

# **Annotated bibliography of literature on transition to adulthood for youth with disabilities**

## **Thematic analysis**

This annotated bibliography was compiled as part of a study on the transition to adulthood for youth with disabilities in Canada, which was conducted in 2007-08. The literature covers the years 2000 – 2007.

The annotated bibliography is organized by qualitative themes that emerged from a critical review of the published and unpublished literature. These themes are simply one way to organize the large amount of literature. Cross-referencing is done for articles that fit under more than one theme.

Within each theme, published and unpublished literature is presented separately. The published literature is primarily ‘evidence-based’ – research reports, studies or review articles. The unpublished literature is a representation of the vast amount of resources available either online or in hard copy that met quality indicators established by CanChild Centre for Childhood Disability Research.

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### **Theme #1: Current Experiences and Outcomes of the Transition to Adulthood for Youth with disabilities**

This theme includes literature about ‘what is happening’ right now related to transition to adulthood – the literature describes current experiences of different people involved in the transition process, and the outcomes, both positive and negative. Most of the literature is from North America. The unpublished literature is subdivided by different perspectives of youth, parents, service providers, community members, and also policy perspectives.

### **Published Literature**

Baltodano, H. M., Mathur, S. R., & Rutherford, R. B. (2005). Transition of incarcerated youth with disabilities across systems and into adulthood. *Exceptionality*, (2), 103-124.

**Synthesis:** This article examines the contextual factors that influence the transition success or failure of youth with disabilities in the juvenile justice system. Specifically, 10 research studies conducted by graduate students and faculty in the special education program at Arizona State University are reviewed. The research focused on identifying factors associated with successful and unsuccessful transition of youth from incarceration to school, work, and the community. The study highlights implications for designing and implementing appropriate programming and transition planning to address the needs of youth exiting the correctional system. The specific research topics related to transition include preplacement planning, locus of control, engagement, peer influence, quality of transition programming, gender specific programming, and adult mentoring and support.

Beresford, B. (2004). On the road to nowhere? Young disabled people and transition. *Child Care Health and Development*, 30(6), 581-587.

**Synthesis:** A key issue and one known to be highly problematic and challenging, concerns the transition of young disabled people from children's services to adult services, and from childhood to adulthood. To inform its recommendations on this issue, the Disabled Children's External Working Group (EWG) for the Children's NSF in the UK commissioned a review of research on young disabled people and transition. The evidence available with regard to transitions of young disabled people provides a clear and consistent picture of the way transitions are currently experienced by young disabled people and their families. There is limited evidence on what works to ensure smooth transitions between services and positive outcomes of transition for the young people themselves. Existing research is very persuasive on the need to improve transitions for young disabled people. This review highlights the importance of 1) not moving an individual from one service to another but seeing transition as a way of supporting a young adult to move towards and onto a new life stage, and 2) that supports for young persons cannot come from one agency alone, 3) transitioning needs to be viewed long term and flexibly, and 4) services, facilities, and opportunities for young people need to be in place and available. The article recommends further research at the level of specific service model evaluations as well as holistic, longitudinal work to provide evidence on the long-term outcomes of young disabled people as they move into adulthood.

Betz, C. L. (2004). Transition of adolescents with special health care needs: Review and analysis of the literature. *Issues in Comprehensive Pediatric Nursing*, 27(3), 179-241.

**Synthesis:** This article summarizes a US article that reviewed and analysed 43 transition studies published from 1982 through 2003. The studies reviewed represented the diverse purposes of international researchers for examining transition issues within health and medical care. Findings of this literature review indicate that transition research is in early stages of development. A number of limitations were associated with these studies, including the lack of theoretical frameworks, the lack of use of valid and reliable instruments, and research designs lacking adequate controls. The results of the review identified numerous barriers to the transition process: some barriers exist within the youth themselves, such as maturity level and age; but most of the barriers were systemic in nature, including lack of communication between providers, lack of expertise of service providers, and lack of educational information. The authors recommend further research studies that overcome the design limitations of past investigations.

Burchardt, T. (2004). Aiming high: The educational and occupational aspirations and of young disabled people. *Support for Learning, 19*(4), 181-186.

**Synthesis:** This review article provides an overview of the aspirations and expectations disabled teenagers form for their future education and employment and the factors which are associated with positive aspirations. The results indicate that young disabled people have similar aspirations to their non-disabled counterparts, although tempered in some cases with recognition that there are likely to be obstacles in the world of work. There is also some tentative evidence that young disabled people feel less well served by advice and support services. A recommendation is made for service providers to ensure that they encourage positive aspirations, especially among young people from disadvantaged backgrounds, while offering practical support in overcoming disabling barriers.

Canadian National Institute for the Blind (CNIB) (2006). *The status of Canadian youth who are blind or visually impaired: A study of lifestyles, quality of life and employment*. Toronto, ON: CNIB.

**Synthesis:** This is a Canadian nationwide study aimed at learning more about the daily lives of youth who are blind or visually impaired. The study was designed to explore the lives of youth in four domains: employment, activities of daily living, social life, and academics. Comparisons were made between blind youth and those with visual impairments. There are three key recommendations that can be drawn from this article. One, that it is important that youth receive extensive vocational counseling as early in their lives as possible. Two, that parents of youth with visual impairments be educated about just how important it is that their children develop and utilize skills of daily living. Three, that counselors have an appreciation for some of the difficulties that youth who are partially sighted may experience as they engage in activities alongside sighted peers.

Committee on Disability in America. (2007). Health care transitions for young people. In M. J. Field, & A. M. Jette (Eds.), *Future of disability in America* (pp. 4-1). Washington, DC: The National Academies Press.

**Synthesis:** This is one section in a large document on "Future of Disability in America" that focuses on the transition to adult care and services for youth with health conditions. A life span perspective is used to review the various individual, family and environmental factors that influence this transition. Barriers are identified in relation to systems, services and attitudes. Two evolving models, the medical home model in pediatrics and the chronic care model in adult health care are summarized as promising approaches. This article also reviews current research on transition to adulthood and recommendations are made for future study, with a focus on evaluation of promising models. Furthermore, better preparation of health care workers and improvements in the organization and financing of the health care system in general are key recommendations.

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.

**Synthesis:** This Canadian report includes a summary of a literature review and informal conversations with professionals in the field of developmental disabilities. More details are provided for the province of British Columbia. The results identify three ways that transition planning is focused: 1. post-secondary education; 2. employment; and 3. day programs. The research found that many of the programs and supports outlined in the review focus on only one area in isolation from other areas of a young person's life. Furthermore, poor outcomes are still found in these areas. Legislation must be accompanied by system

change and needed supports for youth with disabilities. Further research is recommended to explore more holistic approaches to transition, and to learn more about the needs and desires of young adults with severe disabilities.

Geenen, S. J., Powers, L. E., & 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), 225-233.

**Synthesis:** The purpose of this study was to evaluate the role of health care providers in the transition from pediatric to adult health care for adolescents with disabilities and special health care needs (SHCN) from both the families' and providers' perspectives. A total of 753 parents of adolescents with SHCN (e.g. developmental, physical, behavioral/emotional, learning, or health-related disabilities) were surveyed by questionnaire to assess their perceptions of their health care provider's level of involvement in various transition activities and the extent to which they felt it was the provider's responsibility to assist in a particular activity. One hundred forty-one health care providers (primarily pediatricians) completed a parallel survey to assess their level of participation in the same transition activities and the extent to which they felt it was their responsibility to assist with each transition activity. There were significant differences between providers and parents concerning both the level of provider involvement and the extent to which it was the provider's responsibility to assist in various transition activities (e.g., health providers reported significantly more involvement than did parents for 11 of the 13 transition activities and, compared with parents, providers reported that it was more within their role to assist in these 11 transition activities). The findings suggest a need for health care providers and parents to have open discussions about the nature and extent to which providers assist families in key transition activities.

Goupil, G., Tassé, M. J., Garcin, N., & Doré, C. (2002). Parent and teacher perceptions of individualised transition planning. *British Journal of Special Education, 29*(3), 127-135.

**Synthesis:** This article presents the results from a pilot study of individualised transition planning (from school to adulthood) for students with learning disabilities in Québec, Canada. The results, based on the preparation of 21 individualised transition plans (ITP), indicate that while students had limited participation in their own ITP, parents were pleased with the ITP process. Parents and school personnel reported having little knowledge of community options available for the students with respect to residential settings. Finally, parents acknowledged that they had little knowledge and understanding of potential employers' expectations in relation to work for adults with disabilities.

Hitchings, W. E., Luzzo, D. A., 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.

**Synthesis:** The career development and disability knowledge of 97 students with learning disabilities from three postsecondary institutions in the Midwest States was examined through semi-structured interviews. Students with disabilities who were eligible for services while in high school generally did not engage in transition planning as required by federal law. Their career development activities were limited despite having unique career needs. The majority of students had difficulty describing their disability and its impact on their career exploration and planning. For students with learning disabilities at the postsecondary level, it is recommended that career development services should be provided, including training in self-advocacy and career exploration in the first two years

Killean, E., & Hubka, D. (1999). *Working towards a coordinated national approach to services, accommodations and policies for post-secondary students with disabilities: Ensuring access to higher education and career training*. Ottawa, ON: National Educational Association of Disabled Students (NEADS).

**Synthesis:** This Canadian publication presents the results of a survey of 70 service providers and 349 students that examined the level and types of services, the types of accommodations, and policy with respect to postsecondary students with disabilities across Canada. Service providers indicated that the model of service delivery at their institution was highly centralized or partially centralized, with very few indicating a decentralized model of delivery. Students are required to provide documentation in some cases in order to receive services at almost all the institutions represented. Respondents also indicated their institutions were planning modifications to physical accessibility more frequently than modification to programs or policies. Only 58.6 percent of institutions provided written materials to students with disabilities concerning services available to them. Student respondents indicated that most had a learning disability (36.1 percent), two-thirds required extended test time, and a little more than half required academic accommodations. Areas in which respondents frequently identified successful programs were: academic accommodations, adaptive technology, and academic support services. Students reported that the lack of an office that focused on disability service issues was one of the least successful features of access at their particular institutions. Appendices include assessment instruments.

Knapp, M., Perkins, M., Beecham, J., Dhanasiri, S. & Rustin, C. (2008). Transition pathways for young people with complex disabilities: exploring the economic consequences. *Child: Care, Health and Development*, 34, 4, 512 – 520.

**Synthesis:** The authors of this article sought to quantify the costs facing young disabled persons and their families in the United Kingdom. They also identify the societal impacts arising from the challenges these persons face when they reach adulthood. Through a literature review and statistical analyses of birth cohort data, they found that personal, family and social costs resulted from unsuccessful transitions are substantial and wideranging. There are also substantial costs to the state, either through missed opportunities for these young persons to contribute to the economy, or through dependence on social welfare. The authors call for increased spending on youth with disabilities in transition to adulthood to assist them in fulfilling their ambitions to participate fully in society.

Learning Disabilities Association of Canada (LDAC) (2007). *Putting a Canadian face of learning disabilities (PACFOLD)*. Ottawa ON: LDAC.

**Synthesis:** PACFOLD is an applied research study that was started in 2004 by the Learning Disabilities Association of Canada. The three phase project focused on obtaining, quantifying, and disseminating knowledge. The purpose was to provide a better understanding of the impact of learning disabilities on the lives of Canadian children, youth and adults, and the challenges they face. The study gathered data from 10 important Statistic Canada Surveys, including the Youth in Transition survey. The study also held focus groups across Canada in an attempt to help answer questions within the gaps identified from the quantitative data. All of the data are organized into the three main age groupings: 1) children, 2) youth, and 3) adults. The review indicates in its summary that all Canadians with learning disabilities are at a disadvantage, and that the learning disability impacts their lives and those around them. Recommendations also include information for all levels on the Canadian government.

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 & Occupational Therapy in Pediatrics, 25*(3), 19-36.

**Synthesis:** This Canadian qualitative study focused on the experiences of six 20- to 23-year-old persons with cerebral palsy and their parents during the transition to adulthood and explored perceived changes in their relationship. Three interrelated themes emerged: (a) perceptions of readiness for increased autonomy, (b) opportunities for the young adults to make independent decisions and learn from life experiences, and (c) shifting parental roles. The youths' autonomy related to parental perceptions of their readiness and push for autonomy, the parent's personal beliefs and readiness to support the changing relationship, and the parents' needs for separation from the child.

McDonagh, J. E., Southwood, T. R., & Shaw, K. L. (2004). Unmet education and training needs of rheumatology health professionals in adolescent health and transitional care. *Rheumatology, 43*(6), 737-743.

**Synthesis:** The aim of this study from the United Kingdom (UK) was to determine the perceived education and training needs of health professionals involved in transitional care for adolescents with juvenile idiopathic arthritis (JIA). The first survey was completed by 263 professionals. Education needs were reported by 114 (43%) of health professionals. Transition issues and informational resources were the most frequently reported areas of need. The second survey was completed by 22 clinical personnel who rated 'lack of training', 'lack of teaching materials geared towards adolescents' and 'limited clinic time' as the main barriers to providing developmentally appropriate care to adolescents. These unmet education and training needs of health care professionals provide useful directions for the development of future training programs.

Saigal, S., Stoskopf, B., Streiner, D., Boyle, M., Pinelli, J., Paneth, N., et al. (2006). Transition of extremely low-birth-weight infants from adolescence to young adulthood: Comparison with normal birth-weight controls. *JAMA, 295*(6), 667-675.

**Synthesis:** The purpose of this large Canadian study was to describe and compare the achievement and the age at attainment of the 'adult' markers between extremely low-birth-weight (ELBW) and normal birth-weight (NBW) young adults. A prospective, longitudinal, population-based study in Ontario, Canada, of 166 ELBW participants who weighed 501 to 1000 g at birth (1977-1982) and 145 sociodemographically comparable NBW participants assessed at young adulthood (22-25 years). Results found that at young adulthood, 149 (90%) of 166 ELBW participants and 133 (92%) of 145 NBW participants completed the assessments at mean (SD) age of 23.3 (1.2) years and 23.6 (1.1) years, respectively. The proportion who graduated from high school was similar (82% vs 87%,  $P = .21$ ). Overall, no statistically significant differences were observed in the education achieved to date. A substantial proportion of both groups were still pursuing postsecondary education (47 [32%] vs 44 [33%]). No significant differences were observed in employment/school status; 71 (48%) ELBW vs 76 (57%) NBW young adults were permanently employed ( $P = .09$ ). In a subanalysis, a higher proportion of ELBW young adults were neither employed nor in school (39 [26%] vs 20 [15%],  $P = .02$  by Holm's correction); these differences did not persist when participants with disabilities were excluded. No significant differences were found in the proportion living independently (63 [42%] vs 70 [53%],  $P = .19$ ), married/cohabitating (34 [23%] vs 33 [25%],  $P = .69$ ), or who were parents (16 [11%] vs 19 [14%],  $P = .36$ ). The age at attainment of the above markers was similar for both cohorts.

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.

**Synthesis:** This Canadian article critically reviews five review articles on the transition to adulthood for youth with disabilities to identify evidence about (1) the factors that help or hinder the transition process, and (2) "what's working" in transition services. The article identifies important "success" factors and elements of service delivery that are worthy of consideration by service providers and researchers. These include the need for skill development of youth with disabilities, environmental supports, and an individualized approach to service delivery. The article supports recommendations made by all five reviews for the need for more evidence to support the implementation and evaluation of best practice models/approaches that address the complex issue of the transition from paediatric to adult services for youth with disabilities.

Wagner, M., Newman, L., Cameto, R., Levine, P., & Garza, N. (2006). *An overview of findings from wave 2 of the National Longitudinal Transition Study-2 (NLTS2)*. National Center for Special Education Research. USA.

**Synthesis:** This report from the United States is an executive summary of two previously-released reports presenting findings from Wave 2: The Academic Achievement and Functional Performance of Youth with Disabilities and After High School: A First Look at the Postschool Experiences of Youth with Disabilities. Some key findings presented in the Overview include the following: (1) A direct assessment of students' language arts, mathematics abilities, and content knowledge in science and social studies suggests that from 77 to 86% of youth with disabilities have standard scores below the mean for the general population; (2) While about 2% of youth in the general population have standard scores that are more than two standard deviations below the mean (i.e., below 70), among youth with disabilities who participated in the NLTS2 direct assessment, from 14 to 27% had scores that were more than two standard deviations below the mean across subtests; (3) Up to 2 years after leaving high school, almost 8 in 10 out-of-school youth with disabilities have been engaged in postsecondary education, paid employment, or training to prepare them for employment; and (4) About 3 in 10 out-of-school youth with disabilities have been enrolled in some kind of postsecondary school since leaving high school, with one in five attending a postsecondary school at the time of the Wave 2 interview. This rate of current enrollment is less than half that of their peers in the general population.

Wittenburg, D. C., & Maag, E. (2002). School to where? A literature review on economic outcomes of youth with disabilities. *Journal of Vocational Rehabilitation*, 17(4), 265-280.

