Journal of Policy and Practice in Intellectual Disabilities

Journal of Policy and Practice in Intellectual Disabilities
Volume 12 Number 4 pp 272–278 December 2015

doi: 10.1111/jppi.12137

Guidelines for Ear, Nose, and Throat Examination of Adults With Intellectual Disabilities: Report of a Clinical Practice Application

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Abstract

Health problems among people with intellectual and developmental disabilities (I/DD) are considered more prevalent than among the general population, but there are very few studies that have described a detailed ear, nose, and throat examination of this group. The purpose of this paper is to provide a set of guidelines that can result in a structured ear, nose, and throat examination, describe one experience with implementing the guidelines for otorhinolaryngological care with a heteroegnous sample of adults with intellectual disability, discuss relevant care principles derived from the experience, and specifically address the issue of cerumen impaction. The subjects, 356 adult residents of two residential care centers for people with I/DD, were examined by four otolaryngologists, assisted by an audiologist/speech-language pathologist, and a nurse. The examinations lasted 8 h over 2 days. Of the residents, 292 (82%) had at least one main finding; impacted cerumen was observed among 54.9% of the examined ears. Of these, 103 residents (206 ears) were examined again after cerumenolytic treatment and cerumen cleared. The authors concluded that there is a need for focused physical examination in order to recognize and treat ear, nose, and throat disorders in this population. Examinations of adults with I/DD are feasible and important in enabling good communication and maintaining general health.

Keywords: audiology, cerumen, ENT examination, intellectual disability, otolaryngology

Introduction

Once in a while, every physician in a tertiary medical center encounters a situation in which he/she attempts to treat a patient with an intellectual disability. This frustrating situation is in fact mutually challenging, both for the physician and moreover for the patient. It stems from communication problems, distress from unfamiliar environment and caregivers, and unfortunately lack of experience treating people with intellectual and developmental disabilities (I/DD). After facing this situation several times, we concluded that a more proactive approach will be helpful, so we set forth to: (1) Establish a mobile otorhinolaryngological team, (2) generate practice guidelines to be followed by the team and caregivers, and (3) implement the guidelines in residential care centers. This paper describes our experience in two residential care centers.

Health problems among people with I/DD are more frequent than among the persons in the general population due in most cases to associated congenital disorders and derived acquired diseases (Moss, Goldberg, Patel, & Wilkin, 1993; van Schrojenstein Lantman-de Valk et al., 1997). Oral expression difficulties often lead to poor communication, ill definition of complaints and symptoms, and lack of cooperation on examination (Day & Jancar, 1994), thus interfering with proper diagnosis. Examining people with ID can be challenging, frustrating, and time consuming. This also may have direct effect on the quality of provided care.

People with I/DD are at an increased risk for sensory impairments, especially at older age (Evenhuis, 1995a; Evenhuis, Theunissen, Denkers, Verschuure, & Kemme, 2001). The incidence of hearing impairment ranges according to different surveys

Received August 30, 2014; accepted March 3, 2015
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TABLE 1
Guidelines for otorhinolaryngological care for people with intellectual disability

Guidelines for Otorhinolaryngological Care for People with Intellectual Disability

ENT (ear-nose-throat) Screening

Goals are to provide optimal communication skills (hearing, speech, augmentative, and alternative communication), optimal balance, good nasal and laryngeal breathing, proper smell and taste capabilities, good oral hygiene, good eating and swallowing to allow proper nutrition and prevention of aspiration, and identification of salivary gland and neck tumors.

