

# International Encyclopedia of Rehabilitation

Copyright © 2010 by the Center for International Rehabilitation Research Information and Exchange (CIRRIE).

All rights reserved. No part of this publication may be reproduced or distributed in any form or by any means, or stored in a database or retrieval system without the prior written permission of the publisher, except as permitted under the United States Copyright Act of 1976.

Center for International Rehabilitation Research Information and Exchange (CIRRIE)  
515 Kimball Tower  
University at Buffalo, The State University of New York  
Buffalo, NY 14214  
E-mail: [ub-cirrie@buffalo.edu](mailto:ub-cirrie@buffalo.edu)  
Web: <http://cirrie.buffalo.edu>

*This publication of the Center for International Rehabilitation Research Information and Exchange is supported by funds received from the National Institute on Disability and Rehabilitation Research of the U.S. Department of Education under grant number H133A050008. The opinions contained in this publication are those of the authors and do not necessarily reflect those of CIRRIE or the Department of Education.*

# **The transition to adulthood for youth with disabilities: Evidence from the literature**

**Debra Stewart, MSc.**  
**CanChild Centre for Childhood Disability Research; and**  
**School of Rehabilitation Science,**  
**McMaster University,**  
**1400 Main Street West, IAHS Building**  
**Hamilton, Ontario, Canada**  
**Email: stewartd@mcmaster.ca**

**Matt Freeman, MA.**  
**School of Rehabilitation Science, McMaster University**

**Mary Law, PhD.**  
**School of Rehabilitation Science, McMaster University**  
**CanChild Centre for Childhood Disability Research**

**Helen Healy, BOT.**  
**Bloorview Kids Rehab, Toronto, ON**

**Jan Burke-Gaffney, BA.**  
**Hamilton Family Network, Hamilton, ON**

**Mary Forhan, MHSc., PhD Candidate**  
**School of Rehabilitation Science**

**Nancy Young, PhD.**  
**Laurentian University, Sudbury, ON**

**Susan Guenther, MSc.**  
**Research Assistant, School of Rehabilitation Science**

## **Introduction**

Current evidence about the transition to adulthood for youth with disabilities indicates that the process is extremely challenging. While there are substantial personal challenges such as physical, sensory, cognitive and communicative limitations, environmental barriers often present the most significant challenges for transition (Committee on Disability in America, 2007; Stewart et al. 2006). Also, policies, systems and services tend to be uncoordinated or fragmented and youth with disabilities and their families lack the information needed to navigate the transition successfully (Committee on Disability in America, 2007; Learning Disabilities Association of Canada, 2007). As a result of challenges, and the difficulty youth experience in accessing supports, many transitions are not successful (Wagner et al. 2005). This limits opportunities for full participation in

adult life (Stewart 2006; While et al. 2004). Stories from youth and parents indicate that they feel like they “have been dropped off a cliff” once they reach adulthood (Stewart et al. 2001).

Most of the literature about transition to adulthood that has been published in the past ten years is descriptive or conceptual in nature, although the number of ‘studies’ is slowly increasing. Furthermore, the primary focus of the literature has been on identification of the barriers facing youth with disabilities as they make the transition to adulthood (Algozzine et al. 2001; Betz 2004; Wagner et al. 2005; Young 2007). Much of the literature describes a service perspective that views transition as a process that seeks to meet the needs of youth with special needs as they move from childhood to adult services (Blum et al. 2002; Reiss and Gibson 2002). Recent literature however acknowledges that transition to adulthood is more than just a service approach, as it involves a process of taking on new roles and adapting or changing existing roles (King et al. 2005; Osgood et al. 2005) for youth and their families. A holistic, lifelong view of transition is an important principle of any service or support for youth with disabilities, and fits well with current views of family-centred/client-centred practice in child and youth health (King et al. 2005).

With the dramatic growth in published literature on this topic in the past decade, there is a need to keep up with the current evidence that is emerging. This article outlines the findings from a comprehensive review of the literature conducted in 2008 that includes all aspects of the transition to adulthood, not simply transition services, and for youth with all types of disabilities. The discussion section synthesizes the current evidence from the literature to make recommendations for services, supports and research.

## **Methodology**

A comprehensive search of literature about transition to adulthood for youth with all types of disabilities included databases from health, medicine, psychology, education and social sciences, and North American and international databases. The search encompassed policy, services, research and community-based articles.

Inclusion and exclusion criteria were established by the research team (see Figure 1). Search keywords developed from the inclusion criteria were combined with terms related to transition to adulthood, including transition; transition to adulthood; emerging adulthood; growing up; work/employment, life skills, postsecondary education/training, and independent living. The research team also searched through the reference lists of retrieved articles.

It was decided to focus this review on the published literature from the year 2000 and on, as there has been a dramatic growth in the literature on this topic and the research team wanted to identify ‘current best evidence’ for this project.

The initial search resulted in a compilation of abstracts of articles, which were then reviewed by the research assistant and principal investigator to determine if they met inclusion criteria. Accepted articles were retrieved in full and reviewed to determine final

acceptance of each article for this project. All accepted articles were then entered into RefWorks, which is a web-based program for organizing references. A descriptive review process was utilized by the research assistant and principal investigator through which a number of key themes/ categories about the topic of transition to adulthood for youth with disabilities emerged. Articles were organized by these themes and presented to the research team for a critical review and discussion. The findings of the literature review are presented below by the themes/categories that were agreed upon by the research team.

## **Findings**

Over 500 published articles about the transition to adulthood for youth with disabilities were identified in the initial search; however many articles, as well as books on this topic, were found to be purely theoretical or conceptual in nature. The published literature that was selected and reviewed for this report is ‘evidence-based’. The research team chose to take a broad view of evidence that includes research findings, as well as evidence about programs, services and policies, and perspectives of patients/clients (Haynes, Devereaux and Guyatt 2002). This broad view of evidence resulted in the inclusion criteria being set (Figure 1) and the following types of published literature being accepted: (a) articles that provide evidence from research studies, program evaluations, or descriptions (non-conceptual/theoretical) of services, programs or legislation related to transition; (b) reviews of the literature and/or programs; and (c) information briefs that summarize research, programs, or legislation.

Five themes or ‘categories’ emerged from the research team’s review of the accepted literature. The themes represent the common issues and foci of current evidence-based literature (years 2000-2008) on transition to adulthood for youth with disabilities.

### **Theme 1: Current Experiences and Outcomes**

The published literature since 2000 has provided a comprehensive picture of youth with different types of disabilities. Articles cite negative experiences and outcomes for youth with disabilities generally, such as failing to achieve their goals or to meet the role expectations of young adults (Baltodano et al. 2005; Beresford 2004; Committee on Disability in America 2007; Wagner et al. 2006; Wittenburg and Maag 2002). Although youth with disabilities have the same aspirations and dreams as those without disabilities (Burchardt 2004), a gap between their aspirations and outcomes has been described in several articles. Follow up and follow through (i.e. longitudinal) studies have provided generic descriptions of the experiences and needs of different youth populations (Betz 2004; Wagner et al. 2006). The telling finding of these studies is that, despite some different experiences related to a specific disability or population, the overarching issues and outcomes related to the transition to adulthood are similar. These common overarching issues are the themes of this report.

