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Health and wellbeing during transition to adulthood for young people with intellectual disabilities: A qualitative study.

Keywords: Transition, health, wellbeing, young people, intellectual disabilities

Abstract

Background

Transition to adulthood may have negative consequences for health and wellbeing in individuals with intellectual disabilities (ID), but this aspect of transition has received little investigation. This qualitative study aimed to explore the transition experiences of individuals with ID from their own perspectives, and from that of their parents, in order to identify health or wellbeing implications of transition.

Method

Semi-structured interviews were conducted with 17 young people with mild, moderate and severe ID aged 16-27 years and with 23 parents of young people with mild, moderate, severe and profound ID aged 16-26 years. Interviews were analysed using thematic analysis, deploying both emic and etic coding categories.

Results

This study provides direct insights into the issues on health and wellbeing that young people with ID and their parents find important during transition. The primary health implication of transition centred on mental health and wellbeing; young people experienced heightened anxiety during transition, and themes identified as contributing to anxiety included: a lack of meaningful activity following school exit; inadequate support during transition; and difficulties associated with 'growing up'. Problem behaviours and obesity were also implicated.

Conclusion

The transition from school needs to be better supported in order to ease anxiety for young people during this difficult period.

What this paper adds?

Transition is recognised in academic literature and governmental policy as a difficult period for the population with ID. Despite this recognition, there has been little study of health and wellbeing outcomes for young people with ID during transition. This paper employs the perspectives of both young people with ID and their parents to document the ways in which transition to adulthood

affects health and wellbeing, demonstrating that school exit and the transition to adult life have negative consequences for mental health and wellbeing in this population. Perspectives were taken from participants at various stages of the transition, facilitating the elucidation of the effects of this period across the whole spectrum of transition to adulthood. Furthermore, this paper is novel in its inclusion in interviews of individuals with severe ID.

1. Introduction

Transition refers to the movement from school to adulthood; in the population with ID, transition also involves moving from child to adult health and social services. Transition may be a challenging time for young people with ID, since it involves a considerable change in daily routines and available service provision. Traditionally, transition involves leaving school and entering the workplace and developing independence from parents; more recently young people may spend more prolonged periods of time in further education, with continued dependence on parents (Arnett, 2000). Nevertheless, young people with ID may not achieve many typical goals of adulthood that their non-disabled contemporaries go onto achieve. The literature demonstrates low employment figures for young adults with ID (e.g. Scottish Learning Disabilities Observatory, 2016; Verdonschot, De Witte, Reichrath, Buntinx, & Curfs, 2009; Grigal, Hart, & Migliore, 2011), as well as low levels of community participation (e.g. Verdonschot, De Witte, Reichrath, Buntinx, & Curfs, 2009; Small, Raghavan, & Pawson, 2013) and continued residence in the parental home well into the 30s (Gray et al., 2014). Young people with ID may hence be prevented from assuming 'adult' roles, thus delaying some aspects of transition to adulthood (Van Naarden Braun, Yeargin-Allsopp, & Lollar, 2006).

Less is known about health (both physical and mental) and wellbeing outcomes during transition in this population. Wellbeing is defined in the Oxford English Dictionary as: "the state of being comfortable, healthy and happy", involving general life satisfaction and a feeling of fulfilment (Shah & Marks, 2004). Health in children and young people with ID is poor compared to the typically developing population. Those with ID are more likely to have mental health disorders (Rutter, Tizard, & Whitmore, 1970; Linna et al., 1999; Dekker, Koot, Ende & Verhulst, 2002; Emerson & Hatton, 2007a; Emerson & Einfeld, 2010) than their typically developing peers. They are also more likely to be rated as having poor general health by their parents (Emerson & Hatton, 2007b) and to have physical health conditions, including epilepsy (Forsgren, Edvinsson, Hans, Heijbel, & Sidenvall, 1990; Steffenburg, Hagberg, Viggedal, & Kyllerman, 1995; Airaksinen et al., 2000), sensory impairments (Van Schrojenstein Lantmen-de Vaulk et al., 1997; Nielsen, Skov, & Jensen, 2007), and gastro-intestinal disorders (Van Schrojenstein Lantmen-de Vaulk et al., 1997).

A systematic review conducted by Foley, Dyke, Girdler, Bourke, & Leonard (2012) highlighted the importance of environmental factors during transition in the population with ID. A lack of daytime activity may negatively affect mental health outcomes and result in a loss of functional skills (Gauthier-Boudreault, Gallagher, & Couture, 2017). Additionally, disruptions in service provision may have negative consequences for the management of physical health conditions. Transition may also have a negative effect on parents of young people with ID (McKenzie, Ouellette-Kuntz, Blinkhorn, & Démoré, 2017), with potentially transactional, reciprocal and spiralling health and wellbeing interactions for both the young person and the parents.

Transition may be especially problematic given that the support received during this period is often described by families as inadequate (Todd & Jones, 2003; Hudson, 2006; Hetherington et al., 2010; Murphy, Clegg, & Almack, 2011; Gauthier-Boudreault, Gallagher, & Couture, 2017). Qualitative studies demonstrate that transition planning, which aims to map out daily activities and supports beyond school, may be poor, failing to take account of a young person's individual needs and aspirations (Beresford, 2004). Guidelines recommend that transition planning begin when a young person is between the ages of 14 and 16 years, but qualitative studies suggest that current transition planning practices probably occur too late in a young person's school career to be effective (e.g. Hetherington et al., 2010). Furthermore, transition from child to adult services may be discontinuous and chaotic, with differences in style of care provision contributing to difficult moves (Hudson, 2006). It is possible that a combination of these factors may contribute to negative implications for these young people's overall wellbeing.

