

Pathways toward Positive Psychosocial Outcomes and Mental Health for Youth with Disabilities: A Knowledge Synthesis of Developmental Trajectories

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ABSTRACT

Most children with developmental conditions survive to adulthood. To improve adult outcomes there is a need to synthesize our existing knowledge regarding their developmental trajectories. The synthesis in this paper was guided by interactional, life course perspectives and definitions of development and disability. Evidence from 107 published articles, grey literature, and expert opinion demonstrated that there are currently more negative than positive psychosocial and mental health outcomes for youth with disabilities. Evidence is mounting that youth with disabilities experience similar trajectories to their peers without disabilities through positive, developmentally appropriate life experiences and regular opportunities with adequate supports to develop adult social roles.

Keywords: development, transition to adulthood, disability, outcomes, participation, adolescents, adults

RÉSUMÉ

La plupart des enfants atteints de troubles du développement survivront jusqu'à l'âge adulte. Pour améliorer leurs perspectives à l'âge adulte, il est nécessaire de synthétiser nos connaissances actuelles au sujet de leurs trajectoires de développement. Cette synthèse a été guidée par les perspectives interactionnelles et de parcours de vie, ainsi que par les définitions du développement et de l'incapacité. Des constats issus de 107 articles publiés, de la littérature grise et de l'opinion d'experts ont démontré que chez les jeunes ayant une incapacité, il y a actuellement davantage de retombées négatives que positives sur le plan psychosocial et sur le plan de leur santé mentale. Un nombre croissant d'écrits indiquent que les jeunes ayant une incapacité ont des trajectoires similaires à leurs pairs sans incapacité lorsqu'ils ont accès à des opportunités et à des expériences de vie positives adaptées à leur développement avec un soutien adéquat leur permettant de développer des rôles sociaux adultes.

Mots clés : développement, transition vers l'âge adulte, incapacité, retombées, participation, adolescents et adolescentes, adultes

Most children with developmental conditions survive to adulthood. With improved neonatal and paediatric care over the last several decades, life expectancy has changed dramatically for children with physical disabilities, such as cerebral palsy (CP) and spina bifida, and intellectual disabilities. Moreover, as a result of improved health care, many children with genetic syndromes, who historically may have suffered significant mortality as a result of medical complications, are also surviving into adulthood. Many such individuals will have associated intellectual disability. This means there is a whole new generation of adults with childhood-onset disabilities who have the same aspirations and rights to participate fully in society as youth without disabilities.

Although it is estimated that one in five children and youth has a disability (e.g., physical, language, developmental, intellectual, and/or mental health disorder), this growing population is still a minority in society. Children with physical disabilities, speech and language delays, or developmental disorders are at risk for lower community participation (Milner & Kelly, 2009) and social isolation (Shikako-Thomas, Majnemer, Law, & Lach, 2008). Young people with disabilities take part in fewer organized activities and are more likely to engage in passive, solitary activities such as watching television (Poulsen, Ziviani, Cuskelly, & Smith, 2007). They do not experience the widening social world of other teens (King et al., 2010), and their lack

of engagement in leisure roles can affect their self-esteem, self-concept, and sense of belonging (Stewart, Stavness, King, Antle, & Law, 2006). Population-based studies have indicated that children with conditions/ impairments, particularly those with activity limitations, are significantly more likely than children without health problems to have experienced mental health conditions (McDougall et al., 2004). Their health and well-being is affected by not only their health condition, but also by external or environmental conditions and the dynamic balance between opportunities and limitations. The health and development of these youth should be examined in close relation to their context and environment (home, school, community).

To promote positive development and to improve adult outcomes for youth with disabilities, there is a need to synthesize our existing knowledge regarding their developmental trajectories and what is known about personal and environmental factors affecting their outcomes, and to identify gaps in knowledge. A knowledge synthesis concerning developmental trajectories and influential person–environment factors and their interactions will inform future research and youth-related policy development, including policies regarding community mental health services. It will provide a better understanding of the diversity and complexity of the issues as well as the dynamic interactions between stigma, resilience, and other processes that affect the mental health and well-being of youth with disabilities.