Many articles focus attention on one ‘stakeholder’ group, such as youth, parents, service providers or community members. The unique perspectives and experiences of each group are presented below.

**Youth** with disabilities have reported that they have similar aspirations to their counterparts without disabilities, but there are more obstacles during the transition to adult life. The literature often reports youth with disabilities having limited opportunity to participate in assessment and planning services, particularly in relation to educational and career planning (Hitchings et al. 2001). Recent studies have focused more on identifying meaningful and important outcomes from the perspective of youth, including community participation, self-determination, inclusion, and quality of life (Algozzine et al. 2001; Kraemer et al. 2003; Powers et al. 2007).

Many articles focus on one population of youth, including those with learning disabilities (Cameron and Murphy 2002; Learning Disabilities Association of Canada 2007; Salmon and Kinnealey 2007; Ward et al. 2003); health/medical conditions (Anderson et al. 2004, 2006; Betz 2004; Lotstein et al. 2005; O’Leary et al. 2004; Ostlie et al. 2007; Saigal et al. 2006; Verlinde et al. 2004); developmental disabilities (Betz and Redcay 2002; VanNaarden Braun et al. 2006; Pavey 2005; Rapanaro et al. 2008); mental health and behavioural challenges (Armstrong et al. 2003; Carter and Lunsford 2005; Carter et al. 2006; Corbett et al. 2002; Feldman et al. 2004; Vanderstoep et al. 2000, 2002; Wagner and Davis 2006) and deaf/blind youth (Canadian National Institute for the Blind 2006; Nagle 2001; Shroedel and Geyer 2000). Upon review, the research team noted that although each population may have unique needs, the findings are often very similar in terms of the challenges and negative outcomes, such as unemployment and social isolation (Committee on Disability in America 2007; Murray 2003; Stewart et al. 2001).

There is a notable paucity of evidence-based literature on the experiences and outcomes of youth with severe disabilities, including chronic medical conditions, blind and deaf youth, and those with severe developmental disabilities and emotional problems. Recent literature has recommended that these populations receive more attention.

**Parent** perspectives have also been studied (Conti-Ramsden et al. 2008; Cooney 2002; Glidden and Jobe, 2007). For example, in one qualitative study, parents of high school students with disabilities were found to be more pessimistic about their child’s future than parents of students without disabilities and they may experience more challenges with role changes (Magill-Evans et al. 2005). In other research, parents report a lack of information about future options for their child. Recent studies indicate that parents benefit from being actively involved in transition planning, as they can then help their child more in making decisions and planning for the future (Goupil et al. 2002). There is also some evidence that individualized funding options can help many families find the best supports (Lord and Hutchison 2003). Parents have also identified important outcomes of the transition process from their perspective, such as community inclusion and citizenship for all young adults with disabilities (Lord and Hutchison 2003).

Studies identify some differences between **service providers** and parents concerning both the level and type of provider involvement (Geenen et al. 2003), which suggest a need for health care providers and parents to have open discussions about transition planning. In other articles, health service providers and educators identify a lack of knowledge about options available for young adults after they leave high school or

pediatric services (Goupil et al. 2002). This suggests that education and training of service providers is important.

Very little published literature was found about the perspectives of adult **community members**, such as employers. One article described community capacity building as an approach that informs adult community members about the strengths and assets of youth with disabilities (Wynn et al. 2006). There is also an increasing amount of descriptive literature about the influence of societal attitudes and expectations on the participation and inclusion of people with disabilities in general, but there is little research on this, especially in relation to youth with disabilities.

## **Theme 2: Different Types of Transition**

A majority of the literature focuses on the transition to and from services or systems. Health care/medical service transitions or ‘transfer of care’ publications are predominant in most countries (Baldassano et al 2002; Bell 2007; Betz 2004, 2007; Binks et al. 2007; Blum et al. 2002; Bolton-Maggs 2007; Canobbio and Higgins 2004; Freed and Hudson 2006; Kaufman and Pinzon 2007; Kingsnorth et al. 2007; Lotstein et al. 2005; Pacaud et al. 2005; Radovick and DiVall 2007; Reid et al. 2004; Robertson et al. 2006; White 2002; Wojciechowski et al. 2002; Young et al. 2007). There is also a growing body of literature on transition within mental health services (Baltodano et al. 2005; Davis et al. 2006; Jonikas et al. 2003; Richards and Vostanis 2004), post-secondary education systems (Burchardt 2004; Kohler and Hood 2000; Neubert 2001), and developmental services (Alpern and Zager 2007; Community Living Research Project 2006; Mirfin-Veitch 2003). Several reviews include a broad representation of services/systems (Cavin et al. 2001; While et al. 2004). These review articles summarize a growing knowledge base about the needs of young people and parents when they transition from one service system to another. This has led to the identification of success factors for any transition service. These factors include starting early with youth and families to plan for the future, working in a collaborative team approach with the youth at the centre of the team, providing useful and accessible information and education, and providing ongoing supports before, during and after the transition period. (Betz 2004; Ikiugu and Ciaravino 2006; Stewart et al. 2006)

Recent literature is making a distinction between service/system transitions and the natural or ‘developmental’ transition that all youth, including those without disabilities, go through (Beresford 2004; Community Living Research Project 2006). This other type of transition is referred to in the literature as “developmental” or “lifecourse” transition and this literature focuses on the natural process that all youth go through. The other term that is being used in several countries to describe this developmental stage of life is “emerging adulthood” (McDonagh 2006). Literature on this type of transition is sparse but growing, as there is increased recognition that all aspects of a young person’s life need to be addressed for success (Committee on Disability in America 2007; Learning Disabilities Association of Canada 2007).

### **Theme 3: Domains of Transition**

Many articles and resources focus on one specific or particular domain of transition. The domains relate to the main ‘events’ of the transition to adulthood for all young people. The primary domains identified in the literature include employment, education and training, independent living, and social/ community life.

#### **Employment domain**

Within the employment domain, most literature is on “school to work”. For example, education-to-labour market pathways indicate that the presence of a long-term condition is a ‘hindrance’ to further education and thus to future employment (Hango and de Broucker 2005). Some young people with disabilities have reported choosing the type of employment based on the ability of the employer to provide equity and accommodations (Canadian Centre on Disability Studies 2004). Strategies to address school-work transitions are also described in the literature. They include the need for interprofessional and inter-system efforts; real-life experiences and opportunities for work through situated education; and the development of student-focused strategies such as collaboration and data-driven decision-making for service providers (National Secondary Transition Technical Assistance Centre (NSTTAC) 2008).

#### **Education domain**

This domain includes both secondary and post-secondary systems. A great deal of literature in this domain is from the United States. The literature stresses the importance of starting transition planning and services early in high school when services are free and accessible, and youth have time to participate in valuable experiences (Izzo and Lamb 2003). Recent articles also challenge educators and others to focus more on transition planning and career development than just job finding skills (Shroedel and Geyer 2000). Other reviews identify the importance of post-secondary education for successful adult outcomes and the need for careful transition planning to ensure success (Wagner et al. 2006).

#### **Living domain**

Most of the literature about the transition out of the parents’ home is focused on ‘independent living’ services and supports (Hendey and Pascall 2001). The literature from several countries supports the need for more research in this area, and the need to identify a range of options for young people (and their parents) who want to live away from the family home (Blacher 2001; Hendey and Pascall 2001).

