Identifying Hearing Loss in Adults with Developmental Disabilities

Détecter la perte de l'ouïe chez les adultes ayant des déficiences sur le plan du développement

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Abstract

This study investigated hearing disorders in 126 adults with developmental disabilities (DD) who were referred for a variety of services to Surrey Place Centre in Toronto, Canada over a one-year period. Results indicated that 66% of those assessed had some type of hearing impairment. Individuals with a diagnosis of Down syndrome had a higher rate of hearing deficits (74%) than individuals with a diagnosis of unspecified DD (63%). Hearing loss was significantly more common in middle aged to older individuals ($X^2 = 8.97$; df = 1, $p < .003$), and 80% of those over 40 years of age were found to have a hearing deficit. Results of this study highlight the importance of regular audiological assessments for adults with DD, especially as they age, and the need for monitoring of these problems by those who support this group. A case example is included to illustrate the important role that audiological assessment and intervention can play in improving the quality of life of adults with DD.

Abrégé

La présente étude porte sur les troubles auditifs chez 126 adultes ayant des déficiences sur le plan du développement. Ces adultes ont été référés au Centre Surrey Place de Toronto (Canada) sur une période d'une année pour y obtenir différents services. Les résultats indiquent que 66 % des gens évalués souffraient d'une déficience auditive quelconque. Les personnes chez qui l'on avait diagnostiqué le syndrome de Down avaient un taux supérieur de déficit auditif (74 %) que les personnes ayant des déficiences non spécifiées sur le plan du développement (63 %). La surdité était considérablement plus courante chez les gens d'âge moyen et plus ($X^2 = 8,97$; df = 1, $p < 0,003$). On a remarqué que 80 % des personnes de plus de 40 ans souffraient d'une perte auditive. Les résultats de cette étude soulignent l'importance de faire des évaluations audiologiques régulières chez les adultes ayant des déficiences sur le plan du développement, particulièrement lorsqu'ils vieillissent. Elle montre aussi que les spécialistes qui suivent ces personnes se doivent de surveiller ces problèmes. L'article comprend une étude de cas illustrant l'importance qu'une évaluation audiologique et une intervention peuvent avoir sur la qualité de vie de ces adultes.

Key words: audiology, developmental disability, Down syndrome, adult, hearing loss

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The term developmentally disabled (DD) is applied to individuals who have "subaverage" general intellectual ability and significant limitations in adaptive behaviour skills with onset of these deficits in childhood or adolescence (American Psychiatric Association, 1994). Individuals with a diagnosis of DD have an IQ of 70 or lower and limitations in such areas

as communication, self-care, social-interpersonal skills, vocational skills, or self-direction (American Psychiatric Association, 1994).

It has been well documented that hearing loss is common in the DD population (Mazzoni, Ackley, & Nash, 1994; van Schrojenstein Lantman-deValk, Haveman, Maaskant, Kessels, Urlings, & Sturmans, 1994; Zoller, Ruhe, & Dunster, 1985). From infancy to old age, individuals with DD face a higher rate of hearing loss than others for a variety of reasons. In infancy and childhood they can suffer from hearing loss as a result of the same factors responsible for cognitive disabilities, such as intrauterine infections or perinatal asphyxia (Evenhuis, 1995). Conductive hearing loss may occur due to upper respiratory tract infections and general congestion associated with specific syndromes or conditions (Yeates, 1980). As well, a lower level of cognitive ability has been reported to correlate with an increased rate of hearing loss (Zoller et al., 1985) suggesting a link between intellectual and physical problems. In adults, the onset of presbyacusis may begin early (Mazzoni et al., 1994) leading to a gradual downward shift in threshold sensitivity across all frequencies and a decline in central auditory processing (Hull, 1994).

Individuals with specific syndromes or genetic disorders such as Down syndrome may face especially high rates of hearing loss. Van Schrojenstein Lantman-deValk et al. (1994) found that 45% of adults with Down syndrome over 60 years old suffered from auditory impairments. As well, Keiser, Montague, Wold, Maune, and Pattison (1981) found some degree of hearing loss in 74% of the 51 individuals with Down syndrome they assessed. This high rate of hearing impairment found in Down syndrome may be the result of anomalies of the middle ear and/or Eustachian tube (Balkany, Downs, Jafek, & Krajicek, 1979; Cohen, 1999). Other genetic syndromes such as Crouzon's disease and Hunter's syndrome are also known to be associated with hearing deficits (Yeates, 1980).

