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## Caregiver Satisfaction with Healthcare Access for Individuals with Developmental Disabilities

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## Abstract

*This study focused on healthcare (i.e., medical, specialized medical and dental care) for high school students with developmental disabilities (DD). Data obtained from caregivers during telephone interviews indicated that the majority of students with DD used healthcare services regularly. Overall caregivers were highly satisfied with the healthcare services that students with DD were receiving.*

## What Are the Healthcare Needs of Individuals with Developmental Disabilities?

Individuals with developmental disabilities (DD) have the same routine health care needs as individuals without DD. Like all persons, individuals with DD need access to basic medical care from a family physician, specialized healthcare (e.g., cardiology, neurology, etc.), and dental care. In addition to routine healthcare needs, individuals with DD have an increased likelihood of diagnosed health problems including seizure disorders, obesity, dental problems such as gum disease, and vision problems (Cheetham & Lovering, 2003; Krahn, Hammond, & Turner, 2006; Ouellette-Kuntz, 2005; Ruddick, 2005).

Access to healthcare is defined as "the actual use of personal health services and everything that facilitates or impedes the use of health services" (Andersen, Rice, & Kominski, 2001, as cited in Nehring, 2005). By this definition, proper access to healthcare includes being able to use healthcare services on a regular basis and in times of need, and the ability to use healthcare services to fully meet one's health needs. As health and healthcare are considered universal human rights (United

Nations Office of the High Commissioner for Human Rights, n.d.), all individuals should have proper access to healthcare, including those with DD. In Canada, the generally accepted standards for regular healthcare service use include seeing a family physician at least once a year, and seeing a dentist every six to nine months. Regular care guidelines for specialized medical care depend firstly upon whether such services are required, and secondly, on the type of care needed (e.g., pregnant women need gynecological care more frequently than other women: Buell & Minnes, 2000).

### **Are the Healthcare Needs of Individuals with DD Being Met?**

Since the 1960s, service delivery in the field of DD has been influenced by the philosophy of normalization and the deinstitutionalization movement that accompanies this philosophy (Radford & Park, 2003). Deinstitutionalization has meant that most individuals with DD must now rely upon community healthcare providers to meet their health-related needs.

A number of studies have been conducted to evaluate whether community healthcare services are adequately meeting the needs of individuals with DD (e.g., Hewitt, Larson, & Lakin, 2000; Levy et al., 2006; Liptak et al., 2006; Minnes, Lauckner, & Recoskie, 2007; Minnes & Steiner, 2009). While the literature overall suggests that most individuals with DD have some access to healthcare, there are disparities in the quality of care received, and the majority of the literature suggests that the healthcare needs of individuals with DD are not being met consistently. Many studies, from Canada, the U.S. and the U.K. indicate that people with DD have high rates of preventable or correctable health problems (Levy et al., 2006; Ouellette-Kuntz, 2005; Ruddick, 2005), and several studies have reported high rates of unrecognized medical problems among individuals with DD (Krahn et al., 2006).

Some studies from the U.S. and the U.K. have reported instances where individuals with DD are receiving adequate healthcare, and that caregivers are generally satisfied with the care that individuals with DD are receiving (Horrell, MacLean, & Conley, 2006; Liptak et

al., 2006; Martin, Roy, & Wells, 1997; Reichard & Turnbull, 2004). However, even when care is satisfactory, concerns are often reported about service providers' knowledge of DD, their qualifications to manage persons with DD, and their ability to answer questions about the disability (Liptak et al., 2006; Martin et al., 1997). These findings suggest that while some physicians may be able to provide good service in general, they are still limited in their knowledge and skills regarding DD.

### **Why are the Healthcare Needs of Individuals with DD Not Being Met?**

Access to healthcare is an issue that is pertinent to all Canadians, including those without disabilities. Particular concerns regarding healthcare access include the availability of family physicians, and long waiting lists for specialized services (Canadian Institute for Health Information [CIHI], 2007). However, it is important to acknowledge that individuals with DD not only have to deal with these Canada-wide challenges, they also have to overcome additional barriers to healthcare. Krahn and colleagues (2006) describe these additional barriers as a "cascade of disparities" that compound unmet healthcare needs for individuals with DD. These disparities include: differences in prevalence rates of adverse health conditions, disparities in attention to care needs including lack of practitioner knowledge of DD and communication barriers, disparities in preventative care and health promotion practices, and disparities in equitable access to healthcare.

