Scandinavian Journal of Disability Research
Vol. 9, No. 2, 78–90, 2007

Routledge
Taylor & Francis Group

Holistic Aural Rehabilitation: a Challenge

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ABSTRACT *Despite more than 40 years of medical and technical rehabilitation having been offered to hearing-impaired people in Norway, there are still considerable barriers to aural rehabilitation. This paper presents the current state of aural rehabilitation in Norway. The need for a change in aural rehabilitation, from being mainly a medical and technical matter into a holistic, cross-professional and multi-disciplinary approach, is argued. Educational audiology, as well as other professional fields, must be included, e.g. there is currently a lack of emphasis on psychosocial factors, acceptance of hearing loss and communication skills training. Reports and articles from other countries support the arguments for change in aural rehabilitation practice, not only in Norway. There is also a need for change in the educational programmes for professionals, to further emphasize scientific skills and research work.*

Aural rehabilitation, denoted as "a problem-solving process aimed at minimising disability and avoiding or minimising the resultant handicap" (Stephens 1996:57) is, at the beginning of the 21st century, a considerable challenge for professionals. Substantial reasons for this are that the number of hearing-impaired individuals in society is increasing rapidly, and that hearing impairment in adults over 18 years of age is increasingly the most frequent communication disorder (Rosenhall, Jönsson & Söderlind 1999, Sorri, Junio-Ervasti, Uimonen & Huttunen 2001). A further reason is that aural rehabilitation in many countries is fragmented and insufficient (Tesch-Römer 1996, Falkenberg & Antonsen 1997, Sweetow 1999, Lieth 2001, Lorentsen & Berge 2003). This is in spite of the fact that the serious effects of hearing loss on a person's communicative and social functions (Kyle, Jones & Wood 1985, Noble 1996) can lead to emotional problems, with a severe impact on quality of life (Hull 1995, Skollerud 1996, Tesch-Römer 1996, Røykjær & Pedersen 1997, Carmen 2001).

Until the mid-20th century, schools for hearing-impaired people were in charge of rehabilitation for deaf and hard of hearing people in the Scandinavian countries. Around 1950, medical audiologists (ear nose and throat (ENT) doctors) brought aural rehabilitation into the hospitals and made it a medical matter (Lieth 2002). The same pattern was also seen in other countries (Hull 2001). The use of technology, including hearing aids,

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1501-7419 Print/1745-3011 Online/07/0200078–13
DOI: 10.1080/15017410701201329

other amplifying equipment and diagnostic machines, has been considered part of medical audiology. Thus, rehabilitation in the audiological field fits into the tradition of other fields, where rehabilitation is considered to be mainly a health issue, and where patients as well as health authorities have focused primarily on bodily function and repair.

A recent considerable change of paradigm has transformed the view of rehabilitation into a holistic process, a user-oriented approach based on the individual user's own goals and preferences. Such a rehabilitation practice is "all that it takes" for the person to obtain these goals (Hanssen & Lindqvist 2003). Thus, rehabilitation can no longer be limited to the repair of physical functional deficiencies or, more generally, to what the *health sector* does. The individual must receive assistance to be able to achieve the greatest possible independence and to participate in society on his or her own terms on a par with others. This means that other sectors, in addition to the health sector, must be brought on board to help the individual (Normann, Sandvin & Thommesen 2004).

This paper focuses on the system and the unmet needs of *adult* aural rehabilitation mainly from a Norwegian point of view. Based largely on a literature review and a presentation of traditional practice and results from evaluation studies on rehabilitation programmes for the past 20 years, the need for a change – both in the programmes and in the education of professionals to work in this field – is argued. Some of the results referred to show that these unmet needs have also been described in other countries, thus this paper can be considered to be of global relevance.

First, the basic concepts are defined, and the prevalence, needs and present situation described. Secondly, suggestions for changes needed to facilitate holistic rehabilitation for hearing-impaired people and individuals with other auditory symptoms that require professional help are presented. Finally, presumed barriers to development and outcome in the aural rehabilitation field are suggested.

Basic Concepts

The term "hearing-impaired" to describe a group subject to aural rehabilitation includes all types and degrees of annoying hearing loss, i.e. from hard of hearing to profoundly deaf.