1. All patients should receive at least one yearly detailed ENT examination, and be followed up henceforth by either the primary physician or a designated ENT consultant.
2. The service should employ a designated ASLP (audiologist/speech-language pathologist) who will guide the staff, follow up the patients, and work with the appropriate physicians to provide optimal communication and eating skills.
3. For ENT examination performed in-house, the following minimal equipment should be at hand: otoscope (with a sliding viewing window), Hartman ear micro forceps, loops for cerumen removal, metal 13Fr suction tips with connector and a suction unit, nasal speculum, head light, laryngeal mirror, and tongue depressor.
4. The examination should include:

Otoscopy	to exclude infection, foreign body, tympanic membrane perforation, and impacted cerumen
Anterior rhinoscopy	to exclude infection, foreign body, and polyposis
Oral inspection	to exclude infection and malignancy and to evaluate oral and teeth hygiene
Indirect laryngoscopy	to exclude laryngeal lesion and signs of aspirations
Cervical examination	to exclude thyroid enlargement or cervical tumor

Primary Carers Guidelines For Ear Care

1. Otoscopy should be done routinely every 6 months to exclude cerumen impaction, foreign body, infection, or perforated tympanic membrane.
2. Excessive ear discharge, ear pain, or sensitivity around the ears should prompt for otoscopy.
3. In case of recurrent ear infections or perforated tympanic membrane, waterproof ear plugs should be applied during shower and swimming
4. Ear pain should be treated with systemic analgesics and not with ear drops.
5. Change in balance or repeated falls should alert to possible ear disease.
6. Assessment of hearing should be best done by the everyday carers. They should note the resident's response to soft and loud noises and to the surrounding people, and pay attention to changes (e.g., repeated requests to raise the sound volume of the television set). *A useful screening is the whisper test, where the mouth-hidden examiner stands 3 m away from the subject and calls his name.* In case of suspected hearing loss follow section on Irreversible Hearing Loss

Reversible Hearing Loss (cerumen impaction)

1. Cerumen management should be carried out in a case of cerumen impaction or recurrent impaction.
2. The primary treatment should be cerumenolytic drops or spray for a week. Cerumenolytic agent can be applied from the same bin to the ears of different subjects, as long as the tip is kept clean.
3. Cerumenolytic agents are contraindicated in people with perforation of tympanic membrane.
4. If no improvement is noted—an ENT examination is warranted.

Irreversible Hearing Loss

1. In any case of suspected hearing loss, ASLP consultation is warranted, followed by an ENT examination and audiometry.
2. Prior to the audiometry the patient needs to be trained by the ASLP to ensure reliable testing. The hearing evaluation should be conducted by two experienced ASLP.
3. If a hearing aid is recommended by the ENT consultant, the ASLP should be in charge of gradually fitting the hearing aid. Patient's compliance and estimated benefit from the hearing aid use should be taken into account before actual hearing aid acquisition.
4. Once every 2 weeks the ASLP should verify with the everyday carers that the hearing aid is properly functioning and used and that batteries are regularly replaced.
5. A patient wearing a hearing aid should have an otoscopy every 3 months and audiometry every 3 years.
6. In a case of a patient who is not willing or unable to wear a hearing aid, but on specific occasions may enjoy the benefits of amplification, the use of an assisted listening device (ALD) should be considered.

TABLE 1
Continued

Primary Carer Guidelines for Nasal Care

1. Noisy breathing, snoring, or nasal discharge should be noted by the everyday carers and if signs persist more than a week, rhinoscopy should be followed, in order to exclude infection or foreign body.
2. Assessment of smell and taste preferences should be attempted and noted.
3. Clear nasal discharge, sneezing, nose, and eyes scratching should alert carers to the possibility of allergic rhinitis and referral to ENT consultant should be carried out.

Primary Carer Guidelines for Throat Care

1. Eating and swallowing behavior during regular meals should be monitored by the everyday carers.
2. Sudden appearance of respiratory symptoms (i.e., severe coughing, cyanosis) or voice changes, associated with eating or drinking, should alert for possible aspiration.
3. Aspiration prevention requires annual assessment of eating, swallowing and nutrition by the ASLP, and individual adjustments for at-risk residents of posture during eating, food textures, eating utensils, and degree of eating independence.
4. Maintenance of good oral hygiene and regular dental care including tooth brushing is warranted.
5. Any swelling in neck should be noted. [In subjects with obese neck an occasional fond caress may be helpful to identify changes.]

between 12 and 89% (Evenhuis, 1995b; Kerr et al., 2003; van Schrojenstein Lantman-de Valk et al., 1997). Etiologies vary between sensory-neural hearing loss (reflecting congenital malformations or presbiacusis), to acquired, reversible, hearing loss (namely blockage of the external auditory canal by either foreign body or cerumen). Some reports described a 28%–36% incidence of impacted cerumen (Evenhuis, 1995b; Kerr et al., 2003), higher than the 2% to 6% incidence found in the general population (Crandell & Roeser, 1993).