A systematic review of the literature on transition and health and wellbeing outcomes in young people with ID found only 17 relevant articles (Young-Southward, Philo, & Cooper, 2016). While the articles reviewed suggested the presence of some health and wellbeing issues during transition, including ones to do with sexual health, interpersonal conflict and obesity, no studies specifically examined the ways in which transition to adulthood affects young people's general health and wellbeing, including mental health. This gap in the literature is concerning given the substantial changes in life circumstances that transition from school precipitates, as well as the negative vocational and social outcomes reported in the literature that may have both direct and indirect implications for health and wellbeing. Furthermore, data from young people with ID themselves on this topic, as well as data relating to the ways in which transition impacts health and wellbeing in different ways across the ID continuum, is lacking (Young-Southward, Philo, & Cooper, 2016).

This study therefore sought to describe how transition from school to adulthood affects the health and wellbeing of individuals with ID from the perspectives of young people with ID and those of their

parents. As suggested earlier, the process of transitioning to adulthood may take longer in the population with intellectual disabilities than in the typically developing population, perhaps spanning into the 20s. Henceforth, the term 'young people' will be used to describe individuals experiencing this transition period.

2. Methods

2.1 Study design

The study has a hermeneutic qualitative design (Guba & Lincoln, 1994), whereby young people and their families disclosed their own narratives of transition, and the researcher subjectively appraised the claims made by interviewees. In this way, the interviewees' and researchers' frames of meaning were brought into dialogue in order to produce a plausible interpretation of the issues associated with transition. While it was felt important to include the voices of young people with ID in the research, it was also acknowledged that parents could offer important insights into the transition experience of their children, especially in cases where young people would be unable to take part in an interview due to communication impairments.

2.2 Recruitment

Approval for the study was granted from the University of Glasgow College of Medical, Veterinary and Life Sciences Ethics Committee. Seventeen young people with ID and 23 parents of young people with ID were recruited to take part in the study. Recruitment was stopped at this number of participants as robust themes had been identified in the data. Information packs describing the study were distributed to families via special education schools and organisations providing support to individuals with ID across the West of Scotland. Advertisements describing the study were also placed on organisations' social media profiles. Young people/parents were instructed to contact the lead author if they were interested in participating.

In Scotland, children leave school between the ages of 16 and 18. It was therefore decided that young people/parents of young people would be eligible to participate if they were a young person aged 16-35 years with ID or a parent of a young person aged 16-35 years with ID. This age range was chosen to cover the experiences of young people who were approaching their final years of school, and those who had been out of school for a number of years, in order to obtain data across the likely spectrum of the transition experience. The sample was purposively designed to include males and females and a spread of abilities.

2.3 Procedure

Consent to participate in the interview was obtained from each young person with ID who had decision-making capacity. For young people who did not have decision-making capacity, parents consented on their behalf, in keeping with Scottish law. As defined in Scottish law, adults (aged 16+ years) were deemed to not have decision-making capacity to consent to participate if they were unable to act, or make decisions, or communicate decisions, or understand decisions, or retain memory of decisions regarding the research. Scottish law requires that additional human and mechanical approaches to facilitate communication must be taken before inability to communicate decisions can be concluded. The assessment of capacity therefore included whether the young person was capable of making and communicating their choice; understood the nature of what was being asked and why; had memory abilities that allowed the retention of information; was aware of any alternatives, and the right to decline; understood the potential risks and benefits involved; was aware that such information is of personal relevance to them; and was aware of their right to, and how to, refuse. For adults who did not have decision-making capacity to consent to participate, their next of kin/welfare guardian consented, and Scottish law additionally includes an unqualified obligation that account is taken of their present and past wishes and feelings in so far they can be ascertained by any means of communication, and that they are not objecting. The views of children were similarly taken into account when their parents consented on their behalf.

Audio-recorded, semi-structured interviews were completed with parents and all young people who were able to respond to an interview, together or separately depending on individual preferences. The interview topic guide was developed based on a pilot focus group, conducted with three other young people with ID aged 16-17 years. The guide covered aspects of health and wellbeing and transition. The interviews were open-ended, allowing participants to explore topics that were salient to them. Individuals with severe ID were supported to take part by their parents, who helped the researcher probe their children's answers to interview questions e.g. by asking follow-up questions and offered clarification where their children's responses were unclear. The participants in the pilot focus group study rejected the use of a visual aid during interviews, so no visual aid was used during the main study. Interviews were completed by the lead author in participants' homes in all but two cases, where the interviews took place in a café, in view of the participants' preferences. Interviews lasted between 15 minutes and 2 hours, depending on the level of detail in responses provided by participants, and in all but one case were completed in one visit. In addition to the semi-structured interview, young people, or parents on their behalf, completed three questionnaires to provide a measure of level of ID and to identify mental or general health issues quantitatively:

<u>Vineland Adaptive Behaviour Scale-II (VABS-II)</u>

The VABS-II is a measure of adaptive behaviour across the domains of communication, socialisation and daily living skills. It has high correlations to the previous version (Sparrow, Cicchetti, & Balla, 2005) which itself has high internal consistency and convergent validity, and is considered appropriate for use with individuals with ID (de Bildt, Kraijer, Sytema & Minderaa, 2005). Age equivalent scores were derived for each sub-domain, and a mean age equivalent score generated. This score was used to identify the approximate ability of each young person with ID, using the following cut-off scores:

•   Mild disability (mental age equivalent 9-12 years)

•   Moderate disability (mental age equivalent 6-9 years)

•   Severe disability (mental age equivalent 3-6 years)

•   Profound disability (mental age equivalent 0-3 years).