A large-scale study of hearing loss in the DD population was undertaken in Canada by Zoller et al. (1985) at the Huronia Regional Centre in Ontario. These researchers examined 814 individuals for conductive hearing loss using both tympanometry and otoscopy. Results of this study showed that 53% of individuals showed hearing impairment using the otoscopy method, while 25% showed impairment by the typanometry method. They also found that those with chromosomal abnormalities (i.e., Down syndrome) were much more likely to have hearing loss than those with other etiologies. Despite the substantial number of individuals included in the study, this research presented a somewhat limited picture of hearing loss in the DD population due to the focus on conductive loss only. The rates of hearing impairment of other types, such as sensorineural and mixed types, were not investigated. The limited use of testing techniques makes the Huronia study useful for understanding some, but not all of the hearing problems in adults with DD.

Another large study was conducted by van Schrojenstein Lantman-deValk et al. (1994) who gathered data on hearing impairment in individuals, aged under one year to over 60 years, living in the Netherlands that were described as having a "mental handicap." Family doctors' report of hearing loss was used to determine if an auditory impairment was present. The sample was divided into two groups; individuals with an unspecified mental handicap (n = 1121) and individuals with Down syndrome (n = 307). Of all individuals with Down syndrome over the age of 50 years (n = 90), 28% were discovered to have a hearing loss. In the unspecified mental handicap group who were over the age of 50 (n = 557), only eight percent had a hearing loss. For both groups, the number of individuals with normal hearing decreased as age increased, indicating greater hearing loss with age. In the oldest group, which consisted of individuals over 60 years of age, only half of those with Down syndrome had normal hearing, whereas about 80% of those with unspecified handicap had normal hearing.

The van Schrojenstein Lantman-deValk et al. (1994) study included an exceptionally large group of individuals and, therefore, offered an opportunity to gain information from a wide variety of people. However, like the Zoller et al. (1985) study, it is lacking with regards to the comprehensiveness of the auditory testing undertaken. The authors of this study did not actually test the individuals themselves; rather, they sent a questionnaire to each individual's physician requesting information regarding hearing. Family doctors were asked to give an opinion about their patient's hearing ability, based on clinical information and file data. Because formal assessments by an audiologist were not undertaken, it is possible that cases of hearing loss were undiagnosed. Our own clinical experience has suggested that hearing loss often goes undetected by a variety of professionals who have regular contact with our clients. We have found this to be especially true for sensorineural loss. This may be because problems such as impacted earwax or middle ear infection may be more readily observable by professionals or reported by the individuals themselves.

Hassman, Skotnicka, Midro, and Musiatowicz (1998) examined hearing in 14 adults and 47 children with Down syndrome using pure tone audiometry, acoustic reflex, Auditory Brain Response (ABR), and Distortion Products Otoacoustic Emissions (DPOAE). One of

the goals of their study was to assess the usefulness of DPOAE along with tympanometry for diagnosing hearing loss in Down syndrome. The authors noted that it is often difficult to assess hearing in Down syndrome, and that techniques such as DPOAE, which do not require the cooperation of the individual, might be useful for this group. Results indicated that the adults in their study experienced abnormal tympanometry at a rate of 25%. As well, DPOAE examinations of the adult group suggested an early onset of age related inner ear impairment.

Mazzoni et al. (1994) compared rates of hearing loss in adults with DD to rates found in the general population. These researchers examined 23 individuals with Down syndrome aged six months to 59 years, 15 individuals with other types of DD aged 25 to 60 years, and 20 individuals from the general population (no age range was given), to compare level of hearing impairment and investigate factors which might correlate with loss. Audiometric procedures used in this study included pure tone conduction, word discrimination tasks, tympanometry, and auditory brainstem response tests. Results showed that 90% of adults with Down syndrome and 54% of adults with unspecified DD had either significant hearing loss or middle ear anomalies, while individuals from the general population all exhibited normal hearing. The rate of actual hearing loss (disregarding middle ear anomalies) in those with Down syndrome was found to be 82%. Interestingly, this rate of loss is higher than most other studies have reported (e.g., Keiser et al., 1981; van Schrojenstein Lantman-deValk et al., 1994) and it suggests that when a full range of audiological assessments are performed, more adults with DD may be found to have hearing impairments. It also suggests that individuals with Down syndrome may require closer monitoring for hearing loss due to an extremely high rate of risk. However, stronger support for this conclusion might be gained by performing assessments with a larger number of individuals.