#### **Social and community life domain**

This domain covers a broad range of transition outcomes and activities, including community recreation and leisure activities, social relationships, marriage and parenting. Literature reviews address this domain when examining transition to adulthood broadly, and they identify this domain as essential to successful and satisfying adult living (Lehman et al. 2002). In many cases this domain is acknowledged as one that does not receive enough attention (Armstrong et al. 2003; Cooney 2002; Hughes 2001). Further research in this area is needed.

## **Theme 4: Factors that Influence Transition - Barriers and/or Supports**

The literature offers a great deal of evidence about the different factors that influence the transition to adulthood for youth with disabilities. Factors can be facilitators/supports or barriers/inhibitors. Most of the literature describes factors related to either the person/youth, or to the environment.

### **Youth factors – Risk factors/barriers**

Several reviews and reports cite conditions, including physical, mental, behavioural, sensory, developmental and learning disabilities to be strongly correlated with school non-completion and other negative outcomes of transition (Baltodano et al. 2005; Binks et al. 2007; Community Living Research Project 2006; Learning Disabilities Association of Canada 2007; Vander Stoep et al. 2000). The influence of the type of disability has been reported in several published studies, and statistical evidence indicates that type of disability can affect the process and outcomes of adult transitions (Caton and Kagan 2007; Van Naarden Braun, Yeargin-Allsopp and Lollar 2006; Wells, Sandefur and Hogan 2003). Some articles also report increased risk of negative outcomes with a high level of severity of different types of disability (Community Living Research Project 2006; Bowe 2003; Canadian National Institute for the Blind 2006; Caton & Kagan 2007; Wong 2004). Other authors however caution that disability is only one factor in a complex process (Burchardt 2004). These findings indicate that the evidence to date is inconclusive about the influence of type of disability.

Numerous other personal characteristics have been cited in the literature as risk factors for youth. For example, some research has found that gender may be a risk factor, as there are significant differences in transition outcomes between men and women with disabilities (Berge et al. 2007; Jonikas et al. 2003; Powers et al. 2008). Youth with disabilities who are also in foster care face additional complexities (Palladino 2006). The incidence of obesity during transition is addressed in one U.S. study that found the proportion of adolescents who are becoming and remaining obese is high and is increasing (Gordon-Larsen et al. 2004). Ethnicity has also been identified in some studies as a risk factor for some youth (Hussain 2003). Literature about Aboriginal, Hispanic and African-American youth with disabilities speaks to the “double jeopardy” risk factors of disability and ethnicity (Blacher 2001; Blue-Banning et al. 2002). There is statistical evidence that these young people have much poorer outcomes in all domains (Wagner et al. 2005), although a recent study in the United States (Van Naarden Braun et al. 2006) found that when researchers controlled for impairment, no demographic variables, including ethnicity and gender were significant predictors of a successful transition outcome. Further study is required to determine the influence of all of these factors on transition process and outcomes, and how they interact with each other.

### **Youth: Supports and Facilitators**

Numerous personal support factors have been identified in the literature on transition to adulthood for youth with disabilities. Some examples are provided below:



- self-awareness, effective coping strategies, resilience, active engagement, perseverance, and goal setting (Learning Disabilities Association of Canada 2005; Murray 2003)
- literacy level and language skills (Alpern and Zager 2007)
- internal control and adaptive behaviour, and knowledge about self and future options (Baltodano et al. 2005; Blacher 2001)
- self-determination and self-advocacy during transition (Algozzine et al. 2001; Powers et al. 2007; Wehmeyer and Palmer 2003).

It is evident from this evidence that the strengths and capacities of youth should be taken into account at all stages of the transition process.

### **Environmental Factors: Barriers**

Very few research articles specifically address environmental barriers and/or supports, but the influence (both positive and negative) of environmental factors is imbedded in review articles. The primary environmental barriers described in the literature are:

- People's attitudes towards youth with different types of disabilities and ethnic status in general influences all aspects of transition and also interacts with many of the other environmental factors (Annable et al. 2004);
- Lack of knowledge about options and understanding of disability-related needs of youth by service providers, educators, parents and community members affects a young person's transition process negatively (Hitchings et al. 2001);
- Lack of opportunities, choices and experiences in childhood through adolescence and the transition itself has a profound impact on adult outcomes (Foster and MacLeod 2004);
- Barriers at the service level include lack of continuity of services, for example from paediatrics to adult services (Committee on Disability in America 2007; Davis and Sondheimer 2005); stereotyping and expectations of service providers and educators (Annable et al. 2004); lack of access to services and underfunding of services (Callahan and Cooper 2007); and rigid timelines and age requirements for transition services (Galambos et al. 2007);
- The narrow focus of transition services, especially within schools, on preparation for post-secondary education instead of addressing the 'lifecourse' needs of youth in all domains of transition (Bowe 2003); and
- The environment of the family can also pose barriers, such as socioeconomic status (SES). However, one study has found that SES has a smaller impact on youth with disabilities than those with no disabilities (Wells et al. 2003). Other family factors include parents' low expectations for the future (Chambers, Hughes and Carter 2004) and their lack of knowledge and information to help their young adult (Learning Disabilities Association of Canada 2007).

## **Environmental supports**

Numerous **environmental supports** have also been reported in numerous review articles and studies, primarily from the United States, United Kingdom and Canada. These include:

- Pre-programming/planning; high quality programming; gender differences addressed in service delivery; and adult mentors as key supports (Baltodano et al. 2005);
- Collaborative team planning (NSTTAC 2008);
- Supportive community systems such as housing and policy/legislative supports, including financial and insurance aid (Lehman et al. 2002);
- The positive influence of peer networks and mentoring/personal advisor/navigator relationships to provide the support to youth and parents to access opportunities and experiences (Foster and MacLeod 2004; Stewart et al. 2006; Wilson 2003);
- Flexibility and individualized supports can benefit youth entering employment (Golsh 2003; Hart 2001);
- Technology can be a great support if used appropriately (Burgstahler 2003; Mull and Sitlington 2003).

Finally, factors related to policy and legislation in some countries have been studied. For example, in the United States the Individuals with Disabilities Education Act (IDEA) focuses on transition practices within education and the Rehabilitation Act addresses issues of vocational rehabilitation, independent living and personal assistance (Davis and Sondheimer 2005; Edmonson and Cain 2002; Madaus and Shaw 2006; United States Department of Education, n.d.). There is some evidence emerging that legislation is having a positive impact, however, recent studies about the impact of policy on the experiences and outcomes of youth with disabilities report that legislation alone is not enough (Community Living Research Project 2006; Wittenburg et al 2002). Furthermore, there is a call for policy to address all aspects of transition to adulthood, and not just one specific area such as education or health (Committee on Disability in America 2007).

Although this review of the literature found that the different factors that influence transition have been studied mostly in isolation from each other, there is an acknowledgement in recent literature that there are significant interactions between the various physical, cultural, social, institutional and legislative factors (Committee on Disability in America 2007; Murray 2003). This is discussed further in the next theme.