**Synthesis:** This review summarizes the recent empirical literature on post-secondary school outcomes of youth with disabilities. It illustrates the variation in characteristics and outcomes that exist in several subpopulations generally defined as youth with disabilities. The article describes a major limitation in the literature, particularly for special education students and Social Security Insurance recipients in the United States; that is, a lack of information on recent outcomes. Specifically, there were no major data collection efforts, at least at the national level, to track these populations in the mid to late nineties. With the increasing emphasis on improving transitional outcomes of youth with disabilities, particularly employment, it is suggested that policy makers and administrators will need new data to better understand the outcomes of this group. Of particular importance will be the influence of current programs on transition decisions.

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.  
Synthesis: This paper describes a community capacity-building (CCB) approach to facilitating the transition to adulthood for youth with developmental disabilities and their families in Hamilton, Ontario. The results of a qualitative, participatory evaluation demonstrate the benefits and challenges of this approach, with themes of increased community connections for youth and a greater awareness of their strengths and capacities by community members. The perceived outcomes of the participants and the "lessons learned" for future initiatives using a CCB approach with different populations are discussed. This pilot project demonstrates that a CCB approach has the potential to assist youth with disabilities to participate within their own communities.

## Unpublished Literature/Resources

### Youth perspectives

Office of Disability Employment Policy. *Advising youth with disabilities on disclosure*. Retrieved April 9, 2008, from <http://www.dol.gov/odep/pubs/fact/advising.htm>  
This American resource is a website for professionals advising youth with disabilities on disclosing their impairments at school and in the workplace. In addition, there is also a companion resource targeted specifically at youth.

Transition Ontario. (2008). *Door 2 Adulthood*. Retrieved 03/04/2008, from <http://www.bloorview.ca/door2adulthood/default.htm>  
This website for youth with disabilities in the province of Ontario was started by a network of youth, parents and service providers in response to a need for accessible information and resource sharing about the transition to adulthood. A participatory action research approach was used to develop and pilot test the website. The website is still under construction but has information about transition resources and services in Ontario, a 'news' section and a mentorship component for youth with disabilities.

### Parents' perspective

Hamilton Family Network, & CanChild. (2007). *Family resource guidebook for direct funding*. Hamilton, Ontario: McMaster University and Hamilton Family Network.  
This guidebook was developed for families of youth with developmental disabilities to assist them in planning for and implementing direct funding through the transition years. The information is drawn from the experiences of 10 families involved in the "Opening Doors" project of the Hamilton Family Network. It includes information on direct funding, and resources for families.

Johnson, J., & Goldberg, P. (2000). *Transition and beyond...now what? Guide for parents of youth with disabilities*. PACER Center, Inc., 8161 Normandale Blvd., Bloomington, MN 55437; Web site: <http://www.pacer.org>  
This is an online resource from the PACER Center in the United States that provides information for parents.

National Center on Secondary Education and Transition, Minneapolis, MN. (2004). *Parent brief: Person-centered planning: A tool for transition*. Retrieved 28/03/2008, 2008, from

<http://www.ncset.org//publications/viewdesc.asp?id=1431>

This is a brief written for parents of youth with disabilities. The expression, "It takes a village to raise a child," is discussed. Young people with disabilities need a support system that recognizes their individual strengths, interests, fears, and dreams and allows them to take charge of their future. Parents, teachers, family members, and friends in the community who offer informal guidance, support, and love can create the "village" for every child.

## **Service Providers**

Hospital for Sick Children. (2007). *Good 2 Go transition program*. Retrieved 03/04, 2008, from <http://www.sickkids.ca/good2go/>

This website is about adolescents who have been patients at SickKids Hospital in Toronto for many years and must now make a transition to adult health services. It is recognized that many have similar experiences, but also come from a multitude of cultures and family constellations. The transition from paediatric care, with its own distinct culture and ways of doing things, into the adult health care system can be a challenge for teens and their families. The goal of Good 2 Go is to prepare all youth with chronic health conditions to leave SickKids by the age of 18 years with the necessary skills and knowledge to advocate for themselves (or through others), maintain health-promoting behaviors and utilize adult health care services appropriately and successfully. Resources are also provided for parents and service providers.

Division on Career Development and Employment. *Transition specialist competencies fact sheet* Retrieved April 5, 2008 from [http://www.dcdt.org/pdf/trans\\_educators.pdf](http://www.dcdt.org/pdf/trans_educators.pdf)

This Fact Sheet summarizes a "What Every Special Educator Must Know" section listing the competencies for Transition Specialists beyond those of novice special educators.

Division on Career Development and Employment. *Transition-Related planning, instruction, and service responsibilities for secondary special educators fact sheet* Retrieved April 5, 2008 from [http://www.dcdt.org/pdf/transit\\_plan.pdf](http://www.dcdt.org/pdf/transit_plan.pdf)

This report summarizes the promising practices that emerged through research for which secondary special educators should be responsible. The practices are organized according to the five categories in the Taxonomy for Transition Programming and form a foundation for transition-related skill development for secondary special educators. The report provides many specific recommendations for student focused planning. Some include identifying and documenting students' post-school goals, learning preferences, and need for accommodations, as well as developing educational experiences that correspond with post-school goals and objectives, such as participation in college preparatory curricula and/or in vocational and technical education.

## **Community Members**

Alberta Association of Community Living. (2006). *Video - inclusive post-secondary education: Living the dream*. Retrieved 03/04/2008, 2008, from <http://www.aacl.org/resources>

This video from the Alberta Association for Community Living is an example of a video resource that can be used to highlight inclusive postsecondary education. It demonstrates how inclusion benefits individuals with developmental disabilities as well as peers and others in postsecondary communities. The association also argues that involvement in postsecondary institutions allows people with developmental disabilities to not only

contribute more fully to their communities but also further develop social and employment skills which will serve them better in the future.

National Center on Secondary Education and Transition, Minneapolis, MN. (2002). *Research to practice brief: Tapping employment opportunities for youth with disabilities by engaging effectively with employers*. Retrieved 03/28, 2008, from <http://www.ncset.org/publications/viewdesc.asp?id=716>

This American report argues that best practices for encouraging employers to hire youth with disabilities includes education for employers, developing skills among the youth labor force, providing appropriate support for both youth and employers when employees with disabilities begin working. Also, when working with employers to change policy, it should be done with any existing policies within the organization. In general, this report advocates a 'soft sell' approach.

## Policy Perspectives

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.

**Synthesis:** This Canadian report includes a summary of a literature review and informal conversations with professionals in the field of developmental disabilities. More details are provided for the province of British Columbia. The results identify three ways that transition planning is focused: 1. post-secondary education; 2. employment; and 3. day programs. The research found that many of the programs and supports outlined in the review focus on only one area in isolation from other areas of a young person's life. Furthermore, poor outcomes are still found in these areas. Legislation must be accompanied by system change and needed supports for youth with disabilities. Further research is recommended to explore more holistic approaches to transition, and to learn more about the needs and desires of young adults with severe disabilities.

Human Resources & Social Development Canada. (2000). *Youth in transition survey*. Ottawa, ON: Human Resources Development Canada.

**Synthesis:** This overview report describes the Youth in Transition Survey (YITS) which is a Canadian longitudinal survey in partnership with Statistics Canada, Council of Ministries of Education Canada, Provincial ministries and departments of labour and education. The YITS collects information about major transitions in young people's lives, particularly those between education, training and work. Survey results will help provide a deeper understanding of the nature and causes of problems young people face as they manage school-work transitions. Information obtained from the survey will help to support policy planning and decision-making that address these problems. Overall the survey hopes to answer 10 questions, one of which includes exploring the educational and occupational pathways of various sub-groups, particularly "youth at risk." The overview report provides a literature review of current issues and factors affecting the transition to adulthood for all youth.

Federal, Provincial & Territorial Ministers (2000) *In unison: A Canadian approach to disability issues*. Ottawa Ontario: Government of Canada.

**Synthesis:** This document provides a vision for Canada to ensure the full participation of persons with disabilities in all aspects of Canadian society. It was compiled by the federal, provincial and territorial ministers responsible for social services.

Government of Newfoundland and Labrador. (2005). *Foundations for success: White paper on post-secondary education*. St. John's, Nfld: Government of Newfoundland and Labrador.

**Synthesis:** This is a Canadian report that lists in detail the educational reforms in Newfoundland to create greater opportunities for young adults after high school.

Learning Disabilities Association of Canada (LDAC). (2007). *Putting a Canadian face of learning disabilities (PACFOLD)*. Ottawa ON: LDAC.

**Synthesis:** PACFOLD is an applied research study that was started in 2004 by the Learning Disabilities Association of Canada. The three phase project focused on obtaining, quantifying, and disseminating knowledge. The purpose was to provide a better understanding of the impact of learning disabilities on the lives of Canadian children, youth and adults, and the challenges they face. The study gathered data from 10 important Statistic Canada Surveys, including the Youth in Transition survey. The study also held focus groups across Canada in an attempt to help answer questions within the gaps identified from the quantitative data. All of the data are organized into the three main age groupings: 1) children, 2) youth, and 3) adults. The review indicates in its summary that all Canadians with learning disabilities are at a disadvantage, and that the learning disability impacts their lives and those around them. Recommendations also include information for all levels on the Canadian government.

Thiessen, V. (2002). *Policy research issues for Canadian youth: School-work transitions*.

Ottawa, ON: Applied Research Branch, Strategic policy, Human Resources Development Canada.

**Synthesis:** This report summarizes the literature on school-work transitions for Canadian Youth from 1995 to 2001. The goal is to provide information on emerging and ongoing policy issues related to school and work for youth. Although the focus of this report is Canadian youth with no disability, there is one section that addresses "at-risk" youth. It identifies factors that influence school-work transitions for these youth, such as the role of high school counselors and parents, community networks, and vocational courses in high school. The report ends with a call for research that places more emphasis on contextual factors, especially school and community effects on transitions. Multi-level and multi-variate methods are recommended to study individual, familial, school and community social capital.

Youth In Transition Working Committee. (2001). *Youth in transition policy framework*.

Edmonton, Alberta: Youth in Transition Working Committee for Government of Alberta.

**Synthesis:** This report outlines a policy framework for the Government of Alberta, which provides the direction and parameters for policy and program development for the transition to adulthood for youth ages 13 to 24 years. The framework is written for youth with diverse needs, as well as their parents, families, caregivers and community. Guiding principles support an overall vision of youth enhancing their abilities and capabilities to be healthy, happy, active, involved and independent. The framework identifies policy goals and strategic outcomes which can be used to guide program development for youth. It provides consistency and support to ministries in their development of policies, programs and strategies and encourages the development of capacity building for all youth and others around them. This framework takes a holistic approach towards transition by considering all aspects and types of transition, and an overall goal of youth living well-rounded lives and having access to a continuum of supportive opportunities.

## Unpublished Resources on policy in Canada

Canadian Association for Community Living. *CACL: Projects 2007*. Retrieved April 10, 2008, from <http://cacl.ca/english/projects/>

The Canadian Association for Community Living (CACL) and the Council of Canadians with Disabilities (CCD) are co-sponsoring a review to consider options for a community-based research and information function in collaboration with the Canadian Association of Independent Living Centres and the Neil Squire Society. The purpose is to develop options that will best enable the disability community and its allied networks to access and share information, and to mobilize knowledge development and use across society, to assist in advancing full citizenship, inclusion and human rights of people with disabilities. The Task Force is supported through a facilitation team from the Centre for Research and Education in Human Services. The team will collect background information, facilitate consultations, carry out interviews and draft reports.

Canadian Coalition for Family Supportive Policy. (2004). *Canadian coalition for family supportive policy: Declaration* Retrieved April 16, 2008 from <http://www.fncfcs.com/docs/CCFSPDeclarationJune04.pdf>

The webpage of the Canadian Coalition for Family Supportive Policy outlines a declaration for a public policy agenda to support families who have a member with a disability.

Council of Canadians with Disabilities. (2004). Retrieved April 16, 2008 from <http://www.ccdonline.ca/publications/index.htm>

The website of the Council of Canadians with Disabilities has a large amount of information related to disability and policy. Under their publications section is a list of relevant reports and briefs. For example, their 2003-04 annual reports reported on the continuing discrimination facing persons with disabilities. The annual reports also summarize the efforts of the CCD to respond to and analyze documents such as "Advancing Inclusion of Persons with Disabilities" from the federal government. Their recommendations for a disability strategic action plan recognize the increased focus on 'citizenship' as an important outcome for government and organizations. Annual reports in later years demonstrate that their advocacy efforts are paying off, as more disability supports have been put in place.

Government of Newfoundland and Labrador. (2007). *Changes announced to ISSP and pathways models for special education programming.*, 2008, from <http://www.releases.gov.nl.ca/releases/2007/edu/1218n04.htm>

This website provides the most current information on changes to the special education programs and support in Newfoundland and Labrador.

Ministry of Social Services and Seniors Prince Edward Island. (2006). *Multilateral framework for labour market agreement for persons with disabilities: Prince Edward Island third annual baseline report 2005-2006* Retrieved April 6, 2008 from <http://www.gov.pe.ca/photos/original/LMDA-0506.pdf>

In the Multilateral Framework for Labour Market Agreements for Persons with Disabilities, Federal, Provincial and Territorial Ministers Responsible for Social Services committed to building a strong, inclusive society and securing a high quality of life for all Canadians with disabilities. They agreed that all Canadian citizens should have an opportunity to contribute to our social and economic fabric of the country. This means removing barriers so that people with disabilities can live with dignity and realize their capacity for independence.

Ontario March Of Dimes. (2003). *Canada pension plan disability program. The importance of an ongoing return-to-work strategy: A solutions brief* Retrieved April 10, 2008 from <http://www.marchofdimes.ca/NR/rdonlyres/B85C5358-909D-4242-A5B3-299A48747CF6/0/returntowork.pdf>

This report is a solutions brief by the Ontario March of Dimes detailing 16 recommendations ranging from cost savings resulting from return to work and vocational rehabilitation services, to implementing a system to measure longer term impacts of the program and recommending that CPP implement a strategies to enhance the job retention and longer term labour market attachments. The report indicates that there also is sufficient empirical evidence demonstrating that rehabilitation does serve and enhance social development goals and government policy, and could be significantly improved. The report suggests that the program could achieve more, and in fact do more, through partnerships with other government training programs. For example, clients could be linked to career or other training options in conjunction with the rehabilitation plan. This could achieve substantial, long-term results, such as further improving client motivation for rehabilitation, and thereby enhance the underlying social development rationale of an ongoing return-to-work strategy in a meaningful way. This might also assist in achieving such goals as obtaining and maintaining employment over the long-term.

Planned Lifetime Advocacy Network. (2004). *Securing a good life for our family members with disabilities: A proposal for federal reforms*. Retrieved April 6, 2008 from <http://www.plan.ca/documents/PLAN-Securing%20A%20Good%20Life.pdf>

This Canadian advocacy organization has written a report expressing the need for a new social policy framework for long-term care of persons with disabilities through a person first approach across the lifespan. This approach provides for economic stability as well as continuing access to social networks and involvement of people with disabilities in their own communities.

Varga-Toth, J. (2006). *Meeting the needs of children and adolescents with special needs in rural and northern Canada: Summary report of a roundtable for Canadian policy-makers*.

Research Report F|54) Retrieved April 6, 2008 from <http://www.coespecialneeds.ca/PDF/meetingtheneeds.pdf>

This report provides a summary of the research conclusions, policy implications and action priorities developed at a national policy roundtable held on September 9, 2005. The first section highlights the recent policy context for this work, outlines the Centre's work and approach to special needs, and describes the roundtable. The second section focuses on the research findings and recommendations. The third section summarizes the roundtable discussions, and in the last section it draws on all the elements to propose action and research priorities.

## Theme #2: Different types of Transition

This theme pulls together the literature about different types of transition. The two most prevalent types of transition described were 'service' transitions that focus solely on a youth's transition from one service system to another, and 'natural' transitions that describe a lifecourse or developmental approach to transition.

### Service Transitions

These are subdivided into the different types of service systems described in the literature.

#### Health care

Betz, C. L. (2004). Transition of adolescents with special health care needs: Review and analysis of the literature. *Issues in Comprehensive Pediatric Nursing*, 27(3), 179-241.  
**Synthesis:** see annotation under Theme #1: Status, experiences and outcomes

Binks, J. A., Barden, W. S., Burke, T. A., & Young, N. L. (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, 1064-1073.

**Synthesis:** The purpose of this project was to address the lack of synthesis regarding the factors, processes, and outcomes specific to the transition from child-centered to adult-centered health care for people with cerebral palsy (CP) and spina bifida (SB); more specifically, to identify barriers, to outline key elements, to review empirical studies, and to make clinical and research recommendations. The authors searched Medline and CINAHL databases from 1990 to 2006 using the key words: transition, health care transition, pediatric health care, adult health care, health care access, health care use, chronic illness, special health care needs, and physical disability. The resulting studies were reviewed with a specific focus on clinical transition for persons with CP and SB, and were supplemented with key information from other diagnostic groups. Of the 149 articles: 54 were discussion, 21 case series, 28 database or register, 25 qualitative, and 34 survey articles (some included multiple methods). Five key elements that support a positive transition to adult-centered health care were identified as preparation, flexible timing, care coordination, transition clinic visits, and interested adult-centered health care providers. There was, however, limited empirical evidence to support the impact of these elements. This review summarizes key factors that must be considered to support this critical clinical transition and sets the foundation for future research. The recommendation is made to apply prospective study designs to evaluate transition interventions and determine long-term health outcomes.

