CanChild
Centre for Childhood Disability Research

Childhood Disability in the Context of Poverty

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Executive Summary

This paper addresses the topic of childhood disability in the context of poverty. Its purpose is to: (a) summarize the needs of children and youth with disabilities and their families, and, (b) review strong evaluative research and promising practices for ameliorating the adverse affects of poverty in children and youth with disabilities, including specific factors contributing to program and policy successes. To this end, the paper consists of four major sections, including a description of the population, a summary of identified needs, a review of effective policy and programmatic strategies, and a set of recommendations based on these findings.

Childhood Disability in the Context of Poverty

In this paper childhood disability is defined as the gap between a child's functional abilities and the demands of their social and physical environments. In this view, disability is seen as a social construction resulting from a sub-optimal fit between a child's functional abilities and environmental factors such as the accessibility of services, programs, and built environments, the availability of appropriate resources, and societal attitudes.

Children living in poverty are at greater risk for a disability or developmental delay, and caring for a child with disability increases the odds of a family living in poverty. Though reliable prevalence data for childhood disability in low-income families is currently unavailable, an estimated 30% of Canadian children and youth with disabilities live in poverty. The strain of living poor, including material deprivation and social exclusion, coupled with the high costs of caring for a child with a disability creates chronic and unnecessary hardship in families.

Childhood disability in the context of poverty means children and families must cope not only with the disability itself, but with the added burdens of poverty-related health disparities, social disadvantage, inadequate health-related services, and the extra direct costs (time, money, and resources) associated with a child's disability. A child with a disability living in poverty is also more likely to live in problem housing and to experience routine hunger than other children. They also are far less likely to receive appropriate services including routine health care and specialty care. This in turn can contribute to medical complications and secondary disabilities, thereby increasing financial burdens and family distress.

Unmet Needs of Children and Youth with Disabilities and Their Families

Despite the well documented needs of children with disabilities and their families, gaps in essential services and supports remain. These needs will be even more extreme in low-income families. Parents consistently report an urgent, unmet need for respite care, caregiving support, household assistance, and accessible child care. Approximately 50% of children with a disability require some form of assistive technology (i.e., lifts, hand or arm brace, hearing aids or wheelchairs) and just over half of these children do not have all the specialized aids they need. One in four school-aged children with a disability has an unmet need for special education services or educational aids, and at least 16% have unmet needs for health care services. In 2001, nearly two in five school-aged children with disabilities were unable to participate in social or recreational activities in their community.

Key Messages

The goal of ameliorating the adverse affects of poverty for children and youth with disabilities must be part of a larger government effort to reduce child poverty in general and to provide families and communities with the support they need to raise healthy, well-adjusted children.

- Focus on creating positive outcomes for all children, which, from a determinant of health perspective means health gains are only possible if a child and family's basic needs for well-living are met first. For families caring for a child or youth with a disability this includes:

    1. Adequate income – including policies and supplements to offset the costs associated with raising a child with disabilities and parental leaves.

    2. Family support – includes in-home disability supports, in-home and out-of-home respite care, child care, and mental health supports and services.

    3. Supportive community environments – settings which emphasize full access and participation for all children by providing inclusive services and fully accessible built environments.

- Policy-level approaches such as addressing barriers to care, providing income and disability supports, providing coordinated, integrated services, and providing families and communities with the support they need to raise healthy, well-adjusted children, make a difference.

- Government transfers such as Employment Insurance (EI), the National Child Benefit, and the GST credit - make a positive difference. In 2003, the child poverty rate in Canada was 18%; without government transfers, it would have been 27%**.**

- Programmatically, there is no strong evidence of effectiveness for poverty specific interventions for children and youth with disabilities. The exception is the early intervention literature, which provides strong evidence of effectiveness for a range of programs. These findings, however, are limited for children with disabilities because the early intervention literature rarely includes an explicit focus on them.

- In the absence of poverty specific intervention research for children and youth with disabilities, the prevention, resilience, and health/wellness promotion literature, in combination with the disability literature, provides an evidence base from which future programming may be designed and evaluated.

- The childhood poverty-disability concern is more than an income issue. It is a family support issue. A family support approach for promoting positive outcomes for children and youth with disabilities, versus a narrowly focused “child only” approach, is essential.

- Ensuring the views of children and youth with disabilities and their families are represented in conversations about needed services and supports is essential for making certain policies and programs meet the needs of the people they are intended to serve.

Recommendations:

Provincially and nationally there remains “no coherent vision for achieving the best possible policy mix for children [and youth] with disabilities and their parents” (Valentine, 2001). Too often these citizens live in poverty and must struggle to obtain the services and supports they desperately need. It is time to build on what we know and to move into action.

Action Priorities

1. Formation of an Advisory Group comprised of families, researchers, service providers, community stakeholders and policy makers to inform the development of a strategic framework and a concrete action plan with a strong evaluation framework.

2. Formation of a Working Group to develop testable, integrated models of service delivery and supports, followed by pilot testing in selected urban and rural low-income communities.

3. Formation of a Working Group to develop a community-based Ontario Family Support Framework, followed by pilot testing in selected urban and rural low-income communities.

Research Priorities

1. Provide incentives to encourage *solutions focused* research collaborations testing high-risk, high-reward projects with potential for successes in high-need areas. Build evaluation milestones into these initiatives, including monitoring mechanisms, allowing promising solutions to be identified quickly, implemented, and monitored.

2. MCYS should seek out opportunities to add research components to ongoing efforts and demonstration projects funded by other agencies and departments (e.g., CIHR, Ministry of Education, Ministry of Health Promotion, and other Provincial and Federal agencies). Such large-scale efforts can identify the organizational, financial, and intervention drivers of success and can shed light on which components work for whom and under what circumstances.

3. Develop and implement health surveillance and monitoring activities for Ontario children with complex needs and their families, which is essential for tracking outcomes over time.

Introduction

The Government of Ontario's poverty reduction activities include a strategy focused on children and youth. As part of this initiative, the Ministry of Children and Youth Services has asked *CanChild* Centre for Childhood Disability Research to prepare a thorough review and synthesis of current research addressing a range of potential interventions and policy approaches for ameliorating the adverse affects of poverty for children and youth with disabilities.

