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Ribenfors, F , Caton, S  and Rimmer, L  (2025) A Multi-Informant Approach to Exploring Connections, Disruptions, and the Multidimensional Elements of Transition to Adulthood for People with Intellectual Disabilities. *Scandinavian Journal of Disability Research*, 27 (1). pp. 330-344. ISSN 1501-7419

DOI: <https://doi.org/10.16993/sjdr.1202>

Publisher: Stockholm University Press

Version: Published Version

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A Multi-Informant Approach to Exploring Connections, Disruptions, and the Multidimensional Elements of Transition to Adulthood for People with Intellectual Disabilities



RESEARCH

FRANCESCA RIBENFORS 

SUE CATON 

LEANNE RIMMER 

**Author affiliations can be found in the back matter of this article*



ABSTRACT

Transition to adulthood is a challenging time for young people with intellectual disabilities and their families in England. Existing research often adopts a narrow focus, concentrating on a specific area of transition or participant group. In contrast, our study employs a multi-informant approach bringing together young people with intellectual disabilities, mothers, and professionals to explore what a consideration of differing perspectives can bring to understanding of transition. A thematic analysis of focus group and interview data led to 13 subthemes organised into 3 overarching themes: The Transition Minefield, Networks of Support, and Encountering Adulthood. Examining these themes reveals the multidimensional, interconnected, and turbulent nature of transition. As such, we add to disability scholarship by providing an overview of the complexity of transition, emphasising the need to account for the wider contexts people operate in, alongside the diverse and intersecting elements shaping experiences.

CORRESPONDING AUTHOR:

Francesca Ribenfors

Manchester Metropolitan
University, United Kingdom

F.Ribenfors@mmu.ac.uk

KEYWORDS:

Transition; intellectual disabilities; learning disability; adulthood; preparing for adulthood

TO CITE THIS ARTICLE:

Ribenfors, Francesca, Sue Caton and Leanne Rimmer. 2025. "A Multi-Informant Approach to Exploring Connections, Disruptions, and the Multidimensional Elements of Transition to Adulthood for People with Intellectual Disabilities." *Scandinavian Journal of Disability Research* 27(1):330–344. DOI:<https://doi.org/10.16993/sjdr.1202>

Becoming an adult is a significant life milestone. In the UK, it is generally considered a time of change relating to a move away from childhood dependency towards independence, a notion reinforced by current policy and legislation (Burch 2018). At the age of 18 in England, people gain the right to vote, can legally consume alcohol, and compulsory education or training ends. While these changes make reaching the age of 18 an exciting, albeit daunting, time for many, for people with intellectual disabilities and their families, becoming an adult is synonymous with the ‘transition to adulthood’, a period fraught with challenges.

TRANSITION TO ADULTHOOD FOR PEOPLE WITH INTELLECTUAL DISABILITIES

Meanings of transition vary depending on the context, and while transition generally signifies a change, not all changes result in transition. In the transition literature, the transition is often understood as an adaptation to change rather than the change itself (Jindal-Snape 2024) with Kralik, Visentin and van Loon, (2006, 322) stating, ‘transition is not just another word for change, but rather connotes the psychological processes involved in adapting to the change event or disruption’. Transitions are complex; multiple transitions occur concurrently for the individual, while also triggering transitions for significant others (Jindal-Snape 2024).

For people with intellectual disabilities, transition has a different meaning. Rather than a theoretical concept, the term is rooted in policy and national guidelines governing how people are supported by health, education and social care services. Short for ‘transition to adulthood’ or more recently, ‘preparing for adulthood’, transition signifies the period between the ages of 14 and 25 during which professionals across education, health, and care should work with the young person and their family to prepare them for adult life (DfE 2015). This includes the move between child and adult services (Tyers and Sinclair 2019).

To help young people and their families understand transition, local authorities have in place ‘transition pathways’ and guides outlining the various steps involved such as when transition planning should begin, what it should include, and who should be involved. They are designed to make ‘a complicated process look manageable and comprehensive’ (Winters 2005, 4). Consequently, transition to adulthood is often portrayed as a linear, largely individual process with a defined beginning and end.

However, portraying transition in this manner obscures the reality of people’s experiences. Transition is a difficult and complex process (Tyers and Sinclair 2019) described by the Care Quality Commission (2014, 2) as ‘fragmented, confusing, sometimes frightening and desperately difficult to navigate’. It is a time of immense stress, anxiety and disruption for young people and their parents (Codd and Hewitt 2021; Young-Southward, Cooper and Philo 2017). Friendships are lost, social isolation increases, and transition planning is often inadequate (Small, Raghavan and Pawson 2013). Furthermore, it is often a time of conflict as relationships between parents and professionals strain (Tyers and Sinclair 2019).

