Title: Transitioning to Adulthood with a Mild Intellectual Disability – Young People's Experiences, Expectations, and Aspirations

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Running title: Transition to Adulthood for Young Adults with IDs

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Abstract

Aim: Very little attention has been paid to the views and experiences of young people with mild intellectual disabilities on the broad topics of adulthood and adult identity. The following study was undertaken to explore how young adults with mild intellectual disabilities conceptualise, relate to, and experience the process of transition.

Method: 8 young adults with mild to borderline intellectual disabilities participated in semi-structured interviews. Results were analysed using interpretive thematic analysis.

Results: Two umbrella themes were identified: 'On a developmental pathway' and 'Negotiations in the environment'.

Conclusions: The participants concerns were surprisingly similar to those commonly expressed by young adults without disabilities. Self-perceived adult identity appeared to be affected by the participants' personal definitions of adulthood, as well as by social comparisons with both peers and adults. Finally, while concerns were expressed about their capacity to cope with responsibility, most felt optimistic about adopting full adult status in the future.

Introduction

Specific transitions, such as leaving school, moving out, or moving from child to adult services, represent popular topics within the field of intellectual disability research and policy. From these, valuable insights have been gained regarding some of the specific difficulties that young people with disabilities and their parents face during adolescence and young adulthood. However, only one study could be found that directly sought to explore how young adults with mild intellectual disabilities perceive and experiences the broader topics of 'growing up' and adult identity (Midjo & Aune, 2016). This is despite the fact that post-school outcomes may be affected by an individual's expectations of, and attitudes towards, becoming an adult. The following study was undertaken to explore how young adults with mild intellectual disabilities conceptualise, relate to, and experience the process of becoming an adult.

The transition from childhood to adulthood is generally accepted to be one of the most dynamic periods in life. Significant decisions are made, social and legal status changes occur, and new roles are adopted, leading to an increase in opportunity and responsibility, as well as a decrease in protection. In Scotland, for example, young people reach the age of majority at 16 and are therefore considered to be sufficiently mature to leave school, grant their own consent, as well as to be tried as an 'adult' within the criminal justice system. However, while 16-year olds are free to vote in Scottish elections, many other legal permissions and rights are delayed until 17 (driving), 18 (drinking alcohol, smoking, voting in UK government elections), and even 25 (right to receive full minimum wage). Consequently, legal adult status can be thought of as developing over a relatively protracted period of time.

Importantly, 'adulthood' is predominantly a social construct, susceptible to evolve in response to societal consensus. Traditionally, the most heavily emphasized aspects of 'adulthood' have been the achievement of social role transition, such as the completion of formal education, marriage, and parenthood (Mortimer, Oesterle, & Kruger, 2005). Yet, trends across the globe reveal that individuals in their late teens and early twenties are choosing to postpone, or even reject these life-stage markers (Billari, 2004).

Some researchers have suggested that attitudes towards the nature of adulthood may be changing as a result. Evidence suggests that within Western cultures, character qualities such as 'making independent decisions', 'accepting responsibility for oneself', and 'belief in one's own autonomy' may have replaced social role transitions as the most significant indicators of adulthood (Arnett, 1997, 2000; Nelson & Barry, 2005). In many ways, these character qualities of adulthood are mirrored in the construct of self-determination (Field, Martin, Miller, Ward, & Wehmeyer, 1998). A self-determined individual makes choices and decisions regarding their quality of life without undue external influence or interference (Wehmeyer & Bolding, 2001). As such, it is unsurprising that self-determination - and its associated constructs - are frequently cited as important and desirable outcomes of the transition process, particularly for individuals with intellectual disabilities (Field et al., 1998; Mitchell, 2012).

However, it should also be acknowledged that an individual could exhibit all of the dispositional traits of self-determination without *feeling* like an adult (Kirkpatrick Johnson, Berg, & Sirotzki, 2007). Subjective age identity, the extent to which individuals consider themselves to have transitioned to adulthood, is therefore a distinct aspect of the transition process. The confluence model proposed by Shanahan

and colleagues (2005) suggests that, even though adulthood in general is increasingly defined in terms of the personal characteristics identified by Arnett, subjective age identity remains highly influenced by social role change.

Today, intellectual disability remains a risk factor for failing to achieve both the social and psychological transitions associated with adulthood. Studies have repeatedly shown that levels of functional self-determination are low in this population (Wehmeyer & Garner, 2003). The cognitive and adaptive deficits central to a diagnosis of intellectual disability can make a number of the competencies required for independence and self-determination harder to achieve (Khemka, Hickson, Casella, Accetturi, & Rooney, 2009; Mitchell, 2012).

