

Availability and Delivery of Speech-Language Pathology Services for Adults with Intellectual Disabilities in South-Eastern Ontario

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Abstract

This paper describes the provision of speech, language, swallowing, and Augmentative and Alternative Communication (AAC) services for adults with intellectual disabilities (ID) in South-Eastern Ontario. Results reveal that the needs of persons with ID requiring communication supports are not being met. Given this mismatch of service and need, the Communication Helper Program was developed. Sixteen developmental service agencies have designated staff member(s) to serve as Communication Helpers (CH). The purpose of the program is to ensure that communication and/or feeding programs are maintained over time, and for the CH to promote improved communication interactions and swallowing safety within each agency.

Communication is a process by which individuals exchange information and convey ideas (Owens, 1990). All people communicate in some way, although the effectiveness and efficiency of their communication can be affected by intrinsic and extrinsic factors. Communication disorders may arise from congenital causes, ageing, sensory impairments, or neurological trauma. The most common causes of severe communication disorders include: intellectual disability (ID), cerebral palsy, autism, developmental apraxia of speech (Mirenda & Mathy-Laikko, 1989), traumatic brain injury, aphasia, amyotrophic lateral sclerosis, multiple sclerosis, and different types of dementia.

Intellectual disability (ID) is generally understood to describe a set of human characteristics similar to those described by mental retardation as defined by the American Psychiatric Association (2000): 1) sub-average intellectual functioning (IQ<70); 2) concurrent limitations or alterations in adaptive

functioning, lowered ability to cope with common life demands and to meet the standards of personal independence expected of them in at least two of the following domains: communication, self-care, domestic skills, social skills, self-direction, community, academic skills, work, Leisure, and health and safety; and 3) onset before age 18. Persons with ID have a reduced cognitive and intellectual capacity to learn language and communication skills. These individuals are also at greater risk for additional neurological and sensory disorders (epilepsy, hearing impairment, visual impairment, and autism) and, as a result, many develop unconventional, unclear or socially inappropriate methods to communicate. In addition to these intrinsic factors, environmental factors such as social policy, life experiences, and skills of the communication partner may also impact on the communication skills of persons with ID.

The practice of speech-language pathology comprises assessment of speech and language functions and the treatment and prevention of speech and language dysfunctions or disorders to develop, maintain, rehabilitate, or augment oral motor or communicative functions (Audiology and Speech-Language Pathology Act, 1991). In addition to providing direct treatment, Speech-Language Pathologists have assumed a training role to provide caregivers with the skills and strategies to assist persons with communication and swallowing disorders.

All persons, regardless of the extent or severity of their disabilities, have a basic right to communication. Since 1976, the Ministry of Community, Family, and Children's Services has been funding speech-language pathology services in institutional settings. Adequate speech, language, augmentative and alternative communication (AAC), and swallowing services in the community are essential to help individuals attain skills. However, these services may not be available in all geographic areas. A lack of such services can create barriers to inclusion and threaten individuals' quality of life, in addition to putting their health at risk.

Prevalence of Speech, Language and Swallowing Disorders

Estimates of prevalence rates of intellectual disabilities in the general population vary widely depending on research design and diagnostic criteria (McCreary, Peppin & Stanton, 2001). Individuals with ID make up 1-3% of the population in Canada (Bradley, Thompson & Bryson, 2002; Ministry of Health and Welfare Canada, 1988; Ouellette-Kuntz & Paquette, 2001), with 2.25% of the total population considered to be a realistic estimate (Yu & Atkinson, 1993). A significant proportion of these individuals will also have

co-morbid conditions. A conservative prevalence figure of 1% was used here, since prevalence figures of about 1% typically result from estimates based on people known to service systems. Figure 1 provides the estimates, based on a 1% prevalence rate, of the numbers of adults with ID for each county in South-Eastern Ontario.

Figure 1. Estimates of number of adults with intellectual disabilities in South-Eastern Ontario, based on 1% prevalence rates.