This article provides a synthesis of available knowledge about the developmental trajectories of youth with childhood-onset disabilities with a focus on mental health and psychosocial outcomes. At the start of the project an inclusive developmental framework was envisioned, one that is applicable for all youth, including those with special needs. It is hoped that this framework and the supportive evidence obtained from the knowledge synthesis will guide youth policy development and facilitate mobilization and action among the many individuals and organizations who are striving for full social equality for individuals with disabilities.

Developmental Trajectories

Human development is characterized by change in functioning with developmental trajectories describing the course of this change across ages and over time. Current developmental frameworks and theories focus on understanding individuals within their personal, social, cultural, and generational contexts. People speak of a “transactional” developmental process in which a person is constantly changing over the life course through ongoing interactions with their physical and psychosocial environments (Lerner, 2002). Halfon and Hochstein (2002) have proposed a life-course health-development model that views health as a dynamic, multifaceted phenomenon that influences a person’s functioning. Their model builds on the model of human functioning developed by the World Health Organization (2001) as it emphasizes the relationship between the biopsychosocial elements of a person and their participation in everyday activities and experiences in their environment.

Youth with Disabilities

This article focuses on the developmental trajectories of youth with childhood-onset, chronic, lifelong conditions and impairments. The term *disability* or *disabilities* is a concept that is open to interpretation. In the past, disability was considered to be a problem residing within the person, but

recent definitions have adopted interactional perspectives of functioning and disability (World Health Organization, 2001). The definition of disability used for this report is: “a complex phenomenon, reflecting an interaction between features of a person’s body and features of the society in which he or she lives” (World Health Organization, 2011). We will use the term *condition*, commonly associated with a medical diagnosis, or *impairment* when appropriate to represent the level of function and dysfunction. The term *youth* has often been used in the literature to describe these individuals, but the exact age range for this term has not been clearly defined (Gaudet, 2007). In this article, the term *youth* will be used to represent the full developmental continuum of adolescence into young, emerging adulthood, from ages 12 to 25.

Article Objectives

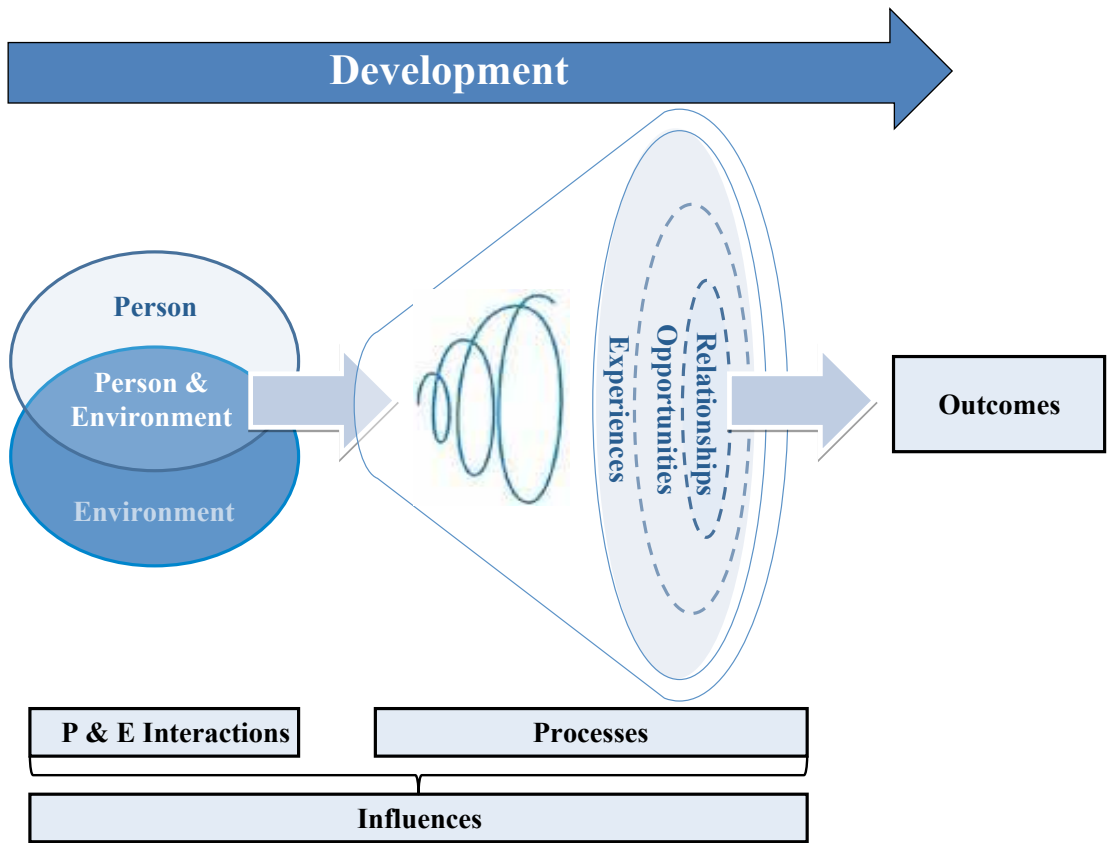
The objectives of this article are to synthesize and disseminate empirical evidence on the developmental trajectories and key hindering and helping (or risk and protective) factors experienced by youth with childhood-onset, chronic, lifelong conditions/impairments with a focus specifically on mental health outcomes and contributing factors for these individuals.

