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The Transitions that Matter

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SUMMARY

The language of 'transitions' in social care is often used when talking about how people move from children's care services into adult support. Yet the concept of transition is much wider than this: it is about the changes that disabled people, older people and people using mental health services want to make (and are facilitated to make) in their lives. As part of exploring transitions for a broader research theme around [Care Trajectories and Constraints](#), we undertook a scoping review of the literature, focusing on how researchers in social care conceptualise and research transitions.

INTRODUCTION

The language of ‘transitions’ in social care is often used when talking about how people move from children’s care services into adult support. Yet the concept of transition is much wider than this: it is about the changes that disabled people, older people and people using mental health services want to make (and are facilitated to make) in their lives. As part of exploring transitions for a broader research theme around [Care Trajectories and Constraints](#), we undertook a scoping review of the literature, focusing on how researchers in social care conceptualise and research transitions. We are aware that in doing so, we are covering ground that has been widely researched in disability studies. This working paper is aimed at those who are not familiar with literature regarding transitions within the field of social care (see for example Elder, 1998; Antonucci, 2001; Kemp et al., 2013). It is a companion piece to our series of commentaries written by people with lived experience of care, in which they set out the [‘Transitions that Matter’](#) to them.

This document begins by setting out the scoping review process and outlining the definitions of a ‘transition’ and other key terms, which are the result of our literature synthesis. The second section outlines and discusses the different concepts and theories of ‘transition(s)’ and how transitions are researched in social care. The third section focuses on the findings from the eighteen articles that were reviewed, beginning with the macro level elements and then moving on to the meso and micro level elements. The fourth section discusses the recommendations that researchers make in the field of transition/s research and outlines the next steps in our research.

The theoretical framework of this review draws from Bronfenbrenner’s (1994) ecological systems model of human development, with a deeper focus on the interconnections of the meso and micro level elements. As Burn and Needham (2023; p.2) state:

“Despite the interconnectedness of actors across the social care system, there has been a tendency for research on social care to separate out the components of the system and study them separately...However, going beyond this to explore the interdependencies between actors, institutions and resources can develop our understanding of the social care system. It can also improve our predictive insight into how policy reforms may (or may not) improve the functioning of the system.”

We have attempted to take an ‘interconnected lens’ on the ecosystem throughout this review, focusing on the intersections and interactions between individuals and the systems and professionals involved within care, caring, and transitions. The convoys of care theory (Antonucci, 2001; Kemp et al., 2013) has also influenced the way in which care is conceptualised throughout this review. Antonucci et al. (2013; p.82) state that:

“Conceptualizing social relations as a convoy enables a parsimonious representation of a highly complex human circumstance. According to the convoy model, individuals are surrounded by supportive others who

move with them throughout the life course. These relationships vary in their closeness, their quality (e.g., positive, negative), their function (e.g., aid, affect, affirmation exchanges), and their structure (e.g., size, composition, contact frequency, geographic proximity). The structure, function, and quality of convoys are influenced by personal (e.g., age, gender) and situational (e.g., role demands, norms, values) characteristics while having significant implications for health and well-being.”

To acknowledge the complexity of social relations, convoys of care and situational characteristics, we use the term and concept of ‘care’ in a flexible manner, whereby ‘care’ is defined as giving one’s attention and time within a space that involves tending to the needs of a person for the purposes of creating and/or maintaining wellbeing. This in turn brings up the dimension of embodiment, in that when a person requires care and/or is giving care, there is a body (or bodies) paying attention to another body (or bodies). The dynamics of care collaborations and relations are embodied and intersubjective and care is often reciprocal. We follow Kelly (2011), in acknowledging the critique of the term ‘care’ in the social model of disability and recognise that care can only be meaningful when separated from its oppressive legacy; this is also why we focus on ‘care’ with a lens of intersubjectivity.

METHODS AND DEFINITIONS

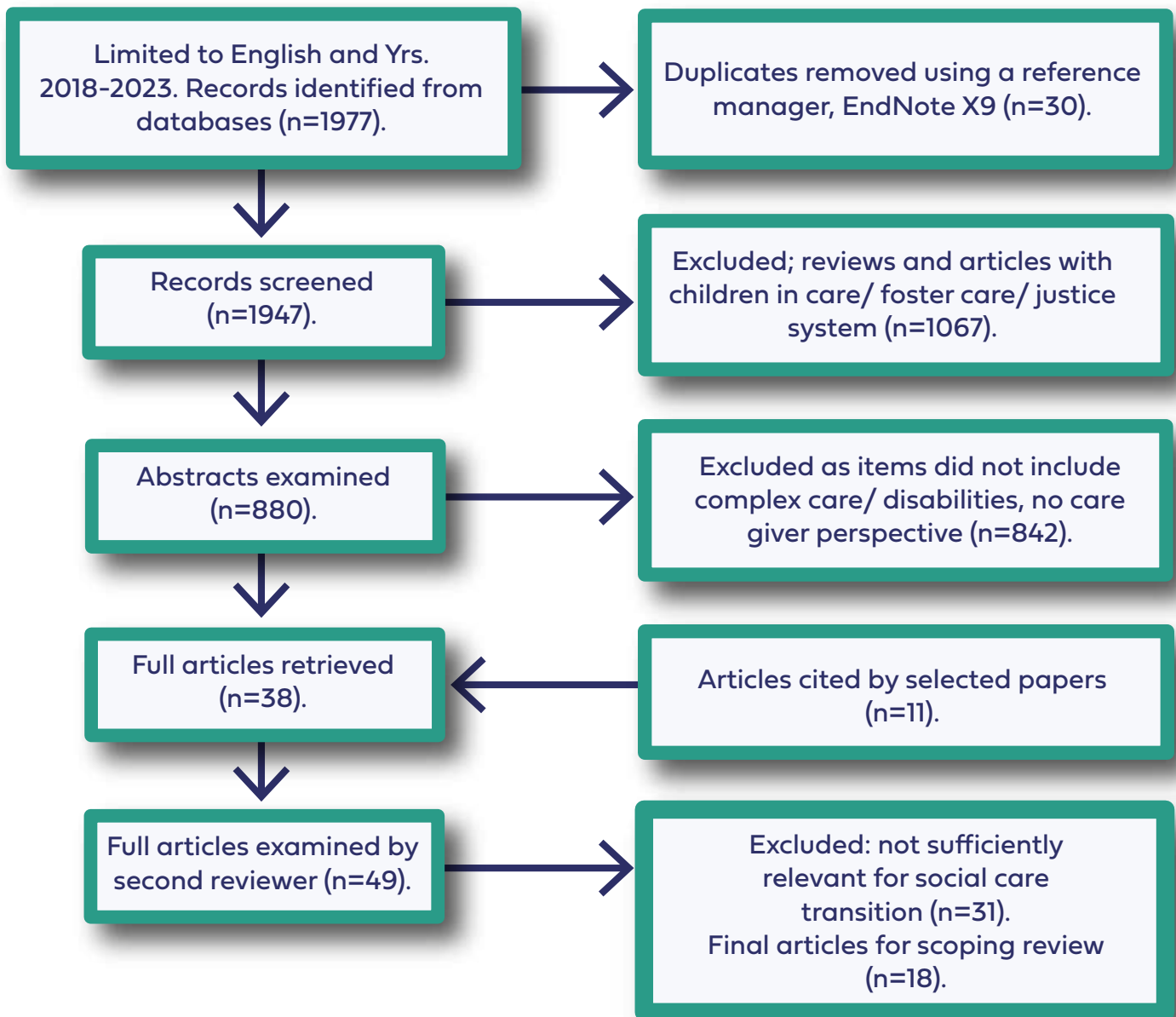
The scoping review examines the state of research activity on ‘transitions in care’ to understand the role of transitions across the life course in shaping people’s experiences of care, and how these can be improved. We use the five-stage framework proposed by Arksey and O’Malley (2005), further developed by Levac et al. (2010), and updated by Peters et al. (2020). This involves identifying the research question, identifying relevant studies, selecting relevant studies, charting the data, and collating, summarising, and reporting the results. According to Peters et al. (2020), scoping reviews draw on evidence from any research methodology and provide a comprehensive overview to address broader review questions.

The searched databases were CINAHL, Scopus, Medline, Web of Science, ASSIA, PsycINFO, Embase, and ProQuest Dissertation. A keyword search, truncation and Boolean operators were used. The terms that were included were ‘transition AND care’, ‘transfer’, ‘moving in/out of care and support’, ‘transition into care system’, ‘care leaver experience’, ‘life span transition’, ‘process of transition’, ‘transition and life events’, ‘transition AND social care’, ‘transition AND health care’, ‘transition and life course changes’, ‘care transition’, ‘transition from’, ‘transition between’, ‘experience of care transition’, ‘transition in education’, ‘transition in housing’, ‘transition into employment’, ‘transition in justice system’, ‘patient transfer’, ‘coping with life transition’, and ‘experience of care transition’.

The search yielded eighteen publications which met the inclusion criteria; Figure 1 illustrates the selection process, and Table 1 includes the details of the final eighteen articles. The studies included international as well as national publications to find as many transition(s) related articles as possible, with most of the studies carried out in the United Kingdom (UK).

Many of the included studies were qualitative, two studies used secondary analysis of quantitative data, and described purposive sampling to recruit participants, and semi-structured interviews as the methods of data collection. Few publications explicitly outlined a theoretical framework.

Figure 1: The selection process for attaining eighteen articles for the scoping review



The final selection of articles is in Table 1, as follows.

