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ORIGINAL ARTICLE

Relationships matter! — Utilising ethics of care to understand transitions in the lives of adults with severe intellectual disabilities

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Accessible summary

- People with severe and profound intellectual disabilities need others to support them in most areas of their life. It can be difficult to communicate with people about change and transitions have been identified as an area of concern.
- As part of this research, we spent time with six adults with severe and profound intellectual disabilities. We talked to their families and professionals about their transitions and how they were involved in decisions that were made.
- Relationships people had with family members and key staff facilitated their engagement and experiences of the world.
- Our findings show that it is important that those who know the person well are closely involved in the planning of transitions. There should be a greater focus on maintaining the relationships that people have so that we can build bridges between settings and improve transitions for people with intellectual disabilities.

Abstract

Background: Within the current literature, there is a focus on early transition experiences, such as people's school years, while adulthood remains a lesser researched chapter in the lives of people with intellectual disabilities. Furthermore, most studies focus on those with mild or moderate intellectual disabilities and people with severe or profound intellectual disabilities are often excluded from research.

Methods: This article explores the transition journeys of six adults with severe intellectual disabilities, including transitions from school to adult services and moving out of the family home. Data collection involved observations, document reviews and interviews with families and professionals in Scotland. Taking an ethics of care perspective, our focus was to explore in how far each person had people in their lives

able to listen to them and if, in turn, those close to them were listened to during times of transition.

Findings: Our findings demonstrate that transitions are complex processes that occur across different systems. Additionally, our findings emphasise the importance to consider relationships that are available to people within their adult lives when planning and supporting transitions. Combining interviews with observations helped us to see how the six adults showed agency and were communicating their preferences through the relationships they had with people within their immediate environment.

Conclusions: The need to reconceptualise participation from a relational and interdependent perspective is stressed to facilitate the involvement of people with severe intellectual disabilities within decision-making processes.

KEYWORDS
ethics of care, severe intellectual disability, transitions

1 | INTRODUCTION

Research and policy reviews that examine the lives of people with intellectual disabilities have identified transitions as a critical topic that requires attention (Jindal-Snape, 2016; Scottish Government, 2013). People with intellectual disabilities will experience numerous changes and transitions across their lives, but often have little involvement in the decisions made. Local government provides many of the services used by individuals, their families and carers, and a wide range of professionals are involved in delivering services. Thus, changes experienced by people and their families are largely shaped by bureaucratic processes and decisions made by professionals (Hardy et al., 2005; Jacobs et al., 2017; Pearson et al., 2020). Within the current literature on transitions, there is a focus on early transition experiences, such as people's school years (Jindal-Snape et al, 2019; Davis et al., 2014), while adulthood remains a lesser researched chapter in the lives of people with intellectual disabilities.

The need to better understand the unique situation of individuals with severe intellectual disabilities transitioning to adult services has been highlighted by both researchers and policymakers (Doran, 2011; Foley et al., 2012; Stalker & Moscardini, 2012). Lives and pathways of those with severe intellectual disability may differ due to higher support needs, dependency on others across the life course and difficulties in accessing further education or achieving employment (Gauthier-Boudreault et al., 2017; Hogg, 1999). While there has been a new policy focus on supporting access to employment and independent living for people with intellectual disabilities (Scottish Government, 2013), the meaning of concepts such as self-determination or independence for adults with severe intellectual disabilities has been called into question (Kittay, 2001). While the need to better understand transitions to adult services for people with severe intellectual disabilities has been acknowledged, studies that examine transitions mostly include participants with mild-to-moderate intellectual disabilities (Foley et al., 2012). Reasons for this include ethical concerns in regard to power imbalances, consent and vulnerability, alongside the complexity of involving individuals with profound communication difficulties (Nind, 2008; Ware, 2004). While it is important to be aware of ethical concerns, the exclusion of people with severe intellectual disabilities from research can further contribute to their marginalisation, because it leads to a lack of understanding of what their lives are like (Klotz, 2004; Mietola et al., 2017; Simmons & Watson, 2014).

1.1 | Taking an ethics of care perspective

Engagement with the lives of people with severe intellectual disabilities poses a challenge to traditional research methodologies (Jacobs et al., 2017; Simmons & Watson, 2014). Most research positions are based on an understanding of humans as verbal, reflective and autonomous. Yet, as Simmons and Watson (2014) argue, such taken-for-granted assumptions cannot be made in the case of people with severe intellectual disabilities. An increasing number of writers within the field of disability use ethics of care to theorise the lives of people with intellectual disabilities (Kittay, 2001; Mietola et al., 2017; Porter, 2006; Rogers, 2016). Ethics of care is a philosophical theory that emphasises the importance of interpersonal relationships and care to understand human flourishing (Tronto, 1993). It stresses that vulnerability and dependence are central to human life. Relationships play a crucial role in understanding human life, as people are dependent on other people (Kittay, 2001). Thus, an ethics of care perspective challenges liberal views that portray people as independent and rational beings. Being a person is not defined by being rational and autonomous but by having the capacity to be in relationships with others (Kittay, 2001). This asserts that people with severe intellectual disabilities are fellow citizens who are able to form meaningful relationships and add value to the lives of others. Yet, while ethics of care is interested in care relationships, it is not only concerned with people's immediate relationships and private lives. On the contrary, ethics of care advocates for the importance of lifting care out of the private sphere and explores its place within the wider socio-political context (Rogers, 2016). Ethics of care was used,

