

Chapter 2

Career Development of Students with Intellectual Disability: A Systems Theory Perspective



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Abstract The focus of this chapter is on the application of systems thinking to the career development, transitions and inclusion of young people with intellectual disability. In essence, intellectual disability refers to difficulty learning and understanding. The special educational needs of young people with intellectual disability result in their transitions from school being more challenging than those of most other students, and their futures, in terms of paid employment and independent living, being less certain. More than people with any other disability, people with intellectual disability have lower participation in the labour market. This chapter provides an overview of intellectual disability and considers the importance of work and purposeful activity in people's lives. Drawing on the Systems Theory Framework of career development, the chapter uses systems mapping and systems thinking to consider the career development and transition from school of a fictional case study of a young Australian woman with intellectual disability.

Keywords Intellectual disability · Career development · School transition · Systems thinking · Systems theory

Introduction

Individuals with special educational needs comprise a diverse group. While it is important to avoid assumptions about the life of any individual, the group with the most negative life outcomes tends to be those with intellectual disability. They are less likely to be in paid employment, to have completed an educational qualification or to be in post-school education. They are also more likely to be socially excluded than those with other types of disability and those who do not have a disability (Gray et al. 2014). In the Australian census of 2012, 39% of persons with intellectual disability

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were in the workforce compared with 55% of those with a disability of another type and 83% of the general population without a disability (Australian Bureau of Statistics [ABS] 2014a). Of those who were employed, the vast majority were in part-time roles. Completion of Year 12 (the final year of secondary schooling in Australia) showed a similar pattern of disadvantage with 25%, 28% and 59%, respectively, of those over 18 having this qualification (ABS 2014a).

Intellectual Disability

A number of definitions of intellectual disability are used in research and to determine eligibility for government services. These are quite similar but are not identical in all particulars. Generally, the definitions include an IQ score that is two or more standard deviations below the mean, difficulties in adaptive behaviour, and a requirement that these are apparent in the developmental period (e.g., Schalock et al. 2010). The definition used by the ABS (2014b) is simply “difficulty learning or understanding things”, and this reflects the common understanding of the nature of this impairment. Intellectual disability occurs in approximately three per cent of the population (ABS 2014a).

The notion of adaptive behaviour is very germane to the issue of transition from school to adult life, as it refers to the skills and understandings required for living successfully within one’s community. Adaptive behaviour is therefore determined by cultural expectations associated with age, gender and other socially constructed roles related to status. Adaptive behaviour is characterized by three broad areas: conceptual skills (e.g., language, literacy, numeracy), social skills (e.g., interpersonal skills, following social conventions) and the practical skills required for the successful negotiation of daily life (e.g., occupational skills, use of devices such as mobile telephones). Successful transition from school to adult lives is predicated on young people having sufficient skills in these three broad areas.

Adult lives comprise a variety of aspects—and when 12 young adults with Down syndrome were asked about what they regarded as a “good life” they identified a number of elements they desired in their lives (Scott et al. 2014). Employment was a desirable outcome, together with engagement in leisure activities. They also identified positive relationships with family, friends, partners and work colleagues as important aspects of a good life. Autonomy in decision-making and independent living away from parents was central to the life these young adults wished to lead. Similarly, in a small qualitative study in Spain, Palliser et al. (2016) found that the young people with intellectual disability whom they interviewed identified a job, a home, a partner and children as things they hoped for in the future, although their plans about how to obtain these were generally vague or absent. These ambitions were also identified in a large study in the USA in which Bouck and Joshi (2016) used data from the National Longitudinal Transition Study (phase 2) to investigate the goals held by the young people with intellectual disability. As is evident from

these studies, the aspirations of young people with intellectual disability are similar to those of young people without a disability.

