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Institute for Research and Development on Inclusion and Society
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Youth with Disabilities in Transition from School to Work or Post-Secondary Education and Training: A Review of the Literature in the United States and United Kingdom

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Kingdom**

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Crawford, Cameron.

Youth with disabilities in transition from school to work or post-secondary education and training: A review of the literature in the United States and United Kingdom /
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ISBN 978-1-897292-04-4

Published by:

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The recommended citation for this publication is:

Crawford, Cameron (2012). Youth with disabilities in transition from school to work or post-secondary education and training: A review of the literature in the United States and United Kingdom. Toronto: Institute for Research and Development on Inclusion and Society (IRIS).

This project was funded by Human Resources and Skills Development Canada. The opinions and interpretations in this publication are those of the author and do not necessarily reflect those of the Government of Canada.

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Executive Summary

This paper reviews the research literature on the transitions from school to work and from school to post-secondary education and training for youth with disabilities. It focuses on the different approaches taken in policy-related research in the United States and the United Kingdom to help place past and future Canadian research in this area in a broader perspective.

A good deal of the research included in this review is specific to particular disabilities, yet some reflects a broader focus, speaking to issues concerning young people with disabilities as a general group. In much of this research, transitions facing youth with disabilities are the primary focus. However, some literature is included that focuses on transitional tensions facing other populations, such as women, the labour force, and people from ethno-racially diverse communities, or socio-economically disadvantaged people.

The review used a wide variety of sources to pull together a reasonably full picture of the transitional tensions/issues that youth with disabilities encounter. This eclecticism reflects the nature of the literature where focuses include the demographic characteristics of youth, analysis of their aspirations and life goals, the supports they require related to their disabilities, post-school outcomes, and cultural and other broad societal factors that affect their aspirations, priorities, decisions, and transitions.

The diversity of this literature in both the United States and the United Kingdom makes the development of generalities and comparisons difficult. However, some differences stemming from the legislative foundations and research approaches of the two countries can be identified.

- The United States tends to have a greater number of large, publicly funded data-gathering initiatives that allow for a broader scale of research on the societal level. In comparison, the United Kingdom relies more on smaller, in-depth studies that reveal a greater level of detail, but make it difficult to obtain reliable data on youth transitions in general to plan and meet service delivery requirements.
- The “social model” of disability appears to have informed much of the research in the United Kingdom; however, evidence suggests this approach may not inform practice, particularly at the local level. This theoretical approach may also be partly responsible for the lack of broad-scale research mentioned above. In the United States, literature tends specifically to reflect issues of gender and ethno-racial factors rather than a broader social justice model.
- The distinctive emphases of the two countries have led to knowledge gaps at different levels. Policy-related research in the United Kingdom typically revolves around issues of disability or issues of youth in transition, but little

research strongly connects the two streams of research, thus providing little direction to policy development focusing on the specific issues facing youth with disabilities. The US literature, on the other hand, provides results with more focused information on youth with disabilities in transition, supporting a more direct emphasis on policy and programs specifically assisting transitions to employment. However, at the same time, it lacks the stronger theoretical framework that strives to improve quality of life more broadly.

It is clear from the data and analysis examined in this review that significant issues continue to exist.

- The unemployment rates for youth with disabilities in both countries are high, but seem to be improving for some groups of youth with disabilities in the United States but less clearly so in the United Kingdom. Often underlying these high rates are problems in finding ways to integrate youth with disabilities into the labour market. For example, establishing mechanisms for forging contacts with potential employers following the end of school careers is problematic and, for many, stretches back to weaknesses in finding opportunities for pre-employment work experience or part-time employment while at school.
- In both countries, youth with disabilities are more likely than non-disabled youth to drop out of secondary school. While this situation seems to be improving in the United States, many still leave school with lower formal qualifications than youth without disabilities.
- Arranging accommodations in post-secondary education remains a challenge for many; in some instances, post-secondary students have difficulty accessing the regular curriculum.
- While considerable strides forward have been made, further progress is needed in developing mechanisms to increase the likelihood of successful school-based transition planning and to encourage self-determination and autonomy in decision making. That is, place youth with disabilities at the core of decision making occurring during transition.
- There has been more applied research attention dedicated to the issue of transition planning in the United States than in the United Kingdom. In the United States, efforts have revolved around developing and implementing methods for teaching youth to become more self-determining about their own lives and providing a supportive venue for articulating aspirations and goals. In the United Kingdom, the focus still seems to be on finding ways to involve young people in substantively meaningful ways in the decision making that will directly affect their lives.
- Research indicates significant deficiencies in both countries in the critical areas of institutional and stakeholder co-ordination needed in supporting

school and school-to-work transitions, particularly transition planning. Common criticisms of existing structures in both countries include stakeholders' lack of understanding of their respective roles and responsibilities, and parochial and territorial attitudes leading to poor collaboration and co-ordination among stakeholders and, conversely, the lack of a holistic approach. The British literature often rues the common circumstance of a complete lack of any sort of co-ordinated transition planning *at all*.

- In both countries a gap remains in bringing gender and ethno-racial/cultural diversity to the foreground as details that affect the direction of transition planning. There is, however, some emphasis in the US literature on socio-economic and disability-related factors connected with the likelihood of smooth and successful transitions into work or further learning after high school. Overall, young people with complex needs, from poorer families and from visible minorities tend to fare less well than others in making these transitions and in achieving successful transition outcomes. While the gender gap seems to be narrowing — at least in the United States — in terms of successful school-to-work transitions, a gap persists nonetheless.
- Several recent general literature reviews in both countries focused on the transitions of youth with disabilities with regard to health-related and social services. They have noted particular difficulties for youth with disabilities in making the transition from paediatric to adult services, where the linkages between those systems tend to be poor overall and whose cultures of care toward youth with disabilities are quite different. Because the focus of the adult system tends to be on older persons, health care professionals within that system are generally much less familiar than in the paediatric system with the kinds of issues with which young people with disabilities (and their families) are dealing.

In sum, while some progress is being made in furthering positive transition outcomes in employment and post-secondary education and training for youth with disabilities, it is clear that in both contexts, movement ahead on policy in these areas can be hampered by limitations in data and in theoretical approaches. Without robust data systems with information specific to the unique and complex challenges faced by youth with disabilities, it has been difficult to develop coherent policy and programs that improve the transition outcomes of this population.

I. Introduction

In May 2008, Human Resources and Social Development Canada convened a colloquium on the transitions and transitional tensions experienced by youth with disabilities. The present literature review gives context to the other research presented at that colloquium by providing an international perspective on research and policy initiatives addressing transitions made by youth with disabilities from school to work or post-secondary education. This perspective comes from new research and policy initiatives being undertaken in the United States and the United Kingdom.

The large volume of research in the United States and United Kingdom is highly varied, with differing conceptual approaches in the two countries. The literature covers diverse subject matters at various levels of analysis. That being said, this review brings to the foreground some overarching issues and themes in the areas of work and learning for youth with disabilities. It then brings out needs for improvement and elements of effective practice in services that deal with transitional issues and draws attention to young people who seem least likely to be at the focus of scholarly and service attention. Finally, it concludes with a summary of notable knowledge gaps and suggests directions for further research.

II. Notes on Methodology

Definitions and Time Frame

Transition

A plain-language approach to defining transitions guided the present research. A “transition” is defined as a change, or preparation for change, from one place, state, or stage to another (e.g., change in labour market state from not working to having a paid job or moving from school into work). It is understood that transitions are often linked and overlap (Aston et al., 2005; Burchardt, 2005; DARE, 2006; Gil-Kashiwabara et al., 2007; Piggott and Houghton, 2007; Rearick, 2007; Trainor et al., 2008; UK, Cabinet Office, 2005; Wagner et al., 2005b). For instance, a young person may have recently sustained a disability as a result of an automobile accident. The youth may be trying to make the transition from high school to post-secondary education as well as find part-time employment so he or she can afford the costs of living, perhaps also seeking to move from the parental home to an apartment with friends who are also studying. The individual also may be trying to arrange various accommodations to ensure successful outcomes in studies and at work.

Youth is a time of many and frequent changes. For example, a test was conducted using Statistics Canada’s 2001 Participation and Activity Limitation Survey (PALS — Statistics Canada’s flagship disability survey) for youth with disabilities 15 to 25 years of age who had recently been involved in selected transitions in areas covered in PALS: education, employment, living arrangements, and involvement with the income security system. In a one-year span, the vast majority of youth with and without disabilities (85.9% and 84.9%, respectively) experienced at least one of these major transitions. That is, they recently either secured or lost a job, moved from the parental home, are attending or recently attended some form of post-secondary school education or had recent dealings with the income security system (e.g., Employment Insurance, workers’ compensation, Canada Pension Plan Disability benefit or provincial social assistance).

Disability

“Disability” is defined variously in the research literature on youth transitions. Some researchers use diagnostic categories such as “cerebral palsy” or “spina bifida” (e.g., Binks et al., 2007). Others are guided by the World Health Organization’s International Classification of Functioning, Disability and Health (ICF) and look at the relationship between specific impairments and activity restrictions (e.g., Van Naarden Braun et al., 2009). Others use a social model of disability less explicitly tied into the ICF framework, but draw a distinction between health condition or impairment and the disadvantage (disability) that accrues as a result of societal reactions to/treatment of people with those conditions (e.g., Burchardt, 2005). Still others use broad descriptive categories (e.g., emotional disturbance) based on a combination of diagnostic, special education, and other categories, (e.g., Wagner et al., 2005a,b).

Given the wide range of definitions, approaches of researchers to defining and talking about disability have been taken at face value here. “Youth with disabilities” includes a mix of adolescents/young adults with a variety of impairments, chronic conditions, activity restrictions, and diagnostic labels connoting some level of functional limitation or restriction of activity, such as those in the areas of hearing, communicating, seeing, moving about, learning, mental health/psychological well-being, and cognitive development. It is understood that disability can be a chronic/stable phenomenon or cyclical/episodic. The present review is inclusive in that regard, although it must be said that scant mention is made in the research literature about episodic disability, particularly as related to youth.

Youth

The present review adopted a general working definition to include, wherever feasible, young persons aged 15 to 24 years, while remaining cognizant of the diversity of approaches to identifying youth with disabilities in the research literature. It must be stated at the outset, however, that researchers are by no means unified concerning the age range they adopt for “youth” and report findings according to their own operational definitions. Seldom, however, are people older than 30 years framed as youth in the research this project reviewed, nor are pre-teen children. Accordingly, the boundaries between childhood, youth, and adulthood had to be treated flexibly in the present research. With that said, this research strives to keep the analysis focused on, or within reasonable proximity to, those 15 to 24 years of age.

In the United Kingdom the phrase “young people” is widely used. In North America, “youth” is more common. This report uses the terms interchangeably, as it does the phrases “disabled young people” and “youth with disabilities.”

Time Frame

This paper primarily references literature published from 2000 onward although, in some cases, material published before 2000 is included where referenced by recent authors.