TRANSITION IN RESEARCH

Given the problematic nature of transition, it regularly garners the attention of researchers who tend to focus on specific aspects or participant groups. For example, studies explore how parents or young people conceptualise adulthood (Murphy, Clegg and Almack 2011; Salt, Melville and Jahoda 2019; Wilkinson, Theodore and Raczka 2015), how parents view the transition process (Codd and Hewitt 2021; Gauthier-Boudreault, Gallagher and Couture 2017), transition outcomes (Caton and Kagan 2007), or transition planning (Small, Raghavan and Pawson 2013). While these studies undoubtedly shed light on the areas under investigation, there is a risk that focussing on one aspect or participant group over another obscures the complexity of transition. Including multiple participant groups within a single study can support the development of a rich picture of transition, increasing the chances of successful initiatives arising from the research (Francis, Stride and Reed 2018; Gauthier-Boudreault, Gallagher and Couture 2017). Despite professionals being critical stakeholders responsible for translating policy into practice (Jacobs, MacMahon and Quayle 2020), they are often omitted as participants. However, their inclusion can help explain the conflicts experienced, as differences in opinion between professionals, parents, and young people become apparent (Dezonia 2008; Gauthier-

Boudreault, Couture and Gallagher 2021). Similarly, within the wider transition literature, Jindal-Snape (2024) argues that a narrow focus on transition within research provides a fragmented picture of the complex, multiple transitions.

This paper differs from much of the existing transition to adulthood literature by adopting a multi-informant approach that endeavours to consider transition in its entirety. To avoid suppressing potential complexity and predetermining or reinforcing areas of importance, the research question guiding the study is deliberately broad: What can a consideration of differing perspectives bring to understanding of transition? Therefore, while we begin from an understanding of transition as a term rooted in social policy, as commonly understood within health and social care services for people with intellectual disabilities, we remain mindful to wider theoretical conceptualisations that emphasise the multiple, layered, and affective nature of transitions (Cox 2017; Jindal-Snape 2024). In doing so, this paper contributes to disability scholarship by providing an overview of the complexity of transition to adulthood for young people with intellectual disabilities and offering a way to engage with the term on a more theoretical level.

METHODS

The study generated data through semi-structured interviews and focus groups conducted by the first author, in person, between 2017 and 2018. Visual methods were drawn upon to facilitate discussion and enhance accessibility with participants with intellectual disabilities choosing how they engaged. Choices included the type of visual method, participating one-on-one or in a focus group, and whether to have someone accompany them. Ethics approval was gained from Manchester Metropolitan University, UK, with a comprehensive discussion of ethics relating to the study found in Ribenfors (2021).

All participants lived in England and are captured in three groups:

1. Young people with intellectual disabilities.
2. Mothers of young people with intellectual disabilities.
3. Professionals working with young people with intellectual disabilities and/or their families during the transition period.

Participants were recruited through local parent carer forums, self-advocacy organisations, and word of mouth using purposive sampling. Although the study aimed to include both mothers and fathers, only mothers expressed interest. Their children were aged between 21 and 25 while the young people who participated were aged between 17 and 25, with most over the age of 18. All participants provided informed consent, supported by easy-to-read information sheets, and consent forms.

In total 23 young people, 7 mothers and 5 professionals participated. The professionals included a local authority transition lead, two employees from charities providing information and guidance to families and young people during transition, a transition social worker, and a professional advocate. Five of the young people participated via interviews and 18 via focus groups. Although there was an uneven distribution of participants across the groups, the higher number of young people was necessary to support focus group dynamics. Furthermore, as not all young people contributed equally within the groups, the higher numbers allowed room for people who were less vocal to participate while ensuring the richness of data.

INTERVIEWS

Interviews lasting between 32 and 120 min took place with mothers, professionals, and five young people. Participants chose the time and location of their interview, with locations including parent/carers forums, participants' homes or, for professionals, their workplaces.

The interviews were considered collaborative, with both the interviewer and interviewee active participants. In line with this, the first author kept a research diary for reflections on each interview including salient moments and thoughts on how and why the conversation moved as it did.

Interviews with mothers and professionals began with a general question encouraging participants to talk freely about their experiences and what transition meant to them. A list of prompt questions then served as a loose guide for the researcher.

Four interviews with young people drew on photovoice (Booth and Booth 2003) to facilitate discussions. Participants used disposable cameras to document what transition meant to them. Once developed, participants had the opportunity to view and remove photographs before an interview with the first author to discuss the remaining photos. Participants were asked about what they had photographed and why, with these discussions facilitating a broader conversation about transition and adulthood. Three participants opted to have someone they knew support them in the interview. Supporters mainly provided moral support but also assisted with communication. While there is a risk supporters may assign their own meaning to the communication (Grove et al. 1999), as the first author did not have a prior relationship with participants and was not always attuned to the specifics of their speech, the supporter’s ability to provide additional context or clarity was helpful.