Moreover, young people with intellectual disabilities often have fewer opportunities to act independently of adult control, as there are acute concerns about the increased risks faced by members of this group (Almack, Clegg, & Murphy, 2009). Service providers have therefore tended to prioritise safeguarding over all other outcomes (Seale, Nind, & Simmons, 2013), despite the necessity of experimentation and positive risk-taking for functional development and maturation (Seale et al., 2013; Wilkinson, Theodore, & Raczka, 2014). Similarly, families of adolescents with intellectual disabilities may feel unable to provide positive risk-taking opportunities that they would afford to their siblings without intellectual disabilities (Pownall, Jahoda, Hastings, & Kerr, 2011), potentially contributing to their lower levels of self-determination (Kishi, Teelucksingh, Zollers, Park-Lee, & Meyer, 1988).

Furthermore, the combination of these factors with long-standing social preconceptions about intellectual disability can negatively impact young peoples' ability to develop an

adult identity (Wilkinson et al., 2014). As valued identity and positive self-concept are highly important to individual mental health, it is crucial that young adults with intellectual disabilities are feel comfortable with the roles and identities that they adopt during the transition process.

However, while independence, self-sufficiency, and responsibility play important roles in the definition of adulthood within typically developing society, very little research has been undertaken to determine what adulthood means to young adults with mild intellectual disabilities. The purpose of the following study was to begin to explore the emotional and socio-cognitive dimensions of transitioning to adulthood as experienced by young adults with mild intellectual disabilities. Particular focus was paid to participants' perspectives on autonomy, responsibility, trust, independence, and self-perceived adult identity.

Methods

Design and Rationale

Semi-structured interviews were undertaken with eight young adults with mild intellectual disabilities to explore their experiences of, and thoughts and feelings towards decision-making, autonomy, independence, and growing up. Interpretative thematic analysis was chosen to underpin the study for providing the flexibility required for undertaking a broader, more exploratory investigation of this type. As with IPA, interpretative thematic analysis can be used to develop an insight beyond the semantic content of the data (Patton, 1990). The process of interpretation is active, with the researcher acknowledging their role in both identifying patterns and selecting the final themes (Ely, Vinz, Downing, & Anzul, 1997). While each transcript was analysed in isolation, attention was given to patterns occurring across each group's

data set. However, salience rather than prevalence served as the defining justification for the themes' inclusion in the final write-up.

As the topics of investigation are both broad and highly personal, interpretative depth, rather than thematic saturation, was the principle goal of the study. As recommended for interpretative studies (Turpin, Barley, & Scaife, 1997), a parameter of between 7 and 10 participants was initially decided upon, as it was felt that a higher number may risk undermining the feasibility of the chosen analysis method. Furthermore, smaller sample sizes are particularly appropriate for smaller populations (Pietkiewicz & Smith, 2012), such as young scots with mild to moderate disabilities.

Participants and Recruitment

Eleven pupils with borderline to mild intellectual disabilities in their final two years of secondary schooling were recruited through the Education Authority in Edinburgh, Scotland. Of these, eight were included in the final analysis. Three young people were excluded from the study for attaining IQ-scores within the normal range. Schools were initially invited to participate through Additional Support for Learning at the Authority. Schools in the area identified potential participants whom they believed to be registered with a mild intellectual disability, able to discuss the topics of interest in sufficient detail, and willing to participate.

A full list of the participants' demographic details can be found in Table 1. All participants were aged between 15.9 and 17.7 years (M =16.9 years, SD = 0.58). As part of the screening process, IQ-scores were collected using the WASI-II. Though the study aimed to investigate individuals with mild intellectual disabilities, three participants with borderline IQ-scores were included, as their schools had identified

them as having sufficiently limited adaptive capacity to be considered to have an intellectual disability. Socio-economic details were established using the Scottish Index of Multiple Deprivation (SIMD), based on the participants' postcodes. For simplicity, overall scores have been converted to quintiles, from highest level of deprivation (1) to lowest (5). All participants were living at home at the point of the interview.

Semi-Structured Interview

Semi-structured interview schedules were developed to help guide the discussions, though conversation was not restricted to these predetermined items or topics. In order to elicit the more nuanced responses required for an interpretative study (Clarke, Braun, & Hayfield, 2015), all main questions were open-ended. However, a number of more specific prompts were included to help scaffold the discussion as required. Stancliffe and Parmenter's *Choice Questionnaire* (1999) provided an initial list of everyday choices and activities for discussion. A number of domains were updated to better reflect life in 2017, such as the inclusion of prompts regarding mobile phone usage, social media, and digital entertainment. Following advice from experienced researchers in the field, an 'opener' question was included to begin the discussion, as it has been shown that participants often need to 'warm into' the interview (Smith & Osborn, 2015). Furthermore, a 'fun' closing-question was added to end the session on a positive note.

Pilot Study

A pilot study was undertaken with three additional young people to inform the schedule's content, develop ways of asking questions that were appropriate for the population, and practice building rapport. The number of open questions was increased

once it became clear that the participants could engage with more abstract topics than was initially presumed. Additional probes were also developed to ensure that the emotional and cognitive dimensions of decision-making were explicitly discussed. A number of questions were simplified to improve comprehension. Time was also taken to ensure that questions were not leading to provide interviewees with the greatest scope to interpret and discuss the topics without external influence.

