Transitions into Older Adulthood by People with Intellectual Disabilities: An Email Conversation

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ABSTRACT

Transitions in older adults with intellectual disabilities are relatively understudied and can operate in ways that differ from typically developing older people. Classification of age and ageing in people with intellectual disabilities has been complex and constructed based upon both traditional 'typically-developing' notions of what equates to old age but also age-related changes that can be specific to particular groups of people with intellectual disabilities. There is as wide a range of personality, preference, ability, and lifestyle at different ages within this population as there is in any group without intellectual disabilities. We need a better understanding of later life transitions in this group including the role played by communities and supports. In this article we present a conversation about transitions and the actors that influence transition in adults with intellectual disabilities as they age and enter old age.

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INTRODUCTION

Transitions in older adults with intellectual disabilities are relatively understudied and can operate in ways that differ from typically developing older people. Classification of age and ageing in people with intellectual disabilities has been complex and constructed based upon both traditional 'typically-developing' notions of what equates to old age but also age-related changes that can be specific to particular groups of people with intellectual disabilities (McCallion & McCarron, 2004). Examples include greater prevalence of dementia in people with Down syndrome and both people with Down syndrome and people with profound and multiple learning disabilities dying at a younger age than populations without intellectual disabilities. Increased prevalence of age-related declines in health and earlier mortality have led some to target older adulthood as beginning as early as 40 (e.g. O'Dwyer et al., 2018). The LeDeR Report (Heslop & Hoghton, 2018) threw the discrepancy in mortality into sharp relief with the average age of death being 20 years earlier for people with intellectual disabilities compared with those without intellectual disabilities. This has only been exacerbated by COVID (LeDeR Report, 2020). Despite being perceived as a relatively homogenous population, people with intellectual disabilities comprise a highly diverse and heterogenous group. Indeed, one of the issues with service provision, job opportunities and access to health and recreation options is that one size does not fit all. There is as wide a range of personality, preference, ability, and lifestyle at different ages within this population as there is in any group without intellectual disabilities as supported by work carried out by the Learning Disability Observatory (Emerson et al, 2012). Below we present a conversation about transitions and the actors that influence transition in adults with intellectual disabilities as they age and enter old age. This conversation was prompted by a recent collaboration on the IncludeAge Project funded by the Economic and Social Research Council (ESRC). The authors, as part of the collaborative process of developing the project, engaged in consideration of how transitions operate in the lives of older people with intellectual disabilities. We also considered what existing knowledge and empirical evidence was available regarding these phenomena, and what salient questions presented gaps in knowledge and endeavours for future review and empirical research work.

EMAIL 1

Hi D,

I've been reading a bit into Jindal-Snape's work on transitions to see how the theory might be applied to the transitions of people with intellectual disabilities in older age.

Jindal-Snape (2016) talks about how Bronfenbrenner's (1979) ecological systems theory can support a multiple and multi-dimensional transition theory – where rather than focusing on the one person who is going through a transition, we need to take into account all of the other people around them and the different transitions that this might also be provoking for them. I found this interesting.

"The Multiple and Multi-dimensional Transitions (MMT) model highlights these multiple layers of transitions and their interactions (Jindal-Snape 2016). To understand it better, it can be visualised as multi-dimensional on a Rubik's cube style base. Each individual and their interactions with others can be seen as one colour. If one set of interaction or aspect of life changes, it can lead to changes across the spectrum. The changes might be similar to a small ripple effect or much more significant like a domino effect. Therefore, it is important to understand the multiple layers and complexities of these multiple transitions" (Jindal Snape, 2016: 67)

So, I thought we might start thinking about the following questions:

When does 'old age' start for someone with intellectual disabilities? What do you think the key transitions might be for older people with intellectual disabilities? How are these transitions negotiated compared to the general population who are reaching retirement age? It does feel like a forgotten group.

Best wishes

S

EMAIL 2

Hi S,

The literature has seemingly come and gone in waves in relation to older people with intellectual disabilities and so I agree they can be overlooked.

