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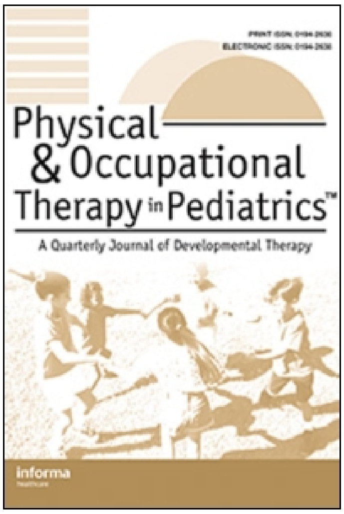

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The Transition Study

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The Transition Study: A Look at Youth and Adults with Cerebral Palsy, Spina Bifida, and Acquired Brain Injury

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ABSTRACT. A group of 100 adults and 190 youth who have cerebral palsy (CP), spina bifida (SB), and acquired brain injuries from childhood (ABIc) participated in a multi-method study focused on the transition to adult health care. The results show that 95% of youth and 61% of adults were living with their parents; 23% of the youth and 55% of adults were employed; and 60% of youth and 42% of adults reported "excellent" or "very good" health. The lowest health scores were reported by adults with SB. These findings provide a starting point for examining health issues specific to youth and young adults with CP, SB, and ABIc. doi:10.1300/J006v26n04_03 *[Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <http://www.HaworthPress.com>*

KEYWORDS. Health Status, social outcomes, survey, transition

INTRODUCTION

Conditions such as cerebral palsy (CP), spina bifida (SB), and acquired brain injury in childhood (ABIc) are complex and physically disabling conditions that require substantial health care service support in childhood. In the past two decades, changes in health care have enabled most individuals with CP, SB, and ABIc to reach adolescence, and 50-90% are now surviving into adulthood (Hunt, 1983; Hutton, Cooke, & Pharoah, 1994; Strauss, Shavelle, & Anderson, 1998). Given the large investment made in health care support during early childhood (Newacheck & SE, 2005), it is imperative that we examine the long-term outcomes of the recipients. At present, there is little systematic information on the living situations and health status of youth and adults who have these conditions. It is important to examine their health later in life.

The importance of health information during adolescence and adulthood is accentuated by the dearth of specialized clinical services available to those with CP, SB, and ABIc as they grow older. The requisite services reside predominantly in paediatric centres, where they are focused primarily on the early childhood years (Stewart, Law, Rosenbaum, & Williams, 2001). In Ontario, there are 20 children's rehabilitation centres (CRCs) that are government funded, and provide health care resources to support these groups (Anonymous, 2005). However, those over 19 years of age are ineligible for medical care from paediatric providers and must break links with specialized and integrated care that were established in childhood.

The current medical literature contains many discussion papers that suggest these individuals have great difficulty navigating the adult health care system (Bax, Smyth, & Thomas, 1998; Blum, 1995; Blum et al., 1993). The challenge is at least partially attributed to the fact that adult health care resources are not structured in the same way as the integrated clinics coordinated at the children's rehabilitation centres. It is possible that a lack of services, lack of experience in navigating the system, and lack of expertise among adult health care providers may compromise the benefits gained over many years of comprehensive care delivered during childhood. Are the health benefits achieved through early investments via the CRCs sufficient to facilitate independent living and to maintain their health during adolescence and adulthood?

Our pilot research from 2002 (Olmsted, 2004) showed that the health outcomes of 25 young adults with CP, SB, and ABIc were extremely poor. Their average Health Utility Index Mark III (HUI) score was 0.31 (SD = 0.34). This mean score was far worse than that of adults following stroke (mean HUI = 0.68) and adults with Alzheimer's (mean HUI = 0.58) reported based on data collected in the National Population Health Survey (Mittman, Trakas, Risebrough, & Liu, 1999). This preliminary evidence supports clinical perceptions of poor health outcomes in adulthood, and emphasizes the importance of examining the outcomes of these individuals as they age.

The purpose of this paper is to present a comprehensive picture of the health and life outcomes of both youth and young adults who have CP, SB, and ABIc.