Table 1: The final selection of eighteen articles for the scoping review

Number	Title	Author/Ref
1	Association between transition readiness and mental health comorbidity in youth with chronic health conditions.	Allemang, B., et al. (2022). <i>Journal of Pediatric Nursing</i> , 67: 161-67.
2	"Listen to us!" A qualitative study of adolescents with disabilities to help plan a transition service.	Brandao, M. B., et al. (2022). <i>Child: Care, Health and Development</i> , 48(5): 833-41
3	Transition from child to adult health services: A qualitative study of the views and experiences of families of young adults with intellectual disabilities.	Brown, M., et al. (2020). <i>Journal of Clinical Nursing</i> , 29: 195-207.
4	The transition from child to adult health services for young adults with intellectual disabilities: An evaluation of a pilot of an online learning resource for Registered Nurses.	Brown, M., et al. (2022). <i>Nurse Education in Practice</i> , 64: 1-6.
5	Having a son or daughter with an intellectual disability transition to adulthood: A parental perspective.	Codd, J. and O. Hewitt (2021). <i>British Journal of Learning Disabilities</i> , 49(1): 39-51.
6	Adjusting to life in a residential aged care facility: Perspectives of people with dementia, family members and facility care staff.	Davison, T. E., et al. (2019). <i>Journal of Clinical Nursing</i> , 28: 3901-13.
7	Prioritizing a Research Agenda of Transitional Care Interventions for Childhood-Onset Disabilities.	Duncan, A., et al. (2021). <i>Frontiers in Pediatrics</i> , 9: 1-6.
8	"The light at the end of the tunnel". Discharge experience of older patients with chronic diseases: A multi-centre qualitative study.	Facchinetti, G., et al. (2021). <i>Journal of Advanced Nursing</i> , 77(5): 2417-28.
9	Relationships matter! — Utilising ethics of care to understand transitions in the lives of adults with severe intellectual disabilities.	Jacobs, P., et al. (2021). <i>British Journal of Learning Disabilities</i> , 49: 329-40.
10	Raising the profile of care leavers with mental health and/or intellectual disabilities: A contribution from Northern Ireland.	Kelly, B., et al. (2022). <i>Children and Youth Services Review</i> , 136: 1-8
11	Residential immersive life skills programs for youth with disabilities: a case study of youth developmental trajectories of personal growth and caregiver perspectives.	Kingsnorth, S., et al. (2019). <i>BMC Pediatrics</i> , 19(413): 1-12.
12	Gender matters in the transition to employment for young adults with physical disabilities.	Lindsay, S., et al. (2019). <i>Disability and Rehabilitation</i> , 41(3): 319-32.
13	The continuity of social care when moving across regional boundaries.	Marsland, D., et al. (2019). <i>Journal of Social Work</i> , 19(5): 557-577.
14	Identity constructions and transition to adulthood for young people with mild intellectual disabilities.	Midjo, T. and Aune, K.E. (2018). <i>Journal of Intellectual Disabilities</i> , 22(1): 33-48.
15	Fear of Incompetence in Family Caregivers and Dementia Care Transitions.	Miron, A. M., et al. (2022). <i>The International Journal of Aging and Human Development</i> , DOI: 10.1177/00914150221106075, 1- 24.
16	Directed content analysis: A life course approach to understanding the impacts of the COVID-19 pandemic with implications for public health and social service policy.	Purkey, E., et al. (2022). <i>PLoS ONE</i> , 17(12): 1-20.
17	Caregivers' perspectives on health-care transition in autism.	Schwartz, J. K., et al. (2020). <i>Advances in Autism</i> , 6(2): 153-64.
18	Experiences of transition from children's to adult's healthcare services for young people with a neurodevelopmental condition.	Shanahan, P., et al. (2021). <i>Health and Social Care in the Community</i> , 29(5): 1429-38.

The selected articles for this scoping review are all in English, meaning that the review is limited to the confines of the English language as well as the concepts used regarding what a 'transition' is and/or may involve. Markus and Kitayama (1991, 2003) highlight that how the 'self' is construed and constructed in different cultures has various implications for how people see themselves/ourselves and how they/we relate to each other. They state that:

"People in different cultures have strikingly different construals of the self, of others, and of the interdependence of the two. These construals can influence, and in many cases determine, the very nature of individual experience, including cognition, emotion, and motivation. Many Asian cultures have distinct conceptions of individuality that insist on the fundamental relatedness of individuals to each other. The emphasis is on attending to others, fitting in, and harmonious interdependence with them. American culture neither assumes nor values such an overt connectedness among individuals. In contrast, individuals seek to maintain their independence from others by attending to the self and by discovering and expressing their unique inner attributes. As proposed herein, these construals are even more powerful than previously imagined." (Markus and Kitayama, 1991; p.224)

In turn, these two kinds of accounts of the self as independent and as interdependent affect relationships, which is also likely to have implications for transitions and care relations and the ways in which the studies were theorised, constructed, carried out, and what was found. Furthermore, the studies were carried out in capitalist countries that have some kind – and levels of – services from the state. Therefore, this is also likely to have influenced the scoping review.

WHAT IS A 'TRANSITION'?

Transitions are changes and life events that can take place in a person's life. The way in which a transition develops can be referred to as a 'transition pathway' or a 'transition trajectory'. As highlighted in the Introduction of this review, within the field of social care, a 'transition' is also very much related to care and embodiment. 'Key points of transition' are moments that a person/people may experience as being particularly significant during the process. Key points of transition may carry importance due to their high-level impact upon a person's quality of life. These could be events such as starting a new job, entering a new relationship, having a child etc.

METHODS AND DEFINITIONS

There are various definitions, concepts, and theories regarding transitions in social care; this is due partly to the complex nature of what a transition can involve for an individual within their given community(ies), and partly due to the different standpoints of researchers.

DEFINING TRANSITIONS

Purkey et al. (2022; p.3) state that:

"Transitions refer to changes in role that make up trajectories. Graduating from school, moving out of the family home, starting a job, having a first child, and retirement, would all be transitions, which happen at different chronological ages, and the timing of which will affect one's life course and trajectory."

Therefore, the interconnected dimensions of 'roles', 'change', 'time' and the 'life course' are present within this definition. The dimension of 'context' is also implicit, in that they highlight contexts that one can transition into and out of, e.g., entering a new job place, and later moving out of the work context and into retirement.

Another definition is from Marsland et al. (2019; p.570):

"Transitions should be understood as significant life events, which include 'social, psychological and emotional dimensions' in addition to spatial or service dimensions, which can be facilitated by practitioners who may support individuals to achieve positive experiences and outcomes (Tanner et al., 2015, p.2061)."

Codd and Hewitt (2021; p.40) draw attention to transitions being 'nonevents' as well as 'events', 'Transition has been defined as "any event or nonevent that results in changed relationships, routines, assumptions and roles" (Goodman, Schlossberg, & Anderson, 2006).'

When researchers draw their definition of transition from formal law or policy this often constrains them to a focus on the move from children to adult services. For example, Brown et al. (2022; p.2) drew from the Department of Health (UK), 'The primary purpose of transition is to provide uninterrupted, coordinated and developmentally appropriate care before and during the move to adult services (Betz et al., 2021a).'

Similarly, Kelly et al. (2022; p.2) base their transition research on the following definition of a care leaver that is used in Northern Ireland:

"A care leaver is defined by the Children (NI) Order (1995) and Children (Leaving Care) Act (NI) (2002) as a young person who has been in alternative care for at least 13 weeks, since the age of 14, and who is in care on their 16th birthday. A care leaver can be aged 16–21 (or up to 24 if in education/training)."

Therefore, a transition can refer to a process or processes, as well as to individuals who are labelled in a way that defines their transitional position within a system of care and beyond it, e.g., a 'care leaver'.

THEORISING TRANSITIONS

The theories and models of transition are outlined in different ways in the literature. For example, Codd and Hewitt (2021; p.40) draw on Chickering and Schlossberg's (1995) work on transition as a three-stage process of "moving in, moving through and moving out". A person's ability to cope with this transition will depend on the 'situation, self, support and strategies' (Codd and Hewitt, 2023; p.40). The same authors also bring in Bridges' (1991) model of three stages of transition: "ending, losing or letting go; the neutral zone; and the new beginning", and they distinguish between change and transition, noting that "whereas change can happen very quickly, transition usually occurs more slowly" (Codd and Hewitt, 2021; p.40).

Purkey et al. (2022; p.3) draw on Elder's (1998) Life course theory in focusing on transitions during the Covid-19 pandemic:

"Life Course theory seeks to explore the individual, family, social and cultural impacts of experiences from a complex and multifaceted perspective, this theory may be helpful in understanding both the immediate, short-term consequences of the pandemic, as well as the long-term impacts that are likely to be experienced throughout the entire lives of individuals and societies affected."

This is similar to the conclusions drawn by Jacobs et al. (2021; p.339):

"The concept of multidimensional transitions has started to gather recognition within transition research...The concept describes how transitions are influenced by the wider socio-economic context, as well as highlighting that transitions never only happen to one person."

Therefore, researchers acknowledge that transitions in themselves are multi-layered and multidimensional – there is a 'horizontal' and a 'vertical' movement(s) in a 'transition'. It involves different individuals, their families, communities, and organisations, with socio-economic factors being the wider context in which transitions take place over a lifelong process(es).

Transitions are also conceptualised in terms of a lifespan. Miron et al. (2022; pp.2-3) conceptualise care as a lifelong process and suggest considering the dyad of carer and person cared for as a unit. This may be relevant, for example, in the dynamics of deciding that a person with dementia transitions from their family home into a care home. Jacobs et al. (2021; p.339) similarly place care and caring in a context of interdependence and transitional processes:

"Thus, if we understand care relationships through the lens of interdependence we can see that we are all in need of care, challenging the neat dichotomy of givers and receivers (Porter, 2006). Moreover, interdependence highlights the political dimension of care by making apparent the need for appropriate resources and support to be allocated to those who provide care (Tronto, 1993)."

Therefore, the care relationship(s) can – and does – involve nuanced transitional processes and 'movements', e.g., the ongoing dance of 'swapping roles' as one who is in the role of the 'carer' and the one who is in the role of being 'cared

for'. Furthermore, the authors also place care relations and transitions in the context of the 'personal is political' (Hanisch, 1969); in that, care can be – and usually is – very personal, and so political policies and resources of funding are intertwined with their theory of care and interdependence.

The examples above highlight the different ways in which a 'transition' is conceptualised and theorised, which also involves the use of a variety of terms of language in conveying different meanings and concepts of what a 'transition' may be. This in turn influences the ways in which researchers study transitions.