Different terms are used related to rehabilitation for hearing-impaired people. The term *aural rehabilitation* has traditionally encompassed training in lip reading, speech reading and auditory skills (Matonak 1999). At the end of the 20th century, another term was brought into the field: *audiological rehabilitation*, also known as *rehabilitative audiology*. These terms encompass the evaluation and management of overall communication skills, the psychosocial aspects of hearing loss, the education of significant others (e.g. parents, siblings and close friends), hearing aid orientation, an emphasis on improving conversational and interactive skills, and the use of assistive listening devices (Kricos & Lesner 1996). In this paper the term *holistic aural rehabilitation* will be used, to include medical, technical and educational

audiology. In Norway today, *educational pedagogical audiologists* are the only people professionally trained to perform communication training and to counsel hearing-impaired people about psychosocial coping. The term *educational audiologist* will be used in this paper. The concept *multi-disciplinary* includes professionals from these three fields and from other relevant fields, e.g. psychologists, social workers and professionals from the vocational field.

Prevalence and Needs

Some studies consider the prevalence of hearing impairment in adults over 18 years of age to be 15%, with a projected increase up to 25% by 2020 (Rosenhall et al. 1999, Sorri et al. 2001). According to surveys carried out the past ten years, approximately 400,000 people in Norway have a hearing loss that requires rehabilitation services. More than one-third of these have a hearing loss due to the ageing process (Falkenberg & Kvam 2001). As the population ages, the need for aural rehabilitation will increase.

Tinnitus, also denoted as "the perception of sound within the head in the absence of external auditory stimulation" (Hazell & Jastreboff 1990), and *hyperacusis,* described as the collapse of loudness tolerance (Vernon & Press 1998), affect the auditory system. Individuals with these symptoms are therefore considered to be subjects for aural rehabilitation. A number of these will also be hearing impaired. Fabianska, Rogowski, Bartnik & Skarzynski (1999) suggest that tinnitus affects about 17% of the general population worldwide. Sanchez and Stephens (1997) found that 8% of people with tinnitus have *hyperacusis*. The prevalence of individuals with hyperacusis is unknown. The co-morbidity of hyperacusis with many other diseases, leads one to believe that hyperacusis is not an extremely rare disease (Demaree 1998).

Cochlear implant is a fairly new, but rapidly growing field in aural habilitation and rehabilitation. Due to technological and medical development, profoundly deaf children can develop a hearing status that is functional for spoken-language development and for communication based on spoken language (Preisler, Tvingstedt & Ahlstrøm, 2005, Wie, 2005). Deafened adults can also obtain functional hearing, provided that adequate rehabilitation programmes are offered.

The increasing number of hearing-impaired immigrants to Norway in the past decades calls for new knowledge in order to provide adequate rehabilitation programmes tailored to these groups.

A number of persons in the groups mentioned above have additional disabilities, such as vision loss (Reiners, Nagel-Wolfrum, Jurgens, Marker & Wolfrum 2006, Nikolopoulos, Lioumi, Stamataki & O'Donoghue 2006), intellectual disabilities (Holt & Kirk 2005) or emotional disturbance (Sinnott & Jones 2005, van Eldik 2005, Pollard 1996, Steinberg, Sullivan & Loew 1998); situations that call for an extended range of skills in order to be able to offer adequate rehabilitation programmes and proper diagnoses.

During the past years, the involvement of *significant others* as a way of seeing the individual as part of the environment, has been increasingly emphasized as decisive for rehabilitation outcome (Getty & Hétu 1991, Hallberg & Barrenäs 1994, Danermark 1998, Rezen 2001, Dwyer & Mawman 2001).

The above-mentioned groups represent the diverse range of needs often neglected in aural rehabilitation.

Current Situation in Aural Rehabilitation

Through several evaluation studies, it has been concluded that a considerable number of the hearing aids fitted are not worn. Kramer (1982) found that this was the in 28% of cases. A survey carried out by Olsholt & Falkenberg (1995) showed that 30% did not wear their hearing aids, whereas Falkenberg & Antonsen (1997) found that 33% wore their aids "seldom" or "never". This low-frequency use of hearing aids in Norway is confirmed by Winther, Hanche-Olsen, Poppe and Tvete (1990), Lippestad and Natvig Aas (1997), Gundersen and Lippestad (2000), Antonsen (2001) and McGlade and Solheim (2003). This is in spite of the fact that 60–70% of the several million adults in the Nordic countries who suffer from hearing impairment are estimated to benefit from hearing aids (DACEHTA, FinOHTA, SBU & SMM 2001). The benefit for the non users is contigent upon a participation in a holistic aural rehabilitation, which most of them are not offered. The percentage of non-users has not changed over the past 20 years – in spite of technological development and more appropriate hearing aids (Falkenberg, Holmberg, Morken & Øygarden 2002).