## **Theme 5: Complexity**

Recent literature acknowledges that researchers are beginning to focus on interactions and complexities involved in transition to adulthood, including the interactions of co-morbidity, secondary disabilities and environmental factors. Although this is a relatively new focus of research about transition, some interesting findings are emerging. For example:

- Recent studies have found that some youth with disabilities may become involved in criminal behaviour and substance abuse (Baltodano et al. 2005), which increases the complexity of their situation and often results in negative outcomes of school failure and unemployment.
- Disability interacts with other forms of disadvantage, for example, ethnicity, poverty and immigrant status, but knowledge about the exact nature and process of these interactions (Black et al. 2003; Burchardt 2004) among different groups of youth is limited.
- Studies have also found that having a disability and completing secondary education positively influences future employment outcomes (Vander Stoep et al. 2002) but how this interaction occurs is also not known.
- Other studies are demonstrating how different domains of transition interact with each other; for example, employment is closely related to young adults' capacity to live on their own (Hendey and Pascall, 2001).

This evidence supports the need for more research that studies the various person-environment interactions that take place during the transition to adulthood. A recent study used an interactional/multidimensional approach to examine the influence of type and severity of disability on transition outcomes and the acquisition of adult social roles. Researchers found that while severity of a developmental disability was an important factor, activity limitations and opportunities in the environment were also part of the picture (Van Naarden Braun et al. 2006). These interactions require further study to better understand the complexity of the transition process.

### **Discussion: What the evidence tells us about “best practice”**

This analysis of the evidence-based literature on transition to adulthood for youth with disabilities indicates that there has been a growth in the number of studies and review articles on this topic in the past eight years. The literature provides a clear picture of the experiences, challenges and desired outcomes of youth with different types of disabilities, and their families. Some literature also identifies experiences and perspectives of service providers and community members who are part of the transition process. To date, many of the studies and review articles focus on experiences of transitioning or transferring from one service system to another, for example from pediatric to adult services. A shift in focus is evident in recent literature that focuses more on a holistic, lifecourse perspective. This approach addresses all aspects of a young person's life and the interactions between person and environment. It also supports a move to connect and relate the different domains of transition – employment, education, living and socialization – to learn more about how they interact with each other.

Although many articles still tend to focus on one particular population of youth, or one particular service system, many of the same factors are identified as important for successful transition outcomes. These factors may be within the person or within the environment. The research team noted that any one factor can be perceived as either a barrier or support, depending on the situation. For example, other people's attitudes towards youth with disabilities can be a barrier or a support during the transition; and current funding sources can be a great support for a young person with disabilities, but

can become a barrier if they are not sustainable. Further study is needed to better understand the interactions between the various factors that have been identified in this report, as it is now evident that the complexities of the transition process warrant an interactional and multidimensional approach.

A more interactional and lifecourse approach to transition services and supports is beginning to emerge in the literature. Recent studies are demonstrating that some services and communities are beginning to combine various ‘success factors’, such as those identified in the findings above, to develop programs and models. For example, a number of promising practice models in education include programs to include students in school meetings, as well as school-supervised work experiences, and functionally oriented curricula (Carnaby et al. 2003). Self-determination models and ecological models of support have some early evidence of success (Agran et al. 2000; Algozzine et al. 2001; Lehman et al. 2002; Weymeher et al. 2006). In health care, the combination of the medical home model in paediatrics and the chronic care health model in adult health shows promise in the United States (Committee on Disability in America 2007), and team approaches have been evaluated in the United Kingdom (Bent et al. 2002; McDonagh et al. 2006, 2007; Shaw et al. 2007) and Canada (Evans et al. 2006). A shared management approach in rehabilitation has shown initial benefits (Gall et al. 2006), and a model of seamless transition service delivery that integrates three systems (education, rehabilitation and developmental services) has shown positive initial results (Certo et al. 2003). Transition guidelines for students going to university (Cook et al. 2005) and models to facilitate the age appropriate participation of youth with developmental disabilities in post-secondary classes (Dolyniuk et al. 2002; Neubert 2001) have been developed. Finally, transition supports through community capacity-building with youth with developmental disabilities (Wynn et al. 2007) also have shown some preliminary success.

The findings from this literature review are supported by a recent qualitative study by this research team about ‘best practice’ during the transition to adulthood for youth with disabilities (Stewart et al. 2009). Focus groups, individual interviews and expert panel consensus meetings took place with over 50 people in one Canadian province, including youth with different disabilities, parents, community members, educators, service providers and researchers. The findings identified six common elements for best practice in transition services and supports:

- collaboration among everyone involved, with youth at the centre;
- building capacity of all persons involved in transition and also within the environments of communities and society at large);
- navigation to support youth and families through the transition;
- information that is accessible and useful to everyone involved;
- education at all levels including youth, families, community members, service providers and society; and
- ongoing research to provide the evidence needed to move forward (Stewart et al. 2009).

Although the evidence from this literature review identifies many successful elements and factors that should be part of best practice, it is not clear yet which combination of the different elements/factors can make the most difference. Furthermore, although recent evidence indicates that outcomes of participation, quality of life and inclusion are important for youth with disabilities in transition, these have not been put into practice or studied in great depth. Pilot projects and demonstration projects are needed to combine the “best practice” factors together using applied research methods and appropriate outcome measures. More research is needed about models that work and outcomes that matter. As more is learned about what does work, rigorous and controlled studies, with sound outcome measures are needed (Bowe 2003). Studies of the effectiveness of services and supports also need to focus on the influence of the environment, including service providers, community members and legislation, and person-environment interactions.

## **Conclusion**

This literature review summarizes a vast and growing body of published, ‘evidence-based’ literature about the transition to adulthood for youth with disabilities. It is evident that there is a great deal of knowledge about separate ‘components’ of transition: the different perspectives and experiences; different types of transition; different domains; and various factors (often separated in the literature into barriers and supports). Although recent literature is identifying that there are many complexities involved in the transition to adulthood, the findings of this review indicate that the various elements and factors that interact with each other have been studied mostly in isolation.

Transition to adulthood is now viewed as a complex phenomenon and this is leading researchers to study interactions of person and environment, as well as dynamic processes, opportunities, and other complexities. The current move towards an interactional framework of practice, research and policy development is not without its challenges. For example, the cyclical and dynamic nature of the transition process challenges methods of inquiry and research to keep up. And some outcome measures that are being used in research studies are not addressing current beliefs about development, experience, participation and disability, and the relationships between them.

Another challenge raised in recent articles relates to the disconnect between youth with and without disabilities. Although recent evidence indicates that they have the same aspirations and want the same outcomes, most research on transition to adulthood is separate for youth with and without disabilities. It may be useful and cost effective to connect ‘typical’ transition frameworks and ‘disability’ frameworks for future study, to learn more about similarities and differences and promote an inclusive approach to research.

Challenges also exist between a holistic/interactional approach to transition and disability that most people, organizations and governments aspire to, and current organizational and system differences and needs. Researchers, organizations and services will need to put aside the view that ‘our group is different/special’ and recognize that, while there will

always be unique situations and needs, more progress in studying this complex issue and providing appropriate services and supports may take place if everyone works together.

