



Inside the Developmental ‘Black Box’ of Young Carers

A literature review prepared for the Young Carers Initiative Niagara (YCIN)

by

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INTRODUCTION

YOUNG CARERS AND THE PUBLIC ISSUE LIFE CYCLE

What is it like to be a young person growing up in a family dealing with long-term disability, chronic illness or other socioeconomic issue such as a language barrier? What does it mean to be a child who must take on an adult caregiving role at an early age in order to help out a family member, including providing emotional support? What kind of impact, if any, does an early caregiving experience have on the young person's childhood and later adulthood?

These are crucial questions which lie at the very heart of the young carer movement. Young carers are children and youth who assume adult caregiving roles for family members needing assistance with their activities of daily living. The family member may be a parent, grandparent, sibling, aunt or uncle with a chronic condition such as multiple sclerosis, brain injury, dementia, autism, mental illness, a developmental disability, substance abuse problem or the need for translating services because of a language barrier. The problem is that young carers as a group have been overlooked, neglected and ignored because professionals working in the field tend to focus on the care recipient, without appreciating the young carer's contribution or own needs (Gays, 2000).

The conceptualization of caregiving children under the rubric of 'young carers' originated in Britain in the early 1990s (Dearden, Becker & Aldridge, 1995). In Britain, the young carer movement has flourished and is spreading as far afield as Australia (Gays, 2000), Malta (Becker, Aldridge & Dearden, 1998) and Zimbabwe (Robson, 2001). The problem from a Canadian perspective is that the critical questions raised above have yet to garner significant public interest because the issue of young carers is virtually unknown in this country. While British young carers have gained substantial public recognition and support throughout the UK at the socio-political level, their Canadian counterparts remain a hidden population (Baago, 2004). It may well be that the young carer problem in Canada is at the very beginning of what is known in management circles as the "public issue life cycle" (Post, 1986).

According to Post (1986), management scholars understand the public issue life cycle in terms of an evolutionary process. That is, any new issue of social concern goes through a predictable series of phases in its evolution before reaching full public awareness. Post (1986) conceives the public issue life cycle as "a measure of continuing public concern about an underlying problem." In this case, the "underlying problem" would be the issue of young carers.

Phase I of the public issue life cycle involves rising awareness and sensitivity to the facts of the issue (Post, 1986). In the case of young carers in Canada, this phase began in 2003 when a group of concerned community agencies in the Niagara Region of southern Ontario found they had a common interest in caregiving children and started the Young Carers Initiative Niagara, or YCIN for short (See Appendix I for a list of

members). The YCIN is the first community group in Canada to address the issue of young carers as a specific population with needs.

During Phase II of the public issue life cycle, the media, government, social agencies, consumers and other interested parties start to recognize that the issue has become an important political matter which may involve a pressing public health concern (Post, 1986). In Britain, for example, young carers attained a high profile on the social policy agenda following a period of sustained awareness-rising by numerous national community organizations, as well as extensive research on young caring conducted by the Young Carers Research Group from Loughborough University which gained media attention (Dearden & Becker, 1998).

Phase III, or the final stage of an evolving public issue, occurs when some government policy or other formal action is developed in order to address the concerns. This may take the form of a regulatory standard, a piece of legislation, or a government program (Post, 1986). To continue with our British example, young carers in the UK are now officially recognized in the Carers Recognition and Services Act of 1995 and are entitled to an assessment of their needs in their own right, at the same time the care recipient is being assessed for community services (Dearden & Becker, 1998). The inclusion of young carers into the Carers Act came after the issue gained increasing prominence from welfare professionals and organizations across the land. The increased profile culminated in a letter to all directors of social services from their federal governing body (i.e. Social Services Inspectorate, Department of Health), followed by a motion in Parliament, a Department of Health research initiative into young caring (Dearden & Becker, 1998), and finally, formal recognition in the Carers Act.

The YCIN recognizes that the young carer movement in Canada is in its infancy, at the very beginning of Phase I of the public issue life cycle. This is the initial period when a compelling need to raise awareness and knowledge in the community-at-large is at stake. The literature review on young carers presented here is an attempt by the YCIN to bring the issue to wider public domains such as the media, social service agencies, government and the general public. The document is intended to serve as a background paper to provoke discussion and action in Canada on the issue of caregiving children. As such, it will be distributed to numerous community and government agencies throughout Ontario as part of an extensive awareness-building campaign to bring the issue of young carers to the forefront of public concern and policy making.

SCOPE OF CURRENT LITERATURE REVIEW

Unlike a previous, broad-based literature review (Baago, Unpublished Bibliography, 2003), which serves as a precursor to this current review, the scope of this paper will be limited to empirical studies that explore the quantitative and qualitative aspects of the lived experience of young carers. Several books on related subjects such as parentification and family systems are examined briefly to give a slightly different perspective, along with some relevant government reports on young carers and their

families, but the list is not exhaustive. The intent is to provide a research-based overview of our current knowledge of young carers and their world.

DEBT TO BRITISH RESEARCH

Awareness of young carers as a social policy issue has stemmed largely from Britain, through the research efforts of the Young Carers Research Group (YCRG) based at Loughborough University and the Carers National Association Young Carers Project (CNAYCP), funded through the Department of Health (Aldridge & Becker, 1993; Gates & Lackey, 1998; Gays, 2000). But even this rather large body of scholarly work has its limitations. As Banks, Gallagher, Hill and Riddell (2002) point out, young carer literature in Britain, with few exceptions, addresses children who assume a caregiving role for parents, while much less is known about the broader picture involving the care of other relatives such as siblings, grandparents, aunts, uncles or non-family members.

In the United States, children in caretaking roles tend to be conceptualized under the terms “parentification” (Byng-Hall, 2002; Jurkovic, 1997; West & Keller, 1991), “filial responsibility” (Jurkovic, 2003) or simply ‘young caregivers’ (Gates & Lackey, 1998; Lackey & Gates, 2001; National Alliance of Caregiving and the United Hospital Fund, 2005; Shifren, 2001). The weakness of the parentification model is that it is mostly written by psychologists and family therapists; the technical language they use is not readily understood by individuals in other fields such as sociology, social work and other social sciences (Winton, 2003). As Winton (2003) points out, psychologists and family therapists also tend to take an extreme clinical, psychiatric and/or therapeutic approach, with child caretaking roles seen as being pathological and deviant. Not only are the positive aspects of young caring omitted or overlooked, so are any cultural differences in familial expectations about a child’s role in the family.

Taking a sociological approach, Winton (2003) examines a broad spectrum of family contexts in which children act as caregivers for their siblings or parents, including drug and alcohol problems, domestic violence, family size, death of a parent, divorce, dual-worker households, military service, language barriers, physical and mental illness, immigration and incarceration. The theoretical framework he uses is grounded on two key concepts: The “parentified child” who takes on a parental role to a parent and the “parental child” who acts as a parent to siblings. Winton (2003) concludes that given all the contexts in which parental and parentified children exist, their caregiving roles are not pathological, but instead are *normative roles in the lives of children living in a post industrial society* (italics added) p. 186. The problem is not that children assume caregiving roles *per se*, but that their caregiving work is taken for granted, with their considerable efforts not receiving adequate recognition and appreciation by other family members, social workers or society-at-large. When their labour is not recognized by others, this undermines their self esteem and diminishes their sense of self-worth. For Winton (2003), the greatest harm perpetrated against young carers is this lack of appreciation for their labour.

Dearden and Becker (2000) point to other studies which have sought to ascertain the experiences of, or effects on, children in families facing a specific disability or illness. These studies constitute a wide body of literature covering various conditions such as Alzheimer Disease (Beach, 1997); cancer (Gates & Lackey, 1998); developmental handicaps (Eisenberg, Bruce & Blacher, 1998; Meyer, 1994); multiple sclerosis (Brandt & Weinert, 1998; Rehm & Catanzaro, 1998); HIV/AIDS (Kmita, Baranska & Niemiec, 2002; Barrett & Victor, 1994); brain injury (Watanabe, Shiel, McLellan, Kurishara & Hayashi, 2001) and alcohol/drug abuse (Kelley & Fals-Stewart, 2002). This body of literature, which incorporates children as caregivers because of the nature of a particular medical condition, has been seen to be complementary and relevant to the child-centred approach taken by researchers examining the lives of young carers (Aldridge & Becker, 1993, Dearden & Becker, 2000). However, as Aldridge and Becker (1993) emphasize, besides considering the level of responsibility the child takes on, this research measures the impact on the child by the severity of the adult's illness or chronic condition. The impact of having a sibling who is developmentally challenged, for example, may not be as severe as having a parent with Huntington's Disease (Aldridge & Becker, 1993). What these children do have in common is that they tend to take on a caring role, giving rise to the potential for all of them to be categorized under the conceptual framework of 'young carers.'