As already shown, aural rehabilitation in Norway is still mainly a medical and technical matter. There is a growing awareness in audiological practice that attention to technical matters alone may miss the point as far as the individual's needs and social circumstances are concerned (Noble 1996, Brooks 1990, Falkenberg & Antonsen 1997, Brooks & Hallam 1998, Antonsen 2001). For instance, the fact is neglected that the educational audiologist is a necessary part of the audiological team (Lippestad 1994, Tesch-Römer 1996, Hétu 1996, Lippestad & Natvig Aas 1997, Gundersen & Lippestad 2000, Norwegian Board of Health 2000, Antonsen 2001). Thus communicative skills training through speech reading and auditory training programmes are rarely carried out, which means that aural rehabilitation programmes are unfulfilled. Likewise, counselling for acceptance of hearing loss and a focus on psychosocial aspects is neglected, and little help is offered (Lorentsen & Berge 2003). This often results in the individual experiencing hearing impairment as a threat to his or her social identity (Hètu 1996). Involving significant others in the rehabilitation programme is also rarely done in aural rehabilitation. In other words, the rehabilitation programmes still focus mainly on the defective ear and hearing loss as such, whereas the consequences of the loss are not taken into consideration. The programmes offered are based more on traditional routines than on an individual, user-oriented approach with the primary focus on the needs of the user. This is in

spite of the fact that there is a considerable outcome from aural rehabilitation programmes that include these aspects, for instance in the increased frequency in use of hearing aids (Montgomery 1991, Winther et al. 1990, Falkenberg & Antonsen 1997). A longitudinal study performed by Antonsen (2001) shows that the positive effect of such a programme is maintained for years after the patient has attended a holistic and user-oriented programme including the above-mentioned aspects.

In spite of having access to modern listening devices, many hearing-impaired individuals are unable to maintain their employment and their social life. Many are forced into unemployment and isolation. A recent study from Denmark shows that unemployment in this group is more than double the average for the total population (Clausen 2003). For the majority this means a significant decrease in quality of life. In most modern societies, including the Nordic countries, employment is arguably the most important criterion for categorizing people in terms of class, status and power (Barnes 2003). Experience shows that access to vocational rehabilitation for hearing-impaired people is haphazard and still at an unacceptable level in Norway. The current lack of this holistic, multi-disciplinary aspect is crucial in aural rehabilitation, which, due to the complex nature of audiology, can never be practised properly by one person alone (Fish 1983).

Legal Rights and Aural Rehabilitation Programmes in Norway

Hearing-impaired people in Norway have a legal right to a rehabilitation programme that includes medical, technical and educational aspects with a considerable focus on communicative skills training, acceptance of hearing loss and other psychosocial aspects (McGlade & Solheim 2003); in other words, a holistic aural rehabilitation programme. Few individuals, however, are offered such a programme.

Norwegian Ministry of Health and Ministry of Social Affairs regulations (2002) state in §1 that rehabilitation services must be provided from a user perspective, be co-ordinated, cross-professional and planned, in or near the user's daily environment and in a meaningful context. This holistic approach is also described by the Norwegian Board of Health (2000).

Individuals needing aural rehabilitation are offered treatment either in one of the 30 audiological wards at public hospitals or by an ENT specialist in private practice. There are 56 of these private practices in Norway. Half of the hearing aids are fitted in hospital wards, half in private practices (Falkenberg et al. 2002).

The professionals seeing the patients are mostly medical doctors and technical audiologists; a rather poor staffing of aural rehabilitation teams, both in public hospitals and in private practice. A few educational audiologists run their own clinics, offering programmes on speech training and communication skills, tinnitus treatment and counselling for emotional aspects of hearing loss. However, in spite of the fact that most of them are paid by the authorities, these professionals are not officially counted as members of aural rehabilitation teams around the country.

As for tinnitus sufferers, very few programmes are offered, in spite of the fact that tinnitus habituation therapy, based on a neuropsychological model brings approximately 70% of tinnitus sufferers to a high level of improvement has been tested and found successful both in Norway and abroad (Falkenberg, Tungland & Skollerud 2003, Sheldrake, Hazell & Graham 1999). The therapy is based on a new approach to tinnitus management, presented by Jastreboff & Hazell (1993). Few professionals have the skills to perform this treatment.

Peer assistance has developed as a rather common support for hearing aid users. Compared with professional assistance, this is inexpensive. In poor communities there is a threat that peer assistance may replace professional assistance.

As for technical equipment supplemental to hearing aids, Norway has 14 centres for the distribution of technical aids. The professionals engaged to advise and assist hearing-impaired people in using such equipment often have very little audiological knowledge. The use of professionals with audiological training is a financial rather than a user-oriented matter.