In particular, this paper focuses on the identification of:

- unmet needs of children and youth with disabilities and their families
- strong evaluative research and promising practices involving non-medical approaches to ameliorating the adverse affects of poverty for children and youth with disabilities, including specific factors contributing to program and policy successes

The approach used was to survey the relevant peer-reviewed and grey literature, identify scientifically sound evidence of effectiveness[1], and to summarize relevant findings that can inform policy planning and decision making. Using a "child in a family within a community" perspective, this analysis considers a broad range of interventions and polices implemented throughout Canada, Europe, and the United States.

In this document, issues of child poverty and disability are viewed through a social model of health lens which recognizes the health-related influences of the social and environmental conditions in which children and family live. This model is based on the understanding that in order for sustainable health gains to occur, a child and family's basic needs for well-living (i.e. housing, safety, food, and adequate income) must be met first.

Definitions of Childhood Disability and Poverty

Childhood disability encompasses a broad range of conditions which vary in scope and severity (Appendix A). In this paper, childhood disability is defined as the gap between a child's functional abilities and the demands of their social and physical environments (Brandt & Pope, 1997). It is a functional, rather than a diagnostic or categorical definition, emphasizing the fit between personal abilities and external opportunities to engage in everyday activities at home, in one's neighborhood, at school, and in the larger community. In this view, disability is seen as a social construction resulting from a sub-optimal fit between a child's functional abilities and environmental factors (i.e., accessibility of services, programs and built environments, societal attitudes, and availability of appropriate resources).

In the absence of an official poverty line, Canada relies on three common indicators of poverty (Campaign 2000, 2007). These include the before and after tax Low Income Cut Off (LICO), the before and after tax Low Income Measure (LIM), and the Market Basket Measure (MBM).

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[1] Literature search strategy and evaluation criteria available from the author.

Campaign 2000, in a recent Senate Brief, defined poverty as “a particular standard of living located toward the bottom of a multi-dimensional socioeconomic status hierarchy” (p.2., 2007). This definition recognizes poverty, which is typically measured only in terms of income, as a complex construct comprised of social position, financial demands, and available assets, which together are powerful determinates of life experiences and health outcomes.

Prevalence of Childhood Disability in the Context of Poverty

Reliable prevalence data on child and youth disability in Canada is currently unavailable making it impossible to accurately estimate the prevalence of childhood disability in the context of poverty. However, it is widely recognized that children and youth with disabilities are more likely to be living in poverty than other children. Canadian children with disabilities are one and a half times more likely than children without disabilities to live in households where the income falls within the lower two income quintiles (Canadian Institute of Child Health [CICH], 2000). An estimated 30% of these children and youth live in income poor or impoverished families versus 18% of children without disabilities (CICH, 2000; Roeher, 2000a).

A five year forecast (2007-2011) of the prevalence of children with complex special needs in Ontario and Canada (Hanna & Law, 2006) estimates between 3.8% and 8% of Ontario children and youth, as many as 2.94 million, have or will have a functional limitation associated with a chronic condition. If estimates of poverty rates among families of children and youth with disabilities are reasonably accurate, at least one in four and perhaps as many as one in three children and youth with chronic conditions will live in poverty.

In the general population, children in single parent families, children of color, and those in First Nations and recent immigrant communities are disproportionately affected by poverty. Although we know children with disabilities are over-represented in lone parent families (Hanvey, 2002), we currently lack a comprehensive understanding of the characteristics of low-income families caring for children with disabilities, including the specific nature and extent of their disability related needs. It is challenging, if not impossible, to develop population-based strategies and measure their effectiveness in the absence of meaningful descriptions of the target population (Rosenbaum, Jaffer, & Russell, 2006) and in the absence of valid and reliable surveillance and monitoring activities (Hanna & Law, 2006).

The Intersection of Childhood Disability and Poverty

The interconnection between childhood poverty and disability is complex and multi-directional. Children living in poverty are at greater risk for a disability or developmental delay (Farran, 2000; Emerson & Hutton, 2005; Msall, Bobis, & Field, 2006), and disability increases the odds of a family living in poverty (Brehaut et al., 2004; Canadian Council on Learning, 2006; Emerson & Hutton, 2005; Hanvey, 2002). Poverty, with its associated risks, increases the odds that a child’s needs will go unmet and it increases the likelihood that opportunities to engage in a range of developmentally enriching experiences will remain out of reach (Masten, 2000).

Poverty also stresses family interactions, and in some cases makes it impossible for caregivers to engage in parenting behaviors that encourage a child's optimal development (Zipper & Simeonsson, 2004).

Children and youth with disabilities often feel socially isolated, stigmatized, and marginalized from society (Baker & Donelly, 2001; Davis & Watson, 2001; Gibson, Young, Upshur, & McKeever, 2007). Bullying, social segregation, and feeling unsafe, which are more common among children with disabilities than their peers (Hanvey, 2001), can lead to feelings of friendlessness and social separation (Ladd & Troop-Gordon, 2003). When peer relation problems are chronic, children are at greater risk for depression, conduct problems, negative self and peer perceptions, and long-term adjustment problems (Ladd & Troop-Gordon). Living in poverty compounds these risks, amplifies their affects, and creates unique challenges for families.

Childhood disability in the context of poverty means children and families must cope not only with the disability itself, but with the added burdens of poverty-related health disparities, social disadvantage, inadequate health-related services, and the extra direct costs (time, money, and resources) associated with a child's disability (Hanvey, 2002; Canadian Council on Learning, 2006). These children are far less likely to receive appropriate services, including routine health care and specialty care than other children (Mayer, Skinner, & Slifkin, 2004; Beisner & Stewart, 2005) which can contribute to medical complications and secondary disabilities, and increase financial burdens and family distress (Gerhardt, Walders, Rosenthal, & Drotar, 2004; Zipper & Simeonsson, 2004).

Needs of Children and Youth with Disabilities and their Families

Despite the well documented needs of children with disabilities and their families, gaps in essential services and supports remain. These needs will be even more acute in low-income families.

