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Who decides? - An ecological exploration of the transition from school to adult services for and with young people with severe intellectual disabilities

Running title: Transition from school to adult services

Keywords: Transition, severe intellectual disability, ecological framework, case study

Abstract

The transition from school to adult services for young people with severe intellectual disabilities has been identified as an area of concern, particularly with regards to how young people can be involved in meaningful ways. Additionally, although available resources and organisational practices seem to play important roles, there seems to be a lack of understanding as to how societal influences shape the process. Our study presents case studies of three young people and their journey from school to adult services from an ecological perspective, examining the decision-making process in the context of multi-agency involvement. We suggest that each transition journey challenged conceptualisations about the involvement of young people in the decision-making process. While the practical aspects of the transitions were described as positive, barriers and limitations were identified in the wider organisational context. The only people who clearly talked about the transition in terms of the long-term future were the parents.

1. Introduction

The transition from school to adult services has been described as the “black hole” (Doran, 2011) in the lives of individuals with intellectual disability and research

has highlighted the need to improve practices in the UK (Stalker & Moscardini, 2012; Cox, 2017; Hudson, 2006). This study builds on a systematic review concerning this transition for young people with severe intellectual disability (Jacobs et al, 2018). The pathway to adulthood often differs for these young people (DeZonia, 2008; Simmons & Watson, 2014) and emerging adulthood can highlight the tension inherent in the gap between the individuals' abilities, possibilities and the acquisition of adult status (Jacobs & MacMahon, 2017; Pilnick et al, 2010, 2011; Biswas et al, 2016).

Within the transition to adult services, research shows that external factors have a significant influence on decision-making. Decisions are made by statutory services and families, and policies and resources available in local areas play crucial roles (Jacobs et al, 2018; Hardy et al, 2005; Lenehan, 2017). An ecological understanding to transitions has been shown promising in mapping facilitators and barriers across systems (Small et al, 2013). Bronfenbrenner's (1979) ecological framework captures how change happens in an interdependent and relational manner. Jacobs et al (2018) utilised an ecological perspective to data synthesis in their systematic review but the influences of wider systems were only tentatively sketched. It was hoped that using the ecological framework for both data collection and analysis in this study would achieve a deeper understanding of intersections between culture, policy, economy, organizational practices, local resources and the lived experience of those affected, particularly at current times of austerity (Hardy et al, 2005; Mansell, 2010; Power & Bartlett, 2018; Stalker & Moscardini, 2012). Promoting participation of those at the core across ecological levels, not solely in relation to their immediate environment, has started to gain importance within policy development (Omeni, Barnes, MacDonald, Crawford, & Rose, 2014; Urek, 2017;). The UN Convention on the Rights of Persons with Disabilities (CRPD, 2006) calls for an active involvement of all persons with disabilities in decisions that affect them, which illustrates a shift

towards putting the emphasis on participation within policy-making and service provision (Mittler, 2015; Loeve et al, 2017).

1.1 Aims

Jacobs et al. (2018) identified methodological gaps within existing research on transitions relating to: (1) a focus on parents and the absence of multiple perspectives, even though the transition process involves multiagency decision-making; (2) a lack of involvement of young people; and (3) a lack of focus on transitions as processes.

This study aims to explore: (1) how different individuals make decisions about the young person's transition; (2) how individuals interact and work together; (3) how the young person is involved in the decision-making process; and (4) the systems and frameworks that surround the process.

2. Research process

2.1 Design

The study utilised case-study methodology. Case study research is an in-depth investigation of a contemporary phenomenon within its real-world context (Yin, 2002). When the focus of the study is on process and interconnections, the use of different data sources and triangulation during data collection and analysis makes case study research an attractive method (Miles & Huberman, 1994; Yin, 2002) because researchers are able to follow converging paths of inquiry and look at the phenomena from different angles (Yin, 2002; VanWynsberghe & Khan, 2007). To be able to allow for an ecological depiction of process including the perspective of multiple stakeholders, inclusive of the young person, a multiple case study design exploring the transition journey of three young people with severe intellectual disability was deemed the most appropriate. Additionally, it was hoped that through the use of different data sources young people would be more present in the research process

compared to their involvement in previous studies. The benefits to case studies of involving people with intellectual disability is illustrated well within research on the social history of learning disability, which is largely presented in the form of case studies and narrative accounts of the lives and experiences of individuals, contextualised in their historical context (Mitchell et al, 2006; Atkinson et al, 2005; Welshman and Walmsley, 2006; Atkinson et al, 2000).