In the present study, an investigation of hearing loss in the clients of a community-based agency serving adults with DD in the Toronto area was undertaken. Our objectives were to investigate rates of hearing impairment for individuals seen in this agency over a one-year period, and to compare these rates to what has been previously reported in the literature.

Method

Participants

A total of 126 individuals were included in this study over a one-year period. Seventy-four (58%) had used our audiological services previously and 52 (42%) were new clients to the service. Overall, 55 individuals (44%) were over 40 years old, and 71 (56%) were under 40. The age distribution of participants was as follows: 32 (26%) were 20 to 30 years of age, 39 (31%) were 31 to 40, 34 (27%) were 41 to 50, 16 (13%) were 51 to 60, and five (4%) were over 60 years of age. Twenty-seven (21%) were diagnosed with Down syndrome, and 99 (79%) were described as having unspecified DD.

Recruitment Process

All adult clients of Surrey Place Centre, a facility serving individuals with DD in the Toronto, Ontario region, who were referred for any form of service during the time of the study (e.g., counselling, psychological services) were offered audiological assessment. The process of including clients in the audiological service was as follows: (a) After initial interviews were completed with the client and their family member or care-provider, specific services were recommended; (b) If the individual had not received an audiological assessment during the past year, this service was strongly recommended prior to beginning any other assessment or intervention; (c) The process of audiological assessment was explained to the client and care-provider, and informed consent was obtained, either from the individual themselves, or a guardian if they were unable to give consent.

Clients included in the study were described as having either Down syndrome or unspecified DD. The category of unspecified DD was used because in a large number of cases, the etiology of an individual's disability was unknown. Participants were also divided into the age groups of over 40 years and under 40 years. Forty was chosen because previous research has shown that individuals with Down syndrome begin to experience physical and functional decline around this period (Collacott, 1992; Maaskant et al., 1996). As well, it has been argued that premature aging takes place in some individuals with DD (Walz, Harper, & Wilson, 1986) and that this group must be considered "old" at an earlier age.

Design and Procedure

The study extended over a period of one year and all clients who agreed to audiological assessment during this period were included. Information was collected in five areas. The first area was assessment outcome of either normal or impaired hearing. Normal hearing was defined as a loss of less than 25 dB. The second area was degree of hearing impairment if one was found. Mild impairment was defined as a loss of 26 to 40 dB, moderate as 41 to 55 dB, moderately severe as 56 to 70 dB, severe as 71 to 90 dB, and profound as greater than 90 dB. These standards are based on the classification system of Goodman (1965) and Davis and Silverman (1970). The third area was demographic information regarding

whether an individual was "new" to the audiology service or previously assessed. The fourth area was participant and/or caregiver response to a question regarding whether a hearing problem was suspected. Before undertaking the assessment the audiologist asked individuals and/or their caregivers if they believed the individual's hearing was impaired and their response to this question was recorded as "yes" or "no." Finally, assessment outcome information regarding recommendations for further assessments or services given by the audiologist was collected.

When assessing participants, the audiologist used a full range of tests to investigate hearing, but the most common procedure employed was conventional pure-tone audiometry tests (121). This procedure required individuals to respond to auditory stimuli such as pure tones, narrow band noise, and warble tones. Experience with this population group has suggested that they are generally more responsive to sound stimuli that are varied and interesting. For this reason it was often easier to maintain their attention, and therefore obtain more reliable responses, using a variety of sounds. The second most common test administered was the sound field test (11). Sound field tests involved the observation of an individual's responses to various auditory stimuli presented via loudspeakers. In a single case, an auditory brainstem evoked response (ABR) test was performed. This is a noninvasive electrophysiological procedure which tests the integrity of the 8th nerve and auditory brainstem. Finally, all clients (126) were assessed using tympanometry to investigate middle ear function.