METHODS

We approached this knowledge synthesis at a synopsis level rather than that of a systematic review (Haynes, Sackett, Gray, & Cook, 1996). We considered three sources of evidence: (a) clinical and research experts, (b) youth, parent, and community experts, and (c) research evidence (for a more detailed description of the literature search, the review process, and knowledge synthesis, see our full report, Gorter et al., 2011). The search focused on articles that addressed youth with childhood-onset, chronic, lifelong conditions/impairments and developmental trajectories or prospective longitudinal studies, and included any publication in the English language up to January 2011. A consultant to the team who is an expert in disability research (G. K.) analyzed the reviews and organized them within a strengths-based conceptual framework. This conceptual model evolved to incorporate all of the factors identified in the literature as well as interactions identified by the experts. The conceptual model in Figure 1 shows how processes of relationships, opportunities, and experiences arise from the person–environment interaction, leading to developmental outcomes over the life course. The model in Figure 1 was used to guide the synthesis and reporting of the information inherent in the evidence gathered by the research team.

Analysis of the literature resulted in the identification of three main categories and a number of sub-categories for organizing the evidence. These categories were (a) outcomes of the developmental process, (b) person–environment interactive factors that influence developmental trajectories, and (c) the developmental process (i.e., trajectories).

Figure 1
Conceptual Developmental Framework



FINDINGS

A total of 136 articles were reviewed, 107 of which met the predetermined inclusion and exclusion criteria. The article types included longitudinal studies ($n = 42$), review articles ($n = 11$), quantitative/cross-sectional studies ($n = 20$), qualitative studies ($n = 16$), quantitative/descriptive studies ($n = 14$), studies with mixed methods design ($n = 3$), and one case study. The majority of articles focused on experiences ($n = 40$), developmental trajectories ($n = 34$), and factors ($n = 15$), or combinations of these ($n = 18$). A summary of the main findings organized by three categories is provided in Table 1.

Table 1
Summary of Outcomes and Synthesis

1. Outcomes	Synthesis
Traditional Markers of Psychosocial Outcome	<ul style="list-style-type: none"> The component or functional area addressed by different outcomes were not just for youth with the same “type” of impairment; i.e., physical outcomes were not just for youth with physical disabilities. A significant finding is that youth with all types of conditions or impairments could have “disability” outcomes in different areas of function; e.g., youth with intellectual disabilities can have limitations in physical, emotional, social and communication activities.
Societal-Level Outcomes	<ul style="list-style-type: none"> Common outcomes are based on adult role expectations such as finishing education/vocational training, starting a career, leaving home, forming a couple. Many of these traditional indicators of adulthood are normative in nature resulting in disadvantaged or “negative” outcome profiles for youth with disabilities, or at least a delayed trajectory. The acquisition of adult tasks is not necessarily viewed as a meaningful outcome by the individual.
Individualized, Person-Centred Outcomes	<ul style="list-style-type: none"> Recent literature includes individualized, person-centred outcomes related to citizenship and meaningful participation. Outcomes need to be conceptualized as dynamic in nature, acknowledging the variability in life circumstances within and between young people with disabilities.
2. Person–Environment Interactions	<ul style="list-style-type: none"> The research on factors that influence the developmental trajectories for youth with disabilities has shifted from a “silo” approach of considering personal and environmental factors separately to an interactive view of person–environment factors that influence and mediate each other. Community experts and professionals with clinical and research expertise are concluding that function, activity, and environmental factors are just as important as, or more significant than, type of impairment in explaining the developmental trajectories and outcomes of youth with disabilities. This new evidence supports the newer definition of “disability” as an interaction between person and environment. It could be said that an individual with a condition or impairment “grows into disability” as their condition and other personal factors interact with environmental barriers throughout their development.
3. Developmental Process (i.e., Trajectories)	<ul style="list-style-type: none"> It can be concluded that “condition” or “impairment” is only one small factor in the developmental trajectory of youth. The research about the processes of developmental trajectories of youth with disabilities is limited in scope and breadth. Research is needed to understand common issues and challenges that make up a complex process of person–environment interactions that influence a young person’s experiences and opportunities. Interactions in relationships (supports and expectations), opportunities, and experiences are essential components of the processes that determine, with person–environment interactions, the outcomes of a person with a disability.