METHODS

This research project, from which data for this paper were derived, began in 2002 and combined three unique methodological approaches: (1) a health services analysis; (2) a life and health outcomes survey; and (3) a qualitative examination of the experience of transition to adult health care. The province of Ontario was selected as the setting for this study for a variety of reasons. First, it has the largest population of all the regions in Canada. Secondly, it is served by a common universal health care system and the fee for service claims data for all physician services and all acute care hospital admissions data in the province were available to the research team at the Institute for Clinical Evaluative Sciences (ICES). Thirdly, there was keen interest and grassroots support from several CRCs in Ontario who were willing to collaborate on the project. This collaboration involved identifying the target population, searching for updated address information, and providing clinical insights and guidance during the analysis phase.

Due to the magnitude of the study, the results will be presented in a series of papers. This paper is the first in the series, and focuses on describing the size of the initial sample, their demographic characteristics, living situations, and global health ratings (GHR). This information was collected from the mail-administered survey component of the project. This paper will form the foundation for all subsequent publications in which we will provide the details of their patterns of health care utilization, hospital admission rates, lengths of stay (LOS) and reasons for hospital admissions, frequency of accessing physician care, the nature and extent of limitations in their health, and their personal experiences of health and transition to the adult health care system.

Sites

Participants for this study were identified from six CRCs across Ontario. These were selected to represent both rural and urban regions as well as northern and southern regions of the province. The CRCs representing southern Ontario were (1) Bloorview MacMillan Children's Centre (Toronto), (2) Erinoak (Peel/Halton), (3) KidsAbility (Waterloo), and (4) Ottawa Children's Treatment Centre. The CRCs representing northern Ontario were the Sudbury Regional Hospital Children's Treatment Centre and the Algoma Treatment Centre (Sault St. Marie).

Identification of the Sample

The sampling frame was limited to the clinical conditions that were the main focus of clinical care at the CRCs: cerebral palsy, spina bifida, and acquired brain injury in childhood. Because we sought to examine changes in health and health-care-related to the transition to the adult health care system, we wanted to identify a group that was clearly moving towards this transition and a group who should have completed this transition. The transition to adult health services in Ontario is enforced at the age of 18 or 19 years depending on the centre because of the mandate that restricts the delivery of most CRC services to "children".[1] Thus, we sought participants for the "youth" cohort who were born during the period 1980-1985 inclusive (i.e., who were 13 to 17.9 year old as of December 31, 2002[2]) and participants for the "adult" cohort who were born during the period 1970-1979 inclusive (i.e., who were

23 to 32.9 year old as of December 31, 2002). Those born between 1976 and 1979 were excluded because they were in the midst of transition at the time of the study (i.e., 18 to 22.9 years old as of December 31, 2002).

Electronic patient records databases were searched at all participating sites to identify potential participants. In most cases, detailed chart reviews were necessary to confirm the diagnosis. Once the eligible population of youth and adult cohorts had been assembled, chart reviews were conducted to abstract demographic data from the health records belonging to the CRC that they had attended in childhood. This demographic data included: full name, date of birth, last known address, parent's name(s), diagnosis, severity,[3] age of injury if the diagnosis was ABIc,[4] and Health Card Number (HCN).

Method Details for Part A: Health Services Analysis

The HCNs were accessed under institutional consent, in accordance with the rules of data security and anonymity in use at ICES (see *www.ices.on.ca* for more details on these rules) and with the approval of the Research Ethics Board at the lead institutions and the participating CRCs. The HCNs were securely transported from the CRC where they were identified, to ICES where the administrative data related to physician fee-for-service claims, and hospital admissions records were housed. All health services analyses were conducted in the secure environment at ICES.

The first step in this analysis was to identify duplications within the population because of the same eligible candidate being identified at two or more CRCs. All duplications were removed. The second step involved examining the records to remove any noneligible individuals who may have moved out of the province or who were deceased without the CRC record being updated. These steps were critical to the identification of the sample.

The remainder of the analysis at ICES focused on the frequency of physician visits, types of physicians visited, and nature and duration of admissions to acute care hospitals. These results will be reported in a separate publication.

Method Details for Part B: Outcomes Survey

Staff in the health records departments at each site conducted reverse phone number searches and Canada 411 searches, to confirm and/or up-date the address information of potential participants. They also attempted to contact all potential participants and/or their families by phone to verify address information. This was only done for the adults owing to the extensive length of time since their last contact with the CRC, and was not feasible to do for the whole group. A letter, inviting their participation in a survey, was mailed to each eligible subject for whom we had identified a potential address. The envelope also contained a consent form and a preaddressed and postage-paid envelope for return of the signed consent form.