alongside Bronfenbrenner's (1979) ecological model, as the theoretical framework of our research. Within research on transitions, ecological frameworks have been used to understand transitions as holistic processes that simultaneously involve the person's family, educational, psychological, social and cultural spheres (Small et al., 2013, Jindal-Snape, 2016). Combining an ethics of care perspective with Bronfenbrenner's model helped us to explore the dynamic relationship between the individual and his/her immediate environment and how this relationship was shaped by peripheral systems and forces. Both models informed the development of research aims, recruitment, data collection and analysis.

1.2 | Research aims

Following an ethics of care perspective, we believe that people with severe intellectual disabilities communicate their feelings, likes and preferences. Thus, the task of researchers is not to "give voice" to people and we agree with Rogers (2016) and Mietola et al. (2017) that the central question should be in how far they and their families are listened to. This highlights the importance for researchers to work closely with those who know the person well and understand them. We hoped that by including families and professionals, we would be able to examine relationships in the lives of people, to understand how professionals and families work together and what influences their actions during transitions. This included an examination of people's immediate environments, as well as examining how far transitions are shaped by organisational practices and political and cultural spheres.

1.3 | Terminology

Throughout the paper, we will use the term severe intellectual disabilities to refer to people with severe and profound intellectual disabilities. However, we are aware that terms also create labels and want to stress that we believe in the importance of understanding that people are more than a diagnosis. When discussing the cases of the young people and adults involved in this study, we use their names (pseudonyms) or refer to "young people" or "adults" as much as possible without adding the label of "severe intellectual disabilities". Additionally, we need to clarify the use of the term "adult service". Throughout the article, we discuss the practices of both social work and social care professionals and services. The term "adult service" is used only to refer to adult social care services, including day services and supported living services. When referring to adult social work services, we explicitly use the term social work.

2 | RESEARCH DESIGN

This article discusses findings that relate to two studies that were conducted as part of the PhD of the first author. Study 1 explored

the transitions from school to adult services of three young people (Jacobs et al., 2020). This was followed by a second study, which explored the transitions of three adults later on in adulthood, including moving out of the family home, as well as changes in routines and support packages, as people's likes and needs changed throughout their adult lives.

Case study methodology was employed in combination with approaches from ethnography and life-story research (Miles & Huberman, 1994; Plummer, 1995; Smith, 1990). Each case referred to the transition journey of one particular young person or adult. Information was collected through different data sources and through the perspectives of different stakeholders involved in the transition and in the life of the person to capture that transitions are processes, which involve networks of people and take place on different levels (Jindal-Snape, 2016). Case studies are a common methodology within research in the area of intellectual disability, particularly when researchers want to include the person with disabilities in the research process. This is illustrated well within research on the social history of learning disability, which is largely presented in the form of case studies and life stories, contextualised in their historical context (Atkinson et al., 2000; Ledger, 2012; Mitchell et al., 2006). Furthermore, in the context of research on educational or healthcare transitions, case studies are often used as they allow for an exploration of multiple perspectives, following the journey of individuals, as well as their close support networks such as families, professionals and friends (Jindal-Snape, 2016).

Ethical approval was given for the studies through the "NHS Scotland A Research Ethics Committee" in two separate applications.

2.1 | Recruitment

Recruitment took place in Scotland and was guided by purposive sampling (Palsy, 2008). Contact with families was made through schools in study 1, and one adult service and one third sector support organisation in study 2. Details of each recruitment organisation, the number of families/participants approached by each setting and the numbers of those included in both studies can be found below (Table 1).

During first meetings, parents were asked to identify professionals who were or had been involved in their child's transition process and this was used alongside review meeting notes to identify key professionals who were subsequently contacted by the researcher with consent from families. Not all professionals who were contacted decided to take part.

2.2 | Participants

Study 1 explored the transition journey of three young people (three cases), who will be referred to as Tom, Emma and Peter (pseudonyms). Tom and Emma lived in the same local authority and went to the same school. Peter's family lived in a different local authority.

TABLE 1 Recruitment organisations and inclusion criteria

Recruitment organisations	Inclusion/exclusion criteria	Number of families approached and included
Study 1: Special school for children and young people with additional support needs Residential school for children and young people with additional support needs	Family affected by current or recent transition from school to adult services (up to two years) of a young person with severe or profound intellectual disabilities aged between 16 and 25 No concerns about possible harm or distress caused by research involvement There is/has been activity: families and professionals (at least one) are involved in the transition process and are interacting	3 families approached, 2 returned and 2 included Over 8 families approached, 4* returned and 1 included (*3 families decided not to take part after an initial conversation)
Study 2: Third sector organisation providing support for parents of children with profound intellectual disabilities Third sector adult day service providing placements for young adults with intellectual disabilities	Family affected by current or past transitions within adult services such as moving out of the family home, moving between services, cases where a transition is wanted but there is nowhere to transition to, placement breakdowns. No concerns about possible harm or distress caused by research involvement There is/has been activity: families and professionals (at least one) are involved in transition process and are interacting	Over 5 families approached, 2 returned and 2 included 3 families approached, 1 returned and 1 included

Study 2 explored the transition journeys of three adults, who will be referred to as Luke, Lisa and Ben (pseudonyms). Luke lived in the same local authority as Tom and Emma. Lisa and Ben lived in different local authorities close to each other. An overview of the participants involved in each case can be seen below (Table 2). More detailed information about each person and their transitions is presented within the findings section.

