit of
  a slap in the face
People go on about teachers
Sitting at home with
All the schools closed
  during lockdown (ED17)

In this poem, the teacher reveals her dedication to helping the transition of a young person with PMLD. Not only did her school, and therefore the staff, work throughout the holidays in 2020 when there were lockdowns, she also was caring for her own children. She took her daughter on visits to a new setting for a school leaver because she had no other option. When normally, teachers would be on holiday in August, she was still facilitating this transition with the handover of relevant information. The image of her own daughter being put in an office with an iPad for entertainment, suggests the personal sacrifices professionals made during this period. The lack of recognition of these sacrifices is described as a personal physical shock.

Subtheme F - Family/work crossover

The emotional impact of the pandemic on the participants' own working patterns was also reflected in their reactions to working from home. The difficulties of home schooling were mentioned by participants. Children of key workers were sent to nursery during lockdowns, or looked after by fathers who were working from home. These solutions also came with emotional costs, as children and parents clashed over school/homework (SC01B, ED17); one mother commented she was unable to combine home schooling with full time healthcare work:

> *the school knew it but I just can't part do this* (HCP14).

Another commented how she was "*battling*" her "*way through...[an] online assessment tool whilst trying to get her [daughter] through her maths"* (ED17).

In both cases the priorities were considering safeguarding vulnerable young people over their own children's needs.

The home environment was also challenging for some:

Poem 7

They wanted me to work from home...

"No" I said "I'm not, I'm not
having this in my home
I'm not".
Yet I have got plenty of rooms
I could use but
I don't want it in my home.

You've got to separate it

I need I need the drive home
I still think about it
All the time but
No, I don't want it in my home.
It has to be separate for me.
It is in my head enough. (ADV06)

This poem describes the view of a participant who had previously cared for a close relative at home, which profoundly affected the way she felt about supporting families and co-ordinating with service providers during the pandemic. She cared deeply about the young people she was supporting but felt that she did not want to bring that element of emotional labour into her home. Her dedication is reflected by "*it is in my head enough*" showing that she has internalised the issues and thinks about them, but does not want to talk about them within this environment, despite having room to set up a home office.

This degree of discomfort was echoed by a social worker:

> *SC01B: social workers would say it's really difficult being in my home having sometimes very angry families talking to you that I can't then go home from that I can't escape that*
> *I: yes*
> *SC01B: I can't leave at work that it's in my home and that's the same for families isn't it... in that you have a difficult conversation with somebody and it's in your home you can't park it in the meeting room emotionally as we do sometimes* (SC01B, 2022).

However, she recognised that this discomfort is also emotionally experienced under normal (non-Covid-19) circumstances by families. She reveals the social workers' ability to "*park*" difficult conversations and distance themselves from the emotion, when it is in a formal work setting, whereas parents may not have that skill.

Summary

We can do no more

Exploring the general context of working during Covid-19 has highlighted the impact the pandemic specifically had on transition processes. Isolation came in various forms: the natural isolation that a family with a young person with PMLD felt before the pandemic was exacerbated by the self-isolation imposed by fear of the impact of the disease, as well as isolation by Government guidelines. The imposed isolation meant lack of social contact and sometimes led to the deterioration of behaviours. Additionally, delays in assessments and the fall in staffing levels observed by participants also impacted successful transitions.

Looking forward, there are two key observations in terms of processes relating to transition. Participants felt that the new ways of working with technology were well established and would continue:

> *I think it will be something that continues definitely* (HCP14).

Secondly, the future of social care provision was uncertain. The parental fears about the availability of services, witnessed by one advocate early in the pandemic (June 2020), became a reality eighteen months later, when Social Care were expressing concerns about supply and demand (Jan 2022) for social support:

> *we don't have the manpower to do it at the moment and that will come back it will come back* (SC01B, 2022).

The final poem, presented in the form of a tanka [16], summarises the angst felt by a social worker, as she acknowledges that young people are lacking prospects, and expresses her desire to be able to help.

Poem 8
Opportunities

Young people who want,
You want to be able to
do more, give them more
Be able to give them more,
Opportunities (SC01B)

Professionals barely acknowledged the emotional impact of general transition working; only one social worker commented that having young people "*knocked* off" their caseload "*that's like emotionally for us that's huge as well a lot of the time"* (SC10). However, focusing on working during Covid-19 demonstrated that professionals were heavily involved in supporting families, and revealed a tension of balancing practical solutions with the emotional impact felt by both families and professionals. Also, within this context the focus seems to shift from the person-centred planning for the young person to working with parents, who were seen as vulnerable, isolated and lacking support whilst protecting their children.

An advocate echoed the sense of disruption, but also hope in a wider context. She felt that, in order for support to improve, the working conditions of key workers needed to be acknowledged in a more concrete way than the "Clap the Carers" gesture prevalent in 2020:

> *so a good day I think we've got an opportunity here and if people were serious about you know about clapping and valuing all our key workers erm be they bus drivers delivery drivers nurses and care workers and personal assistants let's let's make the most of this little window of opportunity we've got (..) so on a good day I think we could effect change and then when I am feeling a bit down I think we might be even worse off* (ADV04).

Her thoughts reflect a wider understanding of the pandemic, which brought adjustments to family situations, working practices as well as societal appreciation and expectations.

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[16] Tanka – a Japanese poem with five-line, 5/7/5/7/7 syllable count formation, which I have shortened for emphasis

Discussion

The aim of this study was to explore the impact of Covid-19 on the professionals who work with young people with PMLD and their families at transition to adult services, in order to understand the working relationships between professionals and parents, and consider what was learnt as a result of the pandemic.

Findings suggest that during the Covid-19 pandemic, parents were isolated with their vulnerable offspring; sometimes this isolation was enforced through lockdowns and shielding although at other times parents chose to withdraw from meeting professionals. Consequently, professionals acknowledged the parent-child interdependence, and turned their attention to the parents, who were often perceived to be acting as gatekeepers. They expressed concern over the parents' wellbeing in these circumstances. Whilst professionals were also affected personally by working during Covid-19, they often went to extraordinary lengths to support families. Covid-19 also affected transition processes, but some new working practices were adopted with success. These findings are discussed in light of the Ecological model, with particular reference to the Individual (Theme 1), Microsystem (Themes 1&3) and Mesosytem levels (Theme 2&3).

Application of Bronfenbrenner's Ecological Model and Twigg and Atkin's Typology of Caring (1994)

In the previous chapters the Chronosystem has represented time as the young person's life course, and the unknown future (Chapter 3) as well as a disruption of time, i.e. the hiatus of transition, between their existing life (Chapter 4), and the planned future life. In this chapter, time is again presented as an unknown future, as well as demonstrating a hiatus in the normal progression towards the future, but because of the disruption of Covid-19. This is the context the participants find themselves in, beyond the specificities of transition. The future wasn't just unknown for the families of young people with PMLD, Covid-19 was a universal disruptor as suggested by Poem 1. Within this discussion relating to professional and parental relations, the emphasis is on the Individual, Micro and Mesosystems. The context of Covid-19 and government restrictions are reflected by Macrosystem and Exosystem, are demonstrated in the model below, but not discussed in depth (Fig. 3).

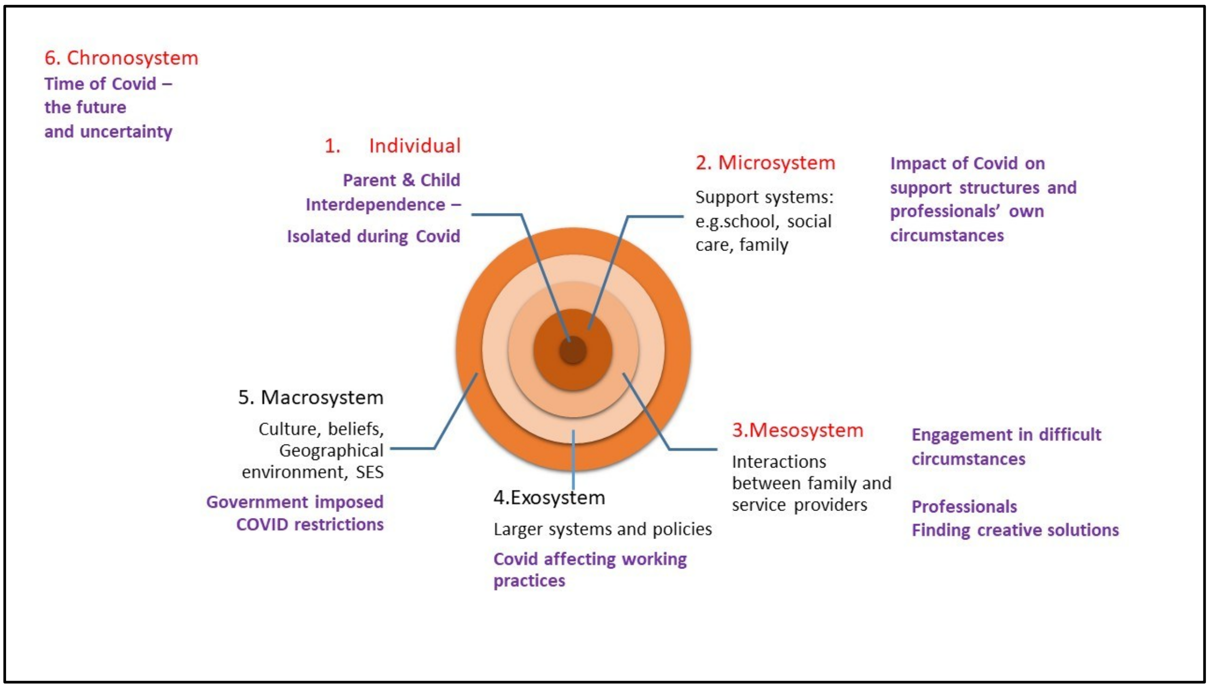

Fig. 3 Showing the themes and key findings mapped onto Bronfenbrenner's Ecological model

Individual

Within these accounts, the parents and their families are seen to be isolated, and sometimes "*stigmatised*" (Poem 3). Parent & child interdependence is therefore clearly demonstrated and acknowledged by the participants. However, as discussed in Chapter 4, professionals sometimes argued that the young person should be seeking independence from their family, and that parents sometimes held them back. This conflict in views between interdependence and independence suggests a shift in positioning during Covid-19. Whilst in theory professionals adhere to the person-centred ideological agenda, in practice they recognise parents play a vital role in supporting their child. Furthermore, professionals also showed admiration for and empathy towards the parent as demonstrated in Poems 2 and 3.

Professionals also recognised that the isolation made the parents vulnerable, owing to the demands of extreme caring duties, without regular sources of support. The parents themselves were subject to safeguarding concerns. Professionals recognised the parents had care needs of their own, which should be met under government legislation, such as the right to a Carers' Assessment or the provision of respite. These needs could not be met because on the restrictions imposed by Covid-19.

Therefore, the parent-child dyad remains isolated at the centre of the model.

Microsystem

Covid-19 also had a huge impact on the personal lives of the professionals who work with families. The accounts demonstrate how they had to adapt their own lives, for example by home schooling, taking their children to meetings, and working from home. Poem 6 not only reflects the personal sacrifices made, but also the frustration that those sacrifices were not understood and acknowledged by the wider public. Poem 7 reflects a very personal and emotional reaction to working from home. In this sense, the professionals were therefore also isolated within their own systems, with their personal and working lives merging and clashing at times. Difficulties in attaining and maintaining a life-work balance were evident, which may in turn have implications for the individuals on their psychological well-being (Pountney et al, 2022).

Mesosytem

The Mesosystem is the point where the Microsystem meets the Individual, and was a key point of the Covid-19 experience. As discussed above, parental isolation was even more prevalent during the pandemic, but more visible, and more relatable in some respects, to the participants in this study. The impact of working during Covid-19 on the personal and working lives of professionals influenced their understanding and empathy for parents, as discussed above. Parents and young people who were already in the system, but unable to access support, were monitored by Social Care and Education and, at times, this increased the closeness between the two groups, bringing a better understanding.

Poems 4 and 5 demonstrate how professionals reached out, giving more than their job required and at the same time being emotionally involved and affected. The resulting burnout within the NHS and social care has been observed, particularly since the pandemic. At times, the effects of burnout may be life-threatening in terms of physical and mental health (Whitehead et al., 2024).

The importance of seeing both young people and their families face-to-face to assess their needs accurately was stressed in Chapter 4. As Covid-19 restrictions often made this proximity impossible, creative solutions were sought, and remote consultations became the norm. They were seen as a positive development in terms of accessibility to both staff and patients and clients, with time saving benefits being stressed. Within the process of assessing and planning for the future through remote technology, professionals had to rely on and listen to parental opinions. Therefore, as Heath et al. (2017) found, the importance of close working relationships and mutual trust are critical to supporting families effectively during transition, in order to achieve effective planning and allay parental fears.

Sometimes remote working was also challenging for all concerned, with lack of accessibility, digital poverty and sometimes lack of technical understanding. Some social care and health care professionals also found technology challenging. Additionally, the limitations of remote consultations with non-verbal and learning-disabled young people was stressed too, which in turn limited their role in the transition decision-making process. This study echoes the findings of Pascoe (2021) which highlight how relationship-based practice was affected by remote working during Covid-19. The areas of relationship building, non-verbal communication and acts of kindness were all impacted.

Twigg and Atkin's Typology of Caring (1994) defines carers as

- *resources*
- *co-workers*
- *co-clients* equal in status with their own needs being met
- *superseded carers* by either independence for the young person being achieved, or by an inability to continue caring.

Within this study, the parent was isolated, supporting their child with PMLD and therefore may be positioned as a *resource*. The data also suggests that, although this role was dictated by circumstances, professionals felt parents often chose not to interact with them as a way of safeguarding their child. The role of parents as *co-workers* was therefore diminished, in some aspects, when services were withdrawn. As the pandemic progressed, and working practices were adapted, parents reasserted their advocacy roles and thus maintained their position as *co-workers*. Additionally, there was a raised awareness that parents have their own needs, and therefore they might be identified as *co-clients* although their needs for support were not met, especially with the cancellation of respite. The *superseded carer* role, which was apparent within the ideological framing of Preparing for Adulthood (discussed in the Chapter 4) regressed in this period of reduced service provision, and transitions were postponed. The parent was still the position of a *resource* and a *co-worker.*

The role of the TRAG

The TRAG group were consulted in all stages of the research, but because of Covid-19 restrictions were unable to meet in person for some time. A meeting was held online in September 2021 to discuss the finding of this study. During the meeting, one member discussed her own experiences of being unable to see her daughter, who had considerable health issues, in person for a year. The group member recounted how when she eventually had been to see her daughter, she systematically checked her and managed to address the issues, with a positive outcome. She also recounted how a GP had stated how frustrated he was that professionals had previously not listened to the mother's point of view. Consequently she was identified as an essential caregiver for her daughter, and was given access to her daughter in her care home, but her husband was still not allowed to visit his daughter due to the one-person policy restriction.

Although this account does not relate directly to transition, it does reflect the issues around life after transition, when young people achieve "independence". The story reflects not only the complexity of caring for a young person away from home within the Covid-19 situation, but also the importance of acknowledging continuing parental input and expertise. In this respect, the TRAG brought insight to the fundamental issues of transition.

Reflexivity – on being a parent-carer during Covid-19

In June, after the first lockdown, I asked a self-employed advocate to take part in my professional study (referred to here as the "first interview"). In return, she asked me to take part in some research she was undertaking, related to the experiences of people whose family members were shielding. With her permission, this "second interview" was transcribed by me and added to my corpus of bracketing interviews. The exchange across the two interviews revealed how we both felt being in the thick of the pandemic. She shared her experiences of working with families and support workers; and I shared my family experiences, how I found "working with" the care home, and the regulations at that time.

These interviews were undertaken when testing was largely unavailable, there were no vaccinations and the public were still "clapping for carers". Rereading the interviews nearly five years later, I am struck by the emotional content of those interviews, and how much about the restrictions, fear and the language of the Covid-19 experience, has either been forgotten or normalised.

At the time of the interviews I had not seen my son in person for several weeks. Since the beginning of the first lockdown care homes were subject to different restrictions to the general public, which in some instances remained even into 2023. I took a photograph and used it to illustrate the time:

> *K: I have this little jar of these shells on my desk and erm about, after about a month I'd sort of emptied some out and counted out the days that … I hadn't seen him, which was about thirty or thirty one, and because they're tiny shells, it looked so insignificant, and then yesterday, when I was sort of thinking about this, I counted them out again and sort of added them up to, … there's about ninety shells there and, in that photo, and it sort of looks like a little heap, but it's that feeling of just adding a little grain of sand, isn't it, to a pile, and so it's sort of beginning to accumulate into something quite, you know, more significant, really, than it felt at the start*. (Second interview)

For me the importance, and poignancy of the shells, is that they are a reminder of my own happy childhood holidays in Scotland, when we were all together as a family. Using them in the different context of enforced separation made me think of the accumulation of time – each day was individual, different, but passed.

The use of shells, which were found dispersed on a wide sandy beach, also made me recall the interviewer's own words of us being "*in a tsunami*". Rereading the excerpt invariably makes me think of the goodbyes at that time, of the uncertainty of when we would see people again, and if we or they would even survive.

During the first lockdown, the support workers stayed with my son and the other residents, and in some cases did not see their own families for seven weeks. I commented on this personal sacrifice during the second interview. I believed then, and still believe now, that this sacrifice gave us all parity in these extraordinary circumstances. However, as time went on the balance shifted. When lockdown ended, we, as parents, were still not allowed to see our children, because they were in a care home, but the support workers were allowed to go between their homes and families and work.

In the first interview, I sat in a position of researcher. However, occasionally, I felt I struggled to maintain that professional position. At one point, I had what I described later as "*an outburst*", when I expressed my views on how people were going to meet family members again,

> *K: I think everyone needs to start having discussions I can understand that sort of like "oh well there's a lockdown" for three weeks but when you are talking three months everyone needs to start looking ahead don't they as to*
> *PA: yeah*
> *K: what happens*
> *PA: yeah most definitely and it's erm weighing up mental health against physical health.* (First interview)

I discussed how my son was spending his days, but then I pulled myself back to continue exploring my participant's views on working during Covid-19. I retrieved my position as researcher. On the other hand, I was situated very firmly as a parent within the second interview, which gave me the opportunity to explain what I was upsetting me:

> *PA: Yeah. So that's been some of the positives, what have been the hardest things for you?*
>
> *K: I feel increasingly frustrated now that I can't see him,... there has been very little communication about the way forward and no engagement with us as parents as to what we'd like or how we think things are going to go...and I <u>don't want to sound critical</u> because they've been so good at looking after him and protecting him and they kept him happy and, you know, so, as I say, some good stuff's come out of it.* (Second interview)

At the time, there was paralysis in the system because no-one really knew how to interpret guidelines. I had to accept that my son's care home saw me as posing a risk to his health (I was denied access because "*he might hug me*"), and by default the other residents and his carers.

I am aware that this experience may have coloured my interpretation of the data by bringing my own understanding into focus. My relationship as a parent-carer co-working with professionals who looked after my son felt very uncomfortable at times, as there was an imbalance in the power dynamics. Covid-19 disrupted established relationships, which during other circumstances worked smoothly. This has led me to wonder if those instances when I felt I might have overstepped the mark in the interview process for this study (mentioned in Chapter 4) were overshadowed by these personal Covid-19 experiences. Although I had prepared to set aside my own transition experiences through reflective thinking at the outset of the project, nothing could have prepared me for these circumstances.

In November 2022, I wrote in my reflexive diary

> *"It's almost like a war zone – you are in this war, looking for support & then COVID drops in like an extreme bombardment – disrupting the normal ongoing fight."*

These reflections have made me wonder more broadly about how times of stress and uncertainty, such as transitioning from one service provider to another, can produce these inequalities in power situations, which in turn give rise to further stress for parents. However, what I was also able to understand through my personal experiences, was the personal sacrifices made and the incredible dedication of the professionals who work with families.

Strengths and limitations

A strength of this study is the breadth of experience through both the variety of participants and the time scale of the project. Although this was not a longitudinal study in design, the length of time that it took to recruit participants allowed me to observe the phenomenon developing over two years. Only one participant was interviewed before the arrival of Covid-19 in the UK, and they undertook a second interview in January 2022. Consequently, there was mixture of interviews when the experiences were very current, and others that had greater retrospective insight. Therefore, one might argue this aspect of the professional study adopted a "line of argument" approach to the developing Covid-19 story. This heterogeneity of experiences was commented on by the TRAG - for example, the group discussed how a school teacher seemed organised working within guidelines, whereas the a health care professional seemed to be working in a crisis response mode. A shorter timeline might have produced a more homogenous dataset, but as NHS staff were redeployed to other departments, it was necessary to delay data gathering in order to represent the healthcare sector.

As in Chapter 3, poetry was used to illuminate individual voices and distil experiences. The focus on individual narratives not only reflects the range of emotional responses to the challenging environments participants found themselves in , but also highlights those personally challenging incidents.

Conclusions

This study builds on the findings of Chapter 4 in exploring the professional-parent working relationship further. In particular, the study has highlighted the isolation of parents during Covid-19. Analysis revealed that the professionals acknowledged the interdependence of the parent and their children, which is at odds with the more ideological beliefs of independence, discussed in the previous chapter. Parents were also seen to be extremely vulnerable and sometimes at risk as a result of their caring duties at this time. The professionals therefore acknowledged that parents have their own support needs, which often went unmet during Covid-19.

The professionals were found to be dedicated to the families they supported, wanting to "*be able to give more*", generating creative solutions and revealing their own emotional vulnerability. Despite their best efforts, restrictions during and as a result of Covid-19 meant that transition processes were often disrupted.

The following chapter returns to focus on the parents. The following empirical study will consider in particular parents' understanding and recent experiences of transition, with specific reference to their support networks.

Chapter 6

Exploring the experiences of parents of young people with PMLD at the transition to adulthood through Interpretative Phenomenological Analysis

Introduction

The previous chapters have highlighted the difference between the parent and young person as an interdependent unit (Chapter 3) and the professionals' ideological vision of an independent future for that young person (Chapter 4). There is recognition of both the practical and emotional problems facing parents during the transition process (Chapter 4), although limited acknowledgement of their needs as individuals. Findings of Chapter 5 however, suggest professionals focused on parents as individuals during Covid-19, recognising their need for emotional and practical support.

This chapter returns to the parental experience of transition (Fig.1). Jacobs et al. (2020) recognised the key role that parents play in the transition decision-making process, working with other stakeholders. However, they also found that parents are unique among those stakeholders in discussing transition in terms of future orientation. It is therefore important to understand how parents experience transition, both as an advocate for their child and as an individual looking towards altered future lives.

Data gathered from parents whose offspring were at different stages of transition are examined, to build a composite account of the process. Findings provide the context of transition in the lives of young people and their families, as well as examining experiences and future hopes. Key events of transition are presented within a longitudinal framework, to explore the impact of transition processes, with a view to identifying sources of support. The findings are considered through an interpretative lens, in conjunction with Bronfenbrenner's Ecological model and Twigg and Atkin's Typology of Caring (1994).

Research Question

What are the experiences of parent-carers of young people with severe and profound and multiple learning disabilities and complex health care needs during the transition to adult services?

Aim

To explore parents' individual experiences of transition at key time points in the process.

To explore the support networks available to both child and parents, in order to identify parents' specific support needs.

Methods

Research Design

The current study mirrors the design of the qualitative poetic synthesis (Chapter 3) by focusing on parents' experiences (Fig. 1). It also builds upon research by Jacobs et al. (2020) in closely considering individual transitions. A longitudinal element is introduced by mapping the three-stage process of the "parental journey through transition" i.e. preparation, the journey itself, and the landing, that is life immediately after transition, (Nguyen & Gorter, 2013) onto the research design (Fig. 2).

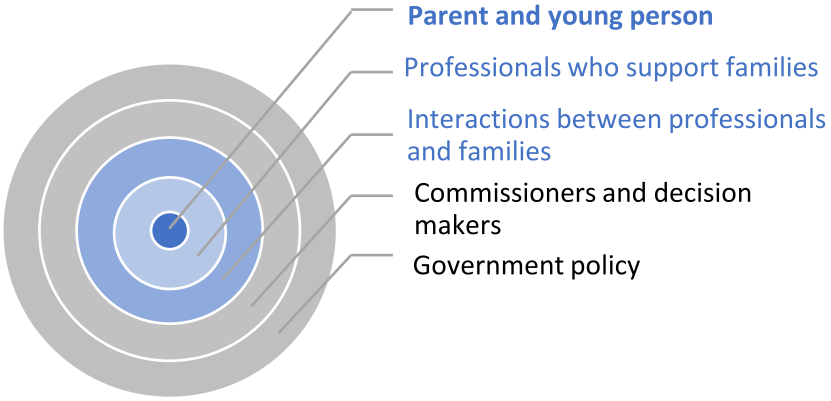

Fig. 1 – Model showing the participant focus of the study

Participants

Five parents (four mothers and one father) of young people aged 17 to 22 took part between November 2021 and March 2023. They were spread geographically across Midland and Southern counties of England (Table 1).

Participant/ Age	**Child /Age** **(at time of first interview)** **Siblings**	**General Diagnosis/cause**
Juliet, 52 married to John	Joe, 17 Younger sister	SLD. Cerebral palsy, Birth trauma
Peta, 53 married to: Phillip, 57	Paige, 18 Younger brother	PMLD, cerebral palsy Birth trauma
Maryam, 43 divorced	Anya, 19 Two younger siblings	PMLD Rare genetic syndrome
Isabel, 56 Partner Ian Divorced from Sam's father	Sam, 21 Half-brother on father's side	PMLD, cerebral palsy Birth trauma

Table 1 – Participant profiles

Inclusion criteria

The initial criteria was for parents of young people with PMLD and CHCN approaching transition, i.e. within the twelve months of their 18th birthday or in their last year of school. However, owing to recruitment difficulties during Covid-19, the criteria was extended to include families of young people who had recently gone through transition, as well as those with severe learning disabilities (SLD) and CHCN. TRAG members felt that the parental experiences of this group would be comparable with the initial inclusion criteria due to the level of support they need.

Recruitment

Recruitment was undertaken on Twitter (X) and through learning disability networks (see Appendix 1). Ten identified people were invited to participate, with five people taking part from four families.

Data Collection

Participants completed demographic questionnaires about their child's disabilities and the services they accessed before the first interview (Appendix 5). This data provided background for the interviews, curtailing the need for parents to recount full medical histories, and thus focusing the interviews on transition processes.

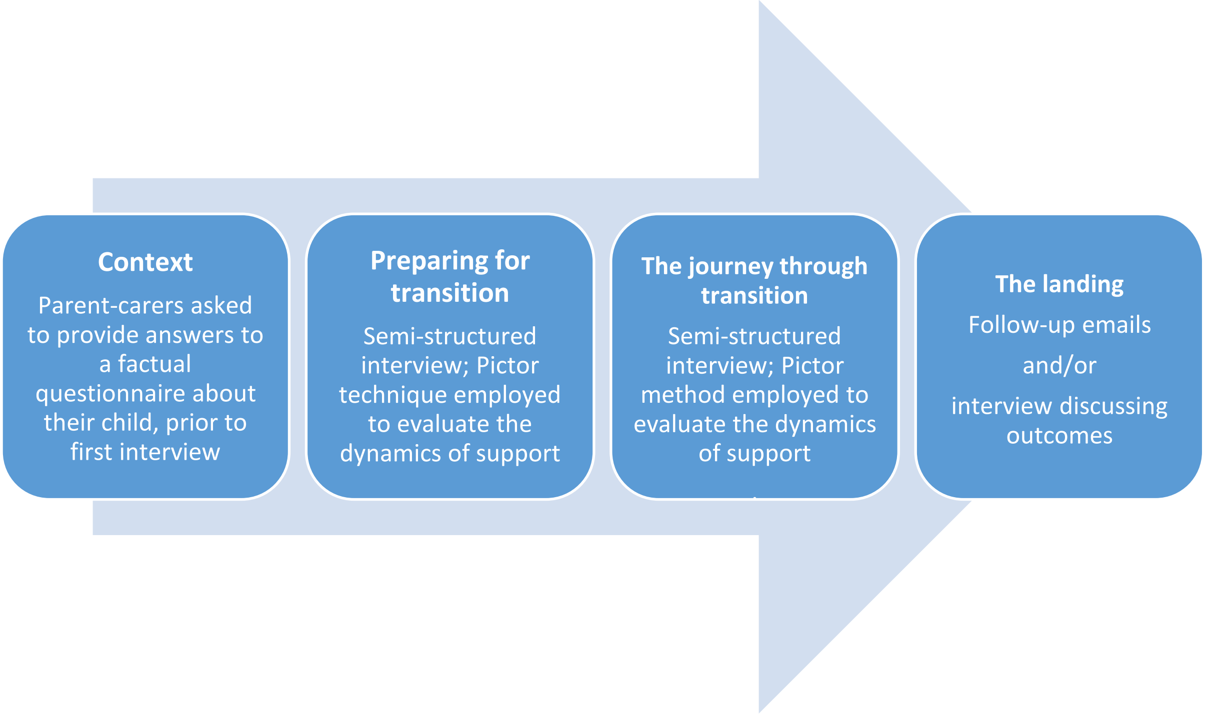

Fig.2: model showing data gathering in relation to transition journey (Nguyen & Gorter, 2013)

Participants undertook a first semi structured interview, in conjunction with Pictor exercises, a relational mapping technique (see Chapter 2). They were invited to take part in a follow up interview six months later (Fig. 2). Two parents were interviewed once; two interviewed twice, and one participant was interviewed three times. Interviews lasted between 2 hours 57 minutes and 28 minutes generating a total of 12 hours 8 minutes of audio-recordings. Three participants sent follow-up emails with summaries of their child's progress (Table 2).

Transition points in relation to ages:
17/18 = medical/healthcare transitions
19 = leaving school & education transitions
21+ = leaving college & transition to supported living

Child Age	**17**	**18**	**19**	**20**	**21**	**22**
Child/ Parent						
Joe/ Juliet	**J1** In person	**J2** Phone call	(email)			
Anya/ Maryam			**M1** online	(email)		
Paige/ Peta		**P1a** in person **P1b** online	(email)		(email)	
Phillip			**Ph1** Phone call			
Sam/Isabel					**Is1a** online **Is1b** online	**Is2** online

Parent initial and number = interview timing in relation to age
1= first time point interviews
2= follow up interviews

Table 2 showing the timing of interviews in relation to the children's ages and transition points

Visual methods

Pictor Technique

Each participant was sent information before the first interview. Materials were sent to those attending online. Each participant produced two Pictor charts in their first interview. This exercise involved two stages.

- Using the arrow shaped Post-it notes, and A1 sheets of paper, participants were asked to place their child at the centre, and then write on Post-it notes who supported them through the transition period, placing these in relation to the child on the paper. They discussed the charts with the interviewer.
- The participants were then asked to repeat the process, placing themselves at the centre, exploring who had supported them.

Participants were given quiet time during the interview to undertake the exercise but continued to develop the charts whilst talking.

- Peta and Juliet compiled charts during in-person interviews.
- Isabel created charts during her first online interview, sharing by holding them up to the camera, as well as taking photographs and sharing these online. She produced another chart before the second interview and shared this online during the interview.

- One participant, Maryam, chose to do her chart before the online interview and sent photographs of the charts beforehand.

Photographic methods

At the beginning, parents were also invited to show photographs of their child, to bring them into the heart of the research. Participants were also given the option of taking a photograph that symbolised the transition process after the interview. Two were produced but only one was eligible for inclusion, due to needing to protect children's anonymity.

Data Analysis

The demographic questionnaires were studied, and individual summaries of health and social history written. All interviews were audio recorded and anonymised, including names, places and services, such as schools and hospitals.

Pictor charts were photographed either by the researcher, or by participants who took part online. Where necessary, charts were reconstructed to ensure anonymity, and re-photographed. Charts were referred to during data analysis.

Participants' accounts were analysed by employing interpretative phenomenological analysis.

Interpretative Phenomenological Analysis (IPA)

IPA aims to examine the individual's lived experiences and meaning-making of the phenomenon under study, here the transition processes involved in moving their offspring from paediatric to adult services. By examining parental meaning-making within the accounts we can build a fuller picture of their experiences, the roles they fulfil and support networks within transition.

Recruitment produced a heterogeneous dataset, with young people at different stages of their transitions. Each participant's account represents a stage of the transition journey. These stories are examined through a longitudinal phenomenological lens, reflecting the way they were accessed (Wanat et al., 2025). Some elements from some participants are retrospective, whilst others are more contemporaneous with the child's transition. As a composite group of accounts, they contribute different aspects of the same experience to produce an overall representation of transition (Larkin, Shaw et al., 2019). This approach to building a picture of transition may be compared to the "line-of-argument approach" used with the data in the poetic synthesis (Chapter 3) (Noblit and Hare, 1988).

Nonetheless, the analysis methods employed were as described by Smith, Flowers & Larkin (2022).

- Interviews were listened to multiple times for familiarity and transcribed.
- Transcripts were read and reread, and exploratory notes were made, in conjunction with reflexivity on my reactions to anecdotes and thoughts expressed by the participants.
- Exploratory notes were examined to develop Personal Experiential Themes (PETS) and these in turn were reviewed for meaningful groupings.
- The clustering of PETs was devised by using Post-it notes on large pieces of paper (see Appendix 5) to consider commonalities and divergences.
- Individual participant summaries were written up.
- Group Experiential Themes (GETS) were generated through examination of the PETS and summaries (Appendix 5).
- Further interpretation took place within the writing up process.

An inductive approach was adopted in developing the PETS. The analysis of the first three participants' data showed that themes from the poetic synthesis (parental/child interdependence; sharing responsibility and the future) carried clear relevance to this dataset. Following a discussion with the supervisory team, it was decided to focus on these themes, while analysing the last two participants' data. This approach has previously been adopted by Toye et al. (2021) in an innovative hermeneutic phenomenological study, where *a priori* themes from a qualitative evidence synthesis were used as "sensitising concepts". Further analysis during the writing up phase led to a more focused development of these themes.

Poetry

At the beginning of the interviews, parents were asked to describe their child's character and what they enjoyed doing. This exercise served not just as an icebreaker but also to understand the strengths of the young person. During the analysis process, these descriptions were taken and adapted into poetry in a similar method used in Chapter 5. Retention of the participants' words was considered central in capturing the parents' perspective of their children.

Results

Interviews revealed that there is no one single transition at a single time point. Transitions were spread across the services, with different authorities and individuals working within those authorities adopting a variety of approaches. The main transition points discussed by the parents are outlined below in Table 3.