HOW TRANSITIONS ARE RESEARCHED

Transitions are usually researched in ways that reflect the researchers' philosophical standpoints. Implicit within this is that when a researcher seeks to carry out research one inevitably is in a position of power – all the way from the very beginning, i.e., in creating research questions, until the very end, i.e., the knowledge and findings that are created and the ways in which they are disseminated or not. Shanahan et al. (2021; p.1429) state that, 'The majority of transition research has focused on what health professionals consider important in the transition process, rather than focusing on the experiences of the young people and those closest to them.'

Jacobs et al. (2021; p.331) state that 'the task of researchers is not to "give voice" to people'; rather it is about working as closely as possible with people and families throughout the research process. They highlight that carrying out research with disabled people can challenge traditional research methodologies. They therefore push for an 'ethics of care' (Tronto, 1993) standpoint that focuses on interdependence between human beings, with vulnerability and dependence recognised to be central to human lives. They also draw on the work of Kittay (2001) to highlight that being a person is about the capacity to be in relationships with others, rather than than to simply be independent and rational beings.

The eighteen studies included here used a wide range of research methods. This varied from ethnographic work to survey analysis. For example, Jacobs et al (2021) carried out ethnographic work and interviewed participants to explore how young disabled people living in Scotland are involved in the planning of their transition from school to adult services and moving out of the family home. Kelly et al. (2022; p.1) used survey analysis to focus on disabled people leaving state care services in Northern Ireland, noting:

"Within the UK jurisdiction of Northern Ireland (NI), young people with mental health and/or intellectual disabilities are over-represented in the population of care leavers and yet very little is known about their specific needs. The overall aim of the study reported here was to examine the profile of care leavers with mental health and/or intellectual disabilities in order to better inform how best to configure child and adult service systems to meet their transitional needs."

They collected survey data from social care workers about the young people they had worked with, or were still working with, in terms of transitioning out of the state care system. In summary, transitions are researched in varied ways.

FINDINGS FROM TRANSITIONS RESEARCH

There were many different findings reported by the authors of the eighteen articles. This is due to the factors that have been outlined and discussed thus far, e.g., different researchers define 'transition' in different ways and focus on different kinds of transitions. The themes they reported can be viewed within a context of three intertwining layers: macro-level elements (e.g., laws, structures and policies), meso-level elements (e.g., services that exist for the purpose of transition/s) and micro-level elements (e.g., how an individual makes meaning of the transition/s they are experiencing and how they approach transition/s). The following themes emerged from carrying out an inductive thematic analysis of the articles. Macro, meso and micro level elements are interconnected, although, for the purposes of clarity of structure here, the macro-level elements will be discussed first and then the meso and micro level elements will be discussed together.

MACRO-LEVEL ELEMENTS

Transitions, the law, social policies and funding

Transitions at a societal level can create and shape the way that social care is provided within a particular country or region. Kelly et al. (2022; p.2) note that the devolved Northern Irish context - which in itself is the product of an ongoing political transition of the relationships between England and the rest of the countries that constitute the UK - has set the legal, policy and funding context. This includes transitions for people leaving the state care system. The legal context is also linked with the way individuals are legally defined and labelled, e.g., Children (Leaving Care) Act (NI) (2002). It affects how people are able to access social care services and broader services, e.g., being supported to access the education system, employment, etc.

Laws and policies can also be influenced by supranational organisations. For example, the UK is one of the founding members of the United Nations, and as Marsland et al. (2019; p.558) point out: 'Article 18 of the United Nations Convention on the Rights of Persons with Disabilities (United Nations, n.d., p. 13) highlights the rights of disabled people to "liberty of movement, to freedom to choose their residence and to a nationality, on an equal basis with others"'. However, Marsland et al (2019; p. 558) go on to note that: 'evidence suggests that disabled people may experience significant barriers in exercising choice about where they live, in comparison with non-disabled peers.'

Lindsay et al. (2019; p.320) also drew from a UN Article to set a legal and policy-oriented context when focusing on disabled women who were trying to transition into employment:

"Article six of the United Nations' Convention [21] [UN General Assembly 2006] recognizes that women with disabilities experience multiple forms of discrimination. Although the gender gap in employment is decreasing for women with disabilities, they are more likely to be unemployed, work fewer hours, and hold lower status occupations compared to men with disabilities [22–25] [Magill-Evans et al., 2008; Park et al., 2007; Wagner et al., 2014; Doren et al., 2013]."

The researchers utilised a lens of intersectionality, in this case gender and disability, and by focusing on employment they inevitably focused on class as well. In addition, they used Article six as a context through which to explore the exacerbated inequalities that disabled women experience when attempting to gain employment. They refer to 'multiple forms of discrimination' (Lindsay et al., 2019; p.320), and this can be the result of different factors including negative societal attitudes towards disabled people, the non-compliance of employers with the law, and laws and policies that may not be as up to date as they ought to be. There was also a lack of funding and services geared towards supporting employers who may wish to employ disabled people but do not know how to make reasonable adjustments within their workplaces (Marsland et al., 2019; Lindsay et al. 2019; Shanahan et al., 2021; Kelly et al., 2022). Therefore, these factors can negatively affect disabled people when they want to make a transition or are put into a situation whereby they have to make a change in their lives.

Laws and policies set by a government are usually intertwined with funding. Funding leads to resources that are required to create, set up, and maintain any kind of service, and this includes social care services. Jacobs et al. (2021; p.337) state that:

"...relationships between professionals and families were dependent on the wider service provision context, being vulnerable to changes in funding, recruitment and retainment of staff and restructuring of services, placing relationships at risk to be suddenly cut-off and discontinue. Future uncertainty seemed to affect the quality of life of parents more than the lives of their children (at this moment in time). The main worry parents had was who would care about their children and ensure their well-being once parents were no longer able to do so."

This example illustrates how not only are current transitions affected by the funding and the kinds of services available to families, but also the way that expectations – and fears for the future – can affect potential transitions.

Health and social care funding also affects the ways in which people can access services; this varies from country to country. For example, Schwartz et al. (2020; p.158) carried out research into health service transitions for people on the autism spectrum in Florida, USA, and found that 'insurance did not cover needed health expenses, such as vision, dental or therapy services.' This led to families having to either pay from their own pockets or not being able to afford the necessary medical treatment for their family member:

"Participant 2 reported: "I have to be debating between his needs . . . or my budget availability. More likely, I'm sacrificing his best results in terms of eyeglasses versus my budget because I cannot really have everything for him because the insurance is not covering it." (Schwartz et al., 2020; p.159)

In summary, macro level elements, such as domestic laws and policies or supranational ones (e.g., UN conventions), are intertwined with funding costs and administrative structures (e.g., health insurance companies) that may or may not facilitate transitions for people at the meso and micro levels.

Transition and societal attitudes

Societal attitudes in this case refers to how people in society generally look upon disabled people. Kingsnorth et al. (2019; p.2) state that:

“Compounding these experiences, functional and/or cognitive limitations often mean that young people with disabilities may not have the same expectations or opportunities for choice-making and problem solving through equivalent interactions [13] [Hojberg et al., 2008]. Moreover, people may perceive them as more vulnerable and at risk than their typically developing peers, and continue to act in protective ways that impede the development of autonomy within periods of adolescence and young adulthood [8, 13] [Peeters et al., 2014; Hojberg et al., 2008].”

Brandao et al. (2022; p.837) carried out research with disabled young people in Belo Horizonte, Brazil, and they learned the following from them:

““There are things that really are limitations, but others are just in our heads, or it’s the society telling us that “no, you cannot do this, you cannot do that”; which stops us. We could go further, but why do not we? Family keeps saying we cannot handle it, friends also say that we may not be able to do it, this ends up freezing us psychologically” (ID4) [‘ID’ is the participant’s ‘Numerical Identification’, i.e., Participant 4]. They reported that, sometimes, they do not feel able to perform a certain activity, without even trying. “I believe I can even do some things, but I limit myself, as if I could not do it” (ID6). On other occasions, they put themselves in situations of going beyond their abilities. “You do not want help. You want to do everything by yourself, you want to say ‘I can do it!’ But I end up getting tired” (ID7).”

Therefore, others’ expectations or lack thereof, for disabled people can also influence individuals’ thoughts regarding making a transition. This can influence the decision-making processes for disabled people at the individual/micro level when it comes to the possibility of making a transition in their lives.

Transitions in a pandemic

In 2020-2021 the Covid-19 pandemic affected the lives of most of the world’s population and therefore also affected transition processes. The spread of the virus created much unpredictability and anxiety. For example, in March 2020 the UK government set regulations for people to self-isolate and not mix with other families and then kept on changing regulations for over a year – with variations in measures amongst the devolved countries of the UK. The pandemic affected already existing transition pathways or trajectories, e.g., students who would normally be in school or university had to study online, people worked from home instead of an office etc. It also created transitions in people’s lives, e.g., the transition/s of death and bereavement.

Purkey et al. (2022; p.13) focused on transitions in South Eastern Ontario, Canada, between June and December 2020 and found that:

“Similar to life-span development, our data illustrated the differential impact of the pandemic depending on the timing in which it occurred in a persons’ life. More than just an age related construct (i.e., this happened to me when I was X years old), respondents described how the intersection of the pandemic with a certain moment in a person’s life (for instance, the impact of a pandemic lockdown that occurred at the same time as an evolving custody battle and change in employment, or the impact of elementary school closures on a mature student trying to complete University studies while being a single parent) would significantly influence the impact the events had on life course, being more significant for some, and less for others, depending on the point of intersection. Generally, our respondents illustrated greatest concern about the impact of the pandemic on the social, emotional, and educational lives of developing children and youth.”

Hence, the researchers drew from Elder’s (1998) Life course theory as a theoretical framework and observed that the participants conceptualised transitions in terms of the macro-level context (i.e., the pandemic) intersecting with time and the expected stage(s) of a transition(s). Furthermore, the respondents’ concern for developing children and youth implies that they viewed them as being already somewhat vulnerable and therefore may experience a deeper impact of the pandemic.