Outcomes of the Developmental Process

Traditional markers of psychosocial outcome. Findings in many studies indicated that outcomes for youth with disabilities were poorer or less satisfying than for their peers with no disabilities. Poor social outcomes in the form of social skills and behaviours were identified as adult outcomes for youth with almost every type of condition including Autism Spectrum Disorder (ASD), mental illness, developmental disorders, and physical impairments (Learning Disabilities Association of Canada, 2007; Rasmussen & Gillberg, 2000; Wagner, Newman, Cameto, Levine, & Garza, 2006). In the domain of socialization and relationships, many studies described poor social outcomes for youth with different types of conditions. Descriptions included fewer or poor-quality close friendships and few intimate relationships (Clegg, Hollis, Mawhood, & Rutter, 2005; Durkin & Conti-Ramsden, 2007; Stewart et al., 2006). Studies also found ongoing social problems for many youth with childhood speech and language problems, which often resulted in psychiatric disorders (Clegg et al., 2005; Durkin & Conti-Ramsden, 2007; Law, Rush, Schoon, & Parsons, 2009). Youth with psychiatric or mental illness (Armstrong, Dedrick, & Greenbaum, 2003) and other types of impairments or conditions (Law et al., 2009; McNamara & Willoughby, 2010; Willcutt et al., 2007; Missiuna, Moll, King, King, & Law, 2007) were shown to have poor emotional outcomes in adulthood, including in psychological functioning, general behaviour, and coping skills. Youth with developmental disabilities, speech, visual, or other health impairments were most likely to have poor outcomes in aspects of cognitive functioning that included problem solving, decision-making, and the completion of self-care activities (Wagner, Newman, Cameto, Garza, & Levine, 2005; Wagner et al., 2006).

Societal-level outcomes. A second type of outcome relates to the typical “domains” or “events” of adulthood, namely, education/training, employment, independent living, and socialization. The results of the National Longitudinal Transition Survey (NLTS) Wave 2 provide solid evidence in this area for youth with different conditions (Wagner et al., 2006). Youth with disabilities were found to be employed at the same rate as their nondisabled peers but not in the same types of jobs, and they were more likely to be employed in part-time or contract jobs. Findings indicated that the severity of disability matters across all areas. Those with disabilities in three or more domains were less likely to be employed; however, those with higher social skills ratings were more likely to be employed. Engagement in work or time with friends was most common for youth with learning disabilities or speech, visual, or other health impairments; more than three-fourths of youth in these categories were engaged in employment (Wagner et al., 2006). In contrast, youth with intellectual impairment (52%), multiple disabilities (54%), ASD (56%), and orthopedic impairments (59%) had the lowest rates of engagement. Other studies provided additional evidence about these outcomes, including the fact that the rate of employment for youth with all types of conditions is usually lower than the general average (Altshuler, Mackelprang, & Baker, 2008; Billstedt, Gillberg, & Gillberg, 2005; Canadian National Institute for the Blind, 2006; Janus, 2009). Youth with psychiatric disorders often do not complete high school and are therefore at high risk of not meeting adult role expectations (Hollar, 2005; Learning Disabilities Association of Canada, 2007; VanderStoep et al., 2000). In the domain of independent living, several studies have shown that young adults with disabilities after the age of 30 are more likely to still be living with their parents (Donkervoort, Wiegerink, Van Meeteren, Stam, & Roebroek, 2009; Janus, 2009; Leiter & Waugh, 2009).

