1 Introduction

The need for this book

There is a wide range of books currently available which cover different aspects of audiological rehabilitation/enablement, so the question arises: ‘Why yet another book?’ We would argue that almost all existing books are orientated towards specific aspects of the rehabilitative process (such as hearing aids, cochlear implants or speechreading/lip-reading), at rehabilitation specific to one particular sociomedical system (e.g. private practice in the Unite States) or, at best, reflect an approach related to the perspective of concerned professionals.

While we would be the last to deny the influence of our backgrounds as a retired audiological physician and an active psychologist working in the field, we try to approach the problems and needs from the standpoint of what the patient/client is seeking rather from what we, as professionals, can provide. In order to do this we shall call upon autobiographical accounts, the general rehabilitative and health psychology literature as well as the audiological literature and our own experience.

In this way, we hope to provide an intellectual and practical source book for a range of professionals who may encounter and be called upon to support individuals with hearing difficulties as well as making it accessible to individuals with hearing difficulties themselves. In the last context, it must be remembered that only a minority of people with hearing difficulties seek rehabilitative help (Davis, 1995; see also Chapter 2). Thus, we would hope that, by making relevant information easily available, this might encourage some of those individuals, reluctant to seek help, to present to rehabilitation departments earlier, and so reduce some of the problems experienced by themselves and by those around them.

Our approach has always been one of problem-solving, aimed at addressing particular and often specific needs experienced by people with hearing difficulties, rather than trying to fit the individual to a particular service model or set of devices. We shall therefore emphasise repeatedly the need to discuss their particular problems with the individual, their reaction to such problems and the reasons behind such reactions. In this context, it is always important to consider the role, attitudes and reactions of the individual’s significant others (e.g. spouse, partner, child, friend), while being sure that the interests of the individual with the hearing difficulties has the dominant role in any rehabilitative approach.

In addition, we are aware that problems experienced by individuals with hearing difficulties will change as a result of any rehabilitative intervention and changes in lifestyle and experiences. We shall consider how this may be addressed and present some preliminary results in this domain collected by some members of the International Collegium of Rehabilitative Audiology in the Appendix.

Most of this book is concerned with individuals experiencing acquired hearing difficulties, from mild to profound, but we shall not neglect those born with such problems. Many such individuals with pre-lingual hearing impairment opt to lead their lives within the Deaf community and are, often justifiably, loath to seek help from health care professionals. However, some Deaf individuals may seek help at certain periods of their lives, such as if they have hearing children whom they want to support orally at critical stages of their lives, or if they find themselves in a particularly difficult employment environment. Even in other situations, they may find aspects of the rehabilitative process, such as updating of environmental aids (assistive listening devices) and help with new legislative arrangements, relevant and important.

Finally, we have taken the decision to restrict the scope of the book to adults with hearing disabilities rather than including all from birth to old age. The balance of hearing problems (e.g. severe vs moderate) and the fact that most affected children have never experienced normal hearing has led us to this decision, although much of what we include will be relevant to the audiological enablement of many children. In addition, we shall include in our text our experiences with hearing impaired school leavers, many of whom had hearing impairments dating from birth. Furthermore, we have excluded a specific section on the impact and needs of ethnicity and religious beliefs, beyond considering them in general terms as they influence the rehabilitative/enablement process. We accept that this may be an increasing problem in a world with more and more population movements, but here we are aiming to propose a universal approach which can encompass any and all such belief groups. For a more detailed discussion of specific needs and problems arising in immigrant groups, the reader is referred to Ahmad *et al.* (1998) and Jones *et al.* (2006).

Terminology

Enablement

The most commonly used terms for what we are broadly addressing in this book are *audiological rehabilitation* or *aural rehabilitation*. These terms have been generally accepted, but have a number of philosophical limitations. These are centred around the fact that they are based on the function of the ears or of the auditory system on one hand rather than on the 'complete' individual, and second that they give the impression of a system into which the person with hearing difficulties is fitted. Early definitions of such processes were along the lines of '*Auditory Rehabilitation* implies the return of persons to a former state of "normalcy", but is used here to describe the treatment and training of all persons with hearing too impaired to permit adequate effectiveness in auditory communication' (Bergman, 1950). We prefer the following definition: 'A problem-solving process aiming to minimise the disablements experienced by individuals with hearing disorders and to maximise their quality of life' (Stephens, 2003), but this still has the negative implications associated with the term *rehabilitation*.

The audiological rehabilitative literature states two goals of rehabilitation:

1. To furnish the individual with the communication tools with which to offset their impairment to an optimum degree
2. To help them gain insight into their disability and the problems it raises (Pauls and Hardy, 1948).

In the general rehabilitative literature, they have been defined as:

1. To optimise social participation of the patient
2. To maximise the well-being of the patient
3. To minimise stress on and distress of relatives.

(Wade, 2005)

The term *enablement* has been used in the neurological rehabilitation literature (Wade, 2003, 2006) and has the implications of helping individuals to do what they would like to do, to the extent that their inherent functional limitations allow. Wade argues that this refers to the *facilitation* of the patient. It is 'Not a passive process' and could refer to 'the patient achieving or having:

- More skills, a wider behavioural repertoire
- A better environment and
- More appropriate expectations'.

Thus, we propose to use within this book the term *audiological enablement*, which we define as a problem-solving process aimed at:

- enhancing the activities and participation of an individual with hearing difficulties
- improving their quality of life
- minimising any effect on significant others
- facilitating their acceptance of any residual problems.

Hearing impairment

While most patients presenting with hearing problems have an acquired disorder and hence *hearing loss*, we do not wish to exclude consideration of those with a congenital disorder, who have never 'lost' any hearing, and so prefer to use the term *hearing impairment*. In addition, this overcomes the problems with the inclusion of patients with King-Kopetzky syndrome (Hinchcliffe, 1992) who, while having hearing disability, have essentially normal hearing audiometrically, and hence no 'loss' of hearing. However, as shown by Zhao and Stephens (2000), on sensitised audiometric testing, most of such individuals have some degree of impairment, so may be regarded as being within the boundaries of *hearing impaired*.

In this context, we follow the recommendations of the European Work group on the Genetics of Hearing Impairment (Stephens, 2001) in which a number of relevant audiometric terms are defined. Following those recommendations, we also eschew the term *deafness* except in the context of the Deaf community, where the word has sociocultural connotations. We are aware that certain people within that community dislike the terms *impairment* and *impaired*, but we would argue that it is a valid term to use in people who have a measurable deficit in their hearing. Such people may, however, neither have a disability nor be disabled.

The terms *disability* and *handicap* will be discussed below in the context of the World Health Organization's (WHO) classifications. At this stage, we would argue that *handicap* is a confusing term, with many different connotations and uses, while the implications of *disability* have changed even within the two major WHO definitions (WHO, 1980, 2001).

‘Patients’, ‘clients’ or ‘people with hearing impairments’

We have thought much about this aspect of terminology, namely the people whom we are dealing with and trying to help. As we have both worked within medical environments and the individuals with whom we are concerned have either a demonstrable pathological lesion or psychological problems, we have opted to use the term *patient*. We accept that some people will be uneasy with this ‘medicalisation’ of the problem but, as we shall show, we reject the simplistic medical model of disease and disability.

We are unhappy with the term *client*, which implies a financial relationship to the service provider, one alien to the sociomedical environments in which we live and work. *People with hearing impairments*, and its acronym PHI, apart from being a clumsy term, implies that the individual with whom we are concerned must have a demonstrable impairment of function. While this is true for the vast majority of those with whom we are concerned, it is a term which excludes those complaining of hearing difficulties but who have no such demonstrable impairment. Like Wade (2006), we would argue that such individuals require rehabilitative help as much as those with clear impairments do, and that the enablement process should be able to encompass both groups.

Environmental aids/assistive listening devices (ALDs)

The role of environmental devices in the enablement process has received increasing attention (e.g. Lesner, 2003). While the term *assistive listening devices* is widely used, particularly in North America, and some of them such as television amplifiers and electromagnetic loop systems may be specifically concerned with listening, others such as flashing light doorbells and vibrator alarms are not. Further, the terminology including such devices in the *International Classification of Functioning, Disability and Health* (ICF; WHO, 2001) of ‘Assistive products and technology for *personal* use in daily living’ misses the point, as most of such devices, as opposed to hearing aids or cochlear implants, may be used by several people with hearing problems at the same time. We would therefore argue that the term *environmental aids*, used for a number of years in the rehabilitation literature, would be most appropriate, as it implies that they are devices which may help a range of people with hearing problems in a particular environment in which they might expect to have difficulties hearing what they would like to hear.