Blum, R. W., Hirsch, D., Kastner, T. A., Quint, R. D., Sandler, A. D., Anderson, S. M., et al. (2002). A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics*, 110(6), 1304-1306.

**Synthesis:** This policy statement represents a consensus on the critical first steps that the medical profession needs to take to realize the vision of a family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent health care system that is as developmentally appropriate as it is technically sophisticated. The goal of transition in health care for young adults with special health care needs is to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from

adolescence to adulthood. This consensus document has now been approved as policy by the boards of the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians-American Society of Internal Medicine.

Freed, G. L., & Hudson, E. J. (2006). Transitioning children with chronic diseases to adult care: Current knowledge, practices, and directions. *The Journal of Pediatrics*, 148(6), 824-827.

**Synthesis:** This review synthesizes existing knowledge and research about transition to adult care for youth with chronic diseases. The authors found few published articles that focused on clinical outcomes or effectiveness of programs. Most of the available literature is descriptive in nature and focuses on youth with chronic illness in general, although some articles focus on a specific illness such as cystic fibrosis, diabetes or sickle cell disease. Recommendations are made for more research to examine transition models, program outcomes and clinical outcomes. Another area requiring further study is education and training for health professionals.

Kingsnorth, S., Healy, H., & MacArthur, C. (2007). Preparing for adulthood: A systematic review of life skill programs for youth with physical disabilities. *The Journal of Adolescent Health: Official Publication of the Society for Adolescent Medicine*, 41(4), 323-332.

**Synthesis:** This Canadian review study aimed to determine the effectiveness of life skill programs emphasizing independent functioning in preparation for adulthood among youth with physical disabilities (acquired and congenital physical disabilities). All studies which were reviewed used a multi-component group intervention containing either a real-world or role-playing experiential component. Conclusions are limited because of heterogeneity of interventions, skill focus, disabilities, and outcome measures with respect to the effectiveness of individual components of the programs. With more youth with physical disabilities surviving into adulthood, there is a need to ensure that they have the skills to successfully manage life demands. There are relatively few rigorously designed, published studies that have evaluated the effectiveness of life skill programs. The authors recommend future research including large-samples, randomized, and controlled studies.

Lotstein, D. S., McPherson, M., Strickland, B., & Newacheck, P. W. (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), 1562-1568.

**Synthesis:** The purpose of this article is to describe the proportion of youth with special health care needs (YSHCN) who are receiving services for medical transitions and to describe which sociodemographic and health care-related factors are associated with receiving transition services. Results show that overall, 50% of respondents had discussed their child's changing health care needs with their physicians, although significantly fewer Hispanic youth compared with other youth reported these discussions. Youth who met criteria for a medical home were more likely to have discussed changing needs and to have a plan addressing these needs. Of those who had discussed changing needs, 59% had a plan to address these needs and 42% had reported discussing shifting care to adult-oriented providers. Younger teens and non-Hispanic black children were less likely to have discussed changing providers. Fifteen percent of YSHCN met the Maternal and Child Health Bureau's core outcome for medical transitions. A multivariate logistic-regression model found that older age and having a medical home were significantly associated with increased odds of meeting the outcome measure. The report concludes that the proportion of YSHCN meeting the medical-transition outcome measure is quite low, particularly for youth from ethnic minorities. Higher rates are seen for older teens and those receiving care

within a medical home. Significant efforts will be required to meet the proposed goal of all YSHCN receiving the services necessary to transition to adult health care.

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.

**Synthesis:** see annotation under Theme #1: Status, experiences and outcomes

Young, N. L., Gilbert, T. K., McCormick, A., Ayling-Campos, A., Boydell, K., Law, M., et al. (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.

**Synthesis:** The purpose of this study is to examine patterns of health care utilization among youth and young adults who have cerebral palsy (CP) and to provide information to guide the development of health services for adults who have CP. The study analyzed health insurance data for outpatient physician visits and hospital admissions for a 4-year period. The authors conclude that it appears that youth and adults with CP continue to have complex care needs and rely heavily on the health care system. Comprehensive services are essential to support their health as they move into youth and adulthood. However, there appear to be gaps in the adult health care system, such as limited access to specialist physicians.

## **Mental Health/Mental Illness Services**

Baltodano, H. M., Mathur, S. R., & Rutherford, R. B. (2005). Transition of incarcerated youth with disabilities across systems and into adulthood. *Exceptionality, 2*(2), 103-124.

**Synthesis:** see annotation under Theme #1: Status, experiences and outcomes

Davis, M. (2005). *State efforts to expand transition supports for young adults receiving adult public mental health services*. University of Massachusetts Medical School with American Institutes of Research (AIR):

**Synthesis:** This American article assesses the quality of mental health services for young adults receiving adult mental health services in the United States by surveying state mental health program directors. The authors findings suggest that emerging adulthood lasts until the age of 30, and that there is a need for the federal government to take leadership in the area of funding mental health services specifically around the transition into the adult world, that mental health organizations and professionals should advocate for improved services and work to further understand the needs of this specific population and facilitate individuals throughout the entire transition period.

Jonikas, J. A., Laris, A., & Cook, J. A. (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), 114-121.

**Synthesis:** This study reviewed literature on the needs and experiences of young adult women, aged 16 to 21, who have a diagnosis of serious emotional disturbance (SED) or mental illness. Given the large numbers of young women with SED, evidence that they are underserved (e.g., services must be community-based and unconditional; individualized; inclusive of parents; culturally competent; with flexible funding and outcome oriented), and the continuity of many disorders from adolescence to adulthood, an integrative review in this area enhances our ability to better address these young women's needs.

Vostanis, P. (2005). Patients as parents and young people approaching adulthood: How should we manage the interface between mental health services for young people and adults? *Current Opinion in Psychiatry*, 18(4), 449-454.

**Synthesis:** This British review of recent research focuses on the mental health needs of young people in transition, including those of young parents. Research indicates that higher mental health needs may be related to life transitions. Protective factors in young people include support by their own parents as they strive for independence; their relationship with their partner, siblings, or peers; educational attainment; and social stability. When these transitions are disrupted, young people require coordinated support from different agencies. The overall knowledge on how to meet the mental health needs of young people in transition is limited, however, this review supports unique and individualized interventions that are tailored to young people's characteristics. Evidence about the effectiveness of early psychosis teams suggest that this type of approach may also be suitable for young people with no diagnosed psychosis, but who nonetheless are facing multiple mental health challenges during the transition to adulthood.

### Developmental Services

Alpern, C. S., & Zager, D. (2007). Addressing communication needs of young adults with autism in a college-based inclusion program. *Education and Training in Developmental Disabilities*, 42(4), 428-436.

**Synthesis:** This article reviews the literature regarding changing communication profiles of individuals with autism as they progress through adolescence and young adulthood. The authors acknowledge the impact of language patterns (e.g., complexity in sentence structure and use of body language) on social and vocational functioning. Recommendations are made for a transdisciplinary collaborative program in a university setting to provide an appropriate and inclusive experience for young adults with autism to learn alongside their chronologically-aged peers. The article also shows that speech-language services that continue to work on conversational interaction and language goals do contribute to the success of young adults in post-secondary programs.

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.

**Synthesis:** see annotation under Theme #1: Status, experiences and outcomes

### Educational Services

Burchardt, T. (2004). Aiming high: The educational and occupational aspirations and of young disabled people. *Support for Learning*, 19(4), 181-186.

**Synthesis:** This review article provides an overview of the aspirations and expectations disabled teenagers form for their future education and employment and the factors which are associated with positive aspirations. The results indicate that young disabled people have similar aspirations to their non-disabled counterparts, although tempered in some cases with recognition that there are likely to be obstacles in the world of work. There is also some tentative evidence that young disabled people feel less well served by advice and support services. A recommendation is made for service providers to ensure that they encourage positive aspirations, especially among young people from disadvantaged backgrounds, while offering practical support in overcoming disabling barriers.

Killean, E., & Hubka, D. (1999). *Working towards a coordinated national approach to services, accommodations and policies for post-secondary students with disabilities: Ensuring access to higher education and career training*. Ottawa, ON: National Educational Association of Disabled Students (NEADS).

**Synthesis:** see annotation under Theme #1: Status, experiences and outcomes

Kohler, P. D., & Hood, L. K. (2000). *Improving student outcomes: Promising practices and programs for 1999-2000. A directory of innovative approaches for providing transition services for youth with disabilities*. Transition Research Institute, University of Illinois at Urbana-Champaign, 117 Children's Research Center, 51 East Gerty Dr., Champaign, IL 61820. Web site: <http://www.ed.uiuc.edu/sped/tri/institute.html>.

**Synthesis:** This review profiles 20 programs that promote post-school outcomes for students with disabilities through inclusive school-to-work systems. Three criteria were used to select the programs: (1) the nomination featured a program or practices that provide transition- or school-to-work-related services or instruction to students with disabilities, (2) the nomination provided sufficient information and evidence to understand the purpose, context, and activities of the program or practices; and (3) the nomination provided evaluation information to indicate the extent of implementation and the outputs and/or outcomes associated with that implementation. Following background information on the National Transition Alliance for Youth and Disabilities (NTA) Transition Practices Framework, the directory provides and organizes key information about the promising programs. For example, the first items featured include the contact information, the program's mission, and organizational details. Information is then presented about the program's consumers, including the target populations and the disability areas represented by the consumers. Next, the NTA Transition Practices Framework categories addressed by each program are identified. Detailed descriptions of the programs and a summary of their evidence of success are included. Finally, success stories that describe students' experiences with some of the programs are provided.

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.

**Synthesis:** This report was prepared for the National Health Centre in New Zealand by the Donald Beasley Institute. Two sections of this report include 1) Transitions and young adults with an intellectual disability, and 2) Adult education for adults with an intellectual disability. The report conducted literature reviews in the areas of: definitions, demographics, relationships, education, income, support for daily living, effective communication, community participation, and work. These reviews, together with the information gathered for the background paper, provided the basis for recommendations for action put forward by the NHC to the Minister of Health. The main recommendation made by this report is the integral nature of citizenship to the transition process. The report further calls for a transitional model based on citizenship to help address the social and structural inequalities that young people with an intellectual disability often experience.

Neubert, D. A. (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), 155-168.

**Synthesis:** This article reviews literature on post-secondary programs and supports for these individuals to (a) identify a philosophical basis for providing such opportunities, (b) identify practices, and (c) summarize research on the efficacy of these efforts. The

literature from the 1970's to 1990's provided descriptions of programs or advocated for the inclusion of adults with mental retardation on college campuses in position papers. Limited empirical data supported the efficacy of these programs. The literature during the 1990's shifted to providing post-secondary programs or individual supports to students with mental retardation and other significant disabilities, ages 18–22, who were still enrolled in public schools. The results indicate that documentation of student outcomes, stakeholders' satisfaction with age-appropriate alternatives, and cost-benefit analysis of post-secondary programs or individual supports must be addressed. The authors also suggest that it is necessary to evaluate the effectiveness of post-secondary efforts in terms of other quality of life indicators. Research is crucial in advancing post-secondary practices and in justifying alternative, age-appropriate programs and individual supports for students with MR, and other significant disabilities during the transition to adulthood.

### **Service Transitions – General**

Cavin, M., Alper, S., Sinclair, T., & Sitlington, P. L. (2001). School to adult life: An analysis of transition programs serving youth with disabilities between 1986 and 1999. *Journal for Vocational Special Needs Education, 23*(3), 3-14.

**Synthesis:** This literature review identified characteristics of transition programs that were described in 33 refereed journal articles between 1986-1999. Results confirm that students with more severe learning and behavioral difficulties receive inadequate transition services; programs emphasize employment competencies over living skills; and there are few community-based programs to provide training in natural settings. Recommendations are made for future research of programs to include clearer descriptions of participants, including the type and severity of disability, and more detailed descriptions of the employment model and skills taught. Wider dissemination of what is happening is also needed.

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.

**Synthesis:** This comprehensive review of the literature aimed to identify practices that promote continuity during the transition between child and adult services by reviewing available evidence. This review found a large range of different practices that focused on either the service, the young person, and/or the family. Best practices address the needs of the young person including the development of skills of self-management and self-determination, support for psychosocial development, support for changed relationships with parents and caregivers, provision of choice and information, and a focus on strengths for future development. Family needs also must be addressed through a family-centered approach, including support for adjustment to changed relationships, parental involvement in service planning and provision of information. Four types of transition models were proposed for further study: a) direct model, b) sequential model, c) developmental model, and 4) professional model.

### **Unpublished literature on Service Transitions**

#### **Health Care**

Children's and Women's Health Centre of British Columbia. (2006). *ON TRAC model for transitional care of adolescents, the progress in transplantation*. Retrieved 03/04/2008,

2008, from [http://findarticles.com/p/articles/mi\\_ga4117/is\\_200612/ai\\_n17193619/pg\\_1](http://findarticles.com/p/articles/mi_ga4117/is_200612/ai_n17193619/pg_1)  
Synthesis: This article describes the framework and clinical pathway for ON TRAC (Taking Responsibility for Adolescent/Adult Care), a model of transition care in British Columbia for adolescents with chronic health conditions, as applied to pediatric transplant transition. This model was developed in 1998 at Children's and Women's Health Centre of British Columbia. It provides a multidisciplinary approach to developmentally appropriate transition planning and skill building. The model is youth focused and family centered, and includes stages of transition care on the basis of the developmental stages and capabilities of adolescents. Important considerations for healthcare providers, specific tools for use in clinical settings, and case studies illustrate the use of the ON TRAC model in a pediatric transplant clinic. The ultimate goal of transition in the ON TRAC model is for all adolescents to reach their attainable levels of independence, self-sufficiency, and self-worth while transferring safely and securely into adult healthcare services and adulthood.

Dunseith, C., & Assi, M. (2008). *A collaborative lifespan approach to the transition of adolescents with chronic conditions*. Retrieved April 3, 2008, from [http://www.sickkids.ca/good2go/custom/CDM\\_ATP\\_conference\\_posterdraft\\_sept28\\_07.pdf](http://www.sickkids.ca/good2go/custom/CDM_ATP_conference_posterdraft_sept28_07.pdf)  
This poster presentation evaluates the need for transitional support for adolescents with chronic illnesses as they enter the adult health care system in Canada. The key findings are that there is a need for increased coordination between pediatric and adult medical services, the need for a more comprehensive regional approach, the need for better communication systems and the need for more psychosocial and educational support for youth and their families and caregivers.

Hospital for Sick Children. (2007). *Good 2 go transition program*. Retrieved 03/04, 2008, from <http://www.sickkids.ca/good2go/>  
This website is about adolescents who have been patients at SickKids Hospital in Toronto for many years and must now make a transition to adult health services. It is recognized that many have similar experiences, but also come from a multitude of cultures and family constellations. The transition from paediatric care, with its own distinct culture and ways of doing things, into the adult health care system can be a challenge for teens and their families. The goal of Good 2 Go is to prepare all youth with chronic health conditions to leave SickKids by the age of 18 years with the necessary skills and knowledge to advocate for themselves (or through others), maintain health-promoting behaviors and utilize adult health care services appropriately and successfully. Resources are also provided for parents and service providers.

Shapland, C., PACER Centre & NSCET. (2006). *Parent brief: What does health have to do with transition? Everything!* Retrieved March 27, 2008, from [http://www.ncset.org/publications/parent/NCSETParent\\_May06.pdf](http://www.ncset.org/publications/parent/NCSETParent_May06.pdf)  
This article discusses the importance in supporting an adolescent to manage their health and include health and well-being in the transitions process. The article recognizes that transferring the responsibility of self-care to an adolescent is a complex process involving the youth's health needs, physical and cognitive abilities, self-determination, and family factors.

## **Mental health/Mental illness services**

Canadian Mental Health Association of Ontario. *NETWORK: Navigating the system*. Retrieved April 3, 2008, from [http://www.ontario.cmha.ca/admin\\_ver2/maps/network\\_23-](http://www.ontario.cmha.ca/admin_ver2/maps/network_23-)

### [3\\_winter\\_2008.pdf](#)

This document is an electronic copy of the Canadian Association for Mental Health Ontario chapter's magazine which highlighted the difficulties for accessing timely mental health services for different populations including new immigrants to Canada.

National Center on Youth Transition. (June 2007). *On the move: Helping young adults with serious mental health needs transition into adulthood, the challenge*. Retrieved March 27, 2008, from <http://ncyt.fmhi.usf.edu/publications/what-we-learned.pdf>  
This online resource brief captures and summarizes lessons learned, major findings, outcomes and policy recommendations related to the Partnerships for Youth Transition (PYT) initiative.