2.2 Inclusion criteria and Recruitment

The research attempted to identify three cases involving: (1) a young person with severe intellectual disability whose life was currently or had recently been affected by the transition from school to adult services (up to two years); (2) parents and guardians of the young person; and (3) professionals involved in the decision-making process.

Severe intellectual disability was defined by impairments of skills and developmental delay in cognition, language and social abilities, resulting in severe difficulties to adapt to daily demands and social environments. There is thus a high degree of reliance upon others to make decisions on behalf of young people. In the study, parents of two of the young people had applied for guardianship under the Adults with Incapacity (Scotland) Act 2000 and in the third case the young person's parents were exploring it as an option. Guardianship is given where an adult is deemed incapable of making key-decisions about their own welfare and guardians can make decisions on behalf of the person, including decisions about where a person lives and their personal and medical care. However, guardianship does not prevent an involvement of young people in the transition process. The Social Care (Self-directed Support) (Scotland) Act 2013 and NICE transitions guidelines (2016) provide that the wishes of young people should be central to the decision-making process. This promotes an awareness that young people with severe intellectual disabilities

communicate their views and experiences and it highlights the importance of involving in the decision-making process those who know the person best (Simmons & Watson, 2014). Exploring how this is achieved in practice is one of the key aims of this study. In the research process we decided to facilitate the involvement of young people by spending time with them and speaking to key people in their lives.

Recruitment of young people and their parents was facilitated by one special needs school and one residential school in two different local authority areas in Scotland. As the schools and organisations knew the backgrounds of the young people well, they assisted in identifying which cases met the inclusion criteria. Purposive sampling was used to identify three families and during initial meetings parents identified other relevant stakeholders in the transition process. Information about the study was subsequently sent out to those persons by post and email.

2.3 Participants

The three young persons involved in each case study will be referred to as Tom, Emma and Peter. An overview of the participants involved in each case is set out below.

Table 1: Participants

2.4 Ethics

A detailed protocol was developed which took into account ethical considerations in relation to: (1) the involvement of young people and their incapacity to give consent; (2) the sensitivity of the topic and potential issues regarding care of vulnerable

children or adults; and (3) the sensitivity of data and anonymity. Details can be obtained from the first author. Ethical approval was given by the NHS Scotland A Research Ethics Committee and the University of Edinburgh. Parents gave consent on behalf of the young people.

2.5 Data collection

The researcher conducted semi-structured interviews and had access to case specific documents that held relevant information about each young person and the transition process. Additionally, the researcher spent time with the young people within their educational and/or adult service settings.

In Tom and Emma's cases, the researcher followed the transition process as it unfolded and met with their parents three months before the move from school, once the adult service had been identified and after the transition had taken place. Earlier interviews informed later ones as the researcher became more familiar with each case. Peter had transitioned one year previously and data collection involved participants reflecting back on the process.

An overview of the use of each data source in relation to different research questions is given in table 2.

Table 2: Research questions

2.6 Analysis

Emphasising the narrative component of qualitative case study research, a linear approach to understanding the process, following beginning, middle and end, was deemed the most appropriate for this study. In a first instance it appeared crucial to

first of all describe each transition process and understand how and why decisions were made. The descriptive insight subsequently informed a deeper exploration of the data across the three cases from an ecological perspective.

Within case analysis

The first step involved the development of timelines and summaries of the transition process for Tom, Emma and Peter (Miles and Huberman, 1994; Yin, 2002). To create timelines, interview transcripts, field notes and case specific documents were coded to identify events and turning points such as meetings and decisions made using Nvivo11. Some events had specific dates that were used in the timeline (such as review meetings), while other occurrences were processes that had no concrete start and end date but were described as occurring within a weekly or monthly time frame (for example, parents starting to think about the transition at the end of another school term or after a review meeting). The timelines are thus not exact representations but give a very close depiction of the process. Events mentioned by one participant were checked with other participants. The timeline and summary of each transition journey was discussed with mothers during the final interviews (in all cases), social workers (in cases 1 and 2) and adult service staff (case 3) to clarify and validate each timeline.

Cross case synthesis

Framework analysis was used to synthesise findings across the cases and to explore differences and similarities among the three transitions. Framework analysis involves the use of an a-priori framework and using it as the basis to code data (Ritchie & Spencer, 1994). We drew on Bronfenbrenner's (1979) ecological model to better understand the complexity of the transition process. An ecological perspective is helpful to capture interactions and relationships between people who are part of institutional, economic and cultural systems. The ecological model was applied across data sources using Nvivo11. Themes did not fit neatly into separate ecological levels and close relationships between systems were apparent throughout the analysis

(for example, conflict between stakeholders seemed to be influenced by cultural *and* economic factors). Where themes corresponded to different ecological levels, a choice was made as to where the content would fit best.