Individualized, person-centred outcomes. A third type of outcome identified by the research team has emerged in the recent literature and is primarily focused on the transition to adulthood for youth with disabilities. With criticism growing about using components of function or specific “event markers” or domains as outcomes of this transition, researchers have begun to study outcomes that are more individualized, person-centred, and dynamic in nature (Stewart et al., 2008; Stewart et al., 2006). The outcomes emerging from this research include participation, citizenship, engagement, contribution to community, life satisfaction, self-determination, interdependence, and quality of life. The challenge inherent in examining these types of outcomes is the lack of use of outcome measures that address these concepts, but this is slowly changing. For example, recent studies have shown that participation in informal leisure activities is restricted and decreases with increasing age among youth with disabilities (King et al., 2010; Shikako-Thomas et al., 2008). Other quantitative measures of participation, community integration, self-determination, and quality of life are being developed and used to assess transition-related outcomes in a person-centred manner. Using qualitative methodologies, researchers are working with youth, families, and community members to identify outcomes that are meaningful and important to them (Jivanjee, Kruzich, & Gordon, 2008, 2009; Kirk, 2008; Stewart et al., 2008).

Person–Environment Interactive Factors that Influence Developmental Trajectories

In the last decade, there has been a significant growth in published literature about the interactions between and among person and environment factors. This research has started to answer questions about the process of influence, that is, how different person and environment factors work together or relate to each other to influence development and, in particular, psychosocial and mental health outcomes. Longitudinal studies most notably have helped to identify interactive factors, for example, relationships between youth and parents (Berzin, 2010). Wells, Sandefur, and Hogan (2003) found that youth with cognitive or multiple disabilities were more likely to have a dependent relationship with their families. The presence of a severely-function-limiting disability influenced a family’s ability to invest in the education and employment of their child, affecting the inter-generational transmission of family status (Wells et al., 2003). In another longitudinal study, the type of impairment and level of care that youth required influenced parents’ level of optimism about the future (Wagner et al., 2005; Wagner et al., 2006). Other examples of how parents’ perceptions and expectations interacted with youth factors have also been described (Coakley, Holmbeck, Friedman, Greenley, & Thill, 2002; Cooney, 2002; Stephenson & Chesson, 2008).

The relationship between youth and peers is also important. Kirk (2008) reported that adolescents with disabilities often felt unwelcome around their peers. Those youth who were in less-inclusive school environments reported fewer and simpler themes related to friendship. Caton and Kagan (2007) also noted that attendance in special schools can result in fewer social experiences in the community. Interactions between youth with disabilities and others’ attitudes have also been described at the societal level. In a study of the experiences of males with muscular dystrophy, the term *embodied marginalization* (Gibson, Young, Upshur, & McKeever, 2007, p. 511) was used to describe the interaction between youths’ low expectations and the experience of being excluded. Kerka (2002) suggested that underemployment of youth with disabilities was due in part to biased attitudes of others, such as low expectations and overprotectiveness. Views of disability

and sexuality were found to be influenced by societal myths that people with disabilities are asexual (Neufeld, Klingbeil, Bryen, Silverman, & Thomas, 2002).

Recent research has demonstrated how person–environment factors can interact with a person’s impairment or condition to influence social and mental health trajectories; for example, humiliation and embarrassment arising from the negative reactions of others had a more significant influence on the psychological development of youth with Developmental Coordination Disorder (DCD) than their physical coordination problems did (Fitzpatrick & Watkinson, 2003). Another study found that, except for youth with severe intellectual impairment, activity limitations can partially mediate the relationship between the type of developmental condition and the attainment of adult social roles (Van Naarden Braun, Yeargin-Allsopp, & Lollar, 2006). This speaks to the importance of person–environment interactions through experiences and opportunities.

Other person–environment interactions that have been studied recently are related to services and systems. Hendricks and Wehman (2009) found that poor quality of adult services influenced a young adult’s reliance on their parents for support, which could influence social-emotional outcomes. Health service professionals’ lack of knowledge and information about the needs of young adults with chronic disabilities can influence a person’s access to quality health care (Young et al., 2009).