Considering classification of people with intellectual disabilities as older, in my early research work and in the light of the lack of customary classifications in the literature, I took a pragmatic approach and typically classified ageing into bands rather than treating this incredibly heterogeneous population as homogeneous. I've used rough bands of 45/50–65 as young old, 65–75/80 as middle old and 75/80 and older as old-old. But given the ageing population these bands will and should shift in response to cultural and societal changes and should also arguably take into account both functioning and the social roles that people inhabit.

Thinking about the MMT model that you mention (in terms of where agency and action fit in with these transitions) and the micro-system of the nested ecological model by Bronfenbrenner (1979), made me think about the experience of support and care in the familial relationships of people with intellectual disabilities and their older carers as they go through the ageing process.

A key transition is in the carer relationship when the older carer experiences age related changes which necessitate the person with intellectual disabilities potentially taking on a more active role in day-to-day activities leading to change characterised by increasing interdependence between the person with intellectual disabilities and their carer (Ryan et al., 2014). This, I think, challenges traditional notions of older people and people with intellectual disabilities as increasingly dependent as they age.

One of the things I was thinking about, which is going to be really important in these transitions, is communication and social interaction. How might communication and interaction in relationships differ in people with intellectual disabilities in older age compared to when people are younger? Also, what factors might influence this? What do you think?

Best wishes

D

EMAIL 3

Hi D,

Yes, as you say, it is interesting to remember that older people with intellectual disabilities often start to take on a caring role themselves for older parents and there is a transition there from being dependent to becoming interdependent. I am sure that this is one type of silent and unrecognised transition that takes place in the lives of people with intellectual disabilities but it causes no fewer shifts in role, activity, behaviour and freedoms than other transitions that might be more recognised by professionals, such as moving to a new housing setting or changing from benefits to a pension as they get older.

Changes in communication as people with intellectual disabilities get older have received little attention in academic literature. However, the general ageing process that affects us all as we get older (Jack et al., 2019) also affects people with intellectual disabilities and may be more noticeable earlier in the life-course. I am thinking of hearing loss, the ability to find the words we want to say, remembering what we wanted to say and being less able to process information quickly, can all become increasingly problematic.

My doctoral research looked at the use of easy read information to enhance comprehension by people with intellectual disabilities. I found that people valued easy read health information above other types of health information and liked to have it given to them. 'Easy read' information in the UK is often produced specifically for people with intellectual disabilities, examples of which can be found on the Easy Health website https://www.easyhealth.org.uk. Key to its format is larger print, pictures, images, and simplified language. However, evidence showed that the simplification of language and use of pictures didn't help people necessarily to understand the content of the documents (Buell et al., 2020). It might be more important to be

able to have a conversation to explain and construct meaning around vocabulary used in easy read information, for example what does someone understand by the words 'retirement' or 'pension'. This will likely differ from person to person. Interestingly, I don't know of any research specifically that looks at easy read information for older people with intellectual disabilities or at any age-related additional or alternative adaptations that older people might prefer.

In terms of getting older, we all need to have something to talk about. Making sure that people with intellectual disabilities have the opportunities to continue with interests and doing the things they find interesting and engaging as they grow older is hugely important. That's where social interaction and engagement come in and are fundamental. Unfortunately for people with intellectual disabilities, this often means being dependent on social care staff who are in a position of power and control, and do not always recognise the changing requirements to support this more rather than less as they get older. Transition into older age can often mean transition into social isolation and loneliness for older people with intellectual disabilities and it should not be that way. Smith et al., (2020) have done a survey of communication difficulties in older adults with intellectual disabilities in Ireland showing how low levels of social participation were linked to communication difficulties.

It seems to be about the assumptions that are made about the ageing process and the transitions involved when considering people with intellectual disabilities. For example, what happens when people with intellectual disabilities retire from work? We do not hear very much about that transition.

S

EMAIL 4

Hi S,

Yes, communication is really fundamental to the interactions people have as they age and the social support networks that exist, which as you say can contract and diminish as people get older, leading to isolation.