Approach to Referencing in This Report

In some instances, the present discussion provides references to illustrate general points and uses the following in-text reference form, for example (Purdam et al., date). It should be understood by the reader that, in some instances, alternative or supplementary citations could have been provided. However, the goal of this review was to be illustrative, not comprehensive, and so the citations included provide a window on the issues at hand rather than a full, exhaustive scan. For those wishing to develop a more comprehensive view of the materials provided, the reader is referred to the bibliographies provided within the cited literature.

Legal and Policy Relevance

By no means is all research on the school-to-work transitions of youth with disabilities explicitly framed by obligations emanating from public law or public policy. It seemed to this author, however, that legal and policy requirements are key factors that practitioners and researchers weigh when considering whether to dedicate attention to facilitating or researching transitions, and in deciding whether initiatives or processes are likely to be considered “good” let alone “best” practices. Accordingly, wherever possible, reference is made to the legal and policy frame under which practitioners operate or under which researchers/analysts have specified transition issues, including but not limited to human rights law and policy. Attention is also widened to include transition research that reflects sensitivity to gender, ethno-racial diversity, and diversity of disability. This approach is in line with current Canadian jurisprudence and legislation, including the Supreme Court of Canada’s (1999)¹ ruling that standards for employment and service delivery must make provision to accommodate human diversity to the extent reasonably possible.

Overarching principles and considerations laid out in the United Nations *Convention on the Rights of Persons with Disabilities and Optional Protocol* (United Nations, 2006) also informed the analysis in this paper. A summary of the Convention’s provisions is provided in the Appendix.

III. Policy and Legislative Framework

United States

The United States has a long-standing and well-developed set of legislation designed to support youth with disabilities through the transition from school to work. It places a strong emphasis on results-oriented, measurable goals, especially concerning employment, and a considerable literature emanates from and reacts to these legislative initiatives.

First and foremost is Title I of the *Rehabilitation Act* of 1973, reauthorized under the *Workforce Investment Act* (WIA) of 1998, which provides for individual states to receive federal grants to operate a comprehensive vocational rehabilitation (VR) program to assess, plan, develop, and provide VR services to eligible individuals with disabilities to prepare for and engage in gainful employment. It was the intent within the WIA to create a comprehensive youth development system at the local level by consolidating into a single system funding streams that were used for job training and development for disadvantaged youth ages 14-21 (NCD, 2008a).

In addition to this legislation, the *Individuals with Disabilities Education Act* (IDEA) requires all states to include, in state performance plans (SPPs), information on the post-school outcomes of former students with disabilities (see Chambers et al., 2008). States must submit SPPs to the US Department of Education, Office of Special Education Programs (OSEP). Among other things, states are required to report on the process for planning student transitions from school and on outcomes of youth who are no longer in secondary school and who have been competitively employed, enrolled in some type of post-secondary school, or both, within one year of leaving high school (e.g., Michigan, 2006). The current authorization of the law, the *Individuals with Disabilities Education Improvement Act* (IDEIA) of 2004, defines “transition” as a results-oriented process that focuses on academic achievement as well as functional activities and includes the requirement of measurable post-secondary goals that encompass training, education, employment, and independent living skills; IDEIA 2004 also requires that the individualized education program (IEP) specify the services needed to assist the young person in reaching her or his transition goals (NCD, 2008b).

Further, the *Americans with Disabilities Act* (ADA), which touches on all areas of labour market participation, has also provided a strong impetus in addressing some issues regarding youth with disabilities. It requires employers with 15 or more employees to make accommodations available to employees who are otherwise qualified for their jobs. Universities are also covered by the ADA and must make reasonable provision for educational accommodations if requested.

The emphasis in the legislation on tangible results has led to a number of broad-scale studies to measure the progress of the legislation. For example, a

requirement of IDEA/IDEIA, as well as the further-reaching *No Child Left Behind Act* (NCLB) where focus is placed on all “underserved groups of children,” is the assessment of the status and progress of youth with disabilities. To support this requirement, the Office of Special Education Programs commissioned the National Longitudinal Transition Study-2 (NLTS2) early in the present decade (Wagner et al., 2005b).

In implementing employment-related legislative requirements, the US Department of Labor’s Office of Disability Employment Policy (ODEP) “provides national leadership on disability employment policy by developing and influencing the use of evidence-based disability employment policies and practices, building collaborative partnerships and delivering authoritative and credible data on employment of people with disabilities” (US, Labor, 2009a). The ODEP is actively involved in youth transitions to employment and provides a range of pertinent resources at its web site. Further, each state runs various programs that touch on post-school transitions of youth with disabilities.

United Kingdom

Legislation in the United Kingdom tends to be more broadly focused, with major emphases on youth or on persons with disabilities. There is not much in the way of legislation or large-scale research that aims at the intersection of these two populations: youth with disabilities. However, the way that disability is framed in the United Kingdom, along with this particular legislative approach, has led to a number of general initiatives to improve the quality of life for persons with disabilities in a more comprehensive sense than in the United States.

The primary legislation covering persons with disabilities in the United Kingdom is the *Disability Discrimination Act 1996* (DDA), which prohibits discrimination in employment on the basis of disability and other enumerated grounds. The DDA specifically requires that places of learning make accommodations available to disabled learners.

In addition, the *Disability Equality Duty* (DED), which came into force in December 2006, is meant to ensure that all public bodies, such as central or local governments, schools, health trusts, or emergency services, pay “due regard” to the promotion of equality for disabled people in every area of their work. The DED covers about 45,000 public bodies across Great Britain (DRC, 2006).

Turning specifically to schooling, the *Education Act 1996* as amended by the *Special Educational Needs and Disability Act 2001* (SENDA) requires that local education authorities conduct formal needs assessments concerning children with disabilities who “authorities” suspect need special education services. The definition of disability in SENDA mirrors that of the DDA. The SENDA needs assessment is to include a transition plan. The organization Connexions (see below) conducts these assessments for 13 to 19 year olds (European Agency, 2008).

Emanating from this legislation, a number of employment policy and program initiatives in the United Kingdom focus on employment and have the potential to touch on transitions from school to work for youth with disabilities. These include the following.

- **Access to Work** provides practical assistance to disabled employees and employers with accommodation issues.
- **Jobcentre Plus** gives a point of contact for people seeking to leave welfare for work.
- **New Deal for Young People** and **New Deal for Disabled People** help unemployed young people and disabled people (respectively) move from benefits into paid employment.
- **Workstep** fulfils a specialist function within Jobcentre Plus for people with an intellectual disability.
- **Connexions** provides general information and advice to youth, including career advice (Dempsey and Ford, 2008).
- The **Pathways to Work** pilot programs develop and implement co-ordinated supports for persons with disabilities seeking to enter employment.

Because of the fairly broad nature of the above initiatives, the related government-based literature proceeding from the legislation also tends to remain at a macro level. In particular:

- *Improving the Life Chances of Disabled People* (UK, Cabinet Office, 2005) is a comprehensive research and strategy report for addressing a range of barriers, including barriers to post-secondary education and employment.
- *Valuing People* (UK, Health, 2001), a white paper, was recently updated to *Valuing People Now* (UK, Health, 2009). It advises person-centred planning to be implemented with respect to transitions and social services, with the active involvement of young people and Connexions. It notes that directors of children services have been given responsibility to link with adult services in the transition of young people with learning disabilities.
- *Aiming High for Disabled Children* (UK, DCSF, 2007) outlines a program that seeks to raise the standards of transition support and provision, and achieve greater consistency in all local areas. The Transition Support Programme is to support local areas to improve transition arrangements across children's health and social care.
- *Progression through Partnership: A Joint Strategy between the DfES, DH and DWP on the Role of Further Education and Training in Supporting People*

with Learning Difficulties and/or Disabilities to Achieve Fulfilling Lives (UK, DfES, 2007) overviews a post-16 education strategy that is currently underway.

A cross-government employment strategy, published in the spring of 2009, implements the *Public Service Agreement 16* (Cabinet Office, 2007). This strategy targets socially excluded/disadvantaged people, including those with “moderate to severe learning disabilities,” for a “significant expansion” of employment opportunities.

IV. Overview of the Literature

A large volume of research touches on the transitions of youth with disabilities. The research covers diverse subject matters at various levels of analysis, and much of it is specific to particular disabilities; yet, some reflects a broader focus, speaking to issues concerning young people with disabilities as a general group. While transitions are the primary focus in much of the analyses, some research pays only marginal attention to the transitions of youth with disabilities among transitions and other issues facing diverse populations, for example, women, workers with and without disabilities, people from ethno-racially diverse communities, or socio-economically disadvantaged people. This review focuses on the predominant literature in the area of youth with disabilities, which examines transitions within and across formal systems related to school and the labour market. Other areas of transition, where coverage is sparse, on relationships with family and friends or changes that occur over the life span (and only incidentally involve contact with formal systems) were left outside the scope of this report.

The areas of research regarding youth with disabilities vary from the demographic characteristics of youth to analysis of their aspirations and life goals, the supports they require across life domains, post-school outcomes, such as employment or socio-economic status, and cultural and other broad societal factors that affect their aspirations, priorities, decisions, and transitions.

Indeed, the research shifts on several conceptual levels, from the individual and family level to the broad societal level (e.g., systems and societal attitudes/prejudice) and various levels in between. Some research focuses on roles and responsibilities of stakeholders in facilitating (or impeding) the transitions of youth with disabilities, such as transition planners and other professionals, and speaks to them directly. Other research takes up these and other analytical stances and speaks to practitioners, researchers/academics, people in government responsible for policy and program development, and to general readerships.

Some research is evaluative or prescriptive in nature, reflecting interest in the policy and programmatic implications of transitions; other research is more clinically focused, paying little or no attention to such issues of policy development.

In the United States, the research on the post-school transitions of youth with disabilities increasingly seems to focus on issues of race and culture. In the United Kingdom, few studies give explicit attention to such issues. Some research is informed by a concern for human rights and social justice with respect to young people with disabilities and applies these approaches to disability, while other research is bio-medically and psychometrically oriented and pays little if any explicit attention to these concerns.

Some — even most — of the research draws from small samples. Much is localized at the individual or family level, or at the specific institution level (e.g., a few colleges/ universities, workplaces, or school districts). In contrast, some of the research is conducted with a view to the national state (e.g., United States or United Kingdom), major sub-region (e.g., Maryland or England) or specific locality (e.g., Baltimore or London). This broader approach is more common in the United States, where data systems seem to facilitate that kind of research.

In summary, the research on the post-school transitions of youth with disabilities to work and further learning is highly eclectic and might better be characterized as a diverse assortment of literatures rather than anything approaching a single coherent body of work.

Theoretical Approaches and Implications for Data Collection and Research

Some of the research reviewed for this project is explicit with regard to the theoretical frameworks used. In other cases those frameworks are implicit. Generally, it would seem fairly safe to say that the “social model” of disability has informed a considerable amount of the research in the United Kingdom, at least nominally. For instance, a “convenience sample” of 80 pieces of UK research in the area of youth transitions found that 18 of them referred to the social model as an orienting framework. As Burchardt (2005: 2) summarized so succinctly:

According to the social model of disability, it is important to distinguish between disadvantage that arises directly from the nature of the impairment and disadvantage that arises from the circumstances in which people with impairments find themselves. Cognitive impairment is likely to have a direct effect on the attainment of qualifications and subsequent labour market experience. By contrast, there is no reason to expect that young people with physical or sensory impairments, or mental health problems, have less academic or labour market potential, on average, than their non-disabled peers. Any difference in achievement can therefore be attributed to circumstances rather than to the intrinsic effects of impairment.