Once signed consent forms were received, the demographic data that had been abstracted and stored at the CRCs, were transferred to the main study site at the Hospital for Sick Children, and a survey package was mailed out to the respondent. The package contained a series of questionnaires regarding their education, current living situation, timing of their transition to adult health services, their use of health services over the past year, and the global health rating question from National Population Health Survey. The package also included several standardized health questionnaires: the Health Utilities Index (Feeny, Furlong, Boyle, & Torrance, 1995; Feeny et al., 2002) the Assessment of Quality of Life (AQoL) (Hawthorne, Richardson, & Day), and the Health Assessment Questionnaire (HAQ) (Fries, 1991; Thompson & Pegley, 1991).

Participants were requested to complete their survey package and return them in the postage-paid envelopes provided. They were asked to indicate on the questionnaire forms whether or not they received assistance with the survey process. Postcard reminders were mailed to those who did not return their completed package within three weeks. Phone follow-up was done if the survey was not returned within six weeks.

This paper presents the information related to the study sample and subsamples, broken down by diagnostic and age groups. It also presents information on severity of their physical disability. Detailed information was only available on severity for the group with CP, using the Gross Motor Function Classification System (GMFCS) (Palisano et al., 1997, 2000) because this measure is only valid for persons with CP. However, we explored the correlation between the GMFCS and ambulation ability (gait classification) using information collected on the survey to determine whether gait could be used as a surrogate for severity in the larger group. Further information regarding the severity of this group is presented in the Results section under the heading of *Severity*.

This paper also presents information on current living situation, educational attainment, and experience of transition to the adult health care sector. Basic information is presented regarding the number of different types of health care providers they reported seeing in the last year. Ratings for their general health status collected in the outcomes survey were reported in table format. These data were first analyzed to describe the entire group, and where relevant, additional subgroup analyses were conducted for each of the six subgroups defined by age (youth and adults), and diagnostic groups (CP, SB, and ABIc). *T*-tests, Pearson's correlation and chi-square statistics were used to explore the strengths of differences between groups.

While there is much information also available from the standardized health questionnaires, presentation of this information is beyond the scope of the current paper. It will be reported in a separate publication.

Method Details for Part C: Qualitative Examination of the Experience of Transition to Adult Health Care

Following completion of the outcomes survey we purposively selected a subset of 15 youth and 15 adult survey respondents to ensure even representation according to several criteria: age group, diagnostic group, region of residence, and transition experience (stressful vs. nonstressful). Those identified by this process were contacted by phone and invited to participate in a semistructured interview. The interviews were intended to explore the experiences of transition and assist with the interpretation of data collected in parts A and B of the methods. In addition, separate concurrent interviews were conducted with the caregivers of these 30 individuals. Interview data were taped, transcribed verbatim and analyzed using qualitative methods, and with the assistance of NVIVO software. This analysis is leading to an extensive body of results that is beyond the scope of this paper, but is in preparation for publication. However, information from these interviews has contributed substantively to our understanding and interpretation of the survey data reported in this paper and is reported here where relevant.

RESULTS

Characteristics of the Sample

The sampling process for this study began with a group of 2,367 candidates being referred from the six sites. However, 266 were determined to be ineligible during the initial part of the health services analysis and were excluded for the following reasons: 64 were deceased, 30 were out of province, 9 were still in the acute phase of their brain injury, and 163 were duplicate referrals from a second CRC. Thus, there were 2,101 eligible individuals who formed the population for the study. The "Health Services Analysis Sample" was a subset of the 2,101 eligible participants for whom we were able to successfully link their health card information to administrative datasets at the Institute for Clinical Evaluative Sciences (ICES). The survey, however, required contacting potential participants by mail. We were unable to identify a potential address for 339, and therefore invitation letters were mailed to 1,762 potential participants. Responses were received from 709 individuals, of whom 352 consented to participate and 290 completed their survey packages. Thus, we had a 40.2% response rate and 49.6% of respondents consented to participate. The 30 members of the "Qualitative Sample" were a purposive sample of the survey respondents.