Caregiver Assistance and Family Support

Providing for the physical, social, emotional, and developmental needs of a child with a disability can be overwhelming for families, particularly in the absence of adequate resources and social supports. The caregiving demands for these parents have been shown to directly and negatively impact both their psychological well-being and physical health (Brehaut et al., 2004; Raina, et al., 2005). Caregivers (principally mothers) have reported spending between 50-60 hours per week, above and beyond household responsibilities and paid work, on personal care, advocacy, coordination of services, and transportation for their child with a disability (Hanvey, 2002). In addition, parents often work to create peer relationships for their child, lobby for needed services and supports, and work to ensure their child's acceptance and participation in the community (Community Association for Community Living [CACL], 2001). Such demands often result in exhaustion and create undue hardships for caregivers, particularly mothers.

Though they are the largest caregiver group in Ontario, families often provide on-going care with little outside assistance and support. Families of children and youth with disabilities consistently report an urgent, unmet need for respite care, which is essential for family well-being. A majority of these families also report an unmet need for help with housework and family responsibilities. Families of children with severe and very severe disabilities report the greatest unmet needs in this area. Seventy percent of these families cite costs as a barrier to receiving needed help, and 42% cite a lack of available services and programs (Fawcett, Ciceri, Tsoukalas, & Gibson-Kierstead, 2004; Statistics Canada, 2003).

Child Care

High-quality child care arrangements and after-school programs provide children and youth with important opportunities to cultivate their skills, competencies, talents, strengths and social relationships with peers and adults. These arrangements also provide supervised child care which allows parents to work, attend to personal and family matters, and to rest. Despite research showing quality child care coupled with recreation programs allows single mothers to leave welfare at twice the rate of other welfare recipients (Browne et al., 1998), such child care arrangements remain under-utilized in Ontario and Canada.

Securing high-quality child care arrangements, in and out of the home, and accessing after-school programs is particularly challenging for families of children with disabilities. A large majority of parents report an unmet need for high-quality child care and after-school programs (Irwin & Lero, 1997; Knoche, Peterson, Edwards, & Jeon, 2006). Barriers to inclusive child care include a lack of availability, high costs, inaccessibility, inadequate facilities, and a lack of disability related training for staff workers (Roeher, 2003).

Securing less formal child care arrangements is also challenging. Approximately 20% of parents of preschool children with a disability report having been refused child care or babysitting services due to the child’s disability (Government of Canada, 2006). Irwin and Lero (1997) found 70% of parents had difficulty finding high-quality caregivers and 68% had difficulty securing alternative care arrangements when they or their child was ill.

Employment, Income Support, Housing and Food Security

The cost of raising a child with a disability can be up to 3 times that of raising a typically developing child (Council for Disabled Children, 2007). Additional financial burdens include the costs of special diets and clothing, child care, medications, supplies and equipment, and home adaptations (Roeher, 2000a). Yet, parents are often forced to choose between caregiving and employment. A majority of parents in two-parent households are likely to either lose or quit a job to care for a child with a disability. Parents who remain in the workforce are often forced to work reduced hours, turning down overtime or promotions and working an altered schedule to care for their child with a disability (Government of Canada, 2006; Irwin & Lero, 1997). Major barriers to parent employment include a lack of assistance with caregiving needs, a lack of high-quality, affordable inclusive child care, and the need for parents to negotiate multiple systems of care (health, education and social services) on behalf of their child (Hanvey, 2002). These burdens will be even greater for single parents living in poverty.

Working low-wage jobs with few benefits is not a viable option for many low-income families who are entitled to receive more child disability-related supports when on welfare. The additional costs of caring for a child with a disability can be overwhelming and for some, particularly single mothers, government support may be the only way to care for their child while keeping their family housed and fed (Hanvey, 2002). In fact, children with disabilities in general are more likely to live in problem housing (Emerson & Hutton, 2005; Hanvey, 2002), and to experience routine hunger (Hanvey, 2002) than other children. Still, a Roeher Institute (2000b) study concluded social assistance for families who are caring for a child with a disability is inadequate. Although parents in this study expressed concerns about the psychological impact of poverty and welfare status on their children, social assistance was an uncomfortable and unpleasant necessity for them.

Disability related supports

Approximately 50% of children with a disability require some form of assistive technology such as lifts, hand or arm brace, hearing aids or wheelchairs. Just over half of these children do not have all the specialized aids they need and costs are cited as a significant barrier to acquiring the aids needed (Statistics Canada, 2008a).

Many youth with disabilities require the assistance of a qualified support worker in order to live lives of independence and to enjoy the benefits of full citizenship (Family Alliance Ontario, 2007). Families are advocating for individualized funding, which would allow them to purchase disability related supports that are responsive to individual needs of their child, and would provide youth and families with disabilities with maximum control over the provision of disability supports. This, according to Human Resources Development Canada (2000), is the hallmark of accessible and appropriate disability supports.

Nevertheless, government funding continues to favor traditional service provider administered care over self-directed supports. Families are advocating for alternatives to traditional disability support services, which they feel separate and isolate children and youth with disabilities. Many prefer funding for self-selected living supports which would allow them to make their own community living choices, like other citizens in their communities.

Support workers hired directly by youth and their families typically have lower salaries and fewer benefits than support workers employed by service agencies. Families see this as a significant barrier to self-directed care and continue to petition the Ontario government to extend the recent salary increases for support workers hired by service agencies (wage gap funding), to the same workers hired privately by families (Family Alliance Ontario, 2007).

Transition to adulthood

There is also a need for an increased commitment to improving transition planning and supports for youth with disabilities. The transition from youth to adulthood is particularly challenging for youth with disabilities and their families and these youth are faced with many barriers to achieving autonomy and independence. To make a successful transition into the adult world they often need support from their family and community (King, Brown & Smith, 2003; Stewart, Law, Rosenbaum & Willms, 2001), support which is often lacking. In a recent report Stewart and colleagues (2007) summarize these challenges and provide best practice recommendations and guidelines for supporting youth with disabilities during the transition to a meaningful adult life.

Integrated Services and Appropriate Health Care

Families and youth are frustrated by long wait lists for services and interactions with fragmented, silos of care and service delivery (Hanvey, 2002). Such interactions, particularly when services are separately located and poorly coordinated, can negatively impact families of children with disabilities. The burden is even greater for low-income families who struggle with transportation needs and in lone parent families juggling household responsibilities, caregiving duties, and employment without adequate supports. The need for an integrated and coordinated service delivery system is especially acute for families of children with disabilities who interact with a range of service providers and systems of care over the course of their child’s development.