There were also positive transitions during the pandemic (Purkey et al., 2022; p.8 - 9), ‘Some participants did report positive change, such as improvements in income through access to government pandemic relief programs, delayed evictions, and reprioritization of personal and family time.’ One of the participants in Purkey et al.’s (2022; p.15) research highlighted that:

““It was really humbling to see finally some indigenous families not having to be in the colonial structure of schools and school boards. That they were connecting to the land. They were including their children in the baking. They were including their children in the measuring. They were going back to our traditional ways of how we teach our young. And it wasn’t the western reading, writing, arithmetic. It was in the most holistic way. So if we’re going to take something good out of it.” (9A) [Participant 9A].”

In this case, the macro-level context of the pandemic enabled the indigenous families within this research study to transition away from the colonialist structures, enabling them to reconnect with their roots as family units on the micro level.

In summary, the usual kinds of transitions that people would have undergone, e.g., transitioning into education or employment, were affected by the pandemic. Governments all over the world dealt with the pandemic in different ways, and the effects of the measures taken in 2020 and 2021 – or lack thereof – continue to affect people’s lives today. Different communities of people experienced the pandemic in different ways, some transitions – or the absence of them – being negative for some and positive for others.

MESO-LEVEL AND MICRO-LEVEL ELEMENTS

Meso-level elements are, for example, social care services, schools, charity organisations, and the community one lives in. Micro-level elements are to do with the individual and their immediate environment, e.g., parents, other family members, teachers etc. The meso level system is so closely interwoven with the micro level systems that the two will be discussed together.

Transition services and funding

Within social care in the UK, 'transition' usually refers to individuals moving from children's social services to using adult social services, and 'transition services' are services provided by social care workers in creating and facilitating the process of this kind of transition. Funding from local authorities is required to create and maintain such services. However, a range of other service moves can also be classed as transitions, such as moving into residential care, or moving from hospital back home after a period as an in-patient.

Jacobs et al. (2021) carried out research in Scotland by exploring the transition journeys of six disabled adults, including transitions from school to adult services and moving out of the family home. They noted that professionals were limited in how much they could support families through the transition:

"Particularly, social workers seemed to be caught in between their role of supporting families and becoming gatekeepers of resources available to local authorities. Social workers and local authority managers talked about how limitations within the systems they worked in did not always allow them to be person-centred or offer choice." (Jacobs et al., 2021; p.337)

When the services themselves are not funded and resourced properly, this affects families in various ways. The difficulty in recruiting social workers and the high staff turnover leads to a lack of continuity for families, whereby parents and family members can end up having to constantly act as advocates for their disabled family member/s and may even have to emphasise the negative nature of their difficulties to ensure support is given (Jacobs et al., 2021). The lack of funding and resources leads to vacuums of power and service that family members and/or friends then may feel pressured to address and compensate for. This situation can lead to burnout for disabled people who are able to advocate for themselves as well as for family and friends who may be assisting those who find it difficult to advocate for themselves (Raymaker et al. 2020; Young et al., 2021).

The policies and funding within the social care and health sectors create and shape transition practices that take place between the two. Researching the move from children to adult services, Shanahan et al. (2021; p.1430) found that although national guidance in the UK suggests that transition planning should begin between the ages of 13 and 14 years, this was not happening in practice. In particular there were issues for people with neurodiversity:

"Reviews of ADHD and Autism Spectrum Disorder (ASD) transition highlight information sharing between services needs to occur and that policies that govern adult services are less comprehensive (Anderson et al., 2018;

Price et al., 2019). Despite calls for policy change to support efficient, timely and gradual approaches based on needs led services, these have not occurred" (Brown et al., 2019)."

Shanahan et al. interviewed six disabled young people and eleven family members within two locations of the UK in 2019 and found:

"A recurrent problem is the lack of continuity between services. This links with a previous theme, availability of adult healthcare and social care services, as the eligibility criteria for child and adult services may differ. This means young people who qualified for support as children may not be eligible for the same type of support as adults. This could leave young people without the support they need." (Shanahan et al., 2021; p.1435)

Continuity between health and care was also a focus for Facchinetti et al. (2021); they carried out research in Milan and Rome, Italy, interviewing elderly people with chronic diseases who were about to be discharged from hospital and found that (Facchinetti et al., 2021; p.2426):

"Patient readiness for discharge is related to the time that healthcare professionals spend in providing exhaustive information useful for discharge. The time spent and the information provided are also the basis for establishing a trusting relationship, which will support the patients and prevent them from feeling abandoned. Moreover, the healthcare professionals should intervene more deeply in the discharge process, balancing patient-centred goals against organizational priorities and determining a 'shared' discharge perspective."

They highlight that 'failure to involve patients in their discharge care could have negative consequences of varying proportions in the future (e.g. future distrust, security errors, readmissions)...' (Facchinetti et al., 2021; p. 2425). Facchinetti et al. (2021; p.2418) go on to report:

"However, healthcare professionals, especially nurses, seem to spend little time on caring for patients at discharge due to high workloads and time constraints, with a number of interventions to perform in a short time, before the patient leaves the hospital (Facchinetti et al., 2019). In this context, the information seems to be given hastily, negatively influencing the patients' participation, causing anxiety, uncertainty and a lack of understanding regarding discharge instructions (Coleman, 2003)."

In summary, the disjuncture between health and social care and between formal service settings such as a hospital and informal setting such as the home can be a barrier to effective transitions.

The individual's family and community(ies)

The family members and communities that disabled people belong to can – and do – play a crucial role(s) regarding transitions. Transitions can be 'imposed' upon disabled people and their families due to the combination of different factors. Jacobs et al. (2021; p.336) state that:

"All parents were strong advocates on behalf of their children, and participants felt that it was the advocacy

work of parents that often resulted in positive outcomes. A number of participants used the term “those who shout the loudest” within interviews. These references seemed to allude to concerns that people with severe intellectual disability often rely on family members to get their voice heard, but that not all families might be able to be strong advocates.”

The authors highlight that it is usually mothers who limit paid work to be effective advocates for their children. Indeed, parents and other caregivers can play such a vital role in assisting with transitions, that the thought of their passing away can be daunting for their disabled child:

““There will come a time when we will not have our parents among us. And then, there is [the] looming question: what am I going to do?” (ID5). In this sense, they questioned whether relatives and friends would help them. “I asked for a brother a lot because I did not want to be alone. My family takes care of me a lot. But taking care of you as a father and mother, I think that nobody can” (ID5).” (Brandao et al., 2022; p. 837 – 838)

One’s social network, or ‘social capital’, can affect transitions, and in turn transitions can affect how one’s social network develops. Midjo and Aune (2018; p.34) found that disabled young people may face barriers in adulthood due to a lack of social capital:

“As such, they tend to be introduced to a pre-structured adult life, which may be defined in accordance with the term ‘accelerating’ transition processes (Lee, 2014), implying that these young people are introduced to adult roles without possibilities for gaining additional social capital that is of importance for their future lives. In light of the traditional markers of adulthood, the roles available for young people with intellectual disabilities might hinder realizing an adult status (Schalock, 2004).”

Further, Jacobs et al. (2021; p.338) found that, *‘The role of friendships and peers was scarcely considered when making decisions about people’s transitions.’* This may reflect ‘western’ cultural norms and concepts with regards to how ‘care’ and ‘transitions’ are conceptualised within a culture, e.g., within the confines of a ‘nuclear family’, as well as how systems and policies that are care-service oriented are set up and carried out – and/or not carried out, e.g., friendships not being considered in people’s transitions.

Purkey et al. (2022; p.17) highlight the importance of having a sense of agency and belonging within a community when undergoing major transitions. Furthermore, Miron et al. (2022; p.15 – 16) outline the benefits of involvement in one’s community for those who provide support:

“Studies have shown that more involvement in social activity outside the home increases dementia caregiver life satisfaction and reduces depression (Wakui et al., 2012) and that higher levels of affectionate support, positive social interaction, and social participation are associated with lower depression scores in dementia family caregivers (Sibalija et al., 2020).”

Moving home from one community setting and into another can be a challenging transition for anyone. However, if one has a care package that is provided by the local authority,

the element of funding and care provision can also play a significant role in whether a person does decide to move. Marsland et al. (2019; p.559) state that:

“Individuals reported anxiety and fear of losing care and support, which may act as disincentives to relocation (Arksey & Baxter, 2012; Dilnot, 2011; National Union of Students (NUS), n.d.; Sayce, 2011). Poor transitional arrangements were identified, with the potential to cause delays and disruption to care delivery as people move (Dilnot, 2011; NUS, n.d.). Accounts were provided of individuals who had lost care and support or who had encountered reduced funding/care hours on moving (Kay & Connolly, 2013; NUS, n.d.), although there was also potential for increased provision. Further, there were examples of decisions about care and support being made ‘at the last minute’, close to the time of moving (Arksey & Baxter, 2012).”

If an individual fears losing care and support then the transition of moving home may not even take place, which may lead to the person becoming stuck in a context that they no longer want to be in. People who do move may receive more or less care support funding/hours within their new local authority. Marsland et al. (2019; p.569) found that:

“...relocation, as well as representing a positive opportunity, could be a time of vulnerability and risk for individuals; some participants’ accounts highlighted a loss of care and support (short or long term) and a negative impact on emotional and physical health and well-being.”

In summary, individuals’ families and communities play very significant roles in their lives, spanning from how their families are able to – or not – provide support throughout transitions, to opportunities for transition that may or may not be available to them through the means of their ‘social capital’, and when wanting to re-locate into a new community. There are macro, meso and micro level factors, e.g. the law, social policy, funding, and social capital, that intertwine in how such transitions play out and/or may be hindered or prevented from taking place.

Transition and identity

Disabled people not only have to work with the opportunities for transition made available through the environment, but they also work with their own sense of agency and identity. Brandao et al. (2022; p.837) found that:

“Other adolescents considered the awareness of their limitations as a way to achieve their self-knowledge and self-esteem and to adjust their expectations and skills. “A sense of identity and self-knowledge are also linked to self-esteem. If you know yourself and you accept yourself as you are, then it becomes much easier to live. So, I think these two things are very connected” (ID1) [Participant 1].”