Supporting the Transition from School to Adult Life

Schools are well placed to assist young people to transition to a successful and satisfactory adult life. In particular, school-based career development practitioners have responsibility for assisting students to progress through school and transition from school to further learning or work. Career development is widely understood to be a complex process through which people manage their life, learning and work across the lifespan (Ministerial Council for Education, Early Childhood Development and Youth Affairs [MCEECDYA] 2010). Evident from this view of career development is that contemporary understandings of the term “career” are broader than simply pathways through work or to an occupational title. Career refers to the work roles (paid and unpaid) undertaken by people throughout their lifetime and includes life roles, leisure activities, learning and work (MCEECDYA 2010). Career development practitioners may offer career development programs and interventions that assist their students to develop the skills, knowledge and attitudes needed to manage their learning and work independently in the context of their life (Canadian Career Development Foundation 2002). Career management skills can be learnt. Career development practitioners and support people such as teachers and parents can assist young people to develop career management skills.

Career development occurs in complex, interconnected familial, social, community and sociopolitical contexts and is, consequently, subject to a myriad of influences. Disability is one such influence and operates at both the individual level and at the level of each of the components of the system in which the individual operates. The attitudes held by potential employers and co-workers, the opportunities and support towards inclusion within the community, including the workplace, all contribute to the career development of young adults with intellectual disability. Contemporary career theories acknowledge the importance of considering career development in context; taking an “individual in context view” of career development is widely accepted in the field to avoid oversimplifying career decision-making and career development (McMahon et al. 2014, p. 30). Career theories, however, have devoted little attention to disability despite its profound influence on a person’s career development (Athanasou 2015).

Conceptualizing Career Development and Transition Through Systems Thinking

Systems thinking offers a way of considering individuals in the dynamic complex contexts in which their career development occurs. Systems thinking is founded in systems theory which was first developed in the early 1900s to facilitate a better understanding of complexity in biology (von Bertalanffy 1968). Systems theory has influenced a range of disciplines such as ecology, philosophy, psychology and engineering and is evident in terms such as education systems, computer systems and transport systems.

A number of career theories incorporate systems thinking in their conceptualizations (e.g., chaos theory of careers [Pryor and Bright 2011]) and some are derived specifically from systems theory (e.g., Vondracek et al.'s [2014] Living Systems Theory of Vocational Behavior and Development [LSVD]; Patton and McMahon's [2014] Systems Theory Framework of career development [STF]). The Systems Theory Framework provides the theoretical perspective for this chapter because it visually depicts a range of influences on career development in a "systems map" that stimulates systems thinking as a way of conceptualizing career development and transition.

The focus of this chapter is on the contribution that systems thinking can make to the consideration of career development and transition from school for those with intellectual disability. Intellectual disability, more than other forms of disability, results in lower labour market participation rates in Australia (ABS 2014b). Transition from school may be more difficult for students with intellectual disability than their peers. The applications of systems theory, in particular, the Systems Theory Framework of career development, systems mapping and systems thinking may facilitate a comprehensive understanding of the complexity of transition from school of young people with an intellectual disability, thus allowing the identification of potential intervention points. Following a brief description of the Systems Theory Framework, systems mapping and systems thinking, the fictional case study of Annie, a young woman with an intellectual disability, will be considered from a systems perspective.

Career Development and Work: Systems Thinking and Systems Mapping

The Systems Theory Framework (Patton and McMahon 2014) portrays visually, in a systems map, the many interconnected influences on career development. Systems maps are diagrams that holistically illustrate, and thus support examination of, the interrelationships between the various elements of the system surrounding a particular topic (Király et al. 2016). The focus topic of the Systems Theory Framework

(STF) is career development. Systems maps illustrate the “complex web of relationships” (Collin 2006, p. 300) between the elements of systems, and they support von Bertalanffy’s (1934) contention that “single parts and processes cannot provide a complete picture” (p. 64) of phenomena. Von Bertalanffy (1968) emphasized the interactive nature of the elements of systems and was particularly interested in systems which are open to influence from outside their boundaries. Systems thinking means thinking in wholes rather than parts and considering the dynamic interaction within and between elements of the system. The STF is applied through systems mapping and systems thinking.