The body of work on young carers that is of primary interest to this literature review is the considerable academic research undertaken by British researchers such as the YCRG at Loughborough University, aforementioned above. The YCRG and many of their British colleagues endorse a child-centred view and examine the social impact of caring in terms of the quality of life of young carers (Bibby & Becker, 2000; Becker, Aldridge & Dearden, 1998; Docking, 2002). Much of their work focuses in depth on the particular experiences and needs of children who care. As Bibby & Becker (2000) point out, children and youth who are carers differ as individuals in many respects. Where they live, who they live with, their family backgrounds, their ethnic origins and their age may be different, but the common denominator binding them together is that they all take on caring responsibilities for one of their family members.

Despite the fact that children who are in caregiving roles are not a homogenous group, this literature review recognizes the significant contribution of the British corpus in using the concept of 'young carer' as a unifying tool. The identification of young carers as a unique population is a useful departure point for studying their common needs and experiences, and is a conceptual framework which has been readily transferred to national and cross-national studies in countries other than Britain, including Sweden (Gould, 1995); France (Brittain, 1995) Germany (Dietz & Clasen, 1995); Zimbabwe (Robson, 2001) and Australia (Gays, 2000). For the purposes of this literature review, the young carer model from Britain appears to be the most advantageous lens through which to view both the quantitative and qualitative experiences of children who care, given there is little or no Canadian research available on the subject.

YCIN BACKGROUND INFORMATION

The YCIN is a collaborative of 14 community agencies which joined forces in 2003 to form a network of support for children in caregiving roles. The driving force of the YCIN is a committee comprising representatives from the various member agencies who meet 10 times per year on a monthly basis to find ways and means to provide information, support and programs for young carers and their families by sharing scarce human, financial and material resources. A major goal is to promote awareness of the young carer issue across the country. Member agencies represent an eclectic spectrum of community services for children, youth and adults, covering diverse health conditions such as HIV/AIDS, multiple sclerosis, brain injury, dementia, autism, developmental disabilities and children's mental health, as well the social concerns of child welfare, seniors' services, education and new Canadians. Out of this diversity, YCIN member agencies found they shared a common interest in the well being of children growing up in caregiving families.

Collectively, YCIN members have a wealth of clinical experience and anecdotal evidence to serve as a foundation for their philosophical position that children in caregiving families have needs that are not being met by the current social and health-care systems. What they have identified is a huge gap in services when it comes to support for adolescents and children living in a caregiving family. When dealing with families in the community, their clinical observations took note that many children in caregiving environments take on a caring role themselves, often to the detriment of their own well-being. But there is no support system in place for these youngest of caregivers. What is even more disturbing is that the valuable contribution young carers make to their family's well being is never recognized. Young carers remain a neglected population in Canada.

The YCIN recognizes that the difficulty most community agencies have is that the primary mandate of Canadian health and social services is to provide support either for the care recipient solely, or for the care recipient/primary caregiver dyad, but not to other members of the family in a holistic sense. The health care system as a whole is also not designed to be proactive or preventative. The needs of young carers, whose own lives may be seriously impacted by the unique circumstances facing their family, are not assessed or even taken into account in the current system. Child welfare or children's mental health agencies tend to get called in only when the child has become 'a problem,' perhaps becoming depressed, suffering from an eating disorder, skipping school, acting out, being aggressive or manifesting a variety of other anti-social behaviours. The YCIN was started because of these underlying concerns about the well-being of young carers.

PHASE I OF PILOT PROJECT

The impetus for the YCIN originated in 2002 with the Alzheimer Society of the Niagara Region (ASNR), which had identified 74 children on its then current case load who were living with a parent or grandparent with dementia. The ASNR has a

comprehensive outreach program by which family support counsellors visit clients and their families on a regular basis. During these visits, family support counsellors had noted that many of the children growing up in caregiving families failed to thrive. Many of them exhibited a variety of behavioural, developmental and emotional problems, including hyperactivity, anxiety, depression, withdrawal, anti-social behaviour, school problems, running away, sleep disorders, eating disorders, regression and stress-related illnesses. The ASNR began a three-year pilot project to find ways and means to support children living with a relative with dementia, with the first year (i.e. Phase I) funded by a \$68,000 grant from the Fowler Family Foundation (Baago, 2003, Unpublished Report to the Fowler Family Foundation).

Phase I of the pilot project consisted of two major initiatives: (1) An extensive literature review on children in caregiving environments and (2) A plan to form a network of community agencies which would work cooperatively to provide support and interventions for children in dementia care families. This network evolved into the YCIN described above and will not be further discussed here.

Literature Review: The scope of the Phase I literature review was wide, covering over 300 entries from journal articles, reports, books, government documents, unpublished papers and reports, text books, information booklets for children on specific disabilities, magazines, newspapers, web sites, brochures and fact sheets (Baago, 2003, YCIN Unpublished Bibliography). Articles from scholarly journals included a complement of longitudinal as well as retrospective studies on young carers. Subject headings included children from specific caregiving environments such as MS, HIV/AIDS, Brain Injury, Alzheimer Disease, Mental Illness, Alcohol and Drug Abuse, Autism and Developmental Disabilities. Other themes included children's rights, disability rights, parentification, resilience and family systems.

The first key finding of the Phase I literature review was the discovery of the young carer movement emanating out of Britain. Up to this point, the ASNR had conceptualized the planned community network as an informal system whereby children from dementia care families could be referred to the appropriate agency for assessment and assistance when necessary. Stumbling upon the young carer literature opened up a whole new dimension to the project. It became clear that the parameters of the project needed to expand to include families coping with any other chronic condition or illness where there was a potential for young carers to be found. Since that time the parameters have once again been extended to incorporate new Canadian families in which children take on adult roles as translators to help overcome parental language barriers.

The second key finding of this initial literature review concerned the lack of solid empirical research about children in caregiving homes from a Canadian perspective. The sole Canadian study to surface was "*Growing Up Strong: Supporting the Children of Parents with Multiple Sclerosis*," a cross-country survey undertaken from November, 2002 to January, 2003 by the MS Society of Canada and funded through a grant from the Population Health Fund of Health Canada. As part of *Growing Up Strong*, a literature review was conducted which failed to find any significant data concerning children of

parents with MS, leading to the “overwhelming conclusion” (Toporas, 2003, p. 4) that more research is needed about the effects of parental MS on children. This study will be examined in greater detail in the main body of this paper.

PHASE II OF PILOT PROJECT

Phase II of the young carer project began in July, 2004 and is supported by a generous two-year grant from the Ontario Trillium Foundation. This phase of the project consists of three principal initiatives: The current literature review, to be based on a shortened version of the 300 entries of the Phase I bibliography; an empirical study on young carers in the Niagara Region (i.e. the Hear Me Now survey) and a conference on resilience to be held in May, 2006. Building community awareness is also an important goal for this phase.

HEAR ME NOW SURVEY

The Hear Me Now survey is a comprehensive tool to collect raw data on two different age groups of young carers in the Niagara Region – i.e. ages 10 to 12 and 13 to 18. The survey is being prepared for the YCIN by Dr. Heather Chalmers, PhD, a faculty member and researcher from the Child and Youth Studies Department, Brock University, St. Catharines, Ontario. The survey is in a questionnaire format and will collect both quantitative and qualitative data using a variety of standardized scales. The questionnaire will be distributed in the fall of 2005 to young carers throughout the Niagara Region through the client bases of YCIN members. When the data is collected, it will be collated, analysed and a report will be written up and distributed. The Hear Me Now survey will be the first of its kind to collect data in Canada on young carers as a specific population. The written report should be available for distribution in late 2007.

