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ASSOCIATION

# Protection of Rights of People Receiving Audiology or Speech-Language Pathology Services

*Task Force on Protection of Clients' Rights*

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## About This Document

This technical report was prepared by the American Speech-Language-Hearing Association's Task Force on Protection of Clients' Rights: Joseph A. Caniglia, Mary Pat Ciccariello, Charles C. Diggs (coordinator), Elizabeth Kennedy, Jean M. Lovrinic (1991–1993 vice president for governmental and social policies, monitoring vice president), and Seleria J. Williams. ASHA's Executive Board approved distribution of the report to members (EB 82B-93).

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## Introduction

In 1986, the Bylaws of the American Speech-Language-Hearing Association (ASHA) were amended (LC resolution 1-86) to include advocacy for “the rights and interests of persons with communication disorders” among ASHA's purposes (Article 2.1 [6]). However, no body of the Association was charged with determining what these rights include.

More recently, people with disabilities have awakened politically and begun to see the barriers to their full participation in society as a civil rights issue. Disability is no longer a source of shame or something to overcome to inspire others. This revolution in self-perception has led people with disabilities to assert and demand their rights. Passage and enactment of the Americans with Disabilities Act of 1992 is strong testimony to the power of such collective action by the community of people with disabilities, including people with speech, language, or hearing disabilities.

These forces of self-actualization are being exerted within society at the same time as the rights of consumers are being increasingly recognized by federal legislators and regulators as well as by private accreditation bodies. The Individuals with Disabilities Education Act (formerly known as the Education of the Handicapped Act) asserts in Section 601(c) that “It is the purpose of this Act to assure that...the rights of children with disabilities and their parents or guardians are protected...” The Omnibus Budget Reconciliation Act of 1990 requires that programs providing services funded by Medicare and Medicaid inform patients of their right to make their own health care decisions. The Health Care Financing Administration's (HCFA) Survey Procedures and Interpretive Guidelines for intermediate Care Facilities for the Mentally Retarded specify that the “individual program plan must also include opportunities for client choice and self-management.” The accreditation manual for hospitals of the Joint Commission on Accreditation of Health-care Organizations (JCAHO) includes a section on patient rights. The outcome-based performance measures of The Accreditation Council on Services for People with Disabilities include sections on choice, rights, and dignity and respect.

Despite these trends and requirements, a model bill of rights for all persons who receive audiology or speech-language pathology services has not been developed by ASHA. The Guidelines for Meeting the Communication Needs of Persons With Severe Disabilities (1992), developed by the National Joint Committee for the Communicative Needs of Persons With Severe Disabilities and approved by ASHA, include a communication bill of rights for this population, and the Educational Rights for Children Who Are Deaf or Hard of Hearing developed by the Council of Organizational Representatives (COR), including an ASHA

## Process of Development of the Model Bill

representative, identified rights for this particular population. However, neither of these documents are generalizable across the broad range of communication disabilities and possible settings of practice.

While professional responsibility to persons served is inherent within ASHA's Code of Ethics, the Code by its very nature focuses on professional conduct and prohibitions. Clients' rights are implied but not explicit.

Therefore, ASHA's Executive Board formed a Task Force on the Protection of Clients' Rights in 1992 to develop a model bill of consumer rights that could be applied across communication disability types and practice settings. This bill was to be developed in consultation with ASHA's Council on Professional Ethics in Speech-Language Pathology and Audiology (COPE).

To develop the model bill, the task force reviewed pertinent background materials, generated a series of draft documents, sought select peer review from ASHA members as well as from national consumer and parent groups, consulted with COPE, and seriously discussed all recommended changes prior to completing the model bill. This process is briefly described in the sections below.

### ***Review of Background Materials***

All members of the task force received review copies of the following documents:

- ASHA's Code of Ethics and Issues in Ethics statements (1992)
- ASHA's Standards for Professional Service Programs in Audiology and Speech-Language Pathology (1992)
- HCFA's Survey Procedures and Interpretive Guidelines for Intermediate Care Facilities for the Mentally Retarded (October 1988)
- A Communication Bill of Rights (from the 1992 Guidelines of the National Joint Committee for the Communicative Needs of Persons With Severe Disabilities)
- COR's Educational Rights (1992)
- The Patient Rights section from the 1993 JCAHO *Accreditation Manual for Hospitals* (together with an example of how one hospital protects patient rights)
- Outcome Based Performance Measures from The Accreditation Council for People with Disabilities (1992)
- A Client Bill of Rights (Flower, 1984)
- Aphasic Patient's Bill of Rights (Tanner, 1986)

### ***Draft Documents***

During its development of draft documents, the task force developed certain criteria for inclusion of rights within the model bill. To be included, a right had to:

- apply to both children and adults receiving services;
- apply to all settings of practice;
- apply to both audiology and speech-language pathology services;
- be understandable to consumers;
- reflect rights advocated by self-help/mutual aid groups concerned with communication disabilities;

- be realizable in the present.

The last criterion eliminated rights such as the right to access services regardless of ability to pay. Such a right does not exist today in other areas of health care delivery and should not be expected from recipients of audiology and speech-language pathology services in these settings.