Layout of the book

We divide the main body of the book into four main sections, which broadly follow the categories of the WHO’s ICF (2001).

In the first section (Chapters 2–4), we cover entry into the process and the underlying dysfunctions found in affected individuals, including non-auditory factors which impact upon them. This has implications both for the affected individual and for those concerned with facilitating their entry into the process of enablement.

The second section (Chapters 5–6) will deal with the effect of such impairments of communication and emotional functions of the individual. It will also examine how the individual's other characteristics (e.g. attitudes, personality and non-auditory disabilities) as well as those around the individual can influence the difficulties which they experience.

The third main section (Chapters 7–9) will consider the individual in their environment, within their family, in work, as well as in broader leisure and other situations. Again, this will cover ways in which the individuals achieving their desired participation in such situations can be facilitated.

The fourth section (Chapters 10–12) provides a discussion of the process of enablement, the factors within the patient which need to be taken into account and what can be done to address the various problems experienced. In addition, we shall examine how these individuals can be helped to accept the fact that there will remain certain situations in which they will be unable to participate despite optimal facilitation approaches.

The World Health Organization classifications

Phillip Wood, a rheumatologist, was the first to propose the concept of a defined terminology for the consequences of disease (Wood, 1980), which was subsequently adopted by the WHO (1980). Previously, a range of terms including *disability* and *handicap* had been used in a variety of different ways by different groups of professionals and in different countries, and it had become clear that a widely agreed classification was going to be necessary if different professional were going to be able to communicate with each other in a meaningful way.

Within this classification – the *International Classification of Impairments, Disabilities and Handicaps* (ICIDH; WHO, 1980) – the three levels of consequence of impairment, disability and handicap were defined (Figure 1.1).

These manifestations were subsequently classified according to whether they referred to:

1. a loss or abnormality of psychological, physiological or anatomical structure or function – *impairment*
2. a restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being – *disability*
3. a disadvantage for an individual that limits or prevents the fulfilment of a role that is normal for that individual – *handicap*.

Thus, *impairments* represent disturbances at an organ level, *disabilities* at the level of the person and *handicaps* reflect interaction with and adaptation to the individual's surroundings.

The overall relationship between these aspects is shown in Figure 1.2

Figure 1.1 The consequences of disease.

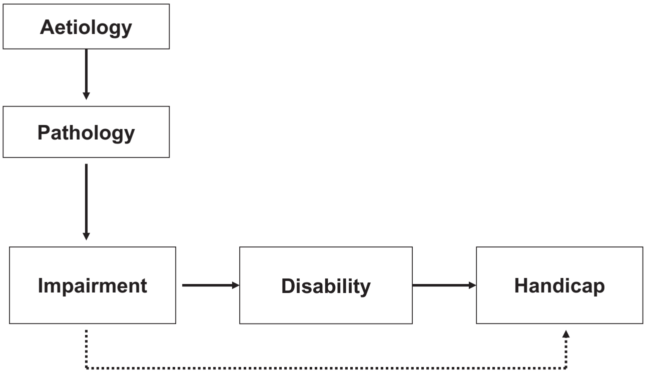

Figure 1.2 The basic classification embodied in ICIDH (1980).

It subsequently became apparent that this model could not cope with various aspects, particularly of the generation of handicap, and that it had a number of internal weaknesses from an audiological point of view. A variety of attempts was made by different authors (e.g. Stephens and Hétu, 1991) to address ways in which the model could be modified to allow for secondary handicaps and the influences of rehabilitative interventions.

Through the late 1990s and into 2001 a number of draft amendments to the ICIDH model were developed by the WHO, taking into account the various criticisms and suggestions made in the intervening years. This led to the publication in 2001 of the *International Classification of Functioning, Disability and Health* (ICF). Apart from changes in terminology, this had a number of key differences from the ICIDH.

1. There was a change from the presentation of the negative consequences of disease (what individuals cannot do) to its positive aspects (what individuals can do). Thus, broadly, 'impairment' was replaced by 'structure and function', 'disability' by 'activities' and 'handicap' by 'participation'. Negative aspects of these are termed 'impairment' (as before), 'activity limitation' and 'participation restriction'.
2. The concept of *contextual factors* – both environmental and personal – was introduced. These are factors around and within the individual, respectively, which can influence the activity or participation within an individual with a certain condition.
3. The third change lies in the fact that an alteration in one element (function, activity or participation) as a result of changes in contextual factors or from some form of intervention can influence those elements which precede it as well as those which follow it. That is, the model does not have just a simple left–right progression, but can show changes in any direction. This includes contextual factors, which can be altered by changes in activity or participation as well as altering them. The overall model is shown in Figure 1.3.

Both models have a number of key features in common. They each have three components of the consequences of the health condition, the first based on effects on the organ or system, the second on effects on the individual per se and the third on the effects on the individual within their environment/society. Second, while there

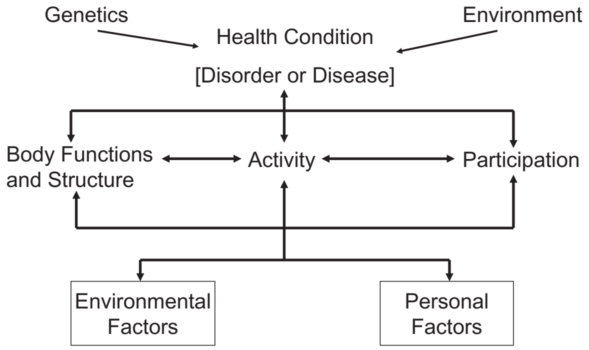

Figure 1.3 A modified version of ICF, including aetiological factors.

are exceptions, the general principle is that the health condition will lead to changes in structure or function, which in turn affect activity, while this modifies participation. Third, while the underlying condition may result in a number of individual effects, there is no attempt to determine an overall impact on the individual, which, for example, Wade (2003) proposes as 'wellness' and elsewhere as 'quality of life' (Wade and Halligan, 2003).

There are a number of specific weaknesses to the model when applied to particular domains, and a number of these have been highlighted by Wade and Halligan (2003) in a general context and by Stephens and Danermark (2005) in the context of people with hearing problems. Thus, Wade and Halligan (2003) highlight the need to specify more about 'the person' (i.e. the individual being considered) in their environment, their society, their body and their organ, and also include a section on the individual's choice: 'free will'. Elsewhere, Wade and de Jong (2000) point out that the model fails to take into account patient's subjective experiences.

Stephens and Danermark (2005) focus on the weaknesses of the ICF term *personal factors*, which, they argue, is poorly defined, and suggest that a well-defined, two-way interaction between *personal factors* and both *activity* and *participation* could overcome many of the problems. They also point out weaknesses from a hearing point of view in the classification of listening activities and of attempts within ICF to provide quantitative assessments of impairments. Wade and Halligan (2003) further argue that there should be more integration of ICF with ICD-10, the *International Statistical Classification of Diseases and Related Health Problems* – 10th Revision (ICD-10) (WHO, 1992), and also that the concept of *time* be applied to disabilities, which may have changed markedly since the onset of the individual's current set of problems.

However, despite these weaknesses, ICF remains a valuable model in the context of considering the impact of disorders such as hearing impairments. It is a model which will guide many aspects of the present book, even if we ignore its putative quantitative elements.

Within ICF, activity limitation and participation are lumped together under the collective term *disability*, which thus has a new definition and replaces the collective term *disablement*, used in ICIDH. The separation of activity and participation is generally based on 'what the person *can* do' for activity and 'what the person *does* do' for participation. However, ICF, in its Annex 3 describes alternative classifications based on a division of the disabilities into a group of 'tasks or actions that an individual does' as activities and 'involvement in life situations' as participations. In practice, there is relatively little difference in the practical outcome of the two classifications, and this will be discussed further in Chapter 10.