Therefore, the ability to be consciously aware of one’s abilities can enable the development of a strong sense of self-belief, which in turn can influence and shape the way one may attempt to make a change in one’s life. Furthermore, being able to explore ‘possible future selves’ can also enhance the potential(s) for being able to make changes. Midjo and Aune (2018; p.45) found that:

“The production of future selves represents having one’s own ‘identity space’ for imaginations that can be actualized everywhere and at any time. Those possible selves and possible futures may indicate a positive part of the path to adulthood as representing an opening to explore different social identities (Gustavsson and Nyberg, 2015: 82). Possible future selves may then function as important starting points and provide a drive to find one’s own way into adult living and to produce self-identifications.”

However, Midjo and Aune (2018; p.45) highlight that there can be – and are – barriers within society that hinder the development of one’s ‘identity space’ and developing ‘alternative identities’; in particular, in their research with people labelled as having mild learning disabilities, they found that institutions and professionals presented a barrier:

“The institutional frame may then act in ways that hinder people with mild intellectual disabilities in realizing alternative identities as part of their need for assistance. Instead of considering alternative identities that might be more important and meaningful for the young persons, the professionals seem oriented to strategies that promote adaption to the institutional identity imposed by the service (Cameron and Murphy, 2002; McVittie et al., 2008).”

Hence, when the individual has to adapt to existing institutional norms it can lead to the limiting of the development of ‘alternative identities’ and ‘future selves’. This in turn can then limit or prevent the possibility of people seeking transitions. In addition, this is not limited to youth, older people also imagine their future(s) and how they want to age (Huang et al., 2022).

Health-related transitions

Health changes are another potential source of care-relevant transitions. In looking at dementia, Miron et al. (2022; p.2) note that:

“Due to the progressive nature of dementia, the person with dementia becomes increasingly dependent on caregivers for performing activities of daily living (ADLs) [Activities of Daily Living], such as getting dressed or bathing (Henskens et al., 2019). These caregivers’ changes challenge family ability to communicate and interact meaningfully with the person in their care (Egan et al., 2010), which creates considerable anxiety and stress (Eggenberger et al., 2013; Huis in het Veld et al., 2016)...As a result, family caregivers must cope with the real and perceived changes in their loved ones with dementia, including changes in human nature characteristics (e.g., emotional responsiveness, interpersonal warmth, cognitive openness, agency/individuality, and depth) and human uniqueness characteristics (e.g., civility, refinement, moral sensibility, rationality/logic, maturity) (Haslam, 2006; Miron et al., 2017).”

The change in one’s medical condition does not only create and affect the service and support that is required, but it can

also change oneself and one’s sense of identity. This ‘identity transition’ can be traumatic for the person experiencing dementia and for their family/support circle (Flannery, 2002).

When the condition reaches a stage whereby the family/ immediate support circle feel that they are no longer able to care for their family member in their own home this may initiate the transition process of the disabled person moving into a residential care setting (Miron et al., 2022).

Transition readiness

The ability of an individual to be prepared for making a transition is referred to as ‘transition readiness’. The authors of the eighteen articles drew upon their different fields of interest to explore transition readiness – be it explicitly by using the term ‘transition readiness’ or implicitly when referring to participants’ abilities to cope with an upcoming transition or transition they were already undergoing.

In their research on young people with chronic health conditions, Allemang et al. (2022; p.165) state that preparedness for transition may be greater than expected:

“Our results challenge commonly held assumptions that youth with co-occurring health and mental health conditions transitioning to adult care simply require more support than those without mental health conditions. This research suggests that this group may have developed transition readiness (i.e., self management, communication and advocacy skills) as a result of coping with mental health challenges throughout adolescence and young adulthood.”

Other research highlights that people may not be prepared for a transition due to a combination of a lack of disability-specific policy development, policy adherence, and the very nature of an individual’s condition:

“Previous research has suggested that some young people with ID [Intellectual Disabilities] are simply not ready to transition to adult services, as their psychosocial and cognitive maturation may be slower than their typically developing counterparts (Salt et al., 2019). This transition period for people with complex needs is not coordinated and the NICE guidance suggesting a flexible age threshold for transition is often ignored (National Institute for Health & Care Excellence, 2015). It is clear that NICE guidance around transition is repeatedly ignored from commissioning to practice across services.” (Shanahan et al., 2021; p.1436).

This can affect the individual’s ability to prepare for a transition and/or then to undergo the transition (Shanahan et al., 2021). Teamwork between the individual, their family and professionals can help to address and ameliorate the anxiety and confusion:

“What seemed to work well was a ‘transitional meeting’ where team members from both children’s and adult services attended to discuss handing over responsibility for support to adult services. Although this was often difficult to organise, the young people and their parents valued this meeting.” (Shanahan et al., 2021; p.1433)

Transition readiness – or the lack of it – can and does also affect the family, as discussed earlier. Miron et al. (2022; p.14) highlight the importance of active skill training and educational programmes for families with a member living with dementia:

“...fear about not having the appropriate knowledge about dementia causes or dementia care (i.e., Fear of incompetence - Knowledge) was the strongest predictor of care transition desire. This suggests that resources need to be invested in alleviating this type of concern by educating family caregivers about dementia and dementia care. Such psychoeducational caregivers’ programs have a small-to-moderate effect on the improvement of ability/knowledge, subjective well-being, burden, depression, and anxiety (Walter & Pinquart, 2020; see also Cheng et al., 2020). However, these programs need to incorporate active skill training rather than information-provision in order to have a long-term effect (Walter & Pinquart, 2020).”

This kind of education program can also be provided for those living with a disability. For example, Kingsnorth et al. (2019) focused on a Residential Immersive Life Skills (RILS) program in Toronto, Canada, called ‘The Independence Program’ (TIP), which is for young disabled people; they spend a summer away from their caregivers/ parents in a residential setting, and they develop their independence skills, e.g., time management, cooking, cleaning etc. Kingsnorth et al. (2019; p.10) found that:

“Caregivers who embraced program-related changes among their youth can facilitate continued and long-lasting skill development, making the TIP experience (and other RILS programs) only the first step in an upward trajectory of personal growth [16, 19] [Kingsnorth et al., 2015; McPherson et al., 2018]. However, when caregivers fail to acknowledge or support the process of maturation, and key acts of redefining oneself through self-directed change, they can interfere with the trajectory towards emerging adulthood.”

Caregivers must also make adjustments with regards to the way they see themselves, to the way they see their role(s) in connection to the person they are caring for, as well as to the way they see the changes in the person they are caring for. Miron et al. (2022; p.4) focused on ‘fear of incompetence’ as a factor that can hinder adjustments and transition/s at the individual level within the family context, noting that:

“Wicklund (2005) defined fear of incompetence as the fear of interacting with certain others due to lacking the necessary interaction skills and knowledge about those others. In interpersonal interactions with a family member with dementia, fear of incompetence is conceptualized as the fear of being unable to interact or communicate in a meaningful way or take care of a close family member with dementia. Fear of incompetence has three components: being afraid about lacking the skills for interacting meaningfully with the person with dementia, being afraid about lacking dementia knowledge, and being afraid about lacking caregiving skills (Thompson et al., 2020).”

The transition of moving to a residential care setting is the focus of Davison et al.’s (2019) research. They found several components to how well new residents adjusted to the move. Staff attitudes were one element of this, as this quote from a manager indicates:

“Staff members that are task orientated, that hinders adjustment because some people and you know some staff either for whatever reason it could be cultural it could be just the way they are, they haven’t got that innate person centeredness so they’ve got three beds to make, four showers to do and they forget that they’re actually working in the resident’s living environment not the resident living in their working environment and so that does hinder [adjustment]. (61-year-old care manager, 38 years in field).” (Davison et al., 2019; p.3908)

Visits from family members may help create and maintain a sense of continuity for the person who has moved into a care home, therefore, increasing the possibility of them adjusting to the transition:

“Family members were viewed consistently as playing an important role in helping residents with dementia to adjust to [a residential aged care facility], in contrast to the findings of a previous study with cognitively intact residents (Lee, 2010). Our respondents considered families a source of support, stimulation and relief from day-to-day life in the facility. Staff advocated for family members to spend longer periods in the facility, rather than the more common brief visits.” (Davison et al., 2019; p.3910)

Forging new relationships with other residents in the care home may enhance the possibility of adjusting – or it may not:

“Some residents talked positively about forming friendships with other residents in the facility, which typically emerged during mealtimes and group activities. Families and staff saw these new relationships as important for resident adjustment, extending reports by residents in previous literature (Brownie et al., 2014), and tried to facilitate this process. However, many residents found it challenging to form meaningful relationships, with reports of conflict between residents and a common view among residents that their peers were acquaintances rather than genuine friends.” (Davison et al., 2019; p.3911)

Therefore, the transition of an individual moving into a care setting can be complex, and various factors can play a role in the person’s ability to transition into their new home, e.g., how staff treat them, whether family members continue to see them, and how they interact – or not – with other residents.

Employment

Employment can open up opportunities for an individual in many ways, be it in terms of increasing one’s social circle and/or networking in ways that can enable further career transitions and development to take place. Lindsay et al. (2019; p.327) reported that:

“Both males and females with disabilities described that having early work and volunteer experiences shaped

career interests. Both groups also shared the importance of having realistic expectations and adjusting their career aspirations based on their (dis)-ability. For example, one youth said, "throughout high school I wasn't able to gain the traditional kind of roles others did – retail and that sort of thing, because physically I wouldn't be able to do the roles" (female 2)."

Here we see that current volunteering opportunities, and future career goals for transition/s are very much influenced by the kinds of roles they feel they can undertake. Furthermore, it is also very much influenced by one's network:

"Most males and females expressed how their social network provided them with support and encouragement. For example, one youth said, "I had a great support network around me. Mainly my family and my parents" (female 13). A female conveyed how her family and social network helped her to find a job, "I had a lot of supports from family. A few of my relatives work at [company] and they had connections...and would introduce me to people and would tell me about different kinds of options" (female 5)." (Lindsay et al., 2019; p.326)

Hence, one's social circle can help to initiate transitions in one's life regarding employment. They can also assist with facilitating the ongoing process(es) of transitioning into employment and the kinds of roles that can be undertaken.