In a study of 427 school age children with disabilities in Ontario (King et al., 2006) parents reported using an average of 5 separate child health services and one third reported using between 6 and 13 services. Health care service use alone, without the added affects of frequency of use and interactions with other systems of care, was found to be a significant barrier to their child’s participation in academic, recreational, community activities. It was also strongly correlated with poorer psychological and emotional well-being among caregivers, regardless of family income (Petrenchik, Law, King, & Xu, manuscript in preparation).

Parents also report unmet needs for health care services. At a minimum, 16% of children with disabilities have unmet needs for health care services (primarily rehabilitation services). Parents cited reasons such as a lack of insurance coverage (33%), high costs (40%), unavailability of local services (34%) and long waiting periods (55%) (Canadian Council on Social Development [CCSD], 2005). There is also a pressing need for greater integration of services for co-occurring mental health problems and emotional difficulties which can often accompany a child’s disability. These needs are especially acute for children and youth who feel socially isolated and stigmatized as a result of their disability.

Educational Services and Supports

In a discussion paper prepared for the National Children’s Alliance, Hanvey (2002) discusses at length the unmet needs of children with disabilities in the education system. In a survey of key informants, only 19% felt children with special needs were having their needs met in the education system (Gibson-Kierstead & Hanvey, 2001).

According to recent Participation and Activity Limitation Survey (PALS) data, nearly 25% of children with disabilities have an unmet need for special education. Nearly 50% of the children needing but not receiving special education have severe to very severe disabilities. In addition, 17% of children with disabilities have an unmet need for educational aids, including tutors, teacher's aides, special software and attendant care services. Parents cite a lack of funding within the school system as the most frequent reason for this unmet need. Parents of children with emotional, psychological, or behavioral conditions report they find it especially difficult to obtain special education services for their child (Statistics Canada, 2008b).

Community-based Participation in Recreation, Arts and Cultural Activities

Participation in organized recreation, the arts, and cultural activities has important benefits for children and youth. These experiences are powerful opportunities to enhance a child and youth's skills, talents, self-confidence, and sense of self-efficacy. Children and youth who participate regularly in such activities, do better in school, have closer relationships with positive peers and caring adults, make better life choices, view themselves more positively, and feel better about their life chances than other children (Mahoney, Larson, & Eccles, 2005).

For a variety of reasons, children and youth with disabilities are often excluded from participating in such activities. In 2001, nearly two in five school-aged children with disabilities were unable to participate in social or recreational activities (CCSD, 2006). The likelihood of being socially excluded increased dramatically with the severity of a child's disability. One in five children with a mild disability was excluded, while nearly one in three with a moderate disability, and one half with a very severe disability were unable to participate in community-based social, leisure and recreational activities (CCSD). Of those with a very severe disability, nearly 75% were unable to participate. While a child's physical limitations and cognitive abilities can contribute to participation restrictions, structural barriers (Table 1) also play a significant role in limiting the community-based participation of children with disabilities in low and middle income families.

Table 1. Commonly Reported Barriers to Child and Youth Participation in Recreation, Arts and Cultural Activities.

- No local facilities available
- Existing facilities are inaccessible
- High cost of activities & equipment
- Language barriers
- Neighborhood safety
- Lack of adult role models
- Lack of transportation or inaccessible public transit system
- Lack of required assistive aid or device
- No attendant available to assist the child
- Lack of service provider training
- Unwelcoming attitudes

(Law & Petrenchik, 2005; Law, Petrenchik, King, & Hurley, 2007; CCSD, 2006; Canadian Parks and Recreation Association, 2001)

Clearly, the childhood disability-poverty concern is more than an income issue. It is a family support issue. Precisely because a child with a disability is more reliant on their family to assist them with their activity needs, anything that disrupts or stresses family processes, such as poverty, is likely to have a significant adverse affect on a child’s health, development and participation at home, in school, and in community life. This implies a family support approach for promoting positive outcomes for children and youth with disabilities, versus a narrowly focused “child only” approach, will be essential.

Review of Policy Strategies and Programmatic Approaches

This section is devoted, primarily, to a review of strong evaluative research and promising practices for ameliorating the adverse affects of poverty on children and youth with disabilities, including specific factors contributing to program and policy successes. A comprehensive review of policy strategies is beyond the scope of this paper, therefore the policy discussion is limited to selected topics of greatest relevance to issues of child disability and poverty.

Policy Strategies

Although policy strategies are notoriously difficult to evaluate, it should be stressed that government transfers such as Employment Insurance (EI), the National Child Benefit, and the GST credit - do make a difference. The child poverty rate in 2003 was 18%; without government transfers, it would have been 27% (CCSD, 2006).

In general, policy-level approaches such as addressing barriers to care, providing income and disability supports, providing coordinated, integrated services, and providing families and communities with the support they need to raise healthy, well-adjusted children, make a positive difference (National Council of Welfare [NCW], 2007).

Lessons from the UK

The United Kingdom (UK) has taken a unique approach to addressing child poverty which has produced better results than Canadian and American strategies to date (NCW, 2007). The two cautions in interpreting these results are additional disability specific outcome information is needed from the UK and policy approaches in other countries may not generalize to child poverty and disability issues in Ontario.

The UK has developed an ambitious plan to cut the number of children living in poverty in half by the year 2010 and to completely eradicate child poverty by 2020. The strategy includes creating affordable childcare spaces for all children aged 3-14 years (and up to 18 years for children with a disability), targeting supports to populations of highest need, getting those who are able to work into the workforce, and the delivery of high quality, well coordinated public services such as The Early Support Program and Sure Start (NCW, 2007).

While a complete evaluation is forthcoming, factors contributing to the apparent successes of the UK initiative include (a) service delivery models specifically designed to achieve better coordinated, multi-agency assessment and service delivery for children with disabilities and their families, and (b) multiagency, universal support system for families with young children in disadvantaged communities which offer early education integrated with child care, family support, and child and family health services, and (c) implementation of 8 observational (surveillance and monitoring) sites throughout the UK (Carpenter & Campbell, 2008).