<u>Strengths and Difficulties Questionnaire (SDQ), Self-report and Parent-report</u>

The SDQ is a behavioural screening questionnaire for children containing 25 items across emotional, conduct, hyperactivity/inattention and peer relationship domains. Three scores are generated: a total difficulties score (between 0 and 40, with a higher score indicating more difficulties); an externalising score (sum of the conduct and hyperactivity domains), and an internalising score (sum of the emotional and peer relationship domains), both scored between 0 and 20, with a higher score indicating more difficulties. A total score of 17 or above is supposed to indicate the presence of a mental health difficulty, and a score of 14-16 indicates borderline difficulties. The measure is suitable for use with children with ID (Emerson, 2005); and, given the developmental age of the sample, it was considered suitable to use in this study.

<u>EQ-5D</u>

The EQ-5D is a standardised instrument to measure general health, involving a visual analogue scale of health status from 0 (poor health) to 10 (good health) 'today'.

2.4 Data analysis

Interviews were transcribed verbatim; all participants were given pseudonyms and any identifying information was removed. Young people's interviews and parents' interviews were analysed separately using thematic analysis (Braun & Clarke, 2006), wherein each transcript was read in detail, noting preliminary themes. Transcripts were read repeatedly to identify patterns within the data. The

data were coded using NVIVO qualitative analysis software (Version 11) according to etic coding categories, reflecting themes identified from literature searches, and emic coding categories, reflecting themes that emerged within the data. Themes that were related to each other were grouped together and themes were organised hierarchically into master themes and sub-themes. Analysis was conducted by the lead author, while the third author analysed a sub-sample of the data to check agreement. A high degree of consistency in identified themes was found.

The qualitative analysis resulted in two groups of master themes and sub-themes: those identified from interviews with young people with ID; and those identified from interviews with parents of young people with ID. These two sets of themes were then compared to identify similarities and differences in young people's and parents' narratives of transition.

3. Results

3.1 Participant characteristics

Participant characteristics are presented in Table 1. Seventeen young people and 23 parents participated in the interviews. All young people who participated did so in addition to their parent(s), except for three young people, whose parents declined to participate, i.e. data was collected about 26 young people.

The 17 young people were aged between 16 and 27 years (mean = 20.5 years). They had mild (n =7), moderate (n = 4), and severe (n = 6) ID, assessed through the VABS-II. There were six young women and 11 young men. At the time of the interview, five young people were still in school. Among those who had left school, the average number of years since school exit was 4.8. Five young people were at college, three were in work placements, two were in part-time employment, and two had no organised daytime activity. Sixteen young people were living in the family home, and one young man was living with his fiancée's parents.

Of the 23 parents who participated, there were 19 mothers; one father; one grandmother; one grandfather and grandmother pair; and one mother and father pair. As the grandparents were in a parental role, all parents/grandparents are referred to as 'parents' throughout this article. Their children were nine young women and 14 young men aged between 16 and 26 years (mean = 19.4 years) who had mild (n = 4), moderate (n = 4), severe (n = 7), and profound (n = 8) ID, assessed through the VABS-II. At the time of the interview, nine of their children were still in school. Among those who had left school, the average number of years since school exit was 4.4. Five of them were at college; five were in work placements; and four had no organised daytime activity. Twenty-one of

them were living in the family home; one was living in residential care; and one was living in his own flat with 24-hour care.

Insert Table 1 here

3.2 SDQ and EQ-5D scores

Ten young people (38.4%) scored in the 'abnormal' range of the SDQ, indicating the presence of a mental health problem, and a further three (11.5%) scored in the borderline range. The mean externalising score (indicating problems with conduct and/or hyperactivity) was 7.7 out of 20 and the mean internalising score (indicating problems with emotions and/or relationships with peers) was 7.5 out of 20. The mean EQ-5D score was 7.5 out of 10.

3.3 Themes identified from the semi-structured interviews

The master themes and sub-themes identified through the semi-structured interviews with young people are presented in Table 2, and with parents of young people in Table 3. While neither young people nor their parents seemed overly concerned about the young people's general health during transition, parents described their children's mental health as being of concern, with many experiencing increased anxiety during transition. All of the themes from young people and parents identified ways in which transition had important implications for their mental health and overall wellbeing.

Insert Table 2 here

Insert Table 3 here

3.3.1 Transition from school/to adulthood

The move from school was the most obvious transition marker for the young people interviewed, and mixed feelings about this significant event were revealed. While some young people did not seem worried: "*It's alright, leaving school*" (James), others reported feeling "*kind of mixed*" (Louis), with sadness about leaving behind friends and the school support network, but also excitement about starting new activities, such as college, offering courses specifically for people with ID, including 'life skills' courses, as well as more conventional courses.

Despite the significant changes associated with leaving school and entering adulthood, young people reported feeling underprepared both for school exit and for their adult life beyond. Transition planning timescales were short-term, with inadequate input from the agencies responsible for supporting the process resulting in a difficult move: "*When I left school I sort of struggled to move because we had a social worker that … left to have a baby … so I had somebody temporary purely for*

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transition … it was like a few weeks before the end of term that [we had the transition] meeting"
(Lara). Furthermore, young people perceived there to be insufficient preparation during school for
the practicalities of the adult world: "*In high school they mostly just taught you about writing a CV
and that was about it, they never taught you about how to manage money or accounts or anything
like that*" (Celia). Arguably, they were left feeling unprepared to tackle the responsibilities of
adulthood.