### **Healthcare Services in South Eastern Ontario**

Research on healthcare access specifically for individuals with ID living in South Eastern Ontario is limited. In its 2007 service plan for South Eastern Ontario, the Ontario government emphasized two priorities for the healthcare system: the need to ensure that healthcare is more accessible, and that the perceived quality of healthcare be improved in the region (South East Ontario Local Health Integration Network [SEO LHIN], 2007). Given these priorities, and past research on healthcare access for individuals with DD, this study set out to investigate whether the

individuals with DD in South Eastern Ontario were accessing healthcare services regularly, and if the healthcare services received were satisfactory.

Specifically, this study looked at three domains of healthcare: general medical care, specialized medical care, and dental care. The following research questions were investigated: (1) Are students with DD accessing healthcare on a regular basis? If not, why not? (2) How satisfied are caregivers with the healthcare services that students with DD are receiving?

## Method

### Participants

Data for this study were collected as part of a larger research project focusing on students with DD preparing to leave high school under the auspices of the South Eastern Ontario Community-University Research Alliance in Intellectual Disabilities (SEO CURA in ID; <http://www.seocura.org/>). This paper focuses only on healthcare related issues whereas other studies have focused on employment, volunteer, social and recreational activities (Burbidge, Minnes, Ouellette-Kuntz, & Buell, 2008; Abells, Burbidge, & Minnes, 2008). The project was reviewed and approved by the Research Ethics Board at Queen's University.

Respondents were 63 caregivers (87% female, 13% male) of high school students with DD from South Eastern Ontario. Their ages ranged from 34 to 63 years ( $M=48.12$ ,  $SD=6.42$ ). The majority of informants were married (63%), and most had a high school diploma (30%) or community college certificate (25%) as their highest level of education. Their median household income level was \$45,001-\$55,000. Income was found to be significantly correlated with education ( $r=.29$ ;  $p<.05$ ).

Sixty-three students (33% female, 66% male) were the focus of the study. All students had some form of DD; disabilities reported included: Down syndrome ( $n=10$ ), Autism Spectrum Disorder ( $n=12$ ) and chromosomal abnormalities ( $n=4$ ). Student ages ranged from 14 years to 21 years ( $M=18.07$ ;  $SD=1.54$ ).

### Procedure

Information packages were distributed through schools, and students were asked to pass the information on to their caregivers. Students who were able to give consent and parents both completed consent forms. Interested parents were asked to contact the researchers to arrange for a telephone interview.

### Measures

The original interview contained several measures, three of which were used in this study:

*Demographic Questionnaire:* Student information (age, gender, type and degree of disability), and caregiver information (age, gender, highest level of education, family income) were collected.

*Scales of Independent Behaviour—Revised Short Form (SIB-R SF):* The SIB-R SF (Bruininks, Woodcock, Weathermann, & Hill, 1996) assesses adaptive and maladaptive behaviour. Adaptive behaviour is measured on a Likert-type scale, ranging from 0 (“never or rarely”) to 3 (“always or almost always”). The SIB-R SF yields six indices: Internalized Maladaptive Behaviour Index (IMI), Asocial Maladaptive Behaviour Index (AMI), Externalized Maladaptive Behaviour Index (EMI), General Maladaptive Behaviour Index (GMI), Support Score (which indicates the level of support that is needed), and an Age Equivalent Score. The SIB-R SF has internal consistency of .80 for the age group of this study, and overall construct validity of .95 (Bruininks et al., 1996). In this study adaptive behaviour will be reported as an age difference score: the difference between chronological age and the SIB-R age equivalent score.

*The AIMS Interview:* The AIMS Interview (Minnes, Buell, Feldman, McColl, & McCreary, 2002) measures the degree to which the needs of an individual with DD are identified and supported in a way that promotes participation in the community. This measure investigates ten domains of service use, three of which were used in this study: medical, specialized medical, and dental services. The AIMS Interview has been shown to have good content and concurrent validity (Minnes et al., 2002).