2.3 | Data collection

The researcher conducted semi-structured interviews and had access to case-specific documents that held information about each person and their transition (including personal plans, social work assessments, review meeting notes). Additionally, the first author spent time with the six adults and conducted observation within their educational and/or adult service settings. In each case, the researcher spent around three months familiarising herself with each transition journey between May 2017 and September 2018. Semi-structured interviews were used to give participants space to highlight topics and issues of their own concern, while a structure of guiding questions allowed for the research to be grounded within an ethics of care and ecological perspective. Mothers were interviewed between two and three times.

2.3.1 | Involvement of the six adults—ethical considerations

Researchers caution that it is important to be aware of the ethical implications of engaging directly with someone who has profound and complex needs, and to avoid causing distress by becoming

another face that drifts in and out of the person's life without him/her having any control over it (Nind, 2008). During transitions, people often experience frequent changes in staff and an increase in professional involvement. Becoming another new and unknown person, without being able to offer a consistent relationship, initially led to the rejection of participatory observations as a method in both studies. However, it became clear that it was difficult to stay an outside observer during data collection as the first author found herself in schools or at people's day services or homes, where interactions happen naturally and often people initiated contact with the researcher. It was important to respond to people and recognise their agency in choosing to interact with the researcher, and the observations can be described as a mix between participatory and nonparticipatory observations. Participation was not structured or initiated, but the researcher followed each person and their setting as naturally as possible, as can be seen in the following vignette from fieldwork.

> When I arrive Ben's support worker Eva invites me for lunch. After lunch I help to tidy up. Eva does the washing up and I dry the dishes. Ben comes to join us. He looks at me and says "car". Eva asks "What colour is your car?" He looks at her and says "car". Eva says "It is red" and she signs "red" in Makaton. He copies and smiles. "You are good at signing Ben. You have a red car", I say using Makaton signs for red and car. "Car" he signs and smiles. Then we get ready to go to the car. Before we go out, Ben reaches out and takes my hand. He pulls me towards him, he squeezes my hand tightly, moves his face closer to mine, gives me a big smile and says "car".
>
> *(vignette based on observation, study 2)*

TABLE 2 Overview of cases and participants

	Case 1 (Tom)	Case 2 (Emma)	Case 3 (Peter)	Case 4 (Luke)	Case 5 (Lisa)	Case 6 (Ben)
Participants	Tom (One afternoon spent with Tom at his school.)	Emma (One morning spent with Emma at her school. One day spent at her new adult day service.)	Peter (One day spent with Peter at his residential adult community.)	Luke (Two half-days spent with Luke at his adult day service.)	Lisa (One meeting with Lisa at her home and one day spent at her adult day service.)	Ben (One day spent with Ben at his supported living house.)
	Mother	Mother	Mother	Mother	Mother	Mother
	Social worker	Father	Social worker	Social worker	Brother	Father
	Teacher	Social worker	Teacher	Day service team leader	Family support worker	Supported living team leader
	Head teacher	Teacher	Adult service team leader	Day service managers (two people)	Team leader local supported living service	Local authority manager
	Children respite key worker	Adult service manager	Adult service admission co-ordinators (two people)	Local authority officer		Family support worker (same person as in Lisa's case)
	Adult service team leader	Speech and Language therapist	Local authority manager			
	Clinical psychologist	Local authority manager (same person as in Tom's case)				
	Local authority manager					

2.4 | Analysis

The analysis of multiple case studies starts with an in-depth exploration of each case and context (within-case analysis), before slowly moving to a synthesis of the data across cases (cross-case analysis) (Miles & Huberman, 1994; Yin, 2003). Thus, the analysis followed a movement that travelled from the inside out, starting with a detailed examination of each individual case and then moving towards a thematic understanding of findings across cases. This article provides short case summaries of each transition journey before discussing the overarching themes that were developed across both studies towards the end of the analytic process. More detailed information about the within-case analysis and a more detailed discussion of the transition journeys can be found in previous publications (Jacobs, 2019; Jacobs et al., 2020; Rodriguez-Dorans & Jacobs, 2020).

Overarching themes across cases were developed by utilising a combination of inductive (data-driven) and deductive (theory-driven) analytic processes (Miles & Huberman, 1994). Principles of an ethics of care perspective guided the analysis, which meant that we were interested in people's relationships with each other, differences in involvement in transitions and how transitions and people's relationships were influenced by the wider organisational, cultural and socio-economic context.

3 | FINDINGS

There were some differences in the six transitions. Tom and Emma were in the midst of the process of leaving school, while Peter had moved to his new adult service one year previously. In the other three transitions, the focus was on transitions out of the family home and into supported accommodation. Additionally, Luke, Lisa and Ben were of different ages (25, 28, 39) and therefore at different stages in their lives. An overview of the six transitions can be found in Table 3.