Educational Programmes for Professionals in the Audiological Field

Educational programmes for professionals in the Norwegian field of aural rehabilitation are few and far from sufficient. There is no education for specializing in *medical audiology*. *Technical audiologists* are trained at a bachelor's degree level. *Engineers* who want to specialize in audiology have no formal audiological education. They are trained at their workplace and are more or less self-taught. *Educational audiologists* are trained at a master's degree level, and are the only professionals in the field, except for medical audiologists, who have a formal education in research work. Only a few people in Norway today have a PhD in audiology. The majority of these are educational audiologists.

This lack of higher and specialized education in the audiological field has lead to Norway having very few professionals with competence in educating new students or carrying out scientific work in the field. Very little research for international publications has been carried out, and "Norway is in fact about to be deleted from the international map of audiology" (Laukli 2001:16).

What is Needed to Succeed?

As a prerequisite, and in order to accomplish the goals of holistic aural rehabilitation, and in order to follow the regulations issued by the authorities, changes are needed both in practice and in the education of professionals. It will be necessary to take into consideration the recent change of paradigm to a user-oriented approach, based on the individual user's own goals, preferences and possibilities for coping.

In the following section, suggested changes will be argued by focusing on three main points: the organization, the rehabilitation programmes and the

education of professionals. All the following "demands" and "suggestions" are made by the author.

Organization of Holistic Aural Rehabilitation

Holistic aural rehabilitation calls for cross-professional and multi-disciplinary work. Both generalists and specialists are needed (Larsby, Andersson, Hallgren, Lundblad, Nyman & Carlsson 2000).

The use of educational audiologists who are trained in counselling to deal with psychosocial and communicative aspects is necessary for the audiological team, both in public clinics and in private practice. In Norway, this is already required by the authorities, and should be a rather easy task to accomplish, assuming that necessary changes in the payment regulations are carried out.

To be able to fulfil the needs and existing requirements of the authorities, the departments in charge must consider their responsibilities, perform a cost-benefit evaluation and be willing, through the established payment routine, to provide for a functional payment system to carry out holistic aural rehabilitation.

Unworn, fitted hearing aids represent a considerable amount of money, in Norway estimated to be approximately 16 million US dollars per year. Some of these people would do better with other technical aids, or may not be able to use any technical equipment. Perhaps they just need educational rehabilitation. Unworn hearing aids or other unused audiotechnical equipment represent a financial resource, and should be re-used for other people. Thus, considerable resources could be diverted from the technical part of aural rehabilitation into another area, for instance educational rehabilitation. The need for proficiency in tinnitus treatment is part of the picture.

There is a need for greater accessibility to professionals, more multi-disciplinary work and a clearer focus on the perspective of the user (Hørselshemmedes Landsforbund 1997, McGlade & Solheim 2003, Lorentsen & Berge 2003). Normann et al. (2004) state that there are numerous examples of the consequences of education and training (rehabilitation) not being carried out or being started too late, stressing the need for accessibility to professional rehabilitation programmes. Such an effort is anticipated to bring a positive change into the cost-benefit discussion, as more people will be able to stay in work instead of going into long-term invalidity. It is decisive for rehabilitation outcome to start the intervention soon after the problems start. The teams must focus on diagnostic work as a basis for rehabilitation. This includes not only an audiological diagnosis, but also a functional assessment, for example of psychosocial factors and communication skills.

Rehabilitation Programmes

In order to achieve holistic aural rehabilitation, the rehabilitation programmes must be considerably developed into holistic rehabilitation, as described in the introduction, by considering the needs of the individual as a

starting-point, and with a programme tailored accordingly. The programme must be based on skilled diagnostic work as a prerequisite for adequate rehabilitation outcome, including not only medical-audiological diagnosis, but also psychosocial function, for instance by using psychological tests intended to detect subjective hearing problems and communication skills. Furthermore, the programmes must emphasize counselling for coping and empowerment. Helping people to cope so that they feel capable is an important part of rehabilitation (Normann et al. 2004). According to Askheim (1998), empowerment deals with the transfer of power. "Power must be given or taken back by those who today are clients or users of the rehabilitation services so that they can gain or regain control over their own lives." Normann et al. (2004:46) comment on this by saying that "An understanding of coping such as this, which is not just limited to mental processes or practical skills but which also includes the infusion and mobilization of power, captures the meaning of the user perspective which holds a central place in rehabilitation." These statements require a programme tailored for each individual, where the client participates in and contributes to the content and the progress of the programme.

As for the psychosocial aspects of the rehabilitation process, positive information can increase rehabilitation effectiveness by: (i) identifying positive factors in people's experience of hearing loss that can be included in an aural rehabilitation programme that seeks to maximize effective self-management of hearing loss; and (ii) generate positive outcome indicators of functioning for inclusion in the assessment and rehabilitation components of the rehabilitation process (Kerr & Stephens 2001). The education of significant others must be integrated in the rehabilitation programmes (Rezen 2001). There is a need for implementing the rehabilitation programme in or close to the user's daily environment.