## Results

### Adaptive and Maladaptive Behaviour

Table 1 indicates the mean score and range of scores on each of the maladaptive behaviour subscales of the SIB-R SF. Students with ID in our sample were reported to have maladaptive behaviour scores within the “marginally serious” to “normal” range according to the SIB-R SF standards. Support scores on the SIB-R ranged from 1 to 91 ( $M=64.7$ ,  $SD=18.6$ ). Based on their support scores, students were categorized into the level of support they needed. Support levels ranged from infrequent or no support to pervasive.

Adaptive functioning levels were calculated by subtracting the students’ age equivalent scores from their chronological ages at the time of the interview, to create an age difference score, which is an indicator of how much lower the student’s level of functioning is from what is expected for a student of the same age without a disability. The age difference scores ranged from 1.8 years (22 months) to 19.6 years (253 months) ( $M=10.17$  years,  $SD=4.09$ ). For this measure, a greater age difference score, corresponds to lower functioning level.

#### 1. Were students with DD accessing health care on a regular basis? If not, why not?

**Medical services:** Based on responses from the AIMS Interview, the majority of students were reported to be seeing a family physician on a regular basis (70.3%,  $n=45$ ). Reasons for students not seeing a family physician regularly included: no physician available ( $n=4$ ), choosing not to go

( $n=1$ ), thinking there is no need ( $n=7$ ), feeling like a doctor can’t help ( $n=1$ ), and only going when sick ( $n=4$ ). No participants reported that they did not see a family physician because of the student’s disability. (Note that participants were able to select more than one reason). In all but two cases, respondents reported in the AIMS Interview that their doctor knew about the person’s disability-related needs. In the two cases where the answer to this question was “no,” the reasons given were that a) the person was not always seen by the same physician during medical visits and therefore the physician would know that there was a disability but would not know the specific details and b) the person had very irregular visits to the doctor. The satisfaction score for the former case was 3 or moderate but was left blank in the latter case.

**Specialized medical services:** Based on responses from the AIMS interview, approximately half of our sample reported having specialized medical needs that required a specialist ( $n=31$ ). A large variety of specialists were reported to have been seen for these needs, including psychiatrists, ear nosethroatspecialists, pediatricians, cardiologists and psychologists (note that participants were able to list more than one specialist, so responses are not mutually exclusive). Seven students (22.6% of students with special medical needs) were reported to have unmet special medical needs including: speech problems ( $n=3$ ), ADHD ( $n=1$ ), psychological needs ( $n=1$ ), physiotherapy ( $n=1$ ), and foot problems ( $n=1$ ). The most common reason given by participants for not seeing a specialist was being on a waiting list ( $n=2$ ). In all cases, respondents reported that specialists knew about the person’s disability-related needs.

Table 1. Student SIB-R SF maladaptive behaviour scores

Maladaptive behaviour subscale	Min.	Max.	M	SD
Internalized	-40.00	3.00	-11.35	11.12
Asocial	-40.00	5.00	-10.68	10.60
Externalized	-36.76	5.00	-4.95	10.60
General	-44.00	0	-12.63	10.70

Note: Lower negative scores indicate more maladaptive behaviour

**Dental services:** Based on the AIMS Interview, most students were reported to be seeing a dentist regularly (84.4%, n=54). The most common reason for not seeing a dentist regularly was “no dentist available.” For three students the reason given for not seeing a dentist regularly was their disability, and one was not going because of fear. Note that reasons are not mutually exclusive, as respondents were able to select more than one reason. In seven cases, respondents indicated that the dentist did not know about the person’s disability. The main reason given was that the parent did not feel there was any reason to tell the dentist or that it wasn’t important for the dentist to know (n=4). One parent indicated that they did not know if the dentist knew, another indicated that the secretary knew and another indicated that they had a new dentist and hadn’t told him yet.