Procedure

Information sheets about the study were sent home to every participant prior to the commencement of the study. All participants signed consent forms before the start of each interview session. As the interview schedule included potentially emotive topics, the discussions were conducted sensitively. Furthermore, the right to withdraw was reiterated each time, and the session did not begin until the researcher was confident that each young person was happy to take part.

Interviews were conducted on school grounds during the school day, as arranged in accordance with participants' timetables. The interviewer was a PhD student with previous experience working with young adults with intellectual disabilities. All interviews lasted between 30 minutes and 1 hour and were transcribed verbatim after each session. Demographic information was collected prior to the beginning of the interview as part of the induction process. However, the WASI-II test was administered at the end of the session to avoid putting participants in the wrong frame of mind before the interview.

Ethical approval was attained from both the MVLS Research Ethics Committee at the University of Glasgow, and Edinburgh Council's Education Authority before the

commencement of the study. All interviews were conducted between March and June 2017.

Data Analysis

Each transcript was read repeatedly to maximise familiarity with the data before being subjected to several rounds of analysis. An initial list of themes was by compiled by undertaking a line-by-line analysis of the text. This process was repeated to create more latent themes, which were then clustered, paired with appropriate quotes from the text, and named to form meta-themes. However, because of the complex, overlapping nature of the transcripts, this process was fluid, with the meta-themes changing and evolving throughout the process.

After the process had been repeated for each transcript, all meta-themes and their associated quotes were re-grouped according to similarity of the theme, from which new meta-themes were created. This was an active process that continued to evolve throughout the write-up. The data analysis was principally undertaken by the lead author, who has a particular interest in the self-determination and autonomy of young adults with mild intellectual disabilities. As a result, the results reflect the researcher's personal interpretation of the data, which is likely to have been influenced by this prior experience. However, to ensure that the process was as rigorous as possible, each transcript was considered in isolation, to prevent previous themes from influencing the analysis. Furthermore, aspects of each stage of the analysis process were undertaken separately by the co-author to establish reliability. The themes presented were agreed upon jointly as a result of this process. A research diary and participant summaries were also written to ensure the themes remained rooted in the original interview.

Results

Table 1. Participant Characteristics

Pseudonym	Gender	Age (years, months)	School	IQ Bracket	Living Situation	SIMD Score
Sam	Male	17, 0	A	Borderline	Shared custody	7
Elliot	Male	16, 10	A	Borderline	Single Mum	3
Emma	Female	17, 8	B	Borderline	Both parents	10
James	Male	16, 0	C	Mild	Single Mum	6
Stuart	Male	16, 11	C	Mild	Both parents	1
Sarah	Female	17, 7	C	Mild	Both parents	1
Amy	Female	17, 1	C	Mild	Both parents	4
Lauren	Female	15, 11	C	Mild	Single Mum	5

SIMD Score: Highest deprivation (1), Lowest deprivation (10)

The themes have been divided into two broad categories: A: On a Developmental Trajectory, and B: Negotiations in the Environment. Themes within category A focus on the young peoples' attitudes towards themselves and their own relationship to transition. Themes within category B place the young people within their socio-ecological context, and therefore concern interactions with the family, friends, and the external world. Importantly, responses were heterogeneous across a number of the topics. As a result, care has been taken to ensure that each theme accurately accounts for the full scope of the experience discussed across the interviews. Please note that pseudonyms have been used in the reporting of all data to maintain anonymity and the following forms of notation are used with the quotes:

… Pause; [ ] Words omitted; [Text] Added for clarity; **Non-verbal expression;** I = Interviewer; P = Participant

Theme A: On a Developmental Trajectory

Old in some ways, young in others

Most of the participants referred to themselves as 'teens' or 'young adults', considering the terms 'adult' and 'child' as inappropriate. In some cases, participants expressed awareness that their level of maturity differed between contexts, while others felt that their behaviour failed to reflect their chronological age. Exceptions, however, were Sarah, whose self-perceived level of adulthood was high despite having very little experience of, or desire for responsibility or independence, and Stuart, who fixated on his own lack of maturity despite being one of the most independent participants:

"I'd call myself a baby…. I know! I'm so childish! It's funny…I'm just like a kid" (Stuart)

One possible explanation stemmed from the different notions of adulthood against which the participants compared themselves. While everyone considered responsibility to be the cornerstone of adulthood, Sarah placed greater significance on being chronologically older, whereas Stuart attributed more value to financial independence. Furthermore, he chose to compare himself against his parents, rather than his peers:

"They're like 'oh, you can do this, you can do that', so it's like… they've got a wee bit more independence than me."

However, while levels of self-perceived maturity differed, all participants acknowledged that they were becoming more mature with time. For some, this

recognition was based upon self-observed behavioural change. Stuart and Amy, for example, reflected on having learned the values of trust and honesty:

I: "How did you feel turning 16?"