Participants received summaries of their individual interviews and of findings as a whole and were given the opportunity to make comments and request changes.

3. Results

The table below sets out a summary of the transition process for each young person including timelines. This is followed by the synthesis across cases using the ecological framework.

Table 3: Three transition journeys including timelines (insert here)

3.1 Case synthesis: an ecological perspective

Table 4: Ecological framework

THE YOUNG PERSON

This theme discusses how far young people's likes and needs informed choices made before questioning how far the move to adult services also marked a step towards adulthood for young people.

Likes and needs

Parents favoured adult services able to facilitate activities that young people seemed to enjoy such as being outdoors, engaging in music, arts and crafts and socialising with peers. However, alongside what these young people liked, their vulnerabilities and associated risks were a central part of identifying an adult service placement. This was particularly striking in Tom's case.

Tom's Clinical psychologist: *He does need like high levels of support in terms of sort of helping him to make sense; he needs high levels of structure and routine to help him make sense of the social world and also he has very high levels of sensory need as well.*

Becoming an adult: changes

All three young people were described as learning and acquiring new skills. This included getting better at using their communication systems or using the toilet independently. However, young people were also described as becoming physically bigger and this could lead to new challenges for parents. When Emma refused to do something, such as get out of the car, her mother said there was nothing she could do. Peter was described as cycling and walking faster and for longer distances than anyone else in the family and as Tom was becoming older it was more difficult to manage some of his behaviours.

Tom's mother: *When he does kick off now he is six foot nearly so it is a lot harder than when he was ten, so it does become more difficult. That is the irony of it isn't it, you are dealing with someone who is more difficult.*

Participants had different views on how to understand young people's step into adulthood and on how far the transition into adult services should also mark a change in attitudes towards, and expectations of, the young people. Teachers and adult service professionals seemed to see a more central role of choice within adult services and greater flexibility to create activities and timetables that were meeting young

people's interests, instead of following the curriculum and meeting the needs of a whole class.

Emma's teacher: *I am not trying to say that adult services don't have structure, but you know, but there is, it's if you are being an adult then you can choose.*

For Emma and Peter, participants emphasised the importance of work activities and practical learning within adult services. All parents emphasised their wish for services to encourage the development of skills, and engagement in activities.

As well as emphasising the importance of meaningful engagement, interviews highlighted tensions between the notion of 'independence', and views of young people continuing to be dependent on adult support. Some professionals connected more independence to the possibility of living in their own flats, fulfilling a step towards 'normal' adulthood, while also describing that to live independently young people would need high levels of support and supervision. Without stable and supportive relationships and environments, a number of participants suggested that young people could easily regress and become more withdrawn. Parents, and some professionals, felt that living in a flat could isolate young people and voiced anxieties about them being dependent on staff and vulnerable to poor quality of care.

Emma's teacher: *I could imagine that she could sit for a very long time if there wasn't that interaction, which I suppose when I think of it, it seems kind of scary.*

Tom's mother: *He is very vulnerable, when someone hurts him he can't tell us.*

Participants described how young people expressed choices and preferences through their behaviour but some described a concern that choices did not always reflect their best interests. This highlighted a tension between notions of choice, independence and responsibilities to support young people to be healthy and engaged.

Peter's adult service: *For me, independence also shows that he is able to show anything what is really him, his choice. What he would like to do. But then that always needs to be guided within the, the necessities of life. I mean that he has the right nutrition and I think there it is important that he still has this, the routine to help him with that.*

Tom's Clinical Psychologist: *I am sure he would like to just be with his family the whole time 'cause he really has a really sort of strong relationships with them, if he had a choice, and not be doing anything in the day but that wouldn't be good for him either as a sort of decision. I think it is good that he is involved.*

MICROSYSTEM

The family, education professionals and social care professionals were identified as the young people's main networks. The existence of additional networks, such as friendships or relationships outside the family not including paid employment, were scarce but a number were described and explored within the theme of additional networks.

Family

The family was the main and central support system for the young people. Interviews with all stakeholders highlighted close and loving relationships between family members. Parents spoke about their love for and commitment to their child. Needs of parents and children seemed to be closely intertwined and parents described that caring for and advocating on behalf of their children to ensure good quality of care was very demanding at times. Parents were aware of their own aging and how it was impacting on their ability to provide care for their adult children at present and in the future.