Programmatic strategies

An extensive search and review of the peer-reviewed and grey literature in areas of health, disability, rehabilitation, behavioral and social sciences, education, recreation and leisure produced no strong evidence of effectiveness for poverty specific interventions for children and youth with disabilities. Consequently, a full systematic review of intervention approaches is not possible.

The exception is the early intervention literature, which provides strong evidence of effectiveness for a range of programs in the U.S. with both immediate and long-term benefits for children living in poverty. Although children with disabilities are included in this population these findings are limited because the early intervention literature rarely includes an explicit focus on them.

Undoubtedly, a variety of successful programs serve children and youth with disabilities in low-income families around the world. However, only programs with documented evidence of effectiveness are included in this review.

Early Childhood Programs

Early childhood interventions are designed to reduce risk in early childhood and to promote healthy development. Two types of early childhood intervention strategies - preschool and home visitation, are perhaps the most commonly known and most studied to date. Preschool programs focus almost exclusively on the child, while home visitation is viewed as a two-generational approach in which professionals work with parents to help them support their infants, toddlers, and young children (Sweet & Appelbaum, 2004).

In a systematic review of early intervention programs Karoly, Kilburn and Cannon (2005) found evidence of effectiveness for 20 early childhood intervention programs in the U.S. As indicated in Appendix 1, sixteen of the programs are identified as having strong evidence of effectiveness based on long term follow-up results, while four are regarded as having a promising evidence base due to shorter-term follow-up results. Although these programs are not disability specific, many of them are designed to serve low-income children, a portion of which will have developmental delays and disabilities.

The authors identify several features of early intervention program that seem to be associated with better outcomes for children including: better-trained caregivers, smaller child-to-staff ratios, and greater intensity of services. Specific factors contributing to the achievements of the

UK's Early Support Program and Sure Start programs mentioned earlier include (a) service delivery models specifically designed to achieve better coordinated, multi-agency assessment and service delivery for children with disabilities younger than 3 years and their families, and (b) multiagency, universal support system for families with young children in disadvantaged communities which offer early education integrated with child care, family support, and child and family health services (Carpenter & Campbell, 2008). Together, these findings indicate the existence of a body of sound research that can guide resource allocation decisions for early intervention programming and policy.

It is important to note these programs are likely to be underutilized by children with moderate to severe disabilities, as appears to be the case in Head Start programs in the U.S. (Beauchesne, Barnes, & Patsdaughter, 2004). It seems many Head Start programs lack the resources needed to adequately serve these children including transportation, flexibility and adaptability of program structure, and flexible hours of operation (Parish & Cloud, 2006).

Promoting Resilience, Positive Development and Social Inclusion

Children and youth with disabilities are, first and foremost, young people. Therefore, *general principles* for preventing negative outcomes and promoting resilience and positive development in the face of life adversity have relevance. In the absence of poverty specific intervention research for children and youth with disabilities, the prevention, resilience, and health/wellness promotion literature, in combination with the disability literature, provides an evidence base from which future programming may be designed and evaluated.

The caveat is the participation related needs of children with disabilities will be more complex; however the basic social-emotional, psychological, and developmental needs of these children and youth are not fundamentally different from other children and youth. All children and youth need opportunities to cultivate their skills, competencies, talents, strengths, and social relationships. Yet, too often, poverty reduces a child's opportunities for participation in developmentally enriching experiences.

> One of the greatest differences in the lives of children growing up in middle class versus poverty is the richness of opportunities for achievement to feed the mastery motivation system. Feelings of self-confidence and self-efficacy grow from mastery experiences. Children who feel effective persist in the face of failure and achieve greater success because of their efforts (Masten, p.5., 2000).

Children and youth with disabilities growing up in poverty would benefit from such opportunities provided their needs for activity adaptations and environmental accommodations are met in a way that affords them full inclusion, dignity, and respect. The nature and extent of the accommodations will vary depending upon the unique needs of the child or youth. For example, the accommodation needs of a young child with an acquired brain injury participating in an after-school arts and recreation programs will differ from the needs of a teenager with significant visual and hearing impairments. In Ontario, Easter Seals' Recreational Choices program is an exemplary, accessible program with integrated supports that enable children with physical disabilities to participate in a range of enriching out-of-school time activities.

Conclusions and Recommendations

The goal of ameliorating the adverse affects of poverty for children and youth with disabilities must be part of a larger government effort to reduce child poverty in general and to provide families and communities with the support they need to raise healthy, well-adjusted children. Numerous resources address broad poverty reduction strategies (see Campaign 2000, 2002; CCSD, 2008; NCW, 2007) and general policy approaches to addressing the impact of poverty on population health (Ross, 2003), topics which are beyond the scope of this paper. An essential and often missing aspect of such strategies is recognition and consideration of the unique, long term impact of disability (both physical and mental) on the health, wellbeing, quality of life, and economic prosperity of low and middle income children and families.

The effects of childhood poverty and disability accrue over time and are a product of complex child-family-environmental relations. It is unreasonable, therefore, to expect relatively brief, narrowly focused interventions to stem the tide of poverty related difficulties and to provide children and youth with large, enduring developmental gains. There are practical limits to what can be expected from even the most exemplary interventions delivered by skilled professionals working in relative isolation.

Ameliorating risk, promoting health, and fostering resilience in children, both with and without disabilities, will mean sustained, coordinated efforts to support children's physical, psychological, social-emotional, and academic development throughout early childhood and adolescence. An early years focus is important, but it remains a single factor in a larger equation of child health and development. The reality is we need investments in a range of services and supports accessible throughout childhood and young adulthood, coordinated in a way that effectively meets the vital needs of children, youth, and families.

The science on these points is clear; better services for children improve their outcomes, programs directed at parents fosters positive parenting, and ensuring families have adequate incomes provides them with access to better housing and nutrition, better education and recreational facilities, all of which has a positive measureable impact on children (Beauvais & Jenson, 2003; Shonkoff & Phillips, 2000). The challenge now is to identify the best policy mix for all children and to fit together services, interventions, and community supports in ways that make it possible for children, youth, and parents to access the resources and services they need throughout childhood and adolescence, including times of major life transitions.