Theoretical/management models in the general rehabilitation literature

Katz *et al.* (1997), in the post-ICIDH era, describe the 'traditional approach' of three stages of 'Functional assessment' (the patient's disorder at a single moment), 'Diagnosis' (merely listing impairments and disabilities) and 'Treatment planning' (concerned with the management of functional problems at the time of assessment). They replace this with their Neurologic Model of Rehabilitation, comprising 'Diagnosis', involving assessment of the underlying brain disorder in relation to the disablements, 'Prognosis', dependent on personal and environmental factors as well as the natural history of the disease, and 'Treatment planning', involving the interactive process of recovery. This is illustrated in the model shown in Figure 1.4.

It may be seen that it emphasises the role of personal, social and environmental factors in interacting with the interventional process, which they call 'Learning'. This, in turn, is superimposed on the natural recovery process, which they argue is influenced by personal and environmental factors.

A similar approach is incorporated in the biopsychosocial model, which has been widely used in the context of pain management (e.g. McMahon and Koltzenburg, 2005) and the management of gastrointestinal disorders (Drossman, 1998). Drossman contrasts it with the previously used biomedical model, which fails to take into account psychosocial factors in the development of *illness* (Figures 1.5a and 1.5b). He argues that the biopsychosocial model takes these factors into account and explains the various psychosomatic disorders. Thus, comparing Figures 1.5a and 1.5b, it may be seen that the biopsychosocial model incorporates psychological predisposing factors with the biological ones as the starting point. The relationship between disease (pathology) and illness (perceived lack of wellness) becomes a two-way process, the balance of which may be changed by psychological modifiers. They, in turn, can be

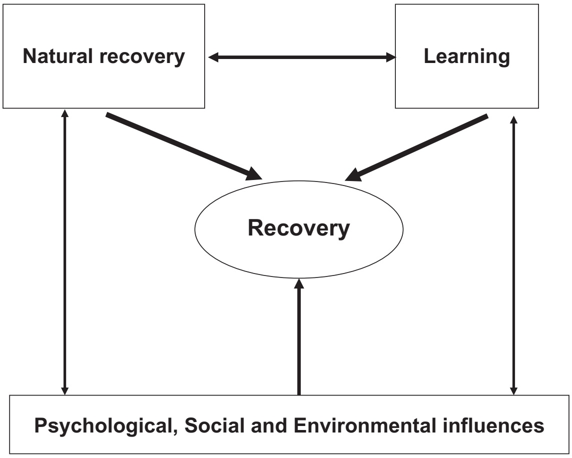

Figure 1.4 Factors contributing to recovery (summarising the model of Katz *et al.*, 1997).

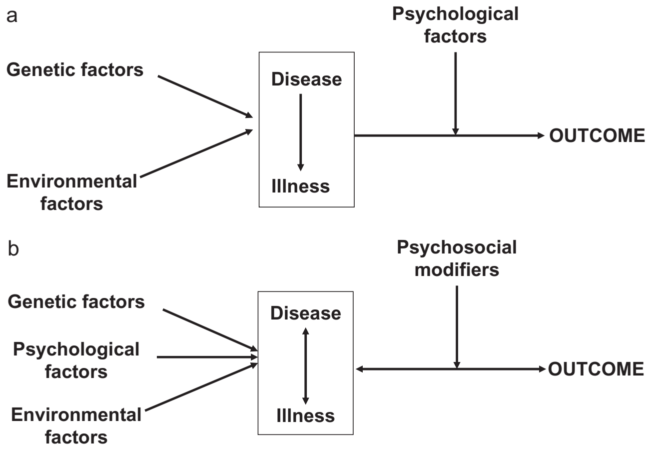

Figure 1.5 **a** Representation of the biomedical model. **b** Representation of the biopsychosocial model.

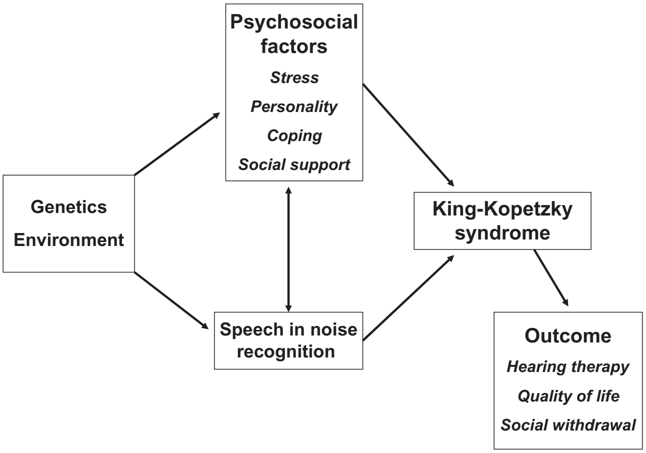

Figure 1.6 The biopsychosocial model applied to King-Kopetzky syndrome.

affected by the disease/illness process. Drossman (1998) argues that this involves a return to the holistic approach, integrating the psyche and physical factors, which characterised Greek medicine.

As an example, Figure 1.6 shows an application of the psychosocial model to King-Kopetzky syndrome, based on Drossman's application to irritable bowel syndrome. Pryce and Wainwright (2008) indicate that this condition comes within the same category of 'medically unexplained symptoms'.

Wade has developed various models of neurological rehabilitation (Wade, 2005, 2006b), considering different aspects of the process. Their focus is predominantly on activity limitations, whereas much of audiological rehabilitation is more orientated towards overcoming aspects of participation restrictions. However, many of the concepts Wade introduces are very relevant to the audiological field.

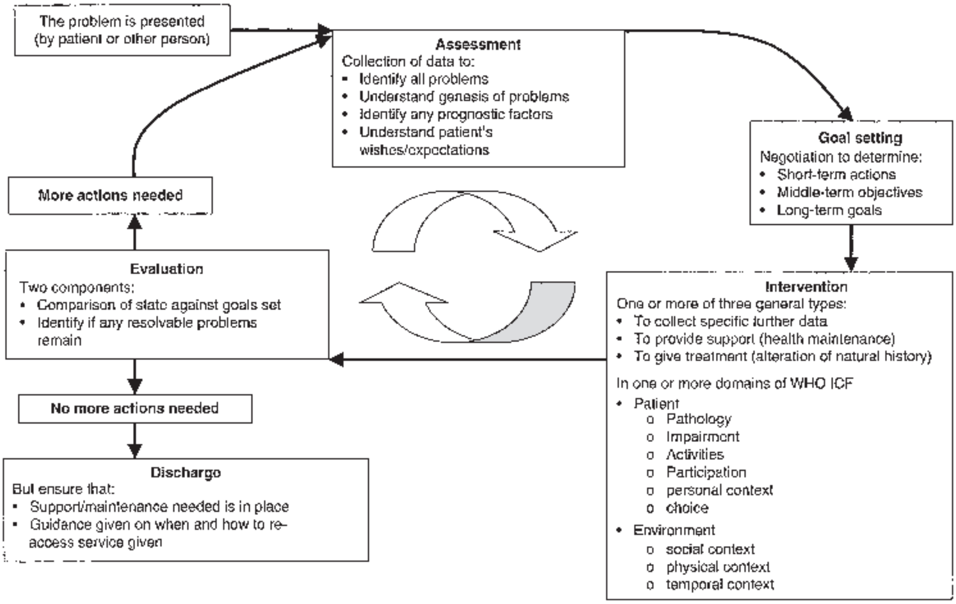

Figure 1.7 The rehabilitation process. (*Source:* derived from Wade, 2005, with permission.)

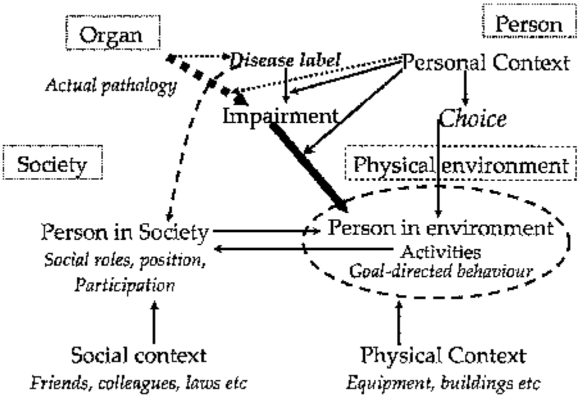

Figure 1.8 WHO ICF rehabilitation analysis of illness. (*Source:* derived from Wade, 2006b, with permission.)