Service **Child (age)** **Parent**	**Education**	**Health Services**	**Social Care**
Joe (17) Juliet – mother	Still attending school; drama course at specialist college being considered	Awaiting spinal operation for scoliosis; approaching other health transitions	Handover from Disabled Children’s Team to Adult Social Care under way
Paige (18) Peta – mother Phillip - father	Home educated; attending college one day a week. Transition from school to these services	Healthcare transition being overseen by Paediatrician; no change to some self-funded services, such as physiotherapy. .	Care team established at home (not social care funded); few age-related transitions
Anya (19) Maryam - mother	Finished school and awaiting award of place at residential college (preparation for tribunal)	Kidney transplant required transition to adult services in preparation for operation. Resultant shielding affecting other health related transitions Continuing Health Care funded carers at home.	Respite ended and awaiting new placement
Sam (21) Isabel - mother	Finished residential college, having transitioned from school to college when 18	Staged healthcare transitions relating to college/supported living locations and parents’ house moves	Transition from residential college to supported living

Table 3 Outline of the main transition points discussed by the parents.

Thematic findings

***"His going to college was as much about him learning to live independently as also us learning to live without him 24/7"* (Isabel)**

Three themes were identified, considering how parents and their children are encouraged to move from entangled to disentangled lives. These themes focus on parents' own transition journey and the parental positioning within their child's move from childhood to adulthood (Table 4).

Theme 1 considers the context of transition within the young person's life, and sources of parental support in preparation for transition (Looking Inwards- Protection). Theme 2 presents a sequence of barriers that parents faced during transition and the support they had at this specific point in time (Looking Outwards - Negotiation). Theme 3 (Looking Forward – Future) describes the experience of post transition, when parents look forwards to the future, considering independence for both child and parent (Table 4).

The three themes were considered in relation to the position of the parent in the world they inhabit. Within the account that follows, I consider the orientations of the parent to the child, and how these orientations are at times disrupted by external forces. I examine the contexts of the parent and the child, what those reveal about the concepts of dependence and independence, person-centred caring and imposition of external ideologies within the transition framework.

To add greater depth to the analysis, the symbolic role of the young person's bed, was examined. Sarah Ahmed (2006 cited by Smith et al., 2022) suggests that meanings become clear when we examine and understand our *orientation towards* an object. This phenomenological approach originates from Husserl's consideration of *intentionality*, the relationship between an object and our conscious consideration of that object. Here, the bed is seen as not just a place to sleep, but an object of belonging, which is used in a variety of ways, in different settings. The positioning of the bed as something near to hand, or distant (such as in a hospital or respite setting) is also discussed. This interpretative account highlights the intense caring of the parental role, and the disruption that transition causes to that role.

Theme 1

Looking inwards: protection

Preparation

- **Subtheme A: Vigilance & Protection: *“everything... revolves around her and her health”***
- **Subtheme B: Supporting roles: *“Sam has this ability to gather up people around him”***

Theme 2

Looking outwards: negotiation

The journey

- **Subtheme C: Navigating multiple transitions:*“it’s all these changes it’s endless changes"***

Paige, Peta & Phillip -	A planned transition
Joe & Juliet -	Planning surgery
Anya & Maryam -	Planning life after surgery
Sam & Isabel -	Planning life after school and college

Theme 3

Looking forward: vision

The landing

- **Subtheme D: Disentangling: "*this last chance she has to learn and to be independent*"**
- **Subtheme E: Parents planning their future: *us learning to live without him 24/7 as well***

Table 4 Table of themes identified in the Interpretative Phenomenological Analysis

Theme 1: Looking Inwards: Protection

Transition was experienced as a stage of life which parents had not expected their children to arrive at. It was therefore another significant hurdle to overcome, amongst lives interrupted by operations and care challenges. Theme 1 explores the context of the parents' care and protectiveness (Subtheme A) and considers to whom parents turn for support at home and on a personal level (Subtheme B).

Subtheme A

Vigilance & Protection: "everything kind of revolves around her and her health" (Maryam)

Parents described being necessarily hyper-vigilant and protective from the time of their child's birth. Isabel describes the level of intensive intervention and support around both herself, and Sam, when he was a newborn baby. There had been birth complications and Sam was not expected to survive. Coming home for the first time was difficult:

> *The first 13 or so weeks Sam was in a hospital bed and you had that routine of visiting and talking to the nurses and you got people you could speak to and then you come home and you're totally on your own and that was just really really tough* (Isabel Int1b[17]).

The image of the hospital bed suggests Sam was very poorly. The bed is also a focus of care, where a newborn is tended, supported, and fed. Eventually Sam was sent home and his parents moved from being supported, to being alone. While the homecoming might ordinarily have been a time of joy, instead Isabel felt abandoned. The bed at home which should have meant that Sam was well, served as a reminder of the dangers in being a novice looking after a tube fed child. Sometimes Isabel felt that *she* was being monitored, which she found uncomfortable:

> *The being checked at home thing definitely happened within the first six months of Sam coming home from hospital where the feed nurse came and said "Oh can I see how the pumps set up in Sam's bedroom" and I was like "Okay" yes, you know but ... there was a definitely was an awkwardness to the request that just stood out* (Isabel Int1b).

Despite the odds, Sam survived into adulthood. Isabel sums up this achievement

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[17] Quotations in the Results section are followed by an interview reference number, as shown in Table 2. The table shows where the young person was in the transition process when these interviews/email exchanges took place.

> *In the early days we were told that Sam wouldn't survive erm what was it two hours two days two weeks two months two years and now he's going to be twenty-two (laughs)"* (Isabel Int1a).

Even though Isabel laughs, there is a backstory of vulnerability; a child fighting off a series of illnesses against the constant threat of death. Additionally, an underlying tension in the relationships with nursing staff, who were there to help, but also to monitor, was established early in Sam's life.

A similar example of progressive survival and resilience was used by Peta's legal team when suing the NHS for a financial settlement when Paige was young:

> *Our legal team obviously wanted annual payments because they said "Well she's already she's already managed to get over the first two weeks then the first month then first winter" you know every time they say this is it and she's still going* (Peta Int1a).

Paige continues to defy the odds, despite overcoming a series of illnesses. While this is seen as a positive progression, there were negative progressions too. Juliet described how Joe's current condition has spiralled from a brain haemorrhage at birth into hydrocephalus[18] and other linked conditions. His cerebral palsy and epilepsy resulted from brain damage following the brain haemorrhage, and his scoliosis is "*linked to the cerebral palsy"* (Juliet Int1).

The complexity of Joe's conditions requires constant vigilance on Juliet's behalf and has led to multiple hospital appointments and admissions. Like Joe, Anya has a range of conditions which meant multiple hospital visits. Operations included day surgeries, "*seven or eight*" major surgeries, such as a spinal fusion, when "*we were in hospital for about six weeks" (*Maryam.Int1). Her use of the pronoun "*we*" indicates the impact of these visits to hospital affected the whole family not just Anya; Maryam had two younger children to look after as well.

> *I think my younger two have grown up in that kind of environment ... so until they were both in full time school every time, I went to the hospital they were with me* (Maryam Int1).

Children's hospitals therefore became a familiar place, and a "*fun*" place for the siblings; a place where they too were looked after and entertained: "*it wasn't like oh you know like an*

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[18] Hydrocephalus, commonly known as "water on the brain", is a build up of fluid in the ventricles deep in the brain. This increases the size of the ventricles and consequently causes pressure which damages brain tissues.

adult hospital it's very very very different" (Maryam Int1). Although hospital beds were places of attendance and treatment, Maryam normalised the experience, as part of her family life.

However, the health of the disabled child dictated the experiences of the whole family who remained isolated:

> *I think everything kind of revolves around her and her health, so you know if she's poorly or we feel that she won't cope in a certain situation we don't go" (*Maryam Int1).

The young person being poorly also impacted mothers physically, as well as socially. Isabel talks about her own health:

> *I've hit the menopause, started with the hot flushes and the night sweats and the lack of sleep and if Sam's poorly we don't sleep either, so you sort of got a constant working carrying lack of sleep downward spiral"* (Isabel Int1b).

Constant vigilance when the child is ill disrupts sleep; and the bed becomes a symbol of exhaustion as well as rest, due to the nature of intense caring. Additionally, Isabel's sleep is disturbed by her own health. She expresses a sense of despair in the "*downward spiral*". Regardless of illness, parents became protective and constantly vigilant at night. Maryam discusses the baby monitor by Anya's bedside. She says it has been "*20 years of almost non-stop*" and that her "*brain doesn't switch off you know every small sound and you're …still wondering has she just moved in the bed"* (Maryam Int1). The baby monitor at night further reinforces the image of young people with PMLD as perpetual children.

In this context, parents try to provide a haven for their offspring, and some teenage children often sleep with their parents. Joe sometimes has the treat of "*a lie-in at the weekend*" with his mother or father when he wakes early. Spending time in bed suggests relaxation, but for the parent on duty, the "lie-in" means being on watch.

Constant vigilance at night sometimes requires external support. Paid carers monitor Paige at night. Although Peta appreciates support from these carers, at times their presence in the home was intrusive. She explained that Paige's bedroom was just off the kitchen in their old house "*so we always had somebody sitting in our lives*" (Peta Int1b). They subsequently moved to a bigger house which gave them and Paige more privacy.

Paige has a special funding package, having received compensation from the NHS following birth trauma. Consequently, Phillip and Peta took control of the organisation of her care. Phillip explains how they moved away from depending on direct NHS and social care support, in order to run Paige's care, on a business model:

> *We ended up evolving into that role where we dispensed with all of these external people and did it all ourselves that's not to say that we you know we don't rely upon external services, we have an HR consultant we have accountants a payroll etc ...but in terms of the general day-to-day and you know setting the direction of everything here and operating it on a daily basis we do that all ourselves, which consequently is far better for Paige because she gets the very very best quality standard of care and when I talk about care I'm not just talking about health I'm talking about her education and her social wellbeing and all the other aspects of life she gets the very very best of everything and also we're able to shape what we do around our family life to make it work for everyone as far as that's possible* (Phillip Int1).

This statement not only reflects the imagination to envisage such a care package, but also the determination required in achieving it. The emotional cost of the legal case was weighed against good outcomes for the family. However, it might also be said that the parents have withdrawn into a world where they can control some services, while dispensing with those over which they had no control. Phillip states they can "*make it work for everyone*" although there is a caveat in "*as far as it is possible*", which hints at existing compromises. Although, the bed is invisible in this passage, there is clear demonstration of the parents controlling the systems that support the young person. The working model within the home reflects the wider models of care.

Support happens around the bed both intensively, and administratively. Philip sets the "*direction of everything...operating it on a daily basis*", very much as a CEO of a business would, mentioning their goal, the *"very best quality standard of care*". This reference to quality standards suggests that alternative arrangements (i.e. care organised directly by services) would be substandard. Furthermore, Philip describes how these "*external people*" had previously impacted his own life and health:

> *To have them sitting at a distance and making decisions whether it be policy decisions or daily sort of task decisions etc that was psychologically as well as physically practically damaging really damaging to the point where certainly in my case …I found I found that aspect of it extremely difficult to deal with and it did affect my mental health* (Phillip Int1).

Phillip did not expand on this "*extremely difficult*" aspect of caring for his daughter, as he was keen to emphasise the positive things they have achieved as a family. However, there is a sense of helplessness in his description of how service providers impacted his wellbeing by removing his control and affecting his decision-making.

Consequently, it is clear in this subtheme that parents arrive at transition with a backdrop of fear for the young person's wellbeing and safety. They are often under enormous stress having to maintain a level of intense caring and constantly monitoring the young person.

They are vigilant, require support and sometimes find themselves scrutinized and in the hands of external forces.

Subtheme B

Supporting roles: “Sam has this ability to gather up people around him” (Isabel)

Parents discussed the people who have helped them, demonstrating that building support around the young person also supports the parent. Peta explains that Paige’s carers are “*a great team*” who “*obviously enjoy working here because they stay (laughs*)”. However, for the carers, “*it’s quite a leap sometimes to come to work in someone’s private home*” (Peta Int1a), suggesting their standards are higher than those of a care home. The context of the bed in a private home also suggests a place of safety, and privilege.

When discussing her own support in the Pictor exercise (Fig. 3), Peta comments that whilst friends are “*more like the emotionally supportive… actually it’s them [care team] that I couldn’t live without*” (Peta Int1a). Peta used different coloured Post It notes to define the distinction between the support provided by staff they employ (green) and the family, friends and external people who help her, such as the GP (yellow).

Fig.3. Peta’s support network as reflected in her Pictor chart. Support is divided into two groups: employed, practical help (green arrows) and emotional and external support in yellow.

However, managing the team has its downsides, and she comments:

> *They're enjoying reading a story to Paige or going to the theatre or something and I'm sitting and I feel like work all the time I just they go home, in my head they go home and have a lovely evening and I'm still on the computer at eight o'clock at night because I'm trying to do a new rota* (Peta Int1a).

There is a gap between Peta working in the home, and what she imagines the carers do in their spare time. She qualifies her statement "*they go home*" with "*in my head*" as she imagines them having "*a lovely evening*", while she continues to work. Paige's hard-won care package has removed her from her maternal role and given her a professional role, which sometimes makes her feel resentful and discontented.

Alternatively, Isabel developed informal support networks, including friendships with people who previously had been employed to care for their son. These people are then seen to support Isabel in a more personal way,

> *Aunty Cerys she was one of the resus nurses when he was born (laughs) and she took us under her wing and I am sure she should not be doing that but she did and she used to come on family holidays with us and all sorts she was one of the family* (Isabel Int1a*)*.

This is a friendship born out of Sam's difficult birth. The nurse, who became known as "Aunty Cerys" was part of the team that resuscitated Sam 22 years previously. The bed here, becomes a place of danger, where life and death hang in the balance but also a place where people sometimes bond through their shared experiences. However, Isabel steps back from claiming her input into this friendship, stating that "*Sam has this ability to gather up people around him that way*". The parents make friends through their children, but in this case, it was almost a forbidden relationship as Isabel was "*sure she should not be doing that",* and Aunty Cerys became *"one of the family".*

In both these accounts, it is possible to see that the carers develop strong relationships with the young people at the centre, and parents are mediators of that care, organising and reaching out for support.

Other friends fulfil other roles. For example, Juliet calls on a friend who is a GP, to check Joe's symptoms: "*to sort of do the triage with a friend before I go to the inevitable visit down to A&E"* (Juliet Int1). Peta also acknowledges that she also has a network of acquaintances who are medics. On occasion she has called on these friends to ease a logistical problem in hospital for Paige.

Friends who understand, such as other mothers of disabled young people, are important. Isabel says: "*it is good to share*" (*Int2, l.531*). Peta talks about a group who have similar aged children, and similar backgrounds, to whom she is close, as does Juliet:

> *I've got other friends ...who are parent-carers... but yeah you get a lot from that support from your friends* (Juliet Int1).

The emotional support that comes with these friendships is, therefore, based on shared knowledge and understanding. Phillip, on the other hand, feels that as her father he is more detached, commenting:

> *Men being men blokes being blokes we don't really. I mean we did in the early years sort of do a few things together but we don't really bother anymore I think we all appreciate our social contacts and lives away from away from the subject (*Phillip Int1).

Family circumstances are individual, as are the relationships with family members. Isabel, for example, acknowledged the pivotal role Sam's father played in his care, despite their divorce:

> *At the end of the day, he was the only other person who really know knew what the reality was of caring for Sam on a 24/7 basis because he was very involved with Sam's life erm until he turned 18* (Isabel Int1a).

She explains that from the age of three, Sam spent half of his time with his father, and the couple shared responsibility. However, Social Care withdrew respite for the family, which Isabel interpreted as: *"The feeling from social care was that... we had this sort of inbuilt respite mechanism"* (Isabel Int1a).

It could be argued that the support of Isabel's ex-husband therefore carried a penalty. Isabel did not contest Social Care's decision, saying she had to choose which battles to fight. Social care's decision seems questionable, however: if the couple had been together, but working shifts or alternately working away from home, there would have been a case for respite. Where Sam slept therefore became a bargaining tool.

Other participants sometimes felt let down by a lack of understanding from family members. Peta's Mother for example, was a nurse and was helpful when Paige was younger, although in recent years circumstances had changed:

> *In the early days they were amazing erm my Mum particularly she used to come and stay she's a nurse though so she wasn't quite so fazed …but now they're elderly and they're more of a hindrance* (Peta Int1a).

Maryam's family also came together to support both mother and child, when Anya was in monitored renal failure. She was "*very poorly … really, really ill"*, in a liminal state between life and death. Maryam and the doctors had ruled out dialysis, as they felt Anya would not be able to cope with the intrusive tubes overnight, meaning a transplant was the only treatment option.

Furthermore, the operation affected Maryam's ability to care for her daughter at this critical time because she donated a kidney to Anya. She explains:

> *MAR: …I donated my kidney to her so I was in hospital at the same time so I came home from hospital three days after surgery erm but I couldn't I couldn't do much.*
> *I: no ... did that affect the lifting I mean apart from just not feeling great presumably lifting and stuff like that would have been?*
> *MAR: I like yeah I couldn't I think I underestimated how difficult the recovery was erm it took me about six seven weeks to actually feel better and I couldn't lift her or anything erm so we had my parents were here Anya's sister she younger sister she spent time with her in hospital the whole day so Anya was in ICU for three four days after surgery so she was there with her from morning till evening.*
> *I: oh wow how old is she?*
> *MAR: She was 15 then she's 16 now*
> *I: Oh that's a grown up isn't it that's amazing?*
> *MAR: Yeah.*
> *I: Gosh it must*
> *MAR: was so yeah it was that was that was a tough time because you know it was trying to ..so before surgery was trying to get all the care in to make sure that there was someone there with Anya throughout and then there was COVID so you know they wouldn't allow they would only allow two people into the hospital to be with her normally they only allow one …but for Anya they allowed my mum and her sister to go in* (Maryam Int1).

As Maryam tells the story of her own operation, her selflessness and protection for Anya becomes apparent. The family are dedicated: a grandmother looks after her granddaughter and a younger (minor) sibling maintains a vigil by her sister's bed in Intensive Care, while the mother recuperates. The bed embodies the intensive care the family give to Anya. However, Maryam describes it as "*a tough time*", not because she underestimated the effects of the kidney donation, but because she was *"trying to get all the care in*" for her daughter when she wasn't available. Following her operation, Maryam couldn't lift Anya (and therefore couldn't undertake essential daily care) but she was helped by her parents. The operation was successful. She brushed aside further questions about her own health by saying she is "*fine now*".

Together Maryam and Anya experienced life-giving and life-saving operations. Mayam's donation of a kidney is an act of great love, demonstrating personal sacrifice for her daughter. Additionally, Maryam is very self-effacing in how she talks about herself in the process: she also does not put herself on Anya's Pictor chart (Fig.7). This example demonstrates how a family focuses in on itself to protect family members. However, it was not just a means to a recovery, but also a major step towards a future transition to independence (discussed in Themes 2 and 3).

This theme demonstrates how families of young people arrive at transition despite facing life threatening illness and life limiting conditions, often requiring major surgery. Parents are seen to be in constant vigil by their bedsides, at home and in hospital. Throughout these years the parents relied on a network of support which included family members, friends and paid carers. The significance of those people lies in the fact that parents feel they understand the needs and vulnerabilities of the young person, having had first-hand experience. When the young person arrives at adulthood, the parents are then forced to shift their gaze to look outwards to transition to adult services.

Theme 2: Looking Outwards – Negotiation

Subtheme C

Navigating multiple transitions: “*it’s all these changes it’s endless changes*” *(Juliet)*

While the principle point of transfer of services is recognised as a child’s 18th birthday, healthcare transitions begin earlier and extend later in Education. Although transitions should be routine and planned, such as the hand over from one paediatric service to an adult department, there are often more complex reactive transitions. The child’s health may prompt a transition, for example finding appropriate hospital provision for an operation. Family circumstances, such as moving house, may also prompt transitions. These transitions do not follow clearly defined pathways and can be confusing for families.

Subtheme C considers the parents’ experiences as they navigated single and multiple transitions and negotiated with service providers for these transitions. Within this theme I consider individual incidents that affected the families, to illustrate the complexity of transitions experienced. Each family’s story represents an aspect of transition, such as moving from a paediatric service to Adult Health care (Paige); a transition within the NHS across hospital settings (Joe); and the move to residential school (Anya & Sam) and to supported living (Sam). Each event highlights what might happen at a certain age. The composite account reflects a journey that one young person with PMLD might make.

The events of these transition, such as meetings and preparation, are seen as part of day-to-day life caring for a young person with disabilities, and it is hard for the participants to separate out their own support from that of the young person. The Pictor charts helped participants to unpick their own needs from those of their child, and demonstrated that help comes from various sources.

The following accounts are presented family by family, and begin with a poem describing the child, as understood by the mother.

Paige, Peta & Phillip

Maybe she's learning

She said
The brain is like
Driving along a motorway
A bridge has collapsed
There's no way round -
She'll never progress

They noticed
She would colour in the page
Fill in every bit.
It was strange –
Other children
Just made random patterns

I thought
"Gosh!
Is there more in there
Than anybody's thought about?"
I was reading to her[19]
Suddenly she'd go "OOOHHH"

I said
"Do you want to learn to read?"
She blinked away like
She said
"yes yes yes yes".
Now she is learning her letters

(Peta on Paige, Int1a)

A planned transition

"This is her words "looking for and grooming" a senior adult consultant who could take her place" (Peta Int1a)

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[19] Eye Can Write: a memoir of a Child's Silent Soul Emerging by Jonathan Bryan

Paige’s transition to adulthood is, in some respects, atypical of the complexity of care packages received by the PMLD community because of her unusual (but not unique) NHS funding. Her support package is run by Peta and Phillip from home, who employ private occupational therapists, physiotherapists, a teacher, and paid carers, many of whom remained in post over Paige’s transition (see Paige’s Pictor chart, Fig.4). However, one of the key professionals in the lives of both young people and their families has been identified as the paediatrician (Chapter 4). Like other young people with PMLD, Paige required ongoing medical assessment and treatment for certain issues, which was overseen by her NHS paediatrician.

Peta had a good relationship with Paige’s paediatrician and viewed her as extremely proactive. Peta described how she worked hard to develop appropriate handovers for the young people with PMLD approached 18:

> *She was a driving force I mean she’s done a lot of … she’s done a lot of culture change there she’s been doing that culture change over the last two years knowing that she’s got all these children going into Adult Services … and she was determined that the her “specials” should have a named consultant at the hospital just like they had her … but in Adult Services so she actually started grooming … looking for and this is her words “looking for and grooming” a senior adult consultant who could take her place for her “specials” so in some respects we’ve had a really good transition”* (Peta Int1a).

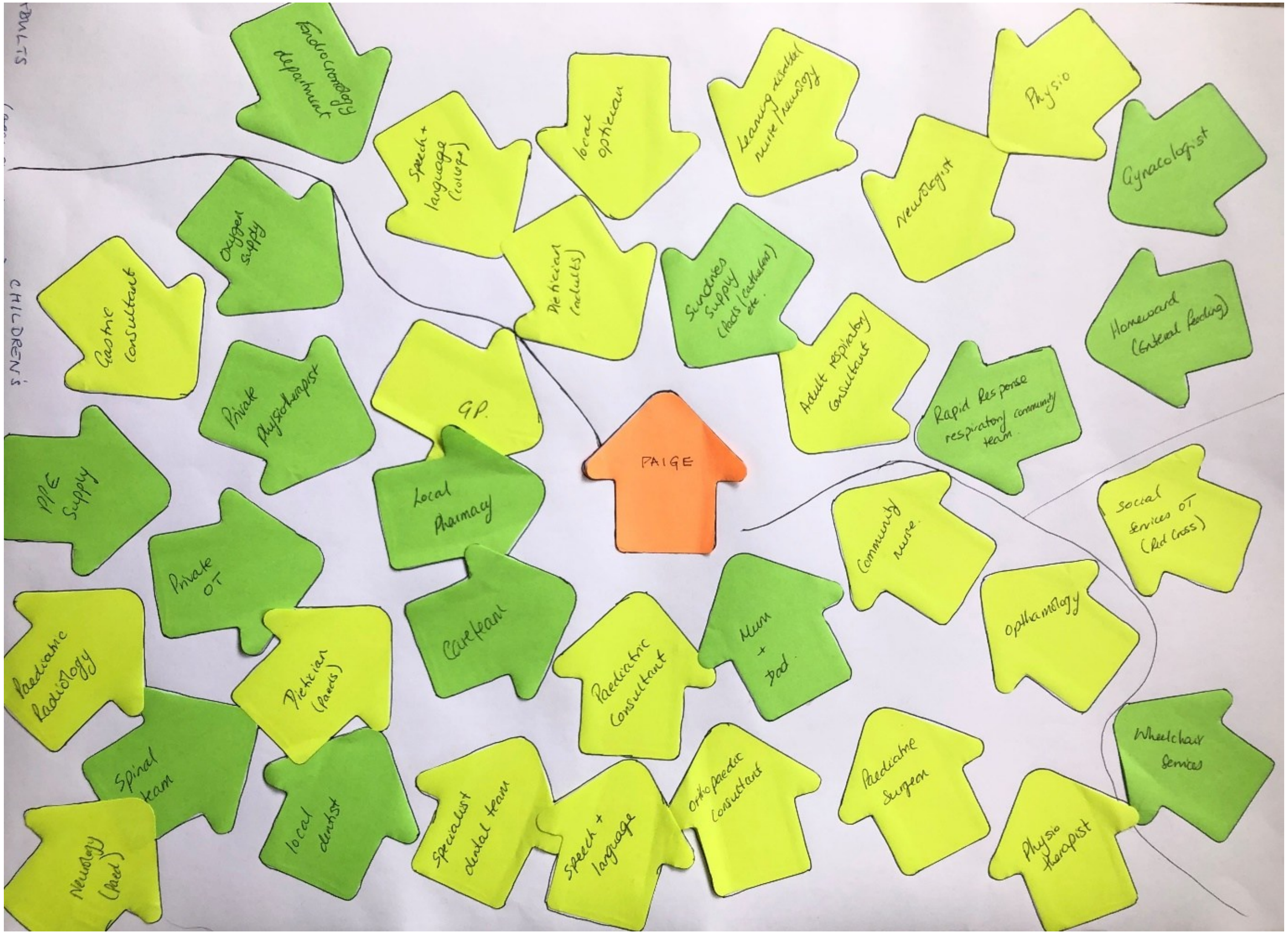

Fig. 4 Paige's support network, showing adult and children's services. Peta drew a line to distinguish between Adult and Children's services, and also used green arrows to highlight services which would continue across transition.

The paediatrician is seen as being proactive on a systemic level, attempting culture change, which suggests her approach is somewhat unique. She took personal responsibility for "*her specials*" looking for appropriate people to handover to within Adult services. However, the paediatrician's own use of the word "*groomed*" suggests this preparation for a handover was done in a subtle and possibly covert manner. As there are no Consultant-equivalents to a paediatrician role in adult services, she may have been asking others to take on the co-ordinating role in an informal way.

However, Phillip believes she had "*power and authority*" to act on the issues she had identified:

> *She anticipated or rather saw the problems that exist post-transition and attempted to do something about it and ...she was promoted into a senior position and had the power and authority to do that.* (Phillip Int1).

Paige's care was then handed over to an Adult respiratory consultant[20]. Yet despite this good handover to a named individual, Peta felt that with regards to other departments no-one else helped her look for successors, she had to ask.

> *Thinking more 'who helped with transition?' and I just think well there are just going to be two people me and (laughs) the paediatrician because I don't feel that anybody else actually helped … but there are lots and lots of people that I had to go to and say 'well who replaces you* (Peta Int1a).

Peta, therefore, still played a key role in identifying the appropriate people to contact going forward. Despite all the planning however, it transpired that different hospitals had different protocols when Paige required a new feeding tube fitted.

> *We ended up going under a gastric consultant at (hospital 1) … she had one tube change done there and it's done completely differently completely different process to (hospital 2) so (hospital 2) we used to arrive at X-ray department …they would be ready with the hoist we'd hoist Paige onto the x-ray table … the interventional radiologist would come in change the tube we'd hoist her back into her wheelchair and we'd go home we were probably in there for about 45 minutes. At (hospital 1) we have to be admitted as a day patient … onto a ward we then have to be put into a bed we have to have all the forms done we then need porters to come and take her down to X-ray* (Peta Int1a).

A more regimented method of admissions in the adult hospital means a tube change can take all day, as opposed to 45 minutes, and this procedure happens every 12 weeks. The young person is confined to a bed on a ward rather than being in a wheelchair. The systems are therefore seen to be restrictive and more disabling and time consuming for both mother and daughter. The bed thus becomes a symbol of hospital procedures, which is

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[20] This is a common route for young people with PMLD, as they are vulnerable to chest infections.: TRAG experience

depersonalised in this account. However, Peta maintained some control, on another occasion, when the tube change was cancelled owing to a technical problem. She "*just pulled some strings and... got it done under paediatric x-ray*".

Phillip is in awe of his wife's "*amazing ability to do what she does*" but suspects that the good transition they seem to be experiencing is down to Peta's own dedication and knowledge about how systems work:

> *It's very difficult for me to judge to what extent is the current set-up successful due to Peta like it was in the past and she's compensating for she might be compensating for less shall we say less input less help she may be compensating for that because she's able to she's able to do it*. (Phillip Int1)

As Peta said the only person who helped with transition was the paediatrician, Phillip's interpretation of her compensating for "*less input*" seems a valid explanation. Peta highlighted other medical support on her own Pictor chart (Fig.3) in the form of the GP. This doctor is also a parent of a *"non-verbal child with special needs",* and Peta considers her to be empathetic. She is reassured:

> *We now have … a good relationship with the GP but obviously that was a real scare around transition when you are being told that your are going to lose your paediatric consultant and everything is going to be GP led...and we didn't have a named GP that we knew we never saw well we just and it was awful ...and now that's great (laughs)* (Peta Int1a).

Peta understands that the problems of transition arise from the improvements in modern medicine. The paediatrician had said *Paige "shouldn't really still be around but a lot of the children still are and they're all living a lot longer".* In this respect, adult services are unprepared for the needs of this group. The paediatrician's comment may also reflect the uncertainty of expectations expressed by the parents in Theme 1, as well as the professionals in Chapter 3.

Joe & Juliet

Life is a big game of bingo

Every number he sees
He does a bingo call-
He loves numbers
ecstatically happy and excited

Or

Joe insists, he is funny,
What words who’s right and who’s wrong
It’s not Mum: “MUMMY!”
anxious and distressed

(Juliet on Joe, Int2)

Planning surgery

“He’s unlucky enough to be needing major surgery ... at this age” (Juliet Int1)

Joe was the only child under 18 years old within the participant group, but transitions were already taking place. Arrangements were being made for major spinal surgery as Joe approached his 18th birthday. Juliet was dealing with the preparations for the operation, the uncertainty of where the operation would take place and who would be doing it. Additionally, at the time of her first interview, his transition to adult social care and the support the family received was unresolved. The chart of Joe’s support therefore reflects the services involved in his pre-transition life (Fig.5)

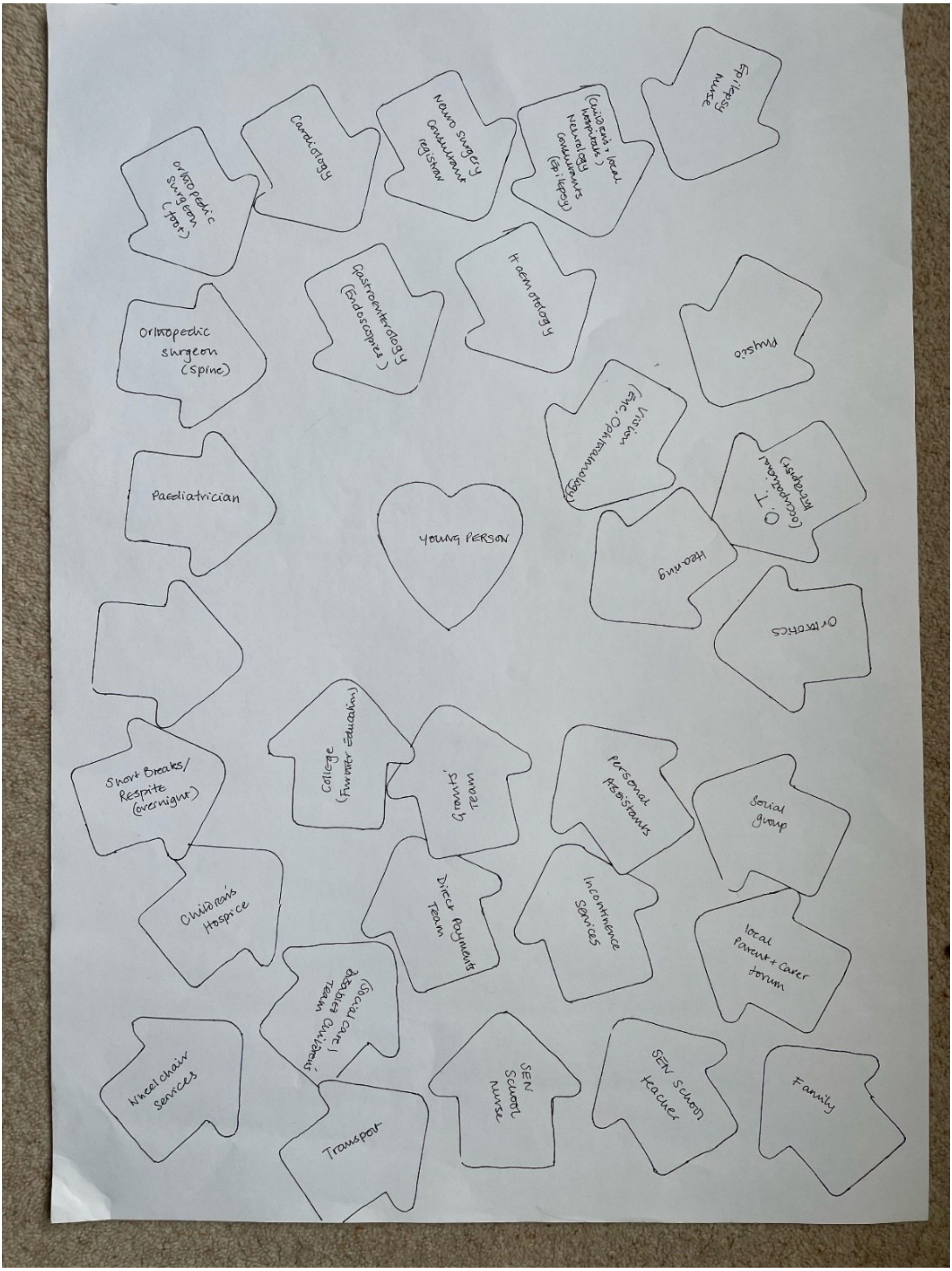

Fig. 5 Juliet's Pictor chart showing Joe's support systems, (developed in the first interview). The chart reveals a divide between health services in the top half of the chart, and social care and social support in the bottom half of the chart. (Blank arrow was marked "Motability").