Across the six cases, transitions involved different overlapping processes. This included emotional processes of adjusting and coming to terms with change, organisational and bureaucratic processes and planning the practical move. Additionally, transitions across the six cases took place at different points in time, reflecting different economic circumstances. Participants across cases reflected on the impact of austerity and discussed how budget cuts had resulted in a change from long-term planning towards a process driven by crisis. Participants highlighted that in a context of decreasing resources choice had started to be linked to what was available instead of what families ideally wanted.

> LA manager: We need to try and get the maximum benefit from an increasingly smaller pot of money. Seventy million pounds have been taken from [our] council in the last eight years. If somebody can tell me that there is not a reduction in quality then I'd love to see their analysis.
>
> (Ben's case)

TABLE 3 Case summaries

Six transition journeys—case summaries

Tom was sixteen at the beginning of the study. He enjoyed sensory activities, walks, art, music, cartoons, spending time with his family and visiting the local library. He could say a few word but mainly communicated through his behaviour and with support was able to use picture exchange. Tom had a diagnosis of autism and severe intellectual disability. He was very sensitive to touch and could often experience periods of low mood. He required close support, mainly due to high levels of self-injurious behaviour he engaged in almost on a daily basis. In 2017, Tom lived at home with his parents and siblings within an urban area of Scotland. He went to a special needs school within his local authority and attended a local respite service. He was described as having close relationships with his key workers at his respite service and within his class. He had two more years in school, but as he was about to turn seventeen he was approaching a transition from respite services for children, to respite services for adults. This was going to result in a significant reduction in respite days. Tom's parents wanted him to continue to live with them but felt that they needed enough respite to be able to support him at home. When a place at a specialist local authority respite and day service became available for summer, his parents took the decision to accept the placement and for Tom to leave one year earlier than planned. The fees of the service were lower than other day services and so the budget allowed for more respite provision. However, the family still experienced a significant cut in respite within adult services. Tom left school in the summer of 2017 and moved to his new day and respite service. His new adult service worked closely with his school, children respite service and his clinical psychologist during the transition. Tom seemed to settle well into the service and was observed to enjoy the company of another young person who he knew from school. However, in an ideal scenario he would have had more time there and his parents were worried about managing with less support in adult services.

Emma was seventeen at the beginning of the study. She enjoyed the company of others, doing craft, dancing and music, and one of her favourite activities was to blow bubbles. Emma had a diagnosis of autism and severe intellectual disability. She was physically able but relied on others to prompt her. She could say some words and sentences but mainly communicated through sign language, picture exchange and through her behaviour. She was described as having a close relationship with her key worker at school and with a regular respite carer. In 2017, Emma lived with her family in an urban area of Scotland. She was in her last year of school. Her parents felt that they were at an age where they would like Emma to start living outside the family home. This had been discussed with their transition social worker but was not an option at present due to lack of provision. Emma had already experienced a transition to adult respite services earlier in the year and the process did not go smoothly resulting in tensions between her parents and social work. Exploring day service options, her parents favoured a local day service where Emma could work in different craft workshops. Its fees were higher than the local authority run day services. To make it possible to fund the day service for five days, the family's respite allocation was reduced. Emma finished school in the summer of 2017 and moved to her new adult day service. Her key worker from school closely supported the transition. Emma seemed to settle well into the service and seemed to enjoy group activities and interacting with staff and peers. Yet, her parents were finding it increasingly difficult to manage with less respite in adult services and the family continued to hope for the possibility of supported accommodation in the near future.

Peter was nineteen at the beginning of the study. He was an active young man who enjoyed climbing, cycling, swimming and hiking. He enjoyed food and to relax listening to music. Peter had a diagnosis of autism and severe intellectual disability. He had only limited speech and mainly communicated through signs, picture exchange and his behaviour. He had a close relationship with his brother, who also had a diagnosis of autism and severe intellectual disability. Peter's family lived in a rural area of Scotland. When the family were looking for a secondary school placement for their sons, they became aware of a residential school setting and Peter and his brother went to live there during term time. The family were very happy with the setting and wanted a similar placement for Peter and his brother within adult services. A primary concern was to find a placement for both young men together. As there were little local options available, his parents applied to a residential community for young adults three hours' drive away. Social work supported the application, and Peter moved from his residential school to the residential adult service in the summer of 2016. His teacher and staff from his residential school were involved in supporting Peter during the transition. Peter was described at settling in well, forming close relationships with key staff and other young people in his house community. The adult community offered placements for young adults up to the age of 25, and in the summer of 2017, his mother anticipated to start planning for the next transition soon.