Prevalence figures for communication and swallowing impairment in adults with an intellectual disability vary according to study methodology, population, type of disorder, degree of intellectual impairment, and other variables. There is limited information in the literature on the prevalence of communication and feeding/swallowing disorders for non-institutionalized adults with ID. What has been clear for some time, however, is that a higher than normal frequency of communication and swallowing disorders, as well as hearing impairments, are found in these individuals (Keane, 1972; Lloyd, 1970; Matthews, 1971; Perkins, 1971; Zarate, Mearin, Hidalgo & Malagelada, 2001).

Using adult subjects living in community residences, Reynolds and Reynolds (1979) found a 51% prevalence of speech and language disorders with a 15% prevalence of hearing disorders, based on caregiver perceptions. A study conducted in the city of Ottawa, Ontario found that 27% of adults with ID were perceived by caregivers as needing speech, language, and audiology services and that 65% of these adults were not receiving these services (Murphy, Paquette, Ouellette-Kuntz, Stanton & Garrett, 1999). Studies reporting the prevalence of speech, language, and hearing disorders in the non-institutionalized intellectually disabled population are limited to the perceptions of caregivers, who may be unfamiliar with the range of the field of speech-language pathology.

Dysphagia is a swallowing disorder that occurs in approximately 13% to 14% of patients in acute care hospitals, in 30% to 35% of patients in rehabilitation centers, and in 40% to 50% of patients in nursing home facilities (Logemann, 1995). Roger and colleagues (1994) found that 33% of adults with an intellectual disability living in a residential facility or community-based homes were referred to a Feeding Disorders Clinic due to swallowing difficulties. Zarate and colleagues (2001) found a prevalence of 50% for swallowing disorders in a small sample of adult Down's syndrome patients.

These estimated prevalence figures for speech and language problems and for dysphagia in the adult intellectually disabled population are not mutually exclusive, and there is probably considerable overlap. It is thought that a minimum of 40% of people with intellectual disability have communication and swallowing disorders. Communication disorders include significant impairments in the areas of: articulation, voice, fluency, comprehending language, using language to communicate information, pragmatics, and literacy.

Availability and Delivery of Speech-Language Pathology Services for Adults with Intellectual Disabilities in South-Eastern Ontario

Survey

To evaluate the availability and delivery of speech-language services for adults with ID in South-Eastern Ontario, information was collected over a 3-month interval (May to July 2002). More than 40 key informants from health care organizations and developmental service agencies were contacted by telephone and asked questions pertinent to the provision of speech-language

pathology services. The survey represents an effort to contact any and all agencies and service providers. In most instances, the informants were staff of developmental service agencies or Speech-Language Pathologists.

Availability of services

- Swallowing assessments (Videofluoroscopic and Bedside) are available for all adults with an intellectual disability across South-Eastern Ontario at designated local hospitals and through Community Care Access Centres, respectively. However, direct treatment, staff training, and follow up services are limited.
- The Community, Communication and Feeding Program (CCFP) provides speech, language, low-tech AAC and feeding/swallowing assessment, consultation, and education/training services for adults with ID in the counties of Hastings, Prince Edward, Lennox & Addington, Frontenac, and Leeds & Grenville. One full-time equivalent position is divided between these 5 counties.
- Lanark Community Programs provides speech, language, and low-tech AAC services to preschoolers and adults with ID throughout Lanark County. Approximately 0.1 full-time equivalent position is currently serving adults.
- Renfrew County and District Health Unit through the Developmental Support Services Program provides speech, language, and low-tech AAC services to preschoolers and adults with ID. This program uses an Ottawa-based S-LP on a fee-for-service basis to complete assessments and supervise the program's Communicative Disorders Assistant (CDA), who implements communication treatment goals. Approximately 0.1 full-time equivalent position is currently serving adults.
- A variety of congenital or acquired impairments can cause the inability to speak or write without adaptive assistance. High-tech AAC services are not available for adults with congenital or acquired injuries in the counties of Hastings, Prince Edward, Lennox & Addington, Frontenac, and North Lanark. Consequently, individuals who may benefit from AAC and who are eligible for funding through the Assistive Devices Program (ADP), are unable to receive these services. In areas of Ontario that have general and expanded AAC clinics for adults, funding for communication devices through ADP is limited to individuals with a primary diagnosis of physical disability, leaving many individuals who are in need of AAC devices