Previous work by the Canadian Policy Research Networks (Valentine, 2001) suggests this will require a mix of policy instruments, involve decision makers at all levels, and coordination among them. The focus must be on creating positive outcomes for all children, using the enabling conditions of positive child outcomes as guiding principles. These are:

1. Adequate income – including policies and supplements to offset the costs associated with raising a child with disabilities and parental leaves.

2. Family support – includes in-home disability supports, in-home and out-of-home respite care, child care, and mental health supports and services.

3. Supportive community environments – settings which emphasize full access and participation for all children which means inclusive services and fully accessible built environments.

Ensuring the views of children and youth with disabilities and their families are represented in conversations about needed services and supports is essential for making certain policies and programs meet the needs of the people they are intended to serve. The inclusion of First Nations and recent immigrant families is especially important because their views are typically under-represented in such discussions.

Recommendations

Provincially and nationally there remains “no coherent vision for achieving the best possible policy mix for children [and youth] with disabilities and their parents” (Valentine, 2001). For youth with disabilities and for parents caring for a child with a disability, the situation is often one of deep frustration, isolation and marginalization, and on-going dissatisfaction with existing health and social services systems. Too often these citizens live in poverty and must struggle to obtain the services and supports they desperately need. It is time to build on what we know and to move into action.

Action Priorities

1. Formation of an Advisory Group comprised of families, researchers, service providers, community stakeholders and policy makers to inform the development of a strategic framework and a concrete action plan with a strong evaluation framework.

    a. Public policy, its development and outputs, must be more closely linked to the lived experiences of children and families (Freiler & Zarnke, 2002) which means the inclusion of a cross-section of decision makers, service providers, and families is vitally important.

    b. One of the first orders of business will be to establish and prioritize a set of realistic, achievable targeted outcomes (i.e. improved access to care, social inclusion, increased health equity, strong families, school success, etc.) with timetables for actions designed to address them. Disability issues will be a part of this larger initiative.

2. Formation of a Working Group to develop testable, integrated models of service delivery and supports, followed by pilot testing in selected urban and rural low-income communities. The group should include policy makers, direct service providers, and families, as well as other agencies involved in science-to-service activities.

3. Formation of a Working Group comprised of a cross-section of professionals, families, and researchers to develop a community-based Ontario Family Support Framework, followed by pilot testing in selected urban and rural low-income communities.

Research Priorities

1. Provide incentives to encourage *solutions focused* research collaborations testing high-risk, high-reward projects with potential for successes in high-need areas. Build evaluation milestones into these initiatives, including monitoring mechanisms, allowing promising solutions to be identified quickly, implemented, and monitored.

    a. Such investments are needed to tell us which combinations of programs and supports, at what cost, are most effective for improving targeted outcomes for specific groups of children and youth living in particular circumstances.

    b. Foci for implementation studies should be determined in conjunction with policy makers, direct service providers, and families, as well as other agencies involved in science-to-service activities.

2. MCYS should seek out opportunities to add research components to ongoing efforts and demonstration projects funded by other agencies and departments (e.g., CIHR, Ministry of Education, Ministry of Health Promotion, and other Provincial and Federal agencies). Such large-scale efforts can identify the organizational, financial, and intervention drivers of success and can shed light on which components work for whom and under what circumstances.

3. Develop and implement health surveillance and monitoring activities for Ontario children with complex needs and their families which are essential for tracking outcomes over time.

With sustained and meaningful policy attention - and a commitment to act decisively on what we know - we have an opportunity to improve the health, well-being, and social inclusion of children and youth with disabilities and their families. The problems are obvious, solutions are possible, and the costs of inattention are too high. The time for informed action is upon us.

References

Baker, K., & Donelly, M. (2001). The social experiences of children with disabilities and the influence of the environment: A framework for intervention. *Disability and Society*, *16*, 71-85.

Beauchesne, M. A., Barnes, A., & Patsdaughter, C. (2004). Children with disabilities need a Head Start too! *Journal of Learning Disabilities*, 8 (1), 41-55.

Beiser, M., & Stewart, M. (2005). Reducing health disparities: A priority for Canada. *Canadian Journal of Public Health*, 96 (Suppl 2), S4-S5.

Brandt, E., & Pope, A. M. (1997). *Enabling America: Assessing the role of rehabilitation science and engineering.* Washington, D.C.: National Academy Press.

Beauvais, C. & Jenson, J. (2003). *The well-being of children: Are there "neighbourhood effects?"* Retrieved July 10, 2008 from http://www.cprn.org/documents/18052_en.pdf

Brehaut, J. C., Kohen, D. E., Raina, P., Walter, S. D., Russell, D., Swinton, M., et al. (2004). The health of primary caregivers of children with cerebral palsy: How does it compare with that of other Canadian caregivers? *Pediatrics*, 114(2), e181-191.

Browne, G., Byrne, C., Roberts, J., Gafni, A., Watt, S., Haldane, S., et al. (1998). *Benefiting all the beneficiaries of social assistance is "Within Our Reach": A RCT of the two-year effects and expense of subsidized versus non-subsidized quality child care/recreation for children on social assistance*. Hamilton, ON: McMaster University.

Campaign 2000. (2002). *Putting promises into action: A report on a decade of child and family poverty in Canada.* Retrieved July 1, 2008 from http://www.campaign2000.ca/rc/unsscMAY02/unintro.html

Campaign 2000. (2007). *Submission to the Senate Committee on Social Affairs, Science and Technology*. Retrieved July 1, 2008 from http://www.ccsd.ca/pccy/2006/pdf/c2000%20Brief%20to%20Senate%20Committee.pdf

Canadian Association for Community Living (CACL). (2001). *Don't Exclude our Children*. Toronto: Author.

Canadian Council on Learning. (2006). *The social consequences of economic inequality for Canadian children: a review of the Canadian literature*. Retrieved July 1, 2008 from http://www.ccl-cca.ca/NR/rdonlyres/EA17B0FD-B723-4253-ADBF-2746914B411E/0/FirstCall.pdf

Canadian Council on Social Development. (2005). *Children with Disabilities: Medication and Health Care.* Retrieved July 1, 2008 from http://www.ccsd.ca/drip/research/drip20/drip20.pdf

Canadian Council on Social Development. (2006). *The progress of Canada's children & youth.* Ottawa: Author.