It would be those extrinsic social factors that “disable” young people with impairments, rather than the impairments themselves (Oliver, 1990). Indeed, disability and disablement are politically charged issues in the United Kingdom. But for all that, remarkably little attention has been paid to ensuring that national data systems in the United Kingdom have the “tools” necessary to shed light on extrinsic factors that help account for disability and disadvantage in the British “social model” sense of those terms. Addressing the issue of high unemployment of disabled young people in two counties within the United Kingdom, Piggot et al. (2005) concluded that, while central government departments such as the Department for Work and Pensions may formally and

publicly subscribe to the social model of disability, this theoretical approach is not informing practice at the local level — or data gathering and research at the national level. Paradoxically, the authors see the solution to the employment problem as lying in the central government providing more and better disability equality and disability awareness-raising training for local organizations (governmental and non-governmental). These authors criticize “individualized” approaches and thus do not deal in concrete and practical terms with the lack of disability-specific supports around individuals and how such supports could be made more widely available. Shakespeare (2006) observed that some political and research leaders who subscribe to the social model of disability have actually resisted empirical research that draws from statistical surveys, decry research that draws attention to specific disabilities, and are even averse to research on disability as a broad if imprecise analytical category.

So, there is a knowledge gap in the United Kingdom. For instance, research that draws from the Youth Cohort Survey and other statistical data sources, such as the General Cohort Survey, generally has little in the way of explanatory information to fall back on, other than conventional categories and factors, to explain why disabled young people are so over-represented in the NEET group, that is, those not in employment, education or training. For instance, Coles et al. (2002) provided explanatory risk factors for people being in the NEET group, which include family disadvantage and poverty, parental unemployment, young people living in high unemployment geographic areas, young people’s truancy and exclusion from school before the age of 16, low or no formally recognized educational achievements at the age of 16, high drop-out rates from post-16 education, dropping out from government-sponsored training, teenage pregnancy, selected minority ethnic group membership, having poor health (including mental health problems and disability), and having a special educational need. Researchers in the area such as Burchardt (2005) focused their explanatory efforts along similar lines, arguably because national data systems allow few other options.

If we were to remove from those “risk factors” the latter two that are about health and disability as perhaps contributing to the other difficulties, the data systems in the United Kingdom would not be able to yield much in the way of cogent, statistically reliable answers to the questions of how these problems arise and what causal factors help to account for them.

Arguably, the difficulties for researchers on the transitions of disabled young people in the United Kingdom are due, in part, to the fact that that country’s major data systems focus on issues and interests of concern to the population in general: sub-samples on disability are quite small and the surveys are simply not designed to capture detailed information about the issues that disabled young people — or disabled older people for that matter — are likely to experience. As a result, a good number of reports based on general information say little about disability, leaving researchers with few options but to continue conducting a plethora of small-scale studies on particular issues.

Without idealizing the situation in the United States, where the data systems are by no means perfect (Livermore and She, 2007), it has become increasingly typical to see concerns about issues of gender, visible minority status, specific disabilities, and the availability of accommodations and other social supports in various situations — most clearly in the areas of education and employment — reflected in the US research literature on the transitions of youth with disabilities. This may be due in part to the *Americans with Disabilities Act*, the *No Child Left Behind Act*, the IDEIA, and the *Rehabilitation Act*, which create rights to non-discriminatory treatment and to accommodations in various contexts up to the point of undue hardship to the organizations that are under obligations to accommodate, such as employers, schools, and post-secondary institutions of learning.² As well, in the United States, a long civil rights history exists in which women, visible minorities, gays/lesbians and, more recently, people with disabilities have struggled for equality both in law and in society, and have won gains on both levels, with implications for social policy and programming.

While there have been difficulties in setting up data systems (Morningstar and Liss, 2008; NCD, 2008b), some data systems in the United States have been intentionally designed to shed light on such issues, and there are obligations for public authorities and incentives for non-government researchers to report on such issues. The National Council on Disability, for instance, tabled reasonably detailed state-level administrative data on the education status of children and youth by disability and race/ethnicity (NCD, 2008b: Appendix). The Data Accountability Center (2009) is replete with administrative data on program arrangements and a range of outcomes concerning children and youth under the IDEA/IDEIA. Research by Wagner et al. (2005b, 2006) using the National Longitudinal Transition Study-2 (NLTS2) is another case in point, which has been drawn on quite extensively by other researchers. Wagner et al. (2005a) provided insight into the theoretical underpinnings of that survey.

Commenting on data gaps in the United States, however, Wittenburg and Maag (2002) observed that until the NLTS2 came on stream, there had been no major data collection efforts at the national level in the mid to late 1990s to track the post-secondary school transition outcomes of youth with disabilities in the United States. Livermore and She (2007) observed that, aside from the NLTS2, no other survey of special education participants or of other disability-specific social program participants allows for comparisons with the non-disabled general population.

Nature of the Available Data and Implications for Research

Overall it would seem that the United States is better served than the United Kingdom by large, publicly funded data-gathering initiatives that seek to shed insight on the transitions of youth. The NLTS2 in the United States began in 2001 as a follow-up to the original National Longitudinal Transition Study, which ran from 1985 through 1993. Both have been financed by the US Department of Education, Office of Special Education Programs (OSEP). The NLTS2 runs until

2010 and consists of parent/youth interviews, student assessment/student interviews, teacher surveys, a school program survey, and a review of student transcripts. The survey drills down into many issues with respect to youth with disabilities, so reporting is feasible by various dimensions, including specific if somewhat aggregated types of disability, age, general health, living arrangements, gender, visible minority status, family income, family involvements, school and extracurricular activities, post-secondary education, employment, youth risk behaviours, feelings, and expectations (US, Education, 2000).

In contrast, reliable data on youth transitions have been difficult to obtain in the United Kingdom. A multiplicity of administrative and other surveys and datasets are maintained in the United Kingdom with respect to education, employment, and pensions. However, Dempsey and Ford (2008) pointed out that data on types of employment accessed by persons with disabilities, wages, and so forth are very difficult to obtain. Moreover, it would appear that the transitions of youth with disabilities with respect to work and learning have not been a major focus of research attention. The longitudinal follow-up survey by Aston et al. (2005) is an exception to this, but that survey is not ongoing.

Nor are transitions of youth with disabilities a major focus in evaluation research conducted for UK government departments. For example, the UK National Audit Office commissioned an international literature review (White and Knight, 2003) as part of its evaluation of that country's New Deal for Young People (NDYP). The study compared the economic impact of the NDYP with those of labour market programs elsewhere. The research placed no emphasis on youth with disabilities. Further, evaluative research focusing on employment opportunities for people with disabilities such as the New Deal for Disabled People provides little or no mention of youth with disabilities.³ One notable exception by Beale et al. (2007) provided data indicating that youth without disabilities are much more likely than their disabled counterparts to be employed or off income benefits as a result of participating in the New Deal for Young People program.

In parallel, published research commissioned by the Department for Education and Skills (DfES)⁴ between 1997 and 2007 provided little data or analysis regarding the school-to-work transition. For example, Knight et al. (2006) featured the views of children and young people with intellectual/developmental disabilities ("learning disabilities") about support they received from various social services. The research did not mention services to assist with transitions from school to work or to post-secondary education.

Another UK report, which peripherally touched on issues pertaining to youth with disabilities, was commissioned by the Equal Opportunities Commission (EOC)⁵ in collaboration with the Department for Education and Skills and Joint Intervention Partners (JIVE). It investigated the extent to which "pathfinder" projects were "challenging inequalities and stereotypes affecting young people's choices and monitoring the outcomes for individuals or groups, with particular reference to

gender, ethnicity, disability, those who are looked after [i.e., in foster care], the gifted and talented and those who are underachieving” (Haynes et al., 2005: iii). Pathfinder projects are preliminary programs locally administered by independent organizations or individuals. They seek, essentially, to determine best practices in improving school and post-school outcomes for 16 to 19 year olds, with a view to a rollout of a national system of services in that regard. The research indicated that, while the organizations that submitted bids for pathfinder funding reported that their projects would serve youth with disabilities, few projects were actually doing so when the EOC’s research data were gathered.

A review of questionnaires in the United Kingdom by the author found that information is not gathered about disability-related supports/accommodations that may be needed at work or in learning environments. Further, almost no survey data touches specifically on the issues of disability and transitions. There are, however, two national surveys where limited amounts of pertinent data about youth with disabilities are available.

- The **Youth Cohort Survey (YCS)** is conducted annually, but aside from general tombstone data and high-level questions on activity limitations that are similar to the disability filter questions on the Canadian census, the YCS focuses on education, training, and employment (GfK NOP, 2007). It does not reflect a holistic approach to researching transitions. Nor does it inquire about accommodations young people may need in learning or work environments, or the availability of such accommodations. In addition, the unweighted sub-sample of youth disabled at some point up to 26 years of age is small, with only about 1,200 cases (Burchardt, 2005).
- The **British Cohort Survey** is complex with many components: initially, a parental interview, a maternal self-completion form, and a questionnaire to be completed by teachers and headmasters on educational arrangements for the child at the focus of the survey. Also included are an educational score form, a medical examination form, reading and math tests, and ability scales, which are like psychometric tests. The original aims of the survey were to look at the social and biological characteristics of the mother in relation to neonatal morbidity, and to compare the results with those of the 1958 National Child Development Study (Centre for Longitudinal Studies, 2005). Since the first survey in 1970, it has undergone considerable expansion. For instance, recent surveys cover lifelong learning, relationships, parenting and housing, employment and income, health and health behaviour, and citizenship and values.

Survey data are not the only way to gain insight into youth transitions. Qualitative studies can also be helpful in that regard, and there have been many of these in both the United States and United Kingdom. For example, with regard to post-secondary students with disabilities in the United Kingdom, experiential research seems to be mainly localized to specific universities as institutional case studies (e.g., Jacklin and Robinson, 2007; Jacklin et al., 2007). Layer et al.

(2002), however, provided a national picture of targets, strategies, and activities undertaken across institutions to enable success in higher education retention.

Specifically focusing on policy and program development, the United Kingdom would seem to lack the sufficient base of statistical information needed to take a wide angle view of the transitions and factors that can impede youth with disabilities. Much of the UK research tends to be based on fairly small samples and is qualitative in both the descriptive and explanatory senses of the term. Data constraints in the United Kingdom have left researchers with few options for shedding light on transition issues except for these smaller studies. The knowledge gap has also hampered the ability of service organizations, schools, local education authorities, health authorities, and the central government to plan and meet service delivery requirements, resulting in difficulties helping young people acquire various aids, devices, and services (Grewal et al., 2004).

Overarching Transitional Themes and Issues

In the area of learning and work, the present review consulted a widely scoped multidisciplinary domain to pull together a reasonably full picture of the transitional tensions/issues that youth with disabilities encounter.