Unique Trajectories for Youth with Different Conditions

An analysis of the literature that addresses the processes or trajectories of development for youth with disabilities resulted in two organizing themes:

1. Unique trajectories for youth with different conditions; and
2. Issues common to all youth along the developmental trajectory.

Many of the studies about developmental processes for youth with disabilities focused on a particular population. These studies described trajectories that were believed to be unique to that population. Caution should be taken, however, as there has not been sufficient research with youth with all types of conditions to conclude that there are unique trajectories. Moreover, expert analysis supported the idea that there was no one clear trajectory for any condition. The current evidence, however, does provide us with some interesting profiles with respect to psychosocial and mental health outcomes.

Many youth with developmental or intellectual challenges have fewer opportunities to develop self-determination during high school (Davies & Beamish, 2009). Other studies showed that these youth experienced more solitary leisure activities in adolescence, or had experiences only through segregated, structured programs. As they grew older and finished high school, their social networks decreased significantly and they experienced more isolation (Hanson, 2003; Matheson, Olsen, Weisner, & Dykens, 2007). Chadwick and colleagues noted that, with age, youth with severe intellectual impairment reported a noticeable decline in their group of friends (Chadwick, Cuddy, Kusel, & Taylor, 2005). On the other hand, there were reports of some youth with developmental conditions experiencing more social and recreational opportunities, for example, if their parents advocated for them and drove them to community and school events. A similar trajectory was reported by Canadian National Institute for the Blind (2006) for youth with visual impairments. Although these youth had some social opportunities while in high school, they were forced to find

new social outlets after graduation, and while some were successful, others were not. In a study that involved parents of youth with DCD, the authors suggested a developmental trajectory that progressed from simple concerns about motor and play skills to more complicated and diverse challenges with social and emotional development (Missiuna et al., 2007).

Some youth with ASD have reported that they become increasingly socially excluded as they transition to late adolescence and adulthood (Howlin, Goode, Hutton, & Rutter, 2004). Co-morbid conditions, most notably anxiety and depression, are common (Eaves & Ho, 2008), with a peak in the prevalence of these conditions in early adulthood (Ghaziuddin, Weidmer-Mikhail, & Ghaziuddin, 1998). Nonetheless, there is wide variation in experiences, with some individuals with higher intellectual function achieving relative success (Farley et al., 2009).

Issues Common to All Youth Along the Developmental Trajectory

Several review articles and longitudinal studies focus on common issues and experiences for youth with all types of chronic conditions.

Opportunities. Some researchers have focused on the importance of “opportunities” as transition points that can influence a person’s developmental trajectory. For example, Carter, Owens, Trainor, Sun, and Sweedent (2009) noted that opportunities at home and school during the adolescent years and during transition to adulthood were associated with an individual’s development of self-determination. Caton and Kagan (2007) found that youth who attended special schools did not have the same opportunities for typical teenage social experiences, and so social isolation could develop, especially during the transition from high school to adult life. Caton and Kagan also noted that youth who had opportunities to participate in community group activities during adolescence were more likely to participate in volunteer activities as they aged; however, youth with orthopedic and speech impairments showed a decline in community and volunteer experiences over time.

Research on the sexual development of youth with disabilities showed they had the same expectations as their peers for sexual identity and activity, but their trajectories were affected by comments about appearance and by lack of sex education. Fears about dependence on others and inappropriate social skills could lead parents to protect their youth from social contacts and from educational opportunities. The trajectory of lack of education and experience has been shown to lead to negative outcomes; people with disabilities are approximately three times as likely to experience sexual abuse (Murphy & Elias, 2006; Neufeld et al., 2002).

Transitions. Kirk et al. (2008) wrote about young people with chronic conditions living into adulthood and experiencing multiple transitions. These can be divided into age-related transitions and system-related transitions. Age-related transitions include developmental events that all youth experience; the most significant event in the age range of 12–25 years is puberty. Most youth reach puberty sometime in early adolescence (or sooner in some cases), but some differences have been found in the experiences of youth with disabilities. These differences may be influenced by poor communication patterns between youth and parents and lack of education (Coakley et al., 2002). When youth transition from childhood into adolescence, their activities tend to become more socially focused and complex (King et al., 2010). Youth with disabilities may give up more social activities at school as they get older because of transportation problems or lack of supports, and

their social isolation may be more evident at the transition from high school. These experiences can continue to snowball into larger impacts in adult years (Halfon & Hochstein, 2002).