In addition to the importance of detecting hearing loss, optimal communication skills require maximal speech abilities. Other otolaryngological issues that need attention are good nasal and laryngeal breathing, proper eating and swallowing abilities to allow proper nutrition and to prevent aspiration, optimal balance, proper smell and taste capabilities, and early identification of salivary glands and neck tumors. These issues, some involving hidden organs, merit particular assessment.

Medical surveys conducted among people with I/DD usually employed review of medical records and questionnaires completed by carers (Kerr et al., 2003; Lennox, Green, Diggens, & Ugoni, 2001; van Schrojenstein Lantman-de Valk et al., 1997; Wang, Hsieh, Heller, Davidson, & Janicki, 2007). To the best of our knowledge, there are no previous investigations describing detailed and direct ear, nose, and throat examination. Given that, in this report on an otorhinolaryngological clinical practice intervention among people with I/DD, in Table 1 we describe the practice guidelines and then report the results of their applications and related interventions.

Method

Subjects

Some 356 (180 males, 176 females) residents of two residential care centers for persons with intellectual and developmental disabilities (I/DD) in central Israel were the subject of the implementation of the guidelines. Their mean age at examination was 53.6 years (±9.92; range 27–81); 177 were women and 179 were men. Most of the residents had resided at one of the two residences for more than 20 years. The majority had moderate ID, 85 required nursing care, and 130 demonstrated challenging behavior. Of the total, 39 were diagnosed with Down syndrome, 9 with fragile X syndrome, and 110 with epilepsy. With respect to mobility, 78 were wheel-chair bound.

Preliminary Orientations

The ENT intervention was done according to guidelines described in Table 1 and began with a large scale screening. Examinations were conucted by a team of four otolaryngologists, closely assisted by the centers' ASLP, nurse, and in-house physician. All of the examinations were approved by the Israeli Ministry of Social Affairs.

Prior to the intervention, a preparatory program was conducted in both centers to achieve awareness and improved cooperation of the staff. Mainstay of this stage was empowering the first-echelon carers, including auxiliary workers (e.g., cleaners), in early identification of ENT disorders. The program included brief educational workshops, daily discussions on some potentially problematic residents, and mutual consultations. The program was led by the center's ASLP, assisted by a nurse and physician. The program's sessions were joined by all professional sectors. Emphasis was on practical key points and on safety. Each session was attended by about 10 people and lasted an hour. A slide presentation showed basic anatomy, and the ensuing talk included numerous examples. Next followed a preparatory phase, which was designed to prepare the residents deemed suitable for the forthcoming visit. Individual explanations and some demonstrations were given, as possible.

Procedure

The examination included facial skin, neck, nose (anterior rhinoscopy), mouth, oropharynx, and ears. Evaluation of hearing