University of South Florida, & Louis de la Parte Florida mental health Institute (FMHI). (May 2007). *The road to successful adulthood: FMHI lays a pathway for youth and young adults with serious mental illness*. Retrieved March 26, 2008 from [http://cfs.fmhi.usf.edu/cfsnews/2007news/clark\\_TIPconferencecall.html](http://cfs.fmhi.usf.edu/cfsnews/2007news/clark_TIPconferencecall.html)  
This U.S. report discusses transitioning to adulthood for young adults with serious mental illness. Suggestions are made for states and the federal government to do more in deliberate efforts to address the transition support of the youth and young adults they serve. One of these suggestions is to extend continuity of care to the ages of 25 or 30 and to eliminate arbitrary age-related barriers to the continuation of services by adjusting official definitions of SED/SMI.

## **Developmental Services**

University of Alberta, Edmonton On Campus Adult Education Society. *The J P das developmental disabilities centre*. Retrieved 4/10/2008, 2008, from <http://www.ualberta.ca/~jpdasddc/inclusion/oncampus/oncampus.html#top>  
This website provides information on the Edmonton On Campus program which provides opportunities for young adults with developmental disabilities to participate fully in on-campus activities.

## **Educational Services**

British Columbia Ministry of Education. (2006). *Students with special needs - how are we doing? Province - public schools only*  
This report summarizes a the government of British Columbia's evaluation quantitatively of special-needs programs in the education system and finds that students with special needs have generally consistently improved in areas such as grade to grade transition and the passing of provincial evaluations. Significantly, no tables are provided as to the number of students with special needs who move forward to postsecondary education.

Petruka, D. R. (2001). *Research report. The transition of special education students from high school to adult life in Ontario*. Unpublished manuscript. Ottawa, ON.  
This report summarizes a research project conducted by the author that explores best practices in Ontario high schools for service coordination and transition planning for special education students. The author examines transition programs and identifies the gaps that exist between current practice in high schools and best practice as identified in the literature. Four strategies are made to reduce the gap between current and best practices: 1. make transition planning a priority; 2. find the right people for the job; 3. provide financial

support for resources and training; and 4. ensure there are job experience opportunities for special education students.

## Natural/Lifecourse/Developmental Transitions

### Published literature

Beresford, B. (2004). On the road to nowhere? Young disabled people and transition. *Child Care Health and Development*, 30(6), 581-587.

**Synthesis:** A key issue and one known to be highly problematic and challenging, concerns the transition of young disabled people from children's services to adult services, and from childhood to adulthood. To inform its recommendations on this issue, the Disabled Children's External Working Group (EWG) for the Children's NSF in the UK commissioned a review of research on young disabled people and transition. The evidence available with regard to transitions of young disabled people provides a clear and consistent picture of the way transitions are currently experienced by young disabled people and their families. There is limited evidence on what works to ensure smooth transitions between services and positive outcomes of transition for the young people themselves. Existing research is very persuasive on the need to improve transitions for young disabled people. This review highlights the importance of 1) not moving an individual from one service to another but seeing transition as a way of supporting a young adult to move towards and onto a new life stage, and 2) that supports for young persons cannot come from one agency alone, 3) transitioning needs to be viewed long term and flexibly, and 4) services, facilities, and opportunities for young people need to be in place and available. The article recommends further research at the level of specific service model evaluations as well as holistic, longitudinal work to provide evidence on the long-term outcomes of young disabled people as they move into adulthood.

Committee on Disability in America. (2007). Health care transitions for young people. In M. J. Field, & A. M. Jette (Eds.), *Future of disability in America* (pp. 4-1). Washington, DC: The National Academies Press.

**Synthesis:** see annotation under Theme #1: Status, experiences and outcomes

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.

**Synthesis:** see annotation under Theme #1: Status, experiences and outcomes

King, G. A., Baldwin, P. J., 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.

**Synthesis:** This Canadian article provides a conceptual model and review of the effectiveness of approaches for providing transition education and planning services for youth with disabilities. The model incorporates four approaches: skills training, prevocational/ vocational guidance, a client-centered approach, and an ecological/experiential approach. The model links these approaches to commonly used transition strategies, which reflect the personal, person-environment, and environmental levels of intervention. The model specifies the short-term goals addressed by the approaches and strategies and links these to the long-term outcome of multifaceted role engagement.

Learning Disabilities Association of Canada. (2007). *Putting a Canadian face of learning disabilities (PACFOLD)*. Ottawa ON: LDAC.

**Synthesis:** see annotation under Theme #1: Status, experiences and outcomes

McDonagh, J. (2006). Growing up ready for emerging adulthood. An evidence base for professionals involved in transitional care for young people with chronic illness and/or disabilities.

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4137427](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4137427). Department of Health, London, United Kingdom.

**Synthesis:** This document published by the Department of Health in the UK is based on a presentation made at a national conference in the UK on youth with disabilities. The presentation highlights that the research process should always include parents and young adults with disabilities. The presentation concludes with future research questions and agendas for studying this field for many categories, including parent, youth, health care provider, and more.

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.

**Synthesis:** This report was prepared for the National Health Centre in New Zealand by the Donald Beasley Institute. Two sections of this report include 1) Transitions and young adults with an intellectual disability, and 2) Adult education for adults with an intellectual disability. The report conducted literature reviews in the areas of: definitions, demographics, relationships, education, income, support for daily living, effective communication, community participation, and work. These reviews, together with the information gathered for the background paper, provided the basis for recommendations for action put forward by the NHC to the Minister of Health. The main recommendation made by this report is the integral nature of citizenship to the transition process. The report further calls for a transitional model based on citizenship to help address the social and structural inequalities that young people with an intellectual disability often experience.

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.

**Synthesis:** This article describes a grounded theory study that employed in-depth interviews with nine student/parent dyads from eastern Canada. Youth with disabilities, aged 16 to 21, contributed narratives describing high school transitions. Shared experience that transcends disability categories produced powerful results. Three categories emerged: (1) transition facilitators; (2) transition constraints; (3) strategies for meaningful transitions. Higher level analysis revealed further relationships: the connection between perceived lack of support and burn out; the importance of self-advocacy; and the sense of "paving rough roads" for the next generation. The core variable, contextual influences, resonates with the five systems presented in the bioecological model of human development. A model demonstrating the interactions among categories, contexts and ecological systems is presented. This framework provides encouragement and cautionary notes for those working toward a meaningful transition and a place to belong for youth with disabilities.

## **Unpublished literature on natural/lifecourse/developmental transition**

Dunseith, C., & Assi, M. (2008). *A collaborative lifespan approach to the transition of adolescents with chronic conditions*. Retrieved April 3, 2008, from [http://www.sickkids.ca/good2go/custom/CDM\\_ATP\\_conference\\_posterdraft\\_sept28\\_07.pdf](http://www.sickkids.ca/good2go/custom/CDM_ATP_conference_posterdraft_sept28_07.pdf)

A poster evaluating the need for transitional support for adolescents with chronic illnesses as they enter the adult health care system in Canada. The key findings are that there is a need for increased coordination between pediatric and adult medical services, the need for a more comprehensive regional approach, the need for better communication systems and the need for more psychosocial and educational support for youth and their families and caregivers.

PACER Center, Inc., Minneapolis, MN. (2005). *Ten tips that may help ease your child's transition to adulthood*. PHP-c107PACER Center. 8161 Normandale Boulevard, Minneapolis, MN 55437. Tel: 800-537-2237; Tel: 952-838-9000; Fax: 952-838-0199; e-mail: [pacer@pacer.org](mailto:pacer@pacer.org); Web site: <http://www.pacer.org>.

A guide for parents to assist their child in transition planning in Minnesota, covering all elements of transition independent living, managing finances, employment etc.

Planned Lifetime Advocacy Network. (2004). *Securing a good life for our family members with disabilities: A proposal for federal reforms* Retrieved April 6, 2008 from <http://www.plan.ca/documents/PLAN-Securing%20A%20Good%20Life.pdf>

This Canadian advocacy organization has written a report expressing the need for a new social policy framework for long-term care of persons with disabilities through a person first approach across the lifespan. This approach provides for economic stability as well as continuing access to social networks and involvement of people with disabilities in their own communities.

### Theme #3: Domains of transition

Much of the transition literature focuses on one specific 'domain' of transition. The most prevalent domains addressed in the literature are: 1. employment, 2. education, 3 living independently/housing, and 4. socialization/community life.

#### Employment

Bowe, F. G. (2003). Transition for deaf and hard-of-hearing students: A blueprint for change. *Journal of Deaf Studies and Deaf Education, 8*(4), 485-493.

**Synthesis:** This study examines issues related to the large and growing number of deaf and hard-of-hearing adults who are "low-functioning deaf" (LFD). The unmet needs of many young people who are deaf or hard of hearing, and the continuing high rates of dropping out of school argue for a change in secondary programming for multiply disabled deaf, hard-of-hearing students, and for others who are at risk of becoming LFD as adults. This article reviews research related to transition for adolescents with disabilities as well as those who are deaf or hard of hearing. Suggestions include the provision of transition programs that focus on on-site vocational and independent-living skills training for students with disabilities to facilitate the development of self-determination skills and the skills related to being a valuable team player.

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.

**Synthesis:** This Canadian report summarizes phase two of a longitudinal project that examined the experiences of post-secondary students with disabilities in Canada during the transition from post-secondary to work environments. Participants in the study included students as well as employers. The report indicates that facilitators to employment included having a 1) post-secondary degree, 2) certain personal qualities, 3) flexibility in the workplace, 4) volunteer and paid-work experience, 5) strong social networks, 6) supportive and accessible environments, 7) and having experience living with a disability. Obstacles to employment included 1) attitudinal barriers of employers, 2) lack of transportation, 3) inaccessible environments, 4) lack of education and work experience, 5) lack of access to interpreters and attendants, and 6) perceptions of uncertain futures.

Davis, M. (2003). Addressing the needs of youth in transition to adulthood. *Administration and Policy in Mental Health, 30*(6), 495-509.

**Synthesis:** This article discusses the needs of young-adult youth with serious emotional disturbance and the current ability of the US mental health and other relevant agencies to meet those needs. The contrast between needs and system status is presented through a framework of contrasting developmental and institutional transitions. This article reviews the barriers (e.g., administrative, program development, public Health Administration/Standards) to effective system reform, and the recommendations for changes using data from participants on national panels focusing on transition and applied research.

Hango, D., & de Broucker, P. (2005). *Education-to-labour market pathways of Canadian youth: Findings from the youth in transition survey.* Ottawa, Ontario: Statistics Canada.

**Synthesis:** This report summarizes findings from the longitudinal Youth In Transition Survey (YITS) in Canada that studied a variety of issues related to the transition from adolescence to adulthood for all youth. One section identifies factors that were found to be

associated with education-to-labour pathways. These included gender (with females less likely to drop out of high school); ethnic background (showing that Aboriginal youth are more likely to have a lower level of educational attainment); and the presence of a long-term condition that limits participation. Findings indicate that individuals with a long-term condition were found to be much less likely to follow pathways that lead to pursuing a post-secondary degree or diploma.

Thiessen, V. (2002). *Policy research issues for Canadian youth: School-work transitions*. Ottawa, ON: Applied Research Branch, Strategic policy, Human Resources Development Canada.

**Synthesis:** This report summarizes the literature on school-work transitions for Canadian Youth from 1995 to 2001. The goal is to provide information on emerging and ongoing policy issues related to school and work for youth. Although the focus of this report is Canadian youth with no disability, there is one section that addresses "at-risk" youth. It identifies factors that influence school-work transitions for these youth, such as the role of high school counselors and parents, community networks, and vocational courses in high school. The report ends with a call for research that places more emphasis on contextual factors, especially school and community effects on transitions. Multi-level and multi-variate methods are recommended to study individual, familial, school and community social capital.

## Education

Cameto, R., Levine, P., & Wagner, M. (2004). *Transition planning for students with disabilities: A special topic report of findings from the national longitudinal transition study-2 (NLTS2)* National Center for Special Education Research. 400 Maryland Avenue SW, Washington, DC. Web site: <http://ies.ed.gov/ncser/>.

**Synthesis:** This report by the National Longitudinal Transition Study - 2 (NLTS2) examines efforts to prepare youth with disabilities for the transition from secondary school to adulthood. It highlights the transition planning process undertaken during high school with and for youth with disabilities as they prepare for life after school. These topics are addressed by using data from two important sources: (1) Parents or guardians of NLTS2 study members; and (2) School staff best able to describe students' overall programs. From these data, NLTS2 provides a national picture of transition planning, including variations in that planning for students who differ in disability and other characteristics. The following are appended: (1) NLTS2 Sampling, Data Collection, and Analysis Procedures; (2) Demographic Characteristics of Youth with Disabilities and Their Households; and (3) Unweighted Sample Sizes.

Izzo, M. V., & Lamb, P. (2003). Developing self-determination through career development activities: Implications for vocational rehabilitation counselors. *Journal of Vocational Rehabilitation*, 19, 71-78.

**Synthesis:** This article begins with a discussion of the relationship between self-determination and career development, and argues that effective programs need to integrate the two together. A review of model transition programs in the United States demonstrates that effective programs include a high level of expertise of school and agency personnel who collaborate with each other and share resources; who promote self-determination and career development skills in tandem. Recommendations for future research includes gathering national data on the nature and frequency of collaborative

practices, and identify the supports and services that are deemed critical by young adults with disabilities.

Killean, E., & Hubka, D. (1999). *Working towards a coordinated national approach to services, accommodations and policies for post-secondary students with disabilities: Ensuring access to higher education and career training*. Ottawa, ON: National Educational Association of Disabled Students (NEADS).

**Synthesis:** see annotation under Theme #1: Status, experiences and outcomes

Ness, J. E. (1996). *The high jump: Transition issues of learning disabled students and their parents*. Learning Disabilities Association of Canada.

**Synthesis:** A brief report for Child and Family Canada outlines the key issues that face students with learning disabilities and their parents. Recommendations for resolving some of the problems include professionals working together more to develop helpful materials and resources for students and parents; helping students to learn how to explain their disability earlier; exposing students to positive role models; finding support groups and inservice training for parents; and begin the transition process early.

Shroedel, J. G., & Geyer, P. D. (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), 303-314.

**Synthesis:** This article from the United States summarizes the results of a longitudinal study of 240 college students with hearing loss. The results confirmed that the students benefitted economically from post-secondary education. Most of the participants were successfully employed and satisfied with life overall. A key recommendation is for secondary school personnel to encourage students who are deaf to think more about 'careers' rather than just jobs. There is also a need for specific career planning and goal setting, as those students who participated in these types of services were more likely to complete their post-secondary education.

Wagner, M., Newman, L., Cameto, R., & Levine, P. (2006). *The academic achievement and functional performance of youth with disabilities. A report from the national longitudinal transition study-2 (NLTS2)*. NCSE 2006-3000

**Synthesis:** see annotation under Theme #1: Status, experiences and outcomes

## Living Domain

Blacher, J. (2001). Transition to adulthood: Mental retardation, families, and culture. *American Journal on Mental Retardation, 106*(2), 173-188.

**Synthesis:** This article describes a conceptual model that was used to guide a study in the United States of 'mental retardation' and family well-being during the transition from late adolescence into young adulthood. It is suggested that the success of transitional experiences in the three realms of residential, vocational and social status will influence family wellbeing, an outcome of primary interest at this stage of the lifecycle of the family. Individual characteristics, environment and culture, and family involvement with programs are hypothesized to influence family well-being, but primarily through their impact on transition success.

## Community Living/Social Domain

Armstrong, K. H., Dedrick, R. F., & Greenbaum, P. E. (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.

**Synthesis:** This report examines the rates of change in strength-and deficit-based behaviors in relation to community adjustment for 292 participants in the 7-year longitudinal National Adolescent and Child Treatment Study (NACTS) as they transitioned from adolescence to the adult world. Six domains were scored, including 1) education, 2) employment, 3) residence, 4) social support network, 5) self-reported and 6) caretaker-reported satisfaction and were combined to form the Index of Community Adjustment (ICA). Participants with higher social-adaptive behavior upon entry into NACTS and whose social-adaptive behavior improved over time attained higher ICA scores. The results of this study indicate the need to provide comprehensive and integrated services that promote development of social-adaptive skills (e.g., self-care skills, home living skills, self-direction, communication, health and leisure, work, and functional activities) associated with successful transition to adulthood for individuals with emotional challenges.

Cooney, B. F. (2002). Exploring perspectives on transition of youth with disabilities: Voices of young adults, parents, and professionals. *Mental Retardation, 40*(6), 425-435.

**Synthesis:** This report used qualitative research methods to examine transition experiences of (a) 9 young adults with severe disabilities during their last year of high school, (b) their parents, and (c) professionals from schools and adult service agencies. Students were remarkably articulate about plans following graduation but had few opportunities to meaningfully fulfill them. Parents hoped their child's talents and abilities would allow them to achieve fulfilling adult lives, but faced uncertain outcomes and unfamiliar procedures. Professionals managed the process and approached transition by matching needs to available programs; however, these programs fostered dependency and denied students a genuine opportunity to achieve full adult status. The article concludes that although both parents and professionals worked for the betterment of young adults, the inability to recognize diverse perspectives (including those of the child) seriously impeded the quality of the transition process.