Located centrally in the STF map is the *individual system* and a range of intrapersonal cognitive, psychological and biological traits that influence career development such as interests, ability, skills, values, ethnic background and world of work knowledge. Disability is depicted in the STF as an individual influence. Individuals live within a *social system* of influences such as family, peers, education systems and workplaces with which they interact and subsequently learn from their experiences in such interactions. Attitudes towards and expectations of individuals with intellectual disability are social influences. Individuals and their social systems exist within a broader *environmental-societal system* that comprises influences such as political decisions, globalization, geographic location and socioeconomic circumstances which, in some instances, may seem remote from the individual but nonetheless can profoundly influence career development. With respect to individuals with intellectual disability living in Australia, the National Disability Insurance Scheme (NDIS—described below) is such an influence. A *recursive interaction* occurs within and between influences over time. All influences in the system *change over time* as does the degree and nature of their influence on other elements of the system. The three interconnected systems of influence are located in the context of past, present and future time, indicating that the past influences the present and together the past and present influence the future. For all young people, including students with an intellectual disability, transitioning from school to an adult life that includes paid and unpaid work occurs in complex systems of influence.

Importance and Role of Work in Adult Life

Work, in all its forms, is central to career development and is a goal and outcome of successful transition from school. Work is an important part of adult life; “Work is essential to an individual’s economic security and is important to achieving social inclusion. Employment contributes to physical and mental health, personal well-being and a sense of identity” (Council of Australian Governments 2011). Moreover, work is an inherently systemic concept (McMahon 2017). Through work, people develop a sense of identity, autonomy, purpose and self-worth (Hulin 2002). Work ensures one’s livelihood through income and security and in doing so enables a lifestyle and improved access to material resources (Blustein 2008; Hulin 2002;

Martin and McKee 2015). Moreover, work leads to the development of social networks and relationships outside the family and opportunities for social exchange (Blustein 2008). Through participation in the world of work, individuals perceive themselves as “vital and constructive members of their own societies” (Ferrari et al. 2008, pp. 438–439); part of the social contract of citizenship is participation in work (Martin and McKee 2015).

Having a sense of the future, as well as having a sense of self-worth, belonging, control and purpose that are brought about by participation in work, is a protective factor against mental health problems (e.g., Goodman et al. 2017). Participation in work is critical to psychological well-being (Ferrari et al. 2008) and leads to improved self-esteem and hopefulness (Martin and McKee 2015). The following case study of Annie, a young woman with intellectual disability, will be considered using systems mapping based on the STF and systems thinking.

Case Study: Annie

Annie is a young woman with intellectual disability who lives at home with both parents and two sisters. Both parents work as professionals and have considerable social capital. Annie is completing her final year of schooling at a mainstream private school. Annie has good communication skills and likes routine. She can become uncommunicative when her routine is upset. When she leaves school, Annie aspires to work in an office, preferably her father’s office where she completed a work experience, the only experience of employment that Annie has had. During her work experience, a staff member was assigned to supervise Annie’s daily activities which included tasks such as photocopying. Once Annie is shown what to do, she is very reliable at completing tasks. Annie hopes that one day she can move into a new apartment of her own. In preparation for her impending transition from school, Annie’s parents have been taking steps to ensure that she has a smooth transition. Her parents do not want her to work in supported employment or to live in a group home with other people with a disability. They want her to live a life that is not defined by her disability. They want for her what they want for their other daughters, employment, independence, with strong links to family and friends. They do not want Annie to be caught up in disability networks. Annie attends a youth group in the local area which her parents found through a support network they had been developing for Annie that includes family and friends. Her parents are pleased that she is well known in the local area because they feel it enhances her safety when she is out and may improve her chances of being included in other activities. Her parents feel that Annie could live independently one day but that someone would have to check on her. They are concerned that she may be isolated if she lives on her own. Annie has an interest in art and her mother is trying to find a way to include art-related activities into her weekly program when she leaves school.