## References

- Agran M, Blanchard C, Wehmeyer M. 2000. Promoting transition goals and self-determination through student self-directed learning: The self-determined learning model of instruction. *Education and Training in Mental Retardation/Developmental Disabilities* 35(4):351-64.
- Algozzine B, Browder D, Karvonen M, Test D, Wood W. 2001. Effects of interventions to promote self-determination for individuals with disabilities. *Review of Educational Research* 71(2):219-77.
- Alpern CS, Zager D. 2007. Addressing communication needs of young adults with autism in a college-based inclusion program. *Education and Training in Mental Retardation/Developmental Disabilities* 42(4):428-36.
- Anderson CJ, Vogel LC, Betz RR, Willis KM. 2004. Overview of adult outcomes in pediatric-onset spinal cord injuries: Implications for transition to adulthood. *Journal of Spinal Cord Medicine* 27(Suppl 1):S98-106.
- Anderson CJ, Vogel LC, Willis KM, Betz RR. 2006. Stability of transition to adulthood among individuals with pediatric-onset spinal cord injuries. *Journal of Spinal Cord Medicine* 29(1):46-56.
- Annable G, Watters C, Stienstra D, Symanzik S, Tully BL, Stuewer N. 2003. Students with disabilities. Transition from post-secondary education to work. Phase I report. Winnipeg, Manitoba: Canadian Centre of Disability Studies.
- Armstrong KH, Dedrick RF, Greenbaum PE. 2003. Factors associated with community adjustment of young adults with serious emotional disturbance: A longitudinal analysis. *Journal of Emotional and Behavioral Disorders* 11:66-76.
- Baldassano R, Ferry G, Griffiths A, Mack D, Markowitz J, Winter H. 2002. Transition of the patients with inflammatory bowel disease from pediatric to adult care: Recommendations of the North American society for pediatric gastroenterology, hepatology and nutrition. *Journal of Pediatric Gastroenterology and Nutrition* 34(245).
- Baltodano HM, Mathur SR, Rutherford RB. 2005. Transition of incarcerated youth with disabilities across systems and into adulthood. *Exceptionality*. 00/00(2):103-24.
- Bell L. 2007. Adolescent dialysis patient transition to adult care: A cross-sectional survey. *Pediatric Nephrology* 22(5):720-6.

- Bent N, Tennant A, Swift T, Posnett J, Scuffham P, Chamberlain MA. 2002. Team approach versus ad hoc health services for young people with physical disabilities: A retrospective cohort study. *Lancet*. 360(9342):1280-6.
- Beresford B. 2004. On the road to nowhere? Young disabled people and transition. *Child Care Health and Development* 30(6):581-7.
- Berge JM, Patterson JM, Goetz D, Milla C. 2007. Gender differences in young adults' perceptions of living with cystic fibrosis during the transition to adulthood: A qualitative investigation. *Families, Systems, and Health* 25(2):190-203.
- Betz CL. 2007. Facilitating the transition of adolescents with developmental disabilities: Nursing practice issues and care. *Journal of Pediatric Nursing* 22(2):103-15.
- Betz CL. 2004. Transition of adolescents with special health care needs: Review and analysis of the literature. *Issues in Comprehensive Pediatric Nursing* Jul-Sep; 27(3):179-241.
- Betz CL, Redcay G. 2002. Lessons learned from providing transition services to adolescents with special health care needs. *Issues in Comprehensive Pediatric Nursing* 25(2):129-49.
- Binks JA, Barden WS, Burke TA, Young NL. 2007. What do we really know about the transition to adult-centered health care? A focus on cerebral palsy and spina bifida. *Archives of Physical Medicine and Rehabilitation* 88:1064-73.
- Blacher J. 2001. Transition to adulthood: Mental retardation, families, and culture. *American Journal of Mental Retardation* 106(2):173-88.
- Black RS, Mraskek KD, Ballinger R. 2003. Individualist and collectivist values in transition planning for culturally diverse students with special needs. *Journal for Vocational Special Needs Education* 25(2):20.
- Blue-Banning M, Turnbull AP, Pereira L. 2002. Hispanic youth/young adults with disabilities: Parents' visions for the future. *Research and Practice for Persons with Severe Disabilities* 27(3):204-19.
- Blum RW. 2002. Introduction: Improving transition for adolescents with special health care needs from pediatric to adult-centered health care. *Pediatrics* 110(6 Pt 2):1301-3.
- Blum RW, et al. 2002. A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics* 110(6):1304-6.
- Bolton-Maggs PHB. 2007. Transition of care from paediatric to adult services in haematology. *Archives of Disease in Childhood* 92(9):797.

- Bowe FG. 2003. Transition for deaf and hard-of-hearing students: A blueprint for change. *Journal of Deaf Studies and Deaf Education* 8(4):485-93.
- Burchardt T. 2004. Aiming high: The educational and occupational aspirations and of young disabled people. *Support for Learning* 19(4):181-6.
- Burgstahler S. 2003. The role of technology in preparing youth with disabilities for postsecondary education and employment. *Journal of Special Education Technology* 18(4):7-19.
- Callahan ST, Cooper WO. 2007. Continuity of health insurance coverage among young adults with disabilities. *Pediatrics* 119(6):1175-80.
- Cameron L, Murphy J. 2002. Enabling young people with a learning disability to make choices at a time of transition. *Journal of the British Institute of Learning Disabilities* 30(3):105-12.
- Canadian Centre on Disability Studies. 2004. Students with disabilities: Transitions from post-secondary education to work. Phase two report. Winnipeg, Manitoba: Canadian Centre on Disability Studies.
- Canadian National Institute for the Blind. 2006. The status of Canadian youth who are blind or visually impaired: A study of lifestyles, quality of life and employment. CNIB.
- Canobbio MM, Higgins S. 2004. Transitional care issues for the adolescent with congenital heart disease. *Nursing Clinics of North America* 39(4).
- Carnaby S, Lewis P, Martin D, Naylor J, Stewart D. 2003. Participation in transition review meetings: A case study of young people with learning disabilities leaving a special school. *British Journal of Special Education* 30(4):187-93.
- Carter EW, Lunsford LB. 2005. Meaningful work: Improving employment outcomes for transition-age youth with emotional and behavioral disorders. *Preventing School Failure* 49(2):63-9.
- Carter EW, Lane KL, Pierson MR, Glaeser B. 2006. Self-determination skills and opportunities of transition-age youth with emotional disturbance and learning disabilities. *Exceptional Children* Spr; 72(3):333-46.
- Caton S, Kagan C. 2007. Comparing transition expectations of young people with moderate learning disabilities with other vulnerable youth and with their non-disabled counterparts. *Disability and Society* 22(5):473-88.