If a person relies on social care support from their local authority, there can be difficulties in moving to another city or town to find work. Marsland et al. (2019; p.558) state that:

"This lack of portability and continuity in respect of social care may act as a significant barrier to individuals who seek to exercise their right to geographic mobility and relocate to a new local authority area. Further, it may reduce opportunities for labour mobility among disabled people in receipt of social care support who need or want to move to access employment opportunities, acting as a source of injustice and disadvantage, and militating against their right to employment equity (Sayce, 2011)."

This again highlights the interrelated nature of transitions. People who are unable to move house due to fears of losing a local authority package are also heavily constrained in the employment opportunities that they can access.

Non-transitions

There are also situations whereby an expected transition, e.g., a child becoming an adult and moving out of home, may not take place. Brown et al. (2020; p.205) state that:

"The majority of young adults with ID [Intellectual Disabilities] continue to live at home with their families who play a central role in their ongoing care and support. International research evidence highlights that this population is living longer with a range of interrelated complex physical, psychological and behavioural support needs, and more will transition from child to adult health services. "

Disabled people who want to make transitions – to live independently, to access higher education, employment and start a family – may find these routes blocked for the reasons

discussed earlier in this paper. Thinking about the future and the kinds of life transitions that one may want to experience also involves a certain kind of vision of the future. In their research with people with mild learning disabilities, Midjo and Aune (2018; p.42) highlight that:

"Future dreams and hopes are important dimensions of emerging adulthood. The analyses show that the young adults taking part in this study have dreams for the future and hopes that take place in different contexts and activities in their daily life."

However, hopes and dreams can also bring up fears regarding whether one will be able to undergo the journey of making one's desired dream and transition happen in actuality. Brandao et al. (2022; p.837) found that:

"The adolescents expressed their fears for their future. "We always have very high expectations for the future, but we do not know how to deal with them" (ID7). They showed their concerns regarding the social expectation of autonomy and responsibilities for their actions in the future. "In adult life, you'll have to think a hundred times before taking a step" (ID7). They also reported their fears regarding the possible achievement of their goals. "Because when we seek autonomy, we have to think about the future, and we are always thinking, what am I going to do when I need to live on my own or when I need to look for a job?" (ID1)."

The use of language and medical labels can create or reinforce fears and barriers regarding the hopes and dreams of making a transition. Being assigned a label and category can in itself lead to misguided perceptions and hinder people:

"For young people with disabilities, one of the most powerful challenges on the path to adulthood is related to the social consequences of being ascribed the categorical identity of intellectual disability. This category refers to a deficit model that implies a stigmatizing identity that tends to overrule any other identities and is thus difficult to escape (Barron, 2002; Harris, 1995; Scior, 2003). There are, however, some signs of breaking in this dominant perspective of who people with mild intellectual disabilities are and what they can do." (Midjo and Aune, 2018; p.34)

Having a medical label can assist families in accessing funding and support, but it can also have negative implications and effects if or when the person wants to make a change in one's life. Codd and Hewitt (2021; p.49) found that:

"Results highlight the importance of viewing people with intellectual disabilities as individuals with strengths and needs beyond diagnoses, and reflecting the discourses around adulthood for young people with intellectual disabilities highlighted by Murphy et al. (2011). Professionals could sensitively support parents with their perceptions of their son/daughter, highlighting the young person's potential and aspirations alongside any difficulties and needs. This links with positive risk-taking and requires support for parents regarding their understandable worry which may unintentionally restrict young adults from gaining independence skills."

Thus, support from professionals can play a role in supporting risk-taking and stopping people missing out on potentially beneficial transitions. However, we need also to acknowledge the point made earlier in the paper: namely that professionals and institutions can also perpetuate risk-averse cultures that block people from accessing new opportunities.

It is also worth noting that ‘non-transitions’ are set against normative expectations of life changes and transitions, which change over time. For example, it is not only disabled young people who may struggle to transition out of the family home but also those who are non-disabled, owing to a lack of affordable housing, low pay etc. (Croucher et al., 2018). Life transitions can therefore be created and influenced by societal attitudes and expectations, by socio-economic factors, as well as by historical and political factors.

SUMMARY OF THE FINDINGS

This section has outlined and discussed how the interaction(s) between micro-level and meso-level elements create and shape transitions in one’s life. It has looked at how transitions can affect and influence micro and meso-level elements – which are also interconnected with the macro-level elements. For example, funding, professional attitudes, and institutional rules can be a barrier to transition, particularly without strong advocacy. Identity roles can influence one’s belief in oneself and the ability to initiate and fulfil transitions in one’s life. Health circumstances, readiness to transition, ability to adjust, hopes and fears about the future, and ability to get into employment can all interact to create the intention to make a change in one’s life. Non-transitions are also relevant here, recognising the ways in which people get stuck and cannot make the changes that matter to them.

RECOMMENDATIONS FROM THE LITERATURE

The authors of the eighteen articles had many recommendations of which better decision-making processes and the need for a holistic model were recurring themes. In terms of the macro level element, Jacobs et al. (2021; p.338) drew from the UN Convention on the Rights of Persons with Disabilities (CRPD) and state that:

“The CRPD (United Nations, 2006) calls for an active involvement of all persons with disabilities in decisions that affect them, seeing participation not solely in relation to people’s involvement in their microsystems, but stressing participation across ecological levels including participation within policy-making and service provision (Löve et al., 2017; Mittler, 2015). Our findings add to the evidence that people with intellectual disability and their families are largely excluded from decision-making processes on wider levels (Löve et al., 2017).”

They set their recommendation within a context of human rights legislation and highlight that disabled people and their families ought to be involved on all levels of decision-making that affect their lives and the transitions they participate in.

Jacobs et al. (2021; p.339) highlight the importance of continuity between the meso and micro levels when

undergoing a transition, e.g., between social services, the individual and/or their family and support circle:

“Loss of knowledge about the person and their way of expressing themselves is a concern during transitions. As Small et al. (2013) point out, people with intellectual disabilities are particularly vulnerable during transitions, when relationships discontinue, because of the “deep but narrow range of support they experience” (p. 286). At times of transition, it seems paramount that people are able to maintain relationships to build bridges between settings and places, to ensure that people are known and so that they can be listened to.”

The sharing of knowledge about an individual and communicating in ways that are inclusive, is likely to create a better transition process.

Furthermore, a holistic and person-centred approach ought to be incorporated into transition processes. In looking at young people with a neurodevelopmental condition, Shanahan et al. (2021; p.1435) found that:

“The abrupt change from children’s to adult healthcare was difficult for the young people to understand, leading to stress and confusion for them and their families. This was a recurrent theme with one interviewee who suggested transition needed to be more individualistic, holistic and less abrupt.”

In terms of families being included in the decision-making processes that affect them, Schwartz et al. (2020; p.161) interviewed nine caregivers of people on the autism spectrum in Florida, USA, and they recommend that, *“Using policies that reward timely transition care planning, provider education and attainment of national health maintenance goals would proactively address barriers to care in this underserved population.”*

Many of these recommendations echo those of earlier studies, as findings about what helps transition processes tend to keep identifying the same patterns. Clear and timely information, early planning, supportive professionals, and strong trusting relationships are all key to good experiences of transition. What is less clear from the studies included in this review is how to overcome the blockages to these factors, which are a recurrent feature in the findings, whether from Canada, the US, England, or Northern Ireland. There are macro political choices to be made here – about funding, training, and skills – but also meso and micro choices and how we support people to envision and access different futures.

CONCLUSIONS

The aim of this literature review was to discuss and analyse the ways in which transitions in social care are conceptualised and researched. It is a thematic analysis of eighteen articles derived from a scoping review focused on transitions in social care. Like all reviews of this kind, it was limited by the parameters of the search strategy and we are aware that there are other studies of care-related transitions that are not included here. Furthermore, the literature is all in the English language and the studies were carried out in 'western' countries, therefore, this has also influenced the concepts of 'transition(s)' and 'care' that are covered in this paper.

The paper provides a discussion of how transition and transitions are conceptualised and theorised. We note that there is no agreed definition or concept of transitions in the field. Diversity in researchers' standpoints and methods have also been noted. A lens of interconnectedness has been applied to the macro, meso and micro-level aspects of transitions, and we have explored the key findings from the literature. Macro elements included policy, law, and funding as well as whole society contexts such as the Covid-19 pandemic. Meso features include the design of local social services, eligibility, and the ease of moving from one locality to another. Micro features included the dynamics within families, and the ways in which people's intersectional identities shaped transition readiness.

This review is the start of a research process around the theme 'the transitions that matter'. This involves talking with disabled people and other people using care services to identify the transitions that are important in their lives. This might be the big service changes that are the focus of much of the transitions literature (e.g. the move from children's to adults services; the move from home into residential care). Alternatively, it may be about identity (Robert Punton has [written](#) about feeling invisible as he transitions into old age with a disability) or embodiment (Katy Evans has [written](#) about the intimacy of transitioning to a new personal assistant). It will be about understanding the unfolding of time through for example the battles for independent living (Anne Pridmore has [written](#) about reversals to the policy advances around independent living) or living through unique eras such as Covid-19 (Adrian Murray has [written](#) about the lockdown transition and ongoing isolation). As part of the broader theme of [Care Trajectories and Constraints](#), we are also working with colleagues to explore care across borders – an element of transition which is often forgotten. Through this work we seek an understanding of what needs to shift in the macro, meso and micro levels of the care ecosystem to enable people to make the transitions that matter.