Scientific aspects. There is an unfulfilled need for trans-disciplinary research in the field and for people who are skilled in doing such work. Information on consumer satisfaction, not only with a focus on hearing equipment, but also on satisfaction and unfulfilled needs in the area of psychosocial function and communicative skills, is decisive for further practice. The results from such scientific work should lead to needed changes and adjustments in aural rehabilitation programmes.

Education of Professionals

Audiology as a professional field demands skilled people to take care of all the needs described in previous sections of this paper. It seems evident that one person alone cannot acquire all of the skills necessary to provide for every need related to aural rehabilitation. To avoid the struggle for power and position among professionals and thus unnecessary barriers to aural rehabilitation outcome, it is important that everyone on the team has a common basis for their training, and that the training programmes offer the opportunity to specialize in current fields, such as multiple disabilities,

cochlear implant, technical audiology, educational audiology, tinnitus habituation therapy, immigrant issues, and so on. To be able to go into research work, at a master's degree level, which might be viewed as the Norwegian follow-up to the Bologna Process. This advanced level education is urgent in countries such as Norway, where scientific work in the audiological field has been so greatly neglected. There is an urgent need for professionals in the field to educate new generations of professionals; these educators need education at a doctor's degree level. Audiology is an academic field that requires highly educated professionals.

The need for trans-disciplinary research in the field stresses the need for elevating the educational level of all professionals who work with audiology and audiological matters.

The authorities are urged to take responsibility for training professionals and providing help to hearing-impaired people and to take into account the human and financial benefits of doing so.

Barriers to Development and Outcome in the Aural Rehabilitation Field

The developmental process in the audiological rehabilitation field in many countries during the past decades can be characterized as haphazard, influenced by different interests, and not always seen from the user's point of view. There are probably many reasons for this, and the picture is rather complicated. Some of the assumed reasons and barriers will be mentioned here.

Hanssen and Sandvin (2003) suggest that the many professional interests and the struggle for power and position among them have the disorderly and chaotic hallmarks of late modernity. Experience shows that these features are present in the audiological professional field, and are likely to represent a barrier (Falkenberg 2001).

Anxiety about change, as often experienced by professionals, might be a hindrance to progress in the audiological field.

An additional obstacle in this field, at least in Norway, is that laws and regulations are neglected in audiological practice and rehabilitation programmes, and that no-one takes financial responsibility for a holistic rehabilitation programme. No one person or agency controls audiological practice, either in hospitals or in private practice. In other words: the barriers are not due to a lack of legal rights, but rather to a lack of implementation of those rights in clinical work. There is a lack, not only of adequate competence, but also of responsibility from those in authority (McGlade & Solheim 2003).

Furthermore, Lorentsen and Berge (2003) report a general complaint about low levels of accessibility to professionals, due to long waiting lists. This might result in a decrease in motivation during the waiting time, which may represent another barrier to rehabilitation outcome. In Denmark and Sweden, the number of professionals engaged in aural rehabilitation per head of population is far higher than in Norway (McGlade & Solheim 2003).

The lack of proper education for professionals in the audiological field is thought to represent a barrier to rehabilitation outcome, as is the lack of educational programmes for those who want to update their skills in the field, including training for scientific research work. Current examples of knowledge and skills that are rarely seen in today's practice are: skills in treating tinnitus and hyperacusis; skills to meet the needs of cochlear-implanted persons; skills to meet the needs of people with multiple disabilities; and skills to meet the needs of individuals with a foreign language and cultural background (Falkenberg et al. 2002).

Securing the quality of rehabilitation programmes offered to hearing-impaired people is a non-existent service. This must be considered a substantial barrier. No official programme has been developed like the ones, for example, in Sweden and the USA. Aural rehabilitation services offered to hearing-impaired individuals are thus haphazard, and depend on where one lives and who one meets when seeking professional help. There is considerable variation in the organization of hearing services in Norway, as is the situation in other Western countries (DACEHTA et al. 2001). In addition to the human factor, there is also a cost-benefit factor, whereby it would be much more appropriate to spend government money on successful treatment than on social insurance benefits.

The overall picture of aural rehabilitation seems to be influenced by money, professional interests and the struggle for power and position, rather than by user-oriented needs. These are extremely strong barriers to success, barriers representing a considerable challenge that calls for involvement from the authorities, the professionals and the organizations representing hearing-impaired people.

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