## 2. How satisfied were caregivers with the healthcare services that students with DD were receiving?

Satisfaction was measured in the AIMS interview on a five-point scale asking “How well are ( )’s medical/special medical/dental needs being met by their family physician/medical specialist(s)/dentist”? Most participants reported that healthcare providers in all three domains were providing support for disability-related needs. When support was not provided, the primary reason given was that support was not needed (i.e., Medical domain (n=7); Additional medical domain (n=1); Dental domain (n=11)).

**Medical services:** The mean score for satisfaction with how well the physician was meeting the student’s needs was 4.22 out of 5 ( $SD=1.09$ ), which falls in the “mostly satisfied” range. Scores ranged from 1 to 5 (out of 5). Satisfaction scores were missing for 9 participants. The frequency of each satisfaction score is displayed in Figure 1. Satisfaction scores for medical services were negatively skewed, however scores were not adjusted to avoid loss of data. In cases where low satisfaction scores were reported 3 or less, 4 respondents referred to problems with their physician’s lack of knowledge (e.g., “the doctor doesn’t think that there is anything wrong (with the child)”; “they have a lack of training and experience with autism”; “doctor is not aware of help available”; “doctor doesn’t have

a lot of experience with disabilities”; and in one case the parent indicated that their child needed a developmental pediatrician but there wasn’t one available. In other instances, parents who gave high satisfaction ratings (4 or 5) still indicated problems with support received from their physician (e.g., “the doctor just doesn’t have time,” “they’re just too busy.” Examples of positive support provided by physicians included: effective communication (e.g., “explaining at child’s level as simply as possible,” “patient, engages with child,” “communicates clearly,” “tries to let her know exactly what they’re doing to decrease anxiety”), friendly and helpful manner; (e.g., “treats child as a person”; “takes things seriously”); flexibility: (e.g., “will see on short notice,” “takes more time,” “open to new ideas”); collaborative approach: (e.g., “makes referrals when needed,” “co-ordinates specialists,” “writes letters and fills out paper work for disability tax credit,” “takes phone calls,” “monitors medications”).

**Specialized medical services:** Overall, respondents were very satisfied with the specialized medical services students received; the mean satisfaction score was 4.53 out of 5 ( $SD=0.76$ ), which falls in the “mostly satisfied” range. The frequency of reported satisfaction scores is displayed in Figure 1. As each respondent was able to report satisfaction scores for up to five different specialists, the mean of specialist ratings was calculated for each participant, for use in later analyses. Mean specialist ratings were negatively skewed, ranging from 3 to 5 but were not adjusted for fear of losing information. Despite these positive ratings, some parents indicated the need for additional services for their child including psychology/counselling (n=2), physiotherapy (n=3), gynecologist (n=1), psychiatry (n=2), occupational therapy (4), speech therapy (7), behaviour therapy (6), pediatric endocrinologist for diabetes (n=1), developmental pediatrician (n=1), a special unit in hospital for people with dual diagnosis (n=1). Examples of positive supports provided by specialists were very similar to those related to medical practitioners above including: clear communication, providing information, taking extra time, being patient and compassionate, writing letters, accommodating child’s behaviour using a separate room if necessary, flexible scheduling of appointments.

*Dental services:* As indicated in Figure 1, the majority of respondents reported being highly satisfied with the dental services that students were receiving. The mean satisfaction rating was 4.53 ( $SD = .82$ ), which falls in the “mostly satisfied” range, with ratings ranging from 2 to 5 out of 5. Satisfaction with dental services scores were negatively skewed, but were not adjusted to avoid losing information. Despite these high ratings, 11 parents suggested additional dental needs including: more training for their child on day to day care of teeth, 5 parents indicated the need for an orthodontist, and 3 indicated that the child needed braces. In one of the latter cases, the parents indicated that the dentist did not think that the child could handle the procedure although the parent disagreed. In another case, the parent indicated that braces were needed but it was not a priority, and in another case, braces were needed but the parent didn’t have the money. Two parents indicated the need for a dentist specializing in the needs of individuals with developmental disabilities.