## Unpublished Literature/Resources

### Employment

Canadian Association of Community Living. *Press release: CACL announces formal partnership with Aramark Canada*. Retrieved April 8, 2008

This press release describes a partnership between Canadian Association of Community Living (CACL) and Aramark Canada, which is a Canadian corporation that provides outsourcing services such as cleaning and office services. This purpose of this partnership is to create an effective working relationship with Aramark to increase employment opportunities for individuals with intellectual disabilities. Pilot projects will be set up initially to begin implementation. This will lead to a set of protocols for service delivery and employment supports.

Canadian Council on Rehabilitation and Work. *CCRW / CCRT - Connecting employers and job seekers with disabilities – inclusive employment*. Retrieved 4/10/2008, 2008, from <http://www.ccrw.org.libaccess.lib.mcmaster.ca/en/about.asp>

This Canadian online resource provides information on employment programs offered by the Canadian Council on Rehabilitation and Work. Some resources, among many, include

Disability Awareness Series, Employment Services, Ethno-cultural portal for youth with disabilities, Job accommodation Service, Partners for Workplace Inclusion Program, Research, etc.

Human Resources & Social Development Canada, & Employment Access. (2003). *Welcome to the coalition for persons with disabilities website*. Retrieved 03/04/2008, 2008, from <http://www.disabilityaccess.org.libaccess.lib.mcmaster.ca/>

This Canadian online resource called "The Coalition" is a community based partnership of persons with disabilities and anyone interested in working collaboratively to affect positive changes for persons with disabilities. Since 1997, the Coalition has operated "Employment Access", a one-stop employment service program dedicated to persons with disabilities who wish to access assistance in preparing for, obtaining and maintaining competitive employment. "Sign of the Times" is the first Practice Firm in North America specifically dedicated to assisting persons with disabilities in finding or returning to full time competitive employment. Practice Firms help to bridge the gap that educated and qualified people face when they lack the necessary work experience or confidence as a result of disability barriers or acquired disabilities. The mission of The Coalition is to promote the independence, inclusion, participation, and personal choice of persons with disabilities in our community through the provision of responsive services and supports.

Ministry of Social Services and Seniors Prince Edward Island. (2006). *Multilateral framework for labour market agreement for persons with disabilities: Prince Edward island third annual baseline report 2005-2006* Retrieved April 6, 2008 from <http://www.gov.pe.ca.libaccess.lib.mcmaster.ca/photos/original/LMDA-0506.pdf>

In the Multilateral Framework for Labour Market Agreements for Persons with Disabilities, Federal, Provincial and Territorial Ministers Responsible for Social Services committed to building a strong, inclusive society and securing a high quality of life for all Canadians with disabilities. They agreed that all Canadian citizens should have an opportunity to contribute to our social and economic fabric of the country. This means removing barriers so that people with disabilities can live with dignity and realize their capacity for independence.

National Center on Secondary Education and Transition, Minneapolis, MN. (2002). *Research to practice brief: Tapping employment opportunities for youth with disabilities by engaging effectively with employers*. Retrieved 03/28, 2008, from <http://www.ncset.org/publications/viewdesc.asp?id=716>

This American researcher argues that best practices for encouraging employers to hire youth with disabilities includes education for employers, developing skills among the youth labor force, providing appropriate support for both youth and employers when employees with disabilities begin working, and when working with employers to change policy it should be done with any existing policies within the organization. In general, the research advocates a soft sell approach.

Office of Disability Employment Policy. *Advising youth with disabilities on disclosure*. Retrieved 4/9, 2008, from <http://www.dol.gov/odep/pubs/fact/advising.htm>

This American resource is a website for professionals advising youth with disabilities on disclosing their impairments at school and in the workplace. In addition, there is also a companion resource targeted specifically at youth.

Office of Disability Employment Policy. *Entering the world of work: What youth with mental health needs should know about accommodations*. Retrieved 4/9, 2008, from

<http://www.dol.gov/odep/pubs/fact/transitioning.htm>

This American website provides information for individuals with mental illness on disclosing their disability. In addition the website offers examples of reasonable accommodations that employers can offer as well as strategies for dealing with disability related issues in the workplace. Interestingly, the site recognizes that, unlike physical disability which is made strides for accommodation in the workplace, mental illness carries a greater stigma.

Ontario March Of Dimes. (2003). *Canada pension plan disability program the importance of an ongoing return-to-work strategy: A solutions brief* Retrieved April 10, 2008 from <http://www.marchofdimes.ca.libaccess.lib.mcmaster.ca/NR/rdonlyres/B85C5358-909D-4242-A5B3-299A48747CF6/0/returntowork.pdf>

This report is a solutions brief by the Ontario March of Dimes detailing 16 recommendations ranging from cost savings resulting from return to work and vocational rehabilitation services, to implementing a system to measure longer term impacts of the program and recommending that CPP implement a strategies to enhance the job retention and longer term labour market attachments. The report indicates that there also is sufficient empirical evidence demonstrating that rehabilitation does serve and enhance social development goals and government policy, and could be significantly improved. The report suggests that the program could achieve more, and in fact do more, through partnerships with other government training programs. For example, clients could be linked to career or other training options in conjunction with the rehabilitation plan. This could achieve substantial, long-term results, such as further improving client motivation for rehabilitation, and thereby enhance the underlying social development rationale of an ongoing return-to-work strategy in a meaningful way. This might also assist in achieving such goals as obtaining and maintaining employment over the long-term.

RBC. *Royal Bank of Canada career opportunities for persons with disabilities*. Retrieved 04/10, 2008, from [http://www.rbc.com/uniquecareers/diversity/div\\_recruitment.html](http://www.rbc.com/uniquecareers/diversity/div_recruitment.html)

This website includes information from the Royal Bank of Canada on their services and strategies to recruit workers with disabilities which includes support through the training process to finding full-time employment with the bank.

Saskatchewan Abilities Council. *The Saskatchewan Abilities council - partners in employment*. Retrieved 4/9/2008, 2008, from [http://www.abilitiescouncil.sk.ca/main/html/services/supported\\_empl/partners\\_in\\_employment.shtml](http://www.abilitiescouncil.sk.ca/main/html/services/supported_empl/partners_in_employment.shtml)

This website outlines the employment services offered by a provincial agency in Saskatchewan, which include job coaching and job development.

Service Canada. *Skills link*. Retrieved 04/11, 2008, from <http://www1.servicecanada.gc.ca/en/epb/yi/yep/newprog/skillslink.shtml>

This Canadian website provides information on the programs to support youth with disabilities, recent immigrants and aboriginals find sustainable paid employment through skill development and long-term support in the workplace working with employers and employees.

York University Learning Disabilities Program. *Learning disabilities program*. Retrieved 04/11, 2008, from <http://www.yorku.ca/cdc/ldp/>

This Canadian website describes the services offered at York University's learning disabilities program. Aside from educational support, there is career support and

mentorship, which focuses around the transition from school to the workplace is a highlight. The mentorship program allows individuals with learning disabilities to connect with employers who are looking to learn more about learning disabilities in their workplace.

## Education

Aboriginal services branch and learning and teaching resources. (2005). *Teaching aboriginal students with learning disabilities: Recognizing gifts and strengths*. Alberta: Alberta Education.

This is a Canadian resource with a purpose to assist teachers to better serve the needs of Aboriginal students with learning disabilities (LD). This chapters' purpose is to help teachers to refine their understanding of LD and to enable them to see Aboriginal students with LD as having unique gifts, strengths, and needs rather than challenges only. The chapter also aims to increase awareness on the recognition of the importance of positive parent involvement in all aspects of the individualized program planning process and to build a repertoire of strategies that will encourage Aboriginal students with LD to develop the study skills that will help them succeed.

Alberta Association of Community Living. (2006). *Video - inclusive post-secondary education: Living the dream*. Retrieved 03/04/2008, 2008, from <http://www.aacl.org/resources>

This video from the Alberta Association for Community Living highlighting inclusive postsecondary education concludes inclusion benefits individuals with developmental disabilities as well as peers and others in the postsecondary communities. The association also argues that involvement in postsecondary institutions allows people with developmental disabilities to not only contribute more fully to their communities but also further develop social and employment skills which will serve them better in the future.

Division on Career Development and Employment. *Student involvement in the IEP process*

Retrieved April 5, 2008 from [http://www.dcdt.org/pdf/DCDT\\_Fact\\_Sheet\\_IEP\\_Process.pdf](http://www.dcdt.org/pdf/DCDT_Fact_Sheet_IEP_Process.pdf)

This fact sheet discusses the Self-Advocacy Strategy, which is a motivation strategy designed to prepare students to participate in any education or transition planning meeting, and it's importance of involving students in their own educational planning process. The fact sheet lists prerequisites that should include a willingness to learn the strategy and the ability to communicate (i.e., gestures or through words). The fact sheet creates an acronym called the IPLAN strategy which allows students to participate more actively in educational transition planning meetings.

Government of Newfoundland and Labrador. (2005). *Foundations for success: White paper on post-secondary education*

This is a Canadian report that lists in detail the educational reforms in Newfoundland to create greater opportunities for young adults after high school.

Government of Newfoundland and Labrador. (2007). *Changes announced to ISSP and pathways models for special education programming.*, 2008, from

<http://www.releases.gov.nl.ca/releases/2007/edu/1218n04.htm>

This website provides the most current information on changes to the special education programs and support in Newfoundland and Labrador.

Grigal, M., Dwyre, A. & Davis, H. (2006). *Transition services for students aged 18-21 with intellectual disabilities in college and community settings: Models and implications of*

success. Retrieved April 3, 2008, from [http://www.steps-forward.org/Transition\\_Services\\_18\\_to\\_21.pdf](http://www.steps-forward.org/Transition_Services_18_to_21.pdf)

Recently in the field of special education in the United States there has been a call for the development and expansion of services for older students with intellectual disabilities outside of the high school setting. In response, local school systems across the country have begun to provide transition services to students ages 18 and older with intellectual disabilities in postsecondary settings such as two- and four-year colleges or other community settings. This brief provides an overview of some successful models of transition services being implemented in postsecondary settings, and describes one such model implemented by the Baltimore City Public School System in three local colleges. The strength of this approach is that young people with intellectual disabilities are able to participate in age-appropriate education and social activities instead of remaining in high school until the age of 21 years.

ISSP & Pathways Commission. (2007). *Focusing on students: The report of the ISSP & pathways commission*

This Canadian report examined the provincial education models in Nova Scotia, which are a reflection of emergent global trends in special education. Extensive public consultations and submissions, surveys and cross-jurisdictional analyses, and a commissioned review of the literature have yielded rich data. The Model for the Coordination of Services to Children and Youth was found to be problematic in several areas, notably: unrealistic demands on personnel; excessive meetings and documentation; unnecessary procedures; and a pronounced lack of commitment from other government agencies. Inconsistent training and different interpretations of both models within education was found, and there still exists what the Commission called, a "crisis of knowledge and leadership" in the area of special education. The vast majority of classroom teachers still have no training in the area of accommodating exceptionalities. There are also no existing systemic mechanisms to permit effective datagathering and monitoring of programs and services for children and youth. The needs of at-risk students (particularly Aboriginal children), warranted immediate attention.

Ministry of Education, & Ontario. (2002). *Transition planning: A resource guide*. Retrieved April 3, 2008, from <http://www.edu.gov.on.ca/eng/general/elemsec/speced/transiti/transition.pdf>

This guide presents a range of suggestions from which educators may select ideas that would be useful in their particular local context. It is not expected that every suggestion outlined here will be appropriate to or incorporated in every school board's or school's transition-planning process. This guide sets out no new policy requirements; rather, it provides a series of detailed examples of steps for implementing the policy (e.g., Individual Education Plans (IEP's), Annual Education Plans (AEP's), health care psychological support plans, etc.), in order to assist all those involved in the transition-planning process.

Mosoff, J. M., Greenholtz, J., Hurtado, T. & Jo, J. (2007). *Models of inclusive post-secondary education for young adults with developmental disabilities (1st year of 3 year research project)*. Retrieved April 3, 2008, from [http://www.steps-forward.org/Research/2007%2012%20IPSE%20CCL%20Final%20Report%20\\_16%20web\\_.pdf](http://www.steps-forward.org/Research/2007%2012%20IPSE%20CCL%20Final%20Report%20_16%20web_.pdf)

A qualitative review of inclusive education in postsecondary institutions in British Columbia. Data was gathered from students participating in the program, instructors of courses with someone with a developmental disability taking the class and peers. The qualitative nature

of the study is an asset because it allowed individuals to demonstrate a growing comfort level with the experience over time on the part of both professors and students.

National Center on Secondary Education and Transition, Minneapolis, MN. (2003). *Research to practice brief: DO-IT: Helping students with disabilities transition to college and careers*. Retrieved 28/03/2008, 2008, from <http://www.ncset.org/publications/viewdesc.asp?id=1168>  
This study is a review of an American high school to college program for students with disabilities. It finds that: "Input from DO-IT scholars and parents suggests that Internet and computer access, summer study with college and career preparation activities, on-line peer and mentor support, and work-based learning have had a positive impact on postsecondary academic and career outcomes for people with disabilities."

National Educational Association of Disabled Students. *NEADS - moving on*. Retrieved 4/10, 2008, from <http://www.neads.ca/movingon/en/about/index.php>  
This Canadian website details information on the Moving On program offered by the National Education Association of Disabled Students, and targeted toward high school students with disabilities in Canada looking to enter postsecondary education. Services include mentorship, the sharing of resources and support when entering an institution.

Neurologic Rehabilitation Institute of Ontario (NRIO). (2008). *NRIO neurologic rehabilitation institute of Ontario: College & university support services*. Retrieved 03/04, 2008, from <http://www.nrio.com/college.html>  
This post-secondary level support program facilitates the young adult's transition from hospital and/or rehabilitation facility to high school, college or university. This is done through the provision of individualized in-home or in-school academic supports.

University of Alberta, Edmonton On Campus Adult Education Society. *The J P Das developmental disabilities centre*. Retrieved 4/10/2008, 2008, from <http://www.ualberta.ca/~jpdasddc/inclusion/oncampus/oncampus.html#top>  
This website provides information on the Edmonton On Campus program which provides opportunities for young adults with developmental disabilities to participate fully in on-campus activities.

W. Ross McDonald School. *W. Ross McDonald academic program*. Retrieved 4/10/2008, 2008, from <http://www.psbnet.ca/webs/wrm/Academic%20Program.htm>  
Synthesis: This website provides information on the W. Ross McDonald School in Ontario for youth who are blind and visually impaired. Integrated into the curriculum is the skills training education program (STEP) to assist in the transition from school to work.

## **Independent Living/Housing Domain**

Canadian Abilities Foundation. (2005). *On my own: A resource guide for living independently - "new release"*. Retrieved 03/04, 2008, from <http://www.abilities/onmyown/index.html>  
This is a Canadian resource designed for young people with disabilities living on their own. Written from the perspective of those who have experienced the transition to independent living and provides tips to those who are going through the change of living independently.

## **Community/Social Domain**

Bose, T. (2007). *Growing up speaking out*. Retrieved April, 2008, from [www.advocacyresource.net](http://www.advocacyresource.net)

This review article summarizes an advocacy resource from the United Kingdom, which includes transitional planning resources, including community resources, for those with learning disabilities as well as other youth "at risk".

## Theme #4: Factors that influence transition

Numerous publications address the many factors that influence transition to adulthood. These factors could be barriers/risk factors, or supports/helpful factors. Our research team organized these factors into four subthemes:

1. Personal factors (i.e., youth characteristics) - a) risk factors/barriers; b) support factors.
2. Environmental factors - a) environmental barriers; b) environmental supports.

### 1. Youth (personal) characteristics

#### Risk factors/barriers to transition

#### Published literature

Baltodano, H. M., Mathur, S. R., & Rutherford, R. B. (2005). Transition of incarcerated youth with disabilities across systems and into adulthood. *Exceptionality, (2)*, 103-124.

**Synthesis:** see annotation under Theme #1: Status, experiences and outcomes

Berge, J. M., Patterson, J. M., 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, & Health, 25(2)*, 190-203.

**Synthesis:** This qualitative study used focus groups to explore the transition into adulthood for young adults with cystic fibrosis (CF). Specifically, the study focused on how these young adults managed the shift in treatment responsibility, viewed their quality of life, and how they perceived their future. Results indicated that treatment compliance as well as mental health/other health related problems depended on differences and attitudes relating to gender. However differences in gender did not affect their future life outlook.

Binks, J. A., Barden, W. S., Burke, T. A., & Young, N. L. (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*, 1064-1073.

**Synthesis:** The purpose of this project was to address the lack of synthesis regarding the factors, processes, and outcomes specific to the transition from child-centered to adult-centered health care for people with cerebral palsy (CP) and spina bifida (SB); more specifically, to identify barriers, to outline key elements, to review empirical studies, and to make clinical and research recommendations. The authors searched Medline and CINAHL databases from 1990 to 2006 using the key words: transition, health care transition, pediatric health care, adult health care, health care access, health care use, chronic illness, special health care needs, and physical disability. The resulting studies were reviewed with a specific focus on clinical transition for persons with CP and SB, and were supplemented with key information from other diagnostic groups. Of the 149 articles: 54 were discussion, 21 case series, 28 database or register, 25 qualitative, and 34 survey articles (some included multiple methods). Five key elements that support a positive transition to adult-centered health care were identified as preparation, flexible timing, care coordination, transition clinic visits, and interested adult-centered health care providers. There was, however, limited empirical evidence to support the impact of these elements. This review

summarizes key factors that must be considered to support this critical clinical transition and sets the foundation for future research. The recommendation is made to apply prospective study designs to evaluate transition interventions and determine long-term health outcomes.