One young person participated in an interview using pictures to facilitate discussion. Similar to a Talking Mat (Murphy 1998), the participant was given a set of small pictures encompassing aspects of adulthood, education, health, social care, and everyday life. From this, they selected pictures to place on the table under an image of either a happy, uncertain, or unhappy face, discussing their reasons with the first author using a combination of Makaton and words. A relative accompanied the participant and assisted with communication.

FOCUS GROUPS

Focus groups took place with three self-advocacy organisations, lasting approximately 2 h and involving 18 participants split across three groups. In advance, a discussion was had with the organisations to share information and discuss structuring the session to suit members’ differing needs. One group requested a topic guide to enable a participant to think through their answers before the meeting. The first author opened each group with a general question to prompt discussion about the meaning and experiences of transition. Participants were encouraged to write or draw their thoughts on post-it notes, with support where necessary. The post-it notes were then shared with the group and formed the crux of subsequent discussions. Staff and family carers who usually supported group members were present throughout.

ANALYSIS

Interviews and focus groups were audio-recorded, transcribed verbatim, and anonymised by the first author before being thematically analysed (Braun and Clarke 2022) as outlined in Table 1. To address the uneven distribution of participants and ensure no group overshadowed another during analysis, the data was initially treated as three separate sets (one for each participant group). Attention was constantly paid to the full data set and areas of shared meaning and difference across the groups. In Step 7, Table 1, the data sets and corresponding themes were brought together resulting in overarching themes that highlight general areas of convergence and subthemes that demonstrate how meaning and priorities diverged according to group.

1. Familiarisation: Listening to audio recordings and reading transcripts and post-it notes.
2. Generating codes: Reviewing a data set and allocating codes to interesting or significant aspects. Revisiting and adjusting codes while moving through the data.
3. Constructing tentative themes: Collating similar codes and sections of data together into tentative themes.
4. Reviewing tentative themes: Ensuring tentative themes align with the coded extracts and the entire data set, consolidating, and adjusting themes as needed.
5. Defining and naming themes: Assigning names to themes and producing written summaries to capture the main points in each theme.
6. Repeating Steps 1–5 for each data set.
7. Uniting the data; bringing the themes for the data sets together, grouping similar themes, and determining overarching themes.

Table 1 An outline of the analysis process adapted from Braun and Clarke 2022.

Post-it notes from the focus groups were included as data and coded alongside the transcripts, ensuring information from participants who opted to write rather than speak was not lost. However, photos and images from the Talking Mat were not coded. As they were used to facilitate discussion, their content was captured within the interview transcripts.

RESULTS

The analysis process generated three overarching themes and 13 subthemes as shown in Table 2. Only one overarching theme, *Encountering Adulthood*, is related to all participant groups.

	THE TRANSITION MINEFIELD	NETWORKS OF SUPPORT	ENCOUNTERING ADULTHOOD
Young people		Loss and connection <ul style="list-style-type: none"> - Support from PAs - Spending less time with family - Loss of college relationships 	Moving towards adulthood <ul style="list-style-type: none"> - Responsibility for self and others - Work - Increasing independence skills Disability and difference <ul style="list-style-type: none"> - Impact of impairment - Desire to change - Comparing self to others
Mothers	Powerlessness <ul style="list-style-type: none"> - Problematic planning - Waiting - Perceived disrespect - Funding decisions Fighting <ul style="list-style-type: none"> - Challenging decisions - Battle language - Advocating for change Life goes on <ul style="list-style-type: none"> - Health issues - Loss of support - Other issues cropping up 	Support to empower <ul style="list-style-type: none"> - Mutual understanding - Sharing information - empowerment - Family support 	Letting go and enabling adulthood <ul style="list-style-type: none"> - Concern for risks/desire to protect - Recognition of adult status - Focussing on 'independence skills' Aspirations bounded by reality <ul style="list-style-type: none"> - Taking what one can get - Discriminatory attitudes - LA perceived as a barrier Worry for the future <ul style="list-style-type: none"> - Lack of trust - Thinking ahead - Concern for state of adult social care
Professionals	Curtailed compassion <ul style="list-style-type: none"> - Belief expectations too high - Understanding of issues experienced - Pressures from above 		Regardless of capacity, they are an adult <ul style="list-style-type: none"> - Tensions between capacity and adulthood - Issues with consent - Educating parents Hindered futures <ul style="list-style-type: none"> - Discriminatory attitudes - LA perceived as a barrier - Lack of role models

Table 2 Overview of themes. The three overarching themes are in the top row with the corresponding subthemes below. Examples of codes are in lists.

THE TRANSITION MINEFIELD

The Transition Minefield captures the difficulties mothers encountered during transition alongside how professionals understood and responded to the issues. Whilst each subtheme connected to mothers – *Powerlessness*, *Fighting*, and *Life Goes On* – highlights distinct challenges, collectively they contribute to transition being experienced as a minefield. As discussions with young people focussed on growing older and adulthood (captured within *Encountering Adulthood*), they are absent from this theme.