One of the interactions that has received less attention is the increased use of digital and online methods for socially interacting. Over the past decades the number of people communicating and interacting online has massively increased and this has only gotten bigger with the COVID-19 pandemic and the need to socially isolate. Despite this, the challenges and benefits of people with intellectual disabilities in transitioning to increased digital inclusion and technology use, including getting online in the first instance and using technology to connect with others, has a limited but growing literature around it (Chadwick et al., 2022).

Older people with intellectual disabilities are often overlooked. For people with profound intellectual and multiple disabilities who have the highest support needs, technology is often not considered to be 'for them' (Chadwick & Fullwood, 2018). This sadly excludes this group from a burgeoning new frontier of life that has myriad possibilities inherent in its use, but also plenty of risks too. Given the heterogeneity of both older people and people with intellectual disabilities there is a lot to think about and a lot of complexity here that we are only just beginning to consider. Some of the work conducted in relation to the Tilda and Digi-ID projects at Trinity College Dublin in Ireland have begun to provide some useful insights here with a recent study suggesting that technology use may be lower for older people with intellectual disabilities living with their families than those who live independently (McCausland et al., 2021). Why this is and how we should address this needs more work.

In addition to interaction, technology also provides opportunities for meaningful occupation, activity, learning and development for older people when they are supported to gain the skills they need and have the opportunity to use them (Díaz-López et al., 2016). The notion of active ageing hasn't often been considered for people with intellectual disabilities, and, when it is, is a little too health focussed rather than relating to what would make people's old age more enjoyable and meaningful for them. Family and extended family are important supports for older people with intellectual disabilities to be active and to maintain the things they enjoy as they get older (Buys et al., 2012a).

Retirement is one transition that can differ a lot for people with intellectual disabilities. Because we live in a meritocratic society, the contribution people with intellectual disabilities can make is often undervalued leading to fewer opportunities for employment. I think around 5.1% was a recent figure I recall in relation to the number of people with intellectual disabilities in paid employment in England, with low rates also reported in other global north countries. So, retirement may equate to a lessening of time in paid or voluntary employment, or a reduction in scheduled day activities or time at a sheltered workshop or day centre. Some research has highlighted the need for individual and diverse needs when considering both retirement and active ageing in older people with intellectual disabilities (Buys et al., 2012b). The level and access to individualised funding, the quality of support people get and whether places and communities can become sufficiently inclusive are all likely to be important in enabling people with intellectual disabilities to gain a sense of purpose and belonging into their old age (Bigby, 2021).

Sadly, in recent years I have heard about people with intellectual disabilities in England more frequently being placed in nursing homes long before they reach the chronological age when typically developing people would be placed in this kind of care. It seems these were sometimes the only residential placements available to provide support for people who might be ageing more rapidly in part due to co-morbidity related to intellectual disabilities. Egan et al. (2022) outline the dearth of support for people with intellectual disabilities who make such transitions in later life. Although someone who has intellectual disabilities might have signs of accelerated ageing, they are still relatively young and have little in common with people in nursing homes who are twenty years older. So, I do have concerns about the adequacy of support for this group of people as it currently stands.

One of the things this chat has also made me think about is how communication about 'retirement' and lessening of activities happens and therefore how choice is managed in this transition. Also, thinking about these reduced social networks, how can we best discuss feelings of loss with people with intellectual disabilities around the bereavement of friends and family as they age?

D

EMAIL 5

Hi D,

It's interesting. We seem to be looking at two levels of transition here. First there's the over-arching transition from being 'young' to being physically older. As you point out, this transition is usually more socially marked in people who do not have intellectual disabilities by retirement and/or taking up new activities once they leave work, or by down-sizing or moving to a different place out of choice. This happens far less frequently for people with intellectual disabilities who might still be involved in the same routines and activities at 60 years of age as they were involved in when they were 17. For others, who have worked and go through the transition of retirement, there is an assumption that this will somehow be different for them than it might be for someone without intellectual disabilities. So how do we mark that transition for people with intellectual disabilities who do not 'retire' in the formal sense, yet are marching along the same trajectory of transition as all of us into older age?