Emma's mother: *Because we are getting older I mean I know it is not that old, 57 it is not old but I don't know if we could take another 20 years of it.*

However, it was striking that parental wishes for the transition to adult services in relation to their own needs as carers were always concurrently discussed by parents in light of the likes and needs of young people. Tom's mother hoped for a placement that could provide extensive day and respite services, allowing Tom to live with his family and to provide continuity. In the other two cases, parents reflected on their children still being young adults and wished for an initial young adult placement before considering 'settling their children'. Tom seemed to express through his behaviour that he enjoyed being at home most, while both Emma and Peter enjoyed social interaction and being busy and engaged, reflecting a focus on young people within the choices made by parents.

Tom's mother: *When he gets home, he is quite happy to be home and if we can cope with him at home for now then we will do that until, until we get to that stage where it's not feasible anymore.*

Peter's mother appeared to be the most positive and talked least about the negative impact of having a son with a severe intellectual disability. This might be due to him being the only participant living outside the family, an absence of challenging behaviour and/or him being very content at his current placement. Living in a residential setting did not seem to be connected to less emotional closeness between Peter and his family nor negatively affect communication between staff and parents.

Peter's mother: *I mean I get pictures on Skype and you know they are always doing wonderful things and stuff. And I think yes I mean Peter can't come home and tell me hey mum I climbed a mountain today or drove my bike around the facilities but he is just a smiler and in fact his house produced a book which I need to add to all his others and it is just a photographic testimony of how, what a great year he has had.*

Peter's transition process had occurred a year ago, thus the day-to-day stress of transition was not present at the time of conducting the interviews.

Mothers seemed to play central roles. However, the inclusion of the father's perspective in Emma's case highlighted similar concerns and levels of stress and worries for him to those of mothers.

Emma's father: *I was worried about what was going to happen to her and I was waking up and by the time we got to that meeting I was wiped out, I was completely exhausted.*

Fathers were involved in meeting with professionals and caring for young people at home, but mothers were described as the main carers, with fathers spending more time at work. In all three cases, taking care of their children had impacted on the mothers' ability to sustain a full-time job.

Parents spoke about siblings as providing important relationships for the young people. In all cases, one of the siblings took on a more caring role as they entered young adulthood themselves, which parents stressed was voluntary.

Professional environment

Overall, parents spoke positively about the support provided and the care offered to young people within care and education settings. Most participants described consistent and trusting relationships with key members of staff as being important for the young people. There was variation reported in the consistency of relationships: while some professionals had been involved in the young people's lives for more than five years (for example, Peter's teacher, Tom's respite key-worker, Emma's class helper), others had only recently become involved. Staff turnover was mentioned as a problem by both education and adult service professionals.

Health professionals were described as offering important, specialist input, but their direct contact with young people was less than that of education and social care professionals. Social workers' roles differed. They all met young people in different settings but their contact was described as being mainly with parents.

Peter's mother: *Well social work (...) will only get involved as and when they are needed. They are not actively ringing up to see how he is. So they are invited to reviews or if there is a meeting involving his life at school then they are obviously there.*

Additional networks

In all three cases it was difficult for families to draw on the support of their extended family, and the immediate families seemed to draw on different support networks. Other parents with children with disabilities were described as a source of support only in Tom's case. Additionally, a close family friend supported the family in an advocacy role. In Emma's case, one of her paid carers was identified by her mother as someone 'special', who cared about Emma and helped out on occasions. She was described as being like a friend to Emma.

All participants talked about the importance of close relationships generally but only eight mentioned peers and friendships (Tom's adult service and teacher; Emma's mother, teacher and social worker; Peter's mother, adult service senior worker and social worker). There were differences in participants' accounts of the role of peers and friendship. While Emma's social worker and both Emma's and Tom's teachers raised doubts about young people's abilities to form friendships with peers, the eight interviews also included accounts of existing friendships and important interactions with peers.

Tom's adult service: *There is a young man who comes to [our service] who was in Tom's class last year and they seem very friendly it is nice. Tom seems to have sort of a calming effect on [him] and [he] can offer Tom lots of cuddles. Often Tom goes up to [him] for a cuddle, which is lovely. That must be reassuring for them both to come into the service and have a familiar face.*

MESOSYSTEM

Practical transition

The practical transition was described as very positive for all three young people, with good communication and sharing of practice among stakeholders.

A disparate health transition to adult mental health services was an issue in Tom's case and was anticipated to happen after the age of 18.