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'The child development process can be likened to a 'black box.' We see children and their environments go into a box, and we see them come out transformed. We know that interactions take place within, but we can't see inside to directly observe how they take place. The difficulty of seeing inside the box is primarily a reflection of the enormous variability and complexity of the child development process. With so many different children, it is hard to isolate the impact of any one factor or influence.'

David P. Ross, Katherine Scott and Mark A. Kelly (1996)

OVERVIEW

This background paper intends to explore a particular kind of 'black box' in child development, the one involving a unique population of children and youth known as young carers. In the early 1990s, researchers, social workers and medical professionals in Britain began to draw attention to young carers as a new social issue which needed to be addressed (e.g. Jenkins & Wingate, 1994; Sturge, Frank & Coster, 1994). Described as being "invisible" (Jenkins & Wingate, 1994), their caring duties characterized by a 'hidden nature' (Dearden, Becker & Aldridge, 1995), young carers in this early literature were depicted as being concealed from public view. It was as if young carers were compartmentalized inside their own singular 'developmental black box.'

Because of the hidden nature of the young carer's role, the emerging social issue was seen through the lens of a "conspiracy of silence" (Dearden et al, 1995). Health care providers, school officials, academics, social policy makers and the community at large failed to recognize that many teens and children, some as young as three years of age, were providing both personal and practical care for ill and disabled relatives, often sacrificing their own well-being in the process (Aldridge & Becker, 1993).

As a specific care-giving population, young carers were usually conceptualized as being children and adolescents under the age of 18 whose lives were restricted by the obligation to look after a sick or disabled relative in the home (Dearden et al, 1995). The care they provided was usually to a parent who had a physical illness or disability, mental ill-health, a sensory disability, was frail or misused drugs or alcohol (Becker, Aldridge & Dearden, 1998). In this early literature, immigrant and refugee families were also targeted as being a specific context in which young carers are found. In inner city areas, doctors and other professionals had observed young members of the family taking on the role of translator for their parents. Overcoming language barriers for parents placed these children in a position of being privy to intimate and detailed information; it was thought that in a developmental sense these youngsters were ill-equipped to deal with such an adult burden (Travis & Bruce, 1994).

Viewed as being at risk of losing their childhoods, and portrayed as being isolated, both socially and physically (Banks, Cogan, Deeley, Hill, Riddell & Tisdall, 2001), young carers gradually emerged on the British social policy agenda as a neglected population with specific needs (Becker et al, 1998).

Although the social issue of young carers was not confined to Britain, awareness on an international level appeared to be minimal. For example, cross-national studies conducted in European countries such as France, Sweden and Germany indicated that the issue of young carers had largely been ignored (Becker, ed., 1995), while in places such as Malta, Ireland, Israel, Australia and the United States, as late as 1998, young caring was found to be just emerging into the public consciousness (Becker et al., 1998).

In Britain, despite more than a decade of growing interest in young carers by academics, policy makers and service providers, the 2001 census showed convincingly that the number of youngsters in familial caring roles was vastly underestimated. Census data released in 2003 on a special question on family care-giving found what the BBC called a 'hidden army' of 175,000 young carers (Casciani, July 1, 2003, BBC News Online). The census number was far larger than anticipated, even though only youngsters who identified themselves as providing a 'substantial amount of care on a regular basis' were included in the count (Casciani, 2003). Nonetheless, the new figure represented a dramatic increase from previous estimates on the prevalence of young carers in Britain. These estimates had varied anywhere from 20,000 to 50,000 (Banks, Gallagher, Hill & Riddell, 2002; Watson, 1999; Underdown, 2002). Despite Britain being the world leader in research into the young carer phenomenon, with much of the work conducted by the Young Carers Research Group at Loughborough University (e.g. Aldridge & Becker, 1999) as late as 2002 researchers were still referring to the 'covert nature' of young people in a caring role (Banks et al, 2002). Young carers themselves have been seen as contributing to the concealment of their care-giving activities from public view, in part because they are reluctant to come forward to either school authorities or health care professionals (Banks et al, 2002).

SCOPE OF THIS PAPER

This background paper is intended to generate discussion on young carers in Canada by getting inside their 'developmental black box.' The review takes a look at common themes on the issue of young carers found in books, journal articles, studies and reports. Some subject headings which will be explored include demographics, problems with definition, young caring tasks and duties, young carers' needs, and the family systems approach to intervention and support.

FINDING YOUNG CARERS IN CANADA

In Canada, a literature review undertaken for the Young Carers Initiative Niagara (YCIN) as part of a pilot project funded by the Fowler Family Foundation in 2003 failed to find any studies on young carers from a Canadian perspective. The review resulted in

an unpublished bibliography of over 300 entries on young carers and related subjects, culled from journal articles, published studies, reports, books, magazines, web sites, newspaper articles and fact sheets (Baago, 2003, YCIN Unpublished Bibliography) but only one Canadian study relating to children growing up with a disabled family member was found. This was a national survey called “*Growing Up Strong: Supporting the children of parents with Multiple Sclerosis*,” conducted by the MS Society of Canada in 2002 - 2003 (Toporas, 2003).

Children and youth aged 12 to 18 who completed the *Growing Up Strong Survey* all had a parent with MS. The study found a general consensus among the children that parental disability hampers the family’s lifestyle to a great extent. The lifestyle limitations were found to affect the entire family in all areas of life, especially having fun as a family. Vacations, the children’s friendships, sports activities and other recreational occupations all suffered to a lesser or greater degree depending upon the individual family circumstances. Although the study does not conceptualize children in homes where a parent has MS as ‘young carers,’ parental responses to the questionnaire indicated their children do assume a care-giving role. The study found that children in MS homes have substantially more responsibility than their peers from non-MS homes. Children in MS homes were found to provide a range of caretaking activities, including laundry, meal preparation, baby-sitting, providing personal and medical care for the relative with MS, and managing the household (Toporas, 2003).

DISABILITY IN CANADA AND THE BLACK BOX

Disability, both physical and psychological, is part of the human condition. Statistics Canada has tracked 3.6 million people, or one in eight Canadians, who suffer impairment affecting their mobility, agility, hearing, vision, learning, cognition or other ability (Statistics Canada, 2004). In the province of Ontario alone, approximately 1.5 million people, representing 13.5 % of Ontario’s population, have disabilities, including mental illnesses (Statistics Canada, 2003). According to a recent Health Canada report, 20% of Canadians will personally experience a mental illness during their lifetime. Data from the Canadian Community Health Survey (CCHS, 2002)) suggest that as many Canadians suffer from major depression as from other leading chronic conditions, including heart disease, diabetes or thyroid. Because mental illness can affect family members, friends or colleagues, this means mental illnesses indirectly affects all Canadians (Health Canada 2002).

On the whole, the above statistics may seriously underestimate the actual number of people in Canada with disabilities. Concerns have been raised about a new survey method adopted by PALS (Participation and Activity Limitation Survey) for Statistics Canada and used in the 2001 census. It is said that the new methodology omitted a substantial number of people with milder disabilities who had been included in earlier statistical studies (Accessibility Ontario, 2003). The overall figures, however, strongly suggest that there could be a significant number of young carers living with a disabled relative in Canada. Common sense dictates that a high percentage of families dealing with a disability would also be engaged in child rearing activities, providing an

opportunity for young caring to take place. At this time, however, there appears to be no Canadian data available which track how many well children under the age of 18 are part of a family dealing with either physical or mental disabilities.

A 2001 Participation and Activity Limitation Survey (PALS), called “Children with disabilities and their families,” (Statistics Canada, 2003) provides an insight into the limitations of Canadian disability data when it comes to caregiving children. The PALS sample consisted of 8,000 children living at home, not institutions, in the 10 provinces. An estimated 155,000 children between the ages of five to 14 (i.e. 4 % of all children in this age group) were found to have activity limitations in 2001. Approximately 35,000 of them, (i.e. 23 %), were found to receive help with their daily activities because of their condition. Most of this help involved personal care. The survey found that while parents provided most of the care, they also relied on the help of other family members, including other relatives who lived with them.