Figure 1.7 shows an overview of the rehabilitation process, developed in the context of neurological rehabilitation, which may be seen as a cyclical process which continues until the evaluation indicates that no further actions are needed (Wade, 2005). At the same time, the model allows for re-entry into the system, should further support be required at a later stage. This reflects, in several ways the model of audiological rehabilitation described by Kiessling *et al.* (2003). It thus demonstrates the existence of many commonalities in the process of rehabilitation applied to different systems, even though details of the interventions will obviously differ. One important aspect of this model is the consideration of short-, medium- and long-term goals.

Elsewhere Wade (2006b) emphasises the importance of considering in the rehabilitation process those individuals presenting to health care services who have no underlying pathology. He argues that the rehabilitation process should be equally relevant to such individuals as to those with a clear pathology. There may be analogies there with the management of King-Kopetzky syndrome, in which many individuals have no clear auditory pathology. In addition, Wade argues that individuals simulating or exaggerating their symptoms could be considered in this context, even if the approach to their detailed management might be different.

In this context, he developed a modification of ICF analysis of illness, taking into account the aspects of personal choice. This is shown in Figure 1.8, which illustrates how the 'person', with their characteristics and attitudes, interacts with other elements of ICF.

Models of audiological enablement

Prior to the end of World War Two, there was little attempt to integrate the different aspects of rehabilitative provision for adults with hearing impairments, with leading authors in Europe and America considering instrumental and non-instrumental support under very separate headings (e.g. Bunch, 1943; Ewing, 1944). The major changes with attempts to provide an integrated service came after that war with the Veterans Association in the United States (e.g. Bergman, 1950) and the establishment of rehabilitation departments in the new National Health Service provisions in the United Kingdom (e.g. Whetnall, 1951) and Scandinavia (e.g. Ewertsen, 1976).

Rehabilitation programmes developed by Bergman (1950) and lasting either four weeks or two and a half days are shown in his Figures 5 and 6. These cover most of the components of clinical audiological rehabilitation currently considered, even if they are not presented in relationship to each other. In addition, auditory assessments are assumed to have been completed prior to the rehabilitative process, and so are not specifically included within it. The total plan of the programme, however, including both assessment and remediation (from Bergman's Figure 6, p. 49) is shown in Figure 1.9. All the components of Bergman's model took place within the institutions of the Veteran's Administration.

Bergman's model (1950) represents a detailed functional descriptive approach to the rehabilitative process, rather than a conceptual or analytical model. Markides (1977a) adopted an approach similar to Bergman's in his comprehensive description of the Danish state rehabilitative system and included external sources of support for people with hearing difficulties, such as voluntary organisations, church and further education. His organisational chart is shown in Figure 1.10. The top half of the chart broadly represents services provided within the institutions and the lower half within the patient's home.

These two models draw together most of the major components of the rehabilitative process but do not specifically address the question of fitting the process to the patient's needs. This is also a criticism which may be made of some of the more recent models, although, on the whole, they do try to address this problem.

The first serious attempts to provide a flow diagram of the process of rehabilitation came with the work of Alpiner (1978) and Walden (1980). Interestingly, Walden's approach is based, like Bergman's (1950), on his experience in the US Veterans Administration.

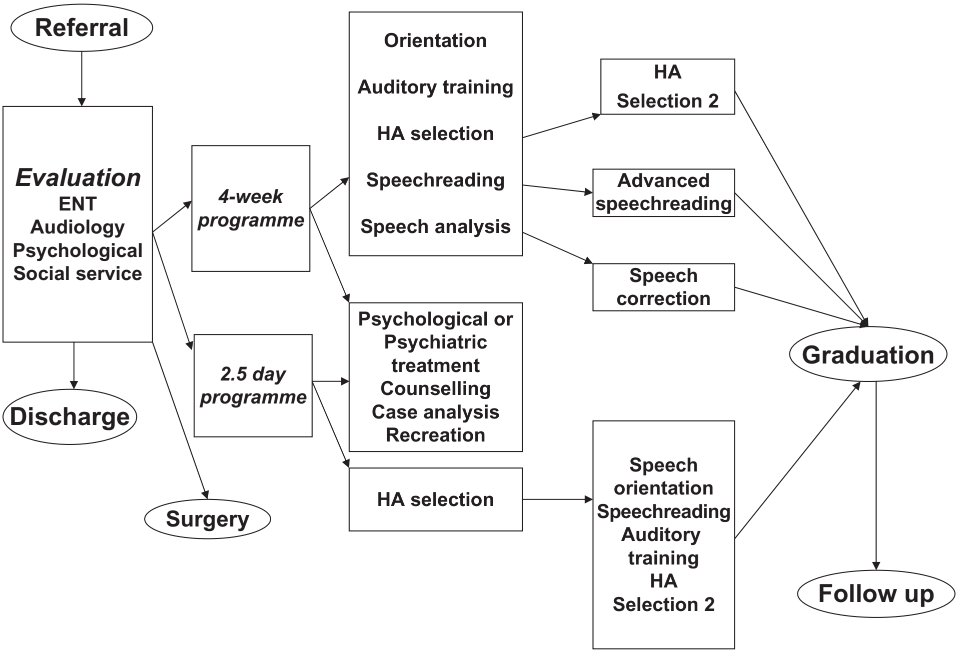

Figure 1.9 Rehabilitation programme developed by Bergman. (*Source:* adapted from Bergman, 1950, p. 49. Reproduced by permission of the author.)

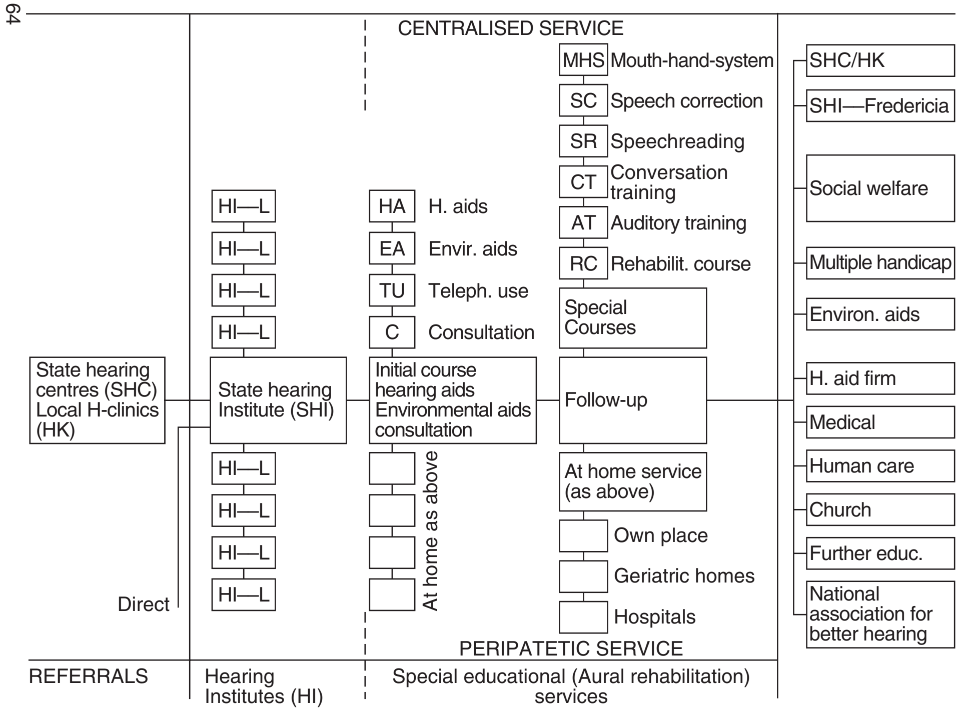

Figure 1.10 Rehabilitative organisational chart for services in Denmark. (*Source:* from Markides, 1977. Reproduced by permission of the author.)

Within his approach, Walden (1980) does consider psychosocial factors, in particular 'Problem awareness' and 'Situation control' and 'Adjustment problems', in both the audiological diagnosis and rehabilitative intervention but does not present them in a specific goal-setting context. In addition, the main elements of the process are the clear audiological components, although he does recommend 'Environmental control training' for those with 'Situation control problems' (identification and assertiveness) and counselling for those with adjustment problems (social, vocational and emotional).

The Goldstein–Stephens model

Goldstein and Stephens (1980, 1981) developed a management model, which they proposed would:

1. highlight the many components which constitute the entirety of the process being considered (in this, we tried to make explicit some of the subtle parameters of the 'clinical art' so that they could be more rationally evaluated)
2. consider the sequences and interaction of these components
3. provide guidance in the training of audiologists.