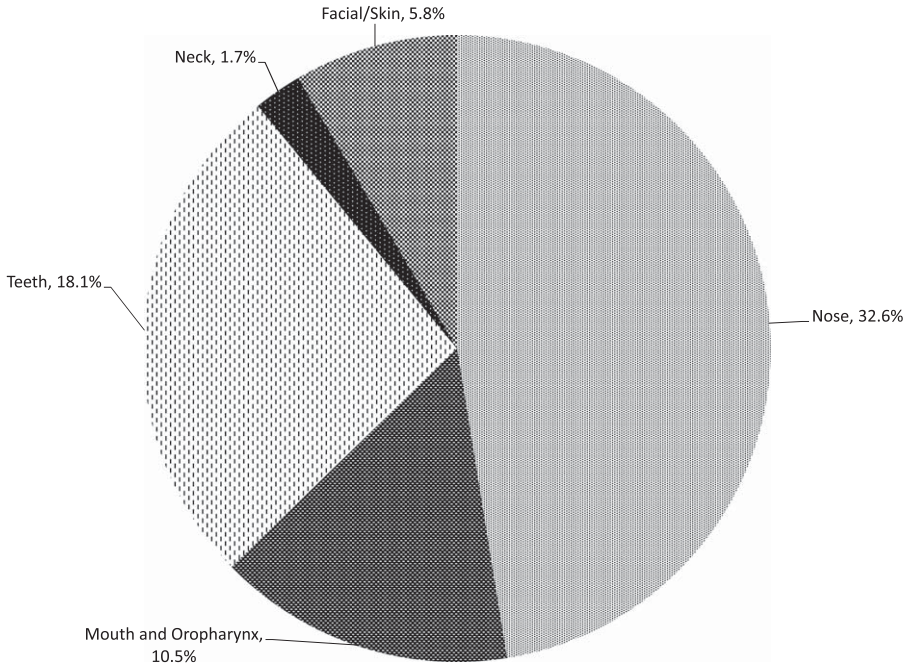

FIGURE 1

Nasal, head, and neck findings.

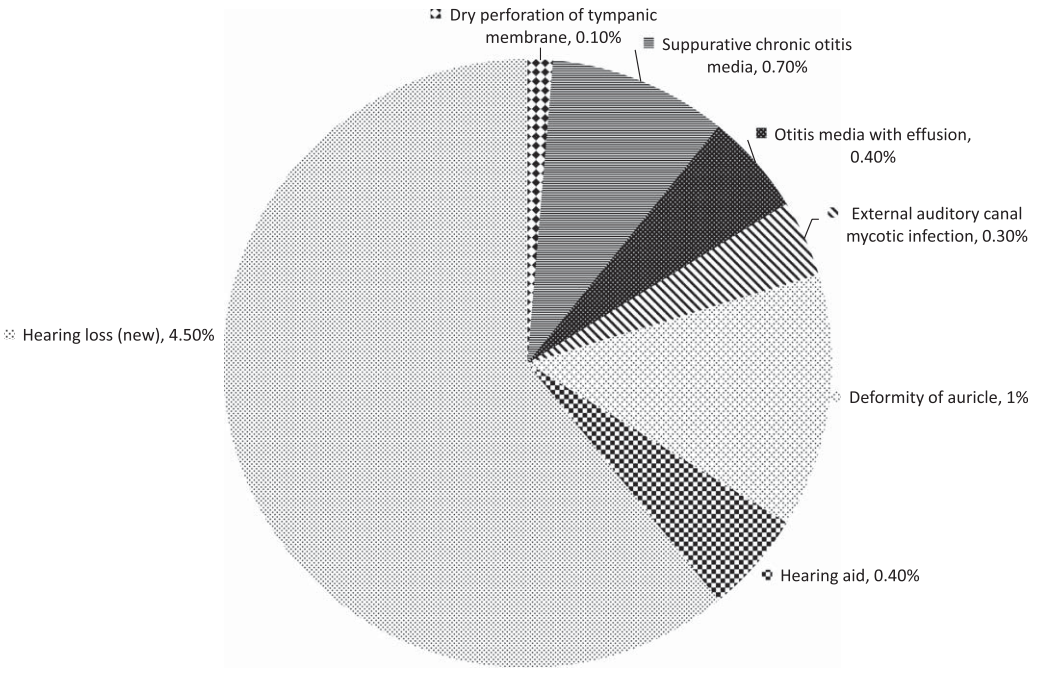

FIGURE 2

Ear findings (excluding cerumen).