Luke was twenty-five at the beginning of the study. He enjoyed hillwalking, art, music and watching clips on his iPad. He used short sentences and words to communicate, but initiation of language was difficult for him. He had a diagnosis of autism and severe intellectual disability, and routine was important to him as he struggled with change and unpredictability. After leaving school, Luke started to go to a local day service five days a week. Two years later, in 2013, he moved into his own flat within an urban area of Scotland. Key staff from his day service who knew him well closely supported the move. After his move, he continued to be supported by his day service Monday to Friday during the day, going to music lessons, art classes and a new course at college and was supported by a different service in his flat. The move into his flat went well, and his day service tried to support visits and ongoing contact with peers from his day service and college. However, since the transition into his own flat, Luke's mother experienced a lengthy process of reviewing his programme and funding packages due to changes in his support needs. Two serious incidents had occurred in public when Luke got agitated by unpredictability in his environment. Additionally, his day service moved to a new building and Luke started to struggle with the new physical layout. His mother was very worried that Luke could suddenly find himself in a much more restricted and isolated environment, and she found it difficult to get social work involved. Luke's new social worker went on sick leave after initial meetings and the allocation of a new social worker took time. When we got involved in the summer of 2018, the process of reviewing his care package had been ongoing for nearly a year.

Lisa was twenty-eight at the beginning of the study. She enjoyed music, her trampoline and going for drives in the car. She was a social young woman and liked to spent time in the common areas of both her day services where it was busy. Lisa had profound and multiple learning disabilities. She had limited vision and epilepsy, and her mobility was restricted. She mainly communicated through her behaviour. She could use words to express how she felt, but some words had their own meaning. For example, she repeated the name of family members when she was in a good mood. After school, Lisa started to go to two different day services, one three days and one two days a week. She was described as having close relationships with her key workers in both settings, as well as with her regular taxi driver and two personal assistants who supported her at home during weekends. Additionally, she regularly socialised with three peers. Lisa's family always knew that the move into supported accommodation was the next step. Her family wanted to avoid a crisis situation and to be able to plan and support the move. The wish for supported accommodation was first mentioned to social work when Lisa was 20 in 2010. When nothing happened, her parents communicated their wish again with more urgency in 2017. A social worker started the assessment but then got sick and the process felt stuck for many months. Towards the end of our involvement in the summer of 2018, a new social worker was eventually allocated. Her family wanted Lisa to move together with two of her peers and to continue to visit her day services and were concerned that this might not be an option.

(Continues)

TABLE 3 (Continued)

Six transition journeys—case summaries
Ben was thirty-nine at the beginning of the study. He loved music and to be outside in nature. He was a communicative man who liked to engage with people. He used a few words, signs and body language to communicate. Ben had complex epilepsy and severe intellectual disability. He lived in a small house with two other women, one of whom used to be his classmate. The three had been supported by the same local service provider for fifteen years. Ben had visited a residential secondary school and later moved to a residential college in England. His parents actively started to look for a place for Ben to live when he was at the residential college. Ben was an only child, and his parents wanted to allow for enough time to support and reassure him and address any problems during the transition into supported accommodation. As there was a delay in the process of finding suitable housing, Ben came back home after college for two years and during this time he was supported by staff from a local support organisation during the day. He moved into the shared house at 25 in 2003. Ben's parents had identified their preferred provider early on and had established a trusting relationship with Ben's team leader who had been involved since the beginning. Staff at the service and Ben needed time to get to know each other, and his team leader described how he seemed anxious and stressed during the early days of the placement. Looking back she felt that it would have been important to more closely involve key staff from his previous services. She felt that he was very settled now and had formed close relationship with herself and staff members. During the last fifteen years, the service had needed to respond to Ben's changing needs, resulting in two main changes throughout the years. When Ben was around 30, a number of incidents occurred, where Ben fell down the stairs. Originally, all bedrooms were located upstairs in the house, but after the falls, a request was made to the local authority to build an extension to allow Ben to have a bedroom downstairs. More recently, people felt that Ben seemed more tired and less active. His parents and staff were not sure whether this was due to a change in his epilepsy or whether he was getting older and therefore needed more rest at times. Ben's parents and the service felt that his night support needed to be changed from a sleeping, to a waking night attendant. While funding for night staff had been made available his service was struggling to recruit staff.

In the following section three overarching themes will be discussed: (1) involvement, (2) interdependence and (3) continuity of change.

The three themes will be discussed in relation to people's immediate environments, as well as exploring influences of organisational, economic and cultural spheres, paying particular attention to the impact of austerity on families.

3.1 | Involvement

There was a clear indication that the six adults were involved in the practical parts of transitions and that they were listened to by those in their immediate environment. However, exploring the organisational parts of the process showed a different picture.

3.1.1 | Involvement in immediate environment

Participants differed in their conceptualisations of how people with severe intellectual disability can be involved in transitions. For example, all parents, except Peter's mother, described at some point during our interviews how their child was unable to be involved due to their inability to understand abstract concepts. Yet, at the same time it was apparent in conversations how all parents saw their child as a person able to express their feelings and preferences, stressing the importance of knowing them well to be able to "listen" to them. Similarly, our observations and many parts of our interviews with professionals showed how people's behaviour and responses to different environments helped those that knew them well to interpret their preferences and likes. At the same time, the complexity of interpreting people's behaviour into views was acknowledged. Participants described how people with severe intellectual disabilities showed their dislikes or likes within the present moment, and thus, their responses were often bound to their immediate experiences and it was difficult to anticipate how people would react to new environments. As people's exposure to different environments was limited, it was difficult to anticipate how they would adjust to new settings.