Age, Gender, and Diagnostic Characteristics

The age, gender, and diagnostic characteristics of the initial population and the survey sample are presented in Table 1. For comparison purposes, we have also included the characteristics of the subgroups who participated in the health services analysis and qualitative interviews (Methods A and C, respectively). No significant sampling bias was observed in terms of age or diagnoses between the initial population and those included in Methods A and B. However, there were differences in the gender, age, and diagnostic distributions in the Method C sample. These were intentional and occurred owing to the purposive sampling which aimed to ensure representation from all subgroups and hence had increased representation from those with SB and ABIc.

There were a variety of important lessons learned from the recruitment process. These included the value of comprehensive and complete electronic medical records. Many of the participating sites did not have comprehensive electronic medical records, and where electronic records were in use, there were great difficulties exporting the relevant records. It was necessary at most sites to complete a manual review of charts to determine eligibility for participation in the study. Identification of current addresses for potential participants was also challenging, but was aided by the use of reverse phone lookup and Canada 411 searches on the Internet. Staff from the CRC was seconded into the project and was critical in making phone calls to confirm addresses on the adult cohort before sending out invitations to participate. In order to compensate for difficulties in locating members of the adult cohort, we increased the range of birth years for the adult cohort so that it was double that of the youth cohort. Even given this adjustment, the youth cohort was larger than the adult cohort. Thus, difficulties locating the adults appear to have reduced the relative representation from adults among the survey respondents.

The breakdown of the sample of 290 individuals who completed the survey, in terms of age and diagnostic groups is shown in Table 2.

A review of how the questionnaires were completed showed that 33% of the questionnaires were completed by the participants on their own, 29% of participants had help with reading the questions, writing the answers or both, and 38% of the questionnaires were completed by a proxy respondent on behalf of the participants. This was not unexpected, since participants were permitted to have assistance to complete the questionnaires if necessary. As expected, those with more severe disabilities were more likely to have had some help or another person responding for them (Pearson's correlation between completion method and gait status was 0.47, $p < 0.0001$).

Severity

Information on severity of physical disability was abstracted by chart reviews for the CP subsample indicated that there was a wide distribution of GMFCS levels among the respondents. It is important to note that the adults were very similar to the youth in terms of severity ($p = 0.997$ from Chi-Square analysis) as shown in Figure 1.

The best descriptor of function in the overall group was ambulation status. Our gait classification was highly correlated with the GMFCS score in the CP subgroup ($r = 0.86$, $p < 0.001$) and was therefore considered a reasonable indicator of mobility function in the larger group. The breakdown of the youth and adult subgroups by gait status is shown in Figure 2.

Severity of communications limitations was also explored. Overall, 19% of our participants were classified as unable to speak, with a further 29% being partially understood verbally.

This descriptive information for the youth and adult cohorts were reviewed by clinicians at each of the CRCs and were considered to be representative of the catchment populations of the CRCs in Ontario. Thus the results are expected to be generalizable to previous clients of the Ontario CRCs. Furthermore, the youth and adult cohorts are very similar with respect to their underlying clinical conditions. Therefore, any dif-

TABLE 1. Characteristics of the Sample

	Sample Size	Mean Age	Proportion who were Youth (%)	Proportion who were Female (%)	Proportion who had CP (%)	Proportion who had SB (%)	Proportion who had ABIc (%)
Initial Population	2,101	20.1	58	44	68	17	15
(A) Health services analysis sample	1,606	20.1	57	45	66	18	16
(B)Survey sample	290	19.4	66	42	69	18	13
(C)Qualitative sample	30	21.2	50	50	40	33	27

TABLE 2. Distribution of the Survey Sample by Age and Diagnostic Group

	Frequencies			Percentages		
	Youth	Adults	Total	Youth (%)	Adult (%)	Total (%)
CP	129	70	199	44.5	24.1	68.6
SB	40	13	53	13.8	4.5	18.3
ABI	21	17	38	7.2	5.9	13.1
Total	190	100	290	65.5	34.5	100.0

ferences in outcomes between youth and adult cohorts are not attributable to underlying clinical differences between the groups.