It aimed to be general and not system-specific, particularly given the different backgrounds of its authors, one a university-clinic-based American audiologist within the US sociomedical system and the other an audiological physician within the UK National Health Service. It was thus broad and independent of setting and philosophy.

Goldstein and Stephens deliberately, however, avoided any consideration of factors which might have determined whether an individual with hearing problems enters the rehabilitation system and also any consideration of the 'completeness' or final outcome of the rehabilitative process. These will be addressed in the present book in a later section in which we consider our present working model (Chapter 10).

The overall model comprising the various components is shown in Figure 1.11. The three columns show different degrees of elaboration of the process, from the basic elements of evaluation and remediation on the left through to the more specific components, such as the individual elements of communication status on the right.

Goldstein and Stephens emphasise the elements of evaluation which were relevant to the rehabilitative process and argue that different components of the evaluation should be assessed in ways appropriate to the particular component. Thus, auditory function should be assessed by formal and relevant audiometric tests, whereas certain other components could be assessed by interview or observation. This has been considered in more detail elsewhere (e.g. Stephens, 1982, 1987a) and we shall return to this question in Chapter 10.

In addition, in their presentation of the model, Goldstein and Stephens discussed ways that each individual component could be elaborated, using computer flow diagrams, similar to those used by Walden (1980). Examples of these are shown in Goldstein and Stephens (1980, 1981), and a more extended elaboration in the context of hearing aid selection was presented in Stephens (1984).

Evaluation

Returning to the basic model, Goldstein and Stephens that, while the communication status of the individual was a key area in the evaluation of the patient presenting for

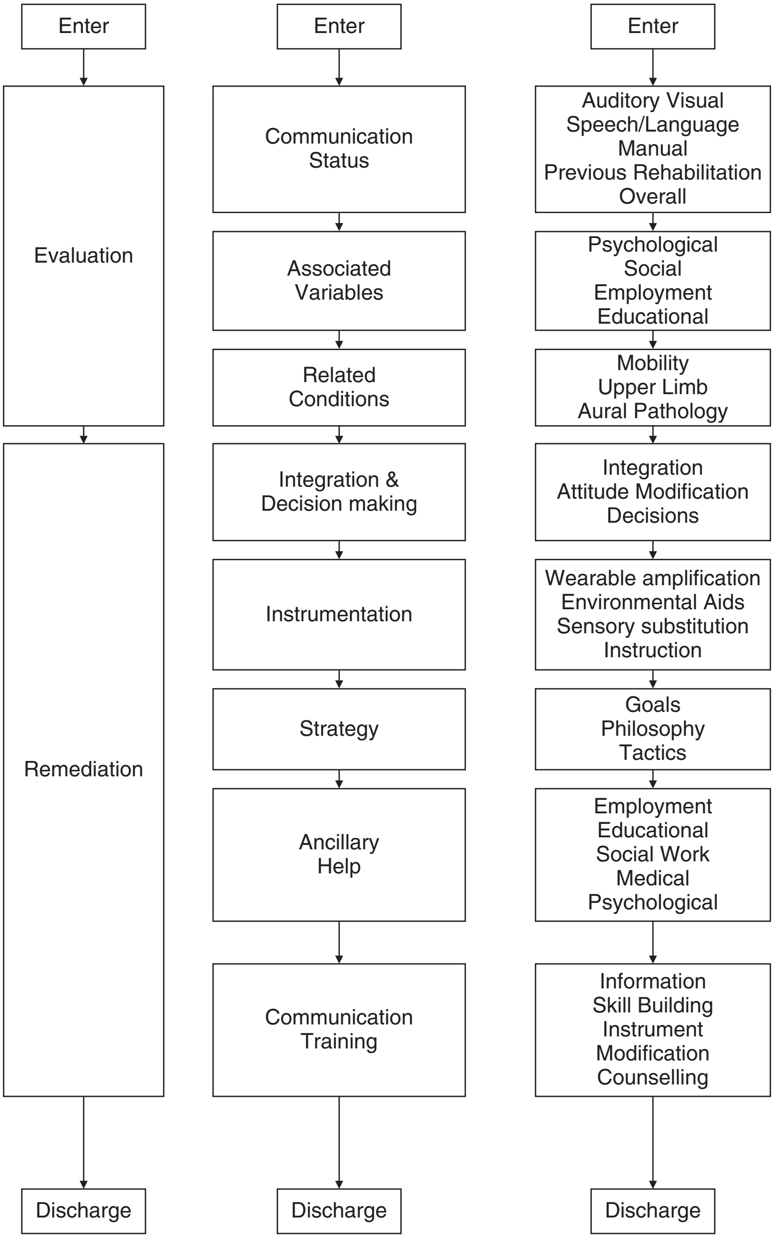

Figure 1.11 Goldstein and Stephens' (1981) model outlined with each column showing increasing detail. (Reproduced with permission.)

rehabilitation, it was only one of several key areas. The other two areas which they identified there were what they call 'Associated variables' and 'Related conditions'. The first of these, associated variables, comprises what may be broadly considered as the psychosocial elements of the process, involving both patients and those around them. The second, related conditions, comprises a variety of other elements of the patient that may complicate the rehabilitative process.

In general terms, communication status comprises the raw materials with which the audiologist has to work, associated variables govern the overall approach to be adopted with the patient and significant others, and related conditions determine detailed aspects of the approach to be followed. Elements of the last comprise, for example, whether the individual is bed-bound or house-bound, whether they have severe tremors and whether they have tinnitus or discharging ears.

Remediation

The first element of remediation is labelled 'Attitude'. This comprises three major components: first, the drawing together of information obtained in the evaluation process, and, second, some preliminary modification of the patient's acceptance, understanding and expectations of the rehabilitative process and third an initial triage of the patients. This last has important implications for the rehabilitative process and has four categories ranging from 'keen and straightforward' through to 'rejecting any rehabilitative intervention'.

This triage/classification of patients has withstood the tests of time for over a quarter of a century, although the proportions in the different categories may vary according to the age breakdown and population under consideration (e.g. Stephens, 1982; Stephens and Meredith, 1991a). However, in all reports, some 90% of individuals come in attitudes/rehabilitation types 1 and 2. A brief description of the four types is shown in Table 1.1.

Type 1 patients are the most common among the younger age bands and require relatively limited resources in terms of ongoing support and pass quickly through the system, returning of their own volition should they have any further problems. Type 2 patients are positively motivated but additional problems may be anticipated. This may be because they have severe/profound hearing loss or a very mild loss,

Table 1.1 Rehabilitation types.

Rehabilitation type	Description
1	***Positively motivated without complicating factors*** will accept relevant instrumental intervention and pass rapidly and effectively through the system
2	***Positively motivated with complicating factors*** will require more attention with regard to specific instrumentation and handling, communication skills and tactics
3	***Want help, but reject a key component*** will require careful handling with counselling and involvement of significant others
4	***Deny any problems*** no intervention for the patient, but the significant others may require support and advice

they may have an audiogram which may be difficult to fit with hearing aids (e.g. a low-frequency sensory loss), or they may have other complicating factors such as tinnitus, otorrhoea, severe tremor etc. Type 3 patients genuinely want help but may reject a particular element which might be most appropriate for them, such as a hearing aid. Alternatively, they may have inappropriate expectations of a hearing aid, thinking it will solve all their psychosocial problems, when in fact counselling is what is needed. Both types 2 and 3 will generally require considerably more time and effort from the rehabilitative service. Subsequently, Piercy and Goldstein (1994) subdivided type 3 patients into 3A, negative about hearing aids, and 3B, expecting hearing aids to solve all their problems.

Type 4 patients are usually persuaded to seek help by long-suffering significant others and will deny any disability even though they patently have marked hearing difficulties. They will never wear a hearing aid if fitted and will reject all other aspects of the rehabilitative process. Little is to be gained by either the patient or the audiologist in continuing with the rehabilitative process, even if it were ethically justified. The patient is usually informed that they have a hearing loss and that they can return to the system if they change their mind and feel that they need help. At the same time, it can be helpful to separately provide the significant other, often at the end of their tether, with advice regarding communication tactics and environmental aids which they could introduce unobtrusively in order to make their life more tolerable.