Results

Hearing Loss

Results of assessments found that 83 (66%) of all those assessed had a hearing deficit. Twenty of the 27 (74%) individuals with Down syndrome, and 63 (63%) of the 99 individuals with unspecified DD had impaired hearing in at least one ear. Because the degree of impairment can vary by ear (i.e., an individual might have mild impairment in the right ear and normal hearing in the left) results for degree of hearing loss are presented by ear, rather than by individual. This means that a total of 252 ears were assessed. In the unspecified DD group, 80 (40%) were found to have normal hearing, 67 (34%) had mild hearing loss, 27 (14%) had moderate loss, seven (3.5%) had moderately severe loss, 12 (6%) had severe loss, and five (2.5%) had profound loss. In the Down syndrome group, 13 (26%) had normal hearing, 27 (47%) had mild loss, 10 (18%) had moderate loss, 2 (4.5%) had moderately severe loss, and 2 (4.5%) had severe loss.

Chi-square analysis indicated that both individuals with Down syndrome and individuals with unspecified DD were significantly more likely to have hearing problems after the age of 40 years ($X^2 = 8.97$; df = 1, $p < .003$). While only 55% of those under 40 had problems with their hearing, 80% of those over 40 had hearing problems. As well, the proportion of individuals found to have a hearing loss increased as age increased. The number of participants who had a hearing impairment in at least one ear for each age group was as follows: 13 (41%) for the 20 to 30 year old group; 26 (66%) in the 31 to 40 year old group; 26 (76%) in the 41 to 50 year old group; 13 (81%) in the 51 to 60 year old group; five (100%) in the over 60 years of age group.

Three types of hearing loss were investigated: sensorineural, conductive, and mixed. For all ears examined and found to have a hearing impairment (n = 158), the most common type of loss was sensorineural in 71 (45%) cases. This was followed by conductive loss 23 (14%), and then mixed loss in 11 (seven percent) cases. In 53 (33.5%) cases, the nature of the loss could not be determined because the participant could not be conditioned to perform air conduction audiometry (using headphones) or bone conduction audiometry (using bone vibrator). The information provided by both these tests was necessary for the audiologist to determine the nature of loss.

Participants who were new to our audiological services and those who had been assessed previously were compared with regards to the degree of their hearing loss. Again, the number of ears in each category of hearing loss is given along with the percentage. For the "newly" assessed group, which contained 52 individuals and 104 ears, 56 (53%) were found to have normal hearing, 35 (34%) mild impairment, eight (eight percent) moderate impairment, one (one percent) moderately-severe impairment, and four (four percent) severe impairment. In the "previously" assessed group, which contained 74 people and 148 ears, 37 (25%) had normal hearing, 59 (40%) had mild impairment, 29 (20%) had moderate impairment, eight (five percent) had moderately-severe impairment, 10 (seven percent) had severe impairment, and five (three percent) had profound impairment. As expected a large portion of the newly assessed individuals (34%) were found to have a mild hearing impairment. However, it is significant that a total of 13% of this newly assessed group had either moderate, moderately severe, or severe impairment, suggesting that hearing problems may have gone undiagnosed.

Before the assessment was undertaken, participants and/or caregivers were asked if they felt that the individual with DD had problems with hearing. Sixty-one

(48%) answered "yes" indicating they felt there was a problem, and 65 (52%) said "no" indicating they felt there was not a problem. Of the 61 participants and/or caregivers who answered "yes," 55 (90%) were found to actually have a hearing impairment, while six (10%) were not. Of the 65 who said "no," 28 (43%) were found to have an impairment and 37 (57%) were found to have normal hearing. This suggests that a large number of caregivers and/or participants were unaware of the hearing problems of the individual with DD prior to the assessment.

After assessing clients, the audiologist offered one or more recommendations for follow-up service. Annual reassessment was by far the most common recommendation, made in 81 (64%) cases. Referral to an otolaryngologist was recommended in 26 (21%) cases, and in another 25 (20%) cases hearing aids were prescribed. Thirty-six (28%) individuals did not require audiological follow-up.