One huge difficulty with the PALS’ survey in terms of young carers is that it does not identify who the “other” family members are. Since it is highly unlikely that most of these disabled children would be the only child in the family, it is not beyond the realm of possibility that the ‘others’ could be brothers and sisters taking on a caring role for their disabled sibling. Another weakness of the survey involves the findings on the effects of having a disabled child on the family. The survey proposes to provide “the most up-to-date and detailed information on children with disabilities in Canada, including information on the impact of their condition or health problem on the family” (p. 6). The problem is that the term ‘family’ appears to be defined in an extremely restricted sense – e.g. mother, father and disabled child. There may be an implicit bias against any healthy children who may be in the family; they are not mentioned as a specific population anywhere in the data. This skews the findings so that any “impact” on the family is largely a parental one – i.e. how the disability affects the lives of the mother and father, such as employment opportunities and so on. The findings of this survey point to a real need for future Canadian studies of this nature to broaden the target population and explore the effects of having a disabled sibling on other children in the family.

One other Canadian study is worth mentioning – The National Longitudinal Survey of Children and Youth (NLSCY). This unique study is building a national data base of statistics on children from birth to adulthood, providing a single source of data for the “diverse paths of normal development” (Brink & McKellar, 2000). The data and research results are based on information collected on a wide variety of outcomes such as health, language, cognitive, social, emotional, and behavioural. Other determinants that are analyzed include the child’s family status - i.e. socio-economic, structure, parenting style, family functioning, social support – as well as child care, school and neighbourhood. In this longitudinal study, the same children are surveyed every two years into adulthood. The aim is to fill an information gap on the characteristics and life experiences of children and youth in Canada as they grow up, using a human development view of the early decades of life. A major strength of this study is that it covers an extremely large sample size from across Canada. The initial cohort, aged 0 –

11 in 1994 when the study started, numbers about 15,000 children, and the group will be followed until they reach the age of 25 (p.112). Another strength of the NLSCY study is that it is providing a 'gold mine' of data for the examination of child development in context – a sort of longitudinal peek inside the black box. This study is important because the data will be used to shape government policy on support for children. Where the study fails is that it may not be representative of children in caregiving roles, unless this data is captured under the category of "family circumstances." This remains to be seen as the data is released.

THE AMERICAN EXPERIENCE

The 'young caregiver' literature in the United States has tended to examine children in caregiving roles against a backdrop of specific illnesses and chronic conditions such as cancer and Alzheimer's Disease (Beach, 1997; Gates & Lackey, 1998; Lackey & Gates, 1997; Lackey & Gates, 2001). A landmark study released in September, 2005, which looked at American young caregivers from a national perspective for the very first time took a more generic stance and found as many as 1.4 million children in the United States between the ages of 8 and 18 providing care for a family member. This study found that child caregivers tend to live in households with lower incomes than their non-caregiving peers, and are more likely to live in one-parent families. Like their British and Australian counterparts, American young caregivers fulfill a range of caregiving duties, including helping with personal care and household tasks. A third (30%) help with medications and 17% help the care recipient communicate with doctors and nurses. The report calls for new resources to be earmarked to fund new studies about this subgroup of family caregivers, as well as for social service, healthcare and caregiver organizations to collaborate with established groups to develop appropriate family-centred services (National Alliance on Caregiving & United Hospital Fund, 2005).

PROBLEMS WITH DEFINITION

Statistics about numbers of young carers are dependent in part on questions of definition, but the problem is there is no standard definition of the term 'young carer' in the literature. Not only does the term itself lack conceptual clarity, but other difficulties are posited (e.g. Docking, 2002). As Gays (2000) points out, there are many definitions and categories of who is a young carer, and what they should be doing to be considered a young carer. The global term is used to refer to a wide range of children and young people undertaking diverse activities in differing circumstances (Read, 2002). In many instances, individual organizations in neighbouring communities use their own specific definition designed to meet their own needs. For example, a study in Wales (2001) found six local authorities that included a definition of young carers in their Social Care Plans, each one being slightly different (Seddon, Jones, & Robinson, 2001). Seddon et al (2001) found other local authority definitions of young carers ranging from the very broad to the more specific:

“Any child between 8 and 18 who is committed to a substantial amount of caring.”

“Any child under 18 who is caring for another family member.”

“Any child who cares for any member of the family, parent, grandparent, sibling or significant other, who may have a physical illness or disability, learning disability, mental illness, sensory impairment, misuse of drugs and alcohol, HIV or AIDS or who is frail”
(Seddon et al 2001, p.18).

Two of the most common working definitions of the term ‘young carer’ in Britain used at the government social policy level are quite narrow, and limit the identification of young carers to children who are in caring roles in which they carry out a “significant amount of care” or “substantial amount of care on a regular basis.”

These two definitions, found in Read (2002), are:

- A child or young person who is carrying out significant caring tasks and assuming a level of responsibility for another person, which usually would be taken by an adult.
(Social Services Inspectorate, Department of Health)
- Someone who provides, or intends to provide, a substantial amount of care on a regular basis for a disabled, ill or elderly person.
(Carers Recognition and Services Act 1995)

Dearden & Becker (2003) point out that a common factor in most definitions of young carers is that they undertake *significant* caring tasks. These are tasks deemed important and would usually be carried out by an adult. Under this view, young carers are not children who happen to have an ill or disabled parent, sibling, grandparent or other relative, but are children who spend many hours a week of their time providing a level of care that is often inappropriate for their developmental age.

From the above definitions it is easy to see that there is a propensity to distinguish and identify children as young carers by the *amount of care they provide*. The problem with using phrases such as ‘substantial amount of caring’ or ‘significant caring tasks’ is that they are open to interpretation. How many hours of care per week constitute a “substantial amount?” Seddon et al (2001) point out that in Britain, the terms “substantial” or “significant” usually refer to adults undertaking informal caregiving tasks for a minimum of 35 hours per week. The majority of caring activities for a young carer take place out of school hours, so this minimum number of hours in many cases is not achieved. Conceptualizing and categorizing young carers according to the amount of care provided also exclude youngsters who are involved in a secondary caring role, such as looking after a sibling (Seddon et al 2001). For these reasons some jurisdictions prefer to adopt a broad working definition of “young carer” which is more inclusive of a variety of situations and includes the *impact* of caring on the child.

The Carers National Association (now Carers UK), in 1998 defined a young carer as:

“Anyone under the age of 18 whose life is in some way restricted because of the need to take responsibility for the care of someone who is ill, has a disability, is experiencing mental distress, or is affected by substance misuse” (Frank, 2002, p. 6).

As Frank (2002) observes, the above definition is significant because it goes beyond simply focusing on the *extent* of the care provided, to recognizing the *impact* that young caring may have on the child.

Some definitions ignore the *extent* of care provided completely and make the *impact* of the disability on family life as a necessary condition. An extremely liberal definition that is inclusive of children whose lives are *affected by having a parent in a caregiving role* is being developed as part of the **Joint Young Carers’ Strategy** for the city of Glasgow in Scotland. This definition includes children who might not be in a caring role themselves, but are not receiving the usual level of parental care or attention because the parents are caring for a disabled family member:

“...a young carer is a child or young person, up to the age of 18, whose life is affected by caring, where the person being cared for has a disability or long-term illness or has mental health difficulties.”

(Glasgow Joint Young Carers Strategy, 2002-2005, p. 4)

The Glasgow definition recognizes that children in caregiving homes take on a high level of responsibility for looking after their own needs, beyond what is usually expected at that stage of development. It also is far reaching in that it incorporates children providing care for someone who is *not* a family member and who may not even be living in the same household as the carer. The latter could be a frail grandparent with dementia, for example. The Glasgow definition highlights the importance of taking into account the actual or potential *impact* that informal caregiving undertaken by parents has on the children in the family. There is a growing consensus that an *impact focused* definition is the most appropriate because it addresses the ways in which young carers’ lives are affected irrespective of the nature and extent of their caring duties (Seddon et al, June 2001). The *impact* is measured in terms of the restrictions on the young carer’s lifestyle, experience and childhood (Becker 1995).