P: "*Mmmm… I felt like I was going to have to mature up a bit. I've done that as well [ ] Being 16, and nearly being 17 means that you have to mature up and work, and your manners and emotions, do all that work mentally. I done that really well, actually, I can actually sit and talk to [teacher] about what I need help with, or what I'm thinking, or what I'm worrying about, and they'll sit and help me. Talk about stuff to. See, I used to sit and lie to [teacher]'s face, but now I just sit and tell her the truth, like this happened, that happened, it was me – that long ago, before I think it was the holidays – the Halloween holiday – me and a few mates we put fake blood over the [area of school], sprayed it all over, and she came out, and 'it was us, it was me', I thought we should decorate up, make it more halloweeny, I thought that would have been a good idea. She was alright with me telling the truth, so she asked us to clean it off, so we cleaned it off.*" (Stuart)

Others cited interpersonal confidence as contributing to their self-perceived maturity, along with learning to speak for themselves. In one case, this was accompanied by the realisation that adults are "just people", and that everyone deserves the same amount of respect:

"*I've got the confidence to sit down and talk to somebody. It doesn't really bother me, you're just another person. Going through the same stuff. We just talk. You're a*

person. Two equal peoples, talking like normal. That's what we're doing now. Perfectly fine. Just be civil, that's what I tell myself, just be civil, and that's you – done." (Stuart)

The march of time

Despite acknowledging their own youth, five participants voiced general unease at the prospect of aging. For Elliot, Amy, and Lauren in particular, the fear death – theirs and their parents' - contributed significantly to this unease:

I: *"How do you feel about getting older?"*

P: *"Scary… **Beginning to cry** I just don't know how to manage it. I just find it hard all the time, because, my mum says that I'm like scared about everything, soon she's gonna get older and older and I'm gonna have to do it by myself, so… but then, like, I just pretend, like, that she's gonna be here forever."* (Lauren)

Others' reluctance to grow older was framed in terms of increased pressure, both in terms of academic performance and the expectation to behave more maturely. In both cases, participants demonstrated an awareness that their social roles were changing with age. For a couple of participants, significant birthdays held only positive associations, built around new liberty and opportunity:

"It was like, really happy, turning 16, because it's an important year, sorta thing… it's the age limit to… vote, or have sex, sorta thing." (Sam)

Importantly, Sam had no desire to take advantage of these new liberties. Their significance to him appeared to come from a point of principal - the desire for increased trust, rather than new experience. In a similar vein, Emma wished to celebrate her 18th birthday with a glass of wine, despite having no particular interest in either the taste or the prospect of getting drunk. Therefore, for a few of the participants, the new rights afforded with significant birthdays were viewed as intrinsic goods, rather than as means to particular ends.

Coping without help

While the majority of participants agreed that adult responsibilities seem difficult, the amount of faith they had in themselves to cope with responsibility varied considerably. Regarding household management, Sarah, Elliot and Lauren demonstrated very low levels of perceived self-efficacy, assuming that they would 'do it wrong', or even be unsafe:

"I like cooking, I just don't want to do it on my own, for safety, so the kitchen doesn't go on fire, like, 'oh no, it's on fire!!'" (Sarah)

The others voiced more confidence in themselves, with some feeling that they simply needed to be shown what to do. However, when it came to responsibilities with significant consequences, such as managing finances and making decisions, several participants were more vocal about wanting support. Elliot, for example, aware of his difficulties with maths, felt that he would always require "someone to help [him] pay the bills and that". Similarly, Sam expressed quite low levels of trust in himself to manage his own money, and admitted to never using his bank account for fear of something going wrong. This lack of trust also translated to decision-making. His

frequent use of the terms 'right' and 'wrong', coupled with his expressed assumption that his parents know best, may explain Sam's apparent preference for delegating responsibility:

"I like to rely on my parents to help me make a decision or make a decision for me sort of thing… I'd rather rely on my parents than get it wrong. [They are] *helping me, trying to help me do the right kind of thing, like I've been trying to say,* [I am] *trying not to do wrong."* (Sam)

The fear of coping experienced by Lauren, however, was felt much more viscerally than by any of the other participants. Lauren discussed her Mum as being the most important person in her life - her sole support, both practically and emotionally. Despite Lauren demonstrating quite high levels of domestic competence, her perceived self-efficacy and confidence were quite low. This, coupled with her mum's recent experience with breast-cancer resulted in a much greater anxiety about coping in the future:

"I'm just scared that, like, if I do something wrong, if I don't, like, feed myself, but I can like cook and stuff, but I'm I just want my mum to be around, and like, I don't know how to manage and stuff." (Lauren)

However, rather than ignoring the problem, Lauren expressed a commitment to "fac[ing] her fears" and taking on new challenges, including doing things on her own. The knowledge that her Mum will not always be there, though highly worrying, may also be motivating her to develop herself in a way that she otherwise might not.