Canadian Council on Social Development. (2008). *Focus on poverty in Canada: Defining the problem, working strategies, and measuring success.* Retrieved June 23, 2008 from http://www.ccsd.ca/perception/2934/perception_2934.pdf

Canadian Institute of Child Health (CICH). (2000). *The Health of Canada's Children* (3rd Ed). Ottawa, ON: Author.

Canadian Parks and Recreation Association (CPRA). (2001). *Recreation and children and youth living in poverty: Barriers, benefits and success stories.* Developed by The Canadian Council on Social Development (CCSD) for CPRA.

Carpenter, B., & Campbell, L. (2008). The changing landscape of early childhood intervention. Strategy, policy, and practice. *Infants & Young Children,* 21(2), 142-148.

Council for Disabled Children. (2007). *Every disabled child matters.* London, England: National Children's Bureau.

Davis, J. M., & Watson, N. (2001). Where are the children's experiences? Analyzing social and cultural exclusion in 'special' and 'mainstream' schools. *Disability & Society, 16*(5), 671-687.

Emerson, E., & Hutton, C. (2005). *The socio-economic circumstances of families with disabled children.* Retrieved July 13, 3008 from the Institute for Health Research, University of Lancaster web site: http://www.lancs.ac.uk/fass/ihr/publications/ericemerson/secchilddisability.pdf

Family Alliance Ontario (2007). *What issues are most important to families?* Retrieved July 7, 2008 from http://www.family-alliance.com/ElectionIssues2007.pdf

Farran, D. (2000). Another decade of intervention for children who are low-income or disabled: What do we know now? In J.P. Shonkoff & S. J. Meisels (Eds.), *Handbook of early childhood intervention* (2nd ed., pp-510-548). Cambridge, England: Cambridge University Press

Fawcett, G., Ciceri, C, Tsoukalas, S., & Gibson-Kierstead, A. (2004). *Supports and services for adults and children aged 5-14 with disabilities in Canada: An analysis of data on needs and gaps.* Ottawa: Canadian Council on Social Development.

Freiler, C. & Zarnke, P. (2002). *The Laidlaw Foundation's perspective on social inclusion. Foreword to the Laidlaw Foundation's working paper series, Perspectives on Social Inclusion.* Toronto, Ontario: The Laidlaw Foundation.

Gerhardt, C., Walders, N., Rosenthal, S., & Drotar, D. (2004). Children and families coping with pediatric chronic illness. In K. Maton, C. Schellenbach, B. Leadbeater, and A. Solarz (Eds.), *Investing in children, youth, families, and communities: Strengths-based research and policy* (pp. 173-189). Washington, DC: American Psychological Association.

Gibson, B. E., Young, N. L., Upshur, R. E. G., & McKeever, P. (2007). Men on the margin: A Bourdieusian examination of living into adulthood with muscular dystrophy. *Social Science & Medicine*, *65*, 505-517.

Gibson-Kierstead, A., & Hanvey, L. (2001). *Special Education in Canada.* Perception. 25(2), 10-12. Ottawa: Canadian Council on Social Development.

Government of Canada. (2006). Young children with disabilities: An overview. In *The Well-being of Canada Young Children,* Retrieved June 18, 2008 from http://www.socialunion.ca/well_being/2007/en/chapter_9.shtml

Hanna, S., & Law, M. (2006). *Prevalence of children with complex special needs in Ontario: Issues in measurement and forecasting. A report for the Ontario Ministry of Children and Youth Services.* Hamilton, ON: *CanChild* Centre for Childhood Disability Research.

Hanvey, L. (2001). *Children and Youth with Special Needs.* Ottawa: Canadian Council on Social Development.

Hanvey, L. (2002). *Children with disabilities and their families in Canada.* Retrieved June 13, 2008 from http://www.nationalchildrensalliance.com/nca/pubs/2002/hanvey02.pdf

Human Resources Development Canada. (2000). *In Unison 2000: Persons with disabilities in Canada.* Retrieved July 23, 2008 from http://www.unionsociale.gc.ca/In_Unison2000/iu00100e.html

Irwin, S. & Lero, D. (1997). *In our way: Childcare barriers to full workforce participation experienced by parents of children with special needs – and potential remedies.* Sydney, NS: Breton Books.

Karoly, L., Kilburn, M., & Cannon, J. (2005). *Early Childhood Interventions: Proven Results, Future Promise.* Retrieved June 21, 2008 from http://www.rand.org/pubs/monographs/2005/RAND_MG341.pdf

King, G., Brown, E., & Smith, L. (Eds.) (2003). *Resilience: Learning from people with disabilities and turning points in their lives.* Westport CT: Praeger

King, G., Law, M., Hanna, S., King, S., Hurley, P., Rosenbaum, P., et al. (2006). Predictors of the leisure and recreation participation of children with physical disabilities: A structural equation modeling analysis. *Children's Health Care, 35*(3), 209-234.

Knoche, L., Peterson, C. A., Edwards, C., Jeon, H. (2006). Child care for children with and without disabilities: The provider, observer, and parent perspectives. *Early Childhood Research Quarterly,* 21, 93-109.

Ladd, G. W., & Troop-Gordon, W. (2003). The role of chronic peer difficulties in the development of children's psychological adjustment problems. *Child Development*, *74*(5), 1344-1367.

Law, M., Petrenchik, T., King, G., & Hurley, P. (2007). Perceived environmental barriers to recreational, community, and school participation for children and youth with physical disabilities. *Archives of Physical Medicine & Rehabilitation,* 88, 1636-1642.

Law, M. & Petrenchik, T. (2005). *Participation of children with complex needs: A final report for the Ontario Ministry of Children and Youth Services*. Hamilton, ON: *CanChild* Centre for Childhood Disability Research.

Mahoney, J. L., Larson, R. W., & Eccles, J. S. (2005). *Organized activities as contexts of development: Extracurricular activities, after-school and community programs*. Mahwah, NJ: Erlbaum.

Masten, A. S. (2000). *Children who overcome adversity to succeed in life*. Retrieved June 23, 2008, from University of Minnesota Extension Service web site http://www.extension.umn.edu/distribution/familydevelopment/components/7565_06.html

Mayer, M. L., Skinner, A., & Slifkin, R. T. (2004). Unmet need for routine and specialty care: Data from the national survey of children with special health care needs. *Pediatrics,* 113(2), e109-e115.