Joe had waited for several months due to Covid-19 delays to see an orthopaedic surgeon for his scoliosis. Then the family were told "*his spine was already too curved for any kind of preventative measures now and that surgery was the best was the only option really"* (Juliet Int1). However, after pre-surgical assessments at a children's hospital, they were told he was no longer eligible to be treated there, as they were "*moving all 16… or 17 year-olds to adults"* (Juliet Int1). Three different hospitals were discussed as locations for the operation; the familiar children's hospital, the orthopaedic hospital where the surgeon is based, and a different adult hospital further away from home. Juliet was keen for the surgery happen at the children's hospital because staff there were familiar with Joe's co-existing conditions. They requested that the surgeon from the orthopaedic hospital would be able to facilitate this request. She explained:

> *One of the benefits of children is that you've got all the services around him so ... then the surgeon told us "no you know I'll have to ask for permission to operate in the children's hospital" even though he is legally still a child well at the moment… so that's been really stressful … and then we got a call to confirm that the director of medicine had given them permission at the beginning of April* (Juliet Int1).

Juliet's account reveals that she found the uncertainty of where the operation would take place confusing. Joe's age was considered against the hospital's policies, although her understanding was that he is still legally a child and should be eligible to be treated in the Children's hospital. However, shortly after the decision was made, Juliet received a letter from the orthopaedic surgeon saying her son had been referred to the Adult's hospital in a different city. The decision to refer him elsewhere, on an adult ward, was an error, but Juliet felt the communication was "*very uncaring*".

The uniqueness of Joe's co-existing conditions made the pathway challenging for both parents and health services, and there was considerable negotiation to achieve the right outcome. Poor communication exacerbated parental anxiety; they were "*devastated*" when an alternative was presented as fact. Juliet found the thought of her son, being on an adult ward very distressing, and this added to her anxiety. In this account, the bed became symbolic of hospital administration as the focus moved away from the needs of the child to the place where surgeons can meet those needs by operating.

Within the wider context of healthcare, there is inconsistency in how different services approach Joe and his various conditions. Julie comments that haematology are interested in him, and his condition, as an adult:

> *There was no interest in it when he was a newborn baby which is why I guess you know it felt sort of strange the way that he was treated differently then and now* (Juliet Int1).

Conversely, Adult Neurology services for Joe's epilepsy did not provide the same input as Children's services. Her belief that things on "*the medical side*" would "*drip through*" and "*to some degree coordinated by the paediatrician*" (Int1), was not founded. As she commented in her second interview:

> *… for example neurology where you know that was kind of a major and continues to be a major issue he he just seems to have been dropped by Children and there's been no transition (*Juliet Int2).

Julie and Joe's story revealed that medical care and intervention were key elements of preparing for adulthood for young people with SLD and CHCN as well as those with PMLD and CHCN. There were changes between equipment provided, hospital policies and locations, as well as attitudes to medical conditions across the services the family access. Consequently, parents felt confused and stressed by the inconsistencies and changes.

When asked about her own support, Juliet discussed the respite provided by social care. In her first interview, Juliet was dismissive of the provided given by the Disabled Children's team. She reluctantly put a sticker on her own support chart (Fig.6) and commented:

> *I'm looking forward to adults when we eventually … to see if it's any better you know but then I'm also fearful about this thing about no longer having parental responsibility from a legal perspective"* (Juliet Int1).

By the second interview things had progressed as Adult Social care had stepped in. Joe was being assessed for eligibility for Continuing Health Care funding, which was still unresolved. Juliet was uncertain which would be most beneficial, saying "*I don't know so if it's better to be funded by Health or partly by Health and partly by Social Care or entirely by Social".* However, whilst there was uncertainty, she felt she was being supported by a good social care assistant.

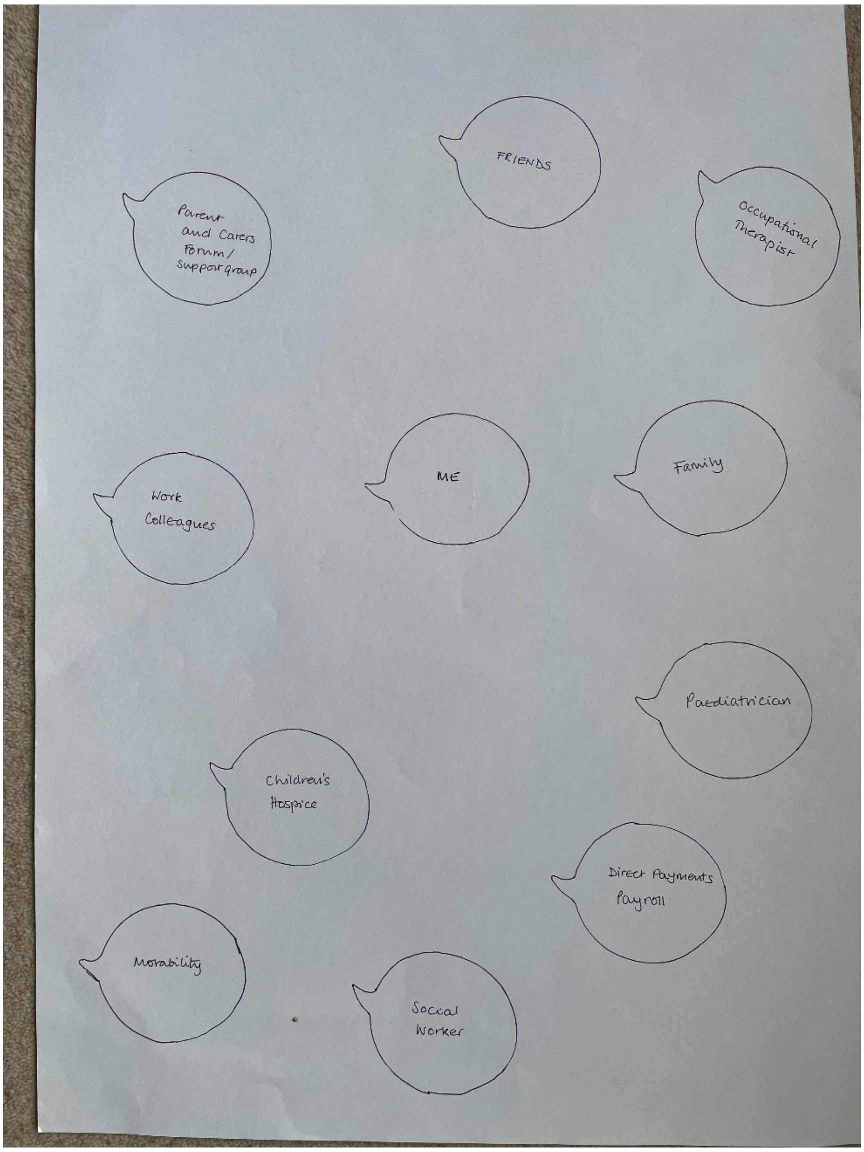

Fig. 6 Juliet's support network pre-Transition. Juliet mostly referred to groups of people, rather than individuals within her chart. She placed the social worker at a distance from herself because she felt ambivalent about the level of support given pre-Transition.

This help positively impacted the family although Juliet found it "*quite difficult*" to let go, explaining "*as a parent because you know it's hard to sort of not think we actually I should be doing those things"* (Juliet Int2). She explained what the help meant to them:

> *Now my husband and I we can sit in the evening together when we haven't been able to do that for years ...and you kind of think actually I… feel guilty I feel guilty that we're doing that and I feel guilty when the carers do things like they'll do my washing up (laughs) and I'm like "you don't need to do that" or anything I mean that that's something that they're paid I don't feel is their responsibility but you know they but even the things that you might are what they're there for I feel guilty about and and it's that it's that transition you know but it but it has been ...erm (..)yeah I mean I'm feeling mentally more resilient as a result of the support"* (Juliet Int2).

She admits to an increased closeness between her and her husband and, without discussing her marriage, reveals the stress that relationships can come under when caring.

Anya & Maryam

That's her!

She's a very happy person to be around
a very bubbly character
she wants to be in the middle of everything
not a solitary kind of person
she loves being out with people
doing things doing different things
she leaves an impression
everywhere she goes
Even if you just met her for five minutes
you'd remember her

(Maryam on Anya, Int1)

Planning life after surgery

"We've now had to start [to] prepare for tribunal" (Maryam Int1)

The stress of dealing with inconsistencies was also demonstrated in Anya's story. As discussed in Theme 1, Anya had life-saving renal surgery, made possible by Maryam donating one of her kidneys. However, Anya's transition was also influenced by the family's needs, as they moved to live in a new area of the country. This move was carefully planned and was also dictated by Anya's needs: good schools, respite and a hospital that could undertake a kidney transplant[21] as well as providing ongoing health care. Once moved, Maryam requested that they transfer into the care of the adult hospital although Anya was not 18 yet, because the journey back to their original Children's Hospital was too arduous.

> *M: we were in the middle of transferring Renal Care so Renal because that was her main one we were seeing them every three to four weeks because at that time they thought that she would need dialysis straight away so they they put us in a transition clinic and there was a consultant from (city) and the renal youth worker who were at that at that clinic so they were our kind of erm (..)*
> *I: link?*
> *M: they were our transition into the (Hospital)* (Maryam Int1).

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[21] There are 19 Adult transplant units in England

Maryam’s Pictor chart shows the extraordinary number of services involved in Anya’s life at this time (Fig.7).

The successful operations gave Maryam hope of Anya attending a residential college, to gain her independence. However, Maryam was then confronted by the Local Authority’s refusal to agree to Anya’s transfer to the identified college. Maryam stated that this transfer had previously been agreed on the basis that Continuing Health Care would fund 76% of the budget, but the placement was being contested by Education, who had overall control of the Education Health and Care Plan required for the placement. She explained the chain of events that led to the refusal stressing “*the overriding concern*” as Anya’s health:

> *...So she left school in July. Local Authority kind of messed up everything so they when they decided within their multi agency panel on Anya’s placement for college Local Authority did not involve Health in that decision and when they made the decision for college they did not take her health into account. Anya gets Adult Continuing Health Care so the overriding concern in her life is her health you know so every decision that needs to be made around her has to be made with her health first but Local Authority haven’t done that so kind of [to] correct that decision we’ve now had to start prepare for tribunal* (Maryam Int1).

Maryam believes Health services, whose evidence and funding was vital to planning Anya’s transition, were deliberately excluded from the process by the Local Authority. She stresses *“they did not involve”* Health, *“they did not allow Health to speak*”. Furthermore, “*they wouldn’t listen*” to Maryam’s opinion about the suitability of local provision. Consequently, Anya’s complex needs were neither acknowledged nor catered for. Maryam’s emphasis on Anya’s health not only stressed the young person’s vulnerability, but also the impact on the whole family.

The dispute is essentially about the need for a residential placement, with overnight care. Again, the fine details of what caring for Anya at night means, is overshadowed by budgetary decisions. Maryam faces legal action to access a bed in an institutional setting, to help her daughter achieve some independence as she approaches adulthood.

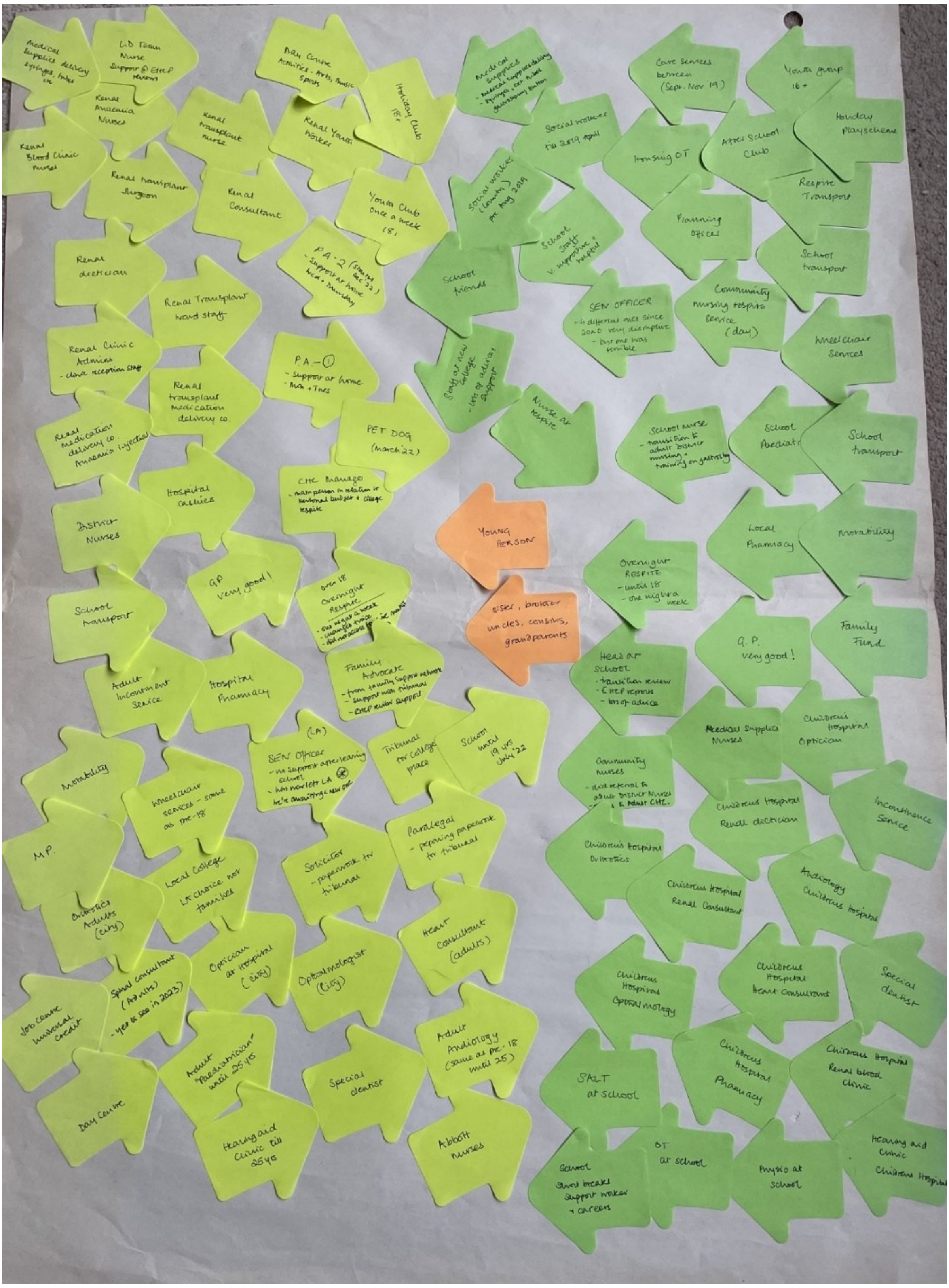

Fig. 7 Anya's support system chart, as defined by Maryam, completed before the interview. There are over 90 arrows but these only relate to services accessed in the last two years. Yellow arrows mostly represent services accessed since 18, including wide-reaching renal services, whereas green arrows represent children's services and support. The complexity of the chart also reflects the family's move to a new area (with repetition of some services, such as SEN officer, and GP).

The result of the Local Authority's rejection of Anya's residential placement was that she remained at home, out of education for a year. Maryam felt disappointed that the Local Authority do not understand her position:

> *I think that's been the biggest let down because I think one thing local authority don't realise is that you know when Anya goes to college it changes everything for us as well... because with her at home there's always got to be somebody around in that's it's always me"* (Maryam Int1).

During this time, Continuing Health Care put support in place which is beneficial for both mother and daughter. The support allowed Anya access to activities, but also allowed Maryam some time-limited freedom. Maryam also engaged with the learning disability team requesting help from the adult speech and language therapist (SALT), the occupational therapist and a physiotherapist, with a view to producing a "*the kind of program that she can work on until we know what's happening".*

All these changes reflected an increased workload for Maryam. She was able to take some control on the home front, whereas within the healthcare decision-making process she felt powerless: "*there was so little we could do about it"*.

Fig. 8 Maryam’s support network as depicted through the Pictor exercise. It is interesting to note that she does not place herself on the chart. “Family” and “Faith” are highlighted in orange and stressed in her interview.

Maryam’s support is complex (Fig. 8) She discusses both emotional support and practical support, but recognises that one complements the other, giving meaning to and rationalising her life. She commented:

> *if you look at it from the other side is my family my faith …so I don't think it's just one person I think it's just the whole thing...Well for me it's about me my faith has been probably the thing that has kept me sane throughout you know since she was born I think my faith (..) erm is very important to me so I think that's what keeps me going”* (Maryam Int1).

Sam & Isabel

If he had a job…

He loves his friends
He loves swimming
He loves big slides
Smiley, sociable, cheeky
He loves being out and about
He loves teacup rides

He loves his family
He picks up vibes
If someone is sad
He will sit with them
be quiet for a minute
his hand on their hand

He loves his music
Lockdown Kitchen Disco
Thought it hilarious
Scrolls through YouTube
Gaga and Rhianna
Timberlake and Olly Murs

He loves his friends
He loves his family
He loves his music
And, if he had a job,
he'd be a DJ!

Planning life after school and college

"It was a sort of chicken blink thing going on" (Isabel Int1b)

In this account, Isabel describes two-stages of transition, school to residential college and then college to supported living.

Despite the personal sacrifices parents make for their children, sometimes parents' own needs must be placed first, and they choose to step back from caring when their child reaches adulthood (as discussed in Chapter 3). Isabel started to plan Sam's independent life when his father (her ex-husband) announced "*when Sam turns 18 I don't think you can necessarily rely on me being around*". Additionally, she had her own health concerns and felt that she would not be able to look after Sam full time. The result was a risk-taking strategy, when the divorced parents worked together to pressurise the Local Authority to take responsibility for Sam's further education. She explained:

> *The reality was when Sam's dad basically had to do this blink thing of saying that once Sam turns 18 [he] was no longer willing to necessarily provide that same level of support as he had provided erm to date and I had to say I wasn't willing to take on Sam's care 24/7 so it was a sort of chicken blink thing going on and because there was no provision that would meet could meet Sam's needs in (county) then we had to consider other options. (*Isabel Int1b).

The term "*chicken blink*" evokes an image of a battle of wills as to who would concede first, with overtones of great risk. In this case Isabel challenged the Local Authority to find a suitable setting for Sam. They requested a place at a residential college. When their first request for a placement was declined, they redoubled their efforts the following year, studying the language of the reports and crafting their appeal to demonstrate that their solution would meet Sam's needs. Isabel's partner, Ian, had attended a legal course for carers facing SEND issues, and they worked together to achieve their goal. She explained how they adopted professional personas:

> *[Ian] then started coming to the meetings with me in his suit just for effect …and just having him turn up in a suit with his notebook and looking at people saying "so what are you going to do and when are you going to do it by" and you know making it we both made it very clear that we would have code words if something wasn't going we didn't feel it was been responded to appropriately we had to be awfully planned meticulously throughout the whole process really but use the tribunal words and said you know we are going to put this as what we think is the best thing for Sam we are going to make this happen but it took two of us and it shouldn't* (Isabel Int1b).

The young person at the centre is lost in the negotiations (Fig.9), and it is the parents who use the "best interests" argument (from the Mental Capacity Act) to focus on need. Their approach to dealing with the professionals was strategic and almost covert at times, devising their own communication systems in meetings. Appearances mattered, but it was apparent that Isabel felt disadvantaged as a woman, as well as a parent:

> *You know I was I was not going in in my pyjamas I was making notes I was I thought talking reasonably intelligently but once you've sort of erm wheel him out different different responses* (Isabel Int1a).

Fig. 9 Sam's support: School to College (interview 1b). Isabel used a timeline design to illustrate the shift from School (on the left) to College (on the right). Services that remained were placed above Sam's arrow. Green arrows highlighted emotional support.

Isabel felt that being a parent was not enough, and status depended on pay grade, reflected by her observation that *"everybody else in those rooms, those meetings were been paid to be there and we were the parents "* (Isabel Int1b). There was a sense that they needed to step up to meet the level of the professionals making the decisions. The professional persona was not just adopted for meetings, the couple dealt with the whole process like a job. Ian drove the process forward with meticulous attention to communication with the Local Authority. At the second attempt they were successful, which Isabel attributed to their professional attitude and the use of legal jargon. Sam started residential college in 2018.

Three years later, Sam faced another transition from college to supported living. Isabel and Ian started another round of negotiations (Fig.10). This transition was driven by the couple's own wish to retire to a different area, and for Sam to be placed near them. Negotiations were tricky because Brokerage[22] suggested settings that Isabel considered "*wholly inappropriate*",

> *[Brokerage] were also putting forward places that .. had "required improvement" with ..CQC they were also putting forward places where all of the other residents were in their 50s and 60s* (Isabel Int1a).

When the couple suggested placements nearer to where they were going to live, Brokerage would not engage with them directly, ignoring their legal status as "*Sam's court appointed deputies"* (Isabel Int1a). Isabel eventually found an appropriate setting, through working with other parents, joined together by the college. Her account reveals the complexity of the interactions, echoing business-like negotiations.

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[22] The commissioning service for social care with the Local Authority

Fig.10 Sam's Support: College to Supported living (Int1a). Isabel used yellow to distinguish a care worker (represented twice) who moved from working at the College to Sam's supported living setting.

When asked about her own support, Isabel initially stated that it was only Ian who helped her feeling unsupported throughout the process. She said, "*you just always felt you're going into battle*" alongside *"the troops in the shape of Ian"* (Isabel Int1b). She also brought his views into the Pictor chart:

> *I asked Ian who else supported us erm and he said you have to give (name) credit the social worker so well I did but also erm there's a parent-carer support group er who … were brilliant at supporting us through the fact that we needed to get Social Care Assessment updated and what was going on with Brokerage and erm making the complaint and things like* (Isabel Int1a).

For Isabel, help falls into two categories: proactive, such as support for planning the future; and reactive support when events are challenging, and people are called in to help (see Fig.11).

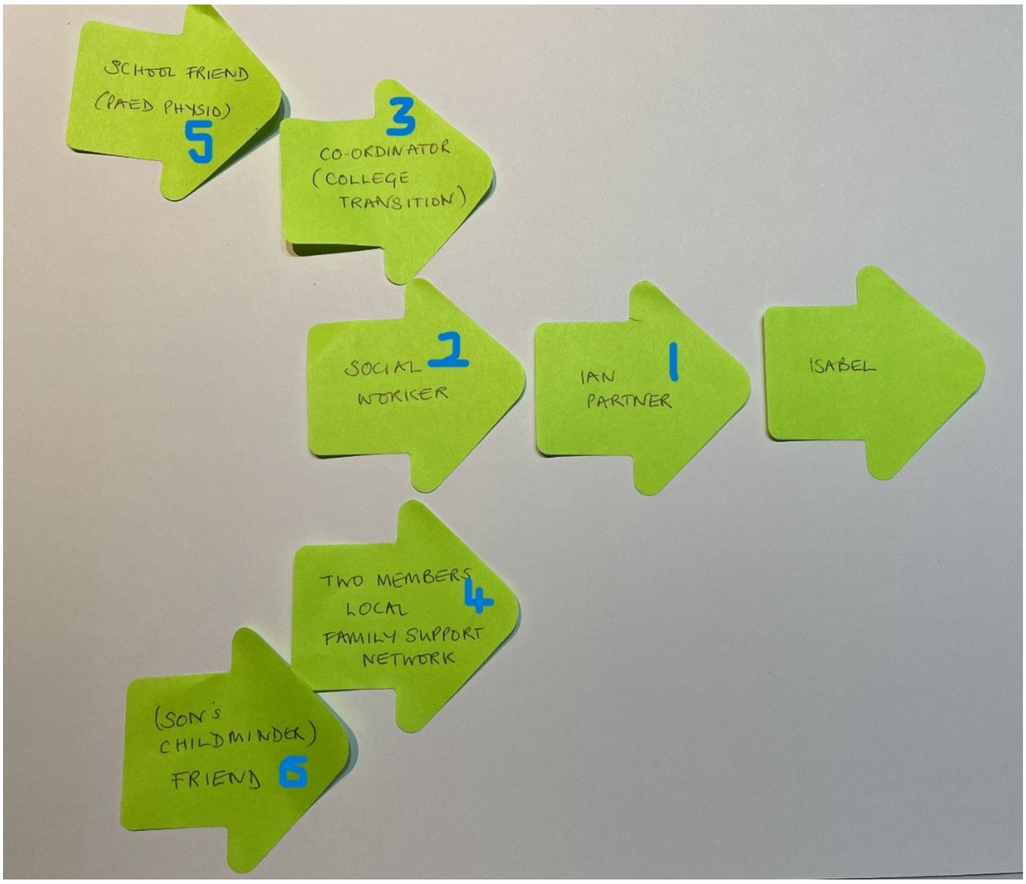

Fig. 11 Isabel's support network at Sam's transition from college to supported living. Isabel developed this chart during the interview, but struggled to name sources of support. (Numbers added post-analysis).

It is possible to see in this chart the type of support parents require:

1. Ian, her partner, who provides both emotional and practical help, in terms of being proactive in filling in forms and attending training, but also reactive in his efforts to achieve the right outcome for Sam.
2. The social worker offers proactive support in helping put forward settings for approval by commissioners.
3. The college transition co-ordinator is proactive in offering suggestions for suitable housemates for Sam.
4. Isabel turns to the local family support network for help obtaining assessments, which constitutes reactive support.
5. Friends have offered practical support to help Sam
6. and made helpful suggestions, about future care provision

This range of support is reflected in the other accounts. For example, Maryam also felt that a local support network has been helpful, especially at the interface with services when she worked with a family advocate. Juliet had found the local Parent and Carer forum helpful for social and practical advice.

The impact of managing transition processes on families is exhaustion and frustration, and parents recognise that they are set apart from the lives of their peers, Juliet comments "*there are challenges you know difficulties that that we face as parent-carers that other families would not relate to*" (Juliet Int2). Isabel thinks that even her friends do not understand the personal cost to them in organising the best outcomes for Sam:

> *"I just don't think people really have a sense of what was involved...still they didn't have a sense of what was involved in Sam's care 24/7 and nor what was involved in getting him to live his best life but that's just the way things are really"* (Isabel Int2).

This theme aimed to present a succession of transitions across the timeframe of 17 to 22 years old when a young person transfers to adult health care, leaves education, potentially goes onto a further education setting and/or is established in independent, supported living accommodation. Beds are no longer a focal point of caring for a vulnerable young person, but part of the settings, and therefore no longer belong to the individual, but rather to the institutions and services which house them. Beds become a commodity to be allocated in hospital, and parents have to bend in to caring within those hospital systems. Beds are also represented by placements in residential accommodation, whether that is school or supported living. They are negotiated and allocated for future living. The parents must adjust to a new focus, and work with services that are driven by budgets, rather than focusing on individual needs.

This composite narrative represents aspects of transition that parents of young people with PMLD or SLD with CHCN experience. Many parents will experience these events such as these in succession, across the whole transition period for a single young person.

Theme 3: Looking forward – Vision

Themes 1 and 2 explored the world the families inhabit prior to and during transition, and the disruption that transition of services brings to their lives. However, as the young people settle into adult services, the parents' focus shifts to consider future lives. Subtheme D explores *"the landing"*, how the parents view their child's future and what their role in that might be. Subtheme E considers the hopes and aspirations for the parents' own future lives.

Subtheme D Disentangling:

"This last chance she has to learn and to be independent" (Maryam)

Parents focused on the young person's health during the early childhood years, particularly as they were told their conditions may be life-limiting. However, when the child approached and reached the milestone 18th birthday, parents were more able to express aspirational visions for their child. Inclusion played an important role, as both Juliet and Isabel expressed ideas which fit well with the social model of disability.

In summarising Joe's love of drama, Juliet reflects a wider ambition for her son:

> *I feel that erm he has something to give to society even though he also has significant support needs and I hope that society will include him so that he can you do what he's good at which is which is you know bringing joy to people really* (Juliet Int2).

She has hope for reciprocity, in that Joe will bring joy to people's lives in an exchange for support. She hopes he will become an active member of society rather than 'just' a care recipient. Isabel would also like inclusion in the form of Sam living with housemates without special needs, similar to the late Jim Mansell's ground-breaking house share in Cardiff in the 1970s[23]. She explained:

> *...if you have an ideal thing he'd be in a house share where perhaps the there would be some other young people living with him who didn't have special needs but that's not going to happen anyway* (Isabel Int2).

Regretfully, she feels that is unachievable, but the underlying hope in this "*ideal thing*" is that other people would want to care and look after Sam in a utopian setting. She wishes he could be fully included in society, by having a bedroom in a regular house share.

However, the parents still concentrate on keeping their children safe. There is no shift in the vision of wraparound care that Peta and Phillip have for Paige (Theme 1), as they have established a system that offers the "*best possible care*". Juliet considers ruling out the option of residential college for Joe. When asked about independent living, she stresses his medical needs:

> *I think at the moment I guess because of his medical needs erm and his vulnerabilities I think it would be difficult to to sort of…think that he would ...that he could be kept safe ... and I think the only reason erm … we know he likes being at home and I think the only sort of I guess thing that would make us have*

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[23] Jim Mansell's Supported living and its unlikely student digs origins https://www.bbc.co.uk/news/uk-wales-67010201 7/10/23

> *to consider that reality would be if we felt that we were no longer able to keep him safe at home? I think he would you know he would prefer to be at home* (Juliet Int2).

She understands his medical vulnerabilities and wants to protect him from the risk of harm. Consequently, it seems there is some conflict between her aspirational view of him being part of society and keeping him safe at home. She furthers an argument for maintaining the status quo by suggesting that it would be Joe's preference in that he "*likes being at home*" and would "*prefer*" to stay there. Home is seen as a safe place, although she concedes that may be difficult in future.

However, being kept safe at home cannot necessarily be taken for granted, as illustrated in Juliet's anecdote about Joe's new bed provided by Occupational Therapy. Although it could accommodate a hoist, which would help his parents with lifting Joe after his operation, Juliet voiced concerns:

> *J: he's had some new equipment like a new bed but then erm*
> *I: oh fantastic*
> *J: he's probably not entirely safe in that now…so that for example when he has a seizure he seems to erm end up on on the floor …and then his head got trapped between a piece of furniture and the bed so all these things…you know the bed's change thing can be hoisted out of his bed now because it [the previous bed] was an enclosed bed but you know obviously you improve things on one side but …actually you then create a risk that wasn't necessarily anticipated on another side but... they've offered sort of bed sides erm but then that presents a risk doesn't it if he if he tries to kind of get out of the bed and you just don't know you've just got try these things but in trialling them … you can't you can't properly trial them until you walk away and leave him to sleep...or be in his room at night … so I guess it's it's all these changes it's endless changes* (Juliet Int2).

The account of the change in bed, whilst ostensibly talking about preparation for the operation and the input of new services, also introduces another ongoing aspect of parental responsibility in managing Joe's epilepsy and ensuring his safety. The problems that arise when trying out the new bed demonstrate the element of risk-taking that parents carry with them whilst attempting to meet both their own and the young person's needs. The bed therefore symbolises the wider issues and risks that parents take in caring for their child. Solutions may be presented by professionals but even the most protective parent cannot foresee all the problems that may arise.

While Juliet saw risk as a reason to keep Joe at home, conversely, Isabel feared that she would not be to keep Sam safe at home. She explained their reasons for deciding on residential care for him:

> *I think we were getting to the stage where if we knew that we just couldn't keep going the way we were...so I think we knew that we weren't getting any younger we knew that we needed to future proof what would happen if something happened to one or other of us where would Sam yeah how would Sam be safe that overriding driver really* (Isabel Int2).

Sam needed to be kept safe, but they were no longer able to provide that support. Her need to "*future proof*" plans arose out of her recognition of her own physical limitations, and the horizons of her own future and that of her son therefore started to separate. Maryam also saw safety as a key factor in deciding where Anya lives after school. She mapped out Anya's options:

> *This last chance she has to learn and to be independent because after college there is no other provision you know so this is an opportunity she has to spend those three or four years with in a provision which is safe enough for her which can provide all that education for her and teach her to be as independent as possible and then after when … she leaves college she has the opportunity to either move in with her peers and be able to live as independently as possible erm or come back home and you know continue living here* (Maryam Int1).

The residential school affords Anya the opportunity to learn independence from her family. Bedrooms in different places symbolically suggest independence for the young people. However, Maryam acknowledges that independence is still dependent on others caring for her by her use of the phrase "*independent as possible".* Isabel also envisages this form of supported independence for Sam if she is no longer able available to help him. She describes this scenario as

> *My under the bus (..) way of doing things you know what happens when I'm not here* (Isabel Int1b),

which suggests a sudden and unpredictable interruption to the status quo. She identifies two factors, communication and physiotherapy, that are important in keeping Sam safe and well in the future:

> *What happens but I'm not here to interpret for Sam can he make his views and wishes known to a complete stranger … and then also the physio thing was I think the second thing that we boiled down in terms of keeping him comfortable for any impact of contractures from his cerebral palsy in his limbs or body* (Isabel Int1b).

It is important that the parents share the relevant physical and medical information with the people adopting responsibility for the care for the young person at transition, as they understand the considerable risk involved and trust required in this handover. Parents are therefore constantly vigilant and monitoring their children in the care of others. Isabel believes this handover also requires diplomacy and self-awareness:

> *It is the establishment of a relationship with the care team and making sure that I'm involved appropriately but not over involved and that's quite difficult to find your way around* (Isabel Int1a).

Learning to step back and let others take over is sometimes difficult for the parent, as is illustrated in Theme 1. When young people move into residential care, the parents become advisors to the care team, losing the overall control they previously had.

The arrangements for the young person may also present risk for the parents' own future security as well. Peta and Phillip bought a house with Paige's compensation money, she explained

> *The move gave Paige her side of the house and gave us our privacy back on our side and we can have friends over on our side and it's not interrupting Paige's life* (Peta Int1b).

This division of sleeping quarters suggests they are disentangling their lives. However, whilst they maintained control of Paige's care, they also felt there was some danger that she might establish her own independence through her ability to communicate:

> *... the more that we push for Paige to learn to read hopefully eventually she'll be able to spell things out and spell words out to us so then she'll have her own voice and she has got an eye gaze where she can say things but it's can be a bit hit and miss erm so if we get to that point you know she could tell us to get out of her house (laughs) … it's hers and she doesn't want us around anymore* (Peta Int1a).

The hypothetical threat that their daughter might force them out has been reinforced by the legal advice they were given not to pool their money with their daughter's to buy the house, in case of a dispute. The overtones of uncertainty in Peta's account suggest a fear of her own legal status, and how that might change. She acknowledges her own vulnerability.

This uncertainty of status is also demonstrated by Juliet. She feels that "*we don't have we can't get Power of Attorney and we don't have Deputyship"* which gives her *"less kind of input in terms of where he lives in the future"*, if he goes to residential college. Thus, the fear of losing control is coupled with a fear of future injury or illness, for which she might feel responsible, stating, *"I just think I couldn't forgive myself if something happened to him".* It reveals a moment of existential crisis where her role as parent-protector is threatened, and uncertainty arises about what that future role might be. Consequently, she feels it is safer to maintain the status quo: if Joe is at home, he is under her protection.