Blue-Banning, M., Turnbull, A. P., & Pereira, L. (2002). Hispanic youth/young adults with disabilities: Parents' visions for the future. *Research and Practice for Persons with Severe Disabilities*, 27(3), 204-219.

**Synthesis:** This article addresses the rapid increase of culturally and linguistically diverse populations in the United States, in particular the Hispanic population. Addressing the needs of individuals transitioning from adolescence to adulthood and their families requires that outcomes of service recognize the cultural differences of people with disabilities. To provide effective support services, a clearer understanding is needed of the perspectives of Hispanic parents of youth/young adults with disabilities concerning their hopes and expectations for their child's future. To address this issue, focus group interviews were conducted with 38 Hispanic parents of youth/young adults with developmental disabilities. The findings suggest that Hispanic parents have a diversity of hopes and expectations concerning future living, employment, and free-time options, for their children with disabilities.

Bowe, F. G. (2003). Transition for deaf and hard-of-hearing students: A blueprint for change. *Journal of Deaf Studies and Deaf Education*, 8(4), 485-493.

**Synthesis:** This study examines issues related to the large and growing number of deaf and hard-of-hearing adults who are "low-functioning deaf" (LFD). The unmet needs of many young people who are deaf or hard of hearing, and the continuing high rates of dropping out of school argue for a change in secondary programming for multiply disabled deaf, hard-of-hearing students, and for others who are at risk of becoming LFD as adults. This article reviews research related to transition for adolescents with disabilities as well as those who are deaf or hard of hearing. Suggestions include the provision of transition programs that focus on on-site vocational and independent-living skills training for students with disabilities to facilitate the development of self-determination skills and the skills related to being a valuable team player.

Burchardt, T. (2004). Aiming high: The educational and occupational aspirations and of young disabled people. *Support for Learning*, 19(4), 181-186.

**Synthesis:** see annotation under Theme #1: Status, experiences and outcomes

Cameto, R., Levine, P., & Wagner, M. (2004). *Transition planning for students with disabilities: A special topic report of findings from the national longitudinal transition study-2 (NLTS2)*. National Center for Special Education Research. 400 Maryland Avenue SW, Washington, DC.

**Synthesis:** This report by the National Longitudinal Transition Study - 2 (NLTS2) examines efforts to prepare youth with disabilities for the transition from secondary school to adulthood. It highlights the transition planning process undertaken during high school with and for youth with disabilities as they prepare for life after school. These topics are addressed by using data from two important sources: (1) Parents or guardians of NLTS2 study members; and (2) School staff best able to describe students' overall programs. From these data, NLTS2 provides a national picture of transition planning, including variations in that planning for students who differ in disability and other characteristics. The following are appended: (1) NLTS2 Sampling, Data Collection, and Analysis Procedures; (2)

Demographic Characteristics of Youth with Disabilities and Their Households; and (3) Unweighted Sample Sizes.

Canadian National Institute for the Blind. *The status of Canadian youth who are blind or visually impaired: A study of lifestyles, quality of life and employment*. CNIB.

**Synthesis:** This is a Canadian comprehensive nation wide study aimed at learning more about the daily lives of youth who are blind or visually impaired. The study was designed to explore the lives of youth in four domains: employment, activities of daily living, social life, and academics. Comparisons were made between blind youth and those with visual impairments. There are three key recommendations that can be drawn from this article. One that it is important that youth receive extensive vocational counseling as early in their lives as possible. Two that parents of youth with visual impairments be educated about just how important it is that their children develop and utilize skills of daily living. Three that counselors have an appreciation for some of the difficulties that youth who are partially sighted may experience as they engage in activities alongside sighted peers.

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 & Society*, 22(5), 473-488.

**Synthesis:** This article uses data obtained from a study that examined transition experiences of young people with moderate learning disabilities. A comparison is made between those experiences and the experiences of both other vulnerable young people and non-disabled youth. It was found that non-disabled youth experience extended transitions with events that signify adult status taking place well into young people's 20s. On the other hand, vulnerable youth transitions are often (out of necessity) rushed, with young people having to take on responsibility beyond their years. The results of the study demonstrate that for young people with moderate learning disabilities the experiences of transition more closely mirror those of other vulnerable youth than they do the non-disabled population.

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.

**Synthesis:** see annotation under Theme #1: Status, experiences and outcomes

Gordon-Larsen, P., Adair, L. S., Nelson, M. C., & Popkin, B. M. (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), 569-575.

**Synthesis:** Information about obesity is abstracted from the National Longitudinal Transition Survey (NLTS) study to examine dynamic patterns of change in obesity during the transition to adulthood for different ethnic populations. The results indicate that the proportion of adolescents who become or remain obese as they enter adulthood remains disturbingly high. There is a call for effective preventive and treatment efforts in the US.

Jonikas, J. A., Laris, A., & Cook, J. A. (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), 114-121.

**Synthesis:** This study reviewed literature on the needs and experiences of young adult women, aged 16 to 21, who have a diagnosis of serious emotional disturbance (SED) or mental illness. Given the large numbers of young women with SED, evidence that they are

underserved (e.g., services must be community-based and unconditional; individualized; inclusive of parents; culturally competent; with flexible funding and outcome oriented), and the continuity of many disorders from adolescence to adulthood, an integrative review in this area enhances our ability to better address these young women's needs.

Learning Disabilities Association of Canada. (2007). *Putting a Canadian face of learning disabilities (PACFOLD)*. Ottawa ON: LDAC.

**Synthesis:** see annotation under Theme #1: Status, experiences and outcomes

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, 28*(15), 915-928.

**Synthesis:** This article summarizes a research project that tested the hypothesis that the difficulties young adults with developmental disabilities have in obtaining adult social roles are not inevitable consequences of their childhood impairment. The conceptual framework of the International Classification of Functioning, Disability, and Health was used to test this hypothesis. The sample (n = 635) came from the Metropolitan Atlanta Developmental Disabilities Follow-up Study of Young Adults, a population-based cohort of young adults aged 21 - 25 years identified at age 10 with childhood impairment. The results suggest that: (i) attaining adult social roles varies by impairment type and severity, (ii) experiencing activity limitations partially mediate the relationship between impairment and adult social roles, and (iii) attending postsecondary education increases the likelihood of attaining markers of adulthood. It is concluded that interventions to reduce activity limitations and to develop strategies to increase attendance in postsecondary education may increase the likelihood for the acquisition of adult social roles among young adults with childhood impairment.

Vander Stoep, A., Beresford, S. A., Weiss, N. S., McKnight, B., Cauce, A. M., & Cohen, P. (2000). Community-based study of the transition to adulthood for adolescents with psychiatric disorder. *American Journal of Epidemiology, 152*(4), 352-362.

**Synthesis:** This longitudinal study examined the transition to adulthood in a randomly sampled, community-based cohort of adolescents in the US. The study compared young adult outcomes of 33 adolescents with and 148 adolescents without psychiatric disorder. After adjustment for differences in age, gender, and social class, adolescents with psychiatric disorder were 13.74 times less likely to complete secondary school (95% confidence interval (CI): 4.17, 45.17), 4.07 times less likely to be employed or in college or trade school (95% CI: 1.4, 12.3), 3.13 times more likely to be involved in criminal activity (95% CI: 1.11, 8.87), and 6.46 times more likely to have gotten pregnant themselves or to have gotten someone else pregnant (95% CI: 1.75, 23.87). While adolescents with psychiatric disorder in this community-based study had outcomes that were somewhat more favorable than those of adolescents with psychiatric disorder in prior treatment-based studies, they nonetheless were reported to be at high risk of failing to meet young adult role expectations.

Wells, T., Sandefur, G. D., & Hogan, D. P. (2003). What happens after the high school years among young persons with disabilities? *Social Forces, 82*(2), 803-832.

**Synthesis:** In this review article, the authors examine the immediate post-high school years of adolescents with disabilities. Using data from the National Educational Longitudinal Study of 1988 and the National Longitudinal Transition Study of Special Education Students, 1987-1991, they examine the transition from adolescence to adulthood

and uncover the specific factors that are associated with the likelihood of making various early transitions to adulthood. Factors that profoundly affect youth's immediate post-high school activities are disability and types of disability. In addition, family socioeconomic resources have a smaller impact on the transition to adulthood among adolescents with disabilities than among adolescents without disabilities. The review concludes by stating that parents can actually block the intergenerational transfer of socioeconomic privilege because many resources that families use to increase education and to promote the transition to adulthood do not apply.

Wong, M. E. (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 Impairment*, 22(1), 37.

**Synthesis:** Two groups of visually impaired (VI) students in Britain confronting post-school transition were followed in this study. One group aspired to enter university, the other group had decided on vocational training. Positive image, employment pragmatics and the notion of 'something extra' were contributing factors shaping these students in their post-school choices. Underlying these influences is a determination to ensure employability is achieved at the completion of their chosen post-school path.

## Personal Supports

Alpern, C. S., & Zager, D. (2007). Addressing communication needs of young adults with autism in a college-based inclusion program. *Education and Training in Developmental Disabilities*, 42(4), 428-436.

**Synthesis:** This article reviews the literature regarding changing communication profiles of individuals with autism as they progress through adolescence and young adulthood. The authors acknowledge the impact of language patterns (e.g., complexity in sentence structure and use of body language) on social and vocational functioning. Recommendations are made for a transdisciplinary collaborative program in a university setting to provide an appropriate and inclusive experience for young adults with autism to learn alongside their chronologically-aged peers. The article also shows that speech-language services that continue to work on conversational interaction and language goals do contribute to the success of young adults in post-secondary programs.

Baltodano, H. M., Mathur, S. R., & Rutherford, R. B. (2005). Transition of incarcerated youth with disabilities across systems and into adulthood. *Exceptionality*, (2), 103-124.

**Synthesis:** see annotation under Theme #1: Status, experiences and outcomes

Blacher, J. (2001). Transition to adulthood: Mental retardation, families, and culture. *American Journal on Mental Retardation*, 106(2), 173-188.

**Synthesis:** This article describes a conceptual model that was used to guide a study in the United States of mental retardation and family well-being during the transition from late adolescence into young adulthood. It is suggested that the success of transitional experiences in the three realms of residential, vocational and social status will influence family well-being, an outcome of primary interest at this stage of the lifecycle of the family. Individual characteristics, environment and culture, and family involvement with programs are hypothesized to influence family well-being, but primarily through their impact on transition success.

Learning Disabilities Association of Canada. (2007). *Putting a Canadian face of learning disabilities (PACFOLD)*. Ottawa ON: LDAC.

**Synthesis:** see annotation under Theme #1: Status, experiences and outcomes

Turnbull, A. P., & Turnbull, R. (2006). Self-determination: Is a rose by any other name still a rose? *Research and Practice for Persons with Severe Disabilities (RPSD)*, 31(1), 83-88.

**Synthesis:** This review paper focuses on the emerging literature related to self-determination funding which holds that individuals with disabilities should have greater control over the money allocated to serve them than they have had in the past and that service-provider agencies have now. The paper reviewed the literature on self-determination funding to analyze terminology/descriptions and anticipated outcomes and identified two concerns: 1) As students with disabilities who have had a self-determination curriculum as part of their special education curriculum move toward transition to adulthood, they are going to encounter a whole different use of the term (i.e., self-determination) as they consider funding options. 2) There are a wide variety of terms regarding self-determination funding that are used interchangeably and that can unintentionally confuse stakeholders, including individuals with disabilities, families, service providers, and policymakers. This article discusses the broad range of terms/definitions and anticipated outcomes related to self-determination and how this affects the funding a student acquires.

## Unpublished literature – Youth (Personal) Characteristics

Division on Career Development and Employment. *Student involvement in the IEP process*

Retrieved April 5, 2008 from [http://www.dcdt.org/pdf/DCDT\\_Fact\\_Sheet\\_IEP\\_Process.pdf](http://www.dcdt.org/pdf/DCDT_Fact_Sheet_IEP_Process.pdf)

This fact sheet discusses the Self-Advocacy Strategy, which is a motivation strategy designed to prepare students to participate in any education or transition planning meeting, and it's importance of involving students in their own educational planning process. The fact sheet lists prerequisites that should include a willingness to learn the strategy and the ability to communicate (i.e., gestures or through words). The fact sheet creates an acronym called the IPLAN strategy which allows students to participate more actively in educational transition planning meetings.

Transition Research Institute at Illinois. *Guide for transition planning*. Retrieved 4/9/2008, 2008, from <http://www.ed.uiuc.edu/sped/tri/GuideTP.html>

This American resource is recommended for individuals by the transition research Institute at Illinois. The transition guide is primarily designed as an assessment tool for teachers and other professionals. The guide track student progress over high school years in the following 12 areas: classroom instruction, career exploration, punctuality and attendance, behavior/social, school performance, transportation, vocational assessment, self advocacy, rehabilitation service, community resources and community based instruction. As the student moves towards her high school from the entry to exit points, they are presented with the opportunity to take more and more responsibility for planning their own future.

## 2. Environmental Factors

### Barriers

## Published Literature

Bowe, F. G. (2003). Transition for deaf and hard-of-hearing students: A blueprint for change. *Journal of Deaf Studies and Deaf Education, 8*(4), 485-493.

**Synthesis:** This study examines issues related to the large and growing number of deaf and hard-of-hearing adults who are "low-functioning deaf" (LFD). The unmet needs of many young people who are deaf or hard of hearing, and the continuing high rates of dropping out of school argue for a change in secondary programming for multiply disabled deaf, hard-of-hearing students, and for others who are at risk of becoming LFD as adults. This article reviews research related to transition for adolescents with disabilities as well as those who are deaf or hard of hearing. Suggestions include the provision of transition programs that focus on on-site vocational and independent-living skills training for students with disabilities to facilitate the development of self-determination skills and the skills related to being a valuable team player.

Callahan, S. T., Feinstein, R., & Keenan, P. (2001). Transition from pediatric to adult-oriented health care: A challenge for patients with chronic disease. *Current Opinion in Pediatrics, 13*(4), 310-316.

**Synthesis:** This paper distinguishes medical transition (the process) from medical transfer (an event), and discusses potential barriers to transition which include the longstanding relationship with the pediatric provider being difficult to end, adult providers not having sufficient knowledge or understanding about youth with chronic conditions, and a lack of consensus on the best timing for the transfer of care. The article is primarily written for healthcare providers who are recognizing the need for coordinated processes to transition adolescents and young adults with chronic conditions to adult health care. New models of coordinated care must include the participation and input of the adolescent, his or her family, and pediatric and health professionals working together to ensure a smooth transition.

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.

**Synthesis:** This Canadian report summarizes phase two of a longitudinal project that examined the experiences of post-secondary students with disabilities in Canada during the transition from post-secondary to work environments. Participants in the study included students as well as employers. The report indicates that facilitators to employment included having a 1) post-secondary degree, 2) certain personal qualities, 3) flexibility in the workplace, 4) volunteer and paid-work experience, 5) strong social networks, 6) supportive and accessible environments, 7) and having experience living with a disability. Obstacles to employment included 1) attitudinal barriers of employers, 2) lack of transportation, 3) inaccessible environments, 4) lack of education and work experience, 5) lack of access to interpreters and attendants, and 6) perceptions of uncertain futures.

Chambers, C. R., Hughes, C., & Carter, E. W. (2004). Parent and sibling perspectives on the transition to adulthood. *Education and Training in Developmental Disabilities, 39*(2), 79-94.

**Synthesis:** The purpose of this investigation was to extend research on parent and sibling perspectives concerning the transition of family members with significant cognitive disabilities to adult life. Eight parents and eight siblings of high school students with significant cognitive disabilities completed questionnaires addressing transition outcomes. Results indicate that parents and siblings believe that they lacked knowledge with respect

to post-school options, and parents report assuming more active roles in the transition process than did siblings. Although future employment and independent living were important to respondents, both parents and siblings anticipated that after high school, their family member with a disability would work in a segregated employment setting and would live in the parent's home.

Committee on Disability in America. (2007). Health care transitions for young people. In M. J. Field, & A. M. Jette (Eds.), *Future of disability in America* (pp. 4-1). Washington, DC: The National Academies Press.

**Synthesis:** see annotation under Theme #1: Status, experiences and outcomes

Council of Canadians with Disabilities. (2004). *About us: Annual reports 2003-04*

**Synthesis:** The annual reports from the Council of Canadians with Disabilities in 2003-04 reported on the continuing discrimination facing persons with disabilities. The annual reports also summarize the efforts of the CCD to respond to and analyze documents such as "Advancing Inclusion of Persons with Disabilities" from the federal government. Their recommendations for a disability strategic action plan recognize the increased focus on 'citizenship' as an important outcome for government and organizations. Annual reports in later years demonstrate that their advocacy efforts are paying off, as more disability supports have been put in place.