The British Social Services Department is careful to point out that young carers are *not* young people caring for their own children, nor are they youngsters who accept an age appropriate role within their families by taking increased responsibility for household and other tasks as they develop into adulthood (Social Services Department, 1997).

One final note on the difficulties underlying definition - in the literature a confusion of age ranges can be found that are used to define the parameters of young caring. In Britain, the upper age limit for a young carer is usually 18 (Dearden & Becker, 1998), with some local authorities undertaking a review to increase the limit to age 21

(Seddon et al, 2002). In Australia the upper limit is 26 years of age (Australian Bureau of Statistics, 1998). For a cross-national study of young carers in Europe which included Britain, France, Sweden and Europe, the Young Carers Research Group (YCRG) from Loughborough University used the “under 18” age limit (Becker 1995) There are also a variety of minimum age limits for young caring found in the literature and this can pose problems in definition. Some British authorities suggest an age range of 7 to 18 years, while others recognize some children as young as two years old in caring roles (Seddon et al, 2002).

The YCIN defines a young carer as:

“An individual under the age of 18 with a relative whose activities of daily living are restricted by a chronic disability, long term mental or physical illness, substance abuse problem or other socio-economic factor such as a language barrier” (YCIN Terms of Reference, Updated May 2005).

The YCIN definition is extremely broad and does not specify that children need to be in a caring role themselves to qualify as a young carer. Nor does it require that young carers be living with the person who needs care. In these respects it is similar to the definition adopted for the Glasgow Joint Strategy described above that is “impact – focused.”

The YCIN definition recognizes that language barriers such as being hard of hearing, stroke-related speech difficulties or the need for a translator can play a role in determining if a child becomes a young carer for his or her family. This is especially important in the Niagara Region, which is home to a significant number of immigrant and refugee families.

This rather lengthy exploration of the conceptual difficulties inherent in the term ‘young carer’ has been made to emphasize the importance of definition. For one thing, different studies can be virtually impossible to compare and evaluate without a standardized concept. For another thing, definitions can be broad or narrow, inclusive or exclusive, and can be used by policy makers to determine who qualifies for services and who does not. Hence it is important that the correct definition be used from the very beginning of the public issue life cycle.

CATEGORIES OF YOUNG CARERS

In the literature, three classifications of young carers can be found that clarify the caring roles adopted by children. These categories are: Sole carer; supportive carer and sibling carer (Frank, 1995).

Sole carers

Sole carers are found in homes where there is no able adult to perform the caring tasks for the care recipient. In the absence of an adult, the young carer assumes sole or primary responsibility in the home for a family member. Frank’s (1995) study of young

carers in the City of Winchester, England, found the majority of children who were sole carers were looking after a parent with a mental health problem such as agrophobia, schizophrenia and chronic depression. These sole young carers performed a variety of tasks, including housework, shopping, parenting younger siblings and dispensing medications to the parent (Frank 1995).

Supportive carers

Young carers classified as supportive carers take on an assistive role, helping out an able adult who is the primary caregiver in the home. Frank (1995) found these young carers in particular to be hidden from the view of professional service providers. This was because an assumption was made that the able adult performed all of the caregiving tasks. Although these young carers were not primary caregivers, the range of their caring responsibilities were as varied and demanding, with some of them expressing anxiety and worry that the able parent had to do too much (Frank 1995).

Sibling carers

There is increasing recognition in the literature that children living with a disabled sibling take on caring responsibilities (Frank, 1995; Meyer & Vadasy, 1994; Faux, 1993). Often the caring parent is unable to cope alone. The caring parent may need support and assistance during the day for either the disabled child or other younger siblings, or to help around the house. Young carers perform a variety of tasks to help a disabled sibling, including lifting, getting them in and out of a wheelchair or bath, toileting and helping them upstairs (Frank, 1995). Frank (1995) observes that sibling carers too may require support as many of their needs duplicate those of young carers who care for an adult relative. This need for support for brothers and sisters of disabled children has been recognized in the United States, as well as in parts of Canada (e.g. Toronto) with the establishment of programs called “Sibshops” which are designed to provide opportunities for siblings to obtain peer support and education within a recreational context (Meyer & Vadasy, 1994).

STATISTICAL PROFILE OF YOUNG CARERS

A comprehensive YCRG study of over 2,300 young carers from across Britain is one of the largest surveys ever conducted on caregiving children. The survey results provide an in-depth, statistical profile of young carers. All the young carers surveyed were drawn from young carer projects (Dearden & Becker, 1998). These projects have been established across Great Britain by various non-profit groups to provide support, interventions, socialization and recreational opportunities for young carers. The projects now number in the hundreds.

The survey findings include:

- Age range of young carers supported by projects – 3 to 18 years old
- 84% of young carers are compulsory school age (i.e. 5 to 15 in Britain)

- 57% of young carers are girls, 43% boys (i.e. gender divisions are fairly equal)
- 86% of young carers are from a white European ethnic background
- 14% are from minority communities
- 7% are from Black African and Caribbean backgrounds
- Over ½ of young carers are from lone parent families
- The majority of care recipients are mothers, as anticipated by the number of young carers living in one-parent families, most of which are headed by women
- Children in two-parent families may be caring for a range of family members, whereas in one-parent families they care for a parent, usually a mother.
- At least 12% of young carers look after more than one person
- 24% of young carers take on a caring role for a sibling

THE CAREGIVING TASKS

Research clearly indicates that young carers provide similar types of care as adult caregivers. The major difference is that young caring has a hidden nature, and it transgresses social norms – society expects children be cared for as ‘dependents’ rather than being ‘care providers’ themselves (Dearden & Becker 2003).

The growing body of literature on the qualitative nature of young caring began with Meredith (1991). Meredith was the first to repudiate attempts to build statistical profiles of young carers and concentrated instead on gaining insight into their ‘lived experience.’ Research which followed Meredith’s pioneering work increasingly revealed a group of children who were making considerable sacrifices in their personal lives to take on caring roles. They were not simply ‘helping out’ at home or giving up a couple of hours of their time whenever they felt like it (Becker, Aldridge & Dearden, 1998).

Frank (1995) found that young carers undertake a broad variety of caregiving tasks. These include practical and physical assistance, as well as coping with the associated emotional stress and responsibility. These findings are reflected in other research projects conducted in other parts of Britain (Banks et al 2002; Dearden & Becker 2003), including Wales (Seddon et al 2001) and Scotland (Glasgow City Joint Young Carers Strategy 2002 – 2005). Dearden and Becker (1995) found the majority of young carers were involved in domestic chores such as cleaning, cooking and preparing meals as well as general or personal care (assisting with mobility, giving medications). One quarter of young carers were involved in offering emotional support to members of the family, while 23% provided “intimate” care such as showering, bathing, dressing and toileting. An international comparison made in a cross-national study *Young Carers in Europe* found homogeneity in the types of young caring in Sweden, Germany, France and Britain (Becker ed, 1996). Australian young carers are no exception. Typically they are found to perform the same caring tasks as adult primary caregivers (Noble-Carr, 2002).

Frank (1995) organizes young carers’ tasks into three general categories: practical, personal and emotional. Frank’s large-scale study found these tasks were

essentially the same whether the young carer lived in an urban environment or in the country:

Practical tasks

The practical or instrumental aspects of young caring include a range of responsibilities including shopping, cleaning, budgeting, banking, preparing meals, yard work and parenting younger siblings (Frank, 1995). Qualitative data suggest that sometimes young carers are happy to go along with age-appropriate or gender-appropriate tasks, while at other times they feel resentful and 'put upon' with no choice of refusal (Dearden & Becker, 1995).

Personal tasks

Personal care tasks involve physical care such as lifting, assisting with mobility, bathing, dressing, grooming, giving medications (including injections) and toileting (Dearden & Becker, 1995; Frank, 1995). The literature reveals a strong emotional component to providing personal care, with the care recipient and young carer alike expressing distress (Dearden & Becker 1998; Frank, 1995). Frank's (1995) research found that young carers expressed the most embarrassment over providing personal care and toileting. In some families sons were helping mothers with toileting needs, while in others daughters helped their fathers. These intimate tasks included emptying and cleaning commodes. Some young carers expressed feelings of resentment against their parent because of these intimate tasks. Many simply wished to stop. Others just "get over it" (Docking, 2002):

"I'm used to it now...Sometimes it's a bit awful when she's had an accident – a big accident – but apart from that we don't really see it like that. She wears pads and things...I just find it embarrassing when she's had a really big accident."