Many studies conclude that major transitions in the health care system, educational system, and social welfare system for youth with disabilities are dictated more by system requirements than by age. All youth face transitions into and out of high school, but youth with disabilities are involved in many more systems that have age requirements for discharge and transfer. The transition from high school to the adult world can be much more complex for these youth. Health care and social services are organized into paediatric systems and adult systems, and the two systems are very different in terms of their expectations of youth and families. This type of transition, therefore, can be highly stressful and require a great deal of planning and preparation (Young et al., 2009).

Opportunities and transitions. On a positive note, some opportunities available in young adulthood could help youth with disabilities improve their trajectory; for example, post-secondary schools were found to be more “student-driven” than “system-driven” (Wagner et al., 2005). In one study, youth with speech-language impairments had more positive experiences in post-secondary education than they had in high school (Palikara, Lindsay, & Dockrell, 2009). In another study, youth with physical disabilities had more opportunities for romantic relationships when they made the transition from adolescence to young adulthood (Wiegerink, Stam, Gorter, Cohen-Kettenis, & Roebroek, 2010).

DISCUSSION

The evidence from the research literature shows clearly that outcomes related to socio-emotional well-being and other mental health parameters are largely poor for youth with disabilities, and this is true across diagnostic categories. Interactions among the person, family, peers, the wider social environment, and experiences/opportunities have been described, along with the impact of these interactions on psychosocial well-being and mental health.

As illustrated in the conceptual developmental framework (Figure 1), different trajectories and outcomes arise from the interaction of cumulative risk and protective factors, which in turn affect youth’s opportunities, social relationships, and life experiences. This conceptual model considers developmental processes that have been outlined in various theories of social and competence development, including Bronfenbrenner and Ceci’s (1994) bioecological model of development, Catalano and Hawkins’ (1996) model of social development, and King et al.’s (2005) model of competence development.

Knowledge of the various interactions that are possible between person and environment helps us to begin to understand the dynamic nature of development. This approach focuses on developmental processes that take person–environment interactions into account within the additional context of time. Person–environment interactions are most important at transition points, when an individual is dealing with significant changes in personal and environmental factors. There appear to be a number of transition points for youth with disabilities, some age-related, but more often system-related. Although it might seem reasonable that youth with disabilities would have the same transition points or markers as their peers, there is insufficient evidence to support this. Published evidence is limited about developmental transitions of youth with disabilities from a process or trajectory perspective. Most literature to date has focused on the factors that influence transitions.

The phrase *growing into disability* represents a negative trajectory that, based on the evidence to date, many youth with chronic conditions experience. A negative trajectory could develop if children with conditions that limit their childhood social involvement experience a “narrowing” of their social pathway as they make the transition into adolescence and high school instead of the more typical “widening” of social experiences. There is, however, an increased focus in the literature on a positive developmental approach for all youth (Hawkins et al., 2011). Halfon and Hochstein (2002) noted that transitions are points of sensitivity at which trajectories can be changed. The identification of these personal and environmental factors, and their interactions, provides evidence about the things that can influence development. Examples include the benefits of starting early the transition planning from high school into post-secondary education or into day programming, and the engagement of youth with disabilities and their parents in the process in schools.

Knowledge Gaps

A number of knowledge gaps were identified in the literature about developmental trajectories and transitions, and psychosocial and mental health outcomes for youth with disabilities. The primary gap is the lack of rigorous longitudinal data about the development of youth with disabilities; there is insufficient data upon which to draw strong conclusions and recommendations for services, supports, and policy. The majority of research about youth with disabilities during the transition from adolescence into adulthood focuses on factors and outcomes. There are significant knowledge gaps about the person–environment interactions and the processes at work to provide youth with disabilities with the experiences, opportunities, and relationships needed for positive development. Our current knowledge about developmental transition points indicates that key transitions to adult services are dictated more by systems than by individual needs, and we need to learn how to change this. Much can be learned by merging the research about the developmental trajectories of typical youth with that of disabled youth, as many of the key constructs are the same, including person–environment interactions and processes of influence and transition points. For youth with disabilities, there is more complexity. In conclusion, there are critical gaps in our research and knowledge about the developmental trajectories of youth with disabilities, which can inform evidence-based policy and decision-making. The gaps are (a) a lack of longitudinal studies; (b) a lack of research that focuses on individualized, person-centred outcomes; and, (c) knowledge about person–environment interactions in relation to the outcomes.