As a result of this lack of preparation for adulthood, parents reported their own anxieties relating to
their child's transition from school, for they recognised their children's vulnerability in the adult
world: "*That's what worries me because she's nearly 18 and she hasn't got the capability … to [be an
adult]*" (Celia's mum). This situation led to concerns over their children's uncertain future, and was
exacerbated by the limited support available to parents, who were forced to 'fight' with the
organisations providing services to their children in order to prepare them for adult life, something
which damaged their own mental health: "*Honestly I don't know what the future is for Zena … I think
I've got another bloody fight on my hands, I need to recharge my batteries … I'm on antidepressant
tablets … I feel there's nobody out there listening to us parents*" (Zena's mum).

3.3.2 General health

A significant number of young people experienced long-term health conditions, such as epilepsy.
Although most did not report concern over their health issues, it was clear that the management of
these conditions was something that would permeate their adult lives, contributing to ongoing
anxiety: "*[I'm worried about] my condition, basically if it deteriorates any more than it already has*"
(Rosie). Hence, young people had to cope with the changes associated with transition from school in
addition to managing their health conditions in new environments. Despite the large number of
long-term health conditions within the sample, most parents assessed their children's general health
as good, and not something about which they were overly concerned: "*He's got a poor bowel, his
bowel doesn't work very well, but other than that he's fine. He's got a hearing impairment, he's got a
visual impairment, but other than that you know his health is good*" (David's mum).

When asked about their health, most young people identified a need to pursue a healthier lifestyle
or to lose weight as their only health concern: "*Not eating right [worries me]*" (Jamie). Many parents
also expressed concern about their children's weight. While many young people had been
overweight for some time, parents described their children's lifestyles as becoming more sedentary
post-school, with young people over-eating in response to boredom: "*She was just sitting eating,
getting heavier and heavier and I thought 'this is no good'*" (Sally's gran). Furthermore, parents of
children with severe and profound ID perceived there to be few accessible options for their sons and

daughters to engage in exercise, which made tackling their weight problems difficult: *"He needs more exercise, but what do you do? … There should be places for children or adults with a disability [to exercise]"* (David's mum). Indeed, often young people reported an awareness of the need to eat healthily and to exercise, yet described difficulties in putting their knowledge into action. Thus, a significant gap in the post-school support received by young people in terms of health promotion is evident.

This inaccessibility extended to other areas of health, such as cancer screening: *"Lara got … a letter to be invited for a cervical smear test. A 14-page leaflet … of course she can't read that"* (Lara's mum). Lara's mum went on to explain that obtaining an accessible version of the leaflet had required phoning two different people, and then printing off an email version of the document, demonstrating how, without significant support, transitioning individuals with ID may be at risk of not receiving crucial health promotion information.

3.3.3 Mental health

Mental health was identified to be a significant concern during transition for most parents, with many reporting their children to be increasingly anxious throughout the experience, primarily due to the uncertainty surrounding their future: *"I think he's more anxious because he's not sure himself what's going on … he worries constantly"* (Jamie's mum). In this way, short-term transition planning, not mapping out young people's futures sufficiently in advance, contributed to negative mental health and wellbeing consequences for young people.

As well as a lack of certainty about the future, anxiety was attributed to young people's inability to cope with change, with young people feeling frustrated and anxious when they left behind the structured school environment, often with no routine to replace it. For those young people with severe and profound ID, this experience had led to the display of challenging behaviours: *"When she actually left [school] … she became … aggressive, she started swearing, she started biting furniture, which is something that she does when she's upset … and her behaviour got worse and worse … [the psychiatrist] think[s] the trigger was the fact that she didn't have a lot to do"* (Sarah's mum). This situation in turn inhibited young people's ability to function in the adult community, resulting in a negative cycle of frustration and behavioural difficulties leading to exclusion from environments which might serve to alleviate the boredom that had precipitated the behavioural problems in the first place: *"She can't do [a placement] because of her aggressiveness … she could have had a place for a college thing to work with kids but for the time being it's a no go … because of the way she is"* (Celia's mum).

3.3.4 Something to do versus nothing to do

Among the young people who had transitioned from school at the time of the interview, a variety of post-school activities were described. College was the most popular choice of activity following school exit, since it offered young people a routine that mirrored the experience of school. However, while college provided young people with an important feeling of stability, they did not appear to be progressing, either through developing their skills or acquiring qualifications: "*Even though I was doing different subjects over four years it was all at the one level, so you weren't really learning*" (Lara). In contrast, the small number of young people who were employed reported mastering new skills as a result of their work: "*[I have enjoyed] learning new things and getting out and meeting other people … it has helped me with travelling 'cause I didn't really know that many places, but for this job we need to travel all over Scotland, so it does give you a bit more confidence when you're out travelling by yourself*" (Josh). Crucially, these skills had conferred significant benefits for young people's confidence, which in turn facilitated their access to other important aspects of adulthood: "*If I didn't have the job I don't think I'd have met my fiancée because … I wasn't really going on nights out with friends … I was more than happy to sit in front of the TV … now [I'm] … going out more often with friends … my social skills improved*" (Darren). In this way, employment served as a gateway to the adult community, equipping young people with the skills necessary to navigate the social world.

It is nonetheless important to note that most young people were prevented from accessing employment spaces due to the inaccessibility of the workplace for individuals with disabilities: "*Trying to find a job that fits me [will be difficult]*" (Daniel). In this way, many young people were excluded from enjoying the benefits of meaningful employment and were left with little to fill their time following school exit; a situation that was a source of frustration for many: "*Now that I'm not in school I find myself absolutely bored out of my mind … sitting in the house all day's kind of annoying in my opinion*" (Celia).