The main elements of the immediate remedial intervention are covered by ‘Instrumental 1’, ‘Strategy’ and ‘Ancillary’, with ‘Communication training’ often being a longer-term component, particularly with rehabilitation Types 2 and 3. Instrumental 1 covers the initial approach to instrumental help for the individual, including both personal (e.g. hearing aids, cochlear implants) and general, covering environmental aids. In both cases, an important element comprises instructing the patient as to how to derive most benefit from the instrument concerned.

In ‘Strategy’ they attempted to break with the ‘one size fits all’ approach to hearing tactics by first considering, in conjunction with the patient, the goals which were both important for the patient and potentially achievable. Further, in the choice of appropriate hearing tactics, it was also essential to take into account the personality and life philosophy of the individual and select tactics in accord with that. Thus, for example, a shy introvert would never adopt highly assertive tactics.

The ‘Ancillary’ section admits that, as audiologists, whatever our background, we are rarely able to meet all the patients’ needs by ourselves. This section is therefore concerned with the involvement of relevant external professionals, physicians, psychologists, social workers, employment support workers etc., who can complement the audiologist in enabling patients to function to the best of their abilities.

Unlike these three components, which are essentially short-term from the audiologist’s standpoint, ‘Communication training’ is an ongoing process which may take just one or two sessions, but which in other patients may continue for months or even years. In all cases, it comprises activities under the four headings of ‘Information (provision)’, ‘Skill-building’, ‘Instrumental 2 (modification)’ and ‘Counselling’. We are not prescriptive here, but it is essential to consider under these headings the ongoing needs of the patient. Thus, for example, the skill-building may range from patiently teaching an older patient how to fit their hearing aid to their ear through to training a patient with a cochlear implant in telephone use.

The initial flow diagram with decision boxes for this process is shown in Figure 1.12. Within this, for example, Rehabilitation type 1 patients may pass through quickly

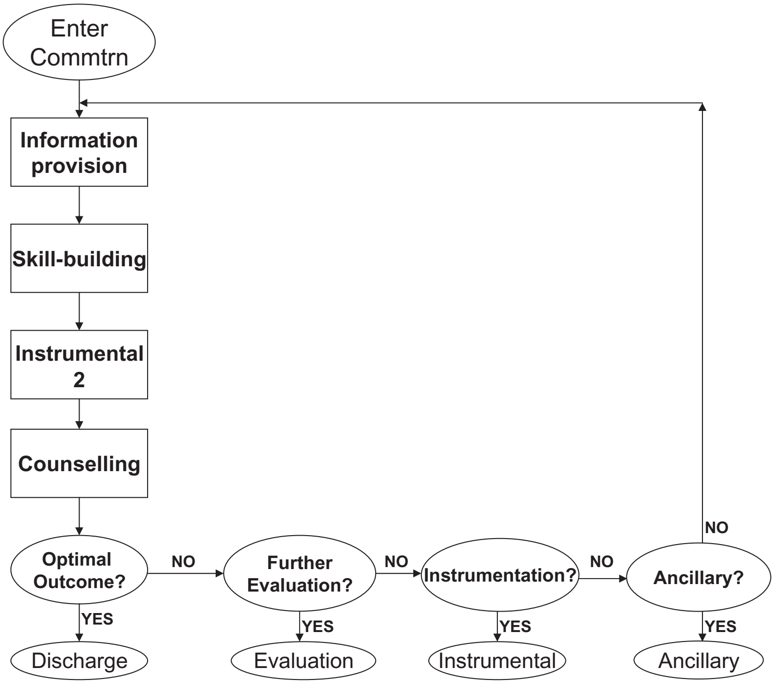

Figure 1.12 Flow diagram for communication training block. (*Source:* adapted from Goldstein and Stephens, 1981, with permission.)

with just some fine adjustments of their hearing aid(s) and further advice on environmental aids. Type 2 patients, on the other hand may require elements of several of the components, and Type 3 patients a considerable input from Counselling, possibly in a group context where they may accept suggestions and criticisms from their peers better than from professionals.

The model continued to retain the same format over the years, although minor changes were made. The first significant change came in the conference proceedings of 'Psychological and psychosocial approaches to adult hearing loss' (Stephens, 1996). Within this, elements of the WHO's *International Classification of Impairments, Disabilities and Handicaps* (ICIDH; WHO, 1980) were incorporated into the model, following some development of the concepts applied to that framework by Stephens and Hétu (1991).

Thus, in this version of the model, the first block of 'Communication Status' was preceded by a block 'Disability and handicap', in order to increase the emphasis on the problems which the individual was experiencing, and we discussed the role of *positive experiences* in the development of *handicap*. (This will be discussed further in a later section of the present chapter.) Following the work of Hallberg and Barrenäs (1993) and of Hétu and Getty (1991), the role of significant others was enhanced in the discussion of the development of handicap and in the 'associated variables' section of the model.

The next change was to separate the block 'Attitude', in which elements of the evaluation were brought together, from the remediation process and have it as a separate block between evaluation and remediation, and renamed 'Integration and decision-making'. While it remains generally the same, an element of preliminary

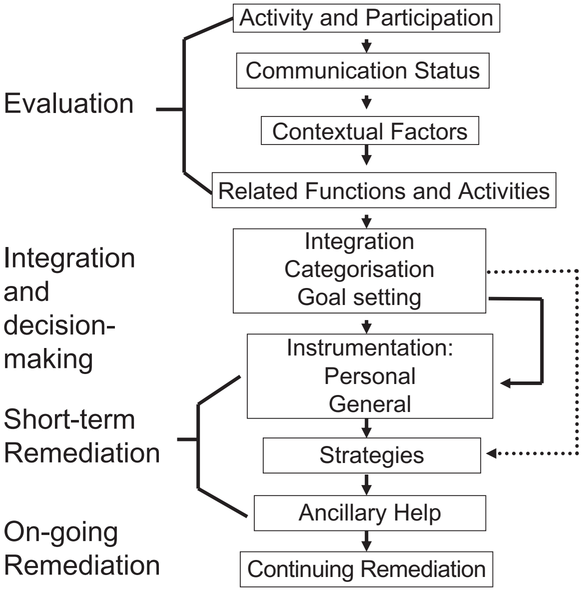

Figure 1.13 Updated model of audiological rehabilitation. (*Source:* adapted from Stephens, 2003.)

goal-setting was incorporated into this block, which would then lead into the Remediation process.

The only other change, a minor one, was to separate the 'communication training' block into 'Ongoing remediation', leaving the three other components as 'Short-term remediation'.

Subsequent changes came with the publication of the WHO's *International Classification of Functioning, Disability and Health* (ICF; WHO, 2001), which led to the incorporation of the terminology of that framework into the model (Stephens, 2003). This is shown in Figure 1.13.

Thus, 'Handicap' and 'Disability' become 'Activity' and 'Participation', and 'Communication status' remains unchanged. 'Associated variables' becomes 'Contextual factors'. This maintains the element of 'psychological factors' in the ICF listing of 'Personal factors'. Social factors include ICF's 'Support and Relationships' as well as 'Attitudes, values and beliefs', which are classified there as 'Environmental Factors'. However, 'Products and technology', including existing environmental aids and hearing aids, are now brought into this section, with 'Services, systems and policies' covering the background provisions which may be available for the individual.

'Related functions and activities' replaces 'Related factors' and covers within it 'Mental functions; Sensations associated with hearing and vestibular function; Touch function; Manipulative activities; and Walking activities'. Most elements are broadly similar to the previous components of 'Related conditions' except for the inclusion of 'Mental functions', which, in this context, covers mainly the intellectual, attention, cognitive and memory functions of the patient. These will obviously have an impact on how the remediation process is implemented.

The four components of remediation remain largely unchanged, although the role of significant others (secondary to that of the patient) is given more emphasis in the

'Strategy' box. In addition, the role of voluntary organisations and self-help groups is brought into the 'Ancillary' section. Within 'Continuing remediation' renamed from 'Communication training', the concept of 'Changes to the physical and cultural environment' is also introduced. This implies involvement of the patient, employers, colleagues, family, caregivers and educators as well as the audiology professionals in an effort to ameliorate the acoustical, visual and stress-related situations confronting the patient.