There are consistent findings that youth with disabilities are more likely than non-disabled youth to drop out of secondary school and leave school without accreditation or with accreditation that is of marginal value in the labour market. Some literature indicates a lower likelihood of formulating a career path on graduation from high school or post-secondary studies, lower levels of access to career advice, and fewer opportunities to establish contacts with employers. In line with these findings, the unemployment rates for youth with disabilities are found to be much higher than for other youth on graduation although, at least in the United States, evidence indicates this situation has been improving.

Compounding this trend, young people with complex needs, from poorer families and visible minorities tend to fare less well than others in achieving successful post-school transition outcomes. While the gender gap seems to be narrowing, at least in the United States, a gap persists nonetheless.

Concerning transition planning as a formal process, common messages are stakeholders' lack of understanding of their respective roles and responsibilities, lack of effective communication, lack of collaboration and co-ordination, lack of a holistic approach, insufficient attentiveness to issues of gender and ethnicity, lack of active and central involvement by youth and, at least for many in the United Kingdom, lack of transition planning at all.

As for issues of self-determination and decision making, it would appear that there has been more practice and research attention dedicated to this issue in the United States than in the United Kingdom. In the United States, efforts have revolved around teaching youth how to become more self-determining while engaged in decision making about their own lives, articulating aspirations and goals. In the United Kingdom, the focus still seems to be on trying to involve

young people *at all* in substantively meaningful ways in the decision making that will directly affect their lives.

While the present author has not examined or detailed the following in depth here, it has been observed that several fairly recent literature reviews focused on the transitions of youth with disabilities in relation to health, health-related services, and social services. These reviews help to provide a general context dealing with the various transitions that youth with disabilities experience and the issues they face during this process. Some of these reviews are international in scope and some are more or less confined to a given country. Recurring themes include the lack of research attention to measurable outcomes and service effectiveness, and the need for better collaboration among health care professionals and between them and young people with disabilities and their families. Particular difficulties are encountered by youth with disabilities making the transition from pediatric to adult services, where the linkages between those systems tend to be poor overall, and cultures of care are quite different. Because the focus of the adult system tends to be on older persons, health care professionals within that system are generally much less familiar than those in the pediatric system with the kinds of issues facing young people with disabilities (and their families). The general picture that emerges is that the transition from one system to the next is often difficult for youth and their families, a picture that is mirrored in the context of education and the labour market.

In addition to the primary themes of drop-out rates and transition planning, a limited amount of literature focuses on greater difficulties in gaining pre-employment work experience or part-time employment while at school. Included in this material is consideration of barriers, for example, youth finding accommodations in the workplace on entering the labour market and in accessing curricula that provide the knowledge and skills development required in the labour market.

The literature seems to have little to say about work-related accommodations and other disability-specific issues with respect to the employment of youth with disabilities, although some research does speak to such issues. Perhaps underlying this knowledge gap is a need to bridge researchers working in the area of youth transitions and researchers working more broadly on issues of disability and unemployment.

V. Specific Issues and Outcomes Identified in the Literature

The above overview of the legislative framework and research literature has been used as a basis from which to explore more generally what the research says about youth with disabilities transitioning from school to work or from high school to post-secondary education. The different approaches found in the United States and United Kingdom have led to differing research trajectories and distinct policies. Underlying the following review of the literature surrounding youth with disabilities in transition is a focus on how the distinctive approaches found in these two countries resulted in differing success rates and unique conceptions of the issue itself.

Persistent Basic Problem: Poor Post-School Outcomes

In the United States, Hughes (2001) drew attention to the low employment and low participation in post-secondary education of young American adults with disabilities, which she noted were problems internationally. To underscore the significant legal framework surrounding the issue, she drew from the *Individuals with Disabilities Education Act* Amendments of 1997, which calls for educational results to ensure “equality of opportunity, full participation, independent living and economic self-sufficiency” and for the federal government to help further those ends. She outlined needs for further research, indicated how transition services could be better organized and suggested how practices could be used to improve outcomes through capacity development at the student and socio-environmental levels.

As Knapp et al. (2008) pointed out, substantial indirect and direct personal and public costs arise from the challenges young people with complex needs face in finding employment. Research by Coles et al., (2002) tended to support this contention.

Drawing attention to the research findings of Wagner et al. (2005b) and the US Department of Education (2003, 2006), Trainor et al. (2008) made the case that poor outcomes for culturally and linguistically diverse youth include comparatively low levels of school completion, low student math and reading achievement especially in high-poverty schools (where there is high enrolment of children of colour), lower levels of post-school employment, lower wages, lower levels of enrolment in post-secondary education, and disproportionately high rates of juvenile delinquency and incarceration. Trainor et al. drew heavily from the research of Gil-Kashiwabara et al. (2007). The National Council on Disability (NCD)⁶ and Social Security Administration (SSA) made many of the same points (NCD and SSA, 2000), which suggests that these problems have persisted. However, other research (Wagner et al., 2005b) painted a less bleak picture of the United States. Improved outcomes are discussed later in this report.

In the United Kingdom, various studies showed that disabled young people are more likely to be in the NEET group; that is, neither employed, in education nor

in training. Mittler (2008) provided an overview of key issues affecting disabled people and their families in the United Kingdom and critiqued the lack of substantive progress on a number of fronts. He used as context the language and concepts from two sources: the Make Poverty History movement (a prominent coalition of UK anti-poverty groups) and the UN *Convention on the Rights of Persons with Disabilities*. He characterized program arrangements regarding the transitions of youth from school as a “black hole,” identifying problems such as a lack of:

- entitlements (access to income supports) beyond school;
- progress in facilitating transitions to employment;
- proper consultation about individual needs and priorities;
- long-term planning for independent living;
- supported living and employment opportunities; and
- implementation of legal and policy requirements for joint planning by social, health, and employment services with the full participation of young people and their families.

Mittler said he was looking to the new Aiming High for Disabled Children initiative to address these issues. Aiming High strives to revamp service provision across the board for disabled children and their families, enhance equality and opportunity, and improve the transition experiences of young people with disabilities.

In their evaluation of the New Deal for Disabled People, Kazimirski et al. (2005) provided tables that included breakdowns of key indicators by age for youth aged 16 to 29. These showed that disabled young people in the United Kingdom had lower rankings than others of the same age in terms of formal educational achievement and formal qualifications. Young people with disabilities in this age group were about as likely as others with disabilities never to have looked for work in the two years prior to registration and were less likely to be with their first post-registration employer. There is no comparative group for non-disabled people in this age group, however.

In terms of post-secondary transition to work in the United Kingdom, several researchers pointed out that for disabled youth who do not plan to attend higher education there are typically few options, and rates of unemployment are high (Beattie, 1999; Burchardt, 2005; Heslop et al., 2002; UK, DfES, 2005a,b;). Based on two qualitative research projects that explored the experiences of disabled learners in multiple transitions from school to post-secondary education and work, Piggott and Houghton (2007) provided an overview of the poor labour market situation for young adults with disabilities, including discrimination based on false stereotyping about their skills as well as difficulties in post-secondary education in acquiring the skills that employers seek. They concluded that young adults with disabilities experience multiple barriers and transition issues require sustained attention in policy and practice.

Even youth with disabilities in the United Kingdom who finish college (youth with intellectual disabilities or complex needs in particular) experience limited options; relatively few disabled college graduates find employment, and their earnings tend to be quite low (Burchart, 2005; DARE, 2006; Knapp et al., 2008). Such problems are leading “further education” colleges to extend their continuing education programs beyond three years for enrollees, with the result that a significant number of college students are approaching 30 years of age (UK, Cabinet Office, 2005).

Key Explanatory Factors and Tensions

The following discussion explores some key factors considered in the literature to account for poor post-school outcomes for youth with disabilities. These fall under the rubrics of high rates for dropping out and suspension from school, lower educational credentials, challenges experienced in the post-secondary education system, quality of school-based transition planning, difficulties formulating career goals, issues of co-ordination and partnership among key stakeholders in the transitions of youth, difficulties with the vocational rehabilitation system, difficulties obtaining work experience, employment disincentives in income security programs, adverse employer attitudes, difficulties obtaining on-the-job supports, and system flexibility in addressing differences related to age, disability onset, and nature of disability.

High Rates of Dropping Out and Suspension from School

Concerned with preventing adverse post-school outcomes, Ryan et al. (2007) provided an overview of the disciplinary provisions of the IDEA of 2004. Their overview indicates that students with disabilities in the United States are three times more likely than non-disabled age peers to be reported as involved in violent behaviours at school. Students with disabilities from minority backgrounds and students with emotional/behavioural difficulties are more likely to be transitioned out of school through suspension. The authors then explored a range of alternatives addressing these high drop-out rates.

To examine underlying factors, Wagner et al. (2005b) measured changes in transition outcomes in the context of intended educational improvements and program accountability for youth with disabilities, as set out in the *No Child Left Behind Act of 2001* and *Individuals with Disabilities Education Act* amendments of 2004 using the National Longitudinal Transition Study-2. For some youth with disabilities, the drop-out rates were very high (e.g., youth with multiple disabilities, including deaf-blindness and youth with health impairments “other” than hearing, seeing, and communicating).

Drawing from the same data source as Wagner et al. (2005b), the National Council on Disability (2008a: Table 7) showed that drop-outs with disabilities were considerably less likely to be engaged in school, work, work preparation, or at college, but were slightly more likely to be enrolled in vocational or technical school. Using statistics from the National Centre on Secondary Education and Transition (2004), the NCD (2008a) also showed that drop-outs with disabilities

are, on the one hand, unlikely to be in the labour force, and on the other, more likely to be in poor health or in prison. Very little research seems to have been conducted on issues associated with dropping out, or being suspended or expelled from school among young people with disabilities in the United Kingdom.

Lower Educational Credentials

It would seem that, just as for young people without a disability, it is helpful for youth with disabilities to remain in high school and graduate with a diploma or other certificate that employers will value (Madaus, 2006; NCD and SSA, 2000). In many cases in the United States, youth with disabilities leave high school with an exiting document other than a regular high school diploma (Gaumer-Erickson et al., 2007; NCD, 2008b; Thurlow and Thompson, 2000). As Gaumer-Erickson et al. (2007) and Johnson and Thurlow (2003) pointed out, little is known about the consequences of different diploma options in terms of access to employment or post-secondary education. Recent research by Hartwig and Sitlington (2008), however, found in a random sampling of employers that they were willing to hire disabled youth who have certificates of attendance, achievement, or completion instead of high school diplomas and were more willing to hire those without regular high school diplomas if they have occupational or general education diplomas (GEDs).

In the United Kingdom, Burchardt (2005) showed that youth with disabilities are considerably more likely than their non-disabled counterparts at age 18-19 (48.2% vs. 28.1%) to have Level 1 education or below as their highest level of educational achievement and, if going to school, are more likely to be pursuing secondary-level or vocational qualifications. Level 1 is roughly the equivalent of high school graduation in North America. Drawing from longitudinal data in the Youth Cohort Survey (YCS), Burchardt showed that young people with a disability at both 16 and 26 years of age (i.e., continuous disability) are twice as likely as their non-disabled counterparts to have no educational or other formal qualifications (8% vs. 4%). Further, the UK Cabinet Office (2005) reported that 20 percent of disabled young people were actually discouraged from obtaining a General Certificate of Secondary Education (GCSE) because of their impairment, with 12 percent discouraged from taking higher levels and 12 percent discouraged from seeking vocational qualifications.