Living Situations

The respondents were predominantly urban dwellers: 33.1% lived in a metropolitan city (predominantly Toronto), 32.8% lived in a large city, 19.7% lived in a small city, and 15.5% lived in a rural community. Note that rural was very generously defined as those living 30 minutes outside a community of 10,000 people or more. The surveys data show that 95% of youth and 61% of adults were living with their parents and/or siblings. A total of 4% of the youth and 10% of the adults were living in group homes. Additional details on the living situations of our participants are presented in Table 3. These results have been subdivided by age and diagnostic groups. Note that the *CP-Youth* and *CP-Adult* subgroups were the only subgroups with members living in group homes. The *ABIc-Adult* subgroup had the highest proportion living with a spouse or partner at 29.4%.

Educational Experiences and Work-Related Life Opportunities

The survey collected self-reported information on the highest level of education completed by the participants. This information is an important part of understanding the life experiences and opportunities of the participants. It is presented in Table 4, which identifies the *SB-Adult* subgroup as the most highly educated subgroup.

Table 4 provides some insight into the range of educational experiences; however, during the qualitative interviews we had the opportu-

FIGURE 1. GMFCS Scores by Age Group for Those with CP

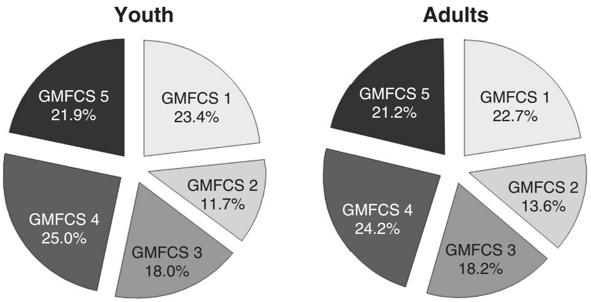
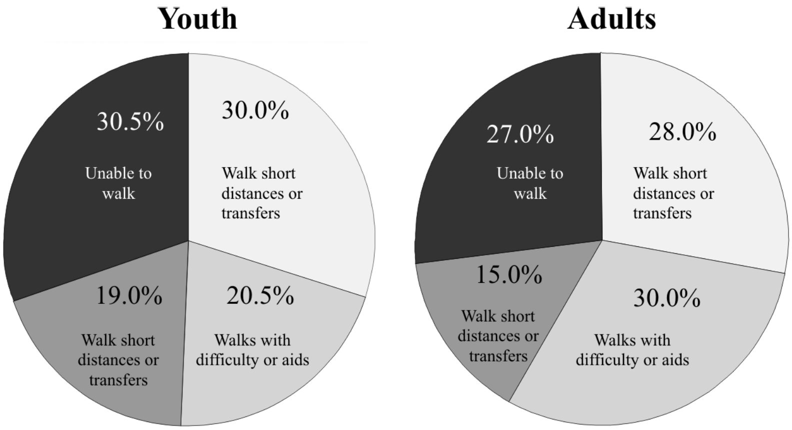


FIGURE 2. Gait Classification by Age Group for All Participants



nity to discuss current education with some of the participants. We learned that many reported "completing" high school or higher education, but had not yet completed it. Thus, we altered the last titles on the three categories to omit the word "completed" to more accurately reflect their educational experiences. Hence, the accuracy of some of the information is uncertain.

We also learned from the interviews that many who "completed" elementary school were in an integrated elementary school program for the required 8-year period, but had not necessarily achieved the educational standards of the province of Ontario for Grade 8 graduates. Furthermore, many of those attending high school explained in the qualitative interviews that they had received an adapted curriculum centered around a "life skills" development. Thus, the information on education must be carefully interpreted.

Information on their life opportunities, specifically the proportion participating in volunteer and paid work, and related financial status is presented in Table 5. This table shows a diversity of work experience. There was a very high proportion of youth who did not answer the questions regarding work (average of 75%), compared with only 27% of the adults. Therefore, the proportion responding to the question has been included in the table. It is likely that nonrespondents may not have been working and might be considered part of the "not working and not looking for work" group. Furthermore, the level of financial independence