Powerlessness

Mothers experienced multiple difficulties as they interacted with adult social care to try and ensure things were organised for their children once full-time education ended. The issues, which lay outside of their control, were attributed to poor or absent planning, difficulties accessing opportunities, fraught relationships with professionals and inadequate information, funding, and support. Janet, whose daughter had attended a residential educational placement, voiced frustration at the lack of planning:

As far as the borough were concerned, she was out of borough until she came back so absolutely nothing, despite me ranting on at various people, got done until she came home. (Janet)

The uncertainty these issues created induced worry and fear in mothers who were concerned about the kind of life their child would lead:

It's just a minefield that you have to get through step by step, and it's frightening, frightening, yeah frightening. Just not knowing what will happen, you know, the years ahead if he gets something, like I say, for the twelve months, what happens after the twelve months? (Sandra)

Furthermore, the uncertainty meant mothers were unable to prepare their children for upcoming changes which impacted their child's mental health.

Fighting

All mothers had experiences of 'fighting' services for the support their child required and were prepared to appeal decisions:

If they say no, I mean, obviously, I will appeal. (Sandra)

The young person's quality of life was viewed as precarious as it depended on their parent's ability to advocate and there was concern for what would happen when parents were no longer around and for people who did not have parents fighting their corner:

I'm on the ball with Sam [...] but what about our other parents who can't read and write? Who can't fight? Who's helping them? They are just falling and falling through the loop. (Cath)

Additionally, some mothers took on campaign or coproduction roles to affect wider change:

I'm on a lot of boards at the hospital, trying to fight for young people with disabilities because I think the transition is really really bad. (Cath)

Life goes on

Alongside navigating transition, mothers contended with day-to-day demands such as car breakdowns or illness. These additional pressures at such a critical time, depleted resources, affected resilience, and impacted their ability to advocate for their child:

Life goes on. Life goes on even though you are going through transition. You want to stop the world when you are going through transition. You want to say give me a break, don't let the washing machine break down, don't let the car break, don't let any health issues, just let me concentrate on this. But you can't because life doesn't work that way. (Claire)

I had been in the hospital, and it was the day after I came out and they phoned me up. I said, 'I'm not well to come up, I've just come out hospital, I'm not well enough.' So anyway, they suspended him altogether and at the time, as I say, I wasn't well enough to fight back, and it's only later I thought I should have done more. (Anne)

Curtailed compassion

Professionals acknowledged that transition is overwhelming and difficult with good outcomes linked to parent tenacity. There was a belief that aspects, such as access to information, support

and opportunities and joint working between professionals, could be improved. However, their position within 'the system' curtailed their compassion. Pressures to reduce or minimise spending influenced their perspectives and affected their ability to be better allies. There was a belief that given the tight financial situation, parents needed to lower their expectations:

It can be quite difficult saying, you know, "do you really need an extra hour at the weekend?" and it's really hard. I think, 'Oh gosh, of course you need it', but when you look at what the absolute minimum amount of support you need to manage on, you don't. (Colette, Transition social worker)

The questions the parent was asking they clearly do not understand the restrictions that we are working within so I think sometimes their expectations are higher than what we can give them. (Katy, Local authority Service manager)

NETWORKS OF SUPPORT

Networks of Support captures the importance of supportive relationships for mothers and young people during transition and how, for young people, these connections changed during transition. As this was not an area raised by professionals, they are absent from this theme.

Support to empower

Peer support was empowering for mothers. Not only was it a vital and trusted source of information, but the support, solidarity, and advice gained enabled them to withstand many of the challenges faced, provided courage to contest decisions, and reduced isolation:

It's a godsend because they are the ones who really get it (Janet)

Three years before that, I would have got that letter, sat down, and cried and thought, there is nothing I can do about this. But because of the journey I had been on with those other parents, I felt empowered to appeal that decision. (Claire)

For some mothers, family support was also important. For example, family members sometimes provided support in the absence of trusted short breaks services and some participants took comfort in knowing that family would be around to care or look out for their child in their absence.

Loss and connection

Young people drew attention to changing family dynamics as they moved towards adulthood. Gradual separation from parents was seen as natural progression, and they envisaged they would spend more time with friends and personal assistants:

You spend less time with family as you get older [...] it's just something which happens. (Kyle)

As such, support from personal assistants was welcomed and enabled a wider range of activities and experiences to occur contributing, in turn, to the development of an adult identity as it gave participants a sense of choice and control over their lives. For instance, support from a personal assistant enabled one young person to pursue his passion for aviation which led to him exploring airport work experience opportunities.