Davis, M., & Sondheimer, D. L. (2005). State child mental health efforts to support youth in transition to adulthood. *The Journal of Behavioral Health Services & Research*, 32(1), 27-42.

**Synthesis:** The ability of state child mental health (MH) systems to facilitate the transition to adulthood of adolescents in their systems was studied by interviewing members of the Children, Youth and Families Division of the National Association of State Mental Health Program Directors (NASMHPD) in the US. Results demonstrated that transition services within the state child MH systems are sparse. Continuity of services as youth age into adulthood is hampered because of generally separate child and adult MH systems, each with separate policies defining who accesses those services, lack of clarity about procedures to access adult MH services, and lack of shared client planning between adult and child MH systems. These findings suggest that adolescents in state child MH systems have difficulty accessing services that will help them with the difficult task of learning to function as an adult. It is recommended that public MH systems should examine their capacity to provide transition supports and make needed improvements.

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), 442-458.

**Synthesis:** A qualitative study of deaf graduates of Rochester Institute of Technology in New York State who became supervisors in work settings found that having a mentor was a primary and persistent element in their career success. In the deaf individual's early years, generally it was a family member or teacher who conveyed a belief in that individual's abilities, encouraged effort, and helped instill self-esteem and confidence. Parents were often their strongest advocates, and teachers were their advisors and facilitators. In the work setting, a supervisor or coworker often served as a mentor by coaching, advising, and teaching the individual what they needed to know to succeed on the job. In many ways, these "informal" mentors provided the foundation that enabled the deaf individual to break through what are often barriers to career success despite their skills and

abilities. The various forms of mentorship and their impact on deaf college graduates are explored.

Hitchings, W. E., Luzzo, D. A., 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.

**Synthesis:** see annotation under Theme #1: Status, experiences and outcomes

Learning Disabilities Association of Canada. (2007). *Putting a Canadian face of learning disabilities (PACFOLD)*. Ottawa ON: LDAC.

**Synthesis:** see annotation under Theme #1: Status, experiences and outcomes

Wells, T., Sandefur, G. D., & Hogan, D. P. (2003). What happens after the high school years among young persons with disabilities? *Social Forces, 82*(2), 803-832.

**Synthesis:** In this review article, the authors examine the immediate post-high school years of adolescents with disabilities. Using data from the National Educational Longitudinal Study of 1988 and the National Longitudinal Transition Study of Special Education Students, 1987-1991, they examine the transition from adolescence to adulthood and uncover the specific factors that are associated with the likelihood of making various early transitions to adulthood. Factors that profoundly affect youth's immediate post-high school activities are disability and types of disability. In addition, family socioeconomic resources have a smaller impact on the transition to adulthood among adolescents with disabilities than among adolescents without disabilities. The review concludes by stating that parents can actually block the intergenerational transfer of socioeconomic privilege because many resources that families use to increase education and to promote the transition to adulthood do not apply.

## 2 (b) Environmental Supports

### Published Literature

Baltodano, H. M., Mathur, S. R., & Rutherford, R. B. (2005). Transition of incarcerated youth with disabilities across systems and into adulthood. *Exceptionality, 2*(2), 103-124.

**Synthesis:** see annotation under Theme #1: Status, experiences and outcomes

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.

**Synthesis:** This Canadian report summarizes phase two of a longitudinal project that examined the experiences of post-secondary students with disabilities in Canada during the transition from post-secondary to work environments. Participants in the study included students as well as employers. The report indicates that facilitators to employment included having a 1) post-secondary degree, 2) certain personal qualities, 3) flexibility in the workplace, 4) volunteer and paid-work experience, 5) strong social networks, 6) supportive and accessible environments, 7) and having experience living with a disability. Obstacles to employment included 1) attitudinal barriers of employers, 2) lack of transportation, 3) inaccessible environments, 4) lack of education and work experience, 5) lack of access to interpreters and attendants, and 6) perceptions of uncertain futures.

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), 442-458.

**Synthesis:** A qualitative study of deaf graduates of Rochester Institute of Technology in New York State who became supervisors in work settings found that having a mentor was a primary and persistent element in their career success. In the deaf individual's early years, generally it was a family member or teacher who conveyed a belief in that individual's abilities, encouraged effort, and helped instill self-esteem and confidence. Parents were often their strongest advocates, and teachers were their advisors and facilitators. In the work setting, a supervisor or coworker often served as a mentor by coaching, advising, and teaching the individual what they needed to know to succeed on the job. In many ways, these "informal" mentors provided the foundation that enabled the deaf individual to break through what are often barriers to career success despite their skills and abilities. The various forms of mentorship and their impact on deaf college graduates are explored.

Grove, B., & Giraud-Saunders, A. (2003). Connecting with connexions: The role of the personal adviser with young people with special educational and support needs. *Support for Learning*, 18(1), 12-17.

**Synthesis:** The Connexions service in the UK has particular responsibility for coordinating transition planning for students with learning difficulties. In this study the authors report on the development of the personal adviser (PA) role in two special schools and one college as part of a Connexions pilot project. The evaluation of the project demonstrated the benefit of a personal adviser for students with learning difficulties who are transitioning to post-secondary settings.

Lehman, C. M., Clark, H. B., Bullis, M., Rinkin, J., & Castellanos, L. A. (2002). Transition from school to adult life: Empowering youth through community ownership and accountability. *Journal of Child and Family Studies*, 11(1), 127-141.

**Synthesis:** The evolution of transition services for youth with disabilities illustrates the transformation that has occurred from a systems-driven to a youth-centered support approach. This article documents the shift that is taking place from a systems-driven to a youth-centred support approach for youth with emotional disturbances (ED). The field of special education in particular is reported to be leading the way toward articulating a new vision for providing transition support by defining services as the coordination of multiple systems to address life domains (e.g., post-secondary education, employment, independent living, and community adjustment). Promising practices, within the context of the conversion to an ecological model of support that contributes to youth self-determination, include utilization of a youth-centered, strengths-based approach to transition planning, beginning in the middle school years. There remain significant barriers to adoption of the practices that may best support the successful transition of youth. These include lack of coordinated efforts across systems, socioeconomic, and community factors. Committed actions by government, the business sector, and private citizens are recommended as essential to address these challenges

Mull, C. A., & Sitlington, P. L. (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.

**Synthesis:** This article summarizes findings regarding the use of technology in helping students with learning disabilities succeed in postsecondary education settings. The primary purposes of this article are to (a) identify the specific technology recommendations

found in the literature, (b) identify issues related to using these recommendations in the transition to postsecondary education, and (c) provide recommendations for planning for the transition to postsecondary education. Based on the literature review, the authors reinforce the importance of assistive technology in transition planning for youth with disabilities. They recommend a thorough assessment early in high school, with funding and training supports put in place to ensure a successful transition.

Ness, J. E. (1996). *The high jump: Transition issues of learning disabled students and their parents*. Learning Disabilities Association of Canada. Website: [www.cfc-efc.ca/docs/ldac/00000357.htm](http://www.cfc-efc.ca/docs/ldac/00000357.htm)

**Synthesis:** A brief report for Child and Family Canada outlines the key issues that face students with learning disabilities and their parents. Recommendations for resolving some of the problems include professionals working together more to develop helpful materials and resources for students and parents; helping students to learn how to explain their disability earlier; exposing students to positive role models; finding support groups and inservice training for parents; and begin the transition process early.

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.

**Synthesis:** see annotation under Theme #1: Status, experiences and outcomes

## Unpublished literature – Environmental Barriers and Supports

Canadian Mental Health Association of Ontario. *NETWORK: Navigating the system*. Retrieved April 3, 2008, from [http://www.ontario.cmha.ca/admin\\_ver2/maps/network\\_23-3\\_winter\\_2008.pdf](http://www.ontario.cmha.ca/admin_ver2/maps/network_23-3_winter_2008.pdf)

This document is an electronic copy of the Canadian Association for mental health Ontario chapter's magazine which highlighted the difficulties for accessing timely mental health services for different populations including new immigrants to Canada.

Division on Career Development and Employment. *Student involvement in the IEP process*. Retrieved April 5, 2008 from

[http://www.dcdt.org.libaccess.lib.mcmaster.ca/pdf/DCDT\\_Fact\\_Sheet\\_IEP\\_Process.pdf](http://www.dcdt.org.libaccess.lib.mcmaster.ca/pdf/DCDT_Fact_Sheet_IEP_Process.pdf)

This fact sheet discusses the Self-Advocacy Strategy, which is a motivation strategy designed to prepare students to participate in any education or transition planning meeting, and it's importance of involving students in their own educational planning process. The fact sheet lists prerequisites that should include a willingness to learn the strategy and the ability to communicate (i.e., gestures or through words). The fact sheet creates an acronym called the IPLAN strategy which allows students to participate more actively in educational transition planning meetings.

Healy, H., & McDougall, C. (2008). *Growing up ready: A framework for preparing youth with disabilities for adult life*. Retrieved April 3, 2008, from

[http://www.sickkids.ca.libaccess.lib.mcmaster.ca/good2go/custom/growing\\_up\\_ready.pdf](http://www.sickkids.ca.libaccess.lib.mcmaster.ca/good2go/custom/growing_up_ready.pdf)

Hospital for Sick Children. (2007). *Good 2 go transition program*. Retrieved 03/04, 2008, from

<http://www.sickkids.ca.libaccess.lib.mcmaster.ca/good2go/>

This website is about adolescents who have been patients at SickKids Hospital in Toronto for many years and must now make a transition to adult health services. It is recognized that many have similar experiences, but also come from a multitude of cultures and family constellations. The transition from paediatric care, with its own distinct culture and ways of doing things, into the adult health care system can be a challenge for teens and their families. The goal of Good 2 Go is to prepare all youth with chronic health conditions to leave SickKids by the age of 18 years with the necessary skills and knowledge to advocate for themselves (or through others), maintain health-promoting behaviors and utilize adult health care services appropriately and successfully. Resources are also provided for parents and service providers.

National Center on Secondary Education and Transition, Minneapolis, MN. (2003). *Research to practice brief: DO-IT: Helping students with disabilities transition to college and careers*. Retrieved 28/03/2008, 2008, from

<http://www.ncset.org/libaccess.lib.mcmaster.ca/publications/viewdesc.asp?id=1168>

This study is a review of an American high school to college program for students with disabilities. It finds that: "Input from DO-IT scholars and parents suggests that Internet and computer access, summer study with college and career preparation activities, on-line peer and mentor support, and work-based learning have had a positive impact on postsecondary academic and career outcomes for people with disabilities."

## Theme #5: Complexity

A theme of "complexity" emerged from the literature review. This theme addresses the complex relationships between person and environment that take place during the transition process. It acknowledges that this transition is an interactional, dynamic process.

### Published Literature

Baltodano, H. M., Mathur, S. R., & Rutherford, R. B. (2005). Transition of incarcerated youth with disabilities across systems and into adulthood. *Exceptionality*, (2), 103-124.

**Synthesis:** see annotation under Theme #1: Status, experiences and outcomes

Burchardt, T. (2004). Aiming high: The educational and occupational aspirations and of young disabled people. *Support for Learning*, 19(4), 181-186.

**Synthesis:** see annotation under Theme #1: Status, experiences and outcomes

Hudson, B. (2006). Making and missing connections: Learning disability services and the transition from adolescence to adulthood. *Disability & Society*, 21(1), 47-60.

**Synthesis:** This article addresses the need for collaborative practices in the field of transition from adolescence to young adulthood for people with a learning disability in the United Kingdom (UK). The UK government agencies have introduced law, regulation, guidance and good practice guides, but these appear to have only limited effect. Drawing upon evidence from a national study, this article examines explanations for the limited progress in this area. It identifies inter-organisational divisions as a crucial factor, and is critical of the 'top-down' approach that has characterised policy responses. It is suggested that a person-centred approach based upon the concept of 'backward mapping', in which policy is based on the grass-roots experiences and needs of people, provides both a tool for understanding and a model for improved implementation.

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.

**Synthesis:** This article describes a grounded theory study that employed in-depth interviews with nine student/parent dyads from eastern Canada. Youth with disabilities, aged 16 to 21, contributed narratives describing high school transitions. Shared experience that transcends disability categories produced powerful results. Three categories emerged: (1) transition facilitators; (2) transition constraints; (3) strategies for meaningful transitions. Higher level analysis revealed further relationships: the connection between perceived lack of support and burn out; the importance of self-advocacy; and the sense of "paving rough roads" for the next generation. The core variable, contextual influences, resonates with the five systems presented in the bioecological model of human development. A model demonstrating the interactions among categories, contexts and ecological systems is presented. This framework provides encouragement and cautionary notes for those working toward a meaningful transition and a place to belong for youth with disabilities.

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*, 28(15), 915-928.

**Synthesis:** This article summarizes a research project that tested the hypothesis that the difficulties young adults with developmental disabilities have in obtaining adult social roles

are not inevitable consequences of their childhood impairment. The conceptual framework of the International Classification of Functioning, Disability, and Health was used to test this hypothesis. The sample (n = 635) came from the Metropolitan Atlanta Developmental Disabilities Follow-up Study of Young Adults, a population-based cohort of young adults aged 21 - 25 years identified at age 10 with childhood impairment. The results suggest that: (i) attaining adult social roles varies by impairment type and severity, (ii) experiencing activity limitations partially mediate the relationship between impairment and adult social roles, and (iii) attending postsecondary education increases the likelihood of attaining markers of adulthood. It is concluded that interventions to reduce activity limitations and to develop strategies to increase attendance in postsecondary education may increase the likelihood for the acquisition of adult social roles among young adults with childhood impairment.

Vander Stoep, A.; Weiss, N.S., McKnight, B., Beresford, S. A. A., & 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.

**Synthesis:** This article reports on a study to test the ability of psychiatric diagnosis, symptom count, and adaptive functioning in adolescence to predict failure to complete secondary school and criminal involvement in young adulthood. <sup>This was a</sup> community-based cohort study in two counties in upstate New York, USA. <sup>Results found that, c</sup>ompared with adolescents without psychiatric disorders, adolescents with depressive, anxiety, disruptive, and substance abuse disorders were 2.86–9.21 times more likely to fail to complete secondary school. Compared with adolescents without disruptive disorders, adolescents with disruptive disorders were 4.04 (1.96–8.32) times more likely to get in trouble with police during young adulthood. The positive predictive value of each measure of adolescent psychiatric disorder for school non-completion was higher in the lowest SES stratum and for young adult criminal involvement was higher for boys. Conclusions made by the authors include: 1. Screening children and adolescents for psychiatric disorders can identify those at high risk of adverse young adult outcomes; 2. Future school and community adjustment can be predicted as easily and accurately on the basis of a simple count of psychiatric symptoms as by applying more complex diagnostic algorithms; and 3. Screening youth for psychiatric symptoms in neighbourhood, school, or primary care settings is a logical first step for early intervention to promote increased school completion and decreased criminal activity in young adulthood.

Vostanis, P. (2005). Patients as parents and young people approaching adulthood: How should we manage the interface between mental health services for young people and adults? *Current Opinion in Psychiatry*, 18(4), 449-454.

**Synthesis:** This British review of recent research focuses on the mental health needs of young people in transition, including those of young parents. Research indicates that higher mental health needs may be related to life transitions. Protective factors in young people include support by their own parents as they strive for independence; their relationship with their partner, siblings, or peers; educational attainment; and social stability. When these transitions are disrupted, young people require coordinated support from different agencies. The overall knowledge on how to meet the mental health needs of young people in transition is limited; however, this review supports unique and individualized interventions that are tailored to young people's characteristics. Evidence about the effectiveness of early psychosis teams suggest that this type of approach may also be suitable for young people with no diagnosed psychosis, but who nonetheless are facing multiple mental health challenges during the transition to adulthood.



## Theme #6: “Best practices”

This theme synthesizes the literature that describes best practices, both in terms of ‘things that are working’ now, and/or recommendations for best practices.

### Published literature

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 and Developmental Disabilities*, 35(4), 351-364.

**Synthesis:** This article describes the field-test results of the Self-Determined Learning Model of Instruction, a model of education designed to enable teachers to facilitate students to set goals, take action on those goals, and adjust their goals and plans as needed. Nineteen students, most of whom had intellectual disabilities, participated in the field test. Seventeen of the 19 students made dramatic changes from baseline to intervention conditions, at levels that exceeded teachers' expectations. Additionally, social validation data obtained from both the students and the participating teachers supported the utility of the model.

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), 219-277.

**Synthesis:** This article represents a comprehensive review of the literature about self-determination. The review accepted 22 articles regarding self-determination interventions. Self-determination is the combination of skills, knowledge, and beliefs that enable a person to engage in goal-directed, self-regulated, autonomous behavior, has become an important part of special education and related services for people with disabilities. The review investigated interventions that have been studied, which groups of individuals with disabilities have been taught self-determination, and the levels of outcomes that have been achieved using self-determination interventions. Although all components of self-determination were reflected in this research, most focused on teaching choice making to individuals with moderate and severe mental retardation or self-advocacy to individuals with learning disabilities or mild mental retardation. The article discusses the need to demonstrate that basic components of self-determination (e.g., choice making and problem solving) can be taught and learned, and can make a difference in the lives of individuals with disabilities. However, information on how to teach more complex components of self-determination (e.g., self-advocacy and goal attainment) still is lacking.