The most recent proposed model incorporating many of these concepts was described by Kiessling *et al.* (2003) and arose from an Eriksholm symposium on 'Candidature and delivery of audiological services: special needs of older people'. While maintaining much of Stephens' (2003) model, it incorporates the concept of *instrumental* and *non-instrumental rehabilitation* as presented in a parallel way, and includes a section on 'Outcome measurement'.

Earlier, the model had demonstrated the applicability of the original model to specific patient groups, including older people (Stephens and Goldstein, 1983) to individuals with central auditory dysfunction (Fourcin *et al.*, 1985) and to those with profound hearing loss (Stephens, 1988). Furthermore, it has been adopted in a number of contexts by Smaldino and Traynor (1982), Schow and Nerbonne (1995, 2007) and others. Within their latest publication, Schow and Nerbonne (2007) have also attempted to modify the model within the context of ICF, although their approach is somewhat different from those described above.

Further interesting approaches along broadly similar lines have been proposed by Hyde and Riko (1994) in their Decision-Analytic approach and by Tye-Murray (1998), among others.

The role of positive experiences associated with hearing impairment

Anecdotal accounts of positive experiences associated with hearing impairment date back several centuries. Thus, for example, the English portrait painter and founder of the Royal Academy, Joshua Reynolds (1723–1792), alluded to it in his correspondence, and as reported by a biographer: 'Reynolds did not let his deafness worry him, it assisted his natural gift for reading character' (Hudson, 1958). Other anecdotal accounts, discussed by Kerr and Stephens (1997) mention the 'development of personal attributes', 'social contacts' and 'contacts with other hearing-impaired groups'.

Systematic investigation of the impact of positive experiences in systemic diseases such as neoplasia, HIV infections and cardiovascular disease date back only to the 1980s and have been discussed by Kerr and Stephens (2000). Such effects include changes in existential values, increased self-knowledge and relationship change.

The first study in the hearing field arose from the PhD study by Patricia Stewart-Kerr (1992) when, investigating handicap in adults with severe acquired hearing impairment, she identified as separate themes 'stronger religious feelings', a 'better understanding of human nature', 'positive experiences of communication' and 'practical and social support from hearing people'. She found that 'positive experiences of communication' and 'stronger religious feelings' were the two which had the strongest positive impact on people's lives.

This work was extended in two qualitative and one quantitative study on patients attending rehabilitation clinics in Cardiff (Kerr and Stephens, 1997, 2000; Stephens and Kerr, 2003). In the qualitative studies, patients were asked to list, in order of importance, any positive experiences which they may have had as a result of their

Table 1.2 Main positive themes identified by Kerr and Stephens (1997, 2000).

Theme	Number of respondents	
	1997 study	*2000 study*
Reduced disturbance from unwanted sounds	26	43
Successful communication strategies	24	24
Affinity to other deaf and disabled people	17	15
Perceived self-development	13	14
Using deafness to self-advantage	10	6
Communicative support from hearing people	9	6
Technical aids (e.g. Teletext)	1	7

hearing loss. This questionnaire was administered to consecutive series of first-time hearing aid candidates and, in the first study, Kerr and Stephens (1997) sought to determine the proportion of patients listing one or more positive experiences and the main experiences listed. Some 22% listed positive experiences and the main experiences listed are shown in Table 1.2.

The second qualitative study (Kerr and Stephens, 2000) obtained positive responses from some 40% of hearing aid candidates, and these responses followed a very similar pattern to that found in the first study (Table 1.2). When Kerr and Stephens demographic predictors of whether an individual was able to identify one or more positive experiences, we found that this was independent of the severity of hearing impairment, gender and the duration of hearing impairment. However, younger patients, those of non-manual social classes and those who had had previous hearing aids were more likely to report positive experiences.

On the basis of these two qualitative studies, Stephens and Kerr (2003) a quantitative questionnaire with 48 statements to which the respondents were required to state whether a particular experience was often, sometimes, rarely or never true for them. From this, they identified eight themes using a factor analysis. They comprised 'Cognitive changes to self-perception', 'Successful communication behaviours', 'Technical facilitators of communication', 'Using hearing loss to self-advantage', 'Effort in communication', 'Social support', 'Social contact' and 'Resignation'.

On this basis, the questionnaire was reduced to 20 questions and presented this together with a number of outcome measures to a further group of patients. This identified six main factors, three of which were predominantly auditory and three non-auditory. These are shown in Table 1.3.

Among the possible demographic predictors, the only one to relate to the total score, and also to the non-auditory factors, was the age of the individual, younger people perceiving more positive experiences. The only other relationship of note was that 'Using hearing loss to self-advantage' related to the duration of the reported hearing loss.

In this study, there was only a limited relationship with other measures including the Satisfaction with Life Scale (Diener *et al.*, 1985) and the more specific Hearing Disability and Handicap Scale (Hétu *et al.*, 1994). The two measures 'Cognitive changes to self perception' and 'Using hearing loss to self advantage' related positively to the handicap measure (basically psychological impact), and the two com-

Table 1.3 Main positive factors identified by Stephens and Kerr (2003).

Factor	Auditory factors	Non-auditory factors	Total variance (%)
1		Cognitive changes to self-perception	14.7
2	Use hearing loss to self-advantage		13.5
3	Successful communication behaviours		9.4
4		Resignation	8.4
5		Effort in communication	7.3
6	Technical facilitators of communication		7.3

Table 1.4 Questions loading on 'Successful communication behaviour' factor.

Questions	Loading
Have enjoyable conversations	0.71
Clinic staff understanding	0.61
Feel important to family	0.57
Take part in leisure activities	0.52
Have own ways of coping	0.40

(*Source:* adapted from Stephens and Kerr, 2003.)

munication based positive factors (factors 3 and 5) related negatively to this measure. Factor 3 also correlated positively with the Satisfaction with Life Scale.

It is thus interesting to note that a perception of successful communication has a positive effect on these approaches to quality of life. Specific questions loading on this factor are shown in Table 1.4.

In addition, it is interesting to note that Dibb and Yardley (2006), studying patients with Menière's disorder, found a significant relationship between a 'Downwards Positive Social Comparison' (e.g. 'When I read about others who experience more difficulties than I do, I am relieved about my own situation') and quality of life as assessed by the SF-36 Health Survey Standard Version. However, it showed no significant relationship with further changes over a 10-month period. Furthermore, no studies have so far been made on the impact of positive experiences on the outcome of audiological rehabilitation.

Relevant measures in assessing patients' needs and the outcomes of interventions

This section is meant as an introduction to a theme to which we shall return at various stages throughout the book. It is a topic essential to any serious consideration of possible benefits of audiological enablement and the demonstration of the effectiveness of different elements of it and their benefits to the patient. There is an extensive literature in this field (e.g. Noble, 1998; Bentler and Kramer, 2000), but what concerns us here is measures which are relevant to the individual with hearing problems. In

Table 1.5 Goals of outcome measures in audiology.

Goal	Goal
1	To assess the rehabilitative outcomes for an individual hearing impaired person
2	To assess the effectiveness of the services provided by a particular clinical unit or agency
3	To assess the effectiveness of new hearing aid technologies
4	To assess the effectiveness of hearing rehabilitation services on quality of life

(*Source:* derived from Cox *et al.*, 2000.)

particular, we are concerned with the definition of the needs of the patient at the beginning of the process of enablement and then an assessment of how well these needs are met when we approach the end of the process. In addition, there will be, inevitably, some measures as to how well the patient perceives that the process has succeeded for them, given the fact that, prior to intervention, they will be unaware of all the implications of the enablement process.

Cox *et al.* (2000) discuss the various purposes of outcome measures. These are shown in Table 1.5. While we shall consider Goals 2–4 where they are relevant to other discussions within this book, in this and later chapters most emphasis will be put on Goal 1. In this context, we shall take the article by Cox *et al.* as our starting point. These goals are discussed further in Chapter 12.

In this context, Cox *et al.* start with the general recommendation that this 'should be designed to facilitate assessing the client's needs and preferences' and later continue that the 'measure should primarily be based on individualized self-report, in which the nature of the assessing items or listening situations is determined by each client rather than being standardized across clients'.

They continue to suggest that both activity limitations and participation restrictions should, optimally, be included in the assessment as well as soliciting reports from significant others. They then give some examples of potentially relevant tools.