- Cavin M, Alper S, Sinclair T, Sitlington PL. 2001. School to adult life: An analysis of transition programs serving youth with disabilities between 1986 and 1999. *Journal for Vocational Special Needs Education* 04;23(3):3-14.
- Certo NJ, Mautz D, Smalley K, Wade HA, Luecking R, Pumpian I, Sax C, Noyes D, Wechsler J, Batterman N. 2003. Review and discussion of a model for seamless transition to adulthood. *Education and Training in Developmental Disabilities* 38(1):3-17.
- Chambers CR, Hughes C, Carter EW. 2004. Parent and sibling perspectives on the transition to adulthood. *Education and Training in Developmental Disabilities* 39(2):79-94.
- Committee on Disability in America. 2007. Health care transitions for young people. In: M. J. Field, A. M. Jette, editors. *Future of disability in America*. Washington, DC: The National Academies Press.
- Community Living Research Project. 2006. Young adults with developmental disabilities: Transition for high school to adult life. literature and initial program review. Vancouver, BC: School of Social Work and Family Studies, University of British Columbia.
- Conti-Ramsden G, Botting N, Durkin K. 2008. Parental perspectives during the transition to adulthood of adolescents with a history of specific language impairment (SLI). *Journal of Speech, Language, and Hearing Research* 51(1):84.
- Cook A, Rushton BS, McCormick SM, Southall DW. Guidelines for the management of study transition. The STAR (Student Transition and Retention) Project. [Internet] [Cited 2009 May 30]. 2005. Available from: [http://www.ulster.ac.uk/star/resources/star\\_guidelines.pdf](http://www.ulster.ac.uk/star/resources/star_guidelines.pdf).
- Cooney BF. 2002. Exploring perspectives on transition of youth with disabilities: Voices of young adults, parents, and professionals. *Mental Retardation* 40(6):425-35.
- Corbett WP, Clark HB, Blank W. 2002. Employment and social outcomes associated with vocational programming for youths with emotional or behavioral disorders. *Behavioral Disorders* 27(4):358-70.
- Davis M, Geller JL, Hunt B. 2006. Within-state availability of transition-to-adulthood services for youths with serious mental health conditions. *Psychiatric Services* 57(11):1594-9.
- Davis M, Sondheimer DL. 2005. State child mental health efforts to support youth in transition to adulthood. *Journal of Behavioral Health Services and Research* 32(1):27-42.

- Dolyniuk CA, Kamens MW, Corman H, DiNardo PO, Totaro RM, Rockoff JC. 2002. Students with developmental disabilities go to college: Description of a collaborative transition project on a regular college campus. *Focus on Autism and Other Developmental Disabilities* 17(4):236-41.
- Edmondson CA, Cain HM. 2002. The spirit of the Individuals with Disabilities Education Act: Collaboration between special education and vocational rehabilitation for the transition of students with disabilities. *Journal of Applied Rehabilitation Counseling* 33(4):10-4.
- Evans J, McDougall J, Baldwin P. 2006. An evaluation of the "youth en route" program. *Physical and Occupational Therapy in Pediatrics* 26(4):63-87.
- Feldman BJ, Conger RD, Burzette RG. 2004. Traumatic events, psychiatric disorders, and pathways of risk and resilience during the transition to adulthood. *Research in Human Development* 1(4):259-90.
- Foster S, MacLeod J. 2004. The role of mentoring relationships in the career development of successful deaf persons. *Journal of Deaf Studies and Deaf Education* 9(4):442-58.
- Freed GL, Hudson EJ. 2006. Transitioning children with chronic diseases to adult care: Current knowledge, practices, and directions. *Journal of Pediatrics* 148(6):824-7.
- Galambos NL, Darrah J, Magill-Evans J. 2007. Subjective age in the transition to adulthood for persons with and without motor disabilities. *Journal of Youth and Adolescence* 36(6):825-34.
- Gall C, Kingsnorth S, Healy H. 2006. Growing up ready: A shared management approach. *Physical and Occupational Therapy in Pediatrics* 26(4):47-62.
- Geenen SJ, Powers LE, Sells W. 2003. Understanding the role of health care providers during the transition of adolescents with disabilities and special health care needs. *Journal of Adolescent Health* 32(3):225-33.
- Glidden LM, Jobe BM. 2007. Measuring parents daily rewards and worries in the transition to adulthood. *American Journal of Mental Retardation* 112(4):275--288.
- Golsch K. 2003. Employment flexibility in Spain and its impact on transitions to adulthood. *Work Employ Society* 17(4):691-718.
- Gordon-Larsen P, Adair LS, Nelson MC, Popkin BM. 2004. Five-year obesity incidence in the transition period between adolescence and adulthood: The National Longitudinal Study of Adolescent Health. *American Journal of Clinical Nutrition* 80(3):569-75.

- Goupil G, Tassé MJ, Garcin N, Doré C. 2002. Parent and teacher perceptions of individualised transition planning. *British Journal of Special Education* September 2002; 29(3):127-35.
- Hart D. 2001. Interagency partnerships and funding: Individual supports for youth with significant disabilities as they move into postsecondary education and employment options. *Journal of Vocational Rehabilitation* 16(3):145-54.
- Haynes RB, Devereaux PJ, Guyatt GH. 2002. Physicians' and patients' choices in evidence based practice. *BMJ*. 324:1350
- Hendey N, Pascall G. 2001. Disability and transition to adulthood. Achieving independent living. [Internet]. [cited 2009 June 16]. 2001. Available from: [http://eprints.nottingham.ac.uk/845/1/Hendey\\_Pascall\\_FINAL.pdf](http://eprints.nottingham.ac.uk/845/1/Hendey_Pascall_FINAL.pdf).
- Hitchings WE, Luzzo DA, Ristow R, Horvath M, Retish P, Tanners A. 2001. The career development needs of college students with learning disabilities: In their own words. *Learning Disabilities Research and Practice* 16(1):8-17.
- Hughes C. 2001. Transition to adulthood: Supporting young adults to access social, employment, and civic pursuits. *Mental retardation and Developmental Disabilities Research Reviews* 7(2):84-90.
- Hussain Y. 2003. Transitions into adulthood: Disability, ethnicity and gender among British South Asians. *Disability Studies Quarterly* 23(2):100-12.
- Ikiugu M, Ciaravino EA. 2006. Assisting adolescents experiencing emotional and behavioral difficulties (EBD) transition to adulthood. *International Journal of Psychosocial Rehabilitation* 10(2):57-78.
- Izzo MV, Lamb P. 2003. Developing self-determination through career development activities: Implications for vocational rehabilitation counselors. *Journal of Vocational Rehabilitation* 19:71-8.
- Jonikas JA, Laris A, Cook JA. 2003. The passage to adulthood: Psychiatric rehabilitation service and transition-related needs of young adult women with emotional and psychiatric disorders. *Psychiatric Rehabilitation Journal* 27(2):114-21.
- Kaufman M, Pinzon J. 2007. Transition to adult care for youth with special health care needs. *Paediatrics and Child Health* 9(12):785-8.
- King GA, Baldwin PJ, Currie M, Evans J. 2005. Planning successful transitions from school to adult roles for youth with disabilities. *Children's Health Care*. 34(3):193-216.