Although parents and professionals did meet at annual or six-monthly review meetings, there was no single meeting where all stakeholders came together. Review meetings at schools seemed to focus on initial plans about possible placements and adult services did not take part in meetings at this stage.

Lack of transport was identified as a potential problem in both Tom's and Emma's cases and while arrangements were made to find a solution by Tom's social worker, Emma's parents experienced a lengthy struggle to get funding for Emma to travel to both her respite and day service.

Emma's mother: *The stress was unbelievable it was absolutely unbelievable. 'Cause I am prepared to support Emma but I am not prepared to have them take absolutely everything off us.*

The local authority had recently changed their transport policy, asking families to contribute. In both Tom's and Emma's case, transport was ultimately provided by the local authority as cars were shared with other young people accessing the same service.

Involvement of the young person

Participants felt that young people had very little involvement in the transition process. This may be because, for participants, choice seemed to be conceptualised as

actively verbalising choices, which was not possible for the young people. However, other parts of the interviews illustrated that young people were involved in the practical transition because they expressed how they felt in different environments and communicated their needs through their behaviour. This was taken into account when identifying adult services, making plans about the move and deciding on programs and activities.

All young people started to visit their new adult services before the move and this gave parents and professionals an indication of the suitability of services. Only Peter visited two other similar residential adult services through his school as part of the transition process. Participants described how young people's need for routine and consistency played a central role in this decision. A number of participants (Tom's head teacher and teacher; Emma's social worker; Peter's adult service and social worker) referred to the limitation of only being able to make choices based on knowing young people in their present settings.

Peter's adult service admission: *I mean at that age you have been used to something and you actually manage extremely well and are very happy within that and an alternative of, for example, living in a flat within the community, I mean who is to say whether or not that would be appropriate for him. I wouldn't know. It is based upon how he is just now.*

The move to the new setting was described as positive and all young people seemed to be doing well considering that the transition involved a major change in environment and routine. Young people were described as participating in activities, following their new routines and positively interacting with staff.

Collaborative Practice: Concord and Conflict

Parents and professionals seemed to have positive relationships and problems only seemed to relate to limitations such as funding constraints or lack of

services. For example, parents were able to differentiate in the interviews between working with social workers and appreciating their work and effort but feeling frustrated to work with the 'system' they represented.

Emma's mother: *I think the social worker had a really difficult job because her hands were tied, completely tied.*

Social workers and local authority managers reflected on limitations within the system and spoke about their own frustrations.

Local authority manager 2: *Local government in terms of finances get tighter and tighter and tighter, so the message is that we need to do things differently to make sure there is money in the system.*

Social workers and local authority managers made reference to the decision-making process being governed by person-centred practice and approaches. However, references were made simultaneously to constraints within existing budgets and reference was also made to the need 'to share resources with everybody'. All parents showed an understanding of the need to share resources and that there was a limit to the funding available. However, parents argued that the inflexibility to respond to individual situations had the potential to create more expensive packages later on. For example, Tom's mother felt that with more respite they could continue to support Tom at home, and Peter and Emma's parents believed that shared accommodation was not only more beneficial to their children it was also more cost effective than single tenancies.

Tom's mother: *I think there is this ridiculous scenario of the fact that if we said right let him go to a flat you are talking upwards of £200,000 a year to fund that. Whereas we are quite happy for him to stay at home and go to "Adult Service A" everyday but we still feel we need more respite. It is not always joint-up thinking is it?*

While professionals needed to work within existing rules and structures, parents were able to fight and to push against some barriers (for example, Emma's parents

succeeding in getting Emma's transport funded by the local authority). The role of parents as advocates for their children will be further explored in the involvement of young people within the exosystem.

EXOSYSTEM

Organisational transition

Families and young people seemed to have very little involvement in 'wider' decision-making, such as deciding when transition planning should start and being involved in the kind of services available to them. Those decisions seemed to be shaped largely by existing service delivery and available budgets.

It seemed that everyone, from parents to social workers and local authority management, felt that their possibilities were limited by strategy and budget decisions that were made 'higher' and which they were unable to influence.

Local authority manager 1: *The budgets are made in Westminster or they are made down in Holyrood [UK and Scottish parliaments]. (...) If it continues to decrease it will present us with, well it already is presenting us with real challenges going forward. I don't have the answer to that question yet.*

Emma's social worker: *We are more in a corporate sort of world and environment and it is, if you are an old school social worker like me it is really not great (...) if you feel like you are fighting a system.*

Adult service providers reflected on their dependency on having agreed funding in place before being able to recruit staff and plan the transition. Furthermore, the high demand they experienced also resulted in them being dependent on current service-users moving on and having their funding confirmed.