but who are not physically disabled (e.g., autistic), without funding. High-tech AAC services are available for this population in the counties of Renfrew, South Lanark, Leeds & Grenville, Ottawa-Carleton, Prescott & Russell, and Stormont, Dundas & Glengarry through the Rehab Centre-Ottawa only if there is an associated significant physical disability and the cognitive ability beyond simple choice making. Successful use of high-tech communication devices by adults with ID in all geographical regions is confounded by the lack of community based S-LPs to monitor the client's progress, train caregivers, and update the device as needed.

· Speech, language and low-tech AAC services are not available to adults with an intellectual disability in Ottawa-Carleton, Stormont, Dundas, Prescott & Russell with the exception of Glengarry County where the local Association of Community Living has acquired low-tech AAC assessment and consultation services on a fee-for-service basis from a Toronto-based S-LP.

Delivery of services

Adequate service delivery requires human resources. There is a shortage of Speech-Language Pathologist's (S-LPs) across South-Eastern Ontario to serve adults with intellectual disabilities. According to a study conducted in Australia (Enderby & Davies, 1989), the equivalent of 4.1 full-time S-LPs per 100,000 adult population are required to provide speech services to adults with an intellectual disability.

Table 1 shows, for each county, the estimated number of adults who require speech-language pathology services, the number of S-LPs currently designated to provide those services, and the projected number of S-LPs needed (based on Enderby and Davies, 1989).

Table 1. Current and Needed Speech Language Pathologists in South-Eastern Ontario

<i>County</i>	<i>Estimated number S-L clients</i>	<i>Current number of S-LPs</i>	<i>Number of S-LPs needed</i>
Hastings	413	0.2	4
Prince Edward	90	0.2	1
Lennox & Addington	134	0.2	1
Frontenac	464	0.2	4

cont'd

Table 1. (Cont'd)

<i>County</i>	<i>Estimated number S-L clients</i>	<i>Current number of S-LPs</i>	<i>Number of S-LPs needed</i>
Renfrew	336	0.1 (CDA)	3
Lanark	210	0.1	2
Leeds & Grenville	334	0.2	3
Ottawa-Carleton	2,592	0.0	26
Prescott Russell	262	0.0	2
Stormont, Dundas & Glengarry	380	0.0	4
Total	5,215	1.1	50
		0.1 (CDA)	

Source: Ontario Population Projections, 1999-2-28, Ontario Ministry of Finance, July 2000.

Education and knowledge issues

While conducting this survey, it became clear that many agencies were either unaware of, or mistaken about, the availability of speech, language, swallowing, and AAC services for adults with ID in their area. Furthermore, caregivers and service providers seemed unclear of the role of a S-LP in serving individuals with ID. There appears to be an obvious need to acquaint care providers with the knowledge that access to services begins with care providers being able to refer to the appropriate service(s).

Also, caregivers need to understand the basics of feeding/swallowing and communication. Swallowing difficulties can be life-threatening which means that risk factors need to be recognized quickly. Communication permeates all daily activities, and it needs to be fostered throughout the life span for individuals with ID. Training caregivers in these areas is paramount to ensuring maximal functioning and quality of life to persons with ID. This training needs to begin at the college level and continue through the provision of in-services in the workplace.

While conducting this survey, it became clear that staffing changes and turnover rates impact negatively on the consistent implementation and use of communication and feeding/swallowing strategies that are set in place for clients by a S-LP. Furthermore, it appeared that once a client had met their therapeutic goals and the services of the S-LP were removed, implementation of the daily functional program was often discontinued.

Successful communication and swallowing skills for adults with ID begin with each agency's individual commitment to maintaining programs established by the S-LP on a long-term basis.