Marianne, 14

There is also the question of a loss of privacy for both the young carer and care recipient (Dearden & Becker, 1995). Parents feel a loss of dignity at having to rely on their child for assistance with toileting needs (Frank, 1995). One young carer, who had been caring for her father since the age of nine, gives a vivid description of what the lived experience of a child providing intimate care for a parent is like, and the loss of privacy it entails for both the care provider and care recipient:

"I did stop showering him at about 14 or 15, but recently that's started again. I didn't like showering him any more. You know, I thought 'I want my privacy; I'm sure he wants his' and I'm sure he doesn't like me having to shower him and I certainly don't like doing it. I suppose it was the embarrassment. You know – it takes up so much time, it takes about an hour from start to finish, you know, get him in the shower and get him out and dressed."

Christine, age 20
(Dearden & Becker, 1995)

The literature suggests that the physical demands of providing personal care can be harmful to a young carer's own health (Becker et al, 1998; Bibby & Becker, 2000; Dearden & Becker, 1995; Gays, 2000). Due to the physical strain of working with an immobile parent or sibling, young carers are at risk for a variety of physical ailments. Muscle strain, fatigue and exhaustion are common (Gays, 2000). An increased risk of back injury from lifting and carrying has also been reported (Bibby & Becker, 2000). Some suggest that such injuries are directly caused by the general provision of care (Gays, 2000).

Emotional care

Frank (1995) found that the emotional responsibilities of young carers included counselling the parent, providing companionship and in some cases parenting the parent. Emotional support can range from "cheering up a parent" to ensuring a suicidal parent is not left alone (Docking, 2002). Research suggests that domestic, general and intimate care are more likely when young carers assist a relative with physical disabilities, with emotional support more likely to occur when a parent has a mental health issue (Docking, 2000).

A groundbreaking, two-year study of 40 children and their parents by the YCRG in 2003 looked at the experiences and needs of children who care for parents with mental illness. The study found that emotional support by young carers includes a range of tasks that is not easy to quantify or measure:

- 'sitting with parents,' when they were unwell
- 'helping when mum can't stop crying'
- 'being there when things are bad'

Several unfavourable outcomes were observed by the researchers, including children worrying about their parents' immediate and long-term well being. Worrying about parents was found to be a key factor in a young carer's lack of concentration and poor performance at school (Aldridge & Becker, 2003).

EMOTIONAL DEMANDS OF YOUNG CARING

The research literature suggests that the emotional demands of caring can be quite exhausting, even for adult caregivers, let alone young carers (Bibby & Becker, 2000; Frank, 1995; Gays, 2000). Some suggest that the worrying and stress involved in young caring can put the child at risk for mental health problems (Bibby & Becker, 2000; Cree, 2003; Gays, 2000).

A study of 150 young carers in Edinburgh in 2003 identified a range of worries and concerns connected to the caring role (Cree, 2003). Many of these were considered

to have the potential to have a serious effect on a young carer's well being, with only a few being within the normal range of adolescent experience – e.g. concerns about appearance. Other worries could be wholly explained in terms of their lives as young carers:

- 81% worried about the health of the care recipient
- 68% worried about their school work
- 67% worried about their own health
- 58% worried about the behaviour of the care recipient
- 53% worried about who would look after them in the future
- 48% worried about money
- 36% worried about being bullied
- 35% worried about not having any friends

Some types of problems were found to increase with age, including sleeping difficulties, eating problems, truancy, trouble with police, substance abuse, self-harm and worries about not having a friend (Cree, 2003; Salter 1999). The evidence from Cree's (2003) study suggests that being a young carer may put additional pressures on young people at a time in their lives which is already stressful.

A pilot study by the Children's Society (1999) in Britain on the health needs of young carers found the health of the young carer can be affected regardless of the nature of the illness or disability of the care recipient. This study of 65 young carers found that young carers exhibited the stresses of caring through age-related behaviours. Younger children tended to be aggressive, withdrawn or have night time difficulties such as nightmares and bedwetting. Adolescents were more likely to exhibit self-destructive behaviours such as self-harming and substance abuse. A few girls were found to have contemplated suicide. Many suffered from low self-esteem, headaches, depression and bullying. Feelings of loneliness, guilt, anger, isolation and confusion were not uncommon (Salter, 1999). The problem with these sorts of stress-related, mental health and emotional problems is that children and adolescents are not mature enough to have developed the necessary coping strategies to deal with them appropriately (Docking, 2000).

An observation by Frank (1995) confirms the emotional stress of young carers. During Frank's comprehensive study of young carers in the City of Winchester, it was found that all of the participants, except one, exhibited some degree of emotional strain. Frank (1995) also found that the role reversals and false maturity seen in many young carers can lead to a change or destabilizing of the relationship between parent and child. The caring role, coupled with the underlying emotional burden, leads young carers to behave in a much more mature way than their peers – assuming a mantle of false maturity. This can lead to role reversals, with a young carer adopting a parental role to either the care recipient, (i.e. parent, grandparent or disabled sibling), or to other dependent, healthy siblings in the family. Many families in the study were found to be dysfunctional, with parent/child role reversals leading to relationship difficulties. Many

care recipients who were parents expressed concerns over loss of their parental role (Frank, 1995).

Isolation plays a major role. A young carer's isolation is seen as detrimental to his or her mental health, with anxiety, depression and illness resulting from emotional distress (Gays, 2000).

THE NEEDS OF YOUNG CARERS

Young carers have been found to have a range of needs, from information about the care recipient's condition to recreational and social opportunities. Educational problems have been found to be significant. Young carers tend to miss school because of caring demands, have difficulty completing homework and suffer from a lack of concentration. There is some evidence to show young carers are at risk for bullying because they are "different" from their peers. Social isolation is rampant. Young carers are inhibited from social activities because of lack of time. Playing with friends, participating in extra-curricular activities such as sports and other leisure activities are past times that, on the whole, are denied to young carers (Docking, 2002; Seddon et al, 2001; Watson, 1999).

As Docking (2002) points out, research clearly identifies the fact that young carers lead very different lives from their peers. Their opportunity to have a 'normal' childhood can be severely impaired (Gays, 2002).

An Australian school-based survey of young carers conducted in 2000 found a variety of needs identified by the young carers themselves:

- Time off
- Less homework
- More help from adults
- Meet other young carers
- Learn what to do in an emergency
- Have someone to talk to
- Better services for the care recipient
- Get paid
- Other – includes help for family members/help from other family members/money to buy equipment/cure for illnesses/camps/better housing/have a friend round more/help from anyone/sign language course

(Gays, 2000)

The above needs of young carers are consistent with those found by other research studies (e.g. Bibby & Becker, 2000; Docking, 2002; Frank, 1995; Frank 2002). According to Docking (2002), young carers have needs similar to all children and young people, but may have additional needs (and rights) related to their caring role.

A major problem long recognized in the literature is the young carer's need for recognition. It is essential that the young carer's contribution to the family be acknowledged and valued, not only by other family members but by health care practitioners, teachers and social workers (Docking, 2002). There is also a need for community support, such as befriending programs (Aldridge & Becker, 1996) and Young Carers Projects (Dearden & Becker, 2000).

INTERVENTIONS: YOUNG CARERS PROJECTS

One response to the needs of young carers in Britain has been the establishment of local Young Carers Projects in most areas of the country (Docking, 2002). Young Carers Projects have evolved to meet local needs and offer a range of direct services to young carers and their families (Frank, 2002). Over 100 projects are now flourishing, providing information, advocacy and support to young carers and their families (Docking, 2002; Frank, 2002). As Docking (2002) points out, most projects are based within the voluntary sector with funding tending to come from temporary sources such as government grants. A majority of the projects are 'generic' in that they are available to all young carers in a given locality, no matter what the nature of the illness or disability of the family member happens to be. The types of services the projects provide tend to be very similar, covering a spectrum of needs:

- Information and assistance to access other services
- Opportunities for socializing with their young carer peers
- Provision of counselling, advocacy, and befriending schemes
- After-school clubs/educational support
- Recreational activities
- Careers advice
- Group work
- Support for the family

(Dearden & Becker, 2000; Docking, 2002)

One well-established project that provides these typical of types of support for young carers is located in Sheffield. The Sheffield Young Carers Project was evaluated by the YCRG from Loughborough University in 1999 (Dearden & Becker, March, 2000).