We are happy with this general approach, and indeed were contributors to the paper, but some recent studies suggest that the approach needs to be extended, and this will be discussed at different points throughout this book. Some missing aspects include the individual's ability to cope with their hearing problems as well as their satisfaction with the treatment which they have received. Furthermore, it needs to be emphasised that the patient, rather than the significant other, is the subject of the enablement process, and while invaluable information may be obtained from significant others, ultimate decisions must always rest with the patient.

Cox *et al.* (2000) very reasonably suggest that the Client-Oriented Scale of Improvement (COSI; Dillon *et al.*, 1997) is a valuable starting point in such assessment. Prior to intervention, the audiologist determines the hearing problems most important to the individual and, after intervention, the improvement and residual elements of such problems.

One of the problems which need to be addressed is how we determine the input to COSI in terms of the patient's problems and how we elicit their real problems. An early intervention study (Stephens *et al.*, 1991a) found that it is the effects on the individual of their hearing impairment (participation restriction and emotional effects) rather than their activity limitations which determine help-seeking. We have long advocated use of the Barcham and Stephens (1980) Problem Questionnaire as a starting point into defining the patient's real problems, supplemented by further

Table 1.6 Mean number of responses per subject in ICF domains elicited using different open-ended questions.

WHO ICF category	Difficulties question (number of respondents)	Life-effects question (number of respondents)
Functional impairments	0.26	0.11
Activity limitations	1.77	1.48
Participation restrictions	0	1.24
Environmental factors	0.12	0.39
Personal/psychological factors	0.08	0.88

(*Source:* adapted from Stephens *et al.*, 2001.)

questioning at interview. However, this approach would appear to be relatively ineffective at eliciting participation restrictions (Cox *et al.*, 2000; Stephens *et al.*, 2000), and Cox argues that this is an area which needs to be addressed.

This was addressed in a subsequent paper (Stephens *et al.*, 2001) in which the original wording of 'Please make a list of all the difficulties which you have because of your hearing loss' was replaced with 'Please make a list of the effects your hearing problems have on your life. Write down as many as you can think of.'

When we used this approach, the number of participation restrictions and psychological factors which were elicited increased considerably and this is shown in Table 1.6.

It may be seen that there were marked differences (significant at $P < 0.01$ or better) in all WHO ICF domains apart from activity limitations. It may thus be argued that this 'life effects' question sent to the patients prior to their clinic visit is useful in eliciting a range of relevant consequences of the individual's hearing impairment. It should always be supplemented by further questioning and clarification during the clinic visit which will then lead to the establishment of the appropriate input to COSI or an equivalent approach and also to goal-setting in the enablement process.

The one potential problem with the use of such open-ended patient questionnaires, and which can generally be clarified at interview, is that it is sometimes unclear as to whether the patient is referring to an activity limitation (what they *can* do) or to a participation restriction (what they *do* do). To clarify this, Stephens *et al.* (2001) examined an alternative classification (WHO, 2001, Annex 3, p. 234) in which the first four disability domains ('Learning and applying knowledge', 'General tasks and demands', 'Communication', 'Mobility') are regarded as activities and the last five ('Self-care', 'Domestic life', 'Interpersonal interactions', 'Major life areas', 'Community, social and civic life') as participations.

This was performed as a retrospective analysis of 100 older patients attending a rehabilitation clinic where activity limitations and participation restrictions had been elicited by means of the Problem Questionnaire and by interview. The results are shown in Figure 1.14, which shows no significant difference in the number of responses regardless of which categorisation of activities and participations was used.

While the most widely used approach to outcome assessment using such personalised measures are used to input to COSI, an alternative approach is to use them with visual analogue scales (VAS). Although COSI is the most appropriate and straightforward approach for most patients with hearing difficulties, for those in whom a number of repeat measures may be required, such as patients with cochlear

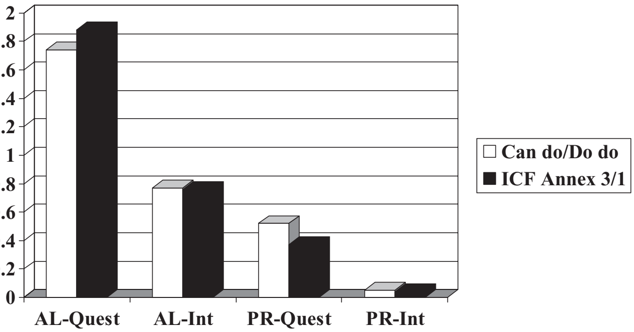

Figure 1.14 Mean number of responses in different categories using the traditional (Can do/Do do) classification of activities and participations versus the separation by disability types (Annex 3/1). AL = activity limitations, PR = participation restrictions, Quest = questionnaire, Int = interview.

implants, the VAS approach may be more appropriate, examples of this approach are given by Andersson *et al.* (1995a), Stephens and Zhao (2002) and Bai and Stephens (2005).

The open-ended questionnaire approach can also be effectively used with significant others of patients who can be asked about both the impact of the patient's hearing impairment on themselves as well as on the patient (e.g. Stephens *et al.*, 1995). There do not, however, appear to have been any quantitative studies using this approach.

Benefits and limitations of audiological interventions can also be used in a personalised way. Thus, Tyler and Kelsay (1990) asked patients who had received cochlear implants to list all the advantages that 'you believe a cochlear implant has provided. List them in order of importance starting with the greatest advantage, list as many as you can.' Their second question used the same format but with 'disadvantage' substituted for 'advantage'. A similar approach was independently introduced by Stephens and Meredith (1991b) in the context of hearing aids. However, the reliability of a quantitative approach to such a measure remains to be investigated.

Finally, an approach to how the patient is coping with their hearing problems needs to be defined on an individual basis. While Andersson *et al.* (1994) developed a 'Hearing coping assessment', the use of a patient-specific visual analogue or categorical scale could be a valuable alternative, which needs to be explored further.

Development of a preliminary model appropriate to hearing impairment

Coming from the earlier consideration of different models, it would seem appropriate to conclude this chapter with an outline of the position from which we are working. Figure 1.15 gives an outline of the stages through which the individual within the community who experiences hearing problems may pass. There will be detailed decision boxes with a range of factors influencing them at different stages and these will be considered in the next and subsequent chapters.

At the present stage, it is premature to consider further details of these, beyond emphasising the paramount importance of the input from the patient in proceeding

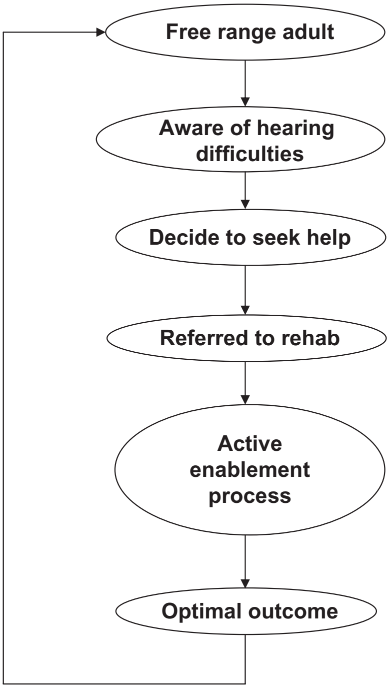

Figure 1.15 An outline of the main stages in audiological enablement.

from one stage to the next. There will, obviously, be various feedback loops at different stages and these will be considered further in Chapter 10.

For a number of reasons, the more detailed model of the active enablement process will follow the earlier version of the model illustrated in Figure 1.13, rather than that proposed by Kiessling *et al.* (2003). One of the main reasons behind such a decision is that we feel the need to separate the short-term elements of enablement which are applicable to almost all patients from many of the longer-term aspects which will be relevant only to a minority. Furthermore, we would argue that the provision of the 'Surveillance and maintenance' feedback loop will not be relevant to a significant proportion of patients. Thus, while it may be offered to all, the decision to accept/participate in this must rest with the individual patient.

Conclusion

The term *enablement* is more appropriate to a patient-centred approach, involving participation by the patient and significant others, than the more traditional term *rehabilitation*. Our model of enablement is based on a combination of WHO's ICF and Goldstein and Stephens' (1980, 1981) Management Model. This model is presented in relation to other models in audiology. On the basis of a number of our studies, the importance of highlighting the positive experiences of patients reporting hearing difficulties is emphasised. We also argue the importance of having patient-friendly and relevant outcome measures for the assessment of the efficacy of the process, such as Dillon's (1997) Client-Oriented Scale of Improvement (COSI).