> Lisa's mother: I really think the only way she can sort of indicate is when she is actually there.

We noted down a similar observation during a visit to Lisa's day service. It was clear that Lisa was a young woman who was able to communicate what she wanted, but this required her support staff and people in her life to be finely attuned to her and to find ways to communicate with Lisa about possibilities available to her.

> A music group has started 10 minutes ago. The room is at the other side of the common space. Mia (support worker) tries to take Lisa's hand and to guide her to the music group, but Lisa pushes her hand away. She sits down on a chair close by. "It is a shame because I am sure she would enjoy going there, but how to tell her that it is happening?" Mia asks me. She then goes to the music room and gets a set of drums. "Maybe we can bring the music to you," she says. She places the drum on the table and starts to tap on it. Lisa smiles. Mia moves the drum closer to Lisa. She pushes it away, gets up and sits down on another chair. Mia plays the drum for a bit longer and then stops. Lisa has moved away from us and now sits three chairs away. She rocks forwards and backwards. The music continues to come out of the room. Lisa sits calmly, rocking, smiling. Her head is turned slightly to the side. "I think she is listening to the music," I say. "Yes," Mia says. "I think she can hear it and she is listening to it."
>
> (Observation vignette, Lisa's case)

In all cases, participants talked about involving the person in the practical parts of planning transitions, identifying activities and introducing new staff. Taking time to communicate what was

happening based on knowing about the person's way of processing information, giving the person opportunities to have different experiences and being attuned to their responses were highlighted as good practice.

3.1.2 | Involvement across wider levels

Families and professionals close to the person were routinely involved in practical questions, supporting the person to move into a new setting in the best way possible. This occurred once decisions about placements and funding had already been made. While teachers or support workers were involved in early review meetings to help create a sense of the preferences and views of the person, those meetings were seldom linked with a discussion of available services, budgets and resources. Education, health and social care professionals reported that they felt they had little involvement or power to influence what was decided and within a social care system stretched to its limits few options were available, resulting in decisions being made based on what was available. Additionally, our data illustrated how professionals' values and beliefs about "normality" influenced their judgements on how a good life should look like for people with severe intellectual disability in adult services. This seemed to be connected to professionals at times struggling to take the perspective of the person and what they knew about them through their daily interactions. This was most apparent in a number of interviews in which professionals talked about people's rights to live independently in their own flat. For example, Emma's teacher voiced his regret that Emma would never be able to live independently.

> Emma's teacher: It is difficult for me, don't get me wrong I would love every kid to be able to move on to something like that, but it doesn't strike me as something that she would be able to do which is a shame.

Yet, asked whether he thought Emma would want to live by herself he referred to his previous observation of how she seemed to thrive in group environments and loved social interactions.

> Emma's teacher: That is a very good question. Part of me hopes that she would say no because as I say, I think she does, she can really come out of her shell.

There was a sense that while there had been many improvements on a policy level, emphasising rights and inclusion, resources had been decreasing for many years, impacting on the quality of care and support services were able to provide. A number of professionals described that in the current context people with intellectual disability were often supported by staff who were working long shifts, without supervision and with less support for staff, often resulting in high staff turnover.

> Ben's supported living team-leader: If you got Gogarburn and Lennox Castle as institutions here, and then you have a single tenancy, "oh my god it does not get much better than that." Now twenty-one years I have been working for this company and I can see massive problems and flaws in single tenancies.

Friendships to peers were mentioned across the six cases and interviews highlighted the role of staff and families to facilitate those relationships after the transition to a new setting.

> Ben's supported living team leader: He had a very good friend, who he knew through kind of the school system and they went to a club together and we managed to keep this friendship going where she would come for dinner to the house. (...) But she then went into supported accommodation as well and it started to fizzle out. It is completely about staff having the right attitude and making that effort to maintain friendships. (...) Imagine your life being dictated by that. That is a real tough one.

All parents were strong advocates on behalf of their children, and participants felt that it was the advocacy work of parents that often resulted in positive outcomes. A number of participants used the term "those who shout the loudest" within interviews. These references seemed to allude to concerns that people with severe intellectual disability often rely on family members to get their voice heard, but that not all families might be able to be strong advocates.

> Luke's mother: There are other young people, who maybe don't have somebody (...) strong enough to challenge people. And what about them, what about those kids?

Next to parents, adult services seemed able to take on advocacy roles in Luke and Ben's case. In Luke's case, his adult day service had argued successfully for the importance for him to be able to continue at the service after his move into his accommodation. Similarly, Ben's adult service had negotiated with social work to get extra funding for an extension and more night support for him.

3.2 | Interdependence

All cases reflected the interdependence of the lives of people with severe intellectual disabilities and those close to them at times of transition. Not only the needs and preferences of the person but also those of main caregivers influenced what happened. Hopes for the future lives of their children were closely intertwined with what parents hoped and wished for in their own lives. All parents

stressed that they were aware of their own ageing and wanted to avoid a crisis situation in the future. Parents felt it was important to step back and to put systems in place that would enable their children to be less reliant on them. This was the main reason for parents to pursue supported accommodation in all except Tom's case.