TABLE 3. Living Situations by Diagnostic Group and Age Subgroups

	CP (%)		SB (%)		ABIc (%)	
	Youth	Adults	Youth	Adults	Youth	Adults
Sample size	129	70	40	13	21	17
Living alone	N/A	14.3	N/A	23.1	N/A	5.9
Living with spouse/partner	N/A	7.1	N/A	15.4	N/A	29.4
Living with parents/siblings	93.0	61.4	100.0	61.5	95.2	58.8
Living in a group home	6.2	14.3	0.0	0.0	0.0	0.0
Other[a]	0.8	2.9	0.0	0.0	4.8	5.9

[a] The youth living in "other" situations were living with grandparents. The adults in the "other" situations were living in shared housing. None of the participants resided in nursing homes.

does not seem to be tightly related to the proportion reporting income from work based on a scatter plot assessment. This may be because of very low wages paid to individuals with disabilities that were insufficient to ensure financial independence. Information corroborating this interpretation was revealed during the interviews in which some participants discussed "workshop" employment for very low wages (i.e., the cost of transportation to/from the participants 'work shop' exceeded the wages earned).

Health Status

The next step in the process was to examine the self-reported health of this population. General health information was collected on the survey using a question employed by Statistics Canada in the National Population Health Survey, which asks "In general, would you say your health is excellent, very good, good, fair or poor?" Due to the extreme rarity of fair and poor responses (3.5% overall), these have been grouped together. This also enabled our data to conform to the Statistics Canada presentation of their data which was used as a reference. The results are shown in Table 6.

The Global Health Ratings from our study have also been presented in graphical format in Figure 3. Thick division lines have been marked on Figure 3 to show the demarcation between those with either excellent or very good health and those with fair, poor or good health. The health of youth with SB is similar to that of other Canadians, but the health of adults with SB is much worse than that of other Canadians. The health

TABLE 4. Highest Level of Education

	CP (%)		SB (%)		ABIc (%)	
	Youth	Adults	Youth	Adults	Youth	Adults
No formal education	3.1	8.6	0.0	0.0	0.0	0.0
Some elementary school	16.3	10.0	5.0	0.0	19.0	5.9
Completed elementary school	74.4	2.9	80.0	0.0	61.9	5.9
High school	6.2	51.4	15.0	46.2	19.0	52.9
College	N/A	15.7	N/A	15.4	N/A	35.3
University	N/A	11.4	N/A	38.5	N/A	0.0

of youth with CP and ABI is similar but slightly worse than that of Canadian youth. However, the difference between the self-rated health of the general Canadian population and clinical subgroups becomes more marked in adulthood. The health of all three clinical groups was noticeably lower among the adults when compared to the youth. This is contrary to the pattern seen in the general population where self-rated health is slightly better among those 24 to 35 years of age in comparison with those 12 to 19 years of age. Furthermore, the SB subgroups show the greatest difference between youth and adulthood: the youth with SB have the best self-rated health, whereas adults with SB have the worst self-rated health of all the clinical subgroups.

Transition to Adult Health Care

We also examined the proportion who believed they had made the transition to the adult health care system. Of the *190 youth participants*, 17.4% (n = 33) reported making the transition, and their mean age at transition reported in this group was 12.5 years (SD = 5.2). These individuals are considered to have made an early and somewhat elective transition, since they remained eligible for child health services at the time the survey was completed. Of the *100 adult participants*, 86% reported making the transition, and their mean age at transition was 18.0 years (SD = 2.64). This is consistent with mandatory age of transition applied by the CRCs. Additional details regarding the transition are provided in Table 7.