- Kingsnorth S, Healy H, MacArthur C. 2007. Preparing for adulthood: A systematic review of life skill programs for youth with physical disabilities. *Journal of Adolescent Health* 41(4):323-32.
- Kohler PD, Hood, LK.. Improving student outcomes: Promising practices and programs for 1999-2000. A directory of innovative approaches for providing transition services for youth with disabilities. [Internet]. [cited 2009 May 26]. 2000. Available from: <http://www.ed.uiuc.edu/sped/tri/institute.html>.
- Kraemer BR, McIntyre LL, Blacher J. 2003. Quality of life for young adults with mental retardation during transition. *Mental Retardation* 41(4):250-62.
- Learning Disabilities Association of Canada. 2007. Putting a Canadian face on learning disabilities (PACFOLD). Ottawa ON: LDAC.
- Lehman CM, Clark HB, Bullis M, Rinkin J, Castellanos LA. 2002. Transition from school to adult life: Empowering youth through community ownership and accountability. *Journal of Child and Family Studies* 11(1):127-41.
- Lord J, Hutchison P. 2003. Individualized support and funding: Building blocks for capacity building and inclusion. *Disability and Society* 18:1, 71-86.
- Lotstein DS, McPherson M, Strickland B, Newacheck PW. 2005. Transition planning for youth with special health care needs: Results from the National survey of children with special health care needs. *Pediatrics* 115(6):1562-8.
- Madaus JW, Shaw SF. 2006. The impact of the IDEA 2004 on transition to college for students with learning disabilities. *Learning Disabilities Research and Practice* 21(4):273-81.
- Magill-Evans J, Wiart L, Darrah J, Kratochvil M. 2005. Beginning the transition to adulthood: The experiences of six families with youths with cerebral palsy. *Physical and Occupational Therapy in Pediatrics* 25(3):19-36.
- McDonagh J. 2006. Editorial: Lost in transition? Between paediatric and adult services. *BMJ*. 332(435):436.
- McDonagh JE, Shaw KL, Southwood TR. 2006. Growing up and moving on in rheumatology: Development and preliminary evaluation of a transitional care programme for a multicentre cohort of adolescents with juvenile idiopathic arthritis. *Journal of Child Health Care* 10(1):22-42.
- McDonagh JE, Southwood TR, Shaw KL. 2007. The impact of a coordinated transitional care programme on adolescents with juvenile idiopathic arthritis. *Rheumatology*. Jan (1):161-8.

- Mirfin-Veitch B. 2003. Education for adults with an intellectual disability (including transition to adulthood): Review of the literature prepared for the national advisory committee on health and disability. Wellington, New Zealand: Donald Beasley Institute.
- Mull CA, Sitlington PL. 2003. The role of technology in the transition to postsecondary education of students with learning disabilities: A review of the literature. *Journal of Special Education* 37(1):26-33.
- Murray C. 2003. Risk factors, protective factors, vulnerability, and resilience: A framework for understanding and supporting the adult transitions of youth with high-incidence disabilities. *Remedial and Special Education* 01;24(1):16-26.
- Nagle K. 2001. Transition to employment and community life for youths with visual impairments: Current status and future directions. *Journal of Visual Impairment and Blindness* 95(12).
- National Secondary Transition Technical Assistance Centre (NSTTAC) 2008. Team planning tool for State capacity building: Secondary education and transition services. Charlotte NC. [Internet] [Cited 2009 June 28. 2009. Available from: [http://www.nsttac.org/pdf/state\\_cap\\_building\\_tool.pdf](http://www.nsttac.org/pdf/state_cap_building_tool.pdf).
- Neubert DA. 2001. Post-secondary educational practices for individuals with mental retardation and other significant disabilities: A review of the literature. *Journal of Vocational Rehabilitation* 16(3):155-68.
- O'Leary C, Wieneke P, Healy M, Cronin C, O'Regan P, Shanahan F. 2004. Celiac disease and the transition from childhood to adulthood: A 28-year follow-up. *American Journal of Gastroenterology* 99(12):2437-41.
- Osgood DW, Foster EM, Flanagan C Ruth GR (Eds.) *On your own without a net: The transition to adulthood for vulnerable populations*. 2005. Chicago, IL, US: Univ Chicago Press.
- Östlie IL, Dale Ö, Möller A. 2007. From childhood to adult life with juvenile idiopathic arthritis (JIA): A pilot study. *Disability and Rehabilitation* 29(6):445.
- Pacaud D, Yale JF, Stephure D, Trussell R, Davies HD. 2005. Problems in transition from pediatric care to adult care for individuals with diabetes. *Canadian Journal of Diabetes* 29(1):13-8.
- Palladino JM. 2006. "Don't sell them dreams without the foundations": Collaboration for the transitional needs of foster care adolescents with disabilities. *High School Journal* 90(1):22-32.

- Password F. 2007. Re-defining 'norms': D/deaf young people's transitions to independence. *Sociological Review* 55(1):104-23.
- Pavey BE. 2005. A survey of transition-to-adulthood education for young people with developmental disabilities in the UK. *British Journal of Developmental Disabilities* 51(part 2(101):117-28.
- Powers K, Hogansen J, Geenen S, Powers LE, Gil-Kashiwabara E. 2008. Gender matters in transition to adulthood: A survey study of adolescents with disabilities and their families. *Psychology in the Schools* 2008; 45(4):349-64.
- Powers LE, Garner T, Valnes B, Squire P, Turner A, Couture T, Dertinger R. 2007. Building a successful adult life: Findings from youth-directed research. *Exceptionality: Special Issue: Self-Determination*. 15(1):45-56.
- Radovick S, DiVall S. 2007. Approach to the growth hormone-deficient child during transition to adulthood. *Journal of Clinical Endocrinology and Metabolism* 92(4):1195-200.
- Rapanaro C, Bartu A, Lee AH. 2008. Perceived benefits and negative impact of challenges encountered in caring for young adults with intellectual disabilities in the transition to adulthood. *Journal of Applied Research in Intellectual Disabilities* 21(1):34-47.
- Reid GJ, Irvine MJ, McCrindle BW, Sananes R, Ritvo PG, Siu SC, Webb GD. 2004. Prevalence and correlates of successful transfer from pediatric to adult health care among a cohort of young adults with complex congenital heart defects. *Pediatrics* 113(3 Pt 1):e197-205.
- Reiss J, Gibson R. 2002. Health care transition: Destinations unknown. *Pediatrics* 110:1307-14.
- Richards M, Vostanis P. 2004. Interprofessional perspectives on transitional mental health services for young people aged 16-19 years. *Journal of Interprofessional Care* 18(2):115-28.
- Robertson LP, McDonagh JE, Southwood TR, Shaw KL. 2006. Growing up and moving on. A multicentre UK audit of the transfer of adolescents with juvenile idiopathic arthritis from paediatric to adult centred care. *BMJ* 332(7547):74.
- Saigal S, Stoskopf B, Streiner D, Boyle M, Pinelli J, Paneth N, Goddeeris J. 2006. Transition of extremely low-birth-weight infants from adolescence to young adulthood: Comparison with normal birth-weight controls. *JAMA* 295(6):667-75.