Discussion

This study investigated hearing loss in 126 adults with DD served by Surrey Place Centre, a community-based agency in the Toronto area. Assessments were performed by an audiologist and included tests of conventional pure-tone audiometry, sound field, and ABR, as appropriate. Because it was recommended that all individuals who received service at the agency undergo audiological assessments, these results are likely a good representation of all adult clients of this organization.

Results of this study support previous research findings and highlight some important issues regarding the provision of audiological services to adults with DD. First and most importantly, it was found that adults with DD of all ages had a high rate of hearing impairment. Two thirds (66%) of all individuals assessed were found to have a hearing loss of some kind. Hearing problems were found to increase with age, and those over 40 years of age were found to have significantly higher rates than those under 40. Hearing loss increased from 41% in the 20 to 30 years of age group, up to 100% in the over 60 years of age group. Overall, those with Down syndrome were consistently found to have higher rates of hearing problems than those with an unspecified diagnosis of DD. Seventy-four percent of individuals with Down syndrome assessed had a hearing loss of some type, while those with unspecified DD had a hearing loss in 63% of cases. These results might be compared to rates of hearing loss in the general population, where approximately 5% of individuals 18 to 44 years and 21% of individuals 45 to 74 years have a hearing impairment (National Information Center on Deafness, 1984).

Types of hearing loss investigated included sensorineural, conductive and mixed. For all those who were found to have a hearing loss, 45% were sensorineural, 14% were conductive, and seven percent were mixed. This suggests that sensorineural hearing problems are common in the DD population and that any assessment which includes only tests of conductive loss, such as was used in the Zoller et al. (1985) study, may fail to identify a large portion of individuals with impairments. As well, since sensorineural hearing loss is known to be correlated with greater age, the high rate of this type of hearing deficit indicates an early onset of age-related hearing loss for this group and supports the necessity of yearly assessments for adults with DD.

For individuals who were new to our audiology service and had not previously been assessed, 34% were found to have a mild hearing impairment and another 13% a moderate to severe impairment. The hypothesis that hearing problems were undetected is supported by the fact that 28 of the 65 caregivers/participants who stated that they did not feel the individual tested had a hearing problem prior to the assessment were found to actually have hearing loss.

Comparing the findings of this study to those of van Schrojenstein Lantman-deValk et al., (1994) suggests the importance of professional audiological assessment of hearing ability. Van Schrojenstein Lantman-deValk et al. gathered data on hearing impairment in adults with DD by consulting family doctors and obtaining their opinion regarding the patient's hearing ability. Note that the rate of impairment they found (i.e., 15%) was substantially lower than the rates reported here. This may suggest that professional audiological assessment can uncover deficits which are not detectable by other service providers and that a comprehensive assessment is necessary to uncover all possible types of hearing loss. Many family physicians do not have the facilities (e.g. sound-proof booths, audiometers, tympanometers) to provide a full assessment and, therefore, would be disadvantaged in detecting all types of hearing loss. The results of our study are consistent with those of Mazzoni et al. (1994) who also undertook professional audiological assessments.

When assessing adults with DD, it is also important to have the services of a professional audiologist who is familiar with this client group. Our audiologist has 16 years experience in assessing adults with DD and has found that it is often necessary to modify testing methods to accommodate clients. For example, it may be necessary to take additional time in an assessment in order not to rush the client, or for the client to return a number of times to complete a full assessment. With very difficult-to-test clients, it may even be necessary to do preassess-

ment work to familiarize the client to the testing procedures.

A Case Study

The story of a client recently seen at our facility offers an excellent example of the importance of audiological assessment, even when hearing loss is not suspected. A number of years ago, a 26-year-old woman with DD was initially referred to us for concerns regarding physical, emotional, and behavioural difficulties. She was assessed by several clinicians and found to have a variety of complex socio-emotional and medical problems including seizures, speech and language abnormalities, depression, and social isolation. No concerns with hearing loss were noted, and because our facility did not recommend audiological testing to all clients at that time, no assessment was done. When the client returned to our facility at 37 years of age, audiological testing was being suggested to all clients and she was assessed. The client was found to have mild to moderate sensorineural loss in both ears, and bilateral hearing aids were recommended. Our audiologist helped the client in applying for funding to purchase these aids and they were obtained soon afterward. At the time of her assessment our audiologist suspected that, although it could not be determined for certain, a hearing loss of this severity had likely developed over a period of many years, and that this loss may well have interfered with the woman's health and development for an extended period of time.