While social work assessments took account of the needs of parents beside the needs of their children, parents felt that there was and had often been a lack of support for them and this impacted greatly on their lives. In all cases, mothers had limited their work to support their children, and in Tom and Emma's case, parents were facing a reduction in support in adult services. The lack of support for parents as carers put parents in the position of having to emphasise the impairment of their child and to emphasise difficulties to ensure they received support. Thus, it seemed that at times needs and risks informed decisions instead of the interests and preferences of each person. For example, when social work decided to stop providing transport for Emma once she transitioned to adult services, Emma's parents felt pushed to their limits and ended up "threatening" social work "to give Emma up", while simultaneously stating they could never forgive themselves for doing so. It was clear that this was not in Emma's best interest, nor was it a decision that took her views into account. A crisis was prevented once social work agreed to fund transport to Emma's respite.

Similarly, the support available to professionals influenced in how far they were able to support families. Thus, wider layers moved into people's immediate environment and impacted on the relationships between professionals and families. Particularly, social workers seemed to be caught in between their role of supporting families and becoming gatekeepers of resources available to local authorities. Social workers and local authority managers talked about how limitations within the systems they worked in did not always allow them to be person-centred or offer choice.

> LA Manager: Are they in a position that they need to be considered for accommodation right now or can it wait until the future. It is based on the principle of risk. (Ben's case)

Furthermore, across adult service providers there was an awareness of the difficulty to recruit and retain staff, which limited what services were able to offer. Parents appreciated the challenging context professionals worked in but felt frustrated by high turnover of social care and social work professionals, lack of communication and slow responses to address concerns and offer support.

> Luke's mother: I mean at the moment we are going through this horrendous thing with trying to sort out his funding, which is still ongoing which has been ongoing for nearly a year now. And it is really horrible and stressful.

3.3 | Continuity of change

The transition journeys showed that change was a continuous experience for families. While all parents spoke positively about the current life of their children, worries about the stability of arrangements were prominent. Thus, the findings were somewhat antithetical. The six cases highlighted the narrowness of relationships available to people with severe intellectual disabilities, whose relationships were almost exclusively with either family members or professionals. On the other side, many of the relationships between professionals and the six adults were described as reciprocal, with some professionals showing close emotional commitments. There was an indication that adult services and key professionals could take on the role of advocates and several participants spoke about adult day services and supported living services being able to offer people a "sense of belonging", Yet, relationships between professionals and families were dependent on the wider service provision context, being vulnerable to changes in funding, recruitment and retainment of staff and restructuring of services, placing relationships at risk to be suddenly cut-off and discontinue. Future uncertainty seemed to affect the quality of life of parents more than the lives of their children (at this moment in time). The main worry parents had was who would care about their children and ensure their well-being once parents were no longer able to do so.

> Emma's mother: This is all I think about it is all that consumes me well the last thing I think at night is settling her, hoping that no one hurts her.

> Emma's father: She eventually will have to, we are going to die at some stage and if you, we are not looking forward to that bit but

> Emma's mother: No

> Emma's father: The point is she is going to have to be in a place that wants her and where we are satisfied that she is going to be looked after properly.

During their transitions, the six adults lost existing networks, as they made the move to a new service. Education and social care professionals stressed the importance of closely involving existing support networks, such as key workers within school or respite settings, in transition planning to ensure that information was passed on and for new staff and the person to have time to get to know each other within a familiar and supportive environment. While transition planning involved a consideration of facilitating an overlap in relationships, there seemed to be little consideration of maintaining relationships with key people in the person's life after the physical move. Additionally, participants described that when people moved into supported accommodation they were likely to lose access to their day services.

LA officer: That has been the direction of travel for a wee bit of time now. The council has downsized its own day service provision and if somebody is moving into residential accommodation, it is the expectation that the new provider will do the twenty-four seven support and I know that some families have found that quite difficult. (Luke's case)

The role of friendships and peers was scarcely considered when making decisions about people's transitions and only Ben, Luke and Lisa's mother and team leaders in Luke and Ben's cases talked about trying to support continuity of friendships.

4 | DISCUSSION

Across the six transitions, the person with severe intellectual disability was involved in the practical aspects of planning transitions and it was evident that relationships people had with supportive others in their immediate environment enabled them to be listened to. However, the six transition journeys also highlighted barriers, concerns and struggles of families, as well as professionals. Those were mainly located within people's interactions with wider levels, their experiences of scarce resources, inflexible organisational structures and a gap between the ideals of policies and actual possibilities within practice, resulting in a sense of helplessness and frustration.