Information, resources and available services

In all three cases, parents started to think about and plan the transition two to three years in advance. Parents felt that there had been little information and support available from professionals at those early stages and parents relied on themselves to find out about available services.

Parents and professionals described a lack of local services for young people with high dependency and complex needs and that existing services seemed to operate at full capacity. Tom and Emma lived in a local authority area with a relatively greater choice of services, yet there appeared to be a lack of services for those with complex healthcare needs and challenging behaviour.

Tom's social worker: *There is a lack of support services for people with complex behavioural needs absolutely. Complex personal care needs absolutely.*

Parents and professionals preferred local services, as this enabled young people to stay close to their families. Yet, there was an awareness that local services were not always able to meet people's needs. This resulted in an out-of-area placement in Peter's case.

LA Manager 2: *I think providers can still be quite reluctant to go down that way. For real high dependency you need a very, very specialised kind of resource and as I say that is why you have difficulties.*

For Emma there seemed to be more choices, but her parents experienced a lack of 'meaningful' services, as they did not want a 'babysitting' service. In her case, the family's preferred service was more expensive and not covered by the allocated budget resulting in a decrease in respite for Emma and her family.

Involvement of the young person: Parents as advocates

The extent to which young people were involved in the decision-making process at an organisational level was difficult to conceptualise. In all three cases parents were strong advocates on behalf of their children and were able to put their concerns forward. However, although individual concerns and wishes were able to be expressed by both parents and professionals, this did not necessarily lead to any changed outcomes. For example, Tom's severity of need was acknowledged by everyone and education and health professionals voiced their concerns about the respite reduction. This seemed to have an influence on a placement being offered to Tom in the local authority run day and respite service, which had limited spaces, but his respite allowance still reduced significantly. In Emma's case, everyone who knew her well talked about Emma showing through her behaviour that she was ready to live outside her family and although this was highlighted in her social work assessment, it did not seem to be an option in the near future due to a lack of accommodation services. Within the exosystem, available resources seemed to shape the process to a large extent.

Fighting for young people and their own right for support caused stress for parents.

Emma's mother: *I mean it is not about the money it is about the principle I think. But every little step brings more problems with it, if you know what I mean, because it is just another anxiety and they know that, so they know that people will get fed up with fighting.*

MACROSYSTEM

Culture

Parents and professionals made references to their experiences of changes within the culture and values of service delivery and attitudes to those with intellectual disabilities in society over past decades. The move away from segregated settings was described as a significant shift in the care and inclusion of people with

severe intellectual disabilities in society. However, parents and some professionals (all education professionals, Peter's adult service and Emma's social worker) discussed how they felt that the closure of day services and funding cuts since the beginning of austerity had resulted in a decrease in the number of possibilities for people with severe learning disabilities and that policy values such as inclusion, choice and person-centeredness were not reflected in the services and resources available to families.

Peter's adult service admission: *The difference between the reality and what is being presented and what is said has never been as wide as it is now ever since I am involved in this work and that is forever. So I have never known a time like this. I think it is really, really desperate*

Involvement and engagement within local communities were important for those that knew the young people well, but especially parents and adult service staff who highlighted the importance of meaningful inclusion in contrast to 'babysitting'. Art, music and workshop-based activities were mentioned as good examples of how to achieve meaning within activities. Access to nature and to public facilities, such as libraries or sport activities, were cited as other examples.

Emma's mother: *I don't want to see her wandering around with some carers on the phone (...) to get something to eat. I want her stimulated.*

Politics and economy

National policies, promoting person-centeredness and individualisation, seemed to describe 'the ideal scenario', while local authority documents and interviews with managers pointed more to limits within service delivery, describing a shift towards providing fewer services. There thus seemed to be a tension between conceptualising choice as what families ideally liked and choices being inherently linked to what was available. For example, in Emma's and Tom's cases, parents were told that choosing

a more expensive service would involve a decrease in respite services. Parents therefore talked about how their choices felt limited, while local authority managers described that it was families who ultimately made the choice as to what they would like.

Tom's mother: *I didn't feel there was any room for manoeuvre at all. Sadly.*

LA manager 1: *So basically if they can do it for five days at that provider but they want five days with this provider, which they can't afford, sorry that is your choice.*

In both Tom's and Emma's cases, the local authority respite policy played a role in the decision-making process. Both young people transitioned to adult respite service on their 17th birthday and not at the end of their school years, leading to difficulties as families were faced with two disparate transitions (from school to adult services, and from child to adult respite). Both families experienced a decrease in support within adult respite services, with Tom's family experiencing a significant drop. A decrease of respite support in adult services, while needs of the young people remained high, was incomprehensible for parents.