This situation caused substantial difficulties; a lack of routine following school exit was parents' most frequently cited cause of young people's mental health difficulties during transition: "*It's got to be like a set routine … if anything breaks the routine … it's stressful for him*" (Jamie's mum). Parents hence stressed the importance of their children having something to do during the day following the transition from school in order to provide them with a new routine, as well as with opportunities to engage in the social world outside of the home: "*I don't want him to stay in the house, sitting about, because the two of us need to get a break from each other as well*" (James's mum). However, a lack of post-school opportunities, such as supported work placements was highlighted: "*There's not a lot about. The employment team did have … some little fruit and veg stalls … but the funding was pulled*

for that … There is a garden centre close by and again the funding was pulled from that … So there's very little about" (Simon's mum).

3.3.5 Relationships

As well as limited opportunities to participate in vocational activities, parents noted a decrease in the availability of opportunities for their adult children to socialise: *"There are lots of … sports groups and things like that for children, whereas [for] adults it's a bit more patchy"* (Louis's mum). The young people hence struggled to make or maintain social connections, especially since they were often unable to maintain the friendships that they had developed at school independently outside of the school environment*: "I did have a really good friend at school but they stayed in Paisley and of course I stay here and we both can't drive. Until we learn how to use transport that was always a struggle" (Lara).* This situation contributed to significant isolation, with some young people describing themselves as having *"no friends"* (Celia).

Furthermore, young people described experiences of intolerance and even bullying in the community*: "[At] college … adults [were] picking on me, calling me names and telling me that I was a baby"* (Rosie)*.* These experiences were a source of anxiety, permeating young people's visions of the future: *"[I'm worried about] going into my first job 'cause I don't know how I'm gonna be, like, taken … 'cause I'm quite different from other people" (Sally).* Thus, a lack of opportunities, both vocational and recreational, as well as a lack of tolerance in the general community, resulted in young people experiencing isolation: "*There's nothing for him to do in the community, so he's kind of on his own*" (David's mum).

3.3.6 Support

The transition from school often coincided with a transition from children's to adult services. This shift resulted in a change in support networks as new staff assumed responsibility for young people's cases, while differences in the availability of funding for adults as opposed to children resulted in the termination of some services. This phenomenon was a source of frustration for young people, who were often confused when the professionals with whom they had worked for many years ceased to be part of their lives: "*[My occupational therapist] has left me*" (James). The limited availability of support for young people after school exit constrained young people's ability to access post-school environments, which resulted in further anxiety as young people struggled to cope: "*I feel like you don't get any help at college, you just get put in and then if you're struggling ... you're on your own really*" (Josh).

Parents described transition planning, including the allocation of personal budgets to cover the costs of care in adult services, as both short-term and chaotic: *"It's supposed to take a year to a year and a half, transition. We've still not got a word yet and we're … [at the] beginning of April and you're talking the end of April before we're gonna get a budget, so that leaves like two months till school leaves"* (Carol's dad). This phenomenon caused delays in the allocation of new services following school, resulting in a period of limbo between school exit and the uptake of new activities that often stretched on for months: *"She left school in June and it was December before she got anything"* (Sarah's mum). As discussed previously, a lack of activity clearly emerged from the interviews as the most significant contributor to young people's mental health and behavioural difficulties.

Besides inadequacies in transition planning, parents described the care that their adult children received as falling short of their requirements. For example, young people ceased to receive the level of individualised support that they required to access the community in adult services: *"The lady phoned me and said she had a place in the [local] club … and obviously Hannah needs personal care during the clubs … and she says 'well you would need to sit with her'… I was looking for somewhere that Hannah can go and it be, like, a wee night out for her"* (Hannah's mum). This situation undermined young people's independence, since they were unable to access the community without the support of their parents. Universally, these difficulties were attributed to a lack of funding in adult services compared to children's services, reflecting austerity measures that resulted in significantly less funding being available to support individuals with ID. For example, Lara's mum stressed the inaccessibility of appropriate mental health support for her daughter outside of the education system: *"She had psychological support on and off … when she was a child that was funded by … education … once she became an adult they couldn't [pay for it] … Lara will not be referred to a service like that now … [in adult services] you get a six week block of CBT where a nurse has gone for a wee course."* (Lara's mum).

3.3.7 Growing up

Independence was identified by young people as a crucial component of adulthood: *"My mum's not gonna be there … for like all my life … so I'll need to learn to … do things myself"* (Zena). The route to independence was not straightforward for most young people, however, and many experienced difficulties in developing independence due to the inaccessibility of adult environments and a lack of organised support to access them, which was frustrating for many: *"It's frustrating for Louis to be so dependent on me, he doesn't like it"* (Louis's mum). Furthermore, parents explained that their children's developmental delay meant that traditional aspects of 'growing up', such as moving out of the family home, were not appropriate options for them until their mid to late 20s. Unsurprisingly,

some young people still desired to achieve such goals, and experienced mental health difficulties when they were unable to do so: *"[Lara has] such unrealistic expectations and that's made her very unhappy, she's been self-harming … she's very frustrated with her lack of independence … she feels great pressure that … she should be [living independently] … by now"*(Lara's mum).

This phenomenon also had implications for young people when navigating the community, since the disparity between their physical and cognitive maturity often resulted in expectations for mature behaviour which they could not fulfil and did not always understand, contributing to considerable stress: *"People look at him as though he's mature because he's that size … people assume that he's going to come across as a mature person and then he says something younger … he comes home upset now sometimes … it's just too much pressure"* (Jamie's mum).