The Sheffield project has three main aims:

- To support young carers under the age of 21
- To increase young carers' social, leisure, educational and employment opportunities
- To raise awareness of young carers' issues.

In the first three years of its existence, the project received more than 150 referrals, with many coming from black and ethnic communities. Demand for programs soon outgrew the project's ability to provide services, and new referrals needed to be

placed on a waiting list. The Sheffield Project offers a full spectrum of services, including one-to-one counselling, volunteer befriending, social activities, peer support, as well as advice, information and support around all aspect of their lives. The educational support and careers advice in particular were found to be helpful in smoothing the young carers' transition into adulthood (Dearden & Becker, March, 2000).

The literature shows that these local community projects go far in addressing the isolation of young carers (Bibby & Becker, 2000; Watson, 1999). The evaluation of the Sheffield Project, for example, found that the impact on enhancing the quality of life for young carers was significant. The project offered the only opportunity available for many of the participants to socialize, to enjoy leisure activities and to escape from their caring role altogether by going on a holiday. Both the young carers and their parents placed a high value on the recreational and social activities provided by the project. As Dearden & Becker (March, 2000) point out, these types of activities are often denied those on welfare or disability benefits.

Other projects have reported similar beneficial effects. An evaluation of the West Lothian Young Carers Pilot Project, located just outside of Edinburgh, Scotland reported a variety of positive outcomes among the 10 young carers who attended. These included:

- high levels of participation
- reduced levels of stress
- increased social involvement without caring responsibilities
- improved educational attainment
- the development of group skills

One negative outcome was encountered when the pilot project came to an end. Some of the young carers had become dependent on the project and had difficulties adjusting to a life without the program (Banks et. al, 2002).

In some projects, much of the work is on a one-to-one basis with individual children and is aimed at building confidence, self-esteem and social skills. This type of intervention may be the prime need among very young carers, who lack social skills and do not know how to mix and talk with their peers when they first come to the projects. Prevention and early intervention are seen to be especially important with very young carers, before problems such as bullying and lack of attendance at school become entrenched and more difficult to tackle (Dearden & Becker, March, 2000). A key goal of the projects is to intervene before families reach a 'breaking point.' One way to do this is to network and collaborate with various community agencies to ensure that appropriate services are in place (Dearden & Becker, March, 2000; Docking, 2002).

One major concern from a research point of view is that the efficacy of these projects over the long term to improve the quality of life for young carers and to address their unique needs has not been evaluated to any great extent as yet. Longitudinal studies which would follow young carers on into their adulthood to measure the effectiveness of the projects over time are needed to 'fill in the blanks.'

POSITIVE ASPECTS OF YOUNG CARING

Although some early literature found no positive aspects of young caring (Frank, 1995), more recent research suggests the caring role is not all negative and can give rise to many positive outcomes. Seddon et al (2001) provides a comprehensive list of the benefits of young caring, and finds that young caring presents important opportunities for children to acquire new life skills, aptitudes, and perspectives.

These include:

- organizational skills
- time management abilities
- interpersonal and communication skills
- awareness of the needs of others
- a sense of fulfillment and usefulness
- assuming responsibility for others
- coping skills/crisis management.

The Glasgow City Joint Young Carers Strategy (2002-2005) compiled a similar list of the positive features of the caring role that were reported by young carers themselves. Through their caring role, young carers reported they gained status, a sense of responsibility and found satisfaction in supporting a close relative. They also acquired useful practical skills and learned to understand the needs of another person.

WHAT HAPPENS TO YOUNG CARERS WHEN THEY GROW UP?

This literature review failed to find even one longitudinal study of young carers which tracked them over several years of their caring experience and on into adulthood. Several studies, however, have found that young caring may result in long term effects that can have a lasting impact throughout adult life (Dearden & Becker, 2000; Frank, 1995; Frank, Tatum & Tucker, 1999; Toporas, 2003). These studies have tended to be retrospective, asking grown up young carers to recall their experiences of family caregiving. One retrospective study of 25 former young carers by Frank et al, (1999), found that being a young carer can have profound social, psychological and emotional effects in later life.

An important aspect of the Frank et al (1999) study is that it drew together a specific range of “concealed consequences” of young caring that were used as a framework for analysis. These hidden consequences of care included:

- Social exclusion/isolation
- Effects on the young carer’s health and well being
- Shaping life chances, education and future opportunities
- Changes in family dynamics
- The ‘invisibility’ of being a young carer
- The ‘conspiracy of silence’ surrounding young caring

Findings from this study indicate that young caring may exact a heavy toll which continues on into adulthood. Many of the former young carers who were interviewed found it difficult to talk about their experiences without becoming emotional and defensive, with 'visions of the past' (p.10) still haunting them.

The literature shows that a critical period of development for young carers occurs during the transition to adulthood. A study of 60 current and former young carers by Dearden and Becker (2000) focused on this challenging transitional period. Their findings indicate that young caring influences in a profound way two of the most important transitional phases in becoming an adult: leaving home and choosing a career. The decision to leave home may be delayed because of the absence of alternative support in the home, thus placing an obligation on the young carer to continue in the familial caring role well into adulthood. Another factor that impinges on a young carer's decision to leave the parental household is the lack of formal qualifications. In the Dearden and Becker (2000) study, it was found that a common problem among the young carer population is missed school and the resultant educational difficulties. A large proportion of respondents had either no educational qualifications, or a minimal standard. This resulted in a negative impact on their transition from school into higher education and the labour market. One positive effect is that many young carers were enabled to find employment in the helping professions because of the skills gained during their caregiving experiences, but some researchers find that adult career choices may be unduly influenced by young caring.

An emergent theme from this body of literature is that unmet needs in childhood can have major repercussions in later life, especially in choice of career. When young carers adopt a caring role as a lifetime occupation, this may not be a healthy choice for them. One consequence that has been noted in the literature is that young caring can lead to what Bowlby (1977) called 'compulsive caregiving.' A compulsive caregiver is a person who may engage in many close relationships, but always in the role of caregiver. According to Bowlby, the typical childhood experience of a compulsive caregiver involves having to care for a family member, while their own needs for care were neglected. This literature review found several studies that have found a correlation between caregiving in childhood and the choice of a career in the helping professions in adulthood.

One noteworthy study in 1997 compared the childhood and adolescent experiences of a group of nursing students to the experiences of a random group of individuals not involved in the helping professions. This study found that a significantly higher proportion of student nurses reported adverse experiences in their childhood and teen years than did the individuals not in the helping professions. The student nurses reported a range of challenging circumstances in their early lives, including the death of a parent or sibling, the long-term illness of a parent, parental divorce, and a major family accident or disaster (Phillips, 1997). In a similar vein, Lackey and Gates (2001) found half of the female respondents in their study of 51 former young carers entered the caring or helping professions. Phillips (1997) suggests that nursing students may be inclined

to choose nursing as a career *because* their increased exposure to family illness or disability in their childhoods gave them an inside look at the work that nurses and other health professionals do (Phillips, 1997). Other researchers, however, express concern that early caregiving experiences may exert too great an influence on adult career choices. Young carers may be limited in reaching their fullest potential because of this ‘undue influence’ (Frank et al, 1999; Lackey & Gates, 2001).