However, the end of college which, as colleges in the UK typically cater for students with intellectual disabilities between the ages of 16 and 25, occurs during transition and also marked a period of loss. Difficulties navigating social media coupled with previous difficult experiences online prevented participants from staying in touch with people. College friendships were often not sustained, and participants missed their relationships with college staff, some of whom they had known for a long time. Feelings of loss were often compounded by the loss of routine and something to do following the end of education alongside difficulties in making new friends:

I'm easily led, and I've been like, if you're my friend, I'm your friend, and so even if they are a bad influence. I'm not really a good judge of character. I think the world is nice and rosy, and then people see me and take advantage. (Stewart)

As a result, some participants felt lonely and unhappy due to the amount of time they spent at home by themselves. Eve, for example, described wanting to spend more time at a social group saying, 'It's what I need really as I don't really go out much.'

ENCOUNTERING ADULTHOOD

Encountering Adulthood brings together the different ways all three participant groups encountered and conceptualised adulthood. It highlights differing priorities between the three groups concerning adulthood and draws attention to the varying challenges faced or acknowledged by participants.

Letting go and enabling adulthood

Mothers recognised and respected their child's changing status and advocated for others to do likewise framing their child's behaviour within a discourse of age-appropriateness:

He wants to be on his own, and who doesn't at that age? You know, "you go out mum," and I will come in here, so he has the living room, and I am thinking, "hang on a minute", but that's him growing up [...] And that's what I did when I was that age.
(Claire)

I said that's a child band and we questioned it at the hotel, and they went "oh well we put a child band on him because of the bar". And we went, "well actually if he wants an alcoholic drink, he is old enough and we accept that he is old enough and it is his right if he wants one. So, put him an adult band." So, we made them change it to an adult band. (Jackie)

However, there was an acute awareness of risks connected to increasing independence as Anne reflected:

I sometimes think that I am quite selfish in that I don't let her do an awful lot as I can see the danger. (Anne)

Mothers were constantly balancing developing their child's independence and keeping them safe:

It's just weighing up taking those risks. Is it worth taking those risks or shall I just keep them safe. (Frances)

Sometimes this created tension with staff whose mothers felt prioritised their child's adult status over keeping them healthy or safe:

They do that thing where "she's an adult now she doesn't want to do that" and you think oh well it might not be the best idea [...] she was coming home, and she would have eaten rubbish. (Janet)

Aspirations bounded by reality

Mothers were frustrated by the gulf between their aspirations for their child's future (often connected to employment) and reality. Jean's son, for example, was being pushed towards a day centre,¹ a decision Jean felt did not take his age into consideration:

It's sending him into places that are, I'm not being funny, but a lot of older men, older people like 50s and 60s. Not being funny, but I don't want my 23-year-old son mixing with people that age, as it's just not right. (Jean)

Discriminatory attitudes from broader society together with a lack of creativity, support and low aspirations from local authorities, led to mothers tempering their aspirations and making compromises to ensure their children had something to do. For instance, Julie's son had 'done nothing' since leaving college a year ago. She was worried he would become deskilled and,

¹ Day centers are a social care provision providing a place for adults with learning disabilities to go during the day. When they work well, they are a place where people with learning disabilities can make friends, be part of and contribute to a community, and take part in a variety of activities. However, their quality varies a great deal.

given his love of dogs, wanted to establish a dog walking business for him. However, their local authority would only support a supported internship:

Maybe if he had a PA he could help with his dog walking business but “oh no we can’t do that we have to go down this route and that and then supported internship” [...] when it could just be simple and long term save money. The red tape holds people back. (Julie)

Worry for the future

The young person leaving the safety net of college amplified concerns mothers had about what would happen when they were no longer able to care or advocate for their child. Transition forced mothers to ‘face things that you don’t want to face’ (Claire). Knowledge of high-profile adult social care failings, coupled with the difficulties experienced with local authorities during transition, eroded confidence in services and made adulthood a worrying place for their child to inhabit. Sandra, for example, described how ‘nought can be trusted’ while Janet described adult social care as ‘scary, definitely scary’. Janet had tried seeking reassurance from the council, but their response only intensified her worry:

You sort of want somebody to say to you “look it’s ok, we will look after her” and nobody is prepared to do that. I’ve sort of asked could we have it in writing, or could we have a charter, or could we just have a promise ‘we will endeavour to do our best to look after her as you would want her to be looked after’ and nobody seems to want to take me up on this point and I do think “well why not?” (Janet)

Regardless of capacity, they are an adult

Professionals focussed on legal roles and responsibilities connected to the young person’s age and the loss of parental responsibility:

It’s about understanding that in adults your son or daughter, regardless of their capacity, is an adult. (Sarah, Advocate)

Attention was drawn to the young person’s ability to make unwise decisions and the difficulties they believed some parents had in accepting changes connected to consent and decision-making:

Trying to explain about capacity, and they’ve not changed. Just because they have gone from 17 to 18, you know, they are not suddenly like, “oh right, I’m all right now. I’m 18. I can make my own decisions.” They struggle that they can’t sign on their behalf or consent on their behalf. (Colette, Transition social worker)

Hindered futures

Like mothers, professionals also highlighted barriers preventing young people from flourishing in their adulthood such as a lack of opportunities, uninspiring pathways, and discriminatory attitudes from potential employers.