Perhaps because of these difficulties, and the aforementioned lack of preparation for adult life that young people received during transition planning, young people reported fears related to assuming responsibility for themselves: *"[I'm worried about] money, having to go places by myself … and getting up at the right time for like work … and making sure the house is clear and all that"* (Jamie). These fears contributed to ongoing anxiety during the transition period, with young people unable to imagine themselves living independent, adult lives: *"It's impossible, I don' t know how my mum does it"* (Celia).

Many parents were similarly unable to envision their children living independent lives, which impacted their own mental health as they adjusted to the idea that they would be caring for their children into old age: *"It's a daunting feeling because … the older they get the more reality hits that you're like 'I'm going to be a carer for the rest of my life'"* (Daniel's mum). It must be noted that this experience was more common for those parents of children with severe or profound ID compared to those with mild to moderate ID, since the latter were making progress towards independence, albeit slowly and with some difficulties: *"It has been a hard year but … we're getting there now"* (Sarah's mum). By contrast, the transition for young people with profound ID involved less progress towards independence and was instead primarily organisational, relating to young people moving from school to adult services. That said, parents still expressed a desire for their children with profound ID to be independent in some respects, simultaneously acknowledging that their children would never be wholly independent, but still hoping them to experience some aspects of a 'normal' transition, which would usually entail living in supported accommodation: *"Molly is reliant … for her total care … [but] I think she deserves to be doing her own thing, so yeah I would like that at some point in the future."* (Molly's mum)

4. Discussion

4.1 Principal findings and recommendations for improving support during transition

This study is the first to examine specifically the impact of transition to adulthood on health and wellbeing in young people with ID from their own perspectives and that of their parents.

Young people experienced increased anxiety during the move from school and beyond. This anxiety was attributed to short-term transition planning, which meant that young people were often left with little or no activity following school exit, and no certainty surrounding their future, as well as to complex issues associated with growing up in an inaccessible environment. Transition planning would ideally hence begin earlier in a young person's school career in order to identify post-school activities well in advance of school exit, thus facilitating a calmer transition experience. Relatedly, this study has identified that the inaccessibility of vocational and social environments for young people with ID may contribute to isolation and mental health difficulties, including behavioural difficulties. Previous studies have also identified a lack of vocational activity to be related to behavioural problems in young people with ID (e.g. Foley et al., 2014; Gauthier-Boudreault, Gallagher, & Couture, 2017). A lack of activity, leading to a sedentary lifestyle, was also associated with weight gain, also echoing previous research (e.g. Gauthier-Boudreault, Gallagher, & Couture, 2017). These phenomena highlight the importance of young people with ID accessing meaningful activity after school exit.

The unsatisfactory nature of transition planning described here is echoed by families in other countries, including the USA (e.g. Grigal, Hart, & Migliore, 2011) and Canada (e.g. Gauthier-Boudreault, Gallagher, & Couture, 2017). Additional support for young people to access vocational and social environments, including funding for paid carers and for supported activities for young adults with ID, would be beneficial. The results of this study were fed back to the schools and organisations that supported recruitment of participants to the study. It is important that the effect that short-term transition planning has on a young person's mental health and wellbeing be heard by those in a position to improve the transition experience for young people.

While general health was not described by any participants as being of particular concern, it is clear that young people experienced a high incidence of long-term health conditions requiring careful management into adulthood. Furthermore, young people experienced barriers to experiencing healthy lifestyles, which had negative implications for their weight specifically, with potential additional health consequences into adulthood. The inaccessibility of health promotion information and activities represents a serious problem for individuals with ID into adulthood. Facilitating access to health promotion information and to opportunities to exercise would allow young people to lead healthier lives into adulthood. Transition is a crucial juncture in a young person's life, and facilitating

access to this information at this time might help to tackle the health inequality experienced by the population with ID (Emerson, Baines, Allerton, & Welch, 2011).

4.2 Strengths and limitations

This study utilised the views of both individuals with ID and their parents. Triangulating data in this way through comparing these different 'windows' to the same issue (Dey, 1993) facilitated a deep understanding of the complex transition experience. Furthermore, this study is novel in its inclusion of individuals with severe ID, highlighting the important contribution that individuals with ID can and should make to research. The interview procedure nonetheless required parents to be present for young people with severe IDs' interviews, and many parents also chose to remain present for their child with mild or moderate IDs' interviews. Given the sensitive nature of some of the topics covered in the interview, the presence of parents could have influenced young people's responses. Additionally, as some of the participants were in their mid 20s, they may have been unable to recollect how they truly felt during their transition from school. However, transition in the sense of achieving independence may continue into the 20s, and these older individuals were able to offer insights into this important aspect of transition. Finally, this study was cross-sectional in design, and a longitudinal study following a sample of young people with ID throughout the transition to adulthood is required in order to more fully elucidate the impact of transition on health and wellbeing.

4.3 Conclusions

This study has identified that transition may have negative health consequences for individuals with ID, including mental health problems and weight gain. More comprehensive transition planning, beginning earlier in a young person's school career, might help to facilitate a calmer transition experience.

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References

Airaksinen, E. M., Matilainen, R., Mononen, T., Mustonen, K., Partanen, J., Jokela, V., & Halonen, P. (2000). A Population‐Based Study on Epilepsy in Mentally Retarded Children. *Epilepsia, 41*(9), 1214-1220.

Arnett, J.J. (2000) Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist, 55*(5), 469-480

Beresford, B. (2004). On the road to nowhere? Young disabled people and transition. *Child: Care, Health and Development, 30*(6), 581-587.

Braun, V., & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*: 3 77-101

de Bildt, A., Kraijer, D., Sytema, S., & Minderaa, R. (2005). The psychometric properties of the Vineland Adaptive Behavior Scales in children and adolescents with mental retardation. *Journal of Autism and Developmental Disorders, 35*(1), 53-62.