Recommendations

There is a lack of adequate speech, language, swallowing, and AAC services for adults with an intellectual disability across South-Eastern Ontario, but most notably in the counties of Ottawa-Carleton, Stormont, Dundas & Glengarry, and Prescott & Russell. It is important that government Ministries responsible acknowledge funding shortfalls that have led to the present gaps in service.

Other inconsistencies need to be addressed as well. For example, the Assistive Devices Program (ADP) provides financial assistance to Ontarians of all ages that have a primary diagnosis of physical disability, to purchase selected, basic, personalized assistive devices. Many individuals with intellectual disabilities have communication impairment but do not have a physical disability (e.g., autism) and therefore are not eligible for ADP funding.

Recommendation 1: Hire Speech-Language Pathologists. An estimated 50 S-LPs are required to provide adequate services to adults with ID across South-Eastern Ontario. Currently, there are 1.1 S-LPs and 0.1 Communicative Disorders Assistants (CDAs) to serve to the communication and swallowing needs of an estimated 5000 adults with ID across South-Eastern Ontario. S-LPs may be hired on a contract, full, or part-time basis. It is recommended that interagency developmental service planning groups work with the MOHLTC and the MCFCS to hire S-LPs.

Recommendation 2: Hire Communicative Disorder Assistants (CDAs). Employing CDAs is an alternate solution to hiring a full-time S-LP. The use of CDAs and other supportive personnel has increased over the years. The primary benefit of using a CDA is that the salary is less than that of an S-LP. According to the College of Audiologists and Speech-Language Pathologists of Ontario (CASLPO), the role of a CDA is to implement treatment plans developed by the S-LP following a complete assessment, conduct speech-language or hearing screenings, assist the S-LP during assessments, and perform general clerical duties. Limitations in using CDAs are that they need to be supervised by a S-LP, they are unable to perform assessments and they cannot modify treatment plans. Local S-LPs could be contracted to provide the required supervision of CDAs.

Recommendation 3: Designate a Staff Member as a Communication Helper. Consistent implementation of communication and swallowing programs over a client's lifetime requires commitment from the supporting agency. This is challenging because of staffing changes and high turn over rates. A solution may be for an agency (or group of agencies) to designate a staff member to ensure that communication and/or feeding programs established by an S-LP are maintained over the long-term and to promote improved communication interactions and swallowing safety in general within each agency. The Community, Communication and Feeding Program has developed the Communication Helpers project to train designated staff members as Communication Helpers (CH). Each CH attends two full days of training conducted by a licensed Speech-Language Pathologist, receives a manual covering information from the training and containing handouts to share with other staff, and receive support from the S-LP through ongoing consultations via telephone, fax, email, and direct visits. Unlike a CDA, the communication helper would not be performing 'therapy' or implementing any specific treatment goals.

Recommendation 4: Include Community Education in S-LP Service Delivery in order to share knowledge. Education is needed to ensure that families and service providers are working together to recognize and address client needs. The Community, Communication and Feeding Program has developed five workshops to educate caregivers on basic communication and feeding/swallowing issues as they relate to persons with ID. These workshops are offered free of charge to agencies in the counties of South-Eastern Ontario. Agencies serving adults with ID need to provide continuing education to their staff in the areas of communication and feeding/swallowing to ensure that their clients achieve maximal functioning in society. Based on a survey of courses available to community college developmental service worker students, there is a striking lack of courses designated to teach communication and feeding/swallowing skills. Students need to acquire such fundamental information before entering the workplace and these skills need to be taught in college programs by Speech-Language Pathologists.

Recommendation 5: Establish a general or expanded AAC clinic for adults. In those counties where there is a S-LP program, low-tech AAC services are available. High-tech AAC services are provided at designated clinics and focus primarily on acquired injuries. Currently, the Rehab Centre-Ottawa provides high-tech AAC services to adults in their catchment area, who are significantly physically disabled and have cognitive ability beyond simple choice making. There are no high-tech AAC services for

adults with congenital or acquired injuries in Hastings, Prince Edward, Lennox & Addington, Frontenac, and North Lanark counties. Consequently, individuals who may benefit from AAC and who are eligible for ADP funding are unable to receive these services. In areas of Ontario that have general and expanded AAC clinics for adults, funding for communication devices through ADP is limited to individuals with a primary diagnosis of physical disability, leaving many individuals that do not have a physical disability (e.g., autistic), but who are in need of AAC devices, without funding.