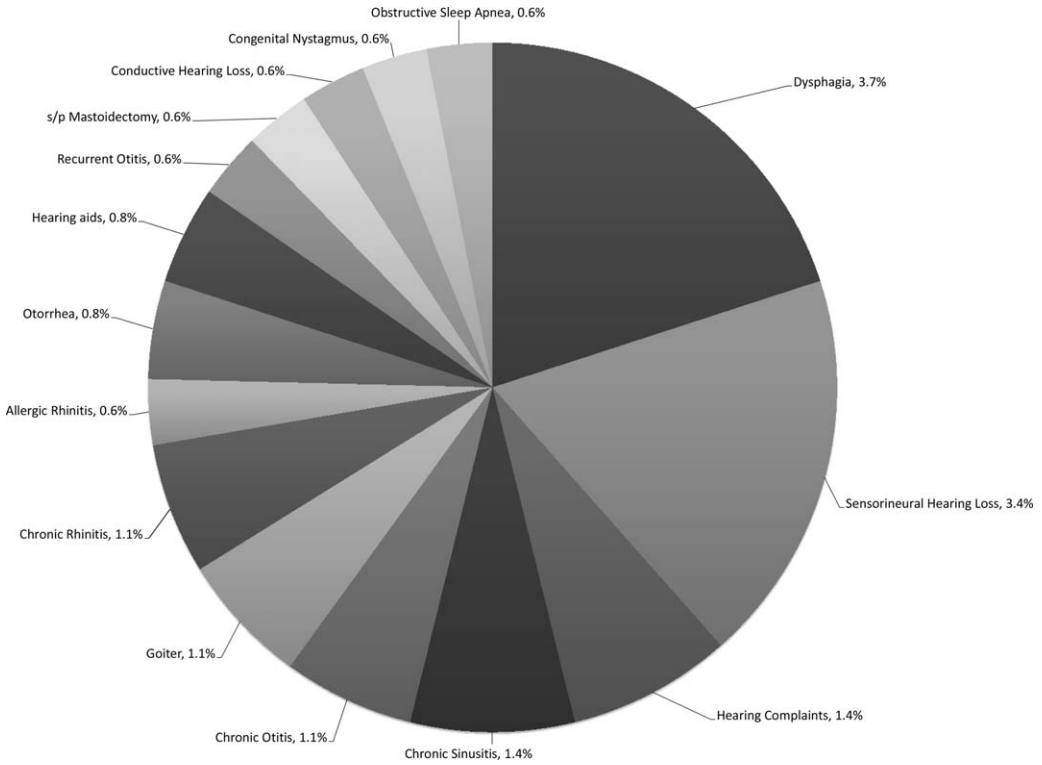

FIGURE 3

Previous ENT problems.

was done using the whisper screening test. Dysphagia assessment was not included as it requires detailed observation during meals. The medical records of the residents were reviewed. The results of the examination were recorded using a standardized form, filled out by the examining physicians. Mobile equipment was provided by the Wolfson Medical Center. Residents of both centers were receiving regular dental care in a designated in-house dental clinic, which also allowed NO_2-based sedation, if needed.

The clinical findings, treatment, and follow-up recommendations were given to the in-house physician and included in the medical records. Cerumenolytics (CleanEars® spray, Naveh Pharma, Israel) were used to treat the residents with impacted cerumen. Cerumenolytics were administered t.i.d. for 1 week by the staff. Cerumen was later removed from the ears of 103 residents in both centers on three different sessions. Both the examination and the treatment were flexibly conducted either at the center's medical clinic or at the various workshops and classrooms, with both the resident and the examiner sitting in.