Antle, B. J., & Stewart, D. (2005). *Best practices in transition to adulthood for youth with disabilities in Ontario: An evidence-based systematic review* (research project summary) Hospital for Sick Children and CanChild Centre for Childhood Disability Research.

**Synthesis:** This is a Canadian report that was submitted to the Ontario Ministry of Health and Longterm Care and the Ontario Neurotrauma Foundation, which funded the project. The report summarizes the best practice guidelines for the transition to adulthood for youth with primarily physical and developmental disabilities that were developed through literature review and focus groups with key informants throughout the province. Six main themes were identified by an expert panel who examined the evidence from the focus groups, and literature review. These themes were: the need for collaboration at all levels; capacity

building (personal and community); navigation; information that is accessible and useable for everyone; education, and research/evaluation.

Bent, N., Tennant, A., Swift, T., Posnett, J., Scuffham, P., & Chamberlain, M. A. (2002). Team approach versus ad hoc health services for young people with physical disabilities: A retrospective cohort study. *Lancet*, 360(9342), 1280-1286.

**Synthesis:** The aim of this British study was to compare a young adult team (YAT) approach with the typical ad hoc service approach in four locations in England, in terms of their ability to enhance the participation in society of young people with physical disabilities, and to compare costs. A retrospective cohort methodology was used in which 254 physically disabled young people and 124 healthy controls were given a questionnaire and standardised measures. Logistic regression analysis tested for the effects of ad hoc and YAT services. The absence of pain, fatigue, and stress increased the odds of participation two-fold to four-fold for youth with disabilities. After adjustment for these factors, young people in the multidisciplinary YAT teams were 2.54 times (95% CI 1.30-4.98) more likely than those who used ad hoc services to participate in society. Resource use did not differ between the two service types. A YAT approach also costs no more to implement than an ad hoc approach.

Betz, C. L. (2004). Transition of adolescents with special health care needs: Review and analysis of the literature. *Issues in Comprehensive Pediatric Nursing*, 27(3), 179-241.

**Synthesis:** see annotation under Theme #1: Status, experiences and outcomes

Bowe, F. G. (2003). Transition for deaf and hard-of-hearing students: A blueprint for change. *Journal of Deaf Studies and Deaf Education*, 8(4), 485-493.

**Synthesis:** This study examines issues related to the large and growing number of deaf and hard-of-hearing adults who are "low-functioning deaf" (LFD). The unmet needs of many young people who are deaf or hard of hearing, and the continuing high rates of dropping out of school argue for a change in secondary programming for multiply disabled deaf, hard-of-hearing students, and for others who are at risk of becoming LFD as adults. This article reviews research related to transition for adolescents with disabilities as well as those who are deaf or hard of hearing. Suggestions include the provision of transition programs that focus on on-site vocational and independent-living skills training for students with disabilities to facilitate the development of self-determination skills and the skills related to being a valuable team player.

Burchardt, T. (2004). Aiming high: The educational and occupational aspirations and of young disabled people. *Support for Learning*, 19(4), 181-186.

**Synthesis:** see annotation under theme #1.

Certo, N. J., Mautz, D., Smalley, K., Wade, H. A., Luecking, R., Pumpian, I., et al. (2003). Review and discussion of a model for seamless transition to adulthood. *Education and Training in Developmental Disabilities*, 38(1), 3-17.

**Synthesis:** This article discusses a model for service delivery in the United States, called the Transition Service Integration Model. The model integrates resources and expertise of 3 primary systems (public schools, rehabilitation and developmental disability systems) responsible for transition from school to adulthood for individuals with significant support needs. The model involves school districts forming a partnership with private non-profit agencies that typically serve adults with significant support needs. Through this partnership personnel from the school district and private agencies work together during a student's last

year in public school to develop a paid direct-hire competitive job and a variety of inclusive community activities to engage in when not working. Maintenance support for these work and non-work activities after graduation is shared by the rehabilitation and developmental disability systems and the non-profit agency. After 4 years of implementation, involving 234 students from 14 school districts in California and Maryland, 63% of all graduates have been employed at school exit and 88% of all graduates have experienced a seamless transition. Three year maintenance information shows that 90% of these graduates are still receiving support from the same non-profit agency and that 71% are still employed.

Committee on Disability in America. (2007). Health care transitions for young people. In M. J. Field, & A. M. Jette (Eds.), *Future of disability in America* (pp. 4-1). Washington, DC: The National Academies Press.

**Synthesis:** see annotation under Theme #1: Status, experiences and outcomes

Evans, J., McDougall, J., & Baldwin, P. (2006). An evaluation of the "youth en route" program. *Physical & Occupational Therapy in Pediatrics, 26*(4), 63-87.

**Synthesis:** Youth En Route (YER) is a transition program for youth and young adults with multiple disabilities at Thames Valley Children's Centre in London, Ontario. It offers a multifaceted approach that includes self-discovery, skill development, and community experience. Underlying the service delivery model is a philosophy of self-determination. This article presents a program evaluation that measured the self-determination skills, sense of personal control over life choices, and community participation of 34 youth prior to and one year following their involvement with YER. Youth reported statistically and clinically significant improvement from pretest to posttest with respect to both self-determination and sense of personal control. Moreover, youth reported spending significantly more time at posttest than at pretest engaged in volunteer/work activities and community leisure activities. On average, youth reported high satisfaction with YER services. Practical and research implications are discussed.

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), 442-458.

**Synthesis:** A qualitative study of deaf graduates of Rochester Institute of Technology in New York State who became supervisors in work settings found that having a mentor was a primary and persistent element in their career success. In the deaf individual's early years, generally it was a family member or teacher who conveyed a belief in that individual's abilities, encouraged effort, and helped instill self-esteem and confidence. Parents were often their strongest advocates, and teachers were their advisors and facilitators. In the work setting, a supervisor or coworker often served as a mentor by coaching, advising, and teaching the individual what they needed to know to succeed on the job. In many ways, these "informal" mentors provided the foundation that enabled the deaf individual to break through what are often barriers to career success despite their skills and abilities. The various forms of mentorship and their impact on deaf college graduates are explored.

Gall, C., Kingsnorth, S., & Healy, H. (2006). Growing up ready: A shared management approach. *Physical & Occupational Therapy in Pediatrics, 26*(4), 47-62.

**Synthesis:** This paper provides an account of the work of the Bloorview Kids Rehab centre in Toronto, Ontario to develop a transition framework reflecting evidence-based practice. Examination of current transition practices, a review of the literature, and site visits to health care facilities and universities were conducted to identify promising practices in the

field of transition to adult services. A transition framework was designed to facilitate the adoption of a shared management approach for helping families and their children to grow up ready. Key elements of the transition framework are described and future plans discussed.

Hitchings, W. E., Luzzo, D. A., 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.

**Synthesis:** see annotation under Theme #1: Status, experiences and outcomes

Hudson, B. (2006). Making and missing connections: Learning disability services and the transition from adolescence to adulthood. *Disability & Society, 21*(1), 47-60.

**Synthesis:** This article addresses the need for collaborative practices in the field of transition from adolescence to young adulthood for people with a learning disability in the United Kingdom (UK). The UK government agencies have introduced law, regulation, guidance and good practice guides, but these appear to have only limited effect. Drawing upon evidence from a national study, this article examines explanations for the limited progress in this area. It identifies inter-organisational divisions as a crucial factor, and is critical of the 'top-down' approach that has characterised policy responses. It is suggested that a person-centred approach based upon the concept of 'backward mapping', in which policy is based on the grass-roots experiences and needs of people, provides both a tool for understanding and a model for improved implementation.

Izzo, M. V., & Lamb, P. (2003). Developing self-determination through career development activities: Implications for vocational rehabilitation counselors. *Journal of Vocational Rehabilitation, 19*, 71-78.

**Synthesis:** This article begins with a discussion of the relationship between self-determination and career development, and argues that effective programs need to integrate the two together. A review of model transition programs in the United States demonstrates that effective programs include a high level of expertise of school and agency personnel who collaborate with each other and share resources; who promote self-determination and career development skills in tandem. Recommendations for future research includes gathering national data on the nature and frequency of collaborative practices, and identify the supports and services that are deemed critical by young adults with disabilities.

Learning Disabilities Association of Canada. (2007). *Putting a Canadian face of learning disabilities (PACFOLD)*. Ottawa ON: LDAC.

**Synthesis:** see annotation under Theme #1: Status, experiences and outcomes

Lehman, C. M., Clark, H. B., Bullis, M., Rinkin, J., & Castellanos, L. A. (2002). Transition from school to adult life: Empowering youth through community ownership and accountability. *Journal of Child and Family Studies, 11*(1), 127-141.

**Synthesis:** The evolution of transition services for youth with disabilities illustrates the transformation that has occurred from a systems-driven to a youth-centered support approach. This article documents the shift that is taking place from a systems-driven to a youth-centred support approach for youth with emotional disturbances (ED). The field of special education in particular is reported to be leading the way toward articulating a new vision for providing transition support by defining services as the coordination of multiple systems to address life domains (e.g., post-secondary education, employment,

independent living, and community adjustment). Promising practices, within the context of the conversion to an ecological model of support that contributes to youth self-determination, include utilization of a youth-centered, strengths-based approach to transition planning, beginning in the middle school years. There remain significant barriers to adoption of the practices that may best support the successful transition of youth. These include lack of coordinated efforts across systems, socioeconomic, and community factors. Committed actions by government, the business sector, and private citizens are recommended as essential to address these challenges

McDonagh, J. E., Shaw, K. L., & Southwood, T. R. (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: For Professionals Working with Children in the Hospital and Community*, 10(1), 22-42.

**Synthesis:** This article describes the development and initial evaluation of an evidence-based transitional care programme recently implemented in a multicentre controlled trial in the United Kingdom. The individual components of the programme are described. Evaluation of the acceptability and utilization of these components employed questionnaires administered to users (adolescents with juvenile idiopathic arthritis and their parents) and providers (rheumatology health professionals). The results confirm the acceptability and utilization of the programme components in addition to further innovative developments during the course of the study. The key components were multidimensionality; age and developmentally appropriate services including adolescent-appropriate information; clear honest communication; training in self-advocacy skills and decision making in preparation for transition; and regular visits with youth who are actively involved in transition planning.

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*, 24(1), 16-26.

**Synthesis:** This review article examines how the related concepts of risk factors, protective factors, and resilience relate to postschool outcomes for youth with disabilities, especially for the adult transitions of youth with high-incidence disabilities. Issues related to best practice are identified, including building resilience through supports being available at the individual, family, school, and community levels. An interactive approach is needed to address all of the factors involved in this process.

Ness, J. E. (1996). *The high jump: Transition issues of learning disabled students and their parents*. Learning Disabilities Association of Canada. Retrieved April 5, 2008 from [www.cfc-efc.ca/docs/ldac/00000357.htm](http://www.cfc-efc.ca/docs/ldac/00000357.htm)

**Synthesis:** A brief report for Child and Family Canada outlines the key issues that face students with learning disabilities and their parents. Recommendations for resolving some of the problems include professionals working together more to develop helpful materials and resources for students and parents; helping students to learn how to explain their disability earlier; exposing students to positive role models; finding support groups and inservice training for parents; and begin the transition process early.

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.

**Synthesis:** This comprehensive review of the literature aimed to identify practices that promote continuity during the transition between child and adult services by reviewing available evidence. This review found a large range of different practices that focused on either the service, the young person, and/or the family. Best practices address the needs of the young person including the development of skills of self-management and self-determination, support for psychosocial development, support for changed relationships with parents and caregivers, provision of choice and information, and a focus on strengths for future development. Family needs also must be addressed through a family-centered approach, including support for adjustment to changed relationships, parental involvement in service planning and provision of information. Four types of transition models were proposed for further study: a) direct model, b) sequential model, c) developmental model, and 4) professional model.

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.

**Synthesis:** see annotation under Theme #1: Status, experiences and outcomes

## Unpublished

Children's and Women's Health Centre of British Columbia. (2006). *ON TRAC model for transitional care of adolescents, the progress in transplantation*. Retrieved 03/04/2008, 2008, from [http://findarticles.com/p/articles/mi\\_qa4117/is\\_200612/ai\\_n17193619/pg\\_1](http://findarticles.com/p/articles/mi_qa4117/is_200612/ai_n17193619/pg_1)  
This article describes the framework and clinical pathway for ON TRAC (Taking Responsibility for Adolescent/Adult Care), a model of transition care in British Columbia for adolescents with chronic health conditions, as applied to pediatric transplant transition. This model was developed in 1998 at Children's and Women's Health Centre of British Columbia. It provides a multidisciplinary approach to developmentally appropriate transition planning and skill building. The model is youth focused and family centered, and includes stages of transition care on the basis of the developmental stages and capabilities of adolescents. Important considerations for healthcare providers, specific tools for use in clinical settings, and case studies illustrate the use of the ON TRAC model in a pediatric transplant clinic. The ultimate goal of transition in the ON TRAC model is for all adolescents to reach their attainable levels of independence, self-sufficiency, and self-worth while transferring safely and securely into adult healthcare services and adulthood.

Grigal, M., Dwyre, A. & Davis, H. (2006). *Transition services for students aged 18-21 with intellectual disabilities in college and community settings: Models and implications of success*. Retrieved April 3, 2008, from [http://www.steps-forward.org.libaccess.lib.mcmaster.ca/Transition\\_Services\\_18\\_to\\_21.pdf](http://www.steps-forward.org.libaccess.lib.mcmaster.ca/Transition_Services_18_to_21.pdf)

Recently in the field of special education in the United States there has been a call for the development and expansion of services for older students with intellectual disabilities outside of the high school setting. In response, local school systems across the country have begun to provide transition services to students ages 18 and older with intellectual disabilities in postsecondary settings such as two- and four-year colleges or other community settings. This brief provides an overview of some successful models of transition services being implemented in postsecondary settings, and describes one such model implemented by the Baltimore City Public School System in three local colleges. The strength of this approach is that young people with intellectual disabilities are able to

participate in age-appropriate education and social activities instead of remaining in high school until the age of 21 years.

Hughson, E. A., Moodie, S. & Uditsky, B. (2006). *The story of inclusive post secondary education in Alberta. Final research report 2004-2005*. Retrieved April 3, 2008, from [http://www.steps-forward.org/The\\_Story\\_of\\_Inclusive\\_Post\\_Secondary\\_Education\\_in\\_Alberta.pdf](http://www.steps-forward.org/The_Story_of_Inclusive_Post_Secondary_Education_in_Alberta.pdf)

In Alberta, inclusive post-secondary education initiatives began almost twenty years ago with a few Edmonton parents who had a vision for their sons and daughter with developmental disabilities. These dreams have become a reality for a growing, but still small number of adults in colleges and universities across the province and in few other places in Canada. More parents and their adult children are interested in pursuing a range of inclusive post-secondary education opportunities just like any other young adult who begins to explore career options and take their place as adults in the community.

Learning Opportunity Task Force (LOTF). (2002). *The Learning Opportunities Task Force report: 1997 to 2002 report summary*. Retrieved April 3, 2008, from <http://www.ontla.on.ca/library/repository/mon/6000/10315068.pdf>

The Learning Opportunities Task Force (LOTF) was the mechanism set up in the 90's in the province of Ontario to manage pilot projects within post-secondary institutions that demonstrated innovative approaches to the transition to post-secondary programs for at-risk youth. This report summarizes the work of the Learning Opportunities Task Force in selecting 13 pilot projects and the evaluation that were conducted. The report includes the LOTF's key findings and recommendations. Each finding is accompanied by a series of supporting data statements, obtained primarily from the student questionnaires and occasionally from the pilot institutions' tracking questionnaires. Some of the findings focus on the need for students to have access to technology, funding and other supports. Other findings focus on institutional barriers and supports, including the need for faculty education and training within post-secondary settings. The applied research approach used by the LOTF is considered to be an excellent model for future research in this area.

Planned Lifetime Advocacy Network. (2004). *Connecting to citizenship: Social policy recommendations to address isolation and loneliness* Retrieved April 6, 2008 from <http://www.plan.ca/documents/PLAN-ConnectingtoCitizenship.pdf>

It is impossible to imagine a good life that is void of relationships. Relationships, however, are also a springboard to other components of a good life such as having a home, making choices and contributing to others. Relationships are the social ties that bind human beings together. Relationships, for the purpose of this discussion, are reciprocal, genuine, enduring and unpaid. The relationships, or networks of relationships of any person, can be referred to as a social network. Social networks are the source of people's and communities' social capital. People who have more relationships, and communities that have more social networks, have more social capital.

Relationships are a critical element of humanity, of identity, of belonging and of citizenship.

Service Canada. *Skills link*. Retrieved 04/11, 2008, from <http://www1.servicecanada.gc.ca/en/epb/yi/yep/newprog/skillslink.shtml>

This Canadian website provides information on the programs to support youth with disabilities, recent immigrants and aboriginals find sustainable paid employment through

skill development and long-term support in the workplace working with employers and employees. This is part of the “Youth Employment Strategy” in Canada.