A Systems Perspective on the Case Study of Annie

Annie’s transition from school may be represented diagrammatically by a systems map that depicts the complex context of her transition (Fig. 2.1). Systems maps provide visual cues to systems thinking which encourages individuals to consider the interrelationships and interaction between influences by “looking inside the ‘space between’” them (Sexton 2012, p. 61). From a systems perspective, Annie’s transition from school is embedded in her intrapersonal, social and environmental-societal systems of influence and her future is integrally connected to her past and present experiences. The various influences on Annie’s transition from school and their recursive interaction are made explicit in her systems map, and these are elaborated in the subsequent analysis.

At the *intrapersonal level*, Annie has some ideas about what she wants to do, but she does not yet have all the necessary skills to enact her future herself. Annie has a limited understanding of the world of work despite having taken some vocational courses at school and completed a work experience. Although she has good

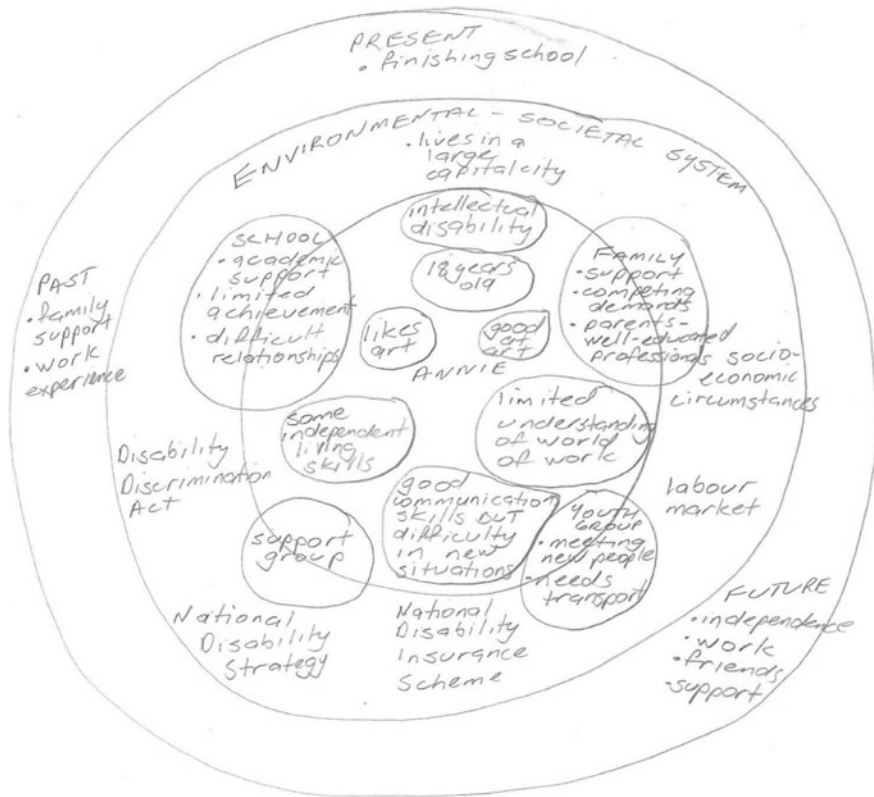


Fig. 2.1 Systems map of influences on Annie’s transition from school

communication skills, in some circumstances such as when she is meeting new people, she is not able to use them. Annie's interest in art is more of a leisure interest, despite having some artistic skills. The influence of Annie's intellectual disability has been and continues to be an important influence on her achievements, her future, and her relationships with others. Annie's completion of secondary school and her work experience is an advantage. For example, in a study conducted using data from the USA, Kaya (2018) found that educational experience was predictive of gaining competitive employment for those with intellectual disability after demographic variables including gender and race were controlled. In addition, those individuals who had work experience and then support within the workplace did better with respect to employment.