Findings

The ENT screening examinations lasted a total of 8 h and were done by four otolaryngologists, assisted by an ASLP, and a nurse. They were done on two occasions, with 200 and 156 residents on each respective day. Mechanical clearing of cerumen was performed in 160 ears by three otolaryngologists during three sessions of 4 h each. Sedation was not necessary. The main survey outcomes are summarized in Figure 1 (nasal, head, and neck findings) and in Figure 2 (ear findings excluding cerumen). The main previous ENT problems of the cohort, before their screening study, are summarized in Figure 3. Some 292 residents out of the total 356 (82%) had at least one positive ENT finding in the survey. The significant results are described next. We found that 90 subjects had deviated nasal septum, yet their records had no history of nasal obstruction, snoring, or disturbed sleep. There were also 13 subjects with nasal discharge or polyposis. One of the two patients with nasal polyposis had previous sinonasal surgery. We found that 21 patients had skin findings and two required further investigation. Enlarged thyroid was found in six patients, with just two previously investigated. Caries were found in only eight patients. Short or missing uvula was found in six patients, with no associated known phenotype.

Chronic otitis media with discharge was found in 15 ears. Only three residents were wearing hearing aids at the time of the survey. Sixteen additional residents were found to have significant sensorineural hearing loss. All were subsequently fitted with hearing aids and adherence found satisfactory.

The most prevalent finding was impacted cerumen—it was observed in 54.9% of the examined ears. As described, cerumenolytics were applied. The cerumenolytic agent used was chosen according to our previous experience (Oron, Zwecker-Lazar, Levy, Kreitler, & Roth, 2011). Some 103 residents (representing 206 ears, 29%) required further cerumen removal. Actual

removal was done in 160 ears. In only 13 ears (8.1%, none bilateral), removal was incomplete due to insufficient cooperation by the residents. Following cerumen removal, foreign bodies were found in two ears; two cases of chronic otitis media were found and otitis externa was revealed in one ear.

Discussion

This application of the ENT Guidelines among adult residents of two residential care centers for people with I/DD was unique in Israel and proved fruitful. Excellent cooperation among residents and staff was obtained after thorough earlier preparation by the centers' ASLP and medical staff, allowing coordinationg and completion of the examination of over 300 people in just two visits. The survey enabled us to reveal findings which were unknown to the treating staff and alerted them to several new problems.

The survey and examininations revealed a low incidence of dental caries, most likely as the residents at both centers were regularly examined and treated by a dentist. Apparently, this proactive approach was beneficial, and if a dental program is deployed there is most likely no need to include this area in a general ENT survey.

Short or missing uvula was found in six patients. This may represent a submucosal cleft. Drooling found in 22 residents may reflect swallowing disorder; however, direct dysphagia detection was not part of this survey. Close attention to possible swallowing disorders, especially among at-risk adults residing in formal care centers, is highly warranted. Such swallowing disorders are not rare and they may be due to poor oral motor dysfunction, antiepileptic and psychiatric drug effects, or dysfunctional eating behavior (e.g., eating excessive amounts) (Aldridge & Taylor, 2012; Gravestock, 2000).

Chronic otitis media with discharge was found in 15 ears. Treatment with ear drops and wetting avoidance was recommended, and adherence to treatment guidelines was good.

Only three residents were found to be using hearing aids, a relatively lower than expected number, considering the average age of the surveyed population and the previously reported higher incidence of usage of hearing aids (Evenhuis et al., 2001). Some new hearing loss cases were found in this survey. While use of hearing aids among people with I/DD is considered to be difficult (Evenhuis, 1995b), there are reports on successful hearing aids adjustment in two surveys among adults with ID (Evenhuis, 1995b; Meuwese-Jongejeugd, Verschuure, & Evenhuis, 2007). Our experience is also good. Residents have adjusted well to using the aids, communication was significantly improved with follow-up, and the staff reported that maintenance was easy. We believe that key factors in the success of using hearing aids were regular visits and continuous encouragement by an ASLP (who was part of the regular staff). Another feasible and practical solution to helping with hearing impairmrent could be the use of assistive listening devices (ALDs), such as personal FM systems, personal amplifiers, and TV amplifiers. These may be fitted in situations when an adult is not willing or unable to wear a hearing aid, but on specific occasions and set-ups may enjoy the benefits of amplification.