### ***Select Peer Review***

After three conference call meetings of the task force, a draft of a model bill that met all the above criteria, along with detailed comments on each right, was sent to 51 ASHA members representing Association committees, related professional organizations (RPOs), and individuals with specific interest in this topic; to 89 consumer and parent groups; to 12 clients of task force members; and to 38 ASHA National Office staff. The documents were also discussed at a meeting of ASHA's Consumer Advisory Task Force.

A total of 67 comments were received: 28 from ASHA members (13 from committees, 10 from RPOs, 5 from individuals), 29 from consumers (28 groups and 1 individual), and 10 from National Office staff. Twenty-six (38.8%) of these responses endorsed the documents without recommending any changes. These responses were distributed equally between members and consumers.

Other commenters recommended adding new rights, expanding and/or clarifying existing rights; changing terminology used, including legal restrictions on some rights; and changing the order of presentation of some of the rights. Comments were distributed equally among all rights presented.

During two additional conference calls, the task force considered all comments seriously, discussed needed changes, and developed revised draft documents that were submitted to COPE. The task force coordinator met with COPE in late May 1993 and provided a written report of their comments to the task force. During a sixth conference call, all changes recommended by COPE were incorporated into the model bill.

## **The Model Bill**

As the result of the above process, the following Model Bill of Rights for People Receiving Audiology or Speech-Language Pathology Services was developed.

### ***Model Bill of Rights for People Receiving Audiology or Speech-Language Pathology Services***

Clients as consumers receiving audiology or speech-language pathology services have:

1. THE RIGHT to be treated with dignity and respect;
2. THE RIGHT that services be provided without regard to race or ethnicity, gender, age, religion, national origin, sexual orientation, or disability;
3. THE RIGHT to know the name and professional qualifications of the person or persons providing services;
4. THE RIGHT to personal privacy and confidentiality of information to the extent permitted by law;
5. THE RIGHT to know, in advance, the fees for services, regardless of the method of payment;

6. THE RIGHT to receive a clear explanation of evaluation results, to be informed of potential or lack of potential for improvement, and to express their choices of goals and methods of service delivery;
7. THE RIGHT to accept or reject services to the extent permitted by law;
8. THE RIGHT that services be provided in a timely and competent manner, which includes referral to other appropriate professionals when necessary;
9. THE RIGHT to present concerns about services and to be informed of procedures for seeking their resolution;
10. THE RIGHT to accept or reject participation in teaching, research, or promotional activities;
11. THE RIGHT, to the extent permitted by law, to review information contained in their records, to receive explanation of record entries upon request, and to request correction of inaccurate records;
12. THE RIGHT to adequate notice of and reasons for discontinuation of services; an explanation of these reasons, in person, upon request; and referral to other providers if so requested.

These rights belong to the person or persons needing services. For sound legal or medical reasons, a family member, guardian, or legal representative may exercise these rights on the person's behalf.

## Comments

During the process of developing the model bill of rights, certain comments were made about each of the rights. These comments are presented below to provide additional information about the rights:

1. THE RIGHT to be treated with dignity and respect.

Clients of audiology and speech-language pathology services are human beings.

Their communication ability may be reduced, and they may present sensory, perceptual, cognitive, or emotional complications. But, these consumers deserve the same dignity and respect that are given to people without a communication disability. This dignity and respect can be shown in many areas that include the manner of greeting and addressing clients; selection of materials appropriate to the consumer's age, gender, interest, cultural background, and disability; and acceptance of the client's unique, non-destructive personality characteristics.

2. THE RIGHT that services be provided without regard to race or ethnicity, gender, age, religion, national origin, sexual orientation, or disability.

Providers of speech, language, or hearing services must not discriminate in the delivery of professional services on the basis of race or ethnicity, gender, age, religion, national origin, sexual orientation, or disability. The inherent nature of a program or the expertise of providers may limit services available to consumers. Such practices can be nondiscriminatory if restrictions are applied uniformly to all potential clients.

3. THE RIGHT to know the name and professional qualifications of the person or persons providing services.

Professional qualifications include the service provider's national and state certification/licensure status as well as level of education, training, and experience. Professional qualifications do not include personal data such as home address, age, marital status, family composition, or sexual orientation.

4. THE RIGHT to personal privacy and confidentiality of information to the extent permitted by law.

Personal privacy and confidentiality need to be preserved during screening, assessment, and intervention, provided that individual well-being is not at risk and disclosure is not required by law. A requirement of consumer permission prior to release of information promotes privacy and confidentiality.

Certain medical, legal, or educational situations may necessitate release without prior permission. The client has the right to explanation of these instances when they occur.

In other specific situations, medical or legal documentation may indicate that the person with the communication disability is not capable of releasing information. In such cases, a guardian or court-appointed representative may be given access to information that is deemed personal and confidential.