Waiting for the right time

The majority of participants admitted preferring to avoid responsibility for the sake of a simpler life. Though attitudes towards their current responsibilities were sometimes positive, the prospect of doing additional work was largely resisted. At the most extreme end of the scale, Elliot found the prospect of helping around the house literally laughable, despite acknowledging that his Mum would appreciate more support. Stuart was equally honest about his preference for being looked after, though was prepared to help around the house as required:

"I: How independent would you like to be?

P: Not that independent. I'm happy with the way my mum is helping me just now."

"[On doing more chores] Oh, I'd hate it. I don't like it just now, but I have to do it"

(Stuart)

The only individual who described actively engaging with new responsibilities was James, who had already gained quite a lot of experience in household management. As well as feeling able and willing to engage with responsibility, James seemed to take pride in his initiative. However, part of this independence appeared to stem from a general aversion to being told what to do:

I: "How strict do you think your mum is?"

P: "*She's strict, but she knows I'm strict with myself, so she's not strict with me.*"

I: "Can you tell me a bit more about that?"

P: "*What, that I'm strict myself?*"

I: "Mmm…"

P: *"Instead of mum telling me to do it all the time, that gets annoying, so I just tell myself to do it, and it works."* (James)

Interestingly, several participants made reference to the fact that more responsibility was neither required nor appropriate for people at their age and stage in life. Sam, for example, found the prospect of learning how to handle bills at the age of 16 to be almost bizarre. Similarly, Emma and Amy implied that their parents *ought* to provide for as long as they remain living at home, as doing so is a parent's "job".

However, responses were not limited to the realm of responsibility. A couple of participants felt that too much freedom would also be inappropriate at their age. Though generally quite independent, James felt that he was too young and vulnerable to travel the world at his age. Similar beliefs were implied by the participants' strict adherence to legal age limits, particularly in relation to alcohol and mature film content.

Working towards independence

Importantly, despite their reluctance to adopt the roles and responsibilities of adulthood at the point of the interview, the majority of participants felt that they would end up gaining independence in the future. Feelings towards this eventuality appeared to be complicated. On some level, Stuart seemed to be resigned to the notion of moving out as being an inevitable step that everyone must take, regardless of how difficult he may

find it. Yet, he also implied that moving out was a personal goal, something that only financial barriers were preventing him from undertaking:

"When I'm old enough, I'll independently myself. That's… what I hope for."
"I wouldn't be able to move out yet, until I've got a good job, then that'll be me."
(Stuart)

Similarly, Amy expressed having a strong desire for freedom, despite also acknowledging how dependent she currently is on her mum:

"My friend, she's put her name on the housing list, and I said I'll move in with you and we'll split the cost"
"I've got an easy life [ ] I rely a lot on mum right now." (Amy)

Interestingly, where Stuart viewed independence as a necessary, albeit difficult part of the transition to adulthood, Amy perceived independence as the inevitable consequence of parental aging and death. Unlike Lauren, Amy's attitude to mortality was discussed in very matter of fact terms:

"What happens when they die, they can't protect me then, can they?" (Amy)

Therefore, despite being reluctant to increase her domestic responsibilities, Amy acknowledged that she would not be able to delay these changes forever. In fact, time-scale appeared to explain a number of the participants' attitudes towards gaining independence. Sam spoke in quite excited terms about moving out. However, it later

became clear that he envisaged waiting until his mid-twenties to do so, practically half of his life into the future. The majority of participants therefore had an abstract desire for independence *at some point*, rather than concrete plans working towards a specific timeframe.

Theme B: Negotiations in the Environment

The impact of disability

Six of the participants specifically referenced their academic difficulties, and acknowledged the problems that these may cause them in the future. However, each demonstrated slightly different attitudes towards these difficulties. For many years, Lauren's confidence suffered as a result of having been told that she would never succeed:

"There was this lady [in the school] ... she was telling me that I couldn't be a teacher, I couldn't be a carer, because I've got a learning difficulty, like, learning problems and like, I went home and I was crying all the time" (Lauren)

In contrast, Sam appeared to accept his limitations, and adjusted his expectations accordingly:

"It does seem a little bit hard to try to find a job, sorta thing. Because… like, some application forms [ ] They might ask me a question that's… everybody would understand, but I won't, sort of thing." (Sam)

However, both had learned to view their achievements as more impressive for having a disability, and demonstrated a defiant commitment to overcoming other peoples' low

expectations. In contrast, James appeared to view himself as falling short of some intangible standard he felt he *ought* to meet. Despite having formal diagnoses of Dyslexia and an Intellectual Disability, James nevertheless understood his struggles in terms of personal failings that he ought to try to overcome. Though to some extent resigned to his academic difficulties, he continued to feel frustrated by how hard he finds concepts that that he felt he *should* find easy:

"I've got to work more on my English, 'cos I'm dyslexic, so my English really bad. It's not the best of the best as it should be right now. That, and just like normal stuff like time. That frustrates me so much. [ ] It's... slow processing, my mind." (James)