TABLE 5. Current Participation in Paid and Unpaid Work

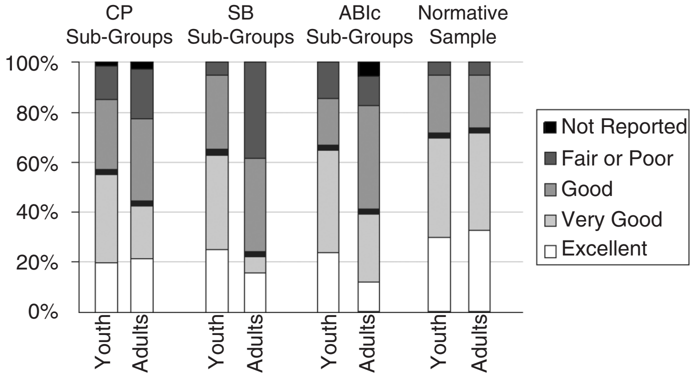
	CP (%)		SB (%)		ABIc (%)	
	Youth	Adults	Youth	Adults	Youth	Adults
Working full-time	0.8	20.0	2.5	30.8	0.0	17.6
Working part-time	2.3	15.7	12.5	23.1	4.8	29.4
Looking for work	6.2	10.0	7.5	23.1	19.0	17.6
Not working and not looking for work	10.1	21.4	15.0	7.7	9.5	23.5
Not reported	80.6	32.9	62.5	15.4	66.7	11.8
Mean rating for degree of financial independence (0 = not independent and 10 = completely independent)	1.3 (SD = 2.6)	3.8 (SD = 4.2)	1.4 (SD = 2.6)	5.8 (SD = 3.9)	3.9 (SD = 3.9)	5.4 (SD = 4.1)
Not reported	4.6	2.9	2.5	7.7	5.3	5.9
Proportion reporting income from work	3.1	28.6	30.4	46.2	4.8	35.3
Not reported	1.5	0.0	0.0	7.7	0.0	0.0

TABLE 6. Global Health Ratings by Age Group and Diagnostic Group

	CP		SB		ABIc		Statistics Canada Data[a]	
	Youth	Adults	Youth	Adults	Youth	Adults	Canadians 12-19 years	Canadians 24-35 years
Sample size	129	70	40	13	21	17	3,242,357	4,172,725
Excellent	19.4%	21.4%	25.0%	15.4%	23.8%	11.8%	30.0%	32.7%
Very good	37.2%	22.9%	40.0%	7.7%	42.9%	29.4%	40.8%	40.6%
Good	28.7%	32.9%	30.0%	38.5%	19.0%	41.2%	24.3%	21.6%
Fair or poor	13.2%	20.0%	5.0%	38.5%	14.3%	11.8%	4.9%	5.1%
Not reported	1.6%	2.9%	–	–	–	5.9%	Not reported	Not reported

[a] The final two columns of the table contain data collected by Statistic Canada as part of the National Population Health Survey. The sample sizes have been weighted to represent the Canadian population. This data was accessed on July 21, 2005 from “Table 105-0022–Self-rated health, by age group and sex, household population aged 12 and over, Canada, provinces, territories, health regions (January 2000 boundaries) and peer groups, every 2 years(1,2,6,7,20)” online at: http://cansim2.statscan.ca

FIGURE 3. Global Health Ratings by Age Group and Diagnosis



Types of Health Care Received

Overall, 30.9% of the sample reported receiving attendant care during the previous year, with an additional 6.3% receiving attendant care within a group home facility. The pattern of attendant care was evenly distributed across a range of 1 to 7 days of attendant care per week. There were 16 individuals (5.5% of our sample) who received daily attendant care. There were 66 individuals (22.8% of our sample) who received respite care during the previous year. An additional 13.5% perceived a significant barrier to accessing respite services. Almost a quarter of participants (22.4%) reported an admission to hospital during the previous year.

The survey also enquired as to whether participants had accessed the services of several health care professionals in the previous year. The list of professionals, in order of prevalence of use, included: Family Physician (95.8%), Dentist (93.2%), Specialist Physician (73.9%), Physical Therapist (61.4%), Occupational Therapist (52.2%), Other Health Care Professional (51.3%), Nurse (36.0%), Social Worker (29.4%), Speech Therapist (18.6%), Dietician (17.1%), and Psychologist (14.6%).

Analysis of the number of different services accessed by those with CP, SB, and ABI, showed that youth were more likely to receive services from a greater number of types of different health professionals in comparison to adults(Figure 4). This relationship holds true when examined within each of the three diagnostic groups. The mean number of services is highest for those with SB, who see 4.5 different types of clinicians on average compared to 3.9 for those with CP and 3.2 among those with ABIc.

DISCUSSION

A careful review of the characteristics of the sample (Table 1) show that the sampling strategies used in this study were effective in recruiting a representative sample, and that the characteristics of the youth and adult cohorts were similar. This suggests that the potential for bias due to attrition of the most severe subset has not manifested itself in this study. Furthermore, despite having different sample sizes in the health services (Part A, n = 1,606), the survey (Part B, n = 290), and the qualitative (Part C, n = 30 + 30 caregivers), all are related to the same eligible sample, and all have similar demographic characteristics. Using mixed-methods design, the linkage of the results from the three different studies has enriched and strengthened the results through our integrated analysis.