Peter, who worked at a charity supporting people during transition, believed the limited experiences people were afforded alongside a lack of awareness of different options limited what they could achieve:

If they haven’t had any different experiences or they don’t know what their options are, it’s difficult isn’t it? They don’t know what to ask for. (Peter, Charity CEO)

There was a belief that young people were set up to fail as they were equipped with skills that they were then unable to use:

What they are going to do in the day. Where they are going to live and what they are going to do in the day. They are the massive things that they have been set up at colleges to be independent...and it feels almost like you are setting people up to fail. (Sarah, advocate).

Moving towards adulthood

For young people, becoming an adult was the main area of focus when discussing transition with three aspects of adulthood prominent: chronological age, changing behaviour, and gaining employment. Summing this up, Fliss stated that adulthood was '*Growing up, being responsible, having a drink of Tia Maria and cola*'. Going to nightclubs, learning to drive and being able to vote were all mentioned as age-related markers of adulthood. However, as with Fliss, it was going to the pub and having a drink that was most frequently cited and was, for participants, an easy demonstration of adult status.

A few participants were anxious about growing older and daunted by forthcoming changes, particularly the end of education:

In an ideal world, every day would be the same, and I don't want where I am now to ever end [...] Like already, my mum is getting me to do everything. She is saying, "You are nearly 18, so you need to do this and this and this." (Conner)

As Conner infers, young people believed their behaviour changed as they became adults. This involved gaining independence (encompassing both 'independence skills', and increased autonomy) and becoming more responsible, for instance, by paying bills, good timekeeping, taking care of their appearance and a shift in dynamics from being the recipient of care to the giver of care. Michael, for example, stated '*I help; I'm an adult*'. Gaining employment or voluntary work was also viewed as a central component of adulthood. For example, one focus group participant commented '*I started doing a supported internship*' when discussing what changed as they became an adult.

Disability and difference

In contrast to parents and professionals who discussed societal factors preventing young people from succeeding, young people perceived their impairments to be the main barrier. This set them apart to their peers as it prevented them from meeting some of the normative markers of adulthood, such as moving out of home or getting a job. Fliss for instance stated: '*Because of the way I am, because of the way my speech and language is, I will struggle*', while Stewart explained how he was prepared to '*change*' to get a job:

See, I'm always looking inward me because I want to change. I don't fit in, so I want to change so I can get a girlfriend, try and get a job. I don't know if the problem is me, but at least I'm willing to try. If there is a problem, well, if people tell me, I'm willing to change. I'm not stubborn. (Stewart)

DISCUSSION

This study adopted a multi-informant approach to explore transition. Treating the three participant groups both separately and collectively within the analysis led to the overarching themes and subthemes summarised above. Examining these themes and the points of convergence and divergence between participants reveals the multidimensional, interconnected, and turbulent nature of transition.

TRANSITION AS MULTIDIMENSIONAL

Taking a multi-informant approach shows transition to be composed of many parts, with the meaning of each part varying depending on the participants' standpoint and specific circumstances. For instance, while mothers and professionals focused on service-related and procedural issues within *The Transition Minefield*, young people were absent from this theme. For them, the crux of transition was gaining an adult identity.

For both mothers and young people, the end of college which typically occurred when the young person was in their early 20s was a major part of transition. For young people, it marked a significant step towards adulthood, whereas for mothers, it signified the beginning of a new kind of life for their child characterised by uncertainty and lack of opportunities. However, transition services are time-limited, and participants found transition social workers who support the move between child and adult services (another part of transition), were no longer

available when needed, such as at the end of education, or, as Beresford (2004) reported, when young people sought aspects of adult status. Hudson (2006) described the move to a post-college destination as an ‘invisible transition’ due to the lack of law or guidance informing what happens. It remains an apt description. Despite the inclusion of preparing for adulthood and outcomes related to employment and community engagement within education, health and care plan reviews from Year 9 (13- to 14-year-olds) onwards (DfE 2015), a lack of planning, information and opportunities persists (Gauthier-Boudreault, Gallagher and Couture 2017; Jacobs et al. 2021) leaving mothers feeling lost and abandoned.

To capture the different parts of transition and the multiple strands of change that occur in health, social, psychological, and relational domains alongside changes in service provision, transition has been described as layered (Cox 2017; Jindal-Snape 2024). These changes, which contribute to the multidimensional characterisation of transition, are evident within our findings as the different participant groups highlighted different areas of change associated with transition. For instance, young people discussed changing behaviour, family dynamics, roles and expectations. Professionals focussed on how they, and parents, navigated changes relating to consent and responsibility. Meanwhile, parents discussed the transformative nature of their friendships with other parents during this time, an aspect of transition unrecognised by professionals (Gauthier-Boudreault, Gallagher and Couture 2017) who were absent from *Networks of Support*.