The second seam of transitions are those we have mentioned that influence social interactions as people grow older, like changes in carers, communication difficulties related to normal ageing processes, moving to full residential care, the deaths of close friends, family members and care workers, and keeping abreast of social networking and technology. The resilience a person has and the support available to them to manage these transitions affect whether someone spirals into loneliness through the transition process into older age or stays afloat with a strong social network around them.

What seems to be missing in the face of increasingly fragmented community support, is the continuity of quality care across the ages for people with intellectual disabilities to weather the storm of this particular set of transitions into becoming older. Facing one's own mortality,

growing older is becoming increasingly necessary to address with older populations of people with intellectual disabilities. Tuffrey-Wijne and colleagues (2020) have done a lot of really practical work and research around talking about death and dying with people with intellectual disabilities. Their research suggests that as a group, people with intellectual disabilities have been kept from being able to talk about these important and inevitable parts of the transition into becoming older.

S

EMAIL 6

Hi S,

Yes, I agree. There are distinctions between the different life transitions: those typically expected life transitions as we age (e.g. retirement), and those transitions that are prompted by societal changes (e.g. increased reliance on technology for almost all aspects of daily life). Though I suppose the social and interactional changes span the two. For example, the loss of loved ones, such as parents, extended family and even partners and friends is much more likely as one ages. This latter experience may happen earlier for people with intellectual disabilities who are ageing because on average they die roughly 20 years earlier than those without intellectual disabilities as I mentioned earlier.

This idea of transitions interacting and colliding with each other I think resonates a little with the MMT theory from earlier in our chat, but also highlights the intersecting nature of transitions. A person may experience the transition of bereavement of a friend as they age and, in missing that person, their supports or carers may look to them adopting technological solutions to broaden their contact with friends and extended family which leads to another transition – that of gaining an internet connection, a device and the skills and supports to use it. Our study found that some people with intellectual and developmental disabilities were now using technology to talk to aunties and uncles in Australia that they hadn't seen in many years (Chadwick & Fullwood, 2018).

Considering life course and life span perspectives (Fuller-Iglesias et al., 2009; Kornadt et al., 2020), I think the marking of life epochs and major life events is more difficult for people with intellectual disabilities as they age, because many of those transitions happen much less frequently; for example, their first academic qualification, getting married, buying their first home, having their first child, getting their first job, children leaving home, and retirement. Nicola Grove (2007) talked about this in relation to people with profound and multiple learning disabilities in particular, but it is I believe also true of people with intellectual disabilities more generally. In the 'All we want to say' project, led by Edurne Garcia Iriarte (Garcia Iriarte et al., 2014), and which I supported in Ireland, they found that many of these typical life events, for example getting married, having the keys to your first home etc., were what people with intellectual disabilities wanted for their own lives (National Institute for Intellectual Disability, 2010; Garcia-Iriarte, 2014).

To mark the important transitions in people's lives I think narrative and story approaches, of which there are many, are an enjoyable way to celebrate and highlight what is and what has been enjoyable or significant in someone's life. Story sharing (Grove, 2017; Grove & Harwood, 2021) has I think been used successfully with people with greater support needs and life story work (Ledger et al., 2021; McKeown et al., 2006), and books also have benefits though both approaches are currently under-evaluated.

Personally, when doing life story work, I have found it can function better than a file in a group home to help carers of people with intellectual disabilities to get to know more about the people they work with. One might hope this would have a knock-on effect on the quality of the relationship and of care provided. They can also help older people with intellectual disabilities recall important events and people from their lives, supporting their sense of identity and self (Ledger et al., 2021). These are aspects of older people with intellectual disabilities that may be somewhat overlooked. I think giving people as much control over the creation and presentation of these stories as possible is also important.

When I was researching in services in both the UK and Ireland, I heard about people with learning disabilities and people with profound and multiple learning disabilities (PMLD) who were never told about the deaths of friends and family. I think this is dreadful and highlights the paternalism that often surrounds people with intellectual disabilities. It also highlights the challenges of communicating about taboo and emotional topics with this group. Nonetheless I see it often presented as a form of protective infantilisation that ignores the adult status of the person. It seems to fail to acknowledge that they are older in age where loss within social networks increases. This balancing of facilitating independence and protecting people, which both fall under the auspices of care, is a knife-edge commonly walked by people providing support for individuals with intellectual disabilities. This knife-edge often appears more acute for those providing support at periods of transition in the lives of people with intellectual disabilities.