Although it was unclear what Maryam's status was regarding Deputyship, both Isabel and Peta have engaged in the process. In her first interview, Peta stated that she was being encouraged to obtain a Health and Wellbeing deputyship by a surgeon, because Paige required treatments that needed authorised consent:

> *the consultant that did the Botox kept saying to us or saying to me "Have you sorted out your health and welfare yet " and he wants us to take control and have*

> *that authority but when we'd looked at it the Courts kind of discouraged that* (Peta Int1b).

Deputyship in this instance was seen to give "*control*" back to the parents, although the legal process was unclear, and the couple were receiving mixed messages about what to do. When interviewed a few months later, Phillip explained they had started the Deputyship application process,

> "*we're not doing that because we've had any specific problem that we've you know come up against something where it would have been you know essential to have had health and welfare deputyship we're doing it more as a bit of an insurance policy in case we come up against a situation in the future*" (Phillip Int1).

Peta and Philip are staking their claim to be part of the decision-making process, and preparing for any future difficulties. Isabel and Sam's dad both have Court of Protection deputyships, but despite their legal status were excluded from the decision-making process whilst negotiating Sam's future accommodation with Brokerage. It is therefore understandable that parents are concerned about their own role going forward at this time.

This subtheme demonstrates that whilst parents are idealistically aspirational about their child's future role in society, in practice they are sometimes fearful of risk-taking. They also have to consider their own futures (as suggested in Chapter 3) as they experience the subtle shift in their own identities from parents who are chief decision-makers for their vulnerable children to advisors and advocates.

Subtheme E: Parents planning their future:

"Us learning to live without him 24/7 as well" (Isabel)

When their offspring were in children's services, both Juliet and Maryam's families received "*respite*". Although government guidelines[24] refer to this as "short breaks" that are designed to benefit the young person as much as the families, the term "respite" continues to be used by families. Respite provides a break from caring for these families and offers time to prepare for the future, the next stepping stone to independence. Places in respite settings are represented by beds away from home, whether that is a children's hospice or social care funded setting. They also offer a way of testing separation for both parent and child.

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[24] https://www.legislation.gov.uk/uksi/2011/707/contents/made

Joe's respite provision ends around his18th birthday and Juliet expresses sadness at losing the support of the children's hospice and discusses Joe's last stay:

> *He's going to be going in for a week and I think it will be the last sort of opportunity where we've never gone away you know we've always talked about it but we've never <u>actually</u> gone away as a family with his sister all of us … so we won't have that option available to us again but on the other hand you know I just kind of keep saying well he's lucky to graduate from (Children's hospice) isn't he a lot of the kids don't so* (Juliet Int1).

They had discussed going away as a family without Joe but never did it because of fear of what might happen. Now she weighs up their own needs as a family against the reality that her son has survived his childhood. He has outlived some of his cohort, but as provision changes in adult services, opportunities for the family are lost. Through this intense caring, holding onto her child's life, she subjugates not only her own needs but those of other family members. She believes that the system does not provide for future breaks, but does not want to risk placing him in residential college, so she is forced into deciding to remain a carer with less support.

Maryam identified respite as "*probably <u>one of the most crucial</u> services"* because it gave her the opportunity to spend time with her other two children and "*gave her [Anya] a chance to be away from home be independent and then to be cared for by other people like in a whole in a whole 24 hour kind of circle".* The significance of the "*24 hour circle"* is that Anya slept in a bed away from home, giving Maryam a break from night vigils, but importantly preparing them both for a bigger separation.

Maryam explained what Anya's move to residential school meant for her own future:

> *Once she goes off to college it will be me then you know sitting down and saying "Okay I need to go back to work" I need to find some kind of work that I can fit into where if Anya is unwell and needs to come home I have that flexibility or you know she's going to be home at midterm she's going to be home in the holidays I need that flexibility so <u>it's a big jump</u> because you're going from 20 years of caring full time 24/7 to actually going six weeks without having to do that and then going back into full time work where I haven't been in full time work since Anya was born so it's it's I think that's a big adjustment on all sides and a big <u>adjustment for her</u> because she's going to be in residential college you know away from home you know where she hasn't been away from home for longer than two nights ...so it'll be a big adjustment* (Maryam Int1).

She hopes to return to work, which she hasn't been able to do since Anya was born, but recognises she needs some flexibility in her working arrangements. Maryam's own independence is therefore only guaranteed by Anya maintaining good health. This vision, which is a seismic shift for all concerned, outlines what the Local Authority failed to "*understand"* in blocking Anya's placement: a young person would gain independence and a mother would be able to return to the workforce.

Maryam and Isabel are at their own respective life stages, whilst one seeks to return to work, the other looks forward to retirement. An independent future has become a reality for Ian and Isabel. As Sam is the only young person in this participant group who has left home, Isabel's account explores the "*landing"* that parents' experience when their child becomes fully independent:

> *His going to college was as much about him learning to live independently as also us learning to live without him 24/7 as well ...and we hadn't seen that second element until he went into supported living we suddenly had this massive realisation* (Isabel Int2).

Whilst her focus had been on successfully establishing Sam's independence, the transitions and placements, described in Theme 2, were driven by the parents' needs. After Sam was settled in his new home, she and Ian had a "*massive realisation"* that they were cut loose from the demands of intense caring.

They relocated to the West Country, and Isabel has built a new life which includes many aspects of wellbeing, such as dress making (creativity), hiking with a group (exercise and sociability) and working with a food project (giving back to society). However, she is also self-monitoring her activities. She reflects "*the risk is that I make myself over busy with lots of other things and so I am being quite careful about that*" and discusses relaxing with her partner.

A new order has been established. They visit Sam regularly, although he lives an hour and a half away, and are building relationships with his support team. Additionally, they looked for a house that could accommodate him when he visits them.

> *So it means with the two bedrooms on the level Sam could come and stay … erm and it turned out I hadn't realised it turned out that I felt quite relieved about that option being a possibility (*Isabel Int1a).

Her concern about sleeping arrangements reflects her ongoing care for and accessibility to her child. She reflects that she has had some concern about these issues and is "*relieved*" that the new house can facilitate ongoing interaction between them. Thus Isabel's account clearly demonstrates a move from interdependence between mother and son to both achieving independence in their own lives.

Peta and Phillip plan holidays with and without Paige, and also for Paige to go on holiday independently with support staff. However, the parents and Paige remain interdependent because they continue to manage Paige's care package and because of their current living arrangements. Peta voices her concern about the future

> *It is Paige's home and whilst we've got Paige obviously everything's fine it's a very expensive house to run so without Paige we wouldn't be able to afford to run it and obviously if we ever lose Paige does that mean that we lose our home at the same time ... Probably wouldn't lose it but we'd probably quite quickly sell it so that is the other thing that we would be.. we would lose more than Paige* (Peta Int1b).

She is unsure what would happen, thinking they would not be able to afford to continue living there. She expects they would have to sell the home that has represented a successful living together/apart arrangement and symbolises enduring interdependence between parent and child.

It is noticeable that across the dataset, only Peta acknowledges the possibilities and concerns of the parents' lives after the death of their disabled children. This is diametrically opposite to Isabel's "*under the bus*" view of Sam's life if she was no longer able to support him. The future for these parents and their families is neither clear nor predictable.

Summary of findings

Planning for the future is difficult and requires much more than achieving individual healthcare transfers. Transitions are complex. The accounts reflected how practically and emotionally challenging this transition period is for parents.

As part of the project, the parents were asked to submit photographs representing their understanding of transition. Peta took part in this activity (Fig.12). Although her focus remained on the transfer of health services, rather than a life course event, I have chosen to include it here:

Fig. 12 Peta's photograph representing transition

Peta wrote

> *It shows the movement from not perfect but sort of joined up health services into a world of very separate individual specialist health services. It not only signifies the divergence but also that feeling of flying off into the unknown alone for an unknown distance.* (Peta, email).

In many ways this photograph represents much more than the individual health services. It illustrates the complexity of multiple transitions. The findings discussed trace the parents' journey from extreme caring and protection, through negotiation with statutory services (who at times did not focus on the young person's specific needs), towards an acceptance or rejection of independence. There was divergence amongst the data set and in each case, those stages looked slightly different.

Parents were closely supported by friends, family and paid carers in their everyday lives. Within the transition process however, they had to call on more official sources of support. By exploring the symbolic role of the child's bed in their lives, I have been able to illustrate how closely parents cared for their children and how they had to adopt a different, more detached professional persona to negotiate for their child's future placements. Even when planning ahead, parents moved towards their own futures with some fear about what lay ahead, both for themselves and their children. In particular, parents' own futures were unknown during the transition process, echoing Peta's sentiment "*flying off into the unknown alone for an unknown distance*".

Postscript

(Update of participating families' stories, Summer 2024)

Joe had his surgery in a children's hospital, Recovery was slow but he was able to start a phased return to school three months later. Juliet said "We hope he will have returned fulltime before he finishes school in early July."
Anya started residential college in September 2023, however, due to illness she spent almost half the Christmas term at home. Maryam said "She has now settled in very well and is really enjoying college, seeing how she has flourished in a well-equipped specialist provision is amazing. We are so proud of her!"
Paige had come to the end of a two-year part-time college placement. Within the last year her health had been "much more precarious". Peta said "Our challenge now is managing our daughter's health as she gets older knowing she has a life limiting condition. There is a fine line between wanting to spend lots of time with her while we can but also trying to give her as much space and independence from her parents as possible in line with the wishes of any young adult. We accept that our next transition will be learning to live without our disabled child and the huge number of people involved in her care... I think she feels that her future is uncertain but she knows we will do all that we can to keep her safe, healthy and happy".
"Sam has been living in supported living with the same 4 housemates, for nearly 4 years,. Overall, he is stable, happy and comfortable. Sam knows what he likes and still uses VOCA on the iPad effectively to express himself." Isabel has concerns about his health with ongoing infections in his PEG site. She is also concerned about turnover of staff on the care team which she sees as "a perennial challenge for the care sector". Otherwise, she feels that Sam is in a good place. (May 2025)

Discussion

The parents in this study approached transition as a life course event, which they did not necessarily expect to arrive at given the vulnerability of their child. Findings confirmed those of previous transition research: that transitions are complex, involving elements of Education, Health and Social Care services, who do not work in unison (Brown et al., 2019). While trying to manage handovers from one service to another, parents focused on achieving positive outcomes for their children, not just in terms of health but also for their future lives and place in society (Jacobs et al., 2020).

However, parents found themselves fighting to prove their child's needs in the face of budgetary constraints from statutory bodies. Pictor Charts demonstrated the number of services that were involved with these families and revealed parents as the main co-ordinators of care at transition. Within the accounts, there was a clear indication that parents are required to prove the needs of their children in order to proceed. Whilst caring intensely for their children, who have often faced life-limiting illnesses, parents found this burden of proof both frustrating and emotionally exhausting. This finding echoes Brown et al. (2018), who identified parents as "advocates in emotional turmoil" (p.2418). At times, parents felt unheard, and turned to others for support. When parents made plans for their own future, (e.g. retirement, moving house), they required support to achieve the vision for independence their children to align practically with their own plans. Fear was an important factor in deciding what course parents would take, either keeping the young person at home or looking for residential placements.

The current study highlights the support networks of parents, using Pictor charts. The charts demonstrated that parents build their own networks prior to transition, but within the transition process they must turn to external sources for both proactive and reactive support. Proactive planning support may be mapped onto Jacobs et al.'s (2020) "practical" transitions, whilst the reactive support appears in response to the "organisational" aspects of transition, whilst negotiating the provision of services.

By examining these findings within the context of Bronfenbrenner's Ecological Model in conjunction with Twigg and Atkin's typology of caring, it may be possible to identify where these support networks are in place, and to identify gaps in provision.

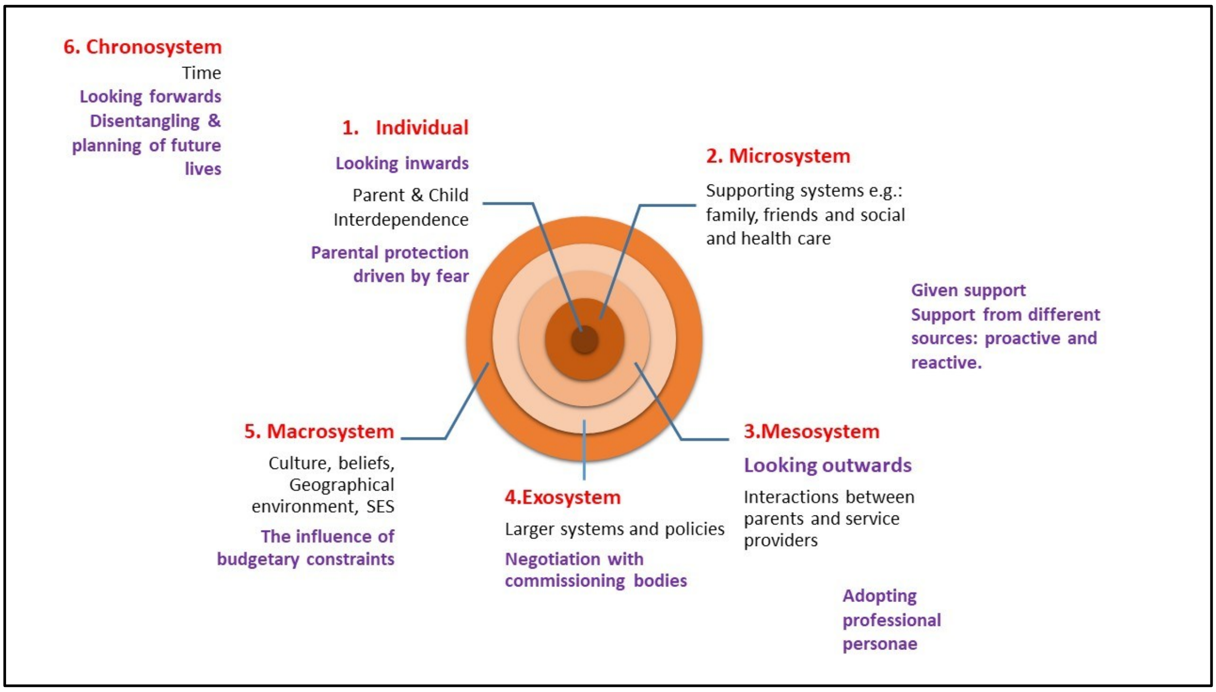

Fig. 13 Showing the themes and key findings mapped onto Bronfenbrenner's Ecological model

Application of Bronfenbrenner's Ecological Model and Twigg and Atkin's Typology of Caring (1994)

The previous chapters explored the parents' and their children's position within the framework of Bronfenbrenner's Ecological model, placing parents and young people at the centre of the model as interdependent (Chapter 3). Parents also worked with professionals, who are closely connected to the child, in the Microsystem and Mesosystem (Chapters 4 and 5). Within this study (Chapter 6), parents also act as advocates in negotiation with commissioners (the Exosystem) (Fig.13).

Individual

The needs of the parent and child are demonstrated to be interdependent throughout childhood, with the mother acting in a protective role between her child and the outside world. However, as the young person approaches adulthood this interdependence between mother and child shifts, particularly if the child goes into residential care. The mother still acts as an advocate and intermediary, but others are also encouraged to adopt more caring and protective roles. The mother moves backwards and forwards between the Microsystem and the Individual position at the centre.

Microsystem

Within previous transition research, the Microsytem (e.g. school, family and social care professionals) is identified as the network of support for the young person (Jacobs et al., 2020). Within the current study, if the parent stays at the centre of the model, the Microsystem is made up of key people including family, friends and established support (e.g. paediatrician and paid carers). At transition there is then a disruption of the Microsystem as people exit (e.g. paediatrician) and others enter (e.g. adult social care worker). Members of the Microsystem are generally people who recognise the needs of the young person and therefore understand the parents' position, as advocate. The parent interacts with all these people, but there is fluidity in the members of the Microsystem suggesting support is not always stable.

Mesosystem

Within the Mesosystem, parents can call upon the support of those people identified within the Microsystem. There are people who help with everyday care, but within transition processes, support is less dependable. For instance, a teacher or carer will not necessarily have in-depth knowledge and understanding of transition processes, and in these instances the parents have to identify other sources of support. Sometimes doctors, community nurses or social workers can facilitate introductions in the handover of care (Jacobs et al.'s (2020) "practical" transitions). In some cases, there were good outcomes, such as support in the home for Joe, which gave Juliet and John time together. However, when turning outwards towards the Exosystem in talking to commissioners, parents may turn to external support, such as charitable organisations, support groups, legal advisors for help. These are people who would not normally fall within the Microsystem built around the child.

Exosystem

Interactions with Education commissioners within Local Authorities in particular, were seen to be problematic. These organisation transitions influenced the way parents interacted with stakeholders. Parents felt obliged to adopt a more professional persona in order to speak the same language and work on the same level with commissioners. They felt they were not listened to, and had to work hard to affect changes, sometimes resorting to legal action. Although these parents were professional people in their work, they felt at times they were only perceived as parents by professionals. Parents therefore needed back up (e.g. advocates or legal representatives) to be heard. Parents felt exasperated and frustrated in the negotiations.

Macrosystem

Although parents supported the person-centred policies and held ideal views of what their child might achieve in adulthood, partly through accessing further education, it was clear that these policies were not reflected in the confrontations with Local Authorities, who referred parents to existing provisions within the local area even if they were not suitable. These policies gave hope to parents on one hand, but refusal of the Local Authorities to provide these services, had a major impact on the emotional state of the parents, as well as affecting their own future plans.

Chronosystem

Parents felt that they were at the threshold of a new period in their lives and in the lives of their children. With this new era, there was a sense that their identity shifted from the main advocate to a member of the team, as demonstrated by the move from the centre of the model into the Microsystem. Their legal status as primary decision-maker changed as their child reached 18; thus, parents felt challenged at this point and going forwards. Additionally, it was difficult for parents to envisage and plan their own futures, while the outcomes of their children's provision were still in question. For some parents, fear of harm to their child by external forces or the threat of the young person's death, due to life-limiting conditions was the deciding factor in remaining as primary carer post 18 years.

Twigg and Atkin's Typology of Caring (1994) defines carers as:

- *resources*
- *co-workers*
- *co-clients* equal in status with their own needs being met
- *superseded carers* by either independence for the young person being achieved, or by an inability to continue caring.

Within this study, parents did not see themselves as isolated, except in the timeframe of Covid-19 restrictions, which affected some of them for longer than the general public, and Anya in particular, because of her vulnerability post-transplant. However, it seemed that the parents worked well with the supporting members of the Microsystem, maintaining the primary caring role, and thus may be defined as *co-workers*. Furthermore, they could be considered *co-clients,* with the provision of respite. However, as provision was patchy (Maryam, Juliet) or non-existent (Isabel) this was not a stable definition. Paige's arrangements allowed for her parents to have their own space and support, so might qualify for *co-client* status, but they had given up work to run the house for Paige, and their position was therefore ambivalent.

In the later stages of transition, it is possible to see that only Isabel had successfully moved to a position of *superseded carer*, with both independence achieved for her as well as for Sam, through their wish to retire to a new area. Isabel's own concerns about no longer being able to "*care for him 24/7*" also defined her as superseded.

Discussing Pictor

The aim of using the Pictor technique was to facilitate discussion, but furthermore to concentrate the focus of the interview on transition experiences. The method was used in a variety of ways, in person, developing the chart in real time online and with a pre-prepared chart online. Although Pictor charts were successfully used to discuss transition, it was inevitable that background history and the personal experiences leading up to that point were also discussed.

The resulting discussions varied in content and to some extent quality. The significant difference was between the charts that were developed within the interview, and therefore simultaneously with the conversation, as opposed to those that were developed beforehand. While working online with Isabel presented some challenges (e.g. sharing the chart as it developed), the flow of the interview was not significantly affected. However, the complexity of the chart Maryam produced and sent to me three days before the interview, required me to study it and influenced the way the interview was carried out. The interview was therefore less spontaneous and was led by my questions about different aspects of Anya's care. Isabel's Pictor chart for the second interview was developed just before the interview, and she shared the pictures online whilst we were talking. This felt more participant-led.

The support networks for young people were explored first within the interview and used to explain background, and what happened at transition. Those charts (Figs 4,5,7,9,10,) visually represented a large number of people and different stories, and are symbolic of the complexity of the lives of these families, where parents are co-ordinators of care. It is therefore possible as an observer to understand how the parents' time is limited for other people like friends.

Three of the participants considered how the chart should look, and how it reflected the relevant support networks. Transition is clearly defined as an event in time, demonstrated in Peta's and Isabel's charts (Figs 4,9,10). The former showing before and after. The latter, the journey's course demonstrated by the direction of the arrows. Juliet who said she was used to working with Post-it notes, adopted a less structured approach, using Pictor as a tool to facilitate discussion, rather than producing a visual reference of support networks. However, the resulting chart might also result from the chaos and inconsistent transitions she felt they were experiencing. Juliet was unable to pinpoint one service to predict what would happen.

The exercise also defined the difference between the parent's support and the young person's support. In comparison, the parents' charts (Figs 3,6, 8,11,) were sparsely populated and highlighted the lack of support for them in the transition process. Variance is reflected in the comments made afterwards. When asked about the process of making the chart, Maryam commented:

> *Oh my gosh I knew a lot of people but you know you don't realize when you until you look at visually how many people there are you know but yeah it takes a lot of different departments different people different I mean they're in completely different areas as well I mean in areas in terms of health education out of education you know there's just so many* (Maryam Int1).

On the other hand, Isabel struggled to name support that was available to her. We took a break in the interview; she talked to Ian about it and came back to the task (Fig. 11). Afterwards she became emotional, I checked she was all right, and she commented:

> *ISA: the upsetting bit is the support I had*
> *I: yes?*
> *ISA: it's not upsetting it just makes me emotional (laughs, tears in eyes)*
> (Isabel Int1a).

Role of the TRAG

The TRAG were involved in every stage of this study. At the outset, they discussed the inclusion criteria as well as the demographic questionnaire and the interview schedules, making useful detailed suggestions, such as significant transition points and the distance travelled to hospitals. Additionally, they trialled the visual methods. Their Pictor exercises were particularly illuminating. On reviewing their own charts, one member said that her son was "*lost*" amongst the services, while another said that there were lots of people available for her son but "*not for me*". Additionally, a parent said her own role was to act as a buffer between her child and the services which provided vital equipment, co-ordinating handovers in care at transition. Generally, looking at the charts, it was agreed that whilst there were lots of services around the young person, there were very few significant people around the parent. Later on, one member trialled Pictor online.

The TRAG reconvened to discuss the participants' Pictor charts and gave feedback on interview content. The group was especially moved by Maryam's story, and struck by her

Pictor exercises, commenting on her absence from the charts. One member commented on how much information regarding service providers Maryam "*must be carrying in her head*".

Reflexivity

Parent-researcher status

At the outset of the project, I was concerned with how I might approach parent participants and bracket my own experiences. Following conversations with my supervisors and other people during the bracketing interview process, I felt quietly confident that this challenge would be easier than interviewing professionals, as discussed in Chapter 4. In some respects, my expectations were met, and in others I found my preconceptions challenged.

I had read the ethnographic work of a social work practitioner, university lecturer, and parent-carer which struck a chord with me. I invited her to take part in my series of bracketing interviews, and we subsequently met online. We discussed the difficulty in researching a topic close to your own experiences, how you bracket that, how you let it inform your research. As discussed in Chapter 3, I was concerned with focusing too much on the negative aspects of transition. I wondered if my own experiences might lead to a negative bias within my research. She replied:

> *PA: Well we work quite closely with people with lived experience and carers and we have people come in and talk to students from their perspective,…overwhelmingly it does seem to be kind of framed in a negative way but like you said, it's more about the interactions with Social Work practitioners, with medical professionals, you know, all that kind of thing and I think I said somewhere in the book, people use that language of war, you know, they talk about it being a battle and you have to fight for things and that seems to be where the sort of sense comes from of it being a burden or challenging rather than, you know, dealing with or having a child with a learning disability, that part seems to be almost manageable for some people but it's the additional pressures, you know, like you were saying to go to tribunals to sort of go through, you know, all sorts of educational stuff as well as health and just people's just general lack of understanding, I think, that makes it so much more difficult. But it would be great to find more positive stories because I think that's, you know, there are some out there but they get kind of swamped by all the negativity, I think.*

She suggested that the negative experiences are well embedded in the service users' discourse, and so I understood I was not so much bringing my own experiences into the research, as discussed in Chapters 4 and 5, but rather acknowledging general experiences, as reflected in both the literature (Chapter 3) and by the TRAG.

Inevitably during the interview process, I found specific parallels with my own experiences. In particular, I was struck by similarities to my own experiences in the participants' accounts of family structures, friendship groups, and minor, but not insignificant, care issues such as nail cutting. Experience has taught me to expect parallels to crop up in interviews, and to deal with these accordingly. Sometimes I acknowledged them, as a way of expressing my understanding or empathy, and at other times I kept quiet. I was pleased when one participant said "*you get it*", and on those occasions when participants asked me about my own experiences it felt like a more natural dialogue.

Strengths and limitations

Covid-19 had a significant impact on this study in terms of recruitment, and contact with participants, as well as influencing the final design. Positively, the cross section of participant experiences at slightly different stages of transition, and their longitudinal contributions, added a new and dynamic aspect to this transition research. It synthesised individual accounts of stages of transition. Whilst Jacobs et al. (2020) adopted a longitudinal approach with a small cohort of young people and their support networks, the emphasis was on how relationships worked and transitions were achieved whilst focusing on the young person's needs, through the transition journey. This study is different in that it explores the parents' own transitions to their (in)dependence. The nature of support has been teased out from their accounts.

However, the study did not produce the quantity of visual material (e.g. photographs), as I had hoped. I feel that there were limitations in the design, which became significant due to Covid-19. It was difficult to access the parents, and I was hesitant to ask too much of them in terms of keeping in touch during the interim period between first and second interview.

The main strength of this study is the adoption of the Pictor Technique to gather complex information. Not only did it help parents to highlight the intricacies of transition planning and execution, but it also highlighted the different types of support parents rely on. Visually, it also demonstrated the number of people involved in the lives of young people with PMLD. Although the previous two chapters have discussed professionals working in partnership with parents to effect good outcomes for the young people, it could also be argued that the Pictor charts revealed that these "partnerships" as transitory and shallow. As Rogers (2011) states: "*knowing 17 different professionals isn't partnership... family life is a partnership too*" (p.572).

Although the visuals are impactful, seen on their own, they do not necessarily reveal much about the quality of those interactions between people on the charts, and are only really meaningful in conjunction with the interview data to help explain them. Further research looking at visual analysis of the relationship mapping, as suggested by Boden, Larkin & Iyer (2018) might elucidate hidden aspects of the charts. In particular, the parents' own support networks might be further analysed to explore the types of support and where they lie in relation to the participant to look for patterns across the whole dataset.

Conclusions

This chapter illustrates the challenges families of young people with SLD and PMLD and CHCN face in multiple transitions across Education, Health and Social care. It highlights that inconsistencies of support are emotionally challenging for parents, leaving them to experience feelings of anxiety, frustration and disappointment. Parents would like to plan for their own futures but feel unable to proceed without clear planning for their child’s future. Parents are sometimes uncertain about their legal status going forward, and fearful of losing their place in decision-making processes. At other times, parents find themselves overlooked by service providers and commissions. These findings will be discussed in conjunction with findings from the previous chapters (3,4 & 5) in the Discussion Chapter that follows.

Chapter 7

Discussion

Introduction

This chapter concludes the thesis. It starts by revisiting the thesis aims and objectives. This is followed by a summary of key findings from empirical studies, considering the role of parent-carers, service provision and disability legislation. In particular, the role of the parent-carer is scrutinised through the application of Twigg and Atkin's Typology of Caring (1994) and in the context of recent political thinking. I highlight how the thesis adds to research on Health and Social Care transitions for young people with PMLD, by presenting a relational view of parents within the transition process and highlighting the maintenance of a hyper-vigilant responsibility, where rescinding that responsibility becomes a source of conflict and uncertainty. Implications for parents' own support networks are discussed, in relation to both parental understanding of their legal rights, as well as professional understanding of and the implementation of the Mental Capacity Act and Best Interest decision-making processes.

The second part of the chapter considers methodological contributions of the thesis. I consider the role of the TRAG; use of creative methods, and use of poetry throughout the thesis. The application of theoretical models is also evaluated. Finally, I reflect on the understanding and insight I gained through the series of bracketing interviews and the value of this exercise within the research process.

Twigg (1993) states "*the duality of focus – the fact that we focus on the carer because of and within context of the relationship with the cared-for person - has to be kept central*" (p.154). Therefore, the parents' position within the transition process and their interaction with the professionals, as well as their child's needs, define the context.

Objectives of the thesis

The thesis considers how parent-carers of young people with profound and multiple learning disabilities (PMLD) and complex health care needs (CHCN), and the professionals who work with them, experience the transition from paediatric services to adult health and social care. The aim was to identify unmet support needs for those parent-carers and to make recommendations to service providers. The focus was on the parent-carers' role within this process, looking beyond how they support and advocate for their children (Jacobs, et al., 2020), to the impact of transition on them as individuals (Heath et al., 2017; Gauthier-Bordreault, 2017; Brown et al., 2018).

Key empirical findings

Three key empirical findings were generated within this thesis. Findings of the individual studies contribute to the literature both independently and as a synthesized body of work.

1. **Parent-carers as resources**

Whilst parent-carers and young people with PMLD and CHCN remained interdependent, the parental role significantly changes during the transition to adult services. Parents move from being experts in their child's care to being viewed as superseded carers. Professionals who worked closely with families were sympathetic to the parent/child relationship, as well as parental needs and concerns. However, the retention or loss of responsibility became a source of anxiety and tension between parents and professionals.

2. **Perceptions of the parent role**

Professionals who were more removed from the family unit, such as commissioners, believe independence is the goal for Preparing for Adulthood. They were less understanding of the interconnectivity of parent and child, and therefore the parental role going forward. Professionals often saw parents as relatives without legal status.

3. **Parent futures and legal status**

Parents could see themselves progressing into the position of superseded carer, and their legal status became an area of concern. Additionally, there were concerns about the future, and conflict between establishing their own futures and the needs of their child.

Discussion of findings in the context of existing literature

Parent-carers as resources

Findings of this thesis showed parents are focused on their children's health and wellbeing, and safety. Parents believe they understand the children's communication styles and act as proxies and advocates (Chapter 4), particularly in hospital settings. This pattern may set the tone for the future and causes fear of adult services (Chapter 4 & 6). Within Twigg and Atkin's Typology of Care (1994), parents may then identify as *resources,* as they adopt the primary caring role, often relying on informal support from family and friends, whilst retaining responsibility. The intense care element may not be recognised, and external support is not provided whilst there is informal family care. Oulton (2019) suggests that there is a risk that the sense of responsibility may become "*self-perpetuating and invisible to others*" (p.925).

Professionals who work closely with families recognise both these parental concerns, as well as the young person's needs (Chapter 4 & 5). The experience of working within Covid-19 restrictions also gave professionals an insight and greater understanding of parents' sense of responsibility towards their children, as well as the children's vulnerability (Chapter 5). Jacobs et al. (2020) also found that there were close working relationships between parents and the professionals who actively supported their children. Parents are seen as *co-workers,* where support put in place for the young person might also benefit the parent; for example, short breaks for children can also be understood as beneficial respite for parents. Within the context of approaching transition, parent-carers are seen as *co-workers* when agencies may work alongside carers, who request help and information from professionals. Conversely, findings here suggested parents wanted to share their knowledge, and felt frustrated when this did not happen (Chapter 6). Heath et al. (2017) stressed the importance of close working relationships and mutual trust to allay fears and achieve effective planning.

Approaching transition, parents want their child to be cared for and to live their "*best lives*" in an environment where their children's communication and needs will be understood (Chapter 6). Parental loss of responsibility is challenging because their role as communicator is threatened, and they move from being chief advocate to being part of a team within the decision-making process, where health and social care are often involved. This shift is a significant reflection of the change from the family-centred care of children's services to symptom-led healthcare and individualisation within social care. However, the attitudes of service providers often dictate the role of the parents. MacKean et al. (2005) found that whilst parents valued healthcare providers who understood the uniqueness of their child and family situations and wanted to work collaboratively, healthcare providers valued parents who were able to take on the role of "*lead care plan designer and implementer and strong advocate*" (p.81). In other words, the role of advocate is not necessarily something that parents have adopted willingly but may have been put upon them. Therefore, the expectation that they would resign that role going into their child's adulthood is both confusing and a cause of anxiety.

As outlined in the Introduction, Twigg and Atkin's (1994) *superseded* carer is defined as when the carer is no longer needed owing to the increasing independence of the care recipient. Two routes may lead to the realisation of *superseded* status: firstly, by focusing on developing the independence of the young person, and parents choosing to step back; secondly, as parents get older, they are no longer able to care. However, within the context of transition, parents move from the role of *co-worker* to the role of *superseded carer*, because they are effectively made redundant by the organisational systems. In this way, the Twigg and Atkin's model (1994) needs a third category of *superseded* carer, who might be called *superseded-marginalised.* Additionally, parents' own needs are not acknowledged, contrary to the model (Table 1 below). Parents therefore feel undervalued, and anxious about their own role.

Perceptions of the parent role

Transition to adult services has historically been compared to falling off a "*cliff edge*" (Turner et al., 2025). This hiatus is clearly demonstrated through the accounts. Support around the child changes, and there is fluidity across the system, as service providers hand families over to adult teams; parents expressed anxiety at losing these established relationships (Chapter 4 & 6).

Within the professional study, key people had developed close relationships with parents. The role of key people such as the paediatrician and the GP were acknowledged across childhood and the life span (Chapter 6). Advocates and social workers, who help to bridge the gap between the parents and the other forms of support, felt parents were reluctant to let them go at this time. Similarly, some professionals expressed reluctance to let the young people go into adult services (Chapter 4). Jacobs et al. (2020) described positive relationships with those people who worked closely with their children, although the consistency of relationships was variable, especially with a high turnover of paid support workers. Other professionals may only appear in the lives of young people in temporary assessment roles, bearing significance in the transition window, but not as future support, which parents sometimes found confusing (Chapter 4). Consequently, parents are in a state of "*emotional turmoil*" (Brown et al., 2019, p.2418) and uncertainty.

Parents talked about family members as a support but also at one place remove, and people who once helped were now missing from the support network. However, when it came to transition, these family members were not able to help with the processes of information gathering, decision making, handovers and appeals. Only partners were able to assist in the processes. Jacobs et al. (2020) also observed that at this level it was difficult to draw on help from the extended family, tending to turn to other families of children with disabilities.