Annie is fortunate to have a supportive *social system* including a family with good personal and financial resources. One of the strongest influences on the life choices and opportunities of young adults who are typically developing is that of parents (Helwig 2008), and Annie's parents have had her transition from school in mind from when she was very young. Unlike their other daughters, however, Annie has required much more support and attention and at school-leaving age is still not yet at the same point as her sisters at the same age. The concerns that parents feel as their child with intellectual disability enters this stage of life can be the source of some stress. For example, in an Australian study, more than half the parents surveyed reported that their health and well-being were negatively affected by their concerns regarding their child's transition (Leonard et al. 2016). Parents reported being worried about their child's capacity to cope with learning new routines at the same time as being required to establish new social relationships. They also identified the loss of long-standing social connections as an additional element that may make the transition difficult for their child. Despite these reservations, the parents also saw the transition to adulthood as a normal and exciting development in their child's life.

Annie's school has provided an excellent inclusive learning environment for her where she received one-on-one support and where staff and other students included her. Despite this, she experienced hostile relationships with some students and staff and had difficulty in communicating in new and challenging situations. The school, and in particular, the school career practitioner, provided assistance for students about their transition from school in terms of future learning and work opportunities. Irish research, however, has suggested that school practitioners may be less informed about appropriate post-school options for students with a disability (Scanlon and Doyle 2018). In another Irish study, Doyle et al. (2017) found variable levels and quality in the school support and guidance provided to young people with special educational needs and breakdowns in communication between schools and parents. A study conducted in Australia found that many students were not included in developing their own transition plan (Leonard et al. 2016), suggesting that they are not seen to have agency with respect to these crucial life decisions, a view that is likely to have a range of negative sequelae.

School naturally filled a significant part of Annie's day, and her parents were concerned about how she would occupy her time after she had finished school. Annie's mother was investigating the possibility of incorporating an art-based activity into

Annie's weekly schedule. Annie's parents want to remain outside the disability support system; however, this may reduce Annie's opportunities for community inclusion in the longer term. For example, Kaya (2018) found that in the USA, 46.7% of people with intellectual disability achieved competitive employment after receiving vocational rehabilitation services, with those receiving more services being more likely to be successful than those receiving fewer services.

Self-determination, which may be defined as individuals having a right to control and direct their lives and a capacity to do so, is central to our conception of adulthood (Wehmeyer 2004). Self-determination does not imply that others' views are not sought or considered, but responsibility ultimately rests with the individual. Transition services may unintentionally undermine the self-determination of young people with intellectual disability through failing to include them in the decision-making processes (e.g., Leonard et al. 2016) or by failing to pay sufficient attention to the need to determine the young person's interests, capacities and wishes. In Leonard et al.'s (2016) Australian study, the majority of parents (80%) reported they had been involved in transition planning with the school with 87% saying they had been involved in decision-making; however, just under 60% of their children with intellectual disability had been involved in decision-making, and those who were included, had lower input than their parents. By contrast, data from the National Transition Study in the USA revealed that all students in a sample with a mild intellectual disability participated in their transition planning (Bouck and Joshi 2016). The level of intellectual disability was not reported in the Leonard et al. (2016) study and differences between studies may well reflect this variable or may be related to cultural/systemic differences.

At the *environmental-societal system level*, a number of factors which could seem somewhat remote from Annie's daily life may influence her transition from school and her ultimate inclusion in the workforce. For example, Annie lives in Australia where the Disability Discrimination Act aims to protect the equality of opportunity for people with disability and also protect them from discrimination (Australian Government 1992). Since 2013, there has been something of a revolution in the way that services are provided to those with a disability in Australia with the passing of the National Disability Insurance Scheme (NDIS) Act by the federal parliament. In essence, the Act moved funding for support for individuals with a disability away from service organizations and to the individuals, with the intention of providing them with control over the supports they receive. By 2020, it is expected that 460,000 persons with a disability will be receiving funding from the NDIS, with two-thirds of these having intellectual disability (Bigby 2014).

This change to the NDIS is revolutionary as it moves Australian service provision away from a welfare approach to a universal insurance scheme. This changes the focus of services from short-term to long-term investment in skill development (Australian Department of Human Services 2016) with employment and community inclusion being high priorities for the scheme. There is the clear recognition that investment in individuals that increases independence and supports their social and economic participation in their community will lead to better outcomes for the individuals and also is necessary for the scheme to be sustainable. It is expected that the focus on

individual choice and control and inclusion will drive increased opportunities for independence and community participation (Reddihough et al. 2016).