Dekker, M. C., Koot, H. M., Ende, J. V. D., & Verhulst, F. C. (2002). Emotional and behavioral problems in children and adolescents with and without intellectual disability. *Journal of Child Psychology and Psychiatry, 43*(8), 1087-1098.

Dey, I. (1993*) Qualitative data analysis, a user-friendly guide for social scientists*. London: Routledge

Emerson, E., Baines, S., Allerton, L., & Welch, V. (2011) Health inequalities and people with learning disabilities in the UK: 2011. Improving Health and Lives: Learning Disabilities Observatory. Retrieved from http://www.improvinghealthandlives.org.uk/securefiles/161111_1201//IHaL%202011-09%20HealthInequality2011.pdf on 11/11/2016

Emerson, E., & Einfeld, S. (2010). Emotional and behavioural difficulties in young children with and without developmental delay: a bi‐national perspective. *Journal of Child Psychology and Psychiatry, 51*(5), 583-593.

Emerson, E., & Hatton, C. (2007). Mental health of children and adolescents with intellectual disabilities in Britain. The British Journal of Psychiatry, 191(6), 493-499.

Emerson, E., & Hatton, C. (2007b). Contribution of socioeconomic position to health inequalities of British children and adolescents with intellectual disabilities. American Journal on Mental Retardation, 112(2), 140-150.

Foley, K. R., Dyke, P., Girdler, S., Bourke, J., & Leonard, H. (2012). Young adults with intellectual disability transitioning from school to post-school: a literature review framed within the ICF. Disability and Rehabilitation, 34(20), 1747-1764.

Foley, K. R., Jacoby, P., Einfeld, S., Girdler, S., Bourke, J., Riches, V., & Leonard, H. (2014). Day occupation is associated with psychopathology for adolescents and young adults with Down syndrome. BMC psychiatry, 14(1), 266.

Forsgren, L., Edvinsson, S. O., Hans, K., Heijbel, J., & Sidenvall, R. (1990). Epilepsy in a population of mentally retarded children and adults. *Epilepsy Research, 6*(3), 234-248.

Gauthier-Boudreault, C., Gallagher, F., & Couture, M. (2017). Specific needs of families of young adults with profound intellectual disability during and after transition to adulthood: What are we missing?. *Research in Developmental Disabilities, 66*, 16-26.

Gray, K. M., Piccinin, A., Keating, C. M., Taffe, J., Parmenter, T. R., Hofer, S., ... & Tonge, B. J. (2014). Outcomes in young adulthood: are we achieving community participation and inclusion?. *Journal of Intellectual Disability Research, 58*(8), 734-745.

Grigal, M., Hart, D., & Migliore, A. (2011). Comparing the transition planning, postsecondary education, and employment outcomes of students with intellectual and other disabilities. Career Development for Exceptional Individuals, 34(1), 4-17.

Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. Handbook of qualitative research, 2(163-194), 105.

Hetherington, S. A., Durant-Jones, L., Johnson, K., Nolan, K., Smith, E., Taylor-Brown, S., & Tuttle, J. (2010). The lived experiences of adolescents with disabilities and their parents in transition planning. *Focus on Autism and Other Developmental Disabilities, 25*(3), 163-172.

Hudson, B. (2006). Making and missing connections: learning disability services and the transition from adolescence to adulthood. *Disability & Society, 21*(1), 47-60.

Linna, S. L., Moilanen, I., Ebeling, H., Piha, J., Kumpulainen, K., Tamminen, T., & Almqvist, F. (1999). Psychiatric symptoms in children with intellectual disability. *European Child & Adolescent Psychiatry, 8*, S77-S82.

McKenzie, K., Ouellette‐Kuntz, H., Blinkhorn, A., & Démoré, A. (2017). Out of school and into distress: families of young adults with intellectual and developmental disabilities in transition. Journal of Applied Research in Intellectual Disabilities, 30(4), 774-781.

Murphy, E., Clegg, J., & Almack, K. (2011). Constructing adulthood in discussions about the futures of young people with moderate‐profound intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 24*(1), 61-73.

Nielsen, L. S., Skov, L., & Jensen, H. (2007). Visual dysfunctions and ocular disorders in children with developmental delay. I. prevalence, diagnoses and aetiology of visual impairment. *Acta Ophthalmologica, 85*(2), 149-156.

Rutter, M., Tizard, J., & Whitmore, K. (eds.) (1970) *Education, Health and Behaviour*. London, UK

Scottish Learning Disabilities Observatory (2016) https://www.sldo.ac.uk/ Accessed on 29/09/2016

Shah, H., & Marks, N. (2004) A well-being manifesto for a flourishing society. London: The New Economics Foundation

Small, N., Raghavan, R., & Pawson, N. (2013). An ecological approach to seeking and utilising the views of young people with intellectual disabilities in transition planning. Journal of intellectual disabilities, 17(4), 283-300.

Sparrow, S.S., Cicchetti, D.V., & Balla, D.A. (2005) *Vineland Adaptive Behaviour Scales, Second Edition, Survey Forms Manual*. AGS Publishing

Steffenburg, U., Hagberg, G., Viggedal, G., & Kyllerman, M. (1995). Active epilepsy in mentally retarded children. I. Prevalence and additional neuroimpairments. *Acta Paediatrica, 84*(10), 1147-1152.

Todd, S., & Jones, S. (2003). 'Mum's the Word!': Maternal Accounts of Dealings with the Professional World. *Journal of Applied Research in Intellectual Disabilities, 16*(3), 229-244.