Within a broader context, the professionals' study (Chapter 4) demonstrates the intersection of the people who work with families, and the influences of commissioners and funding bodies, and macrosystems, such as Government models, policies and legislation, and societal values. Jacobs et al. (2020) found that families and young people had "*very little involvement in 'wider' decision-making*" (p.1074). Decisions around service provision and planning were shaped by availability and financial constraints. Within the current studies it was found that whilst these constraints are present, the ideological frameworks of individualisation and independence permeate discussions about transition.

Larkin and Mitchell (2015) remind us that personalisation is a political agenda which promotes greater personal independence and control, by offering choice. This discourse was clearly seen within the professionals' study, particularly those working in social care and advocacy, discussing designing services around young people. These goals were also echoed by Isabel's hope that Sam would live his "*best life*". However, within this discourse there is an assumption that the young person becomes independent on achieving adulthood, like their neuro-typical counterparts. There is a risk that parents become marginalised, not by the people who actively support families, but by those commissioners who do not have first-hand experience of the young person or their parents. Larkin & Mitchell (2015) state:

> "*Individualism is premised on personal fulfilment and self-actualisation, i.e. autonomous identity and agency for both carers and the cared for person" (p.193*),

but within these studies, there is little evidence of support for carers to facilitate fulfilment and self-actualisation; for example, Maryam's need to resort to a tribunal to achieve independence for Anya **and** the opportunity to return to work. Consequently, I argue that parents again can be viewed as *superseded-marginalised* carers. Jacobs et al. (2020) found

> "*differences in conceptualisation of independence as an absence of support, compared with a more relational understanding that valued consistent and supportive relationships in young people's lives*" (p. 1077).

Furthermore, a shift was observed in the interactions of parents with commissioners (Chapter 6) in terms of how they presented themselves and their self-identity, such as presenting a business-like persona (Isabel and Peta), and using appropriate language (Juliet). However, there was also suspicion that transition goals, such as further education, were meeting parents' own needs and not necessarily in the best interests of the young person. This finding contradicts Jacobs et al.'s (2020) observation that it was "*striking*" (p.1069) that in relation to their own needs as carers, parents' wishes for transition were always discussed in respect of the needs and choices of their children.

Parental futures and legal status

With the ideological discourse around independence, commissioners see transition as a cut-off point, when the parent should step back. The parents' legal position was not always understood within the studies. Professionals comment that parents do not understand their new role, especially when assessments are made (Chapter 4). Some parents also discussed their lack of understanding of their own rights. Additionally, some professionals stated they did not understand what the parents' rights to contribute to the decision-making processes were, in terms of consultation.

Although the Care Act (2014) and NICE guidelines (2016) state that parents should be involved in decision making in the transition process, there is uncertainty beyond transition as the parents' legal status changes, from the key decision-maker to one of a team at Best Interests meetings for their child (Chapter 4). This major shift in identity is central to parental worry. Understanding around deputyship and Mental Capacity are often unclear for parents, as they potentially lose control (Chapter 6). Brown et al. (2019) found that parents "*lacked detail on the legal dimensions that would allow them to remain fully involved in decisions about their child's health care*" (p.204).

Professionals expressed concern that parents should engage with the issue at an early age, but also believed that parents might not be ready to deal with the emotional implications (Chapter 4). Within the small group of parent participants, there was a variety of approaches: from Isabel's application for Deputyships, backed by Ian's efficiency and legal training, to Juliet's uncertainty about the process. It was clear the onus was on the parents to find out about the processes of becoming a deputy, which is complicated and expensive (UK Govt, 2025; Scope, 2025). When the child reaches the age of majority, defined as legal independence at the age of 18, parents may apply for Deputyship. The young person has to be assessed to ascertain whether they lack mental capacity in decision making. These assessments, often made by doctor, or senior social worker, are followed by applications to the Court of Protection for Deputyships in Personal Welfare, and/or for Property and Financial Affairs. Fees are payable for registration as well as an annual fee for supervision (Scope 2025; UK Govt 2025). Gauthier-Bordreault et al. (2017) suggests that acquiring guardianship (in Canada) is a complex process and is a new responsibility for parents to take on. Furthermore, Codd & Hewitt (2021) found that some parents used their Deputyship powers at a Best Interest Meeting to ascertain the outcomes they wanted for their child.

There was fear of what the future might hold for both parents and their children, contrasting a sense of limited time (Peta) with the longer view of who might look after their children after they die (Isabel). These findings echo those of the poetic synthesis. Preparations were made for care in the event of their death (Isabel's under the bus scenario) whilst parents in the poetic synthesis (Chapter 3) questioned who would care for their child after their death. Such concerns meant parents of young people with PMLD were afraid of dying before their child, sometimes expressing a wish that their child might die before them (Kruithof et al., 2021).

Identifying support needs – a call for change

The marginalisation of parents at this stage, sometimes on grounds of legal status, requires consideration by policy makers and commissioners. When Brown argues

> *"parents and families have to be recognised as equal partners in care, who provide expertise on their children's complex needs as well as vital, unpaid support to the adult health service." (2022, p.6)*

he stresses the benefit of parental expertise and labour to the system, which are often unrecognised. Furthermore, it is suggested that, focusing on promoting the health and well being of families may alleviate "*the strain on services*" (Crotty, 2016, p.32).

This interdependence, which has been illustrated throughout the studies, is therefore a concept that might have more value than independence or dependence in the lives of young people with PMLD (Jacobs et al., 2020). Whilst it has been argued within the Disabilities Rights movement that interdependence might disable young people further by avoiding positive risk taking (Tomkins and Eatough, 2013) it is apparent that parents have a continued but altered role to fulfil as advocates for their children (Brown et al., 2022). Jacobs et al. (2022) argue that "*if we understand care relationships through the lens of interdependence we can see we are all in need of care, challenging the neat dichotomy of givers and receivers*" (p.11) and it is therefore acknowledged that parents need their own support at this time.

Gauthier-Bordreault et al (2017) identified four types of support that parents felt they needed: material, informative, cognitive and emotional. Whilst cognitive support relates to professionals understanding the needs of the young people, material and informative support relates to transition planning and information about the availability of services. Parents suggested their own emotions are dependent on the availability of the other support, stressing their frustration and feelings of helplessness. Additionally, Gauthier-Bordreault et al. (2017) suggest that the awareness that the young person has reached adulthood, but is still dependent, makes it difficult for parents to anticipate their own transitions. Thus, they require access to emotional support services, such as "*group meetings to share and offer opportunities to socialise*" (Gauthier-Bordreault et al., 2017, p.24). Additionally, it is recognised that both parents and professionals require education in the implications of the parents' change of legal status (Brown et al., 2020, Gauthier-Bordreault et al. 2017). Cairns (2012) emphasises that assumptions should not be made about parent-carers knowing about their rights and entitlements.

Ways of providing support

Codd and Hewitt (2021) make familiar recommendations for improvements within systems, such as increased collaboration between statutory services; but also suggest health services might facilitate meetings bringing parents in similar circumstances together. This dichotomy of top-down as well as bottom-up support is illustrated through two recent projects, and highlights the need for bi-directional support to be instigated.

Firstly, a top-down approach: Brown et al. (2019) suggest nurses have a key role in providing information and support to parents of young people with complex intellectual disabilities, as well as co-ordinating care. A transition specific education resource was therefore devised for nurses. It was trialled with child and adult health nurses, as well as other health and social care managers and health care professionals.

Four modules were developed based on

1. Understanding multiple co-existing conditions and health inequalities pertaining to young people with complex intellectual disabilities;
2. concepts of transition and good working practice;
3. the needs of young people and families based on **five** principle concepts;
4. the welfare system and legal system changes relevant to transition.

The **five** principles outlined in the family needs module were: strategic level planning; focus on early planning from 14 plus; clear transition pathways; multi- agency co-ordination; and continuity of care in the facilitation good handovers (Brown et al., 2022). These principles mirror government guidelines (Ofsted, 2024).

This training would facilitate nurses to advise and inform parents. Whilst Brown et al.'s (2020) model could meet the needs of parents who come into contact with such qualified nurses, the training only improves the knowledge of people within the families' immediate support network (Mesosystem). For real change to take place, the model would need to be adopted on a wider scale to include commissioners and policy makers.

Secondly, a bottom-up approach: a small-scale project within Shropshire, established by Shropshire Parent and Carer Council[25], demonstrated that bottom-up support is beneficial to those parents who access it (Shropshire PACC, 2025).

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[25] funded for three years through the Integrated Care Board

Launched in 2022, the Navigator project aimed to create peer support; promote quality of life outcomes for young people; support parent-carers to think ahead and participate in decision making; improve parent wellbeing and reduce the sense of isolation. Workshops covering EHCPs and finances, deputyship, post-16 law were well attended; initiatives for healthy lives, opportunities for friendship, and celebration events were promoted. The feedback from parents was positive in many aspects, including improved parent knowledge, sociability, empowerment, and wellbeing. This echoes a pilot study of a Family Facilitator-led Peer support group, in Canada (Kingsnorth et al., 2011), which found that parents were less focused on health transitions than the whole life course, as suggested by Jacobs et al. (2020) and the parents' study (Chapter 6).

The local project was deemed a success with parent-carers. However, it was reported that, despite developing working relationships with service providers and commissioners, the project co-ordinators were unable to make an impact on systematic issues and service development. As co-production working towards service improvement is a key principle of Parent-carer Forums, this lack of engagement was felt to be disappointing (telephone contact). Parent-carer Forums might seem ideally placed to facilitate support, as they are established to deliver support, but they are dependent on limited Department of Education budgets and applying for grants (Clarke, 2024). Scorgie and Wilgosh (2008) reported some parents find support and encouragement through contact with others with disabled children. However, parental attendance at support groups fluctuates depending on the age of the child, often attending post diagnosis.

Support directed at caregiver needs

Beach et al. (2022) argue that caregiver policy should not just support the caregiver in their caring role but also support them to flourish. They propose a positive model which describes social flourishing within relationships as well as on an individual level, in maintaining good health and self-actualisation. Although this model is achievable (for example, Isabel's post-transition life) it requires considerable support, encouragement and even bravery to adopt a new mindset.

While joining together with other parents to undertake training, and discussions about the future, might prove fruitful, there is still a need for practical support for those parents whose offspring still live at home. Overnight respite care post-18 is limited. As parents are classed as carers, they have rights to their own need assessments under the Care Act 2014, which should be independent of the needs of the person they care for (Larkin & Mitchell, 2015).

However, there has been a decline in the number of carers assessments since the Care Act (2014), due to the necessity for local authorities to keep within budget (Fernandez et al., 2020). Furthermore, Marczak et al. (2021) found that local authorities were building carer resilience through providing information and advice, but this support may be seen as preventative measures to keep parent-carers away from statutory support. Signposting parents to good transition information and support, such as provided in the Navigator project, may help parents but does not address underlying unmet needs in terms of practical support for their own wellbeing.

In summary, existing systems deflect social and economic costs onto families, making demands which extend beyond normative understandings of 'caring/parenting', such as legal advocacy, and service coordination. Support provision is patchy. Inevitably, there will be gaps that parents may fall through, as each child has different needs and each family reacts differently, so not everyone attends support groups or has contact with a specifically trained nurse. It is therefore essential that top-down support across all these issues is embedded at policy and funding levels.

Methodological contributions

Transition Research Advisory Group (TRAG)

Within the last ten years, there has been increased debate about the goals of Patient and Public Involvement (PPI); it is subject to much greater scrutiny, examining how it involves members of the public and represents their views ethically, ensuring it is not just a tick-box exercise for ethics approval (Martin et al., 2025). As documented in the Methodology chapter (Chapter 2), I established my own public involvement group, the Transition Research Advisory Group (TRAG) at the outset of the project and it is important to reiterate that they were involved in all stages of the project.

Reflecting on how this aspect of the project has developed, I consider two themes: firstly, relationships, and secondly, ethical working, which are closely intertwined.

I considered my own position within the group. I was their friend or acquaintance primarily; I had become a researcher running a group that fed into my research. I was trying to harness their experiences in order to bring issues they were concerned about to light, and in this respect we moved to a more collaborative way of working. I felt more confident to bring their opinions and experiences into the research interview exchanges. At the outset, I had barely discussed how the group would work with the project data, but this stage followed seamlessly on from previous work. We discussed their understanding of my findings as well, and their contributions are included in discussion sections. I learnt to listen, especially when their reactions and experiences were different to mine. In effect they became “ideas people” as well as “process people”.

There is a difference between an Advisory Group and full co-production. This group was devised as a group to advise me on aspects of caring for people with PMLD and working with their families. We worked together across all stages of the project, and went beyond my original plan for the group. Full co-production involves services users to help identify the topics that require scrutiny. Working practices in co-production have developed over the past seven years (Martin et al., 2025) and I feel in future projects I could work more inclusively and ethically. For example, we would work together to define their roles within the research, rather than handing them a job specification at the start. Furthermore, co-production can involve members presenting research findings, to wider audiences as demonstrated by Runswick-Cole et al. (2024).

Qualitative methods

The aim of the thesis was to explore the parents’ experiences and their role within transition, not just to discuss the services or the child’s needs. Combing the experiences and understandings of both parents and the professionals within the project allowed for the groups to reflect and comment on each other. The use of qualitative methodology illuminates parental lived experiences, in conjunction with the preconceptions of the professionals, bound with ideology, and sometimes conflict. In this respect, the qualitative methods employed also brought new perspectives to the findings of previous research relating to young people with intellectual disabilities.

Creative methods

Pictor

The individual cases presented in Chapter 6 demonstrate the complexity of care that parents provide. Pictor charts show the extraordinary number of professionals with whom they interact and the length of time that takes. Conversely, the parents' own Pictor charts show few sources of support for them. The visual representation of lived experiences, including putting names on paper, brought the reality of the experience to the interview. The names represent real people not just service provision, demonstrating the number of people involved, and reflecting the parents relationships with them. Thus, the Pictor exercise helped both researcher and parents to visualise and understand their support.

As discussed in Chapter 6, there were different ways of producing the Pictor charts, both in person and online. Online interviewing was new to me, but became necessary due to Covid-19. I have wondered whether my own lack of confidence in interviewing online, and the challenges that the Pictor charts raised in that respect may have affected the quality of the semi-structured interviews.

Whilst the professional study (Chapter 4) gave in depth insight into how social and health care workers understand the parents' role at transition, interestingly, professionals found it difficult to discuss parents' needs, except within the context of the Covid-19 pandemic. Therefore, it might have been enlightening to ask them to discuss a specific case study using Pictor. Firstly, this would potentially draw them away from the official discourse around transition and independence (King et al., 2013). Potentially, we would have been able to compare the charts with those of the parents, to further explore similarities and differences in understanding.

Use of Poetry

Within this thesis, I have used poems to tell the participants' stories in in an "*ethical, caring and empathetic*" manner (Faulkner, 2020, p.39). In order to reveal the breadth of data, the poems represent composite tales from the participants in 19 studies (Chapter 3) as well as the individual voices of participants in the original studies (Chapters 5 and 6). In particular, poetry has been used to represent the parents' experiences of caring (Chapter 3), the professionals' own experiences of working with families during difficult times, i.e. during

Covid-19 (Chapter 5), and finally to present descriptions of the young people at the heart of the research (Chapter 6).

Faulkner citing Prendergast (2020, p.161) states that

> *"Over the millennia, poets have spoken the truth as they have seen it about themselves, and the world around them, and oftentimes those truths have been challenging to speak and in difficult times and places" (p.161)*

The reader therefore understands the participant's truth, spoken within the poetry, through a phenomenological lens. We understand that the events existed but that our access to them are through the participants' descriptions of their experiences of caring, or working, at a particular time and place (Shaw, 2010), and often those times were challenging. The "*life-world*" is the focus of the accounts, that is "*the everyday world …which is lived, felt and understood by a conscious actor*" (Eatough & Tompkins, 2022, p164).

Eatough & Tompkins (2022) continue that "*language lies at the heart of [the] endeavour to understand emotions*" (p.163) and in this sense the poetry is used to understand and explain the emotional impact of events. In staying as close as possible to the participants' original language, I have aimed to convey their emotions. Two poems, in particular, I believe illustrate this emotional revelation through the exceptional use of language and imagery. In *Preparation for Adulthood* (Chapter 3), the image of the parent searching for a parachute, "*left hanging*" conveys shock and fear at the impending transition. In *They wanted me to work from home,* (Chapter 5) the narrator's emphasis that she is *"not having this"* in her home, because it is in her "*head enough",* highlights the emotional labour involved in working with families with disabilities, and mirrors the emotional challenges families face too.

However, the poems are also used to convey joy, as demonstrated in the parents' descriptions of their children. The young people interact with their families, are sociable, happy, and "*bubbly*". The poems distil the positive experiences of being with these young people and reflect the love and pride the parents have in their children. As Maryam states

> *"Even if you just met her for five minutes*
> *you'd remember her",*

and I would argue that the reader will remember these young people more through reading the poems than they would through reading a list of attributes.

Galvin & Todres (2009) refer to "*touched understanding*" (p.310) in the context producing research poetry. This is searching for something that touches the researcher, so it can touch others, with the goal of sharing insights "*in a way that is alive and has possible resonance and applicability*" (2009, p.310). As discussed in the reflexivity throughout this thesis, my own response to the stories I heard and read was often emotional and led me to work with the data in this way. The emotional content of the resulting poems has resonated with and moved audiences when presented at conferences[26], and seminars. Although, in a broad context, there may be resistance to poetry because may be seen as "*difficult …triggers more uncomfortableness in how to "read" it" and uncertainty about what it means*" (Camic, 2024 p.2), within this research context, I consider it to be an effective method of highlighting single accounts or bringing together multiple viewpoints.

Application of the models

Bronfenbrenner argued that "*research should be informed by social policy, the opposite of what scholars typically think, which is that research should guide social policy"* (Rosa & Tudge, 2013, p245). By adopting the Ecological Model, and building on Jacobs et al.'s (2020) findings, I have been able to explore how the downstream effects of the social and health care policies affect the impact of transition on parent-carers, and their support needs (Fig.1).

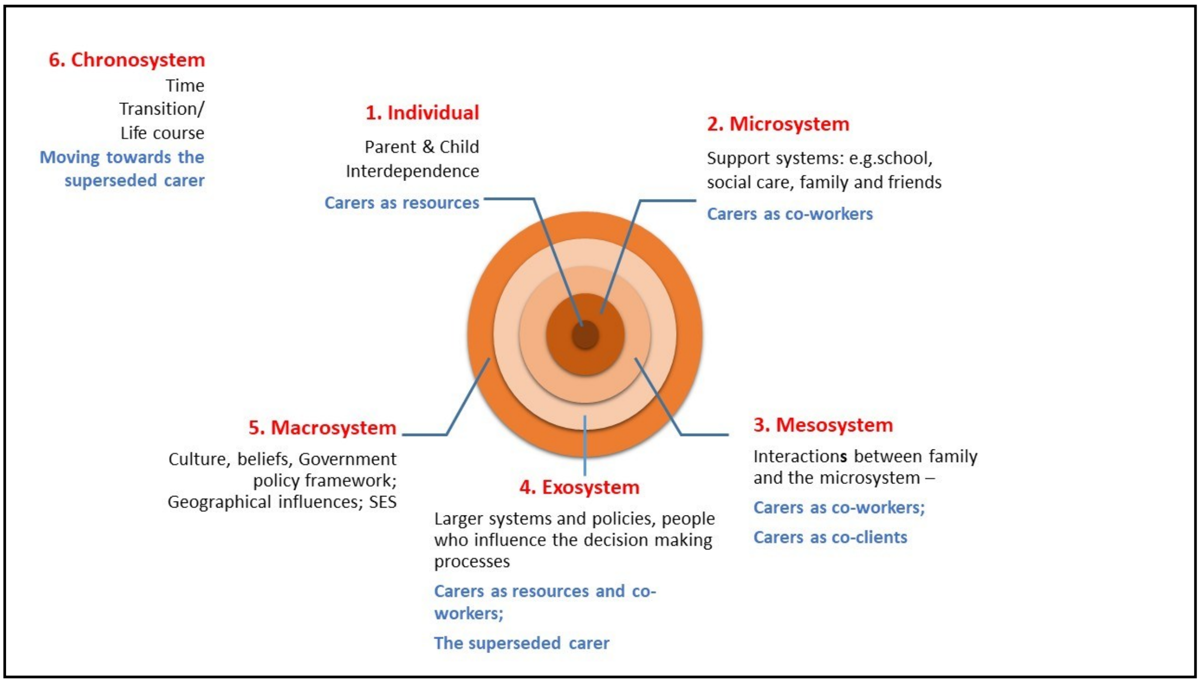

Fig.1 Bronfenbrenner's Ecological Model, adapted by Jacobs et al. 2020) in relation to Twigg and Atkin's Typology of Caring (1994) as generated through analysis within this thesis.

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[26] PIMD Special Interest Research Group at the IASSISS conference (2022): BPS QMiP (2022)

Eriksson, et al. (2018) claim a pragmatic view of Bronfenbrenner's Ecological theory "*which implies that concepts of a theory could be potentially useful even if used in a way that was never intended*" (p.429). Therefore, the additional layer of Twigg and Atkin's Typology of Caring (1994) (Table 1) is used to explain how the interactions described across the systems of the Ecological model relate to the role of carers within the power dynamics of relationships with professionals (Fig. 1).

	Carers as *resources*	**Carers as *co-workers***	**Carers as *co-clients***	***Superseded carer***
Definition of carer	Very wide	Wide	Narrow	'Relatives'
Focus of interest	Disabled person	Disabled person with some instrumental recognition of carer	Carer	Disabled person and carer, but separately
Conflict of interest	Ignored	Partly recognised	Recognised fully, but one way	Recognised, but in relation to both carer and disabled person
Aim	Care maximisation and minimization of substitution	Highest quality of care for the disabled person. Well-being of carer as means to this	Well-being of carer	Well-being of carer and independence for the disabled person, but seen as separate

Table 1 Twigg and Atkin's "Four Models of carers" reproduced from Twigg and Atkin (1994, p.13)

A strength of the adoption of this model is that some of those relationships were also observed by Jacobs et al. (2020), but with a different focus on the parents' lived experiences. Therefore, the current research adds to and builds on her findings.

Specifically, the Bronfenbrenner model brings together the experiences and opinions of both the parents and professionals involved in the transition process. The application of Twigg and Atkin's model (1994) adds a layer of interpretation to the findings of Bronfenbrenner's analysis, to expose the power dynamic between parent and the system.

Implications for practice

Implications for practice were drawn from findings and discussed with members of the Transition Research Advisory Group, who have first-hand experience of caring for young people with PMLD.

- Improved training for professionals in communication with young people with PMLD, as well as recognition of parental expertise, for example: Northway (2017) has suggested that an increased awareness within healthcare settings of the needs of young people with PMLD, would help parents to feel supported. Nurses need to understand that this is not solely a paediatric group and that young people will move into adult services (TRAG recommendation). Examples of health issues specific to people with PMLD should be included in general training modules for all nurses (such as within respiratory modules) – as opposed to specialist learning disability modules. (Chapter 3)
- Improving joint working. Consideration to be given to modes of communication to balance online and in person meetings. Online meetings save time and bring busy people together but also miss the fine detail from face-to-face meetings. Gathering professionals together with parents online is useful to share information, especially if the young person is not being assessed. The TRAG acknowledged the advantages of online meetings introducing the medical professionals whom their offspring would encounter in Adult Services The group commented that these sorts of introductions historically have been impossible due to time constraints and geographical limitations placed on healthcare professionals. However, the TRAG thought that parents and young people should still be offered to face-to-face consultations, particularly within the assessment process. They felt it was hard for professionals to understand the limitations imposed by the young person's disabilities, especially within communication and decision making, and this was echoed by health care professionals in the study (Chapters 4 & 5). The specific context of meetings (home or clinic) may also impact behaviours of the young person and should also be considered.
- A lack of understanding of the implications of the Care Act and the Mental Capacity Act was identified. Training should be promoted to parents as part of the 14+ review

process, so that they are prepared for the changes at transition. Although courses and information packs are offered by parent-carer forums, local authorities, third Sector organisations (e.g. Mencap) and national bodies such as Social Care Institute for Excellence, awareness needs to be raised amongst parents, and opportunities given to discuss their changing role with someone who knows their circumstance, such as their child's social worker. (Chapters 4 & 6)

- Exploration around life planning for parents. Person-centred planning, adopting tools such as MAP and PATH[27] (NDTi, 2025), for both parents and their children should be encouraged. Person-centred plans were part of the labour Government's initiative *Putting People First: A shared vision and commitment to the transformation of Adult Social Care* (Department of Health, 2007), with young people in transition as a target group. However, funding was cut under the Coalition Government in 2010. An educational psychologist in the Professionals study (Chapter 4) discussed how life plans were currently being used to help develop goals for young people within EHC plans, within her local authority. Developing such plans clearly set out goals and responsibilities for the people closely involved with young people to plan transition as a life stage and help achieve those goals.

  Whilst plans for young people may help achieve good outcomes for individuals (Martin & Carey, 2009), plans for parents may help them to focus on their own needs. Cairns et al. (2012) found that parents who had no plans were more likely to consider they had "*no future*" (p.41) whereas those with some sort of plan were less likely to view the future less negatively. Therefore, planning goals which may include their own interests and needs, alongside those of their offspring, may help envisage the future more positively. (Chapter 4 & 6).

- Parents should be supported from an early stage to discuss death, with professionals, carers and through support groups. There are two goals: firstly, to make plans for the young person's life in case of an unexpected death of a parent; secondly; consideration of advanced care planning for young people with PMLD and complex healthcare needs should take place (Lahaije et al., 2023; Todd, 2021). (Chapter 6)

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[27] Further information from National Development Team for Inclusion (NDTi, 2025) and Inclusive Solutions (2025)

Strengths and Limitations

A strength of this thesis is the adoption of multi-perspective and multi-method approach, situated in phenomenological epistemology, to understand parents' and professionals' experiences of transition.

Within the professionals' study (Chapters 4 & 5), a strength of the design was the inclusion of professionals from differing disciplines. Additionally, professionals were recruited from a variety of roles within those disciplines. The breadth of experience and multifaceted viewpoints were explored through the template analysis, giving a rich account of transition for families of young people with PMLD. To my knowledge, this is the first interpretative account that focuses on such a cross-section of professionals' beliefs in this context. The multi-perspectival design helped illuminate the difference in understanding transition as a process or as an ideology, both within the group of professionals, and between the groups of parents and professionals.

Additionally, the exploration of a sub-set of the data using IPA, highlighted the professionals' empathy with parents of young people with disabilities during Covid-19. Using research poetry to explore the emotional impact of working in constrained circumstances reflects subjectivity in the accounts and reveals hidden professional vulnerability.

There is a lack of published research involving the professionals relating to transition for young people with PMLD (Jacobs et al., 2020), therefore, the examination of the parents' role within the transition process from the professionals' viewpoint is an addition to the published literature.

In the parents' study (Chapter 6) the small number of participants and heterogeneity of the children's diagnoses could be interpreted as a limitation. Recruitment of families of young people with PMLD was difficult because they are a small, and hard-to-reach population, and was disrupted by Covid-19. However, the resulting participant group reflects the differing stages of transition that any one young person with severe learning disabilities (SLD) and CHCN or PMLD might traverse. The design was novel, in that it is not only focuses on parents' own needs, but also explores their experiential accounts. The findings are therefore emotionally nuanced, reflecting the parents' lifeworld.

Although the family of a young person with SLD and CHCN was included, it was clear that the parents' concerns and experiences closely aligned with those families with children with PMLD (Chapter 6). The common ground was the complex health care needs of the young people, which require constant monitoring, as well as the learning disabilities which severely affect their understanding within their daily lives. As discussed in the Introduction, the definition of profound and multiple learning disabilities varies from country to country, and, within the research literature, from study to study. Young people with PMLD are often pooled together with other diagnoses in research (Chapter 3), and therefore not recognised as an individual group. Within this study, three of the four children had suffered birth trauma, and were consequently diagnosed with cerebral palsy. The other young person had a diagnosed rare genetic disorder. However, I believe there is validity in exploring these families' experiences together. The parents are dealing with not **why** their child is disabled, but **how** they are disabled and consequently **how** they interact in the world. The findings reflect the universality of the many challenges parents of these young people face.

Quality Assessment

As outlined in Chapter 1, I have assessed the quality of this research according to Yardley's (2000) four criteria; sensitivity to context; commitment and rigour; transparency and coherence and impact and importance. I have held these criteria close to the research process throughout.

Sensitivity to context was considered by embracing the previous research, weighing up the contribution of Jacobs et al. (2018) approach, and adopting their adaptation of Bronfenbrenner's Ecological model, which gave context to the parents' situations. Whilst Jacobs et al. (2018; 2020) used a framework methodology, I used a more interpretative and phenomenological approach, aiming to yield new insights into parental experiences. Additionally, accessing the lived experiences of the TRAG helped to approach all participants with appropriate questions. Their knowledge was particularly useful in setting the interview schedules and trialling research techniques. The TRAG also contributed to the discussion of ethical issues, particularly emotional distress within interviews.

Commitment and rigour were demonstrated in the recruitment process as well as the analysis of findings. Covid-19 brought recruitment challenges, but time was spent developing the participant group, to obtain a representative cross section of people who work with families of young people with PMLD. Significantly, we had to wait for NHS staff to become available to take part. While the recruitment of parents was affected, the resultant line-of-argument longitudinal IPA allowed for a holistic view of the transition process. In both studies, several rounds of analysis in the Template Analysis and the IPA were undertaken. Discussions were held with supervisors, at every stage of the thesis, about its progress, findings and analysis. Findings were shared and discussed with the PHaR[28] group when available as well as the TRAG.

Transparency within the process is demonstrated with the process of bracketing interviews, the reflexive analysis and presentation of the findings. In particular, the discussion of my position within the research process has demonstrated transparency, in attempting to understand the participants' experiences, whilst considering my own experiences and beliefs. Coherence within the methods adopted a phenomenological approach, through semi-structured interviews across the dataset, but allowing for further exploration of lived experience through the use of the Pictor Technique.

The importance of this research is that it gives a new perspective on the experiences of parent-carers of young people with PMLD at transition to adulthood. In particular, it shines a light on the parents' marginalisation at that significant point in their lives, as a result of the systems and policies involved. This adds substance to the findings of other studies (Gauthier-Bordreault et al., 2017, Jacobs et al., 2020 Brown et al., 2020) furthering the argument for support.

The impact of the research is demonstrated through the use of poetry to bring the findings to a wider audience than the fields of study of intellectual disabilities and health psychology. Poetry conveys emotional content to a wider audience, whilst also enlivening the presentation of results within an academic context. Presentation of the findings of the poetic synthesis at BPS QMiP conference in 2022, led to a piece on poetry for The Psychologist's Communication themed issue (Slade, 2024).

Reflexivity

As previously stated, during this PhD I have actively engaged with reflexivity through the process of bracketing interviews, use of a reflexive diary, note keeping and talking to my supervisors and members of the PHaR group.

The recurring theme has been my combined role as a researcher and as a parent, which has been discussed within the studies. My different positions can be summarised as a parent with relevant experience, which I brought to the research process as follows:

- In Chapter 3 this gave insight to the interpretation of others' experiences

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[28] Phenomenology of Health and Relationships group, based at Aston University

- Chapter 4, I expressed a feeling of unease at being ill-informed and occasionally bridling those feelings within the research process,
- Chapter 5, the sense of power imbalances between myself and the professionals who cared for my son during Covid-19, was weighed against a deeper understanding of the personal sacrifices professionals made during that time, and
- In Chapter 6 recognising an empathy and understanding with the parents who participated in the study.

As a researcher, I remained aware of these positions, and hoped to use them to question my assumptions, but also gave them consideration when looking at my findings.

However, I also found that these varying positions were situated in the broader context of being a human, who might be both fallible and vulnerable. Whilst my parental position will always be acknowledged as part of being a human, this element also played into my role as a researcher, particularly when I felt I had adopted the parental stance too strongly. One of my bracketing interviewers suggested that we may need to give something of ourselves in order to put the participant at ease, and give ourselves permission to do that:

> *"I think we just develop, have to allow ourselves to be human".*

Furthermore, I felt that there was a dynamic between the theoretical Husserlian approach to bracketing, of laying aside all my preconceptions, which conflicted with the more involved Heideggerian approach of my research being informed by own experiences and those of the TRAG, when I stated

> *K: I suppose that's the thing is that, you know, you start off doing a PhD and it's a research project but it is qualitative, you know, so you start off with this well I'm going to be detached and then it's qualitative so you can be a bit more invested and then it's like, I'm human. That's exactly it, you know, I am a human in this story as well, I think, but...*

I was being a human reacting to stories, as a researcher, but also as the mother of a young person with severe learning disabilities. Consequently, the grid from the Axiology section of Methodology (Chapter 2) is redesigned to reflect my different positions within the research process, including my understanding of myself as a human at the core (Fig. 2). I believe that this position made me open to the lived experiences of both parents and the professionals in the analysis.

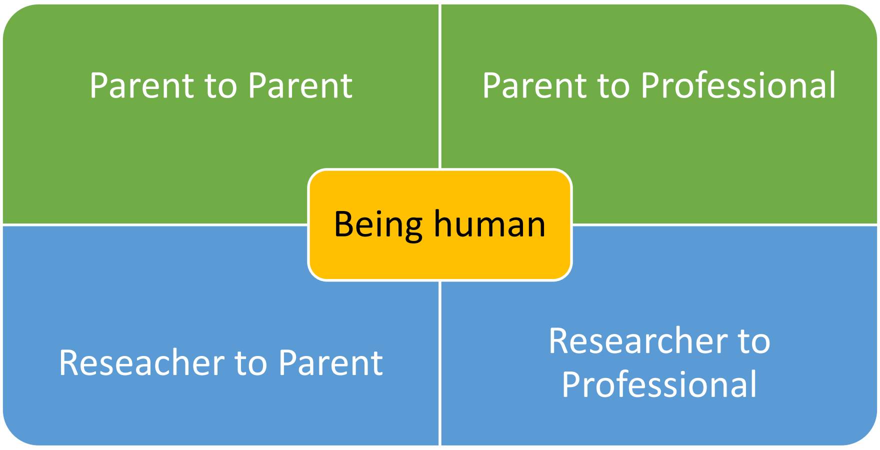

Fig. 2 Model reflecting my different roles within the research process

Langdridge describes defines two types of reflexivity: the "***personal*** (*the effect of the individual)*", in this case my position as a parent, and "***functional*** (*the influence of one's role as a researcher*)" (2007, p. 60) and cautions against drawing "*a realist epistemology in which the author is brought into the analysis to objectively validate the findings"* (Gough, cited by Langdridge, 2007). In considering my reflexivity in this way, I do not claim that my position as a parent adds validity to my findings, but rather it shows both transparency and rigour throughout the study (Yardley, 2000).

Am I an activist?