REFERENCES

- Allemand, B., Dimitropoulos, G., Patten, S.B., Sitter, K.C., Brobbey, A., Mackie, A.S. and Samuel, S. (2022). Association between transition readiness and mental health comorbidity in youth with chronic health conditions, *Journal of Pediatric Nursing*, 67: 161-67.
- Anderson, K. A., Sosnowy, C., Kuo, A. A. and Shattuck, P. T. (2018). Transition of individuals with autism to adulthood: A review of qualitative studies, *Pediatrics*, 141(4): 318–27. <https://doi.org/10.1542/peds.2016-4300>
- Antonucci, T.C. (2001). [Social relations: an examination of social networks, social support, and sense of control](#). In Birren, J.E. and Schaie, K.W. (Eds.). *Handbook of the Psychology of Aging*, pp.427 – 453. San Diego, California, U.S.A; Academic Press.
- Antonucci, T.C., Ajrouch, K.J. and Birditt, K.S. (2013). The Convoy Model: Explaining Social Relations From a Multidisciplinary Perspective, *The Gerontologist*, 54(1): 82–92.
- Arksey, H. and Baxter, K. (2012). Exploring the temporal aspects of direct payments, *British Journal of Social Work*, 42(1): 147–64.
- Arksey, H. and O'Malley, L., (2005). Scoping studies: towards a methodological framework, *International Journal of Social Research Methodology*, 8(1): 19-32.
- Barron, K. (2002). Who am I? Women with learning difficulties (re)constructing their self-identity, *Scandinavian Journal of Disability Research*, 4(1): 58–79.
- Betz, C.L., Coyne, I. and Hudson, S.M. (2021a). Health care transition: the struggle to define itself, *Comprehensive Child and Adolescent Nursing*, 2021 June 28, 1–15.
- Brandao, M.B., Bueno, K.M.P., Silvério, A.P.M., Antunes, F.I.T., Feitosa, A.M., Figueiredo, P.R.P. and Mancini, M.C. (2022). "Listen to us!" A qualitative study of adolescents with disabilities to help plan a transition service, *Child: Care, Health and Development*, 48(5): 833-41.
- Bronfenbrenner, U. (1994). [Ecological models of human development](#). In *International Encyclopedia of Education*. Vol 3. Second Ed. Oxford, UK: Elsevier.
- Brown, M., Higgins, A. and MacArthur, J. (2020). Transition from child to adult health services: a qualitative study of the views and experiences of families of young adults with intellectual disabilities, *Journal of Clinical Nursing*, 29: 195-207.
- Brown, M., MacArthur, J., Higgins, A. and Chouliara, Z. (2019). Transitions from child to adult health care for young people with intellectual disabilities: A systematic review. *Journal of Advanced Nursing*, 75(11): 2418–34. <https://doi.org/10.1111/jan.13985>
- Brown, M., MacArthur, J., Truesdale, M. and Higgins, A. (2022). The transition from child to adult health services for young adults with intellectual disabilities: An evaluation of a pilot of an online learning resource for Registered Nurses, *Nurse Education in Practice*, 64: 1-6.
- Brownie, S., Horstmanshof, L. and Garbutt, R. (2014). Factors that impact residents' transition and psychological adjustment to long-term aged care: A systematic literature review, *International Journal of Nursing Studies*, 51: 1654–66. <https://doi.org/10.1016/j.ijnurstu.2014.04.011>
- Bridges, W. (1991). *Managing Transition: Making the Most of Change*. Massachusetts, U.S.A.: Addison-Wesley.
- Burn, E. and Needham, C. (2023) [What does the concept of an ecosystem offer to social care? A narrative review of the ecosystem literature](#). Centre for Care Working Paper 2, CIRCLE, Sheffield: University of Sheffield

REFERENCES

- Cameron, L. and Murphy, J. (2002). Enabling young people with a learning disability to make choices at a time of transition, *British Journal of Learning Disabilities*, 30(3): 105–12.
- Cheng, S.T., Li, K.K., Losada, A., Zhang, F., Au, A., Thompson, L. W. and Gallagher-Thompson, D. (2020). The effectiveness of nonpharmacological interventions for informal dementia caregivers: An updated systematic review and meta-analysis, *Psychology and Aging*, 35(1): 55–77. <https://doi.org/10.1037/pag0000401>
- [Children \(Leaving Care\) Act \(Northern Ireland\) 2002.](#)
- [Children \(Northern Ireland\) Order 1995.](#)
- Codd, J. and Hewitt, O., (2021). Having a son or daughter with an intellectual disability transition to adulthood: A parental perspective, *British Journal of Learning Disabilities*, 49(1): 39–51.
- Coleman, E. A. (2003). Falling through the cracks: Challenges and opportunities for improving transitional care for persons with continuous complex care needs, *Journal of the American Geriatrics Society*, 51(4): 549–55. <https://doi.org/10.1046/j.1532-5415.2003.51185.x>
- Croucher, K., Quilgars, D. and Dyke, A. (2018). [Housing and life experiences: making a home on a low income.](#) A Joseph Rowntree Foundation report
- Davison, T.E., Camões-Costa, V. and Clark, A. (2019). Adjusting to life in a residential aged care facility: Perspectives of people with dementia, family members and facility care staff, *Journal of Clinical Nursing*, 28: 3901–13.
- Dilnot, A. (2011). [Fairer care funding: The report of the Commission on Funding of Care and Support.](#) London, UK: Commission on Funding of Care and Support.
- Doren, B., Yan, M-C. and Tu, W-M. (2013). Key program features to enhance the school-to-career transition for youth with disabilities, *Prevention Researcher*, 20(2): 11–13.
- Duncan, A., Luong, D., Perrier, L., Bayley, M.T., Andrew, G., Arbour-Nicotopoulos, K., Chan, B., Curran, C.J., Dimitropoulos, G., Hartman, L. and Huang, L. (2021). Prioritizing a research agenda of transitional care interventions for childhood-onset disabilities, *Frontiers in Pediatrics*, 9: 1–6.
- Egan, M., Bérubé, D., Racine, G., Leonard, C., & Rochon, E. (2010). Methods of enhancing verbal communication between individuals with Alzheimer's disease and their formal and informal caregivers: A systematic review, *International Journal of Alzheimer's Disease*, 2010, 1–12. <https://doi.org/10.4061/2010/906818>
- Eggenberger, E., Heimerl, K. and Bennett, M. I. (2013). Communication skills training in dementia care: A systematic review of effectiveness, training content, and didactic methods in different care settings. *International Psychogeriatrics*, 25(3): 345–58. <https://doi.org/10.1017/S1041610212001664>
- Elder, G. (1998). The Life Course as Developmental Theory, *Child Development*, 69(1): 1–12.
- Facchinetti, G., Albanesi, B., Piredda, M., Marchetti, A., Ausili, D., Ianni, A., Di Mauro, S. and De Marinis, M.G. (2021). "The light at the end of the tunnel". Discharge experience of older patients with chronic diseases: A multi-centre qualitative study, *Journal of Advanced Nursing*, 77(5): 2417–28.
- Facchinetti, G., Ianni, A., Piredda, M., Marchetti, A., D'Angelo, D., Dhurata, I. and De Marinis, M. G. (2019). Discharge of older patients with chronic diseases: What nurses do and what they record. An observational study, *Journal of Clinical Nursing*, 28(9–10): 1719–27.
- Flannery, R.B. (2002). Addressing psychological trauma in dementia sufferers, *American Journal of Alzheimer's Disease and Other Dementias*, 17(5): 281–85.
- Glaser, B.G. and Strauss, A.L. (1967/2017). *Discovery of Grounded Theory: Strategies for Qualitative Research*. New York; Routledge.
- Goodman, J., Schlossberg, N. K. and Anderson, M. L. (2006). *Counseling adults in transition: Linking practice with theory (3rd edition)*. New York: Springer Publishing Company.
- Gustavsson, A. and Nyberg, C. (2015). 'I am different, but I'm like everyone else': the dynamics of disability identity. In: Traustadóttir, R., Ytterhus, B., Egilson, S. and Berg, B. (Eds.). *Childhood and Disability in the Nordic Countries. Being, Becoming, Belonging*. London: Palgrave MacMillan, 69–84.
- Hanisch, C. (1969). [The Personal is Political](#)
- Harris, P. (1995). Who am I? Concepts of disability and their implications for people with learning difficulties, *Disability & Society*, 10(3): 341–52.
- Haslam, N. (2006). Dehumanization: An integrative review, *Personality and Social Psychology Review*, 10(3): 252–64. https://doi.org/10.1207/s15327957pspr1003_4
- Henskens, M., Nauta, I. M., Drost, K. T., Milders, M. V. and Scherder, E. J. A. (2019). Predictors of care dependency in nursing home residents with moderate to severe dementia: A cross-sectional study, *International Journal of Nursing Studies*, 92: 47–54. <https://doi.org/10.1016/j.ijnurstu.2018.12.005>
- Højberg, A.L. and Steffensen, B.F. (2008). Developing and maintaining of user-defined personal competencies among young adults with congenital physical disability. *Developmental Neurorehabilitation*, 11(3): 225–35.
- Huang, S., Yeoh, B.S.A., Liew, J.A. and Ho, E.L.E. (2022). Who Cares? Older Singaporeans Negotiating Care Expectations and Aging Future, *American Behavioral Scientist*, 66(14): 1828 – 45.
- Huis in het Veld, J., Verkaik, R., van Meijel, B., Verkade, P., Werkman, W., Hertogh, C. and Francke, A. (2016). Self-management by family caregivers to manage change in the behavior and mood of their relative with dementia: An online focus group study. *BMC Geriatrics*, 16(95): 1–8. <https://doi.org/10.1186/s12877-016-0268-4>
- Jacobs, P., Quayle, E., Wilkinson, H. and MacMahon, K. (2021). Relationships matter!—Utilising ethics of care to understand transitions in the lives of adults with severe intellectual disabilities, *British Journal of Learning Disabilities*, 49(3): 329–40.
- Kay, A. and Connolly, P. (2013). [Facing blindness alone. What government needs to do now to stop the isolation of blind people.](#) London, UK: RNIB.
- Kelly, B., Webb, P., Davidson, G., Pinkerton, J. and McShane, T. (2022). Raising the profile of care leavers with mental health and/or intellectual disabilities: A contribution from Northern Ireland, *Children and Youth Services Review*, 136: 1–8.
- Kelly, C. (2011). Making 'care' accessible: Personal assistance for disabled people and the politics of language. *Critical Social Policy*, 31(4): 562–82.