Given that higher education credentials are quite common, and therefore less crucial as a single screening criterion for employment, Piggott and Houghton (2007) enjoined young adults with disabilities in the United Kingdom to develop other “personal credentials.”

Challenges in the Post-Secondary Education System

Although drop-outs generally do not do well in terms of post-school employment prospects, in the United States, completion of post-secondary education improves the chances of an individual with a disability securing meaningful employment (Zafft et al., 2004). Barriers to obtaining post-secondary education

and training for youth with disabilities, however, include not being aware of post-secondary education opportunities and requirements, the lack of academic, transition, and self-advocacy skills, no responsiveness by post-secondary programs and personnel to the comprehensive needs of individuals with disabilities, and the lack of partnerships between secondary and post-secondary schools, the business community, and adult agencies (Dowrick et al., 2005; NCD, 2003; NCD and SSA, 2000,; Tagayuna et al., 2005).

Students with more severe and complex disabilities may have difficulty accessing the regular curriculum (Neubert et al., 2004). While universities and colleges are covered by the *Americans with Disabilities Act* and must make reasonable provision for educational accommodations, they are obliged only if requested to do so. Accordingly, in many cases youth with disabilities bear primary responsibility for arranging their own accommodations, particularly if they delay self-reporting their needs to people in positions to assist at college or university, such as disability support co-ordinators (Stodden et al., 2003).

Mull and Stington (2003) examined detailed technology-related issues in transitions to post-secondary education for students with learning disabilities in US post-secondary schools. Issues included the limited availability and high cost of the technologies, the abandonment by students with disabilities for a variety of reasons, lack of “fit” between what the technologies can do and the needs of learners, the lack of technology training (for students, instructors, and other professionals), and restrictive eligibility criteria for gaining access to the technologies.

While their data are somewhat old (1999 and 2001), Tagayuna et al. (2005: Table 1) showed, based on their survey of about 1,500 disability support co-ordinators, that there has been quite limited disability-specific assessment/evaluation of needs in post-secondary education and limited transfer of accommodations from post-secondary education to work settings. In their participatory action research of the educational experiences of youth with a range of disabilities and ethnicities in 10 states, Dowrick et al. (2005) found a need for improved co-ordination across post-secondary support services, more adequate staffing levels in student disability service offices, better outreach by those offices, less wieldy and more timely processes for gaining access to post-secondary accommodations, and less discriminatory attitudes on the part of faculty and peers. Depending on the type of disability and other differences, key barriers are experienced in relation to peers (e.g., for students of Alaskan ethnicity, physical disability, or traumatic brain injury), college/university administration (for students with mental disabilities), and links to employment (for students of African-American ethnicity). More general barriers include an undue focus being placed on impairment rather than on individuals (for sight-impaired students).

One focus of the UK literatures is on base statistics: attendance and successful completion of post-secondary education of youth with disabilities. Jacklin et al. (2007) found an increase in attendance from 2000 to 2004 by disabled young

people living in the United Kingdom, rising from 4.1 percent to 5.8 percent of total entry cohorts. However, the UK Department for Education and Skills (2005b) indicated that youth with disabilities are less likely to be in full-time education than other young people (31% vs. 41%), particularly in higher education (23% vs. 36% overall). They are three times more likely not to be in any educational program, employment, or training (27% vs. 9%).

Moreover, the Cabinet Office (UK, 2005) observed that people with disabilities are over-represented in further education colleges, which tend to focus on developing general literacy and numeracy skills, graduate relatively few people with disabilities (i.e., there is a “revolving door” back into the same programs), and run the risk of becoming “the new day centres” (e.g., like adult day programs in the Canadian context) due to segregated service provision.

A second thrust in the literature has been on factors influencing attendance and successful post-secondary program completion. For example, Burchardt (2005) reported that period of onset was a significant variable influencing post-secondary school completion. The majority of young people with disabilities who had decided at age 16 that they would pursue higher education obtained a degree. However, those disabled at both 16 and 18 years were more likely than non-disabled students to have fallen short of reaching their educational aspirations. In addition, Riddell et al. (2005) provided an overview of how the access to higher education of learners with disabilities has improved in recent years, but argued that the benefits have been unevenly distributed according to type and degree of disability, ethnicity, and socio-economic status. They pointed out that disabled students have been associated in the minds of academics with “managerialist” agendas in higher education and, in the process, have been adversely affected by the academic backlash against those agendas.

A third focus in the United Kingdom generally points to overall positive experiences of students with disabilities at college and university, but then identifies a number of structural issues to be remedied. Jacklin et al. (2007) identified a number of frequently observed problems: lack of inclusive teaching style, non-availability of support, insufficient time with tutors, unhelpful responses and negative attitudes of tutors, inaccessibility of the built environment for wheelchair users, lack of tactile signage for students with visual impairments, stress for students with mental health difficulties, and delay in receiving the Disabled Student Allowance. The National Disability Team (2004) identified additional issues: the lack of timely, accurate and accessible information, particularly for ethnic minorities, few opportunities to develop study, independent living, and social skills as well as skills for using adaptive technology, poor inter-agency collaboration, concerns about the implications of disclosing a disability, and the general discriminatory treatment of disabled students. More generally, Bolt (2004) recommended modifying approaches to curriculums to render them less “ableist” and more inclusive for disabled students.

Transition Planning

Regardless of whether they intend to go directly from high school to work or to post-secondary studies, ideally, youth with disabilities would have some kind of plan in that regard, whether formal or informal, that reflects practical strategies for achieving successful outcomes. The Office of Disability Employment Policy (US, Labor, 2009b) outlined key guidelines to assist in accomplishing this goal. Youth would be directly involved in developing the plan and would feel they have a direct, but not necessarily sole, stake in operationalizing it. Key stakeholders in their future who have knowledge and who can provide practical and emotional support, such as parents, educators, school-based counsellors, personnel from employment agencies, and so on, would ideally be involved in developing the plan. The plan would consider the youth's interests and strengths, and gender, and would be culturally sensitive and appropriate. Ideally, the plan and practical follow-up arrangements would make provision to ensure that necessary transportation is in place. The plan would take a broad view of the youth's future and would be integrated with what they require to maintain health and wellness and, one day, to move from the family home to live more independently.

In the United States and United Kingdom, there are obligations, incentives, and practice guides for formal transition planning to involve youth with disabilities as central participants in the process with respect to schooling, health, and post-school options. Common messages in the research literature, however, are stakeholders' lack of understanding of their respective roles and responsibilities, poor collaboration and co-ordination, not pursuing a holistic approach, insufficient attentiveness to issues of gender and ethnicity, the lack of youth's active involvement and, at least in the United Kingdom, no transition planning at all for many youth.

Youth Participation in Transition Planning: A recent report by the National Council on Disability (2008b) in the United States noted that, while states have obligations to make transition planning services available, youth are not obliged to participate. While the majority of students with disabilities do participate in some way in the school-based transition planning process, only **58 percent** provide input and a small minority (12%) play a leadership role (Cameto, 2005b).

The problem of marginal youth engagement in school-based transition planning for life beyond school has been persistent: in 2000, the NCD and SSA pointed to insufficient involvement of youth with disabilities and their families in transition services planning.

In the United Kingdom, the Gillick ruling of 1984⁷ advocated that children should be consulted about decisions that affect their lives. The *United Nations Convention on the Rights of the Child* (1989), the *Children Act* (UK, 1989), the *Every Child Matters* program (UK, HM Treasury, 2003), the *National Service Framework for Children, Young People and Maternity Services* (UK, Health, 2004), the *Special Educational Needs and Disability Act 2001* (UK, DfES, 2001), the *Special*

Educational Needs Code of Practice (DfES, nd) and *Valuing People* (UK, Health, 2001) all stress the importance of seeking and taking into account the views of children and youth in decision making. Knight et al. (2006), however, discussed the “patchy” experiences that young people and families face in transition planning and the lack of involvement of young people in planning for their own transitions. Other researchers observed much the same, including the lack of *any* transition planning at all for life after leaving school for many young people (Aston et al., 2005; Heslop et al., 2002; Ward et al. 2003b). Franklin and Sloper (2006) observed that planning processes tend to privilege those young people who are articulate and self-confident.

Quality of Transition Planning: As required under the IDEIA, there would seem to be more school-based transition planning now than previously in the **United States**. Yet researchers have identified several problem areas. These include **the** lack of:

- congruence with the goals of the IDEA/IDEIA, *Rehabilitation Act*, and other federal legislation, and lack of detailed planning with attention to issues of gender and ethno-racial diversity (Gil-Kashiwabara et al., 2007; NCD and SSA, 2000; Trainor, 2008; Trainor et al., 2008; US, Education, 2003, 2006; Wagner et al., 2005b);
- attention to the additional challenges faced by youth in rural areas, including tribal (Aboriginal) communities (e.g., geographic isolation, transportation and access needs) (NCD and SSA, 2000);
- comprehensiveness in planning (Kardos and White, 2006; Repetto et al., 2008; Trainor, 2008); and
- facilitation of youth self-determination in decision making and planning (Agran et al., 2000; Bowe, 2003; Izzo and Lamb, 2003; Lehman, et al., 2002; Trainor, 2008).

In the United Kingdom, Heslop et al. (2002) and Knight et al. (2006) found that the quality of transition planning varies widely and, in some cases, is ad hoc and unco-ordinated. Looking at person-centred planning (PCP) under *Valuing People*, which involved but was not limited to youth, Robertson et al. (2007) found that widespread barriers to effective PCP and successful outcomes include the lack of trained facilitators of planning, inadequate funding for planning, turnover of facilitators, reluctance of people in local communities to provide the time and support needed for the planning, limited choice and long wait lists for services, and limited employment opportunities. Franklin and Sloper (2006) found much the same with regard to young people with disabilities in particular. It remains to be seen whether *Aiming High for Disabled Children* will make a positive difference in terms of transition planning and outcomes.

Difficulties Formulating Career Goals

While most American youth with disabilities include employment among their goals (Cameto et al., 2004), research evidence in the United States indicates

some youth with disabilities may have difficulty formulating a sense of the career they would like to enter on graduation from high school or post-secondary studies, and need assistance in this regard with career counselling and opportunities to explore career options (Hart et al., 2004; Punch et al., 2004; Shroedel and Geyer, 2000). Punch et al. (2004) specifically pointed out the paucity of representative research in this regard concerning youth with significant hearing loss.

Whether currently in the education system, or working, in vocational training or doing none of those things, the most widely held aspiration of disabled young people in the United Kingdom is to be working (Aston et al., 2005). McConkey (2005b) observed, however, that young people with disabilities have limited access to information on post-school options and resources and lack career advice.