Other parts of transition that entered participants’ narratives and contributed to their overall understanding and interpretation of transition include budgets and finances, policies, support systems, people, opportunities, information, and plans. While each component varies in its role within overall understandings and experiences of transition, they all fall under the multidimensional umbrella. Adding or removing any one of these elements has the potential to improve, or worsen, individual experiences much like altering one of the more prominent aspects of transition. Therefore, transition is more than just a process or an event; it’s an intricate body of parts that connect and affect each other.

TRANSITION AS INTERCONNECTED

Connections between people during times of transition are akin to a Rubik’s cube; as one person, or colour, on the cube changes so too do those around them (Jindal-Snape 2024). Therefore, although the young person is at the centre, transition affects the whole family. Our capacity to be in relationships with others and to shape each other’s worlds is central to conceptions of personhood (Kittay 2001). Accordingly, participants in our study shaped each other’s worlds. While young people grappled with their changing identities, mothers renegotiated their roles from mothers of children to mothers of adults. Similarly, the difficult relationships with local authorities were affective. Fear, anger, and injustice led mothers to fight for their children. For some, advocating for their child remained at an individual level. However, tying in with Ryan and Runswick-Cole’s (2009) notion of the internal activist continuum, other mothers took on enhanced advocacy roles, motivated to affect wider change.

Although young people were primarily concerned with becoming adults, the inclusion of different participant groups exposes how connections with others shaped the kind of adulthood entered. Within *Aspirations Bounded by Reality* and *Hindered Futures*, for example, mothers and professionals highlighted barriers and discriminatory attitudes facing young people affecting what they were able to achieve. Connections with adult social care led to ‘placements’ within day centres, limiting young people’s ability to work, and shaping the friendships possible. When something was in place following the end of full-time education, it was often connected to the mother’s tenacity and ability to challenge decisions. However, as *Life Goes On* and *Support to Empower* demonstrate this in turn was connected to, and thus affected by, the support systems surrounding parents. Multiple factors, ranging from illness to washing machines breaking, or as often coincides with transition (Dyke et al. 2013), the loss of informal support, affected their capacities. Therefore, there is a need to consider the wider contexts and the networks within which young people and parents belong; professional definitions of transition to adulthood are insufficient if they ignore the ways in which people’s relationships with those closest to them change over time (Cox 2017).

Likewise, the wider contexts professionals operate in need consideration as their actions and communication are affected by their surroundings. Supporting this, Jacobs et al. (2021) found that the support available to professionals influenced the support they could provide to families; professionals appeared caught between supporting families and acting as gatekeepers of resources, the systems around them limiting what they could offer and how they could act. The inclusion of professionals within our study supports this with *Curtailed Compassion* showing how the pressures professionals experienced limited their ability to be better allies for families.

Alongside shaping the adulthood entered, other people enable or constrain the development of an adult identity (Midjo and Aune 2018). Within *Letting Go and Enabling Adulthood*, for example, we see mothers encouraging their child's independence while *Loss and Connection* shows the role of personal assistants. Being able to drink alcohol was a marker of adult status, welcomed by young people. However, demonstrating how connections with others can restrict one's sense of adult status, one mother shared how her son was automatically allocated a child's wristband on holiday which removed this privilege. Our findings support Slater's (2015, 63) statement that 'rather than think about youth-as-becoming-independent-adult, we should think about it as a time of dynamic and increasing relations of interdependency, within which autonomy is at times enabled and at other times denied.'

The interconnectedness within transition extends beyond interpersonal relations as objects also enable or constrain adulthood. Photographs taken by young people as part of their interviews included mobile phones, a cup of tea, and smart shoes. When discussing these photos within their interviews, the young people described how these items, among others, reflected or reinforced their adult status. The cup of tea demonstrated a young person's independence as they had made it themselves, while another person explained they wore the shoes to look smart when volunteering, demonstrating they could take responsibility for themselves. Another less explicit connection is visible in *Disability and Difference*. Echoing Wilkinson, Theodore & Raczka (2015), although young people desired a 'normal' adult identity some felt constrained by their disabled status believing their impairments held them back (rather than a lack of suitable opportunities or support) demonstrating the impact of the individual deficit model of disability (Hodkinson and Burch 2019).

TRANSITION TURBULENCE

Transition is known to be a time of immense upheaval and discontinuity (Hudson 2006; Jacobs et al. 2021). Paying attention to the multidimensional and interconnected aspects of transition, also draws attention to this. Each part of transition (i.e., the different people, processes, events, and elements) is continuously affected by its connections to other parts. Returning to the Rubik's cube imagery, we are reminded that when one person or thing changes, there are ripple effects for others (Jindal-Snape 2024). This is particularly visible within our findings relating to the end of college. While the end of education was a significant change, further ripples of change were evident. For instance, as shown in *Loss and Connection*, support systems around young people changed as they lost friendships and the support of education staff. Familiar routines, established around the college day, were disrupted with parents noting the detrimental impact this had on their child's mental health which had further ramifications for the family while Timmons et al. (2004) reported additional changes as parents sometimes had to give up work to care for their child following the loss of education.