One possible explanation is that, despite having one of the lowest IQ scores of all the participants, James's more developed adaptive capabilities meant that he did not view himself as being different. As well as socialising with predominantly typically-developing friends, he spoke of his schoolmates as being substantively less capable than himself in the "important" aspects of growing up:

"There's some people in this school who I think will never get to go by their self, [ ] you can speak to them and that – but I'm like, they don't know the simple stuff... The stuff you need to know [ ] how to... do a washing machine." (James)

Thus, while James's academic difficulties may have felt more pronounced as a result of his comparing himself to his mainstream friends, in comparison to his intellectually disabled classmates, his greater potential for self-reliance assured him of his own future.

Stuart, in contrast, expressed levels of optimism about his academic potential that may not be justified by his current level of achievement. Similar to James, Stuart also expressed a need to work hard to reach a certain level of academic attainment. However, his academic goals were concrete, specifically targeted towards achieving the qualifications necessary to apply for Mechanics at college:

"I've been trying really hard to get my [ ] maths so I can do that in college, mechanic work at college… It's quite hard, but I'm just gonna have to keep trying with it." (Stuart)

Despite having demonstrated little improvement in the subjects required to pursue his chosen career, Stuart expressed high levels of optimism and perseverance. Rather than feeling doomed to failure, he was committed to the belief that success may be possible with a lot of hard work and dedication.

Separate Spheres of Decision-Making

For the most part, participants described themselves as sharing the responsibility for making decisions about their own lives with their parents. For Stuart, the balance of power appeared to be tipped in his favour - his parents playing more of an advisory role than anything else. However, the majority of participants described having decision-making control in only a limited number of areas. For these individuals, 'shared' appeared to be defined in terms of having distinct decision-making domains, rather than collaborating as equals. While these participants were afforded decision-making autonomy in relation to low-level or routine matters, more significant decisions rested firmly with the parents. In some cases, having separate spheres of decision-

making was very clearly felt; however, others perceived their contribution to decision-making as being equal if they had voiced preferences that were later realised. This was despite their acknowledgement that their parents still had the final say:

"That, like, um… um… it was… well, that was sort of half and half, too. But, like, some… like, for, like, yeah. That was sort of half and half. Like, my mum first of all didn't want me to go to college, but I think… over the last, sort of, [school year], she sort of got used to me, yeah." (Emma)

Importantly, regardless of how much decision-making autonomy participants had, *feeling* in control of at least some decisions was important to them.

Demanding trust and respect

Though levels of independence varied significantly between participants, the desire for trust and respect was universally conveyed. With Amy as a notable exception, participants seemed to consider obedience to be an inherent good, and expressed feeling motivated to do the "right thing". Though both prone to 'cheeky' behaviour, James and Stuart acknowledged and appreciated the amount of trust their parents placed in them, and responded by acting sensibly. James in particular admitted that, even though 'forbidden fruit' is more tempting, he would never choose to deliberately do anything that might hurt or disappoint his Mum:

"[On being obedient] Not because I'd get told off, just because my mum's not happy with it." (James)

As a result, both participants felt entitled to a minimum level of trust and respect.

Much as Stuart had learned to view adults as 'just people', James perceived himself as having rights on a par with his Mum. Rather than viewing her as having a special parental authority to intrude on his life, he expected to give and receive the same level of respect. Interestingly, lack of parity did not seem to frustrate or annoy James, as it did with other participants. At the prospect of his mum breaching his privacy, James voiced a preference for calmly and rationally explaining his preference, or responding in kind to 'right the injustice':

I: "If [your Mum] did come into your room without asking, how would you feel about that?"

P: *"I'd be ok with it, but I'd say 'next time, can you just knock, please?' And if she did it again, I'd be cool with it, just 'can you knock' again. No point in getting frustrated over it. Waste of time."*

I: "How would you feel if she checked your phone?"

P: *"I'd be fine with it. I'd just check hers **laugh"*** (James)

In contrast, half of the participants expressed profound frustration at the prospect of their parents trying to control their lives. For three, this manifested as feeling patronised and underestimated. At the prospect of his mum reading his texts without permission, Elliot anticipated feeling "betrayed", as if such an act represented a significant breach of trust. This feeling was more pronounced for Sam and Amy, whose Mums checked their phones regularly. Sam's irritation in this matter stemmed from feeling ostensibly 'micromanaged' and unable to take ownership of his own affairs:

"I'm not really happy with that, because it's my personal own space, sorta thing. So I don't want my parents to do. It's my business and my business alone… it's my private business, sorta thing, it's not your [Mum's] business." (Sam)

In contrast, Amy felt that she was being denied the right to make her own mistakes:

"I'm like a little girl, so they've got to try and protect me in the most responsible way they can, but then, I need to find these things out for myself." (Amy)