The Need for More Co-ordination and Partnership

Most research in the United States in this area indicates that effective employment transition programs, irrespective of target population, require partnerships. This includes secondary and post-secondary schools, the business community, and adult employment and vocational rehabilitation agencies (NCD, 2003; NCD and SSA, 2000). The NCD (2008b), however, has pointed out that students, family members, special education personnel, and community service providers frequently do not understand their roles and responsibilities in transition planning, and there is a lack of effective involvement of vocational rehabilitation counsellors in the process. Effective collaboration among service agencies is also problematic, especially in rural areas and for youth with learning disabilities or emotional disabilities.

In the United Kingdom, Hudson (2006) described several factors that complicate the school-to-work transitions of young people with disabilities. One is fragmentation of services. Issues with inter-agency collaboration have been noted by a number of other researchers in the United Kingdom as well (e.g., Greco et al., 2005; Heslop et al., 2002; Sloper, 2004; Ward et al., 2003b). Hudson (2006) also pointed to aggravating factors:

- competition for funding between post-secondary educational authorities and various social services;
- the low priority that service agencies have attached to issues of youth transition in the face of financial constraints and competing demands to implement person-centred planning, reform day services, and close long-stay institutions; and
- the failure of systems and social workers to anticipate proactively that those young people with disabilities who have been in the education and social services system their entire lives would want to transition onto college or other adult options at the completion of high school and would need social workers' assistance to do so.

Merton (2004) reported that statistics on young people with disabilities in contact with youth (social) workers are seldom kept; it is difficult to see how youth workers can anticipate future trends and demand without access to such baseline information (see also McConkey, 2005b).

Difficulties Obtaining Work Experience

American research conducted since 1990 (e.g., Brewer, 2005; Certo et al., 2003; Wittenburg and Maag, 2002) indicates that youth who have employment experience while at school are more likely to be employed three to five years following school than those who have had no work experience. Barriers to gaining work experience can include the sheer complexity of needs that have to be addressed for some students, for example, those with cognitive disabilities in addition to linguistic, academic, and social challenges (Neubert and Sherril, 2006).

Another obstacle to gaining work experience can be the prospect of youth (and their families) losing what could be significant cash and in-kind disability benefits (e.g., for drugs and assistive devices) from publicly funded social programs for children if, on re-application for adult benefits, there is evidence of the youth's employability (Wittenburg and Loprest, 2007). This issue is examined below.

Research by White and Weiner (2004) focused on the nature of the employment experience, examining the impacts of applying IDEA-based requirements of making training "least restrictive and community-based." They found that, for transitioning students aged 21-22 years of age, practices positively correlated with integrated employment outcomes (i.e., a paid job with non-disabled coworkers at graduation) were duration of community-based training, which included on-the-job training, and age-appropriate physical integration with non-disabled peers. The researchers found that participant demographics, such as mental ability (as measured by IQ), behaviour problems, and physical disability did not correlate with success of integrated employment outcome. Innovative teacher advocacy, however, contributed positively to integrated employment outcome. Their study found most school districts to be uncompliant with the "least restrictive and community-based" requirements.

Tagayuna et al. (2005) showed that only about half of post-secondary institutions provided work experience, work-study opportunities, or internships/externships when the researchers' surveys were administered. Dowrick et al. (2005) also commented on the need for more internships and other programs that link students with employers.

In the United Kingdom, the lack of employment for disabled young people is partly due to their comparatively lower skills overall; in a competitive labour market they are not as desirable to employers when considered against the educational and employment backgrounds of their non-disabled counterparts. However, lack of work experience may be an even more important consideration

for employers (Newton et al., 2005). Even if disabled young people participate in programs that target upgrading of disadvantaged and excluded youth, Roberts (2004) reported that they, along with others in similar programs, tend to be stigmatized and to be considered by employers as less preferable as prospective employees than others. Additionally, there is reportedly little exposure to employment possibilities for college students in the United Kingdom with intellectual disabilities (Beyer et al., 2004).

Issues with Vocational Rehabilitation

In the United States, the NCD's recent research (2008a) on vocational rehabilitation (VR) outcomes of youth with disabilities transitioning from school to work found a steady increase in the number of youth served by VR agencies in recent years, and employment rates and earnings of youth served appear reasonable given their age and prior work experience. However, only a small percentage of youth who could potentially benefit from transition services are being served; available data are insufficient to develop precise estimates of the number, characteristics, or service needs of potential beneficiaries.

The NCD also found that prior research has not documented the effectiveness of specific VR services and rigorous studies using experimental designs or comparison groups have not been completed, although there is evidence of promising practices in multiple demonstrations. Available data confirm, however, that VR agencies provide considerable support for individuals with disabilities enrolled in post-secondary education. While prior research documents the increased employment success that results from the participation of youth with disabilities in post-secondary education and training, problems related to selection bias in study samples limit the usefulness of that research.

In the United Kingdom, McConkey (2005a) pointed to training schemes that are ineffective and to under-skilled trainers with inappropriate attitudes toward disabled young people. Somewhat like the vocational rehabilitation system in the United States, the New Deal for Disabled People is more focused on helping workers who become disabled to return to work rather than assisting young people entering employment for the first time. At the same time, the New Deal for Young People has not placed major emphasis on working with disabled youth (UK, Cabinet Office, 2005).

Employment Disincentives in Income Security Programs

The present review was unable to find much research on the issues youth with disabilities face with respect to income security programs and the implications for school-to-work transitions. However, the issues are important, and research articles that were found point to similar problems in the United States and United Kingdom.

In the United States, a barrier to gaining work experience and employment can be the prospect of youth (and their families) losing what could be significant cash and in-kind disability benefits (e.g., for drugs and assistive devices) from publicly

funded social programs. The benefits may have been available to the youth as a child. However, on re-application for adult benefits at age 18, there may be evidence of the youth's employability (NCD and SSA, 2000; Wittenburg and Loprest, 2007). In demonstrating the capacity for substantially gainful employment activity on having to re-qualify, programs such as Social Security Disability Insurance (DI), which requires a prolonged and very severe level of disability as an eligibility criterion, could take evidence of work experience as an indicator that the youth's disability is not severe or prolonged enough to meet the program's requirements. The prospect of establishing employability and, as a result, losing benefits can deter young people from seeking access to the work experience and other opportunities that would develop their human capital.

Livermore et al. (2007) pointed out that a sizeable share (about one third) of DI beneficiaries in the United States first experienced disability onset before age 25. While a fairly low overall percentage indicated, on a nationally representative survey of beneficiaries,⁸ that they felt discouraged from looking for work due to the possibility of losing benefits. Their income profile, the need for various services, and an inability to pay for those services on their own suggest that attachment to the income system may be more in keeping with their own and their families' income requirements than moving into employment.

Other problems noted by Wittenburg and Loprest (2007) for recipients of social security cash and in-kind benefits are the lack of youth and family knowledge about incentives offered by the programs, for example, extended health coverage after leaving the program and exemption of the value of some fixed assets in eligibility determination, such as property essential for self-support.

In the United Kingdom, the Foundation for People with Learning Disabilities (FPLD) provided a summary of how the income security system creates barriers and disincentives for people with disabilities who want to move off disability allowances (social assistance) into employment (FPLD, 2005). While that policy briefing is specific to people with intellectual ("learning") disabilities and not confined to issues that affect youth, many youth with a range of disabilities are likely affected. Issues include the underlying assumption that disabled people will probably never work and the lack of incentives and practical support for them to pursue that possibility. Disincentives include limits on the number of hours that can be worked and the low earning threshold beyond which the disabled individual faces the prospect of losing established benefit status. In losing benefit status by establishing employability beyond the threshold, there is the prospect of losing housing benefits as well as the local council tax benefit and then having to cover the charges for personal support services that were previously financed while reliant on income support. Reportedly, such issues often leave people with disabilities who opt for employment worse off, or at best no better off, no matter how much they work after leaving the income security system. In addition to FPLD, DARE (2006), Parker (2008), and Grewal et al. (2004) made similar observations.

The Cabinet Office (2005) further observed that, much like in the United States, disability allowances and benefits can be important sources of family income, especially where family members provide long-term care with respect to disabled young people; for financial reasons family members may not encourage employment and other forms of adult independence for such youth.

Adverse Employer Attitudes

The research was sparse with regard to employer attitudes toward youth with disabilities in the United States. Studies on hiring people with disabilities, however, indicate that employers with no experience hiring workers with disabilities and sales-related job openings typically believe that customers and other workers would find individuals with disabilities to be offensive in some undefined way (Mcloughlin, 2002). As well, these employers tend to be concerned about performance, productivity, and how hiring people with disabilities would impact the company's bottom line (Domzal et al., 2008). Uninformed and discriminatory employer attitudes toward people with psychiatric, intellectual, and learning disabilities remain common despite the evolution of many employer perceptions and attitudes over the past several decades (Luecking, 2008). Once young people have secured experience on the job, however, employers are quite often prepared to extend an offer of ongoing employment (Luecking and Fabian, 2000).

Similarly, in the United Kingdom, employer perceptions of risks and benefits reportedly inform attitudes toward hiring people with disabilities: employers tend to overestimate the risks and underestimate the benefits. The latter issue has been researched with respect to persons with disabilities in general in the United Kingdom (e.g., Needels and Schmitz, 2006), but the present review could find only very limited research on this issue with respect to disabled young people in particular (e.g., DARE, 2006; UK, Cabinet Office, 2005).

Difficulties Securing On-the-Job Supports

Ensuring that job-specific supports are available at work is a predictor of employment retention for youth with disabilities, especially for youth with disabilities facing other disadvantages, such as being from urban ethnic minority communities and living in poverty (Garcia-Iriarte et al., 2007). It is unclear to what extent needed job accommodations are available, however. Employers with 15 or more employees are required under the *Americans with Disabilities Act* to make accommodations available to employees who are otherwise qualified for their jobs. Drawing from the NLTS2, Cameto (2005a) reported that many employers are unaware of the disabilities of their young employees and only four percent of these youth reported receiving any accommodations or other help at work due to disability. This four percent would seem to indicate that youth with disabilities who find employment in the United States have fairly mild levels of impairment requiring little in the way of on-the-job support.⁹

As in the United States, researchers in the United Kingdom pointed to the challenges in assisting young people with complex needs in making the transition

to employment. For instance, drawing from evidence from recent UK research, policy, and related literatures, and both statistical analysis and data gathered from case studies, Knapp et al. (2008) provided evidence that young people with complex needs have problems with unmet needs for adaptations, physiotherapy, personal assistance (attendant) services, social workers, and equipment, including wheelchairs and other aids (Beresford, 2003; DARE, 2006; Kersten et al., 2000; McConkey, 2005b; UK, Audit Commission, 2000). Other problems include difficulties with accessible transportation, finding workplaces that will accommodate equipment, discriminatory employer attitudes (DARE, 2006), and the lack of employer awareness about programs such as Access to Work, which seeks to improve the employment chances of people with disabilities by assisting them and employers with job accommodations (McConkey, 2005a). Knapp et al. (2008) concluded that health service and local authority expenditures need to be increased and redeployed to assist young people requiring high levels of practical and communication support to reach the educational and employment goals to which they aspire.