When opportunities were in place for a young person following education, it was often down to their parent's involvement. However, the success and stability of the opportunity depended on multiple factors aligning such as funding, support and transport. As highlighted in *Powerlessness*, these factors lay outside of parent's control and at any point they could change and the opportunity collapses. Something as simple as a bus route alteration or a staff member being absent could completely derail post-college plans. Additionally, the time-limited nature of many opportunities and the reliance on funding from local authorities, meant stability was elusive. Parents were unable to relax, fearing that decisions could be overturned, and funding withdrawn. Jacobs et al. (2021) noted a similar issue, explaining how professionals often took on the role of advocate and facilitated a sense of belonging. However, these relationships were dependent on the wider service provision context they were operating within and thus vulnerable to changes in funding, recruitment, and restructuring, which placed the relationships at risk of being severed.

Therefore, 'transition turbulence' captures the instability and precarity experienced by participants which persisted alongside and independently of the major transition events. The term challenges the sense of forward motion implied when presenting transition as a 'pathway' with participants' experiences far from linear. For instance, although young people felt they were moving towards adulthood and gaining adult status, they were often pushed back, such as by the wristband on the all-inclusive holiday or the prominence of the individual model of disability creating a belief that the participants' impairments were holding them back. Likewise, a sense of backward motion was present in the accounts of those who feared young people would become deskilled by staying at home with nothing to do, or by being 'placed' in uninspiring day centres.

A sense of precarity was also present within *Support to Empower*. Although mothers were empowered through their friendships and as their experience and knowledge of transition grew, empowerment itself carries the notion that power is given and thus can be taken away. Therefore, there was a sense that mothers could, at any time, encounter a different process, hurdle or system for which they were unequipped with the necessary to traverse, leading to further experiences of powerlessness and disempowerment, again contesting the notion of transition as a linear journey.

LIMITATIONS

Siblings and fathers are often underrepresented in research (Francis, Stride and Reed 2018). As we did not include siblings and were unable to recruit fathers, our research does little to address this. Furthermore, since transition affects the whole family, including wider family members would provide an even richer and more thorough understanding of transition.

CONCLUSION

By adopting a multi-informant approach and treating the three participant groups both separately and collectively, the analysis draws attention to where participant groups converge and diverge in their understanding of transition. Within the themes, we see differing priorities and areas of concern, most noticeably in the absence of professionals from *Networks of Support* and young people from *The Transition Minefield*. Examining these differences and reading within and across the different themes exposes the three features of transition focussed on in the discussion. In line with wider transition literature (Jindal-Snape 2024; Kralik, Visentin and van Loon 2006), we argue transition comprises many different yet interconnected parts. As connections between these parts shift and elements are added or removed, transition remains turbulent and a time of immense disruption and precarity for people with intellectual disabilities and their families. As such, this research calls for those researching or working within transition to adulthood for people with intellectual disabilities to adopt more nuanced understanding of transition. Engaging with the term theoretically while also focussing on its current application, offers the opportunity to consider the wider contexts people operate in alongside the multiple and diverse elements affecting peoples' experiences during the transition period.

FUNDING INFORMATION

The research was funded by Manchester Metropolitan University as part of a Vice Chancellor's Scholarship.

COMPETING INTERESTS

The authors have no competing interests to declare.

AUTHOR CONTRIBUTIONS

The first author led the design of the study, data collection, and analysis with contributions from the second and third authors. The first author drafted the manuscript with support from the second author. All authors reviewed and approved the final manuscript.

AUTHOR AFFILIATIONS

Francesca Ribenfors  orcid.org/0000-0002-5012-4816

Manchester Metropolitan University, United Kingdom

Sue Caton  orcid.org/0000-0001-9013-8721

Manchester Metropolitan University, United Kingdom

Leanne Rimmer  orcid.org/0000-0002-3472-6710

Manchester Metropolitan University, United Kingdom

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TO CITE THIS ARTICLE:

Ribenfors, Francesca, Sue Caton and Leanne Rimmer. 2025. "A Multi-Informant Approach to Exploring Connections, Disruptions, and the Multidimensional Elements of Transition to Adulthood for People with Intellectual Disabilities." *Scandinavian Journal of Disability Research* 27(1): 330–344. DOI: <https://doi.org/10.16993/sjdr.1202>

Submitted: 16 September 2024

Accepted: 29 May 2025

Published: 12 June 2025

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Scandinavian Journal of Disability Research is a peer-reviewed open access journal published by Stockholm University Press.