Recommendations

To address the knowledge gaps, we suggest the following recommendations to guide knowledge development and research:

1. Promote large longitudinal studies about development involving youth with disabilities;
2. Study the person–environment interactions and the processes at work to provide youth with disabilities with the experiences, opportunities, and relationships needed for positive development;

3. Merge the research about the developmental trajectories of typical youth with that of disabled youth, because although there is more complexity for youth with disabilities, many of the key constructs are the same;
4. Include youth with disabilities as participants in studies or active members of a research team, so their voice and perspective is represented;
5. Study whether challenges and developmental gaps between youth with and without disabilities continue to persist into emerging adulthood;
6. Study the developmental trajectories and transitions of youth with “hidden” disabilities, such as mental illness and learning disabilities;
7. Study the needs of youth with high levels of severity of impairment, particularly those with significant cognitive impairments;
8. Study the impact of legislation and policy, including policies for community mental health, on the developmental outcomes of youth with disabilities.

The team also agreed on the following key messages for policy and decision makers to consider as they address the needs of youth with disabilities:

1. Focus on participation, citizenship, community engagement, and other outcomes that are meaningful to youth with disabilities and their families;
2. Promote collaboration to provide person-centred planning at important transition points. This involves useful and relevant information for youth and families to help them make informed decisions for the future;
3. Ensure that adequate resources and supports are available to youth with disabilities and their families to maximize participation and inclusion in the community;
4. Evaluate services and models that promote positive youth development and transitions;
5. Make knowledge translation to families, educators, practitioners, and youth with disabilities an expected part of any research.

Consistency and collaboration are needed across all systems on issues such as defining the age-range of youth and related services; definitions of disability; studying the complex, interactional factors and processes at work; addressing the needs of youth with multiple conditions requiring diverse services and supports; and developing meaningful outcome measures. There is a need to overcome inconsistencies between the different systems (education, health, social services, etc.) that address developmental and transition issues for youth with disabilities. Moreover, supports and opportunities for youth with disabilities should be seen as a shared responsibility of families, communities, and government. The findings in this research indicate the need to ensure that adequate resources and supports are available to youth with disabilities and their families to maximize participation and inclusion at the community level. This includes a range of options for funding, housing, education, and employment.

CONCLUSION

This knowledge synthesis concerning the developmental trajectories of youth with disabilities has revealed the importance of considering person and environmental factors as interacting determinants of psychosocial and mental health outcomes. The diverse findings in the literature were consolidated and interpreted in light of an inclusive conceptual model that proposes that developmental outcomes over the life course are influenced by key processes of relationships, opportunities, and experiences that arise from the person–environment interaction.

With respect to relational processes, the findings suggest the importance of community members' attitudes, peer relationships, and the key role of the family in influencing youths' developmental trajectories and outcomes. With respect to opportunities, the findings suggest the importance of participation in everyday activities at home, at school, and in the community. With respect to experiences, the findings suggest the importance of real-world experiences from the transition into early adolescence onward.

The synthesis of knowledge about outcomes shows the importance of going beyond the traditional psychosocial outcomes and societal-level outcomes. Meaningful outcomes for individuals with a disability include participation, citizenship, engagement, contribution to community, life satisfaction, self-determination, and a healthy sense of self and well-being.

The developmental trajectories of youth with disabilities can take many different directions depending on the interaction of risk and protective factors with environmental barriers and supports and opportunities to participate in developmental experiences that are part of growing up. These interactions are most important at transition points when an individual is dealing with significant changes in personal and environmental factors. Transition to adulthood, when youth graduate from high school and are also discharged from paediatric services, has been identified as a significant transition point that can affect future adult experiences and outcomes. Evidence is mounting that youth with disabilities can experience similar trajectories to their peers without disabilities through positive, developmentally appropriate life experiences and regular opportunities with adequate supports to develop adult social roles.

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