There is some evidence (Beyer et al., 1996) that supported employment has been successful in furthering the employment of people with intellectual disabilities in the United Kingdom, and that some successes have been experienced with respect to youth in particular (Kilsby et al., 2009). However, job coaches funded under Access to Work for supported employment are usually short-term positions and funding for supported employment by local authorities is often unpredictable and short term. Supported employment funded in the United Kingdom by the European Social Fund has also been short term, all of which reportedly makes it difficult for organizations to sustain efforts to support individuals who require long-term assistance at work (FPLD, 2005).

Age at Disability Onset, Nature of Disability, and Effects on Post-School Outcomes

Some literature examines the effects of disability onset and the continuation of impairment from childhood into adulthood vs. onset in youth/early adulthood and the aftermath. The dominant theme seems to revolve around educational and employment transitions and outcomes.

In the United States, for example, Loprest and Maag (2007) examined employment outcomes for those with disability onset before young adulthood (prior to 22 years of age) vs. during young adulthood (between the ages of 22 and 35 years). Using the 1994 and 1995 National Health Interview Survey – Disability Supplement (NHIS-D),¹⁰ they examined employment rates among young adults. Among those with early onset, a reduced investment in human capital (education) lowered the probability of both completing high school and of employment compared to those without disabilities. Lower employment rates resulted from both lower levels of high school completion and the direct impacts of disability on work. Still, however, those with early onset had significantly higher employment rates than those with later onset. The researchers speculated that people with early onset either tend to choose careers that can be more easily

accommodated than the careers of people with later disability onset, or that people with early onset of disability are more likely than those with later onset to be adept at seeking and using accommodations.

In the United Kingdom, Burchardt (2005) framed onset of disability in a broader social context. Drawing from two major British statistical data sets and in-depth interviews with disabled young people, she examined a range of social and disability-related factors¹¹ that may help account for different educational, employment, and earnings outcomes for these young people, including those with disability onset early in childhood and those who experienced onset while attending secondary school. Generally, she found that parental aspirations, education, and social class all had an important bearing on youth outcomes, as did young people's own motivations and outlooks. However, holding these factors constant, disability-related factors interacted to influence outcomes across three important dimensions: age (irrespective of disability onset), timing of disability onset, and the nature of disability.

First, educational and occupational aspirations began as similar for youth with and without disabilities at age 16-17. Second, in line with the findings of Loprest and Maag, those whose disability occurred in the later teenage years seemed to be at particularly high risk of poorer employment outcomes: a significant and widening gap emerged in aspirations, educational qualifications, rates and durations of unemployment, and pay and occupational status as young people got older. Third, the type of disability had a significant role in influencing the likelihood of poor employment outcomes, with those experiencing the onset of mental health problems in their teenage years faring particularly badly.

Improvements in Outcomes

Despite the difficulties of youth with disabilities encounter that have been examined in this literature review, some research evidence suggests things are getting better — at least in the United States.

For instance, Wagner et al. (2005b) conducted research based on statistical samples drawn in 1987 and 2003 for youth with disabilities who had been out of secondary school for two years. The research compared secondary school completion status and timing, living arrangements and social involvement, participation in post-secondary education, employment rates, job characteristics, and overall engagement in the community. It provided statistics concerning youth with disabilities in general and for nine sub-groups. The researchers found that, generally, there have been gains in positive post-school outcomes for youth with disabilities from 1987 through 2003 in most of the areas explored. There was a 17 percentage-point increase in high school completion by youth with disabilities between 1987 and 2003, and youth with disabilities were merging with drop-out levels of their same-age peers in the general population.

Cameto (2005a) reported a range of changes in the employment situation of youth with disabilities from 2000/2001 to 2003. Overall there was a 10

percentage-point increase in employment for out-of-school youth, with a decrease in the share of personal care jobs (e.g., baby-sitting) and an increase in working trades (e.g., carpentry, plumbing). Overall there was an increase in wages earned, too. Cameto provided these and other data by high school completion and drop-out status.

However, while the gender gap narrowed and there were improvements for African-American and Hispanic youth with disabilities, inequalities associated with gender and race/ethnicity persist. Further, young people from poorer families are much less likely to reap benefits than others (Wagner et al., 2005b).

Although students with disabilities usually perform at levels below their general education peers on district and state education assessments, the NCD (2008b) noted improvement in student performance since the *No Child Left Behind Act* was signed in 2002.

When the research was conducted for the present report, the author was not able to find many examples of significant positive change in the post-high school outcomes of disabled young people in the United Kingdom. On the one hand, there seems to have been an increase in participation in post-secondary education as discussed previously in this paper. On the other hand, the Commission for Social Care Inspection (CSCI) released research on what some have called the “nightmare” of transitioning from children’s to adult health services experienced by young adults who have combinations of acute and chronic medical conditions, multiple and severe impairments, behaviour problems, and learning difficulties (CSCI, 2007). This research may shed light on similar transitions to education and the labour market for youth with disabilities.

Drawing from research literature, case studies, and individual interviews, the CSCI found that services are not comprehensively meeting national standards for health services transition planning as set out in the *National Service Framework for Children, Young People and Maternity Services*, Standard 8 (see UK, Health, 2004). It observed that good practice is inconsistent and that poor service co-ordination and planning continues to result in “anxiety, delays, multiple assessments and confusion” (vi) for young people and their families. However, the CSCI noted some improvements in that transition planning focuses more attention now than previously on the aspirations and ambitions of youth with disabilities, and there is better co-ordination across service sectors (e.g., social care, education, health, housing).

Obligations created by public policy in the face of a dearth of information and analysis in the area of mental health services for youth in the United Kingdom spurred the National Institute for Health Research Service Delivery and Organisation Programme (SDO) to undertake research to examine issues of transition for young people with disabilities moving from Child and Adolescent Mental Health Services (CAMHS) to services for adults (SDO Project 08/1613/117).¹² This research will help bridge the knowledge gap that exists in

the United Kingdom. Results had not been reported as of the preparation of the present report.

Promising Practices

A number of practices for furthering positive post-school outcomes for youth with disabilities have been identified in both the US and UK literature, and an illustrative and representative sample of these are provided below.

In the United States, a number of documented best practices focus on effective collaboration among key public- and private-sector stakeholders. A number of authors point to successful partnerships, which include private-sector job placement agencies that have been successful in finding employment for youth with disabilities (Luecking, 2004; Wehman et al., 2008). Certo et al. (2003) documented good outcomes where multi-agency collaboration involves vocational rehabilitation providers. Flannery et al. (2008) found that a short-term, post-secondary training program co-delivered by a college and vocational rehabilitation was effective in providing an individualized, worksite-based curriculum within the context of existing labour market realities. Employment in this program led to comparatively higher wages, more hours worked and steadier work during the first year after program exit. Supplementing the emphasis on multi-sector collaboration, this program also included financial support, career services, and vocational coursework.

A similar example is provided in the UK context by Haynes et al. (2005), which singled out one community (North Nottinghamshire) as providing a promising example of effective collaboration between training providers and employers concerning disabled young people, which the authors believed had the potential to be more broadly reproduced.

However, in the United Kingdom, the scope of this collaboration often tends to expand into consideration of wider individual and societal factors. For instance, Hudson (2003) argued that efforts to overcome social exclusion difficulties for young adults with intellectual disabilities require new policies, processes, and machinery to engage young people with disabilities and foster inter-agency partnerships and collaboration within and across the social services, health, education, and other service sectors. His discussion emanated from the Department of Health's (2001) *Valuing People* white paper and frames collaboration in a broad context of supporting citizenship rights and social inclusion to increase choices in everyday decision making and opportunities for independence. Thus, educational and labour market transitions are seen as part of broader issues of transition into adulthood for young people with intellectual disabilities, which often include radically different life trajectories, tendencies to avoid risk taking, "routinization" of parental control, absence of self-determination, social isolation, and sexual inexperience.

The UK literature also emphasizes developing engagement capacity along multiple dimensions. For example, Knight et al. (2006) documented numerous practical strategies in that country to engage young people in decision making during a spectrum of life transitions.

VI. Summary of Findings and Further Directions

Focusing on the United States and United Kingdom, this paper provides a review of the research literature on the transitions of youth with disabilities. A large volume of research covers diverse subject matters at various levels of analysis. Of necessity, this paper has been selective. It has looked mainly on youth transitions with respect to formal systems in the areas of learning and work, bringing to the foreground some key transitional tensions and issues that significant numbers of young people with disabilities face. It provides a general view of the literature and draws attention to some recurring themes, and then presents a high-level discussion of implications for research that are driven, in part, by the limitations of the data and the different theoretical approaches of each country. It also points to key lessons in terms of effective practice in furthering successful transitions and to knowledge gaps that require further research.

While the research and practice literature on the transitions of youth with disabilities spans many thematic areas, much of it tends to fall within the following categories broadly defined:

- learning and work;
- health and related health services, including mental health and the broader world of social services, which are frequently organized under departments of health;
- formal transition planning processes or other processes for determining life and social services pathways;
- multi-dimensional/cross-sectoral transitions; and
- the development of individual self-determination with respect to transitions within and across formal and informal systems.

The transition from school to work or from high school to post-secondary education as a prelude to work seems to be an area of marginal public policy interest, and numerous sources had to be pieced together to create a reasonably full picture of transitions and transitional tensions/issues and policy responses in this area.

The Likelihood of Successful Transitions

An important overall finding is that youth with disabilities are more likely than non-disabled youth to drop out of secondary school. Although that situation seems to be improving in the United States, many youth with disabilities still leave school with lower formal qualifications than their non-disabled counterparts. Some have difficulty formulating a sense of the line of work they would like to pursue on graduation from high school or post-secondary studies and cannot always gain access to career advice for assistance. Arranging accommodations in post-secondary education and the workplace is also challenging. Some students who have made it into the post-secondary education system have difficulty accessing the regular curriculum.

The unemployment rates for youth with disabilities are high, a problem that seems to be improving for some groups of youth with disabilities in the United States, but less clearly so in the United Kingdom. Establishing contacts with employers is problematic, as is garnering pre-employment work experience or part-time employment while at school. Disincentives embedded in income support programs discourage employment for some youth, although the extent of this problem is unclear. There is also evidence that employer attitudes are very often uninformed and have been outright discriminatory despite legal sanctions.

Based on this review, it would seem that youth with intellectual or emotional difficulties, those who are deaf or hard of hearing, young women, youth from visible minorities, and youth from less affluent families are least likely to fare well in terms of post-school transition outcomes and are most likely to require focused assistance.

Further Directions — Practice

Further directions for effective practice in furthering smooth transitions and positive transition outcomes for youth with disabilities seem reducible to several key considerations.