CHRONOSYSTEM

A life course perspective

Narratives of parents were framed within reflections of past experiences, going back to their children's diagnosis and early education experiences, and in anticipation of the far future and worries about their own aging.

What stood out in the transitions of all three young people was that, after the transitions, many questions and concerns about the nearer future for their children remained for parents. In interviews with parents, once the transition to the new adult service was made, issues and questions that had concerned parents in the beginning of the present transition started to be raised again and parents talked about a lack of information on what would happen next. In Peter's case, his placement was coming to

an end at the age of 25 and issues were raised around a lack of local services. Emma's parents were still looking for a placement outside the family but were anxious that this should not impact on her being able to access her day service. Tom's mother hoped to have found the right place for Tom to settle but wondered what would happen if she found the family was not coping with the reduced respite. Losing the involvement of the transition social worker and not having a new named person worried her.

Tom's mother: *If we decide in six months he is not, we are not getting enough respite, where do we go then? Apart from having a nervous breakdown and ending up in [the mental health hospital]?*

While all participants reflected on the near adult future of young people, parents were the only ones who explicitly talked about the transition in terms of planning for a time when they would no longer be able to look after, or advocate on behalf of, their children.

Tom's mother: *What will happen when we are dead is my main concern. Who will look after him? Will he be happy? Will he have a fulfilled life?*

4. Discussion

This study highlights concerns about the transition that have been identified by others, specifically the lack of early planning and information for parents (Hardy, 2005; Cox, 2017); tensions between an understanding of the transition as an event from one service to another within the organisational context and families asking for a whole life-course understanding (Jindal-Snape, 2016); and a widening gap between ideal-led policies and resource-led practice at times of austerity (Mansell & Beadle-Brown, 2004; Roulstone & Morgan, 2009). While increasing attention has been paid to the topic of transitions over past decades there seems to be little improvement in them.

This study was able to add to existing findings through a focus on multiple perspectives and processes within an ecological model. Tensions were identified

within and across ecological levels, namely differences in the involvement of young people within the Meso- and Exosystem; and striving for independence while emphasising the need for consistent support networks for young people throughout their lives. Using an ecological model helped us to make a distinction between the 'practical transition' (Mesosystem) and the 'organisational transition' (Exosystem). Young people moving from school to a new setting described a more practical transition, while decisions in relation to funding and access to services related to structural processes that began earlier and continued after the move. It is suggested that the involvement of the young person differs between practical and organisational processes, between young people's Micro- and Mesosystems and their Exo- and Macrosystem, as has been suggested in literature on healthcare transitions (Care Quality Commission, 2014; NICE, 2016).

Focussing on the transition as a process helped to map where key decisions were made and what influenced them. Available resources played a central role in identifying the service provider and the amount of support available to families. Additionally, funding and availability of services influenced the timing of the transition. For example, Tom left school one year earlier than had been anticipated and in Peter's case, although his placement had been agreed almost a year in advance, details about his exact placement at his present adult service could only be confirmed three months before the move, once current service-users were identified as 'moving on'.

Within the practical transition there seemed to be a stronger emphasis on the involvement of young people. It seemed that young people's needs and behaviour within their immediate environments influenced decisions that were made to some extent. Young people communicated their needs and likes or dislikes through their behaviour, for example by refusing to do an activity, by showing signs of distress or by showing their enjoyment through laughing and increased levels of interaction. At the same time, the study highlighted familiar complexities in interpreting young

people's behaviours and tensions between 'choice' and 'best-interests' (Dunn et al, 2010; Ferguson et al, 2011). Translating young people's preferences and actions into views requires a level of interpretation but a collective approach seemed to help those that knew young people well to collectively negotiate their views and preferences and to facilitate their involvement within the practical move. Similarly, Simmons & Watson (2014) describe that a collective approach to 'meaning-making' can facilitate the inclusion of young people. Using an ecological model illustrated how the wishes and needs of young people, as identified by those close to them, could not always be met due to a lack of available resources and organisational barriers within the Exosystem.