At the outset, one of my supervisors asked me if I was an activist. I wasn't sure how to answer the question, and as a result I drew the following poem from my first bracketing interview:

I am: a poem

I am the parent of a child with disabilities
I want the best for my children
I had to say "no I can't manage him anymore"
I felt I was being manipulated
I feel we've been through all this
to get to that level playing field
I see it was absolutely the right decision
I am quite confident
I pretend
I wonder sometimes, I sort of, you know …
I am still James's mum

I am a researcher who has personal experience
I understand my motivation for doing it
I feel they are up there,
floating around somewhere: little angels
I try to take a step back, let people tell their story
I hear their anger
I feel really privileged
I am feeling a bit more prepared
I hope to increase understanding
I dream of change
I am still James's mum. (2018)

In my final bracketing interview with a fellow researcher at Aston, we revisited this question of "Activism". Ryan and Runswick-Cole (2008) argue that

> "*mothers' (of children with ASD) experiences do not sit comfortably within existing articulations of activism but suggest that advocacy and activism may be experienced on a continuum. This may also explain why mothers take on what appear to be activist roles and yet do not identify themselves as such*" (p.52).

Within this continuum, I now find myself in the position of both a parent (as an advocate) and as a researcher (as an activist). Other (self-described) "parent-scholars" unsurprisingly have found that their position as parents informed their work within the field of Disability Studies, but also that their work has the "*potential to positively influence*" their own understanding of disability (Vaughan & Super, 2019, p. 1002), and I concur with these two assumptions. Furthermore, they suggest that their work in the field of (Critical) Disability studies "*articulates a need and responsibility for parents to grapple with alternative understanding of disability and alternative (collective) ways to create better social conditions for their children"* (Vaughan & Super, 2019, p. 1002).

Recommendations for further research

Further studies around the understandings of the change in legal status for parents of young people with SLD and PMLD at the transition to adult services are needed. It was found that both professionals and parents are uncertain of the implications of and specific interpretations of the Mental Capacity Act and Deputyship. It is suggested that these elements might be explored through both qualitative and quantitative methods.

Current research concentrates on the lead up to the transition process. Research exploring the outcomes for both the young people and their families in the years immediately after transition, as they adjust to new routines and potentially new settings, might help parents in the pre-transition phase to imagine and plan future lives. Furthermore, exploration of the use of life planning tools might be beneficial for parents. Additionally, the outcomes of young people with PMLD moving out the parental home to supported living might consider the implications the concept of independence for this vulnerable group.

Further use of the Pictor Technique to support interviews might help to explore and develop the method, particularly considering current developments in online working.

Concluding remarks

This thesis has explored the experiences of parents of young people with profound and multiple learning disabilities at their transition to adult Health and Social care. A poetic synthesis of qualitative evidence illuminated parents' experiences of caring for young people during the transition years of 14 to 25 years old, exposing intense caring, difficulties sharing responsibilities with service providers and a fear of the future. A template analysis rooted in phenomenological interpretation considered how professionals view both transition and the parents' role at this time. Differences in attitudes between professionals, who work closely with families, and the commissioners, who have less direct contact with families, were found to reflect a difference in how parents are perceived. The lived experiences of these professionals working during Covid-19 were further explored and presented through research poetry. Parents shared their transition experiences through a longitudinal lens, supported by a relational mapping technique, Pictor. The parents' role as superseded marginalised carers was established through the application of Bronfenbrenner's Ecological Model (1979) and a secondary analysis employing Twigg and Atkin's Typology of Caring (1994). The results were used to make recommendations for support for parents through top-down systemic education and bottom-up interventions for parents. It is also suggested that, if parents are well supported in this way, they should be able to plan their own futures.

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Young-Southward, G., Cooper, S. A., & Philo, C. (2017). Health and wellbeing during transition to adulthood for young people with intellectual disabilities: A qualitative study. *Research in Developmental Disabilities, 70*, 94-103. https://doi.org/10.1016/j.ridd.2017.09.003

APPENDICES

Appendix 1

Chapter 2: Methodology

Ethics paperwork:
Distress protocol for participant
Example of Parents' study Consent form
Letter of ethical approval from South Birmingham and West Midlands REC, 2019
Parents' recruitment poster, 2021

Appendix 2

Chapter 3: Poetic Synthesis

Theme Table
GRADE-CERQual SUMMARY table of qualitative findings

Appendix 3

Chapter 4: Professionals' study

Final table of Themes
Example of Theme Development Process (Theme 2)
Template Development Document
Marked up Transcript

Appendix 4

Chapter 5: Covid study

Final Template
Mind mapping of themes identified
Quotations for emotional impact
Developing a poem

Appendix 5

Chapter 6: Parents' study

Excerpt from Child's Demographic Questionnaire
Example of theme chart – Juliet's own support
Marked up transcript
Mapping the group experiential themes

Appendix 6

Transition Research Advisory Group

Recruitment:
Recruitment leaflet
Pen portraits of the key members of the TRAG
Consultation
Statement for Ethics Committee

- Meeting notes July 2018

Collaboration

- A pilot example of a Pictor chart
- A pilot example of photo elicitation exercise
- Meeting notes July 2023

APPENDIX 1

Chapter 2: Methodology

Ethics paperwork:

Distress protocol for participant
Example of Parents’ study Consent form
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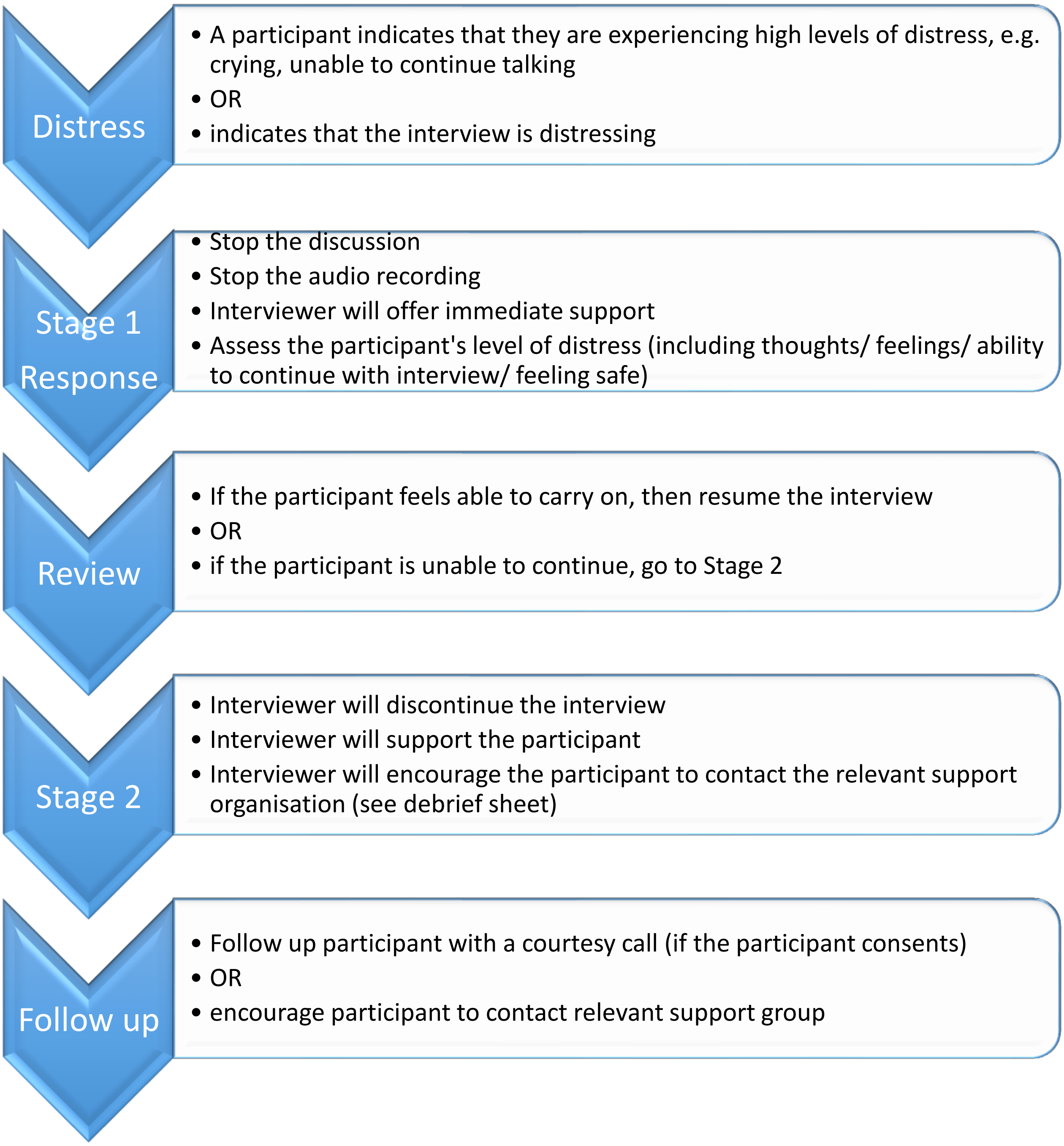
Parents’ recruitment poster, 2021

INTERVIEW DISTRESS PROTOCOL

The experiences of parent-carers of young people with profound and multiple learning disabilities at the transition from paediatric services to adult health care services



Distress

- A participant indicates that they are experiencing high levels of distress, e.g. crying, unable to continue talking
- OR
- indicates that the interview is distressing

Stage 1 Response

- Stop the discussion
- Stop the audio recording
- Interviewer will offer immediate support
- Assess the participant's level of distress (including thoughts/ feelings/ ability to continue with interview/ feeling safe)

Review

- If the participant feels able to carry on, then resume the interview
- OR
- if the participant is unable to continue, go to Stage 2

Stage 2

- Interviewer will discontinue the interview
- Interviewer will support the participant
- Interviewer will encourage the participant to contact the relevant support organisation (see debrief sheet)

Follow up

- Follow up participant with a courtesy call (if the participant consents)
- OR
- encourage participant to contact relevant support group

Aston University

The experiences of parent-carers of young people with profound and multiple learning disabilities at the transition from paediatric services to adult health care services

Consent Form for Parent-Carers

Name of Chief Investigator: Dr Rachel Shaw

Please initial boxes

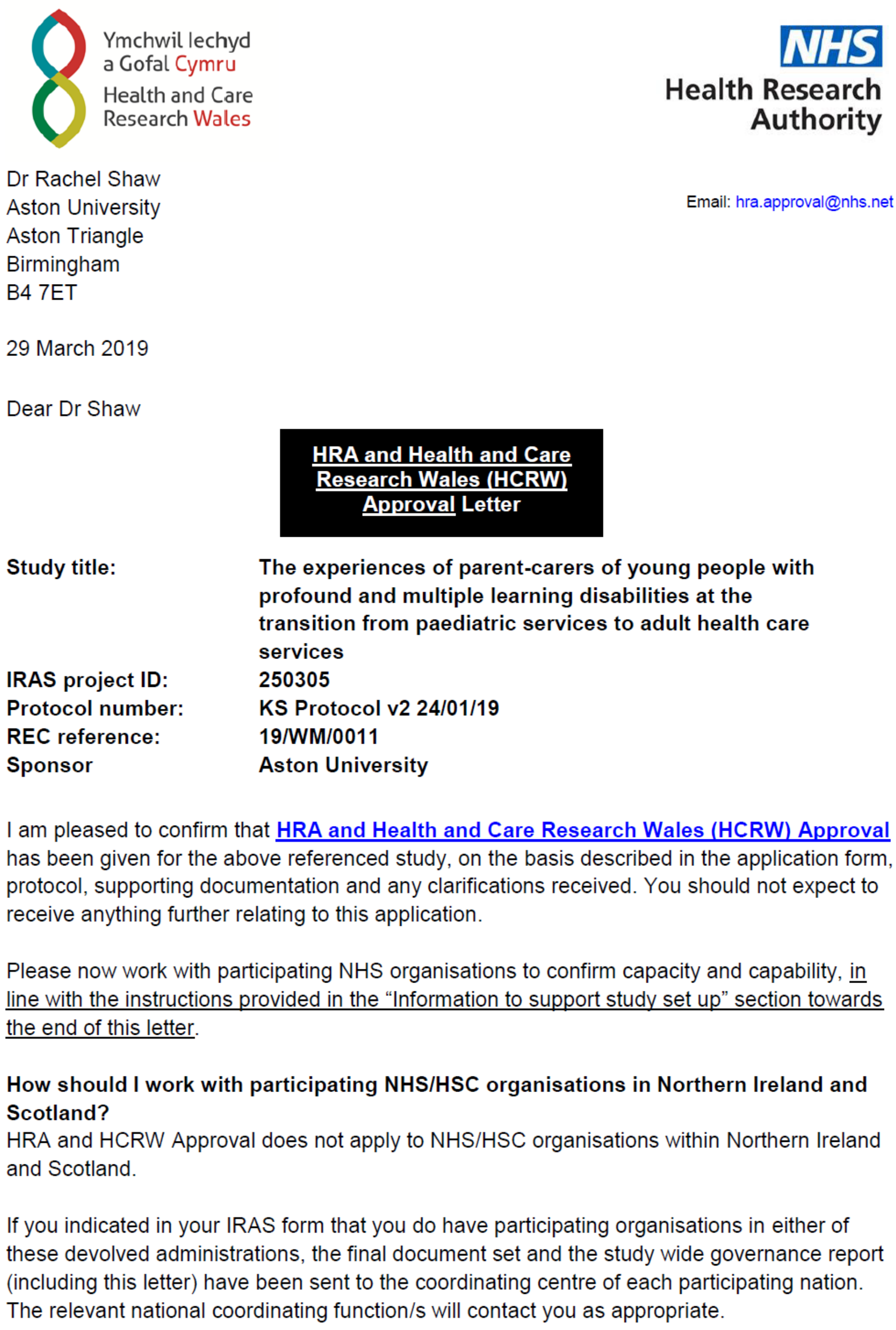
1.	I confirm that I have read and understand the Participant Information Sheet for Parent-Carers (Version 4, 19/02/2023) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
2.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my legal rights being affected.	
3.	I agree to my personal data and data relating to me collected during the study being processed as described in the Participant Information Sheet.	
4.	I understand that if during the study I tell the research team something that causes them to have concerns in relation to my health and/or welfare they may need to breach my confidentiality.	
5.	I agree to my interviews being audio recorded and to anonymised direct quotes from me being used in publications resulting from the study.	
6.	For Telephone/Skype/Zoom call interview only – I agree to my video call interview being audio recorded and to anonymised direct quotes from me being used in publications resulting from the study and for educational purposes.	
7.	For WhatsApp/Facebook Messenger/email interview only – I agree to my responses being logged and to anonymised direct quotes from me being used in publications resulting from the study and for educational purposes.	
8.	I agree to my personal data, being processed for the purposes of inviting me to participate in future research projects. I understand that I may opt out of receiving these invitations at any time.	
9.	I agree to take part in this study .	

____________________ ________________ ____________________

Name of participant Date Signature

____________________ ________________ ____________________

Name of Person receiving consent Date Signature



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Email: hra.approval@nhs.net

Dr Rachel Shaw
Aston University
Aston Triangle
Birmingham
B4 7ET

29 March 2019

Dear Dr Shaw

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**The experiences of parent-carers of young people with profound and multiple learning disabilities at the transition from paediatric services to adult health care services**
IRAS project ID:	**250305**
Protocol number:	**KS Protocol v2 24/01/19**
REC reference:	**19/WM/0011**
Sponsor	**Aston University**

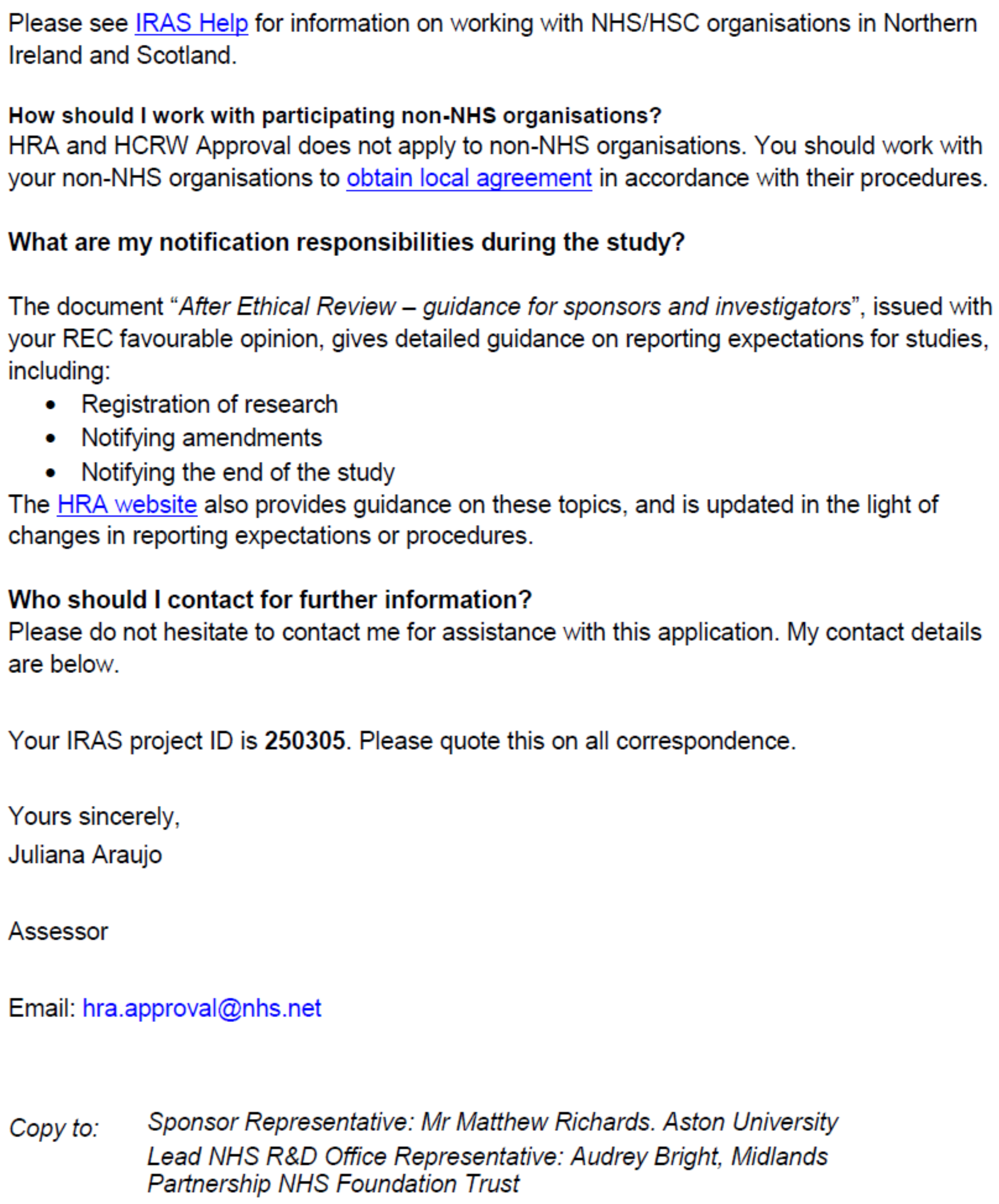
I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.



Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

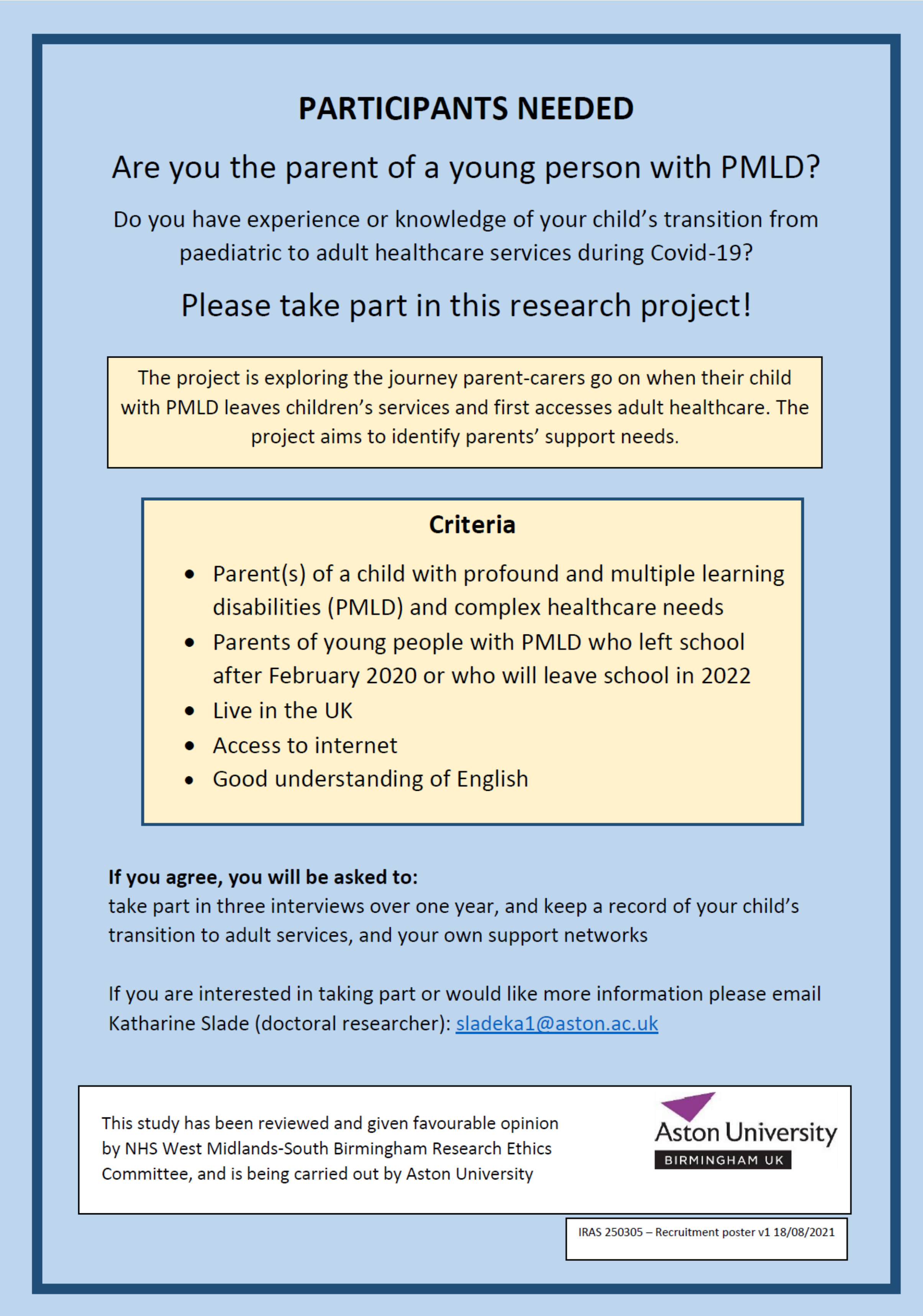
Your IRAS project ID is **250305**. Please quote this on all correspondence.

Yours sincerely,
Juliana Araujo

Assessor

Email: hra.approval@nhs.net

Copy to: *Sponsor Representative: Mr Matthew Richards. Aston University*
Lead NHS R&D Office Representative: Audrey Bright, Midlands Partnership NHS Foundation Trust



PARTICIPANTS NEEDED

Are you the parent of a young person with PMLD?

Do you have experience or knowledge of your child's transition from paediatric to adult healthcare services during Covid-19?

Please take part in this research project!

The project is exploring the journey parent-carers go on when their child with PMLD leaves children's services and first accesses adult healthcare. The project aims to identify parents' support needs.

Criteria

- Parent(s) of a child with profound and multiple learning disabilities (PMLD) and complex healthcare needs
- Parents of young people with PMLD who left school after February 2020 or who will leave school in 2022
- Live in the UK
- Access to internet
- Good understanding of English

If you agree, you will be asked to:
take part in three interviews over one year, and keep a record of your child's transition to adult services, and your own support networks

If you are interested in taking part or would like more information please email Katharine Slade (doctoral researcher): sladeka1@aston.ac.uk

This study has been reviewed and given favourable opinion by NHS West Midlands-South Birmingham Research Ethics Committee, and is being carried out by Aston University

Aston University
BIRMINGHAM UK

IRAS 250305 – Recruitment poster v1 18/08/2021

APPENDIX 2

Chapter 3: Qualitative Poetic Synthesis

Theme Table

GRADE-CERQual SUMMARY table of qualitative findings:

Chapter 3 Poetic synthesis - Themes across the included papers

		THEME 1 **INTERDEPENDENCY**		**THEME 2** **SHARING AND SHIFTING RESPONSIBILITY**		**THEME 3** **AN UNCERTAIN FUTURE**	
NO	Author	Retaining parental Responsibility	Communication	Negotiated care	Sharing Expertise	(In)dependence	Fear of Death
1	Bhopti					x	
2	Bindels-Heus	x	x		x	x	x
3	Brown	x	x	x		x	
4	Croot	x		x			
5	Davey	x				x	
6	Davies				x	x	
7	Davis	x					
8	Doyle		x	x	x		
9	Gauthier-Boudreault	x	x	x		x	x
10	Gibbs	x	x	x	x		
11	Griffith	x	x	x	x	x	
12	Lee	x	x	x	x		
13	Mitchell				x	x	
14	Oulton	x		x	x	x	x
15	Sim	x		x		x	
16	Stahle-Oberg		x		x		
17	Thackeray	x	x			x	x
18	Tomczynszyn	x		x			x
19	Young-Southward	x				x	

GRADE-CERQual SUMMARY table of qualitative findings:

THEME	SUMMARY OF THEME	PAPERS INCLUDED IN THEME	METHODOLOGICAL LIMITATIONS	COHERENCE	ADEQUACY OF DATA	RELEVANCE	CONFIDENCE
1. INTERDEPENDENCY							
RETAINING PARENTAL RESPONSIBILITY	Parents adopt a sense of responsibility which has no boundaries: they are responsible not just for caring for their child, but keeping them alive in complex medical situations. Parents are driven by intense love	**2,3,4,5,7,9, 10,11,12, 14,15,17,18, 19**	Moderate methodological limitations (2 papers with methodological limitations (unclear design, data collection and analysis; one paper with unclear ethical considerations; 2 papers with recruitment strategy issues) 9 papers with unclear reflexivity	No or very minor concerns about coherence	No or very minor concerns about adequacy	Minor concerns about relevance: 1 quite valuable; 4 valuable; 7 very valuable	High confidence
COMMUNICATION	Parents learn how their child communicates in the absence of verbal communication, and acts as a translator, mouthpiece, and advocate for their child	**2,3,8,9,10,11, 12,16,17**	Moderate methodological limitations: (one paper with inadequate design and unclear analysis; 2 with recruitment strategy issues; 8 papers with unclear reflexivity)	No or very minor concerns about coherence	No or very minor concerns about adequacy	Minor concerns about relevance: 2 quite valuable; 1 valuable; 5 very valuable	High confidence
2. SHARING AND SHIFTING RESPONSIBILITY							

NEGOTIATED CARE	It is difficult for parents to trust other people to care for their child. However, in medical situations parents turn to professionals for help. Parents sometimes seen as extensions of the child and are expected to maintain constant vigilance.	**3,4,8,9,10,11, 12,14,15,18**	Minor concerns about methodological limitations: (one paper with unclear recruitment, ethical considerations, and unclear analysis; 6 papers with unclear reflexivity	No or very minor concerns about coherence	No or very minor concerns about adequacy	Minor concerns about relevance: 1 quite valuable; 2 valuable; 5 very valuable	High confidence
EXPERTISE	Parents are experts in the care of their child due to the intense nature of their caring. When their child approaches adulthood, parents are often sidelined by professionals as the attention focuses on the young person as an individual in their own right. Parental expertise is often overlooked or ignored.	**2,6,8,10,11, 12,13,14,16**	Minor concerns about methodological limitations: ((one paper with possible limitations of data analysis; 4 papers with unclear reflexivity)	No or very minor concerns about coherence	No or very minor concerns about adequacy	Minor concerns about relevance: 2 quite valuable; 1 valuable; 5 very valuable	High confidence
3. THE UNCERTAIN FUTURE							
INDEPENDENCE V DEPENDENCE	While some services fall away at transition to adulthood, some parents feel their caring duties will continue indefinitely.	**1,2,3,5,6,9, 11,13,14,15, 17,19**	Minor concerns about methodological limitations (one paper with unclear recruitment, ethical considerations, and unclear analysis;	No or very minor concerns about coherence	No or very minor concerns about adequacy	Minor concerns about relevance:	High confidence

	Parents feel unsupported in this transitional period which leads to anxiety. Parents acknowledge and consider the possibility that their child can live an independent life.		one paper with possible recruitment limitations; 8 papers with unclear reflexivity)			2 quite valuable; 9 very valuable	
FEAR OF DEATH	Parents worry who will look after their child should they outlive their parents. Fear is compounded by negative emotions. They do not want to pass on the caring role to their other children. Some wish their child dies before them.	**3,9,13,17,18**	Minor concerns about methodological limitations (one paper with unclear recruitment, ethical considerations, and unclear analysis; one paper with possible recruitment limitations; 5 papers with unclear reflexivity)	No or very minor concerns about coherence	Minor concerns about adequacy (five studies with few quotations)	Minor concerns about relevance: 1 valuable; 5 very valuable	High confidence (limited data but strongly expressed)

Definitions of the components of the CERQual approach

Component Definition

Methodological limitations
The extent to which there are concerns about the design or conduct of the primary studies that contributed evidence to an individual review finding
Coherence
An assessment of how clear and cogent the fit is between the data from the primary studies and a review finding that synthesises that data. By ‘cogent’, we mean well supported or compelling
Adequacy of data
An overall determination of the degree of richness and quantity of data supporting a review finding
Relevance
The extent to which the body of evidence from the primary studies supporting a review finding is applicable to the context (perspective or population, phenomenon of interest, setting) specified in the review question
Descriptions of level of confidence in a review finding in the CERQual approach

Level Definition
High confidence It is highly likely that the review finding is a reasonable representation of the phenomenon of interest
Moderate confidence It is likely that the review finding is a reasonable representation of the
Low confidence It is possible that the review finding is a reasonable representation of the phenomenon of interest
Very low confidence It is not clear whether the review finding is a reasonable representation of the phenomenon of interest

APPENDIX 3

Chapter 4: Professionals’ Study

Final table of Themes
Example of Theme Development Process (Theme 2)
Template Development Document
Marked up Transcript

Final template

Theme 1 – Ideological thinking versus processes

THEME 1 **Transition v Preparing for Adulthood:** Historic context Legal framework around PfA (not MCA) **1. Ideology driven:** • Young person at the centre of the framework/choice • Preparing for Adulthood (Independence) • Social Care/Ed framework (inc Employment) • The role of education in preparing YP (Life skills etc) • Belonging – (Community)
2. Process driven: • Ongoing review • Early Preparing for PfA (inc 14+Healthchecks) (Healthy Living) • Assessments, eligibility, responsibility • Transfer of services: (Facing the Cliff Edge? (Language?) • Funding • Measurable outcomes/ goal setting?
3. Joined up working ▪ Working in teams (Childrens/Adults or Schools/colleges) ▪ Working across teams/(SC/Health/Ed) ▪ Working across Authorities   • Fragmentation

Colours indicate the differing rounds of analysis and template development

Theme 2 -Professionals and parents working together

1. **Understanding the parent**
    - Experts by experience
      {Advocacy – warrior mum v individual
    - Seekers and holders of information
      {Communication/Sharing information v ignorance?
    - Caring role
      Meeting basic needs & Admin
    - Social context:
      Resilience/social isolation/mutual support

2. **Working with parent/ family:**
   “Sitting by the parents’ side”:
    - Relationship building
        - (face-to-face)
        - Professional distance
        - Power Dynamic

    - Considering the future:
        - Person Centred Planning
        - Creative thinking, /Aspirations/
        - (what parents want?)
        - Managing Expectations (what parents get?)