References

- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders: Text revision*. Washington, DC: Author.
- Audiology and Speech Pathology Act, 1991, S.O. 1991, c.19, s. 3(2).
- Bradley, E., Thompson, A., & Bryson, S. (2002). Mental retardation in teenagers: Prevalence data from the Niagara Region, Ontario, Canada. *Canadian Journal of Psychiatry*, 47, 427-434.
- Enderby, P., & Davies, P. (1989). Communication disorders: Planning a service to meet the needs. *British Journal of Disorders of Communication*, 24, 301-331.
- Keane, D. V. (1972). The incidence of speech and language problems in the mentally retarded. *Mental Retardation*, 10, 3-8.
- Lloyd, L. (1970). Audiological aspects of mental retardation. In N. R. Ellis (Ed.), *International review of research in mental retardation* (Vol. 4). New York: Academic Press.
- Logemann, J. A. (1995). Dysphagia: Evaluation and treatment. *Folia Phoniatrica et Logopedica*, 47(3), 140-164.
- Mathews, J. (1971). Communication disorders in the mentally retarded. In L. E. Travis (Ed.), *Handbook of speech pathology & audiology*. New York: Appleton-Century-Crofts.
- McCreary, B. D., Peppin, P., & Stanton, B. (2001). *Catalysts for university education in developmental disabilities*. Developmental Consulting Program, Queen's University, Kingston, ON.
- Ministry of Health and Welfare Canada. (1988). *The epidemiology of mental retardation*. Ottawa, ON: Government of Canada.
- Mirenda, P., & Mathy-Laikko, P. (1989). Augmentative and alternative communication applications for persons with severe congenital communication disorders: An introduction. *Augmentative and Alternative Communication*, 5, 3-13.
- Murphy, K. E., Paquette, D. M., Ouellette-Kuntz, H., Stanton, B. L., & Garrett, S. (1999). Survey of the need for speech, language and audiology services among adults with developmental disabilities in the community. *Journal on Developmental Disabilities*, 6(2), 1-14.

- Ontario Ministry of Finance. (July 2000). *Ontario Population Projections, 1999-2028*. Retrieved January 7, 2004, from www.gov.on.ca/FIN/english/demogeng.htm
- Ouellette-Kuntz, H., & Paquette, D. (2001). The prevalence of developmental disabilities in Ontario. *Journal on Developmental Disabilities, 8*(1), 1-16.
- Owens, R. E. (1990). Communication, language and speech. In G. Shames & E. Wiig (Eds.), *Human communication disorders* (3rd ed.). Columbus, OH: Merrill/Macmillan.
- Perkins, W. (1971). *Speech pathology: An applied behavioral science*. St. Louis, MO: The C.V. Mosby Company.
- Reynolds, W., & Reynolds, S. (1979). Prevalence of speech and hearing impairment of noninstitutionalized mentally retarded adults. *American Journal of Mental Deficiency, 84*(1), 62-66.
- Rogers, B., Stratton, P., Msall, M., Andres, M., Champlain, M. K., Koerner, P., & Piazza, J. (1994). Long-term morbidity and management strategies of tracheal aspiration in adults with severe developmental disabilities. *American Journal of Mental Retardation, 98*, 490-498.
- Yu, D., & Atkinson, L. (1993). Developmental disability with and without psychiatric involvement: Prevalence estimates for Ontario. *Journal on Developmental Disabilities, 2*(1), 92-99.
- Zarate, N., Mearin, F., Hidalgo, A., & Malagelada, J. R. (2001). Prospective evaluation of esophageal motor dysfunction in Down's syndrome. *American Journal of Gastroenterology, 96*, 1718-1724.

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