However, these individuals demonstrated a greater sense of resignation to external authority than their more independent peers. Elliot, for example, described an on-going struggle regarding the colour of his room. His mum's decision to paint - and subsequently keep - his room blue, rather than pink as he wished exemplified the sense of disempowerment he felt at home. By repeatedly failing to engage her on the topic, Elliot had developed quite a pessimistic attitude towards his own capacity to influence change:

"If I had my way, my room would be pink and purple by now, but instead she always decides on blue, unfortunately [ ] it's my room, and she should put colour I want in it. It's my room, not hers [ ] we've been having this conversation for years. I've always wanted it pink." (Elliot)

As a young man with conventionally feminine interests, it is possible that this argument is symptomatic of his mum's struggle to accept her son's non-conformity. Taking room colour to be emblematic of identity, the rejection of Elliot's wishes

carries more significance – as if his mum were dismissing *him*, rather than just his superficial interests. The subsequent frustration and sense of powerlessness is liable to be more profound as a result. However, despite their frustrations, the majority of participants acknowledged that their parents' rules and restrictions came from a place of love, rather than lack of trust:

"I know she's trying to look out for me." (Amy)

Discussion

Aside from themes specific to having an intellectual disability, the participants' perspectives were generally very similar to those one might expect to record amongst typically-developing young adults (Furstenberg, Kennedy, McLoyd, Rumbaut, & Settersten, 2004; Nelson & Luster, 2016). As only one other paper could be found that directly explored this population's attitudes towards growing up and adulthood (Midjo & Aune, 2016), there is very little extant literature with which to compare our findings. In some ways, for example, this similarity was unexpected, as previous research has suggested that young adults with mild intellectual disabilities may have different concerns to their typically developing peers at this stage in life (Forte, Jahoda, & Dagnan, 2011). Instead, the desire for increased autonomy, coupled with the aversion to responsibility aired by the participants in this study closely mirrors the attitudes towards growing up reportedly held by many members of their generation (Smith et al., 2017).

Yet, as suggested by Midjo and Aune (2016), today's young adults with intellectual disabilities have been brought up in time that places great emphasis on equal rights and

opportunities. Consequently, it may not be surprising that many young people with disabilities have grown to expect that they will lead 'ordinary' lives in the long run.

In contrast to the suggestion that self-determination ought to be considered a holistic phenomenon (Field et al., 1998), our participants' willingness to engage in "goal-directed, self-regulated, autonomous behaviour" instead appeared to be highly domain specific. Several participants expressed frustration at being denied control over particular aspects of their lives, and yet considered it their parents 'job' to continue to protect, provide, and make decisions for them.

Part of this inconsistency may be explained by the fact that the participants' emotional relationship to the notion of independence appeared to be complicated. Several participants seemed to feel burdened by the social expectation for independence, simultaneously wanting to meet the transition norms for their age group while fearing their own inability to cope. Others equated 'doing the right thing' with compliance, and were more concerned with appeasing their parents than pushing for greater autonomy. Emotional factors like low hopefulness and negative perceptions have been posited as direct obstacles to the development of self-determination (Wehmeyer & Palmer, 1998). Yet, the possibility that more complex emotional and socio-cognitive processes contribute to the lower levels of self-determination in this population warrants further investigation.

It is also important to acknowledge that the transition to adulthood is often expected to occur over a longer time period for young adults with developmental delay. Though the quality and provision of support varies, transition services for young adults with disabilities can often be accessed until the age of 25, as the process of psychosocial and

cognitive maturation typically takes longer for individuals with developmental delay. From this perspective, the tentative desire for independence voiced by the participants in this study is to be expected, as they are comparatively much 'younger' than their typically developing peers.

In line with the majority of adulthood identity research, 'responsibility' was considered to be the most significant marker of adulthood. However, in contrast to the work of Arnett (1997, 2000), our participants were more likely to define 'responsibility' as meeting the responsibilities associated with social role transitions (e.g. marriage, parenthood, employment, property ownership). Moreover, in some cases there appeared to be a greater emphasis placed on familial responsibilities (looking after parents/children etc.) and interpersonal maturity (following rules, acting sensibly etc.) than on personal responsibilities or self-sufficiency (independent decision-making, managing one's own affairs etc.). It should be noted that the amount of importance each participant attributed to these transition criteria varied considerably. Nevertheless, the possibility that young adults with intellectual disabilities adopt broader, or more social-role orientated criteria for adulthood is worth further investigation.

The participants' definitions of adulthood also appear to influence their subjective age identities. Those who either had, or were soon to meet the criteria that they personally considered to be the most significant markers of adulthood felt older than those who did not. Proponents of the confluence model of age identity (Shanahan, Porfeli, Mortimer, & Erickson, 2005) have suggested that social role transitions make individuals feel older, "regardless of whether [those individuals] identify role transitions as necessary for people in general to be considered adults" (Kirkpatrick Johnson et al., 2007, p. 257). In contrast, our findings suggest that the impact a role

change has on an individual's age identity may be relative to how much significance they place on it as a criterion of adulthood.