Msall, M. E., Bobis, F., & Field, S. (2006). Children with disabilities and supplemental security income. Guidelines for appropriate access in early childhood. *Infants & Young Children,* 19(1), 2-15.

National Council of Welfare. (2007). *Solving poverty: Four cornerstones of a workable national strategy for Canada.* Retrieved July 7, 2008 from http://www.ncwcnbes.net/documents/researchpublications/ResearchProjects/NationalAntiPovertyStrategy/2007Report-SolvingPoverty/ReportENG.pdf

Parish, S. L., & Cloud, J. M. (2006). Financial well-being of young children with disabilities and their families. *Social Work,* 51(3), 223-232.

Petrenchik, T., Law, M., King, G., & Xu, L. (2008). *Predictors of perceived barriers to recreational, community, and school participation for children and youth with physical disabilities.* Manuscript in preparation.

Raina, P., O'Donnell, M., Rosenbaum, P., Brehaut, J., Walter, S.D., Russell, D., et al. (2005). The health and well-being of caregivers of children with cerebral palsy. *Pediatrics*, 115(6), e626-636.

Roeher Institute. (2000a). *Count us in: A demographic overview childhood and disability in Canada.* Toronto: L'Institut Roeher Institute.

Roeher Institute. (2000b). *Finding a way in: Parents on social assistance caring for children with disabilities.* Toronto: L'Institut Roeher Institute.

Roeher Institute (2003). *Inclusivity of the child care policy environment in Canada: Much work to be done*. Toronto: L'Institut Roeher Institute.

Rosenbaum, P., Jaffer, S., & Russell, D. (2006). *Measuring outcomes for children with special needs and their families: Part 2. A report for the Ontario Ministry of Children and Youth Services.* Hamilton, ON: *CanChild* Centre for Childhood Disability Research.

Ross, D. P. (2003). *Policy approaches to address the impact of poverty on health. A scan of policy literature.* Retrieved June 12, 2008 from http://dsp-psd.pwgsc.gc.ca/Collection/H118-11-2003-2E.pdf

Shonkoff, J. P., & Phillips, D. A. (Eds.). (2000). *From neurons to neighborhoods: The science of early childhood development*. Washington, D.C.: National Academy Press.

Statistics Canada. (2003). *Participation and Activity Limitation Survey, 2001: Children with Disabilities and their Families (Catalogue no. 89-585-XIE).* Retrieved June 10, 2008 from http://dsp-psd.tpsgc.gc.ca/Collection/Statcan/89-585-X/89-585-XIE2003001.pdf

Statistics Canada. (2008a). *Participation and Activity Limitation Survey 2006: A Profile of Assistive Technology for People with Disabilities (Catalogue no. 89-628-X no. 005).* Retrieved June 10, 2008 from http://www.statcan.ca/english/freepub/89-628-XIE/89-628-XIE2008005.pdf

Statistics Canada. (2008b). *Participation and Activity Limitation Survey 2006: A Profile of Education for Children with Disabilities in Canada (Catalogue no. 89-628-X no. 004).* Retrieved June 10, 2008 from http://www.statcan.ca/english/freepub/89-628-XIE/89-628-XIE2008004.pdf

Stewart, D., Antle, B., Healy, H., Law, M., & Young, N. (2007). *Best Practice Guidelines for Transition to Adulthood for Youth with Disabilities in Ontario: An Evidence-based Approach*. Available at http://www.canchild.ca/Default.aspx?tabid=1878

Stewart, D., Law, M., Rosenbaum, P., & Willms, D. (2001). A qualitative study of the transition to adulthood for youth with physical disabilities. *Physical & Occupational Therapy in Pediatrics*, 21(4), 3-21.

Sweet, M. A., & Appelbaum, M. I. (2004). Is home visiting an effective strategy? A meta-analytic review of home visiting programs for families with young children. *Child Development*, 75(5), 1435-1456.

Valentine, F. *Enabling Citizenship: Full Inclusion of Children with Disabilities and their Parents.* Ottawa: Canadian Policy Research Networks, 2001. Available from http://www.cprn.org/documents/3594_en.pdf

Willms, J. D. (2002). *Vulnerable children: Findings from Canada's National Survey of Children and Youth.* Edmonton, Alberta: University of Alberta Press.

Zipper I., & Simeonsson, R. (2004). Developmental vulnerability in young children with disabilities. In M. Fraser (Ed.), *Risk and resilience in childhood: An ecological perspective* (pp. 161-181). Washington, DC: NASW Press.

Appendix A

Conditions Typically Classified as a Disability

Disability includes:

- autism
- deaf-blindness
- emotional disturbance
- hearing impairment
- mental retardation
- motor impairment
- multiple disabilities
- orthopedic impairment
- other health/neurological impairment
- specific learning disability
- speech or language impairment
- traumatic brain injury
- visual impairment

OR, any diagnosed physical, mental, or behavioral condition that results in activity limitations or participation restrictions

Appendix B

What Works in Early Childhood Intervention Programs

Home Visiting or Parent Education

- Nurse-Family Partnership (NFP)
- Developmentally Supportive Care: Newborn Individualized Developmental Care and Assessment Program (DSC/NIDCAP)*
- Parents as Teachers*
- Project CARE (Carolina Approach to Responsive Education) - no early childhood education HIPPY (Home Instruction Program for Preschool Youngsters) USA
- Reach Out and Read*
- DARE to be You
- Incredible Years

Home Visiting or Parent Education Combined with Early Childhood Education

- Early Head Start*
- Syracuse Family Development Research Program (FDRP)
- Comprehensive Child Development Program (CCDP)
- Infant Health and Development Program (IHDP)
- Project CARE (Carolina Approach to Responsive Education)—with early childhood education Carolina Abecedarian Project
- Houston Parent-Child Development Center (PCDC)
- Early Training Project (ETP)
- High/Scope Perry Preschool Project
- Chicago Child-Parent Centers (CPC)
- Head Start

Early Childhood Education Only

- Oklahoma Pre-K

NOTES: Programs marked with an asterisk are designated as having a promising evidence base because a substantial number of children were as young as age 2 or 3 at the time of the last follow-up. All other programs are designated as having a strong evidence base.