- Salmon N, Kinnealey M. 2007. Paving rough roads: Transition to life beyond the classroom as experienced by students with disabilities and their families. *Exceptionality Education Canada* 17(1):53-84.
- Shaw KL, Southwood TR, McDonagh JE. 2007. Young people's satisfaction of transitional care in adolescent rheumatology in the UK. *Child: Care, Health and Development* 33(4):368-79.
- Shroedel JG, Geyer PD. 2000. Long-term career attainments of deaf and hard of hearing college graduates: Results from a 15-year follow-up study. *American Annals of the Deaf* 145(4):303-14.
- Stewart D. 2006. Evidence to support a positive transition into adulthood for youth with disabilities. *Physical and Occupational Therapy in Pediatrics* 26(4):1-4.
- Stewart, D, Freeman M, Law M, Healy H, Burke-Gaffney J, Forhan M, Young N, Guenther S. "The best journey to adult life" for youth with disabilities. An evidence-based model and best practice guidelines for the transition to adulthood. [Internet] [Cited 2009 May 28]. 2009. Available from: <http://transitions.canchild.ca/en/OurResearch/bestpractices.asp>
- Stewart D, Stavness C, King G, Antle B, Law M. 2006. A critical appraisal of literature reviews about the transition to adulthood for youth with disabilities. *Physical and Occupational Therapy in Pediatrics* 26(4):5-24.
- Stewart D, Law M, Rosenbaum P, Willms DG. 2001. A qualitative study of the transition to adulthood for youth with physical disabilities. *Physical and Occupational Therapy in Pediatrics* 21(4):3-21.
- United States Department of Education (n.d.). Special education and rehabilitation legislation. Retrieved May 1, 2009 from: <http://www.ed.gov/policy/speced/leg/edpicks.jhtml>
- Van Naarden Braun K, Yeargin-Allsopp M, Lollar D. 2006. A multi-dimensional approach to the transition of children with developmental disabilities into young adulthood: The acquisition of adult social roles. *Disability and Rehabilitation* 2006 Aug15; 28(15):915-28.
- Vander Stoep, A., Weiss, N.S., McKnight B, Beresford SAA, Cohen P. 2002. Which measure of adolescent psychiatric disorder—diagnosis, number of symptoms, or adaptive functioning—best predicts adverse young adult outcomes? *Journal of Epidemiology and Community Health* 56(1):56-65.
- Vander Stoep A, Beresford SA, Weiss NS, McKnight B, Cauce AM, Cohen P. 2000. Community-based study of the transition to adulthood for adolescents with psychiatric disorder. *American Journal of Epidemiology* 152(4):352-62.

- Verlinde F et al. 2004. Belgian Study Group of Paediatric, Endocrinology. Health and psychosocial status of patients with turner syndrome after transition to adulthood: The Belgian experience. *Hormone Research* 62(4):161-7.
- Wagner M, Kutash K, Duchnowski AJ, Epstein MH. 2005. The special education elementary longitudinal study and the national longitudinal transition study: Study designs and implications for children and youth with emotional disturbance. *Journal of Emotional and Behavioral Disorders* 13(1):25-42.
- Wagner M, Newman L, Cameto R, Levine P, Garza, N. An overview of findings from wave 2 of the National Longitudinal Transition Study-2 (NLTS2) [Internet]. [cited 2009 May 26]; 2006. Available from: <http://ies.ed.gov/pubsearch/pubsinfo.asp?pubid=NCSER20063004>
- Wagner M, Davis M. 2006. How are we preparing students with emotional disturbances for the transition to young adulthood? Findings from the National Longitudinal Transition Study - 2. *Journal of Emotional and Behavioral Disorders* 14(2):86-98.
- Wagner M, Newman L, Cameto R, Levine P. 2005. Changes over time in the early postschool outcomes of youth with disabilities. A report of findings from the national longitudinal transition study (NLTS) and the national longitudinal transition study-2 (NLTS2). National Center for Special Education Research, Washington, DC.
- Ward L, Heslop P, Mallett R, Simons K. 2003. Transition: The experiences of young people with learning disabilities and their families in England. *Tizard Learning Disability Review* 8(4):19-28.
- Wehmeyer ML, Garner N, Yeager D, Lawrence M, Davis AK. 2006. Infusing self-determination into 18–21 services for students with intellectual or developmental disabilities: A multi-stage, multiple component model. *Education and Training in Mental Retardation/Developmental Disabilities* 41(1):3-13.
- Wehmeyer ML, Palmer SB. 2003. Adult outcomes for students with cognitive disabilities three years after high school: The impact of self-determination. *Education and Training in Develop Disabil.* 38:131-44.
- Wells T, Sandefur GD, Hogan DP. 2003. What happens after the high school years among young persons with disabilities? *Social Forces* 82(2):803-32.
- While A, Forbes A, Ullman R, Lewis S, Mathes L, Griffiths P. 2004. Good practices that address continuity during transition from child to adult care: Synthesis of the evidence. *Child: Care, Health and Development* 30:439.



- White J. 2004. Influence of least restrictive environment and community based training on integrated employment outcomes for transitioning students with severe disabilities. *Journal of Vocational Rehabilitation* 21(3):149-56.
- White PH. 2002. Transition: A future promise for children and adolescents with special health care needs and disabilities. *Rheumatic Disease Clinics of North America* Aug; 28(3):687.
- Wilson J. 2003. Mentors: Paving the transition from school to adulthood for students with disabilities. *American Rehabilitation* 27(1):0-2.
- Wittenburg DC, Maag E. 2002. School to where? A literature review on economic outcomes of youth with disabilities. *Journal of Vocational Rehabilitation* 17(4):265-80.
- Wojciechowski EA, Hurtig A, Dorn L. 2002. A natural history study of adolescents and young adults with sickle cell disease as they transfer to adult care: A need for case management services. *Journal of Pediatric Nursing* 17(1):18-27.
- Wong ME. 2004. Higher education or vocational training? Some contributing factors to post-school choices of visually impaired students in Britain. Part 1, Great Britain. *British Journal of Visual Impairments* 22(1):37.
- Wynn K, Stewart D, Law M, BurkeGaffney J, Moning T. 2006. Creating connections: A community capacity-building project with parents and youth with disabilities in transition to adulthood. *Physical and Occupational Therapy in Pediatrics* 26(4):89-103.
- Young NL. 2007. The transition to adulthood for children with cerebral palsy: What do we know about their health care needs? *Journal of Pediatric Orthopedics* 27(4):476-9.
- Young NL, Gilbert TK, McCormick A, Ayling-Campos A, Boydell K, Law M, Fehlings DL, Mukherjee S, Wedge JH, Williams JI. 2007. Youth and young adults with cerebral palsy: Their use of physician and hospital services. *Archives of Physical Medicine and Rehabilitation* 88(6):696-702.

## **Figure 1: Inclusion and Exclusion Criteria for literature review**

### **Inclusion Criteria**

- Published in past 8 years (2000-2008)
- ‘Evidence based’ references – including research, evaluations, ‘review’ articles, research/policy briefs and descriptions of programs and services related to transition to adulthood
- International scope
- The population of interest is young people, ages 14 to 29 years of age with “disabilities”
  - disabilities/impairments that are chronic (lifecourse) in nature. This may include conditions that are congenital in nature (including physical, developmental, learning, behavioural/emotional, mental,) or acquired (e.g. traumatic brain injury, spinal cord injury)
  - Multiple or complex disabilities
  - Chronic medical conditions, such as cystic fibrosis
  - Language/communication disorders
- Articles need to specify ‘transition to adulthood’ (or similar phrase, for example, ‘growing up’) in the title, abstract, or keywords

### **Exclusion**

- Literature that is purely theoretical or conceptual about transition to adulthood
- Literature that is focused on a concept or service delivery issue that is related to transition to adulthood but not directly focused on transition. For example, articles that focus on adolescent issues only but not the transition to adulthood.
- Older articles, pre-2000