After obtaining her hearing aids caregivers and clinicians noted marked improvements in the woman's social skills and confidence. The average length of her utterances increased and her ability to follow instructions improved. Caregivers also noted increased social interaction and more use of the telephone, a device the woman had previously avoided. As well, a clinician who initially felt that this woman would be unsuitable for counselling services due to a lack of verbal responsiveness now believed that she would be a good candidate for counselling since her verbal output had increased. It was presumed that her past problems with hearing had interfered with the woman's ability to respond in conversation during her initial counselling interview. Finally, during an informal interview conducted three months after fitting the hearing aid, the woman stated that she felt "safer" when she was wearing the hearing aids. This suggests she was able to understand and interpret her environment more effectively after receiving hearing aids, and that this helped her to feel more in control.

We believe that this case study highlights the importance of monitoring hearing status in all clients with DD. Hearing problems do not always present in a typical way for this group and familiar signs such as complaining of others "mumbling," requests for others to repeat themselves, or increasing the volume on the TV or radio, may not be present. When individuals are nonverbal or minimally verbal, it is unlikely that they will complain of hearing loss. There may simply be a lack of response to verbal commands or conversation and this may be interpreted by caregivers as noncompliant behaviour and lead to social and interpersonal difficulties. As well, the early age at which hearing loss begins in this group relative to the general population may lead caregivers to overlook it as a possible cause of behavioural symptoms.

In the case study described above audiological assessment and intervention was fundamental to the success of other clinical interventions and may have helped to improve the client's quality of life. Studies investigating the effects of the long-term use of hearing aids have found that they may increase level of social interaction (Tesch-Romer, 1993), generate positive attitude (Brooks, 1989), and increase self-esteem (Weinberger, 1980).

Limitations of Present Study and the Need for Future Research

Although this research study offers some information regarding the audiological needs of clients with DD, there are several limitations that must be considered. First, this is a clinical sample composed of those who presented for services to a community-based health facility. It may not be , therefore, representative of all individuals with DD, especially those who do not seek out community services. Based on information about birth rates for individuals with DD, studies in Ontario suggest that only about 23% of adults with DD are associated with DD service agencies (Brown, Raphael, & Renwick, 1997). This is a small portion of all adults with DD and it is possible that the remaining 77%, who do not require the assistance of community service agencies have different audiological needs. Results from this study should therefore be seen as reflecting the needs of individuals who are known to DD services and present for assistance to community agencies.

A second limitation of the study is the lack of available information regarding the diagnostic make-up of the unspecified DD group. Although our results can offer some insights into the audiological requirements of adults with Down syndrome compared to adults with a DD in general, it is possible that the unspecified DD group contained individuals from a variety of diagnostic categories. In future studies it would be useful to gather more descriptive information about the unspecified DD group if it can be obtained from case records or caregivers. It has been suggested, for example, that individuals with autism have higher rates of conductive loss and serous

otitis media when compared to the general population (Rosenhall, Nordin, Sandstrom, Ahlsen, & Gillberg, 1999). However, since reported rates of hearing deficits among samples of individuals with autism have ranged from zero percent (Novic, Vaughn, Kurtzberg, & Simson, 1980) to over 44% (Taylor, Rosenblatt, & Linschoten, 1982) it is not clear how this group would compare to the individuals studied here.

Summary

The results of this study support the necessity of yearly audiological assessments for adults with DD and Down syndrome. This may be especially important for individuals with communication difficulties who may be disadvantaged in their ability to self-report hearing deficits. As hearing loss is an "invisible" handicap it is easily missed if the individual does not report symptoms. When comprehensive yearly assessments are not performed, undetected hearing loss could affect an individual's ability to function at home and in the workplace and may result in a variety of social, emotional, and interpersonal difficulties for the individual and those around them.

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Although all individuals presenting for service to our facility during the one-year period of July 1997 to June 1998 were originally included in the analyses for this paper, data from four individuals were lost. For this reason, the next four consecutive clients seen in July 1998 were included in the final group.

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