Examples of support provided by dentists included: dentist’s manner and personality (e.g., “friendly,” “gentle,” “calm,” “patient,” “very careful,” “joking”); efforts to alter communication (e.g., “speaking in simpler language”; “giving instructions for hygiene as needed”; “going slower and telling the child exactly

what he is doing”); Additional examples included: “following the parent’s lead”; “using sedation”; “using general anesthesia and more staff if needed”; “scheduling more frequent appointments,” “taking more time,” “flexibility”: “seeing the child on short notice” and “knowledge and experience of developmental disabilities.”

## Discussion

This study examined access to healthcare for high school students with DD living in South Eastern Ontario. The majority of students in this study were reported to be seeing a family physician on a regular basis. The most common reason for not seeing a family physician regularly was that no physician was available. These findings reflect the serious shortage of family physicians in Canada (CIHI, 2007) but also in the Kingston region. In 2006, approximately 20,000 Kingstonians were estimated to be without a family doctor (Kingston City Council, 2006) and these numbers were expected to increase as many primary care physicians in the Kingston area were projected to retire in the next few years. According to the informants in this study, basic access to regular appointments with a family physician was not limited by the students’ disability. Other reasons given for not seeing a family physician regularly were personal choice and attendance only when sick.

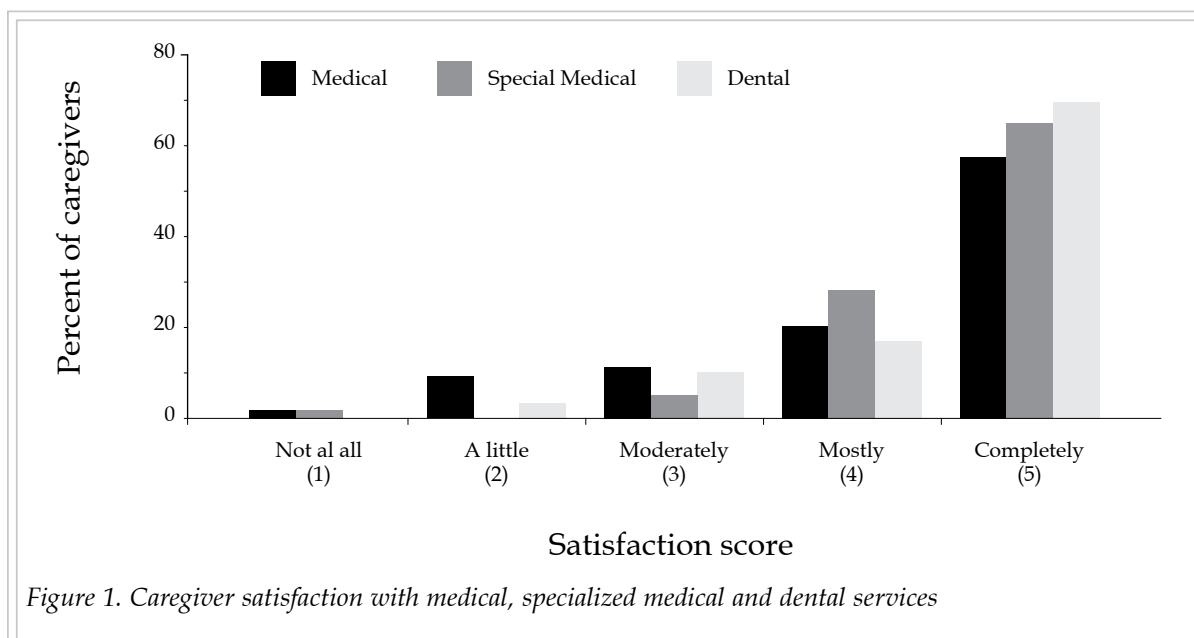


Figure 1. Caregiver satisfaction with medical, specialized medical and dental services

Future research needs to expand on the reasons that participants choose not to use healthcare regularly in order to determine if these reasons are disability-related. Furthermore, research is needed to investigate whether individuals and families are aware of guidelines for regular healthcare use and, if so, reasons for not following them.