Involving the perspectives of different stakeholders highlighted differences in conceptualisations of the transition as a step towards adulthood. There seemed to be differences between conceptualisations of independence as an absence of support, compared to a more a relational understanding that valued consistent and supportive relationships in young people's lives. The interdependence of families and institutions is particularly significant in the context of severe intellectual disabilities (Pilnick et al, 2011; Young, 2001). Interdependence emphasises the importance of social networks and resources to support young people throughout their life journey, as well as emphasising the agency young people have within their relationships instead of seeing them as passive and merely dependent. This study adds to a growing awareness that the concept of interdependence might be more valuable than independence or dependence (Hogg, 1999; Young, 2001). We suggest that it can help to understand the attainment of adulthood from a relational perspective that bridges dichotomies between independence and dependence. Grove (2012) argues that an inquiry into interdependence is of particular interest when examining the lives of people with severe or profound intellectual disabilities to develop "(...) *an ethic of social inclusion that promotes interpersonal interaction and relationships as the fundamental mechanism of achieving social inclusion*" (p. 346).

The interdependence of the decision-making process lies at the heart of this study. Our findings suggest that if those close to young people are attuned and receptive to the young people's communication, they are able to advocate on their behalf. Yet, this also highlights the vulnerability of young people who do not have closely involved families as advocates. Individuals with severe or profound intellectual disability have little influence over their social networks and the family often remains the individuals' main and only social network outside of professionals (Wilder, 2008; Kamstra et al, 2015). Moreover, high staff turnover in both social care and social work further contribute to this problem (Skills for Care, 2017; Moritay, Manthorpe & Harris, 2018).

The involvement of professionals in the study highlighted how all stakeholders felt that their choices were limited by available resources. Not only named stakeholders played a role, but 'the system' emerged as an actor. This seemed to be a dubious actor, referred to as 'government', 'budgets', 'higher up', 'corporate world' or 'money'. Similarly, Altermark (2017) describes that 'the opponents' disabled people are faced with might not be actors or groups but systems and ideologies.

4.1 Limitations

This study is based on three cases, giving a picture of three different transition experiences. Understandably, findings need to be understood within the context of each case but we argue that there is high value in presenting stories able to highlight difficulties faced by those at the core, as have others (Lenehan, 2017; Cox, 2017).

Parents in this study were all proactive and able to advocate on behalf of their children. The study demonstrated the challenges for researchers to access views of parents who experience greater levels of conflict and who might feel less able to take on strong advocacy roles.

5. Conclusion

The CRPD (2006) promotes participation of persons with disabilities in all matters including policymaking and service commissioning. Our study suggests that while families and young people are involved within practical decision-making there continues to be a need to improve participation across all levels. Our study highlights a lack of involvement of young people within the organisational sphere despite a call for inclusion within policies and international agreements. This is mirrored within the involvement of young people in research. Few studies focus on those with severe or profound intellectual disabilities, and even fewer involve the person in the research process (Jacobs et al, 2018). Studies are typically concerned with interventions and there is a lack of studies that provide a detailed understanding of the lives of people with severe or profound intellectual disabilities. This reflects persisting assumptions that view people with severe intellectual disabilities as passive (Simmons and Watson, 2014). This study aimed to have a stronger involvement of young people. The attempt to include an account of young people's lives and experiences relied on the accounts of others, focusing on young people within interviews, accessing personal plans and spending time with young people. The inclusion of multiple perspectives enriched the data in relation to young people and spending time with young people helped us as researchers to understand the importance of knowing about the person's everyday life. Detailed knowledge of young people's everyday lives was present within the Micro- and Mesosystem, while there seemed to be less of a connection between knowing about young people's lives and influences and decisions made within the Exo- and Macrosystem. Detailed knowledge about everyday life experiences has been suggested by others as a way to facilitate participation of marginalised groups within research, policy making and service commissioning and to bridge the gap between policy and practice (Loeve et al, 2017; Smith, 1990).

To facilitate an involvement that is based on detailed knowledge of people's everyday life experiences requires time (Ward and Stewart, 2008) and to work closely within collaborative teams. Our study echoes best practice guidelines that recommend that

planning should be available from age 14 and should continue to at least age 25 (Scottish Transitions Forum, 2017). Yet the needs and preferences of young people will change throughout adulthood, which requires ongoing collaboration between families and professionals to be able to plan for future changes. Careful thought needs to be given where there are concerns about the continuity of professional involvement to ensure that detailed information is recorded and passed on and that families do not feel left alone once the transition to adult services has been completed.

Additionally, our study emphasises the importance of the wider service provision context. Specifically, this study highlights the importance of meaningful activities for young people within adulthood, as have others (Mietola & Vehmas, 2018; Haddow, 2004). Involving families in the process of service commissioning appears crucial to explore what meaningful services can look like.

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