5. THE RIGHT to know, in advance, the fees for services, regardless of the method of payment.

Prior to receiving services, the consumer has the right to be advised of fees and provided written documentation when requested. To evaluate fees completely, clients need to know the length of any treatment sessions, the number of scheduled sessions per week, and whether individual and/or group sessions will be provided. It is also important that specific information on fees for missed or canceled appointments and fees for consultation be provided. The right to fee information exists whether payment is to be made directly by the consumer or by a third party.

6. THE RIGHT to receive a clear explanation of evaluation results, to be informed of potential or lack of potential for improvement, and to express their choices of goals and methods of service delivery.

The spirit of this right is to enable clients to become active participants in service delivery. Within a reasonable time after completion of an evaluation, consumers need to be informed of the results in a form and manner comprehensible to them. The use of highly technical terminology without a full explanation does not provide the understanding needed.

Inclusion of the client in the development of both the general approach to services and the individualized plan also promotes active participation in service delivery. Provider explanation of options that exist, including their advantages and disadvantages, and serious consideration of the consumer's preferences in determining goals and methods of service delivery likewise encourage active participation.

Whenever possible, the client is entitled to know the predicted outcome of proposed services that includes how effective services might be and how long they might take. Consumers are likewise entitled to know the reasons why services may not be recommended and any changes in their prognoses.

7. THE RIGHT to accept or reject services to the extent permitted by law.

In some unusual situations, certain legal edicts may supersede this right. An example would be participation in services as ordered by a family court judge. In other situations where medical or legal documentation indicates that the person needing services cannot understand their implication, a family member, guardian, or legal representative may exercise this right on the person's behalf.

8. THE RIGHT that services be provided in a timely and competent manner, which includes referral to other appropriate professionals when necessary.

The timeliness of initiating services may vary from setting to setting because of such factors as due process procedures required by law, medical concerns, state regulations, or third-party reimbursement policies and guidelines. The client has the right to ask about any delays in the initiation of services, receive an explanation, and be given other alternatives. Once services have started, they should be continuous and sufficient in number, frequency, and manner of delivery to meet established goals.

Consumers have the right to seek services from other audiologists or speech-language pathologists. In some situations, referral to professionals other than audiologists or speech-language pathologists is necessary for the client's welfare.

9. THE RIGHT to present concerns about services and to be informed of procedures for seeking their resolution.

Concerns about services need to be considered seriously and resolved as appropriate. When the service provider cannot resolve concerns, referral to other personnel within the facility who can provide further assistance is appropriate.

10. THE RIGHT to accept or reject participation in teaching, research, or promotional activities.

Participation in teaching, research, public relations, marketing, or other activities of the facility is completely voluntary and requires the informed consent of the consumer. The client needs to know the relevant features of the activity to the extent that such information could conceivably influence the decision to participate. When consumers perceive a penalty, real or implied, if they decline or withdraw from participation, then participation is not voluntary. Even if the activity is integral to service delivery, the consumer has the right to refuse participation. In such cases, clients have the right to know that alternatives exist within the same facility and within the community.

11. THE RIGHT, to the extent permitted by law, to review information contained in their records, to receive explanation of record entries upon request, and to request correction of inaccurate records.

Consumers have the right to request access to their records to the extent permitted by law and to receive explanation of record entries upon request. Also upon request, clients have the right to timely receipt of copies of these records. A reasonable fee may be charged for duplication and/or mailing.

Prompt, appropriate corrections to records are also part of this right. When disagreement about the accuracy of records exists, notation of the consumer's viewpoint as part of the records is appropriate.

12. THE RIGHT to adequate notice of and reasons for discontinuation of services; an explanation of these reasons, in person, upon request; and referral to other providers if so requested.

Services may be discontinued for many reasons. They include, but are not limited to, achievement of education/habilitation/rehabilitation potential, failure or inability to pay for services, irregular attendance, or lack of client motivation. Consumers are entitled to an explanation of these reasons, in person if so requested, so that they understand that the decision is neither arbitrary nor capricious and can make any necessary behavioral changes to improve future relationships with providers.

Sufficient notice that present services will be discontinued will facilitate the client's arrangement for services from another provider or team, if so desired. A referral list of such providers is also helpful in this regard.

## Use and Dissemination

The model bill was developed for voluntary use by programs offering audiology or speech-language pathology services. Its use can assist programs to meet the federal and accrediting body requirements discussed in the introduction. Even without such external pressures, distribution of this model bill to all persons receiving audiology or speech-language pathology services and its prominent display within a facility demonstrates a program's commitment to clients as consumers of professional services and its sensitivity to their needs. Such an atmosphere promotes client trust, confidence, and satisfaction and can contribute to efficacy of intervention. Use of the model bill implies a program's willingness to redress any abrogation of the rights via appropriate channels within the facility.

The task force recommends that the model bill of rights and the task force's report be published in *Asha* to inform all ASHA members of their availability. The task force further recommends that the model bill and task force report be sent to the consumer and parent groups who received draft versions for comment. Finally, the task force recommends that both documents be sent to appropriate standards bodies of the Association so that the content of the model bill and the report of the task force can be considered for inclusion in future standards for clinical certification, ethics, academic program accreditation, and professional service program accreditation.

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