The examinations also revealed that about half of the ears examined had excessive or impacted cerumen. This proportion is relatively high, compared to other investigations, where an incidence of 6% to 42% was found (Brister, Fullwood, Ripp, & Blodgett, 1986; Crandell & Roeser, 1993; Fulton & Giffin, 1967). This finding, causing conductive hearing loss, affects the ability of the residents to communicate with their surroundings. In addition, the cerumen may prevent the in-house physician from identifying underlying pathologies of the ear, as proven during the present investigation. The improved communication gained by meticulous ear survey cannot be overestimated. It may reflect on the daily interactions with the staff or others, on the performance in the various workshop activities, and contributes to a more relaxed and amicable environment for the affected adults. The management of excessive cerumen is simple once diagnosis is made.

Commentary

Carrying out an extensive ENT examination for people with I/DD can be challenging, as difficulties in communication with the residents and possible anxiety due to unknown examiners can turn the examination into an impossible mission. To be useful, the examination requires the adults' cooperation, for example, when it comes to the examination of the throat and the larynx. Therefore, an important aspect of the Guidelines' implementation was obtaining the cooperation of the residents. This was achieved by preparatory discussions with the staff, their respective preparations with the residents, and by providing the examination at the center, in familiar surroundings and not in an outside site. We were able to examine and remove the cerumen from most of the subjects without any need for sedation. The contact person between the survey team and the residential care staff was the audiologist/speech-language pathologist, who made the initial coordination and most importantly followed up the outcomes. Thus, it is useful to have a coordinator who can organize the preliminaries and ensure that everyone is briefed as to what will occur.

The examination process, while seated and leaning toward the subjects, was ergonomically as well as mentally challenging. Frequent breaks should be planned ahead in any similar survey. Timely examinations of any grouping of adults with I/DD is important in maintaining good level of diagnosis and treatment of various pathologies in the ear, nose, and throat. Repeated examinations of the ears at an interval of 6 months is recommended. Higher frequency is required for adults with I/DD who tend to have repeated cerumen impaction. Performing hearing evaluations for adults who have suspected hearing loss requires the removal of cerumen, and thus enables the rehabilitation of adults with hearing aids.

Similar frequent ear and hearing examinations was recommended by Evenhuis (Evenhuis & Natzgam, 1997). With respect to adaptive devices, such use appears to vary. One study found that 43% of hearing aids users were still using their hearing aids in a survey held in the general population (Gianopoulos, Stephens, & Davis, 2002). This incidence may be even higher in the population with I/DD, and regular follow-up and support may increase this rate of use among these individuals. Among

individuals with Down syndrome, closer audiological monitoring has been advised (Shott, 2006).

It is our view that early ENT intervention can reduce communication difficulties, improve social functioning, and generally increase the quality of life of people with I/DD. In some cases, setting up a mobile ENT team for the evaluation of a group of people with I/DD may be more cost-effective than the alternative of referring each patient at a time to an ENT clinic—depending on the health scheme present in any nation. In addition to that, the early identification of ENT-related diseases during routine examinations may reduce the costs of treating the complications of such diseases which remaine undiagnosed until they are seriously problematic.

This investigation and report of the application of ENT Guidelines has certain strengths: it was conducted in a controlled environment and with the cooperation of the staff at the care centers. In addition to that, the examiners adhered to the described guidelines to ensure that all the residents would receive complete examination and intervention. Its limitation are related to the fact that it was performed in a care center, and not in the community, where it may be more challenging to adhere to these Guidelines.

We believe that the approach we demonstrated was simple and practical, and as such can be applied to people with I/DD living in the community, whether in formal settings or at home. We also believe that the guidelines we constructed will have value in any medical or clinical setting and will help frame a comprehensive ENT examination and subsequent interventions to address any adverse finding.

Acknowledgments

The support of The Morris Slivka Legacy, to honor the memory of Leo Aryeh Greenberg, is gratefully acknowledged. We thank the residents, staff, and management of the two residential care centers, especially Dr. Bessmertny, Dr. Dobman, Ms. Hayat, and Ms. Shemer, for their collaboration and cooperation.

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