The literature leaves little doubt that there can be both positive and negative aspects of young caring which last well into adulthood, perhaps for a lifetime. In a descriptive, retrospective study of 51 former young carers, (age range 19 to 68 years old), Lackey and Gates (2001) examined both the positive and negative effects of the young caring experience. These former young carers had looked after family members diagnosed with a variety of ailments, including cancer, stroke, cardiovascular disease, multiple sclerosis, ALS, respiratory disease, diabetes and arthritis. When looking at the effects of young caring on their current lives, most of the study participants viewed their caring experiences in a positive light. They believed that as adults, they were more caring, nurturing, compassionate and respectful of others as a result of their early caregiving. On the other hand, Frank et al. (1999) found that young caring resulted in much unresolved anger, guilt and grief among the former young carers. And Toporas (2003), in her Canadian study of children of parents with MS, found that adult children - i.e. former young carers – consistently reported a higher negative impact on themselves than expressed by children currently in the role. The reasons for this were not clear to the researchers, but they found that being part of a strong family while growing up seemed to alleviate the negative memories in adult children to a great extent. The MS research revealed that chronic disability is truly a ‘family event.’ All family members are affected by the physical pain of their loved one and the emotional losses related to the family lifestyle changes. One adult child described the “*emotional pain in seeing the daily struggles*” [author’s italics] (p. 22).

The MS study, which compared the experiences of “strong families” to “weak families,” found that across the board, strong families fare much better than weak families in all aspects of life in dealing with MS. While this study focused strictly on MS families, it nonetheless makes a compelling case for professionals to look at the whole family in these kinds of circumstances and assist family members to build strong bonds and develop effective coping strategies. It is not enough to look solely at the situation from a child-centred perspective.

THE CHILD RIGHTS/DISABILITY RIGHTS DEBATE

The 1989 UN Convention of the Rights of the Child was the first international legal structure which recognized that children should have a specific set of identifiable ‘rights’ to cover specific areas in a child’s life concerning prevention, protection, provision and participation (Becker et al, 1998). The UN document has since been liberally used to endorse the rights of young carers. For example, Article 2 states that the rights set out in the Convention have to apply to all children without discrimination of any kind, including the disability of the child’s parents or guardian (Banks et al, 2002).

The early young carer literature in Britain adopted the view that children providing care for adults constituted an infringement of the children's rights. This child-centred view took the position that a 'rights-based' approach as a basis for developing policy and practice would be the best way to meet the needs of young carers (Frank et al 1999). Focusing on the rights of the child was seen to be an outgrowth of the developed world's construction of 'childhood' as being a time in which the child has a safe and protected status during which a gradual introduction to the responsibilities of adulthood takes place (Becker et al, 1998).

As Becker et al (1998) point out, the phenomenon of young carers pose fundamental challenges to the societal norm that the family should provide care for dependent minors. While the social role of adult family caregivers in caring for relatives who are disabled, chronically ill, frail and elderly in the home setting has been reinforced by policy and legislation, caregiving children do not fit these normative roles. Young carers transgress current norms and social expectations in Western societies (Becker et al, 1998). Because of this, researchers have found that many of the rights of young carers have been violated (Banks et al, 2002; Becker et al, 1998; Frank et al, 1999).

The child-rights focus described above served to generate a diametrically opposed view which centred on the rights of the disabled. The controversy sparked a number of papers which supported the view that the focus on child rights created distorted, stereotypical images of the disabled (Newman, 2002). One huge issue was that there was an assumption that the children of disabled parents should be seen as 'in need' or 'at risk' (Wates, 2003). Newman (2002) argued that there is limited empirical evidence for the claims that young carers "suffer." According to this view, any legitimate concerns that arise in regard to young carers are more likely to be related to poverty, social exclusion, and unsupported or inadequate parenting, none of which necessarily are due to having a disabled parent (Newman, 2002). The disabled rights movement took the position that the concept and practice of 'young carers' in its current form undermines the parenting role of disabled people, to the detriment of their family lives as a whole (Becker et al, 1998; Wates, 2003). From the view of the disability rights movement, what is really needed is more community support for disabled parents to assist them in their activities of daily living and their parenting role instead of supporting their children in isolation in Young Carers Projects. It was thought that providing increased services for disabled parents would be a preventative measure that would alleviate the problem of children being forced to adopt inappropriate caring tasks or levels of caring in the first place (Banks et al, 2002).

The polarized debate between child-rights and disability rights advocates led many to call for a fresh start in theory, practice and ideas in regard to young carers and their needs (Olsen, 2000), with some arguing that an integrated, holistic model for assessing the needs of the whole family should be adopted (Aldridge & Becker, 1997; Bibby & Becker, 2000; Docking, 2002).

THE NEED FOR A FAMILY SYSTEMS APPROACH

The advocates for a 'whole family' approach take the position that offering support either to the young carer or to the care recipient independent of the needs of the entire family is not sufficient. The family as a whole must be considered. As advocates from the Stirling Carers Centre (2002) point out, a substantial body of the young carer literature has failed to describe the reciprocal nature of care-giving, in which young caring is a 'two-way street.' The fact that most cared-for parents still maintain a parenting role is largely ignored. In situations where one-sided caring by young carers does occur, the holistic model would allow for a two-sided, 'more natural' process to develop, in which parents are **enabled** to look after their children (Bibby & Becker, 2000; Docking, 2002).

The family-perspective paradigm would replace the old medical model of disability and would transcend the debate about service provision between disability rights advocates who call for provision of services to the disabled adult, and child rights advocates who take a child-centred view (Bibby & Becker, 2000). A holistic approach recognizes that a young carer's independence and well-being cannot be separated from the parent's (Bibby & Becker, 2000). To many young carers, their helping activities are done to benefit the whole family, including themselves, and not the 'cared for' person only. For example, in a 2002 study undertaken in Stirling, Scotland, researchers found that many of the young carers who took part noted the reciprocity and interdependence inherent in their care-giving role (Department of Applied Social Science, University of Stirling, Research Briefing for the Stirling Carers Centre, Nov., 2002).

A holistic approach would meet the needs of the care recipient, build on family strengths, recognize any difficulties or problems from a family perspective and nurture, not undermine, parenting skills. In a holistic approach the children's voices are heard and their feelings taken into account, while society as a whole upholds its duty to consult, inform, support and protect children in a caring role (Frank, 2002). The desired aim would be to facilitate a sort of 'natural exchange' of help and affection between family members. This in turn can reinforce family relationships and lead to a successfully functioning family. Sufficient parenting support would prevent children and youth from being forced into a caring relationship in the first place (Bibby & Becker, 2000).

CONCLUSIONS

This literature review has attempted to look inside a specific 'black box' of child development, the 'lived experience' of young carers in Canada. The review found that there is a dearth of material on Canadian young carers, who remain very much a hidden population. To capture a sense of what the day-to-day experience of being a child in a caring role is like, the extensive body of work coming out Britain was consulted, complemented by some studies from Australia. This literature confirms that young carers have a common 'lived experience' and share a set of common needs which transcend political, ethnic and cultural boundaries. There is also recognition that young caring can be detrimental to a child's health and well-being, as well as to his or her educational, social, and recreational opportunities. It is clear that these effects can last well into

adulthood. Positive aspects of young caring were also found, including the acquisition of important life skills and building a sense of self esteem for a job well done. Nonetheless, the literature clearly shows that young carers have a variety of unmet needs, including information about the parental disability or illness, counselling and support, social and recreational activities and a chance 'just to be kids.' Society as a whole must also start to recognize the significant contribution of young carers to the overall well-being of their families.

This review strongly points to a need for a review of current community care practices in Canada in order to address the profound "invisibility" of young carers in this country, and to find ways to eliminate the gap between child services and adult services. One way to do this would be to adopt a whole family approach. A family systems approach would look at the needs of all family members and help the family to become more resilient by adopting effective coping strategies. Young carers would be identified early and steps could be taken on a preventative basis to ensure the well being of these family helpers in all aspects of their lives, education included. Experience from other countries show that interventions need to take place before the child becomes a "problem." The whole family should be supported so that they can lead the best life possible for them.

There is a great need for Canadian data in order to compile a complete profile of the lived experiences of being a young carer in Canada. The MS study, *Growing Up Strong*, is a pioneer in that it takes a Canadian perspective for the first time, but it is limited in terms of young carers in general in that the sole focus is on children in MS families. The planned "*Hear Me Now*" survey to be distributed in the fall of 2005 in the Niagara Region for the Young Carers Initiative Niagara (YCIN) will be of a much broader scope, and will be the first of its kind to address young carers as a unique population in Canada. The findings from this study should help to draw attention in Canada to young carers as an emerging social issue that ought to be addressed by all levels of government.

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