3. **Support**
    - Sharing information/transfer of knowledge
    - Assessments

    - Practical support:
        - Information support
        - Planning support
    - Emotional support
      (Empathy/sympathy/trust)

Theme 3 – Barriers to Ideology becoming Reality & Recommendations

1. **Barriers to good transitions for young people**
    - Reasonable adjustments
    - Time
    - Communication

2. **Barriers to good transitions for parents**
    - lacking in information
    - time & energy,
        - physical impact
        - Poor practice
    - Financial status
    - Understanding Capacity & Parental Legal Status –
        - (Mental Capacity Act)
    - Emotions (Confidence, fear, stress, daunted)
    -

3. **Barriers in the wider context:**

    - Demographics
        -
    - Politics etc
        - Internal
        - Local
        - National
    - Lack of:
        - Communication
        - Understanding complexity
        - Training
        - Expertise
        - Preparation for group
        - Resources
        - Aspiration

          Time
    - Ethical dilemmas
    - Discrimination

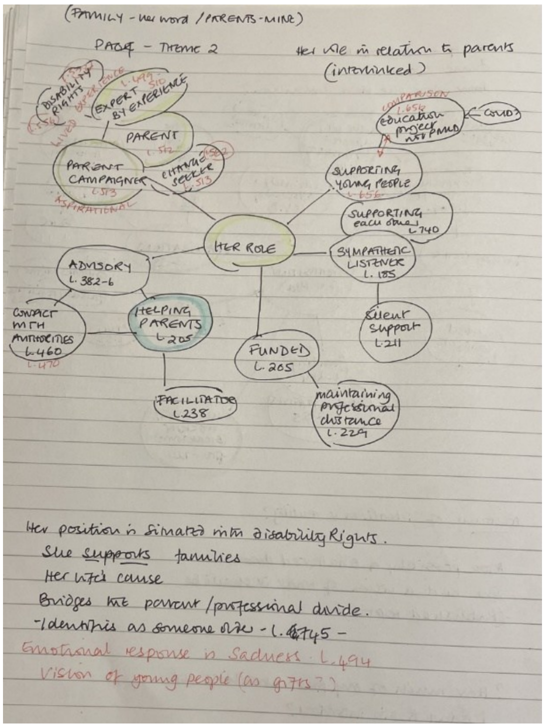
Recommendations:
Considering Others' roles:

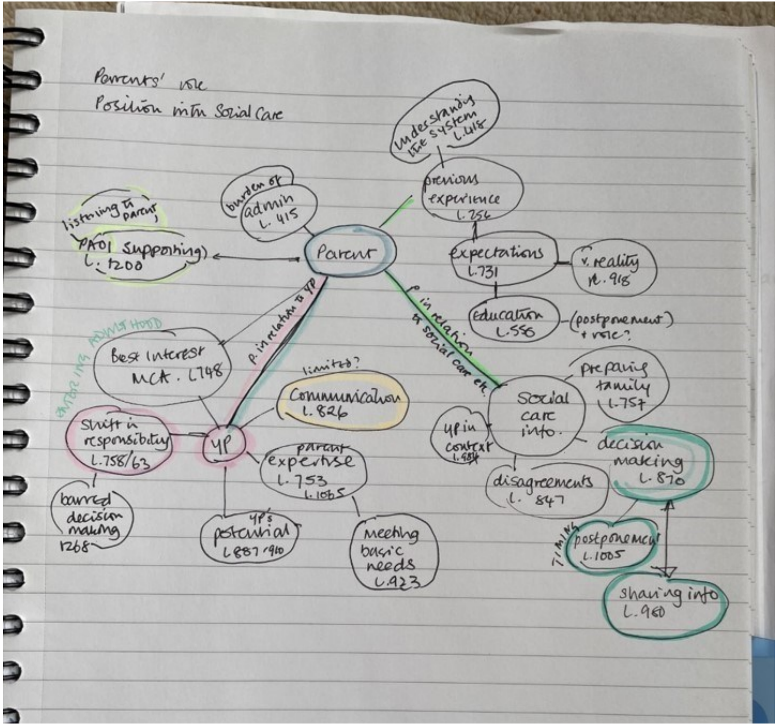
- Health
    - GP
    - Consultant
    - Paediatrician
- Social Care
    - Commissioners/brokerage
    - Social worker
    - Key worker?
    - Paid carers

- Education
    - Teaching staff
    - Connexions
- Third Sector
  - Advocate

Development of Theme 2 – From "Individual Roles" to "Professional and Parent Working Together"

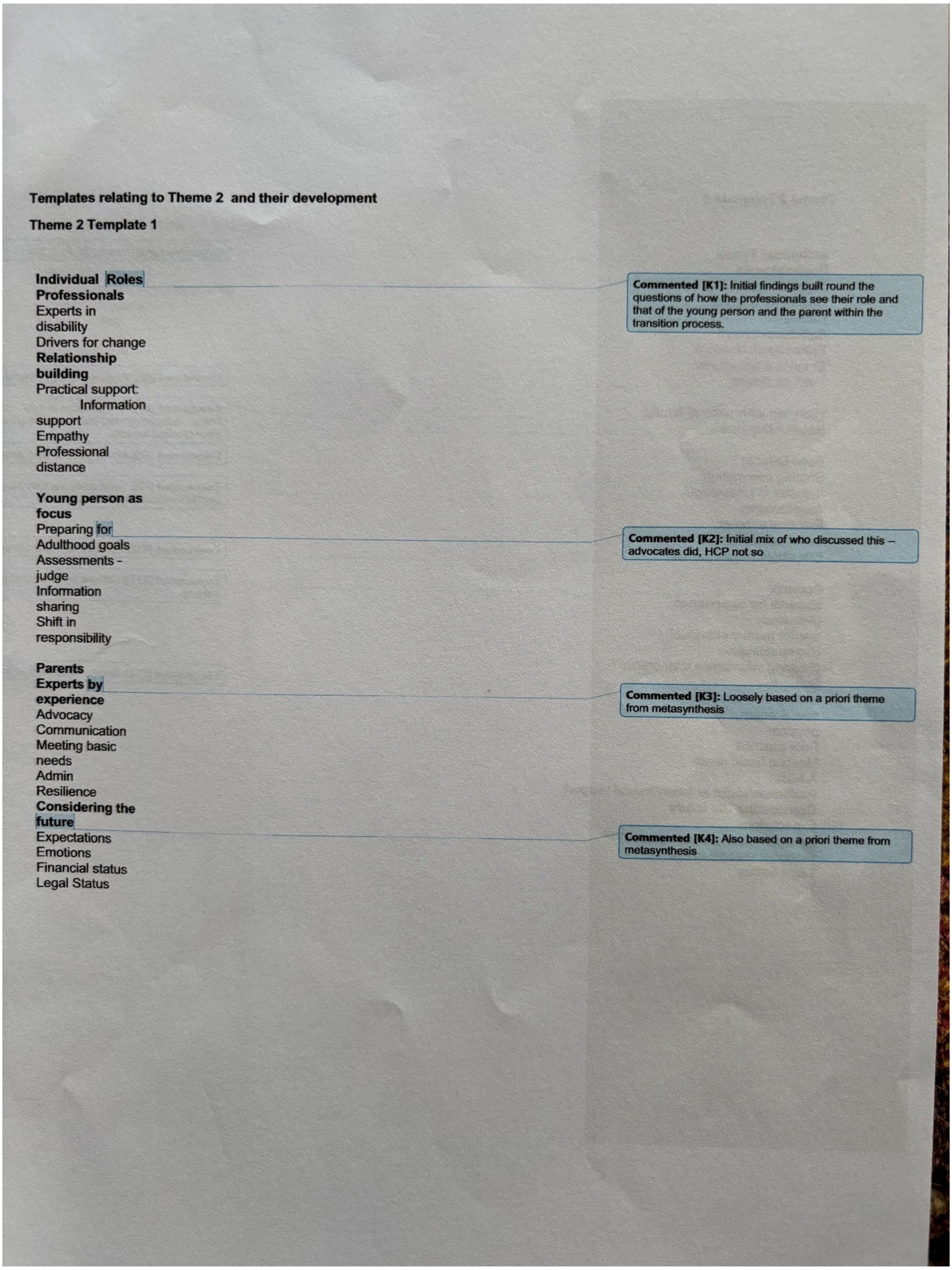
Examples of Extracts of Themes from Individual interviews in the first round of coding





Individual roles mapped out to access key ideas

Templates relating to Theme 2 and their development



Templates relating to Theme 2 and their development

Theme 2 Template 1

Individual Roles
Professionals
Experts in disability
Drivers for change
Relationship building
Practical support:
Information support
Empathy
Professional distance

Young person as focus
Preparing for
Adulthood goals
Assessments - judge
Information sharing
Shift in responsibility

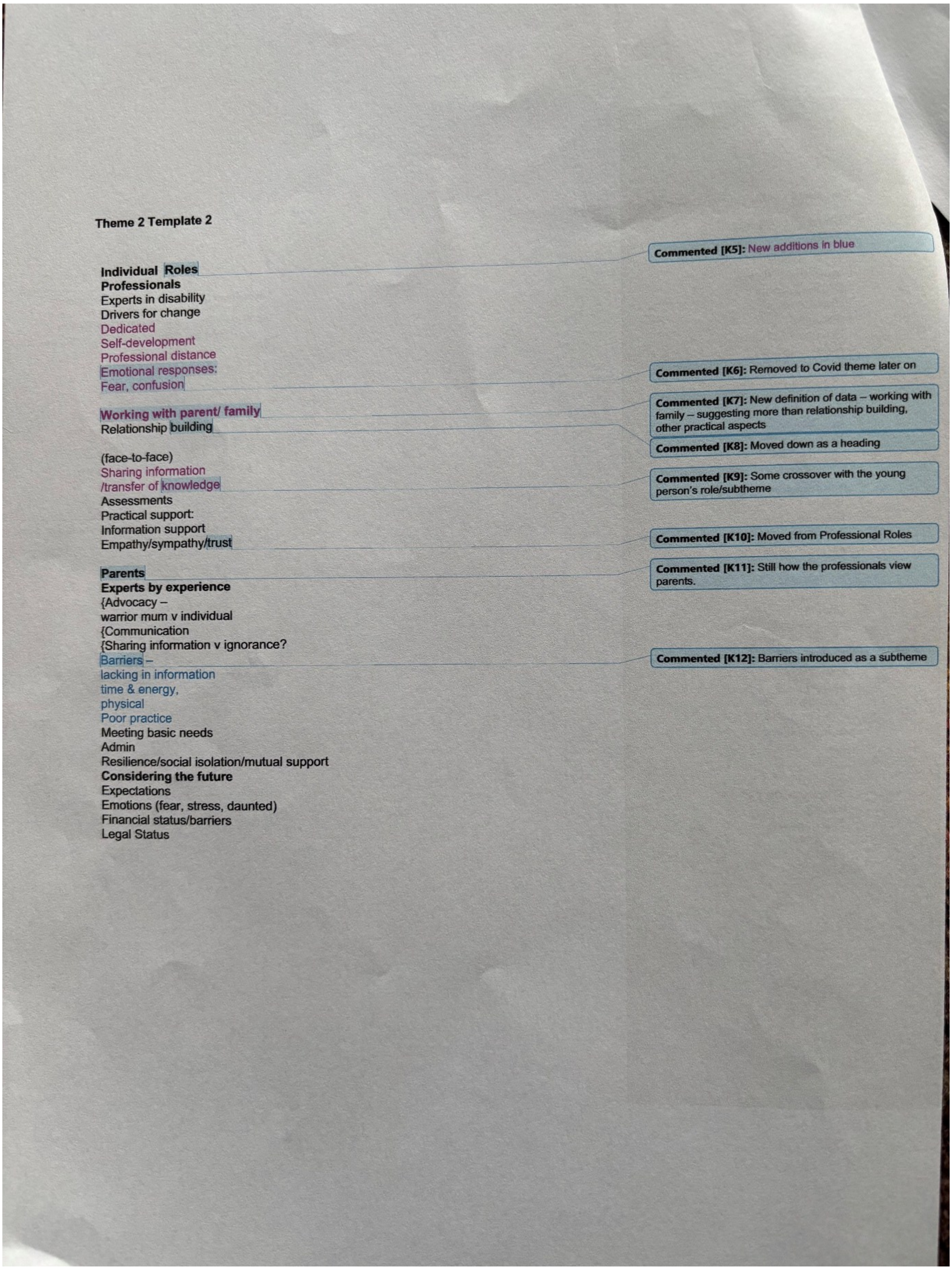
Parents
Experts by experience
Advocacy
Communication
Meeting basic needs
Admin
Resilience
Considering the future
Expectations
Emotions
Financial status
Legal Status

Commented [K1]: Initial findings built round the questions of how the professionals see their role and that of the young person and the parent within the transition process.

Commented [K2]: Initial mix of who discussed this – advocates did, HCP not so

Commented [K3]: Loosely based on a priori theme from metasynthesis

Commented [K4]: Also based on a priori theme from metasynthesis



Theme 2 Template 2

Individual Roles
Professionals
Experts in disability
Drivers for change
Dedicated
Self-development
Professional distance
Emotional responses:
Fear, confusion

Working with parent/ family
Relationship building

(face-to-face)
Sharing information
/transfer of knowledge
Assessments
Practical support:
Information support
Empathy/sympathy/trust

Parents
Experts by experience
{Advocacy –
warrior mum v individual
{Communication
{Sharing information v ignorance?
Barriers –
lacking in information
time & energy,
physical
Poor practice
Meeting basic needs
Admin
Resilience/social isolation/mutual support
Considering the future
Expectations
Emotions (fear, stress, daunted)
Financial status/barriers
Legal Status

Commented [K5]: New additions in blue

Commented [K6]: Removed to Covid theme later on

Commented [K7]: New definition of data – working with family – suggesting more than relationship building, other practical aspects

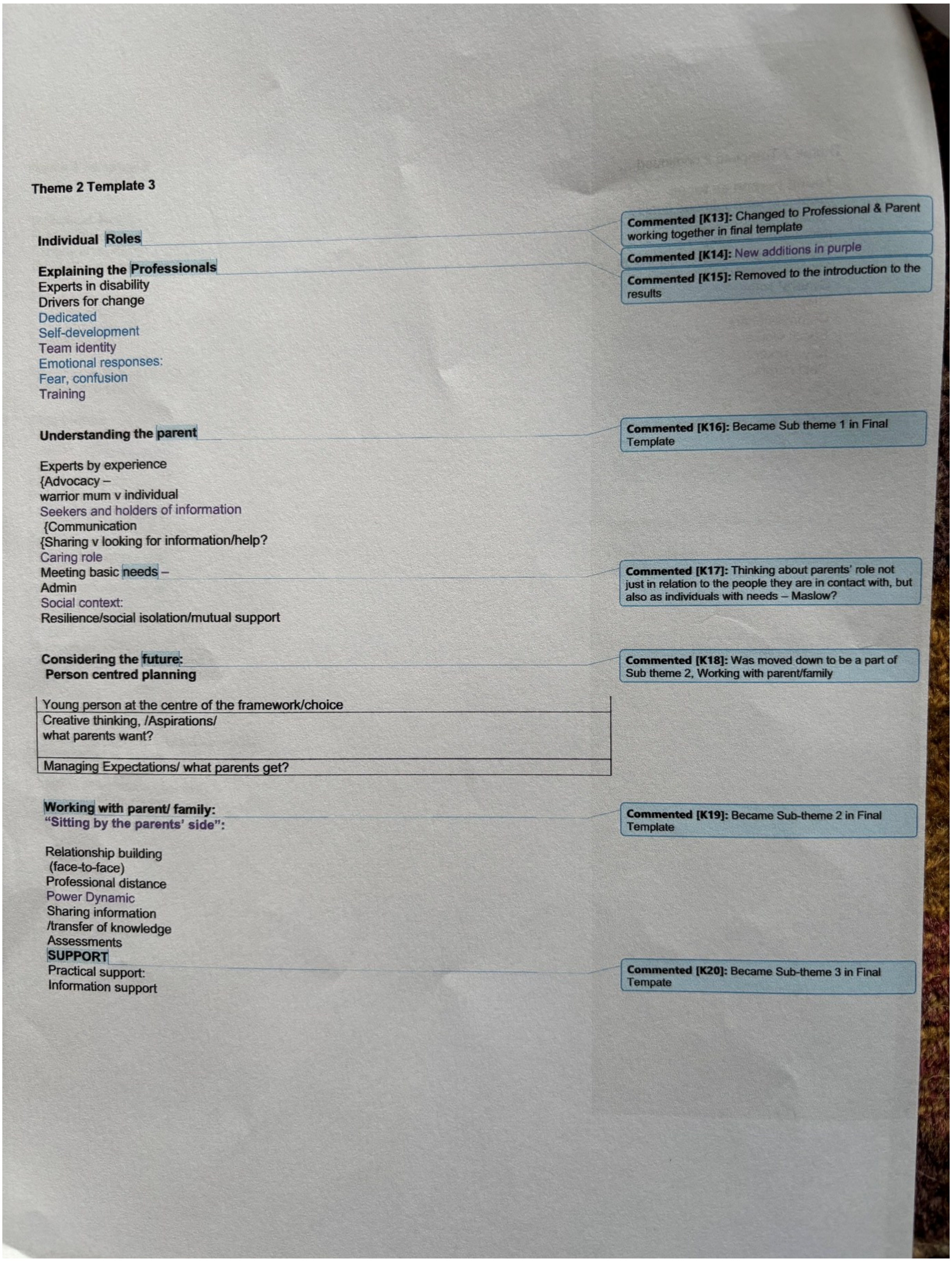
Commented [K8]: Moved down as a heading

Commented [K9]: Some crossover with the young person's role/subtheme

Commented [K10]: Moved from Professional Roles

Commented [K11]: Still how the professionals view parents.

Commented [K12]: Barriers introduced as a subtheme



Theme 2 Template 3

Individual Roles

Explaining the Professionals
Experts in disability
Drivers for change
Dedicated
Self-development
Team identity
Emotional responses:
Fear, confusion
Training

Understanding the parent

Experts by experience
{Advocacy –
warrior mum v individual
Seekers and holders of information
{Communication
{Sharing v looking for information/help?
Caring role
Meeting basic needs –
Admin
Social context:
Resilience/social isolation/mutual support

Considering the future:
Person centred planning

Young person at the centre of the framework/choice
Creative thinking, /Aspirations/ what parents want?
Managing Expectations/ what parents get?

Working with parent/ family:
"Sitting by the parents' side":

Relationship building
(face-to-face)
Professional distance
Power Dynamic
Sharing information
/transfer of knowledge
Assessments
SUPPORT
Practical support:
Information support

Commented [K13]: Changed to Professional & Parent working together in final template

Commented [K14]: New additions in purple

Commented [K15]: Removed to the introduction to the results

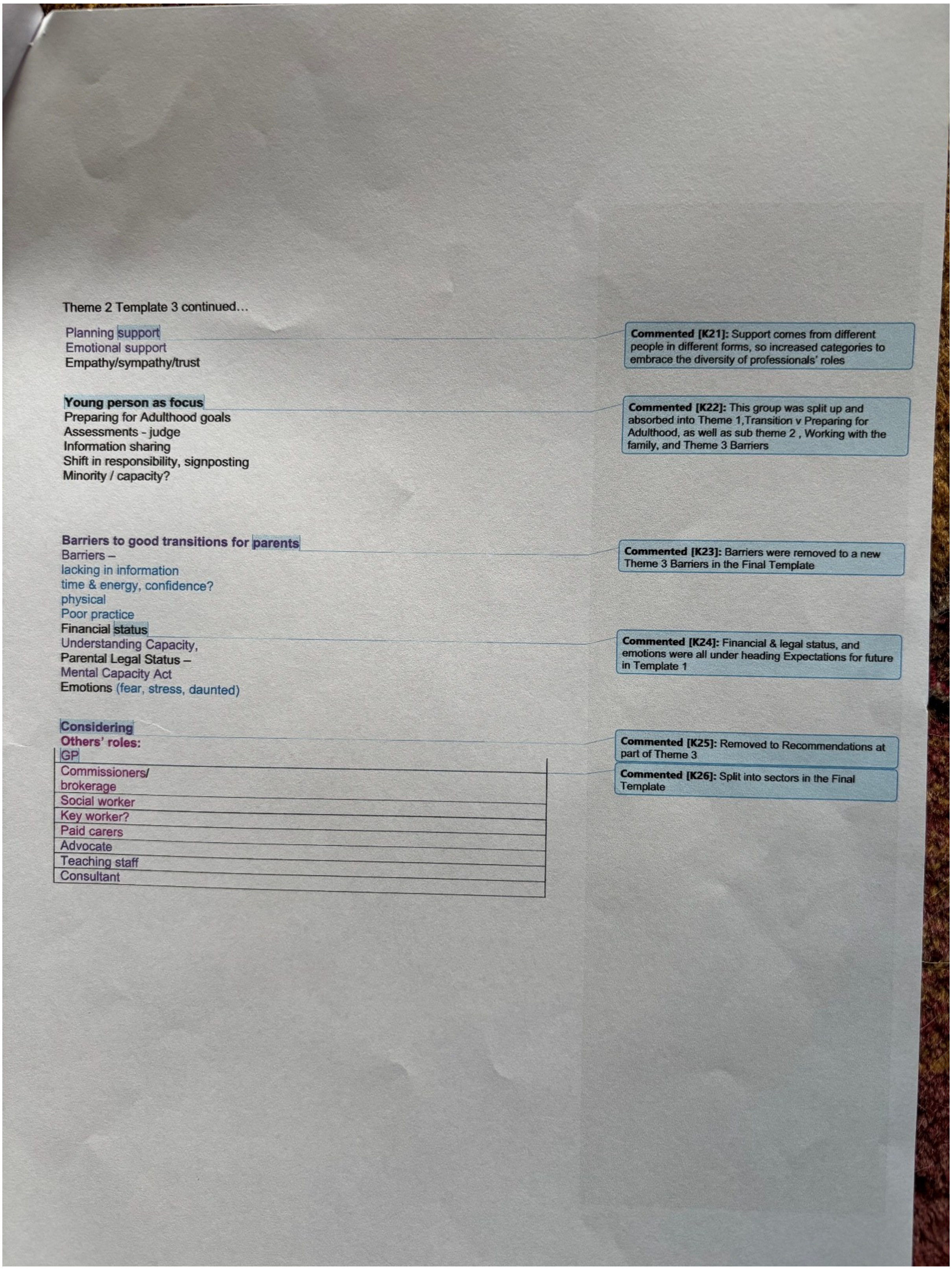
Commented [K16]: Became Sub theme 1 in Final Template

Commented [K17]: Thinking about parents' role not just in relation to the people they are in contact with, but also as individuals with needs – Maslow?

Commented [K18]: Was moved down to be a part of Sub theme 2, Working with parent/family

Commented [K19]: Became Sub-theme 2 in Final Template

Commented [K20]: Became Sub-theme 3 in Final Tempate



Theme 2 Template 3 continued…

Planning support
Emotional support
Empathy/sympathy/trust

Young person as focus
Preparing for Adulthood goals
Assessments - judge
Information sharing
Shift in responsibility, signposting
Minority / capacity?

Barriers to good transitions for parents
Barriers –
lacking in information
time & energy, confidence?
physical
Poor practice
Financial status
Understanding Capacity,
Parental Legal Status –
Mental Capacity Act
Emotions (fear, stress, daunted)

Considering
Others' roles:

GP
Commissioners/ brokerage
Social worker
Key worker?
Paid carers
Advocate
Teaching staff
Consultant

Commented [K21]: Support comes from different people in different forms, so increased categories to embrace the diversity of professionals' roles

Commented [K22]: This group was split up and absorbed into Theme 1,Transition v Preparing for Adulthood, as well as sub theme 2 , Working with the family, and Theme 3 Barriers

Commented [K23]: Barriers were removed to a new Theme 3 Barriers in the Final Template

Commented [K24]: Financial & legal status, and emotions were all under heading Expectations for future in Template 1

Commented [K25]: Removed to Recommendations at part of Theme 3

Commented [K26]: Split into sectors in the Final Template

Theme 2 Final Template

PROFESSIONAL & PARENT WORKING TOGETHER

1.Understanding the parent

- Experts by experience
  {Advocacy – warrior mum v individual
- Seekers and holders of information
  {Communication
- Caring role
  Meeting basic needs & Admin
- Social context:
  Resilience/social isolation/mutual support

2.Working with parent/ family:
“Sitting by the parents’ side”:

- Relationship building
  - (face-to-face)
  - Professional distance
  - Power Dynamic

- Considering the future:
  - Person Centred Planning
  - Creative thinking, /Aspirations/
  - (what parents want?)
  - Managing Expectations (what parents get?)

- Sharing information/transfer of knowledge
- Assessments

3.Support

- Practical support:
  - Information support
  - Planning support
- Emotional support
  (Empathy/sympathy/trust)

Theme 2 , Mapping the data: sub theme 2 table with references

	PA01	**PA02**	**PA04**	**PA05**	**PA03**	**PA06**	**PA07**	**PA08**	**PA09**	**PA10**	**PA11**	**PA12**
1. Working with parent/ family:	I.449	I.814		I.231		I.93		I.201	I.525-8	I.710-36		
Relationship building												
(face-to-face)								I.238, 263,	I.485-90, I.517-24, I.771-9 I.828	I.218-25 I.710-18 I.722-33 (shouted at)	I.306-11 I.656-59	I.276-81
Professional distance			I.194/2			I.910	I.291	I.310	I.530			
Power Dynamic									I.506-7, I. 24, 526-31	I.199		I.431

	PA14	PA15	PA16	PA17	PA01B							
Relationship building												
(face-to-face)	444-8 (zoom) 480,602(FPOC) 604-10	116-124 526-38	208-12, 298-308, 691/ 722-3	1084	B522-5, B546-55 (YP)							
Professional distance	612-4, 660-1 (no distance)	370			B655-60							

Power Dynamic			806-7, 691-3, 786-8	1069-75								
Considering the future:	I.816			I.481								
Person centred planning Young person at the centre of the framework/choice	I. I.52/57 3, 409, 584-605 848		I.369/389	I.141-5/288 /325	I.743-746	I.629 friends	I.565, I.552, 1096	I.155	I.185, I.433-39 I.189-98 I.700-1 I.808-834 (PATH)			
Creative thinking, /Aspirations/ what parents want?			I.34-5 /I.390-410	I.231	I.1138				I.562-591, I.700, I.836 I.878		I.298, I.313	
Managing Expectations/ what parents get?	I.731		135-7 /454	I.387 I.528	I.630	I.206-8, 67	I.607,615	I.285-91, 496	I. 433-9, I.461, I.524, I.542, I.562-84, 657-8, 683-96, I.833-7, I.843			I.425
Sharing information /transfer of knowledge	I.827, I.980 /1186-1193	I.242/662,679 /805/814, I.695} MCA}		I.534-546	I.710	I.167, 284	I.369, 419	I.148, 154, 211-5, I.435 472, 910-19,	I.472-491, I.529-32, I.569, 782-9 I.874-5	I.192-8 I.787-9	I.148-55 I.320-24	766-69, I.888-94

Assessments	I.650	I.54/73, I.372		EHCP I.199/451	EHCP I.660	I.177, 36	I.592, I.60	I.190-2,	I.761-4	I.165-71 I.66, 168	I.101-3 I.142-8	I.220-40
Considering the future:	PA14	PA15	PA16	PA17	PA01b							
Person centred planning Young person at the centre of the framework/choice	394-402 (comms) 781, 1301-6		123-30, 496, 508-12, 558-61, 565-8, 657-61, 1089-91	329-34								
Creative thinking, /Aspirations/ what parents want?	790-4, 834-43, 1305-6		140, 357-9, 525-31,	1087-8	B181-3 (crisis avoidance) B380-2 (Covid)							
Managing Expectations/ what parents get?	822-6	751-63										
Sharing information /transfer of knowledge	354-63, 390-9 (1PP), 432-38		794-807									
Assessments	1288-91, 1293-1302											

Theme 2 template 3 diagram showing the separation of the professionals' own identity from the working relationship with parents

Template Development Document

TEMPLATE 1 - January 2023

Three themes: Preparing for Adulthood v Transition, Individual Roles and the Impact of Covid19.

- The first round of analysis attempted to examine the data to answer the research questions:
- What is the professionals' understanding of transition?
- How do they view their role, and those of the young person and the parent in the transition process?
- What has been the impact of Covid19 on the research process

The themes were developed very closely to those questions.

Theme 1 Preparing for Adulthood v Transition

It was apparent that Social Care was very aspirational and looking at the model of Preparing for Adulthood, in other words preparing for a life after children's services. Health care professionals were more focussed on the handover of services from paediatrics to adult healthcare, and therefore were less aspirational and more process-driven. The first template aimed to draw out the differences between the ideological standpoint and the more practical standpoint, by also drawing on the working processes that facilitated these differing views.

Theme 2 Individual Roles

Examined the varying roles of the professional in relation to the parent, and explored the variety of standpoints that the parent inhabited – expert, advocate, carer, as well as their emotional states (as perceived by the professionals). Their financial and legal positions were also commented on. With regard to the young person, they were deemed to be very closely linked in practical terms with their parents, who advocated for them. There was some but not much sense of the participants interacting directly with them regarding their plans for the future.

Theme 3 Impact of Covid19

This theme looked at the impact on the physical health (environment?) of the young person and family, and their emotional response. It also examined the impact on transition processes, including communication. Positives were mentioned by the participants in relation to online working and electronic communication. These interviews were done in the early days of Covid (2020) with some comments being supplied afterwards, so the full impact had not been felt.

TEMPLATE 2 -14th February 2023

In developing the second set of templates, the three themes were retained, but slightly altered.

Theme 1: It was recognised that there is a difference between PfA and transition of services, and this is between two groups. Firstly, social care and health, as outlined before, but also there may be a difference in how the process is seen by those who are hands-on and close to the families (such as teachers and doctors) and those who are more remote (commissioners). Therefore, it felt appropriate to maintain the structure of this theme for further investigation. However, some of the processes, such as assessments and sharing information were removed to Theme 2, which focusses more on the interaction between the professional and the family. The major change was the introduction of a set of points around **barriers** identified which prevent the ideological position becoming reality**.**

Theme 2 is therefore moving away from "individual roles" to the relationships between individuals, the professional and the parent. Additionally, as part of that establishment of professionals as individuals, a subtheme of how professionals view themselves as well as their roles was introduced. Similarly, how they regard parents is explored, with a view to understanding the parenting role. Further exploration of these interactions will help unfurl these relationships.

Theme 3 remained largely unaltered, but was tightened up to look at the parent's position and then the professional's working within the restrictions of Covid19. Comparisons to other groups and pre- and post-Covid were listed as minor themes.

TEMPLATE 3 - March 18th 2023

Template 2 to Template 3

Another three interviews, with four participants were included in this latest round. It was found that the template wasn't very clear and there was a cross over at times between the themes. It didn't feel like it was explaining the data or answering the question very well. It had been commented by one of my supervisors that it felt like the previous themes were "holding the data".

In order to make the Template more manageable and concise in addressing the questions, I have spent some time having a look at the fit of the quotes with the themes to make sure they hold, merging some themes and then rearranging the order. The template now has some shape, in terms of presenting the data as an argument.

1. Introduction to the participants – as experts, drivers for change, delivering training, team members and as individuals with emotional responses.
2. Theme 1 – Transition versus Preparing for Adulthood(PfA):
   The theme maintains the Ideology v Process, approach. I have given some thought to how the various subthemes map onto the four principles for PfA. Health still is retained in the Process part, but it became even more apparent that those working closely with families (such as social workers from the Disabled Children's Team) are very focussed on the processes involved. The way teams work together is also retained in this theme, as the principle of joined up working is central to the delivery of transition.
3. Theme 2 – Has changed to Professional & Parent Working Together in order to focus more on the parent in the process. Subthemes include Understanding the Parent, Working with parents/family ("sitting by the parent's side"). It explores the process of relationship building and the power dynamic, how they two parties work together to plan the future, and in what ways the professional offers support.
4. Theme 3 – NEW THEME – Barriers to Ideology Becoming Reality, pulls the identified barriers from the general context of transition together with the barriers that parents face. In this way it is hoped that we can make some general recommendations about

services parents may need. Tacked onto the end of this theme, for now is how professionals considered the role of others, sometimes making recommendations.

5. The Covid theme remains largely unaltered.

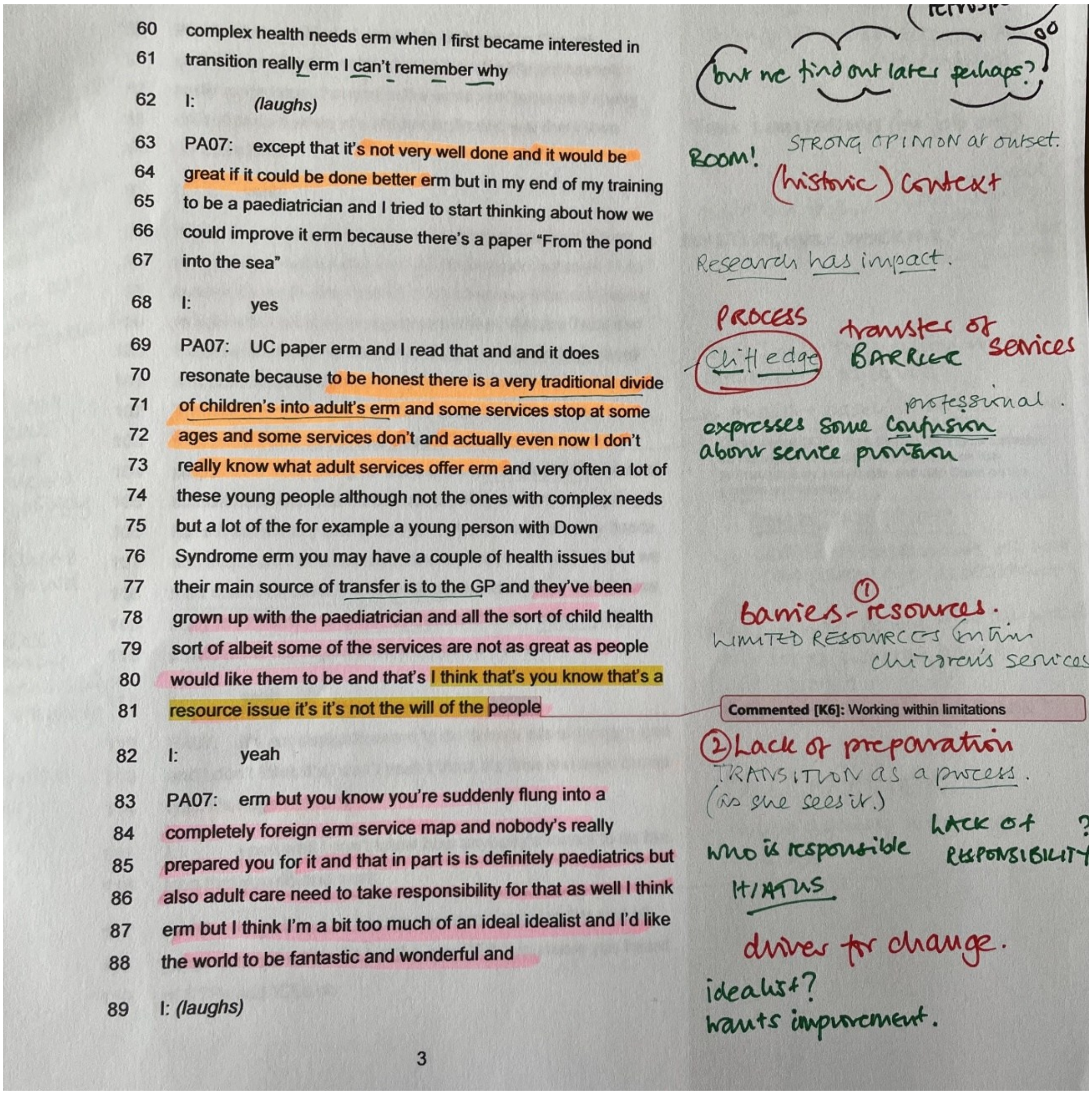
The running order isn’t set in stone at this stage,, and may not be until the write up.

There are another 4/5 interviews to analyse.

Is largely based on Template 3. The fit with the data feels appropriate, although a new subtheme” barriers to good transitions for young people” is a bit disparate, partly because some participants talk about the young people and others focus on the parents, and each service is coming from the problem at a different angle, so the focus on young people is a bit diffuse.

It was decided to remove the Covid theme, and use that data in a different chapter.

Marked up transcript



complex health needs erm when I first became interested in transition really erm I can't remember why

I: *(laughs)*

PA07: except that it's not very well done and it would be great if it could be done better erm but in my end of my training to be a paediatrician and I tried to start thinking about how we could improve it erm because there's a paper "From the pond into the sea"

I: yes

PA07: UC paper erm and I read that and and it does resonate because to be honest there is a very traditional divide of children's into adult's erm and some services stop at some ages and some services don't and actually even now I don't really know what adult services offer erm and very often a lot of these young people although not the ones with complex needs but a lot of the for example a young person with Down Syndrome erm you may have a couple of health issues but their main source of transfer is to the GP and they've been grown up with the paediatrician and all the sort of child health sort of albeit some of the services are not as great as people would like them to be and that's I think that's you know that's a resource issue it's it's not the will of the people

I: yeah

PA07: erm but you know you're suddenly flung into a completely foreign erm service map and nobody's really prepared you for it and that in part is is definitely paediatrics but also adult care need to take responsibility for that as well I think erm but I think I'm a bit too much of an ideal idealist and I'd like the world to be fantastic and wonderful and

I: *(laughs)*

3

(retrosp

but we find out later perhaps?

BOOM!

STRONG OPINION at outset.

(historic) context

Research has impact.

PROCESS

Cliff edge

transfer of services

BARRIER

professional

expresses some confusion about service provision

①

barriers - resources.

LIMITED RESOURCES within children's services

Commented [K6]: Working within limitations

② Lack of preparation

TRANSITION as a process.

(as she sees it.)

who is responsible

LACK of RESPONSIBILITY ?