It's interesting you mention resilience because this has seldom been investigated in people with intellectual disabilities. Indeed, there is a societal belief they are more vulnerable and hence will be less resilient. I think most of the typically developing majority seldom think about the adversity people with intellectual disabilities face while living in a world which is not set up to accept or value them as equal citizens, or to provide reasonable support adjustments to enable them to flourish. Taking that perspective, I see people with intellectual disabilities as much more resilient than the rest of society. Taking a strengths-based approach to life transitions and active ageing for people with intellectual disabilities for me seems a worthwhile way forward to challenge these embedded societal stereotypes.

I've really enjoyed this chat it's really brought back to me the issues around quality of life and how transitions and society impact on this. I did my PhD over 20 years ago on this topic and it is really interesting to revisit it, and to think around it again.

Thanks S,

All best wishes

D

RECOMMENDATIONS FOR FUTURE RESEARCH

More research is needed which includes the voices of people with intellectual disabilities. In a recent study (Strnadova, 2019), older people with intellectual disabilities identified various different types of transitions they experienced as they aged. "These included: (1) transitions in relationships; (2) residential transitions; (3) work transitions; (4) transitions to retirement; and (5) transitions related to getting older (i.e., in abilities, health status)." (Strnadova, 2019, p. 61). Several researchers have explored loneliness (Alexandra et al., 2018; McVilly et al., 2006; Robinson & Idle, 2022) and reduced social networks for people with intellectual disabilities generally, but have not necessarily focused on older people (Wormald et al., 2019). Working towards building resilience in the older population, the gaps in current literature point to the need for research into the use of technology in everyday life for older people with intellectual disabilities (Chadwick et al., 2019). Further areas to address are how older people with intellectual disabilities celebrate the high points in their life courses and express their needs around health and well-being, or how they navigate decisions that affect their environments and impact on their daily lives as they get older.

PRACTICES THAT MAY SUPPORT TRANSITION

Given the breadth of life areas where transition can occur, it is difficult to provide a comprehensive overview. However, some recommendations have been made in recent papers. Studies have highlighted proactive planning for the future that is person-centred, and where appropriate involves families, as fundamental best practice for successful transition for older adults with intellectual disabilities (Bigby et al., 2011; Jokinen et al., 2012). For older people with intellectual disabilities and behaviours that challenge others, successful transition was enabled by: suitable residential settings; proactive support by skilled staff who facilitate creative engagement

with individuals and their families; stable social work input; and responsive access to good quality healthcare (Tilley et al., 2022). To enact inclusion and participation of older adults with intellectual disabilities in decisions about their lives, individualised reasonable adjustments and personal advocacy support have been effective (Heslop et al., 2019).

In all aspects of transitions, the observed reduction in autonomy and choice-making by people with intellectual disabilities as they age, needs to be challenged and overturned. To do this, maximising opportunities for every-day choice-making needs to be a dedicated consideration by carers and within support services (Strnadova, 2019).

CONCLUSION

For older adults with intellectual disabilities, transitions appear less pronounced and more challenging to delineate in the life course. There are examples where age-related transitions have been overlooked and poorly handled (e.g. residential transitions leading to social isolation and disconnection from the past and where the voices of people with intellectual disabilities have not been heard in decision making (Egan et al., 2022). There are also instances where transitions have been adequately acknowledged, well supported and facilitated for example, inclusive and responsive residential transition linked with improvements in health and wellbeing (Egan et al., 2022). We need better understanding of later life transitions in this group, including the role played by communities and supports. Work is needed to enable parties to communicate more effectively around transition and for older adults with intellectual disabilities to be active agents in their life transitions. A renewed focus is also needed when considering how we can use strengths-based and active ageing approaches to support people with intellectual and developmental disabilities to flourish in old age.

COMPETING INTERESTS

The authors have no competing interests to declare.

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