- Whether formal or informal, planning for transitions should be an integral part of the educational process, preferably earlier rather than later in the high school years.
- This planning should be holistic and individualized, taking into account the strengths and needs of the individual, gender, cultural background, and the many domains of life that may be encountered (e.g., work, further learning, access to decent income, housing, friendships). It should also consider the specific implications of the youth's particular disability (e.g., supports required for maximum participation in the community, self-determination, and to ensure general health and well-being).
- The planning should involve key stakeholders who share — or should be sharing — concern for the well-being of the young person: parents, educators, counsellors, service providers and, ideally, employers.
- There should be solid lines of communication between these stakeholders, who should devise methods for collaborating effectively in transition planning and post-planning follow-up.
- Stakeholders should understand their respective roles and responsibilities and should take ownership for doing their part, individually and together, in furthering the well-being of the youth for whom they have responsibilities.
- Whether there should be “one big planning process” or several involving different stakeholders is unclear. In all likelihood, transition-specific processes would feel less intimidating to a young person. Whichever form the

exploration of and planning for the future takes, it should be well co-ordinated. The young person should be central to the process and instrumental in driving that process to the largest extent possible; that is, the youth's preferences and choices should be heard and respected.

- Young people with disabilities may need opportunities to “try on” various options, such as through work experience, career counselling, and counselling about post-secondary educational interests and options.
- There should be something meaningful for youth with disabilities to transition to after high school.
- Supports for participation in post-secondary education and employment should be accessible, affordable, and reasonably convenient for youth to bring into place in a timely manner, and youth should not be left solely responsible for obtaining and co-ordinating the supports they may require.
- Goals and outcomes should be clear and measurable. There should be a process to determine whether outcomes have been achieved and flag where alternative measures or additional supports may be required.
- Goals and outcomes to be achieved by service providers in supporting youth with disabilities in transition should also be clear, measurable, and monitored.
- Employers need general information about disability, compelling “business case” reasons for hiring youth with disabilities and practical support to work through whatever work-related issues may arise for these young people. Dissemination of positive employer testimonials about the business benefits of hiring youth with disabilities would likely be a useful way to enhance their employability.

Thinking about the more general issue of low employment rates for adults with disabilities, it has long been the present author's view that disability organizations and governments should place focused, sustained attention on successful transitions to employment of youth with disabilities in particular. Once successfully employed, the focus of attention will need to be broadened to address issues of long-term retention, promotion, and re-employment in the event that people lose their jobs. This needs to be accomplished without losing focus on getting young people into employment in the first place. Getting people “in the door” is the first challenge. Arguably, this will be easier to accomplish for young people who have not yet acquired secondary disabilities and the health problems that typically occur later in life.

Once a young person demonstrates value to their employer, there is strong evidence of a high likelihood of job retention (Luecking and Fabian, 2000). The business case will already have been built for that person and the employer. Issues of retention, promotion, and re-employment will become second-phase

considerations that will have to be addressed. However, trying to address those issues before making a major effort to get young people into employment in the first place would only dissipate the efforts and resources of governments and non-governmental organizations. Placing a sustained focus on the transition of youth into employment, then dealing with second-phase considerations as they arise would set in place a multi-generational employment strategy that is likely to yield better results in the long term than present policy and program approaches that try to address all issues at the same time and therefore tend to be unfocused, ad hoc, and not very effective overall.

Further Directions — Research

This report identified a range of challenges that hamper the transitions of youth with disabilities from school to work and to post-secondary education and training. Along the way, mention has been made of knowledge gaps. The following is a summary that could guide further research in this area.

- Relatively little research seems to have been conducted with a view to onset of disability during the adolescent years, the causes, impacts on youth and their families, and effects on youth transitions and transition outcomes. How youth who become disabled in adolescence thrive and make successful transitions requires attention.
- More meso-level research is needed to span the territory between macro-level generalities about employment (e.g., employment rates) and micro-scale studies that identify challenges and describe program outcomes about a few individuals. Ideally, we would have a better grasp not only of transitional issues and tensions with which youth with specific disabilities contend in employment, but broader insight into employment situations that seem to work reasonably well and the general factors that help account for those successes. Ideally, that research should be better synthesized or “rolled up” to identify cross-cutting principles, strategies, and supports that seem generally applicable regardless of type of disability or workplace, as well as those that likely need to be considered for youth with a given disability (e.g., intellectual disability vs. blindness) where there is no cognitive impairment. Aside from educational attainment, what are the other predictors of successful and unsuccessful employment outcomes? How widely applicable might these be? What are employers looking for in youth employees and what deters employers from hiring those with disabilities? How widely are these marketable or deterrent characteristics in evidence among young job searchers with disabilities?
- Much the same could be asked about post-secondary education. What are colleges and universities doing to further the unimpeded inflow, education, and successful outflow of youth with disabilities? What challenges do these organizations and learners with disabilities face? Where learners seem to be succeeding in their studies, what success factors account for this aside from personal motivation, intelligence, and access to financing? Are colleges,

universities, and other places of higher learning implementing strategies that stand a strong likelihood of ensuring student success? If so, what are these about? Aside from secondary school educational attainment, what other measures might be developed for tracking student success and distress in post-secondary situations? Why do some youth with disabilities drop out of post-secondary school? Is it all about illness, impairment, and disability? Are structural factors at play? Who is most at risk of dropping out? Why are they at risk? How widely operative are the risk factors?

- What barriers to positive transitions and transition outcomes do youth with disabilities experience in relation to income security programs? Where young people have successfully moved from these programs into employment, what success factors account for that? Have there been positive incentives and support? If so, what are these? How widely available are they? To what extent are youth with disabilities utilizing these? What accounts for youth with disabilities not seizing the opportunities and supports that may be available? Are there cases where youth with disabilities have not become completely independent of publicly financed income support yet have employment? How widely is this occurring? Who are the young people that are benefiting? What is the policy and program mix?

Further Directions — Data Needs

While the volume of literature is considerable, many unanswered questions remain. One thing seems reasonably clear: it would not be possible to answer those questions convincingly with a view to public policy development without access to robust data systems that provide information about the many unique and multi-faceted challenges experienced by large numbers of youth with disabilities. Regardless of the specific theoretical approach taken, without better, more comprehensive and more in-depth data it is not possible to develop insight into the transitions of youth with disabilities, and the factors that are likely to hamper their successful movement into adult roles and responsibilities. In the absence of these data, there is a high risk that policy and program attention cannot focus on these issues, and that the gap between the aspirations and outcomes of youth with disabilities and their non-disabled counterparts will widen. In other words, continuing data gaps in these two countries contribute to significant policy-related research vacuums. As a result, innovative policies are not being developed to address the issues of youth with disabilities and support the full access to social and economic opportunities enjoyed by others in society.

In applying these findings to the Canadian context, it is vital that we have access to reasonably detailed survey data on disability, and on work-related and educational supports that can shed light on the transition into work, job retention, and job loss of youth with disabilities. In this regard, Canadian data sources are far from adequate. The existing Workplace and Employee Survey and Youth in Transition Survey are longitudinal, allowing a focus on transition, but are general in nature and do not provide adequate data on how employers manage disability-specific issues in particular. The Participation and Activity

Limitation Survey, on the other hand, provides considerable information about barriers faced by youth with disabilities in looking for employment and seeking training, but does not take a longitudinal perspective, nor does it focus well on transitions from school to work. Despite these gaps, there remains a need to mine these resources more fully.

Data systems in Canada need to be specific enough to the particular and multi-dimensional natures of youth facing transitions, yet amenable to “rolling up” these detailed pictures into more than a kaleidoscope of disparate, disconnected images to assist organizations and governments that are working to improve matters. By incorporating the best aspects of the US and UK data systems and research approaches, we can make progress toward developing the knowledge necessary to improve the lives of youth with disabilities as they transition from school to post-secondary education and the labour force.

VII. Appendix: *United Nations Convention on the Rights of Persons with Disabilities and Optional Protocol*

While not yet binding on Canada, the United Nations *Convention on the Rights of Persons with Disabilities and Optional Protocol* (UN, 2006) also informed the analysis in this paper. It contains no provisions specific to the transitions of youth with disabilities, yet several features of this Convention are pertinent. These include the rights to:

- accessible schooling, medical facilities, housing, and workplaces (Art. 9);
- make choices about where and with whom to live and to have access to related support services (Art. 19);
- inclusive education at all levels (Art. 24);
- health and gender-sensitive health services (Art. 25);
- to employment without discrimination and with reasonable accommodation, and to technical and vocational guidance programs, placement services and training (Art. 27);
- an adequate standard of living (Art. 28); and
- equality of participation in political, cultural, recreational, leisure, and sporting activities (arts 29 and 30).

The preamble recognizes principles of individual autonomy, independence, freedom to make personal choices, active involvement in decision making, and the need for gender sensitivity.

Article 3 provides general guiding principles that affirm specific rights, namely:

- respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
- non-discrimination;
- full and effective participation and inclusion in society;
- respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- equality of opportunity;
- accessibility;
- equality between men and women; and
- respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

VIII. References

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IX. Endnotes

¹ See *British Columbia (Public Service Employee Relations Commission) v. British Columbia Government and Service Employees' Union (B.C.G.S.E.U.)*, [1999] 3 S.C.R. 3; and *British Columbia (Superintendent of Motor Vehicles) v. British Columbia (Council of Human Rights)*, [1999] 3 S.C.R. 868.

² Such rights also exist in the United Kingdom, but were formally set in place more recently than in the United States.

³ See University of York (n.d.) or White and Riley (2005). More generally, work done for the Department of Work and Pensions on employment rarely refers to school work transition. (See, for example, Berthoud, 2006; Berthoud and Blekesaune, 2007; Bewley et al., 2007; Greenberg and Davis, 2007; Hasluck and Green, 2007.)

⁴ The DfES has been split into the Department for Children, Schools and Families (DCSF) and the Department for Innovation, Universities and Skills (DIUS).

⁵ The EOC has been merged into the Equality and Human Rights Commission.

⁶ The NCD is a 15-member panel, appointed by the president and confirmed by the US Senate, that advises Congress. Most NCD members are people with disabilities, and are broadly representative of minority and other individuals and groups.

⁷ *Gillick v. West Norfolk and Wisbech Area Health Authority* [1985] 3 All ER 402 (HL).

⁸ That is, the 2004 National Beneficiary Survey (NBS).

⁹ As a comparator, the author found, using the 2001 Participation and Activity Limitation Survey, that in Canada, 38.6 percent of youth 15 to 24 years need one or more employment-related accommodations that would typically fall within the purview of the employer to make available in order to work. Further, the likelihood of requiring these supports increased with the severity of the disabilities reported. These include various forms of human assistance (e.g., interpreters, reader job coach, personal assistant), modified work hours or duties, technological aids (computer with adaptive technology, technical aids such as voice synthesizers, portable note-takers), communication aids (e.g., Braille or large print materials) and accessibility features in the built environment (ramps, appropriate parking, modified workstation).

¹⁰ The NHIS is a nationally representative cross-sectional survey administered to approximately 45,000 households each year. It collects a wide variety of information on health, employment, and income. In 1994 and 1995, a supplemental questionnaire on disability was administered.

¹¹ To minimize the skewing effects of impairment/health condition itself on the outcomes and their measurement so she could attend mainly to social factors, Burchardt excluded youth with intellectual disabilities from the research.

¹² See downloads for National Health Service, National Institute for Health Research. 2011. *SDO Project 08/1613/117*. Retrieved April 21, 2011 from <http://www.sdo.nihr.ac.uk/projdetails.php?ref=08-1613-117>.