REFERENCES

- Kemp, C.L., Ball, M.M. and Perkins, M.M. (2013). Convoys of care: theorizing intersections of formal and informal care, *Journal of Aging Studies*, 27(1): 15-29.
- Kingsnorth, S., King, G., McPherson, A. and Jones-Galley, K. (2015). A retrospective study of past graduates of a residential life skills program for youth with physical disabilities, *Child: Care, Health and Development*, 41(3): 374-83
- Kingsnorth, S., Rudzik, A.E.F., King, G. and McPherson, A.C. (2019). Residential immersive life skills programs for youth with disabilities: a case study of youth developmental trajectories of personal growth and caregiver perspectives, *BMC Pediatrics*, 19(413): 1-12.
- Kittay, E. F. (2001). When caring is just and justice is caring: Justice and mental retardation, *Public Culture*, 13: 557-79.
- Lee, G. E. (2010). Predictors of adjustment to nursing home life of elderly residents: A cross-sectional survey, *International Journal of Nursing Studies*, 47: 957-64.
- Lee, J.A.S. (2014). An institutional framework for the study of the transition to adulthood, *Youth & Society*, 46(5): 706-30.
- Levac, D., Colquhoun, H. and O'Brien, K.K. (2010). Scoping studies: advancing the methodology, *Implementation Science*, 5: 1-9.
- Lindsay, S., Cagliostro, E., Albarico, M., Mortaji, N. and Srikanthan, D. (2019). Gender matters in the transition to employment for young adults with physical disabilities, *Disability and Rehabilitation*, 41(3): 319-32.
- Löve, L., Traustadóttir, R., Quinn, G. and Rice, J. (2017). The inclusion of the lived experience of disability in policymaking, *Laws*, 6, 33.
- Magill-Evans, J., Galambos, N., Darrah, J. and Nickerson, C. (2008). Predictors of employment for young adults with developmental motor disabilities, *Work*, 31(4): 433-42.
- Markus, H. R. and Kitayama, S. (1991). Culture and the self: Implications for cognition, emotion, and motivation. *Psychological Review*, 98(2): 224-53. <https://doi.org/10.1037/0033-295X.98.2.224>
- Markus, H.R. and Kitayama, S. (2003). [Culture, Self, and the Reality of the Social](#), *Psychological Inquiry*, 2003, 14(3/4): 277-83.
- Marsland, D., White, C. and Manthorpe, J., (2019). The continuity of social care when moving across regional boundaries, *Journal of Social Work*, 19(5): 557-77.
- McPherson, A. C., Rudzik, A., Kingsnorth, S., King, G., Gorter, J. W. and Morrison, A. (2018). "Ready to take on the world": Experiences and understandings of independence after attending residential immersive life skills programs for youth with physical disabilities, *Developmental Neurorehabilitation*, 21(2): 73-82.
- McVittie, C., Goodall, K.E. and McKinlay, A. (2008). Resisting having learning disabilities by managing relative abilities, *British Journal of Learning Disabilities*, 36(4): 256-62.
- Midjo, T. and Aune, K.E., (2018). Identity constructions and transition to adulthood for young people with mild intellectual disabilities, *Journal of Intellectual Disabilities*, 22(1): 33-48.
- Miron, A.M., Groves, C.L., Thompson, A.E., McFadden, S.H., Bowers, H.R. and DeBraul, J.M. (2022). Fear of incompetence in family caregivers and dementia care transitions, *The International Journal of Aging and Human Development*, DOI: 10.1177/00914150221106075, 1-24.
- Miron, A. M., McFadden, S. H., Hermus, N., Buelow, J., Nazario, A. and Seelman, K. (2017). Contact and perspective taking improve humanness standards and perceptions of humanness of older adults and people with dementia: A cross-sectional survey study, *International Psychogeriatrics*, 29(10): 1701-11. <https://doi.org/10.1017/S1041610217000989>
- Mittler, P. (2015). The UN convention on the rights of persons with disabilities: Implementing a paradigm shift, *Journal of Policy and Practice in Intellectual Disabilities*, 12: 79-89.
- Murphy, E., Clegg, J. and Almack, K. (2011). Constructing adulthood in discussions about the future of young people with moderate-profound intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 24, 61-73. <https://doi.org/10.1111/j.1468-3148.2010.00565.x>
- National Institute for Health and Care Excellence [NICE] (2015). [Transition from children's to adults' services for young people using health or social care services](#).
- National Union of Students. (n.d.). [Life not numbers. A report into the experiences of disabled students in higher education using personal care packages](#). London: National Union of Students.
- Park, S-K., Yoon J-Y. and Henderson, T. (2014). Factors affecting employment among people with mobility disabilities in South Korea, *International Journal of Rehabilitation Research*, 30(1): 19-25.
- Peeters, M.A.C., Hilberink S.R. and van Staa, A. (2014). The road to independence: lived experiences of youth with chronic conditions and their parents compared, *Journal of Pediatric Rehabilitation Medicine*, 7(1): 33-42.
- Peters, M.D., Marnie, C., Tricco, A.C., Pollock, D., Munn, Z., Alexander, L., McInerney, P., Godfrey, C.M. and Khalil, H. (2020). Updated methodological guidance for the conduct of scoping reviews, *JBI Evidence Synthesis*, 18(10): 2119-26.
- Porter, F. (2006). *The Ethics of Care and Care of Adults. Working Paper 13*. Queen's University Belfast.
- Price, A., Janssens, A., Woodley, A. L., Allwood, M. and Ford, T. (2019). Review: Experiences of healthcare transitions for young people with attention deficit hyperactivity disorder: A systematic review of qualitative research, *Child and Adolescent Mental Health*, 24(2): 113-22.
- Purkey, E., Bayoumi, I., Davison, C.M. and Watson, A. (2022). Directed content analysis: A life course approach to understanding the impacts of the COVID-19 pandemic with implications for public health and social service policy, *PloS ONE*, 17(12): 1-20.
- Raymaker, D.M., Teo, A.R., Steckler, N.A., Lentz, B., Scharer, M., Delos Santos, A., Kapp, S.K., Hunter, M., Joyce, A. and Nicolaidas, C. (2020). "Having All of Your Internal Resources Exhausted Beyond Measure and Being Left with No Clean-Up Crew": Defining Autistic Burnout, *Autism in Adulthood*, 2(2): 132-43.
- Salt, E., Melville, C. and Jahoda, A. (2019). Transitioning to adulthood with a mild intellectual disability—Young people's experiences, expectations and aspirations, *Journal of Applied Research in Intellectual Disabilities*, 32(4): 901-12.
- Sayce, L. (2011). [Getting in, staying in and getting on. Disability employment support fit for the future](#). Norwich, UK: The Stationery Office.
- Schalock RL (2004) The concept of quality of life: what we know and do not know, *Journal of Intellectual Disability Research* 48(3): 203-16.
- Schwartz, J.K., Agrawal, M., Treminio, I., Espinosa, S., Rodriguez, M. and Richard, L. (2020). Caregivers' perspectives on health-care transition in autism, *Advances in Autism*, 6(2): 153-64.

REFERENCES

- Scior, K. (2003). Using discourse analysis to study the experiences of women with learning disabilities, *Disability & Society*, 18(6): 779–95.
- Shanahan, P., Ollis, L., Balla, K., Patel, R. and Long, K. (2021). Experiences of transition from children's to adult's healthcare services for young people with a neurodevelopmental condition, *Health and Social Care in the Community*, 29(5): 1429–38.
- Sibalija, J., Savundranayagam, M. Y., Orange, J. B. and Klooseck, M. (2020). Social support, social participation and depression among caregivers & non-caregivers in Canada: A population health perspective, *Aging and Mental Health*, 24(5): 765–73.
- 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: 283–300.
- Tanner, D., Glasby, J., and McIver, S. (2015). Understanding and improving older people's experiences of service transitions: Implications for social work, *British Journal of Social Work*, 45(7): 2056–71.
- Thompson, A. E., Miron, A. M., Rice, R. and Rogers, J. M. (2020). The development and psychometric validation of a comprehensive measure assessing fear of incompetence among adults who have a family member with dementia, *International Journal of Alzheimer's Disease*, 1910252. <https://doi.org/10.1155/2020/1910252>
- Tronto, J. C. (1993). *Moral boundaries: A political argument for an ethic of care*. London: Psychology Press.
- UN [United Nations] General Assembly (2006). *Convention on the Rights of Persons with Disabilities*. Report nr A/RES/61/106.
- United Nations. (n.d.). [Convention on the rights of persons with disabilities and optional protocol](#).
- Wagner M.M., Newman L.A., and Javitz, H.S. (2014). The influence of family socioeconomic status on the post-high school outcomes of youth with disabilities, *Career Development and Transition for Exceptional Individuals*, 37: 5–17.
- Wakui, T., Saito, T., Agree, E. M. and Ichiro, K. (2012). Effects of home, outside leisure, social, and peer activity on psychological health among Japanese family caregivers, *Aging & Mental Health*, 16(4): 500–6. <https://doi.org/10.1080/13607863.2011.644263>
- Walter, E. and Pinguart, M. (2020). How effective are dementia caregiver interventions? An updated comprehensive meta-analysis, *The Gerontologist*, 60(8): 609–19. <https://doi.org/10.1093/geront/gnz118>
- Wicklund, R. A. (2005). The solidarity of distance, *Zeitschrift für Sozialpsychologie*, 36(3): 103–15. <https://doi.org/10.1024/0044-3514.36.3.103>
- Young, E., Milligan, K., Henze, M., Johnson, S. and Weyman, K. (2021) [Online]. [Caregiver burnout, gaps in care, and COVID-19 Effects on families of youth with autism and intellectual disability](#), *Canadian Family Physician*, 67 (July 2021): 506–8.

KEY FINDINGS

- There is no set agreed definition for what a 'transition' is. Different researchers draw from different definitions and philosophical standpoints, e.g. from international law and human rights, to define a 'transition', to set their research questions, and to carry out research.
- Clear and timely information, early planning, supportive professionals and strong trusting relationships are all key to good experiences of transition.
- Barriers to transition include professional attitudes and institutional rules. Identity roles, health circumstances and ability to get into employment can all interact to support or block the intention to make a change. Non-transitions are also relevant - people often cannot make the changes that matter to them.
- What is less clear from the studies included in this review is how to overcome the barriers which are a recurrent feature in the findings. There are macro political choices to be made here – about funding, training and skills – but also meso and micro choices about how we support people to envision and access different futures.
- This review is the start of a research process around the theme 'the transitions that matter'. This involves talking with disabled people and other people using care services to understand the transitions that are important in their lives.

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