This study also supports previous literature that reports that individuals with DD have a greater number and variety of medical needs (Ouellette-Kuntz, 2005). Approximately half of the students in the sample were reported to have medical needs requiring a specialist, and a wide variety of needs were reported. Contrary to expectation, most of the students with specialized medical needs were reported to be seeing a specialist for these needs, and those who were not were mostly on waiting lists for services such as speech therapy or psychology.

The majority of students in this study were seeing a dentist regularly. Of those students who were not seeing a dentist, the primary reason given was unavailability of dentists, although some respondents indicated that the disability limited their use of dental services. Across the three domains of healthcare, dental care was the most likely to not be used for disability-related reasons, suggesting that dental care is particularly inaccessible for students with DD. According to past research, individuals with DD may have particular difficulty finding a dentist (Allison et al., 2000; Schultz et al., 2001). In addition, the invasive nature of dental care, the length of procedures and requirement that the individual sit in a chair may create additional barriers for individuals with DD.

Boychuk (2002) suggests that, particularly in Canada, there is a discrepancy between general and individual perceptions of satisfaction with healthcare such that many Canadians report believing that most Canadians are dissatisfied with the healthcare they receive, but on an individual level report being satisfied with the healthcare they receive. This perception may also come into play with the DD population (i.e., there may be an overall perception that the quality of healthcare received is worse than what individuals report). In the current study, caregivers reported being very satisfied with

the healthcare that students with DD were receiving in all three domains (i.e., medical, specialized medical and dental care). The high satisfaction ratings found may be attributable to the amount and variety of support provided for the students' disability-related needs. Such supports included careful communication, referrals, extra time, and a supportive manner. In previous literature, caregivers of individuals with DD have reported that these supports are particularly helpful and that they increase their satisfaction with healthcare services (Liptak et al., 2006; Martin et al., 1997; Minnes et al., 2005; Minnes & Steiner, 2009). Most participants reported that healthcare providers in all three domains were providing support for disability-related needs, and when support was not provided, it was most often not necessary. Correlational data and regression analyses exploring demographic characteristics, and levels of adaptive and maladaptive behaviour as predictors of caregiver satisfaction will be reported in a future publication.

## Limitations and Future Directions

The results of this study need to be considered with some caution. The sample may not be representative as it comprised relatively high functioning students with DD in high schools in South Eastern Ontario. As well, participating families were highly involved in services and self-selected for involvement in the study. Further research with a larger, more diverse sample including individuals without DD is needed.

The AIMS Interview used in this study obtained useful initial information regarding healthcare access and supports through the use of open-ended questions. However, further research is needed to investigate the issues raised in more detail by asking specific questions. The use of caregiver satisfaction ratings to evaluate access to healthcare also has some limitations. There may be a lack of consistency in standards of satisfactory healthcare among participants. Furthermore, satisfaction doesn't necessarily indicate good healthcare. Future research would benefit from a new proxy and direct measure of healthcare access and quality. The measures of health status and satisfaction with care currently in the literature (e.g., parent satisfaction surveys: Liptak et al., 2006, examination of medical

conditions: Levy et al., 2006) may be focusing on two important, but very different aspects of healthcare access. Future research should utilize both of these measures and include other measures of healthcare access, such as reports from care providers as well as parents and observational methods.

This study originally intended to collect data from both caregivers and students with DD, but the interview was soon found to be too difficult for many students to complete. Some literature suggests that as the subjectivity and detail of questions increases, the agreement between individual and proxy responses decreases (McVilly & Rawlinson, 1998). However, as most of the questions asked in this study dealt with fairly concrete topics, the issue of proxy responses may not be as significant as it would be if we were measuring more abstract constructs. In addition, it is not clear whether the students would have been able to answer many of the questions regarding supports provided. Future research would benefit from consideration of methods to gather information from students with DD as well as caregivers.

A number of additional factors that were not investigated in this study may have relevance to caregiver satisfaction with healthcare. These factors include the health status of the students with DD, as well as potential preventative health concerns. Future research is needed to examine factors including the health status of students with DD and preventative health concerns. Furthermore, useful information could be obtained through follow up interviews with caregivers who reported being dissatisfied with healthcare to determine reasons for their dissatisfaction and to consider strategies to better meet their needs.

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