Van Naarden Braun, K., Yeargin-Allsopp, M., & Lollar, D. (2006). A multi-dimensional approach to the transition of children with developmental disabilities into young adulthood: The acquisition of adult social roles. Disability and Rehabilitation, 28(15), 915-928.

Schrojenstein Lantman‐de Valk, H. V., Akker, M. V. D., Maaskant, M. A., Haveman, M. J., Urlings, H. F. J., Kessels, A., & Crebolder, H. F. J. (1997). Prevalence and incidence of health problems in people with intellectual disability. *Journal of Intellectual Disability Research, 41*(1), 42-51.

Verdonschot, M. M., De Witte, L. P., Reichrath, E., Buntinx, W. H. E., & Curfs, L. M. (2009). Community participation of people with an intellectual disability: a review of empirical findings. *Journal of Intellectual Disability Research, 53*(4), 303-318.

Young-Southward, G., Philo, C., & Cooper, S.-A. (2016) What is the effect of transition to adulthood on health and wellbeing in young people with intellectual disabilities? A systematic review. *Journal of Applied Research in Intellectual Disabilities* online early access

Table 1: Participant characteristics

Young person	Age	Interviewees	Gender	Ability	Current activity	N years since leaving school	Living situation
Aaron	20	Mother & father	Male	Profound	Work placements	2	Home
Adrian	17	Mother	Male	Profound	School	N/A	Residential care
Arnold	25	Young person + mother	Male	Severe	Work placements	9	Home
Carol	17	Father	Female	Profound	School	N/A	Home
Caroline	17	Mother	Female	Profound	Nothing	0.5	Home
Celia	17	Young person + mother	Female	Severe	Nothing	1	Home
Daniel	16	Young person + mother	Male	Severe	School	N/A	Home
Darren	27	Young person	Male	Mild	Part-time employment	9	With fiancée's parents
David	24	Mother	Male	Profound	Nothing	6	Own flat with 24 hour care
Hannah	17	Mother	Female	Profound	Nothing	0.5	Home
Jake	18	Mother	Male	Profound	School	N/A	Home
James	17	Young person + mother	Male	Severe	School	N/A	Home
Jamie	17	Young person + mother	Male	Severe	School	N/A	Home
Jeremy	25	Young person + mother	Male	Mild	Work placements	10	Home
Josh	26	Young person	Male	Mild	Part-time employment	6	Home
Lara	25	Young person + mother	Female	Mild	College	10	Home
Louis	21	Young person + mother	Male	Moderate	College	5	Home
Mike	21	Young person + grandmother	Male	Mild	College	5	Home
Molly	18	Mother	Female	Profound	School	N/A	Home
Rosie	21	Young person	Female	Mild	Nothing	4	Home
Sally	21	Young person + grandparents	Female	Mild	College	5	Home
Sam	16	Young person + mother	Male	Moderate	School	N/A	Home
Sarah	19	Young person + mother	Female	Severe	Work placements	2	Home
Simon	23	Mother	Male	Severe	Work placements	4	Home
Tim	19	Young person + mother	Male	Moderate	College	2	Home
Zena	16	Young person + mother	Female	Moderate	College	N/A	Home

Table 2: Themes identified from the semi-structured interviews with young people with ID

Master theme	Sub-theme	Description
Transition from school/to adulthood	Leaving school	Interviewees' feelings regarding leaving school
	Support to transition	Support available to young people during transition from school/to adulthood
General health	Health conditions	Health conditions experienced by the interviewees and their continued impact into adulthood
	Healthy lifestyles	Opportunities for young people to engage in healthy behaviours e.g. exercise
Something to do versus nothing to do	Daytime activity	Opportunities available for young people to participate in meaningful daytime activity following school exit
	Confidence	Positive impact of having meaningful activity following school on young people's confidence
Relationships	Socialising	Experiences related to socialising following school exit
	Experiences of intolerance	Experiences of intolerance of disability within the community, including bullying
Support	Changing landscape of support	Changes in the support networks available to young people during transition
Growing up	Independence	Young people's perceptions of their increased independence (or lack thereof) in adulthood
	Responsibilities	Young people's perceptions of their increased responsibilities in adulthood

Table 3: Themes identified from the semi-structured interviews with parents of young people with ID

Master theme	Sub-theme	Description
General health	Health conditions	Health conditions experience by the young people with ID
	Healthy lifestyles	Opportunities to engage in healthy eating/exercise
Mental health	Stress and anxiety	Feelings of stress and anxiety experienced by young people in response to the changes associated with transition
	Challenging behaviour	Behaviours e.g. self-harm or aggression that young people exhibited in response to the frustrations and anxieties of their transition experience
Something to do versus nothing to do	Something to do	Importance of young people having meaningful daytime activity in the absence of school and the difficulties associated with achieving this
	Barriers to accessing something to do	Factors that prevented young people from accessing activities in the community following school exit
	Routine	Importance of routine in maintaining young people's wellbeing and the struggle to adjust to new routines or the absence of any routine following school exit
	Socialising	Challenges involved in facilitating opportunities for young people to socialise with peers in the absence of school
Support	Inadequate care or support	Perceptions among parents that the care or support that their child received during transition was inadequate
	Funding	Limited funding for support or services for young people with ID as contributing to difficult experiences
	Timescales	Transition planning as too short term to be effective; delays experienced as a result of inappropriate timescales
Growing Up	Independence	Parents' attempt to facilitate age-appropriate independence in their adult children and the challenges associated with doing so
	Adult identities	Difficulties experienced by young people in relation to growing up and developing adult identities