HIATUS

driver for change.

idealist?

wants improvement.

APPENDIX 4

Chapter 5: Covid study

Final template

Mind-mapping of themes identified

Quotations for Emotional Impact

Developing a poem

Final Template (March 2023)

IMPACT OF COVID

1. **FAMILIES' RISK MANAGEMENT**

(In wider Covid Context)

Physical health:

- Parents/families **gatekeeping**
- /Risk Assessing
- Vulnerability

Isolation:

- Withdrawal (non-attendance)
- lack of peer support
- Safeguarding/Respite
- Tests & PPE, Vaccines
- Re-entry into society
- Family commitments/other children
- Technical barriers for families

2. **PROFESSIONAL WORKING**

Impact on Transition Processes

Change:

- Hiatus
- Breakdown in process

Communication:

- Reduced person contact
- Assessments (missing info)
- **New Practice**

Technology changes:

- Technological assistance
- Facilitating multi-disciplinary working
- Time savings
- Eco benefits
-

3. **EMOTIONAL IMPACT OF COVID**

Emotional Response (families)

- Fear
- Trust/Distrust
- Stigma/lack of understanding
- Family Resilience
- YP Behaviour changes
- Reasonable adjustments

-

Personal impact on professionals

- Emotional
- Self-isolation/shielding
- Preparing for future
- Self-reflection
- Adaptability

Mind mapping of themes

Quotations for Emotional Impact

PA10 because it's huge expectations on everyone that at 18 that's it you know they're knocked off our caseload I mean that's like emotionally for us that's huge as well a lot of the time

PA06: you know initially they wanted me to work from home and I said no I'm I'm not I'm not having this in my home ... I'm not and yet I've got plenty of rooms I could use but actually I don't want it in my home

I: yeah you've got to separate it

PA06: I need the I need the drive I need erm I mean obviously I still think about it all the time but (*sighs*) I I think I think no I don't want it at home ...it has to be separate for me because it's in my head enough

PA12 even now that we've all been vaccinated you know you add in people being pinged like me which is why I am working remotely at the moment (*with humour*)

PA04 and I feel so sad that erm when I was a young parent we had hope that if we worked really hard we could make it better for the families after us in our slipstream

I: (*laughs*) I know that feeling

PA04: yeah yeah and I don't think we have and that feels sad (transition not Covid)

PA09 it has made a lot of us feel erm (.) like we just don't have very much we can offer them? ...anymore that that feels quite quite sad when I think we are usually a service that is right in there of "what can we do how can we help?"

PA08 I'm currently shielding as well so that's another sort of ...it doesn't allow me to face-to-face visits at the moment but I'm really hoping that will change soon ...cos it's that's frustrating

PA16 and it's been erm really frustrating actually because you have to kind of stand back have your mask on erm and obviously children and young people might come and approach me but I I try to keep my distance which is quite quite hard but I'm watching the interactions between like the staff in class and the and the children and also the peers

PA12 I think it's hugely frustrating for all of us you know we we we desperately feel for patients that need erm need the testing they need appointments they need to see the specialists they need surgery and yet we're all sort of now in a situation where everything is taking much longer and there's a huge backlog to get through as well so it's just ... the perfect storm really

PA09 things I think constantly constantly in awe of the staff that work in the special schools they are completely underrated and I think the way they work with parents is phenomenal it really is they are like a huge a big hug for those families a lot of the time and they can meet any of their needs so erm so I just think they are wonderful

PA12 most people with fairly significant learning disabilities were not able to tolerate wearing the mask ... weren't able to socially distance themselves so were automatically at a much higher risk erm you know and yeah that was extremely difficult and extremely sad really

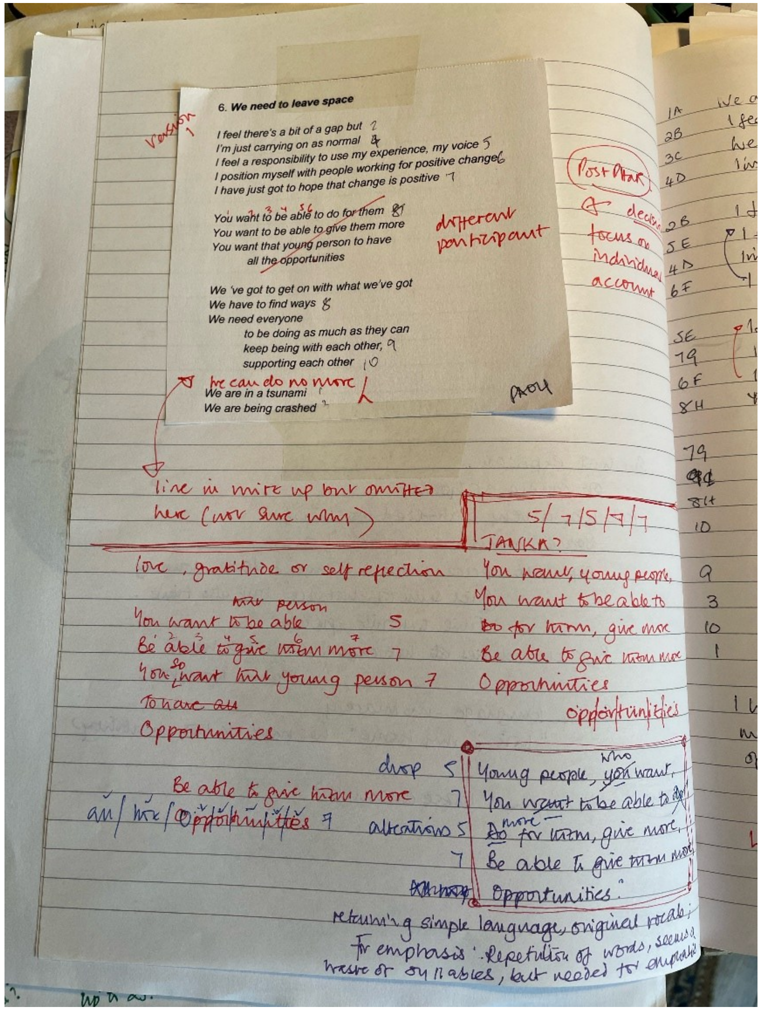
PA12 do you know what it was hugely emotional it was a massively emotional day and you know I had to you know it was on occasions quite difficult to give people vaccinations because they couldn't consent but for me to give it in their best interests and make sure that they were protected erm and mean that they could go out again and see people and have you know a relatively normal life was was so important

PA01Bthe team is still as dynamic and passionate doing it as they always have been erm they've just they've just had to work in a slightly different way ...and maybe deal with their own frustrations about not being able to do what they would what they feel like they should come to work to do it felt like doing your job with one arm tied behind your back for a lot of Covid I think you know a lot of your resources and skill were taken away

it's really unpleasant to see people struggling isn't it it's it's really uncomfortable to see families not doing well ... and young people not achieving and not reaching their potential in the way that we'd want PA01B

you want to be able to do for them and you want to be able to give them more and you want that young person to have all the opportunities and we just have to do the best we've got with what we've got at the moment which is what everybody's doing PA01

Developing a poem



version 1

6. **We need to leave space**

I feel there's a bit of a gap but 2
I'm just carrying on as normal 4
I feel a responsibility to use my experience, my voice 5
I position myself with people working for positive change 6
I have just got to hope that change is positive 7

~~You want to be able to do for them~~ 8
~~You want to be able to give them more~~
~~You want that young person to have~~
~~all the opportunities~~

different participant

We 've got to get on with what we've got
We have to find ways 8
We need everyone
to be doing as much as they can
keep being with each other, 9
supporting each other 10
we can do no more
We are in a tsunami 1
We are being crashed 2

P4O4

Post Phar
decision focus on individual account

1A
2B
3C
4D

2B
5E
4D
6F

5E
7G
6F
8H

7G
9I
8H
10

line in write up but omitted here (not sure why)

love, gratitude or self reflection

You want ^that person^ to be able 5
Be able to give them more 7
You ^so^ want that young person 7
~~To have all~~
Opportunities

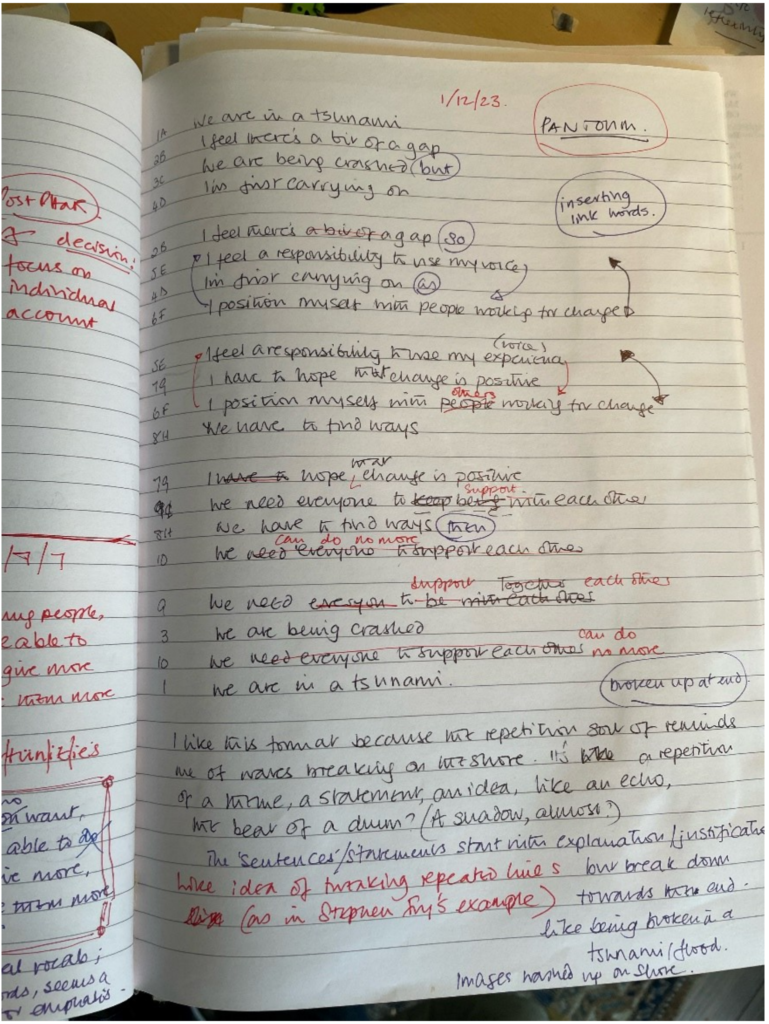
5/7/5/7/7
TANKA?

You want, young people, 9
You want to be able to 3
~~Do~~ for them, give more 10
Be able to give them more 1
Opportunities
opportunities

drop 5
Be able to give them more 7
all/ the/ Opportunities 7
alterations 5
7

Young people, ~~you~~ ^who^ want,
You ~~want~~ to be able to ~~do~~
~~Do~~ ^more^ for them, give more,
Be able to give them more,
Opportunities.

returning simple language, original vocab; for emphasis. Repetition of words, seems a waste of syllables, but needed for emphasis



1/12/23.

PANTOUM.

1A We are in a tsunami
2B I feel there's a bit of a gap
3C We are being crashed (but)
4D I'm just carrying on

2B I feel there's ~~a bit of~~ a gap (so)
5E I feel a responsibility to use my voice
4D I'm just carrying on (as)
6F I position myself with people working for change

inserting link words.

5E I feel a responsibility to use my experience (voice)
7G I have to hope that change is positive
6F I position myself with ~~people~~ ^others^ working for change
8H We have to find ways

7G I ~~have to~~ hope ^that^ change is positive
9I We need everyone to ~~keep being~~ ^support^ with each other
8H We have to find ways (then)
10 We ~~need everyone to support each other~~ ^can do no more^

9 We need ~~everyone to be with each other~~ ^support Together each other^
3 We are being crashed
10 We ~~need everyone to support each other~~ ^can do no more^
1 We are in a tsunami.

broken up at end.

I like this format because the repetition sort of reminds me of waves breaking on the shore. It's ~~like~~ a repetition of a theme, a statement, an idea, like an echo, the beat of a drum? (A shadow, almost?)
The 'sentences'/statements start with explanation/justification but break down towards the end. like being broken in a tsunami/flood.
Images washed up on shore.

Like idea of breaking repeated lines (as in Stephen Fry's example)

APPENDIX 5

Chapter 6: Parents' study

Excerpt from Child's Demographic Questionnaire

Example of a theme chart – Juliet's own support

Mapping the group experiential themes

Excerpt from Demographic Questionnaire:

4a. **Education:**

If your child is still in education, what type of school/college does your child attend:

Specialist day	
Specialist residential	
Mainstream	
Home educated	
In between settings	
Currently excluded	
Choosing not to attend	
Other:	

4b. Does your child have an Education Health and Care Plan?

Yes	
No	
Not sure	

1. Please look at the list below and tick all the services which your child is currently using or has access to, and those you have accessed in the past.

	Currently has access to	**Accessed in past**
Health services		
Local Hospital		
Specialist Children's Hospital		
GP		
Health Visitor		
Paediatrician		
Child Development Centre (CDC)		
Specialist Nurse Consultant		
Community Nurse		
Continued….		
Sensory inclusion service (visual/auditory impairment)		
Speech and language therapy (SALT)		
Audiology		
Ophthalmology		
Health and/or Social care funded Occupational Therapy		
Physiotherapy		
Wheelchair Services		
Continence Services		
Gastrostomy unit		
Neurology		
Epilepsy nurse/service		
Respiratory services		
Oxygen Service		
Cleft Palate Clinic		
Child and Adolescent Mental Health Service		
Child and Adolescent Mental Health Service (Learning Disabilities)		
Continued..	Currently has access to	Accessed in the past
Special Needs Dentist		
Podiatrist		
Health funded short breaks: Health-led nursing hours		

Specialist respite (hospice)		
Privately funded nursing hours		
Social Services		
Social Worker		
Overnight respite (social care)		
Direct Payments		
Social care assessed short breaks		
Short breaks (not assessed by social care) such as school holiday clubs, after-school clubs		
Privately funded childcare		
Other sources of support:		
Advocate		
Support groups		
Ombudsman for social care		
MP		
Police		
Educational tribunal		
Transport		

Continued….	Currently has access to	Accessed in the past
Any other services, please list below:		

5b. If your child regularly uses specialist hospitals, please can you state the distances travelled from home:

………………………………………………………………………………
……………………………..

2. Informal (unpaid) support: who provides support for your child:

	Please tick
Other parent	
Siblings	
Other family member (grandparents, aunts etc)	
Friends	
Other: please state	

Theme chart for Juliet relating to her own Pictor chart

Mapping Group Experiential themes

APPENDIX 6

Transition Research Advisory Group

This appendix contains a selection of documents relating to the Transition Research Advisory Group (TRAG), previously known as the Public Involvement Group.

The documents reflect the three phases of co-production, as outlined in Chapter 2.

Recruitment:
- Recruitment leaflet
- Pen portraits of the key members of the TRAG

Consultation
- Statement for Ethics Committee
- Meeting notes July 2018

Collaboration
- A pilot example of a Pictor chart
- A pilot example of photo elicitation exercise
- Meeting notes July 2023

Transition to Adult Healthcare

Public Involvement Group

Do you care about young people with profound and multiple learning disabilities (PMLD)(1) and their families during the transition from children's services to adult healthcare?

A Public Involvement Group, such as this one**,** aims to actively include members of the public (e.g. patients and carers) in healthcare research, allowing us to ensure that findings from the project better meet people's needs and are more likely to be put into practice.

The Project

"The experiences of parent-carers of PMLD children at transition from paediatric to adult healthcare" (working title)

The project will explore the journey parent-carers go on when their PMLD children leave children's services and first access adult healthcare services, with a view to identifying areas where parents have support needs. These needs may relate to supporting their children's access to appropriate care or to the parent's own individual support needs.

To do this, parent-carers will be interviewed and their journey across a year's transition will be followed. Groups of professional healthcare workers, from both children's and adult services will also be interviewed, in order to understand their views and experiences of transition as well as commenting on parents' experiences at this time. The project is original doctoral research, contributing to a PhD being undertaken by Katharine Slade at Aston University's School of Life and Health Sciences.

What does joining the group entail?

It is envisaged that the group will initially help the researcher identify appropriate topic areas for discussion with both parents and professionals and advise on recruitment of participants for the project. It is hoped that both parent-carers and professionals will join the Public Involvement Group. As the project progresses, members may be asked or may volunteer to help with tasks, such as providing your views on the interview questions, and reading, and feeding back on, the results.

Joining the group does not mean you are volunteering to participate in the research, but that you are advising on and shaping the research by sharing your specialist knowledge in the preparation process. As the project progresses, opportunities will arise to join in with other activities, however, it is not envisaged that all members of the group will be needed or want to do this. Therefore, there is flexibility in the amount of time you wish to commit.

Time commitments:

- Initially, there will be a meeting to outline the project and discuss the role of the group, and at this people can decide whether this is something they would like to join.
- Follow-up monthly meetings for the first three months to discuss various topics.
- After that it is envisaged meetings will take place once a quarter.
- If you are unable to attend meetings but would like to participate, you may join in by reading information and viewing slides on-line, or request paper copies, and provide your feedback via email or phone.

If you are interested and would like to know more please contact:

Katharine Slade at sladeka1@aston.ac.uk or on [redacted].

The Researcher

The project is being undertaken by Katharine Slade (PhD Candidate), who has a Master's degree in Health Psychology from Aston University, and is the parent carer of a young man with autism and learning disabilities. She has also undertaken two research projects funded by Healthwatch Shropshire, exploring both patients' and parent-carers' experiences of health and social care services.

Note:

(1) The NHS give the following definition:

Profound and multiple learning disability (PMLD)

"A diagnosis of a profound and multiple learning disability (PMLD) is used when a child has more than one disability, with the most significant being a learning disability.
Many children diagnosed with PMLD will also have a sensory or physical disability, complex health needs, or mental health difficulties. People with PMLD need a carer or carers to help them with most areas of everyday life, such as eating, washing and going to the toilet."

https://www.nhs.uk/livewell/childrenwithalearningdisability/pages/whatislearningdisability.aspx#Profound retrieved 17/01/2018

Pen portraits for members of Transition Research Advisory Group

Eleven people were involved with the Transition Research Advisory Group over the course of the project (2018-2024). Outlined below are eight pen portraits of the key members, which reflect their lived-experiences and expertise relevant to this research topic. Four were written at the outset of the project (2018). I have chosen to leave these as they were originally drafted, as they reflect that transition was still a recent event for them when they joined the group.

Sarah Cox

I am the parent of 21 year old young man who falls within the PMLD category. He lived at home until he was 18 years old and has for the past 3 years lived in a residential specialist college in our home county. I also have an 18 year old daughter. I have been working as a teaching assistant at a large specialist school (2-19 years) for the last ten years.

Being the parent of a child with special needs means acceptance, patience and resilience. It means accepting the diagnosis (and those visits to Holland while your friends are off to Italy![29]); patiently waiting for milestones to be reached (or even smaller markers than milestones); and resilience when times are difficult through illness, setbacks or fighting for help. It means hoping for the best while planning for the worst. (2018)

Anne Lanham

I am a parent of a daughter who was born with a rare chromosome disorder which resulted in profound and multiple learning disabilities and complex health needs. I have experienced transition across a wide range of services. I was the Primary carer for my daughter until she sadly died in December 2016 at the age of 22. I also have one son who has a diagnosis of an autistic spectrum disorder.

For 10 years, I was a volunteer/trustee of Shropshire Parent Carer Council - a charity which supports and empowers families of children with SEND, and which works with the Local Authority and Healthcare providers to influence and improve the services they provide. (2018)

Pat Davies

My entire career was spent in social work, mostly working in children's services (including five years with the NSPCC). I was one of the original social workers in a local authority Disabled Children's Team that was set up in 1991, and worked there until I retired in 2014. (2018)

Name withheld:

I am a parent of three children, my youngest has a significant learning disability. I am also a Social Worker for a Local Authority. My previous work experience has been with Looked After children and a personal assistant for an adult with complex health needs and learning disability. (Withdrew from the group at the end of the Consultation phase; contributed to questionnaire design and ethics proposal.) (2018)

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[29] Welcome To Holland — Emily Perl Kingsley

April Normandin

I am the parent of a young man with a rare chromosome disorder (Rubenstein Taybi Syndrome), which resulted in complex health care needs and severe learning disabilities. By the time he was 18, my son had undergone more than 20 operations. Transition was therefore a difficult time, as he is still under several consultants and now has regular check-ups at more than one hospital. Although he now lives in residential care, I still attend all his appointments and co-ordinate his care with his carehome manager.

When he was at school, I worked as a teaching assistant providing one-to-one support for a young person with special needs in mainstream school. Now, I work in a hospital as a Health Care Assistant. (2025)

Sarah Elcock

I qualified as an adult and paediatric nurse in 1987 (RGN/RSCN) working at The Royal London, Guy's and Great Ormond Street Hospitals in children's departments including A&E, ITU, Psychiatry and Renal. I also helped to set up the separate Paediatric A & E Department at Broomfield Hospital, Chelmsford. More recently I have worked as a practice nurse in the community and I am currently a coach for Riding for the Disabled. I have four adult children. (2025)

Mandy Parks

I am the parent-carer to a non-verbal, severely disabled and visually impaired young adult, whose care has required considerable co-ordination, being supported by many paid carers.

I qualified as a paediatric nurse in 2009. Since then, I have been a patient and public contributor at Keele University: supporting the Nursing & Midwifery unit; acting as an outside speaker for the Learning Disability Branch of Nursing, and as a member of the Lay Involvement in Knowledge Mobilisation group (LINK), whilst continuing within Neonatal practice. Latterly, I continued to work in the private sector, as a paediatric nurse, and as a recovery and daycare nurse, but currently am not working. (2025)

I have also contributed to research. I authored "A Mother's Story; caring for a child with profound disabilities" in *Learning Disability Practice* (2012). I was privileged to co-author a chapter *"*Shattered Dreams*"* in *Supporting People with Intellectual Disabilities, Experiencing Loss and Bereavement*[30]. Additionally, I have reviewed NIHR research proposals.

Sarah Thomas

I am Mother to five young men aged 13 – 27 years. My two youngest sons live with us under a Special Guardianship arrangement and are diagnosed with Autism, ADHD and impacted by Adverse Childhood Experiences (ACE). My three birth children all have additional support needs including Autism, ADHD, Epilepsy, Learning Disabilities, Speech and Communication disorder and Specific Learning Difficulties.

My 25 year old son was born with a rare chromosome disorder, impacting his learning, physical ability and speech. He moved in to Supported Living 3 years ago with 24 hour support. While we have done everything we can to support his transition to independence

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[30] Read, S. (2014) (Ed) *Supporting People with Intellectual Disabilities, Experiencing Loss and Bereavement,* Jessica Kingsley

it has been a very difficult journey, which is not delivering the outcomes hoped for. His quality of life, including his physical and mental wellbeing, remains dependent on our involvement.

Since 2008 I have been involved in the Shropshire Parent Carer Forum (PACC) and between 2010 and 2016 I was a Steering Group member of the National Network of Parent Carer Forums, representing the West Midlands. I am currently the strategic lead for ‘Influence and Change’ for PACC, working to deliver co-production in Shropshire. (2025)

Statement for Ethics Committee:

To be a parent carer of a child with a disability is something that most people cannot imagine, because it is so far removed from what we all expect parenthood to be. Increasing societies understanding of the role of the parent carer, what helps or makes it harder when individuals take on this role, is essential and the only way this can happen is to talk to parent carers about their lives and how they feel about their experiences.

This is why we have been willing to take part in research that explores our experiences of being parent carers. This process has helped us and others to understand the impact of parenting a child with a disability, and creates opportunities to improve the lives of parent carers, both by developing systems and services that are informed by the knowledge and experience of those who use them, and improving our own understanding of how this unexpected role has changed our lives.

It isn't always easy for parent carers to participate in research that explores aspects of their lives that they may find difficult and upsetting. In our experience, however, the opportunity to do this in a safe and non-judgemental environment has been beneficial, providing an opportunity to explore our own feelings and responses to being parent carers and to talk about things and feelings that we usually do not have the opportunity to speak about.

Sarah and Stephen Thomas

Transition Research Advisory Group

Meeting held at [redacted]

Tuesday July 3rd , 12-2pm

Present:
K.S, P.D., S.E., A.L.

Apologies:
[redacted]
J.C., S.C., A.N., M.P.

Information also sent to:
S.T.
[redacted] (redacted)

The meeting was always intended to be an informal gathering to discuss progress and allow for feedback, and as only a few managed to attend, we did not tackle an agenda. It was also intended to be a social meeting, as a thank you to those who have given their time and contributed in a variety of ways over the past few months.

Discussion

KS outlined the progress made lately on her project.

In particular, this related to the filling in of the ethics approval application, which has changed from a university ethics committee form to an NHS application, which is 30 pages long (when filled in). We discussed how filling in Disability Living Allowance forms was good practice for such demands!

We discussed the eligibility criteria for the potential participants, and how this had been outlined on the ethics form. It had been suggested that interviewing people twice, once either side of their child's 18th birthday would be a clear definition (since transition from pediatric to adult healthcare starts at the point of the patient's 18th birthday). However, AL pointed out that in reality it was about funding, and that her daughter was still in full time education, at school, until she was almost 20; (specialist school full time education [redacted] continues until the July after a young person's 19th birthday- ie the end of the school year in which the young person's 19th birthday falls). The main impact of transition was therefore felt after she left school, when Continuing Healthcare funding was put into place.

As a result of the discussion, KS has revised the inclusion criteria on the ethical approval application.

There was also a discussion about what happens when funding for placements is agreed, the placements are taken up by the young people, but the local health authority does not actually pay the bills.

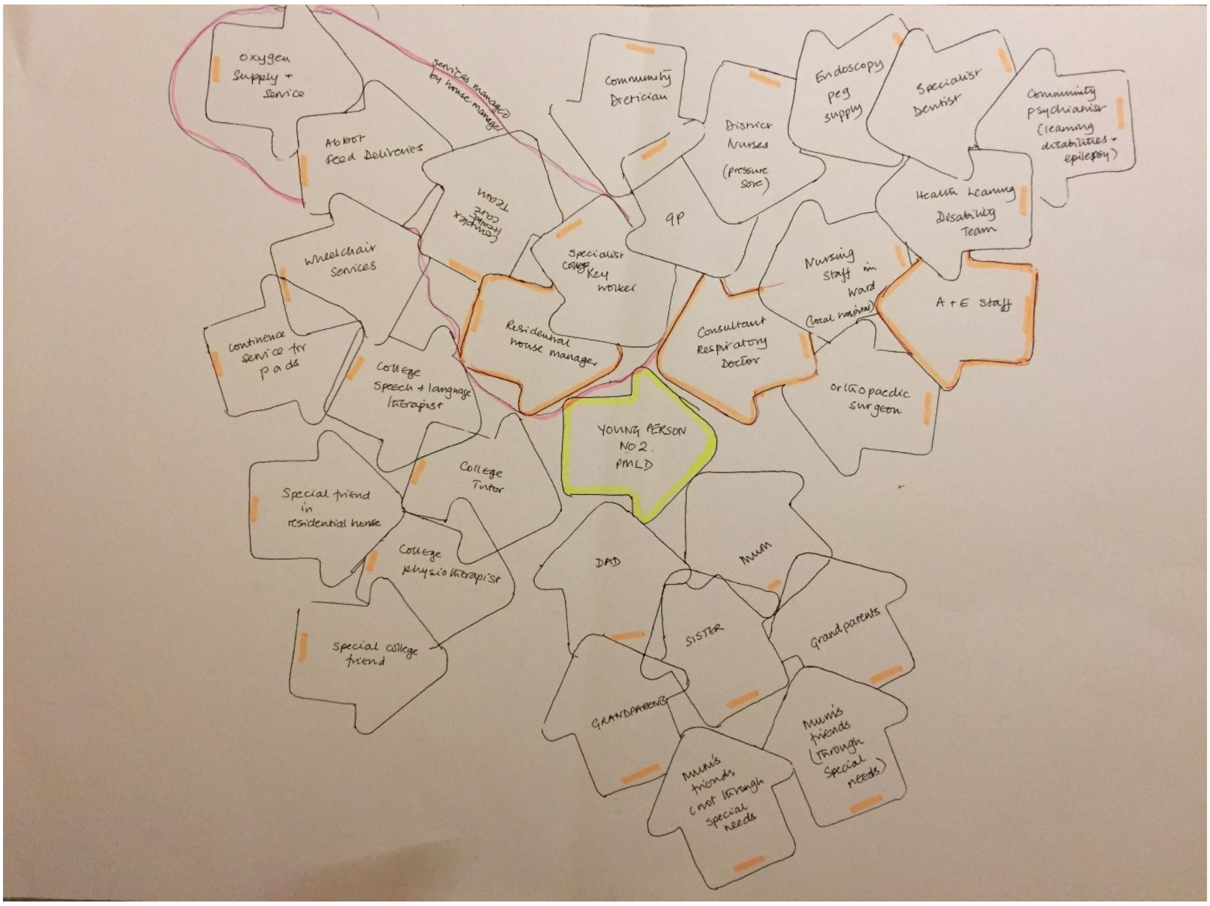
The group didn't have any comments to feedback (about the group structure), and KS is considering a more structured approach to feedback. Details to follow!

Plans to discuss ‘what the term “parent carer” means’, and how parent carers feel about the term ‘PMLD’ have been carried over until the Autumn.

Many thanks to everyone who has contributed over the past few months, and special thanks to PD for the delicious pavlova.

The next meeting will be at the end of September/early October.

TRAG exercise: Pictor chart



Example of a Pictor Chart produced by a TRAG member at a meeting in 2018, exploring the support networks for her child, (anonymised)

The participant highlighted the services that were managed by the manager of the young person’s care home. (upper left hand quarter).

TRAG exercise: photo elicitation

TRAG members were asked to take a photograph of a significant object that symbolised transition to them, and either write a piece or discuss the object with the group.

Chosen object: Prom dress.

I chose this item as it brings with it several significant thoughts and memories. Firstly there was the joy (and stress) of choosing a dress for my daughter to mark this momentous occasion. Finding an outfit that was both appropriate (for the occasion) and practical for a young lady who was a difficult shape (due to scoliosis) whilst being confined to a wheelchair and difficult to try clothing on was no mean feat, but every young lady has the right to look the part on their prom night. Thankfully with the help of a friend who is very talented in the art of sewing, we were able to find a dress from a High Street store and my friend was able to ‘fit’ the dress whilst my daughter lay on her bed. We still laugh now about how the friend stabbed a pin into the mattress to free up her hand whilst I let out a loud “Nooooooo” - as the mattress was an NHS provided airflow mattress – so sticking pins into it was not a wise thing to do – thankfully no harm was done!

Dressing up in finery and attending a dinner at a ‘posh’ hotel is not the type of occasion that arises very often (if at all) for young people with complex needs so it was fantastic that this event had been introduced by the school a few years earlier so that everyone had the opportunity to celebrate the end of an era in the same way that their peers would do.

TRAG MEETING NOTES 2022, [redacted]

29th July 2023

Attended: AL, SC, SE, PD & KS

1. Personal statement: It was lovely to see everyone after all this time. I really appreciate the ongoing support of the group after five and a half years. Having these discussions really helps me to focus on the topic as well as the goal of completing the PhD.
2. KS brought everyone up to date with the progress of the PhD:
    a. Contibutions to two book chapters : one discussing Pictor as a creative method for data gathering, the other discussing the use of poetry as a method of presenting experiences and stories. One is under review, one is in press. The full poetry paper has also been submitted to a journal for consideration and hopefully publication.
    b. Currently writing up the Professionals study, which falls into three parts.
    Firstly, the gap between the ideology of Preparing for Adulthood, aka Transition, framework (which includes independence, employment, healthy living and being part of a community) versus the handover processes.
    Secondly, the impact of Covid, with particular reference to communication between professionals and parents, via face-to-face and online consultations.
    Thirdly, the emotional impact of Covid on professionals.
    My supervisors suggest that there is too much to put into the PhD here so some will be written up for publication but not included (probably the emotional impact part, since the focus of the project is the parents' needs).
    c. The parents' study: AL commented that the group's Pictor exercise seems ages ago (which it was!) and KS showed the group a couple of Pictor charts done by the parents. This lead to a discussion about kidney transplants, was it ethical to talk about the donor, and the value of life of a young disabled person. We also discussed how details might reveal the identity of the interviewee in this particular case, given the rarity of kidney transplants by donor (about 1000 per annum) and those going to disabled young people. AL felt this was potentially identifying.
    KS also outlined the participant group, and the disabilities of the young people whose parents took part. We discussed the difference between brain injury at birth and genetic syndromes, and SC made a good point about interrupted normal brain development at birth and brain development that was not normal, ie atypical, in the womb.
3. Topics:
    a. What is PMLD?
    KS had printed out the draft write up of this section. PD commented that it was shocking that professionals still referred to young people with PMLD as "a baby", and there was some discussion about lack of understanding and respect. SE mentioned that in her experience this was not uncommon.
    b. Parental role in communication.
    KS told the group about a Shropshire Council training day she had attended, the topic being PMLD & communication. We discussed the role of a parent as advocate/source of information about the young person. AL & PD both mentioned young people being assessed without being seen. KS voiced her concern about the parent being called a proxy, and their own role/identity is not being acknowledged.

c. Data analysis
   KS explained (very generally) Bronfenbrenner's ecological model (this is quite a useful link for a clearer explanation: https://www.simplypsychology.org/bronfenbrenner.html).
   The model is used in transition research with the young person at the centre. However, KS intends to put the parent in the centre with the young person because their needs are so interlinked. KS hopes to use this model to look at the position of the professional participants in relation to the parent and young person, and consider how that relates to the ideals of transition (independence etc) or the processes. In order to explain this a bit better, we did a Post-It note exercise.
   The role of each participant was written on a post-it note and the group had a discussion to as to where they thought those people might be in relation to the family and the support system. See below:

1. *Post-it notes representing the professional participants on an ecological model of transition, as interpreted by members of the TRAG group*

It was interesting to see that mostly the participants had direct contact with the parents. SE noted that a consultant paediatric neurologist might have a lot of contact with the family. Some participants, such as the Adult Learning Disability nurse and Adult OT, might be assumed to have a lot of contact, but described their role as assessors in the transition process, with little follow up input. KS explained that the participants in Education demonstrated a good example of the hierarchical interaction from the hands-on teacher, to the ed psych working with the teachers and occasionally the families, to the commissioner who was reflective about the role of education. (see below)

2. Post-it notes of professional participants, placed by KS

Comment: - I found this a really helpful exercise and I really value the group's input. The limitation is that people who are not directly involved with the parents, such as commissioners, were under represented in the research process.

If anyone has any questions about this, please ask!

Special thanks to SE who brought lovely biscuits from the bakery at Wem and PD who brought lovely flowers.

Thank you everyone for the time and effort.

More information will follow in early October (as September is being put aside for family).