This paper has shown the living situations to be slightly different between the youth and adult cohorts, with >92% of youth living with their parents and/or siblings whereas less than 62% of adults were living with

TABLE 7. Ratings of Health Care and Transition Satisfaction

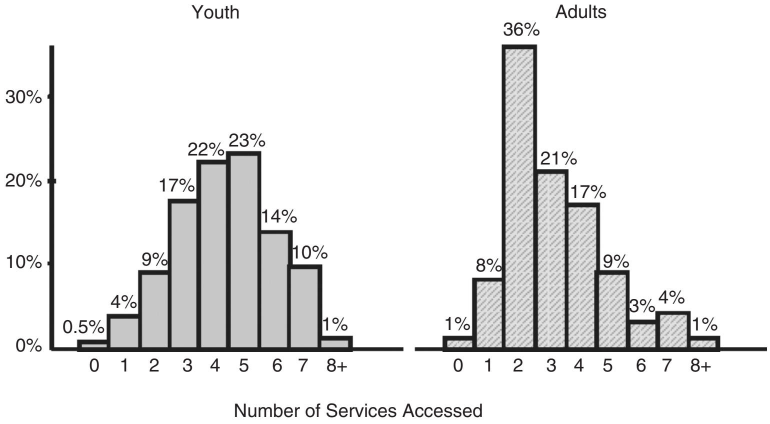
	Youth		Adults	
	Not Yet Transitioned (n = 154)	Have Transitioned (n = 33)	Not Yet Transitioned (n = 154)	Have Transitioned (n = 84)
Proportion who were satisfied with childhood health care	92.2%	93.9%	92.3%	88.4%
Proportion who were satisfied with current health care	90.3%	81.8%	61.5%	73.8%
Mean self-reported difference (Scale of 0 to 10)	5.3 (SD = 2.2)	4.7 (SD = 2.7)	5.1 (SD = 3.2)	4.6 (SD = 2.7)
Degree of stress during transition	N/A	58.3% "Not at all stressful" 29.2% "Extremely" or "Very stressful"	N/A	50.7% "Not at all stressful" 22.0% "Extremely" or "Very stressful"

their parent and/or siblings. The largest difference in living situation occurred as a function of diagnostic groups rather than age groups. While many of the adults with SB or ABI were living with a spouse/partner or on their own, adults with CP were the only group found to be living in group homes. Adults with CP also had the highest frequency of being unemployed and not looking for work, likely because of their disabilities. However, the employment questions were left blank by 75% of the youth, suggesting that "work" may be considered irrelevant or a very sensitive topic for some respondents and should be interpreted with caution.

The information on global health ratings (GHRs) proved very startling. The sharp contrast between moderately good GHRs among the youth, yet much poorer GHRs among the adults was seen most dominantly in the group with SB. The SB-adult subgroup was also the group most likely to have completed higher education and to be living on their own. Further exploration is necessary to better understand this.

Overall, this study has provided a detailed picture of the lives and health situations of a diverse group of youth and adults. This level of detailed information is not yet available elsewhere in the literature. While we expect these results to be generalizable to clients and graduates from children's rehabilitation centers across Ontario, these results will need to be replicated in other samples. It is also important to examine how

FIGURE 4. Number of Health Care Services Accessed by Youth and Adults



life and health outcomes of this group may change over time. This will be the focus of future research.

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NOTES

1. Although most CRC services are limited to children younger than 19 year old, one of the centres also delivered dental care and drivers' education training to adults.

2. December 31, 2002 was selected as the date used in the age calculations because this was the end of the 4-year period of administrative data that was used in the Health Services Analysis (1999-2002) and was the beginning of the Outcomes Survey component of the study.

3. Severity was classified as close to age 10 as possible based on a retrospective review of their chart. The Gross Motor Function Classification System was used for those with cerebral palsy. Level of lesion (functional) was obtained for those with spina bifida. No good marker of severity was available for the group with ABI.

4. Those known to have an acquired brain injury after age 12 were excluded, because the etiology and adaptation to ABIc are known to be different among teens.

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