While policy mechanisms such as these are designed to improve the circumstances of people with a disability, the reality of employment for people with a disability (especially those with an intellectual disability) has historically been very negative, as detailed above. There has been no published research to enable us to ascertain the impact of the NDIS on employment rates to this point. With respect to Annie, because her family lives in a large capital city, many more employment and leisure options are available to her than there would be if they lived in a rural or remote location.

Annie's *future* is also to a large extent being determined by the family in which she has been raised, their socioeconomic circumstances and their attitude towards disability. While Annie aspires to get and hold a job and to live independently, she is not able to achieve these things at this point in her life without the needed support, which is likely to be ongoing. Moreover, it may take Annie longer than young people without a disability to achieve these milestones of adulthood. In a longitudinal study of individuals with intellectual disability and their families in Australia, Gray et al. (2014) reported that in adulthood the majority of those with mild or moderate impairment were living at home, whereas, those with more severe impairments were more likely to be living away from home. Only 11% were in paid employment at the time of data collection with another 22% working in sheltered employment. Daytime activities were rarely undertaken in inclusive settings.

The desire to be productive is a basic human need (see Pierce 2003) and is generally at least partially filled by paid employment. The importance of work for the individual and for the community is well recognized, and there has recently been an increase in efforts to assist individuals with a disability to make the transition from school and into paid employment. In Australia and many other countries, post-compulsory education is increasingly seen as an option for young adults with intellectual disability. In a large study in the USA, Bouck and Joshi (2016) found that approximately one-quarter of the respondents were interested in pursuing further education.

Inclusive post-secondary education is an area in which change and growth is occurring in a number of countries (see, e.g., Qian et al. 2018). Prohn et al. (2018) found there were benefits to those who participated in an inclusive college program. The possibility of continuing education should not be overlooked when transition plans are being made with individuals with intellectual disability, although it may not be part of the future thinking of some of these students (Bouck and Joshi 2016). There are several potential reasons for students with intellectual disability overlooking this pathway with the most obvious being that it is never presented to them as a possibility.

Conclusions

The transition from school to further learning and work for young people with intellectual disability may be more complex and challenging and take longer than that of

their peers without a disability. In addition, young people with intellectual disability may require considerably more support to make a successful transition. Through the use of systems thinking and systems mapping, the complexity of the transition can be realized, resources and barriers identified, priorities determined, and action plans developed and implemented.

Considering the construction of Annie's future from a systems theory perspective is reflective of Millington's (2012) claim that "The culture in which the person is embedded creates the meaning of disability, creates the identity of the individual, and in very real ways, directs what is possible in terms of adjustment and adaptation" (p. 82). For example, Annie lives in the cultural context of a country that has implemented enabling policies for people with disability. Moreover, she lives in the cultural context of a family system that is well-resourced and well-informed, and that while recognizing Annie's limitations will work with her to achieve her goals of employment, friends and independent living. What is possible for Annie may be different if, for example, she lived in a remote area of Australia with limited access to support and resources, if her parents were less well-informed, or if the degree of her disability was greater.

A systems perspective of career development and transition, particularly when it is aided by a systems map, provides insight into the complexity and challenge of transitioning from school for a young person with an intellectual disability. Systems maps also depict the uniqueness and person-specific nature of each transition. Systems maps may assist people to organize their thinking and subsequently identify future actions (Checkland and Poulter 2010). These maps may be constructed by support workers or by families or sometimes by a young person with intellectual disability and may be constructed individually or in collaboration with others, e.g. career development practitioners.

The chapter provided an overview of intellectual disability and considered from a systems perspective the fictional case study of the transition from school of a young woman with intellectual disability. Systems theory was first proposed in response to complexity. This chapter offers systems mapping and systems thinking as a way of understanding the complex transition from school of young people with intellectual disability.

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