Consistent with previous findings, social comparisons also appear to be linked to the participants' adult identities (Benson & Elder Jr., 2011). The transformation from viewing one's parents as authorities to peers with equal status has been proposed as playing a key role in the development of an adult identity (Smollar & Youniss, 1989). However, while subjective identities are generally thought to be constructed through comparisons with significant others (Stryker & Serpe, 1994), age identities are typically formed in relation to those at the same stage of life (Kaufman & Elder Jr., 2003). No other studies could be found in which adolescents' age identities were formed in comparison with parents, rather than peers.

The participants' social comparisons also appeared to be linked to their perceptions of and attitudes towards their own disabilities. Previous studies have suggested that pupils in special schools may feel more positively towards their own educational attainment than those in mainstream schools (Kelly & Norwich, 2004). However, in our study, participants with typically developing friends voiced greater levels of frustration towards their own academic difficulties than those whose friends also had intellectual disabilities, regardless of the type of school they attended. Social-comparisons with friends have been shown to be more affecting than comparisons with strangers (Tesser, Millar, & Moore, 1988), therefore the possibility that friendship-group configuration may mediate the relationship between the school-type and self-concept warrants further investigation.

It is also possible that social attitudes to specific diagnoses affect the way in which these social comparisons manifest (Dorozenko, Roberts, & Bishop, 2015). The diagnostic label of 'autism', for example, has arguably become more socially salient, and individuals with known autism are increasingly finding a sense of identity and belonging through participation in online communities (Bagatell, 2010; Davidson, 2008). In contrast, the narrative surrounding 'intellectual disability' appears to have remained negative, and individuals with intellectual disabilities and their families continue to experience social stigma as a result (Diez, 2010; Gilmore & Cuskelly, 2014; Scior, Potts, & Furnham, 2013; Wolfensberger, 2000).

These attitudes were to some extent mirrored by the autistic participants in our study, who appeared to embrace and take comfort from their autism diagnoses, in a way that they did not with having an intellectual disability. However, while previous work has suggested that autism diagnoses can be protective, and even enhance self-esteem (Jones, 2001; Willey, 2006), research in this field is limited, and the findings mixed (Macleod & Johnston, 2007). Therefore, it is advised that these findings be interpreted with caution.

Limitations

The authors are aware that a larger sample may have broadened the scope of the findings and that the study's sample size was too small to achieve thematic saturation. However, due to the scope of the research topic, thematic saturation was not an intended outcome of the study. Instead, the researchers adopted an interpretative strategy to facilitate a more in-depth analysis of the participants' unique perspectives. Consequently, the themes presented are not exhaustive, but rather reflect a snapshot of

our participants' perspectives on, experiences of, and aspirations for the transition to adulthood.

For the purposes of this study, participants were regarded as having a mild or borderline intellectual disability on the basis of diagnostic information provided by their school, as well as their scores on the 2-scale WASI-II. However, this instrument is only capable of providing a general indicator of an individual's cognitive ability. Furthermore, levels of adaptive capacity were not assessed. As a result, the screening process was incomplete and insufficient to conclusively determine that every participant had mild intellectual disabilities.

This was an interview study and, as with all human interactions, the discussions were likely to have been influenced by contextual factors that cannot be replicated or generalised.

Current Implications and Further Research

Our findings suggest that some young adults with mild intellectual disabilities may have similar aspirations for adulthood as found amongst typically-developing adolescents (Furstenberg et al., 2004; Smith et al., 2017). This is despite the fact that members of this population encounter very different obstacles and challenges to their typically developing peers that stand to affect their attitudes to, and plans for, their futures. Only one previous study could be found that sought to investigate how young people with mild intellectual disabilities think and feel about the holistic topics of growing up and adulthood. Therefore, while this similarity may be unsurprising to

some readers, the sheer deficit of prior research on this topic makes this finding particularly important.

Moreover, the implications of this finding are notable. Scottish adults with intellectual disabilities are currently significantly less likely to undertake a number of these transitions (Ormston, Eunson, & McAteer, 2017; Scottish Learning Disabilities Observatory, 2018a, 2018b). Concerns have been raised that opportunities for independent living and employment may even be *decreasing* for individuals with mild intellectual disabilities in Scotland and the UK (McMurray, 2017; Ormston et al., 2017). As mental ill-health in young adults with intellectual disability has been shown to increase between the ages of 13 and 44 (Hughes-McCormack et al., 2017; Young-Southward, Rydzewska, Philo, & Cooper, 2017), there are grounds for thinking that poor transition experiences may directly affect these outcomes.

More knowledge is required to find out which outcomes are and are not important to people at this age and stage so that members of this population can be supported to both set and achieve goals that are personally salient. Doing has the potential to maximise their opportunities for leading happy and fulfilled lives, which in turn, is likely to have positive implications for society as a whole.

Word count: 7574 without abstract

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