Findings demonstrated that people with severe intellectual disabilities can be involved in transitions, if involvement is understood relationally. Within their immediate setting, people were clearly making choices and had a degree of agency. Yet, many key events and decisions were made without the person being present. The CRPD (United Nations, 2006) calls for an active involvement of all persons with disabilities in decisions that affect them, seeing participation not solely in relation to people's involvement in their microsystems, but stressing participation across ecological levels including participation within policy-making and service provision (Löve et al., 2017; Mittler, 2015). Our findings add to the evidence that people with intellectual disability and their families are largely excluded from decision-making processes on wider levels (Löve et al., 2017). This mirrors findings of research on person-centred practice, which has found that detailed knowledge about a person's interests and preferences has often little influence on operational aspects of service provision, such as service commissioning (Cambridge & Carnaby, 2005; Small et al., 2013). Thus, our studies mirror the findings of past research that transition planning emphasises involvement foremost in relation to the physical move from one setting to another. Small et al. (2013) argue that in relation to transition planning, person-centred approaches currently only "prepare young people for transition into existing services in a person-centred way, not plan a person-centred service" (p. 285), a statement that rings true in relation to our six transition journeys. Equally, research on SDS in Scotland highlights that local authorities

and service providers struggle to be person-led within the current funding climate (Mittchell, 2015), reflecting that a system, which does not provide the needed resources and continues to be budget-driven, is unable to provide true choice and person centredness. Our findings highlight the importance of advocacy to involve people with severe intellectual disability in wider decision-making and for local authorities to work with and listen to family members and frontline staff who know the person well when planning transitions, to have honest and open conversation and to try and find solutions together amidst the challenges of austerity.

Overall, the central role of mothers in advocating for their children and caring for and about them stood out. Research has long highlighted the central role mothers play in the lives of their disabled children (Kruithof et al., 2020; Rogers, 2016), showing how mothers and their children's lives are closely intertwined and needs are interdependent. Our two studies show that the family often remains the main and only social network outside of professional systems in the lives of people with severe intellectual disability (Kamstra et al., 2015), but our findings also add to an awareness that professionals and people can form close relationships (Hall, 2010; Power, 2013). Relationships between people with intellectual disability and professionals are often portrayed as problematic, highlighting the unequal nature of relationships (Altermark, 2016). However, there are also more positive portrayals that describe staff maintaining relationships after they have left services and staff extending the social networks of people by inviting them into their social worlds (Forster & Iacono, 2008; Johnson et al., 2012; Newton et al., 1995). Across both studies, people considered whether relationships with professionals could be positive and whether services could offer a sense of belonging. In a UK context, social care is often described using professional language. Emphasising choice and personalisation, care relationships are portrayed to be between "clients" and "service providers" (Clarke, 2006; Glendinning, 2008). Gaventa (2019) criticises models that are built on professional distance, stating that they are unable to perceive the complexity of human relationships. He argues that views of professional distance negate people with intellectual disability the right to be involved in defining care relationships. Thinking about the relationships we observed between people and staff, we recall how the six adults related to key staff members by looking for emotional and physical closeness, as well as clearly indicating when they wanted their own space. The six adults were reaching out to hold hands, requesting hugs, laughing and smiling when songs were sung together, or meals were shared. We do not want to ignore or disregard the power dynamics that are inherent within care relationships, particularly in relationships with people who are nonverbal. Rather, our findings question whether concepts of independence, professional distance and autonomy are able to reflect how care relationships are experienced by people, including the person with severe intellectual disability.

Close collaborative practice between those that knew the person well helped people to successfully support the person during the practical part of the transition, but relationships with staff at

previous settings often discontinued after the physical move. Loss of knowledge about the person and their way of expressing themselves is a concern during transitions. As Small et al. (2013) point out, people with intellectual disabilities are particularly vulnerable during transitions, when relationships discontinue, because of the "deep but narrow range of support they experience" (p. 286). At times of transition, it seems paramount that people are able to maintain relationships to build bridges between settings and places, to ensure that people are known and so that they can be listened to.

Taking an ethics of care perspective added to an understanding of transitions as multidimensional. The concept of multidimensional transitions has started to gather recognition within transition research (Jindal-Snape, 2016). The concept describes how transitions are influenced by the wider socio-economic context, as well as highlighting that transitions never only happen to one person. Instead, others within the person's immediate environment will be influenced by the change and will simultaneously influence the process (Jindal-Snape, 2016). This was apparent in relation to families, as well as professionals. Taking a relational perspective showed how not only the "cared-for" had needs, but likewise carers had needs and required support. There was not only a lack of choice for the person, in terms of services and available support, but inevitably also a lack of choice and alternatives for the "carers," a lack of support for them. Thus, if we understand care relationships through the lens of interdependence we can see that we are all in need of care, challenging the neat dichotomy of givers and receivers (Porter, 2006). Moreover, interdependence highlights the political dimension of care by making apparent the need for appropriate resources and support to be allocated to those who provide care (Tronto, 1993).

5 | LIMITATIONS OF RESEARCH

Parents in all cases were proactive and able to advocate on behalf of their children. While the six cases highlighted many concerns, all six adults were able to access services and there was an awareness across cases that this was not a reality for all families. Case studies are context-dependent and idiographic (Plummer, 1995). Thus, while our aim was not to generalise or for cases to be representative, it is still important to keep in mind that the experiences of people in this research do not reflect the range of experiences that other families and adults with severe intellectual disabilities will have.

Similarly to Oulton et al. (2018) and Mietola et al. (2017), our observations helped us to see how each person showed agency and was making choices through their behaviour within their immediate environment such as expressing emotions, leaving an activity, approaching staff members and choosing when to be active and when to rest. Yet, the attempt to include an account of the lives of the six adults relied on the accounts of others, focusing on people in interviews with those that knew them well and spending time with them during observations and we cannot claim to have represented the views or experiences of the six adults.

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