

**Interpreting the Meaning of Messages Generated by
Persons with Complex Communication Needs
*Position Paper***

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Introduction

It has come to the attention of the California Speech-Language-Hearing Association that in some settings individuals without training in communicative disorders may be called upon to interpret the meaning of messages regarding major life decisions that are generated by persons who have complex communication needs. In the context of this position statement, “persons with complex communication needs” are defined as those who employ means other than oral language as their primary method of communication. Specifically, this position statement is pertinent to interpreting messages generated by such individuals who may be attempting to express choices regarding major life decisions.

Concerns leading to the composition of this position statement were voiced by representatives from the California Association of State Hospitals – Parent Councils for the Retarded (CASH-PCR). This organization represents the parent groups associated with the five developmental centers operated by the State of California. The concerns stated were in regard to anecdotal reports involving incidents in which facial expressions, actions, and vocalizations of developmental center residents were interpreted as meaning they had a desire to leave the facility, resulting in a relocation of those residents to community-based group homes. CASH-PCR representatives believed some of these interpretations to be erroneous and the result of an overzealous policy of relocating individuals with developmental disability from congregate care facilities such as developmental centers, commonly referred to as “institutions,” to smaller, community-based group homes.

Anecdotal Evidence Supporting Inappropriate Interpretation of Messages

The concern raised by the California Association of State Hospitals – Parent Councils for the Retarded officers and members centered around anecdotal reports, such as the following:

- Clients selected as candidates for community placements were told they were going on an outing to visit a group home. Many of them enjoyed outings to any destination, but their enjoyment was interpreted as meaning they wished to be placed outside of the developmental center.
- Once at the proposed group home, the clients were offered good things to eat, and favorite music and activities. If the clients smiled or otherwise expressed happiness, it was interpreted as meaning they wished to leave the developmental center.
- One parent had to appear in court several times to explain to the judge that his son would respond affirmatively to the words, “Want to go?” no matter what the destination and that agreement did not necessarily signify a desire to drastically change his living situation.
- One client packed his radio to take with him whenever he went anywhere. This action was interpreted as meaning he wanted to pack up and leave the developmental center.
- Another client, blind, deaf, and using a wheelchair, was reported to have “enjoyed” the van ride to a proposed group home, which again was interpreted to indicate a desire to leave the developmental center.

These anecdotes were gathered from a variety of individuals. Specifics and names cannot be provided due to confidentiality issues. An attempt was made to contact speech-language pathologists (SLPs) working at the developmental centers. Three SLPs responded and all reported no knowledge of these sorts of incidents. However, parents and caregivers providing the anecdotal information remain convinced that these sorts of incidents do occur and are the result of a “push” to get developmentally delayed people out of the developmental centers and into community-based group homes. It should also be noted that the case of the 62-year-old man who packed his radio was widely reported in local newspapers. The man was moved to a community group home over the objections of his family, and a further newspaper article reported he died at the age of 63 of pneumonia within a year and a half following his relocation (Metro, 2005; Sacramento Bee, 2007).

Debates Surrounding Institutionalization of Persons with Developmental Disabilities and Complex Communication Needs

According to figures released by the Department of Developmental Services for the State of California, there were 3,026 clients with developmental disabilities residing in developmental centers in the year 2005-2006. That figure is projected to decline. The pervading philosophy guiding professionals working with individuals with severe disabilities continues to encourage movement away from institutionalization (Department of Developmental Services. (2005).

In 2006, the United Nations held a *Convention on the Rights of Disabled People* and released a statement that included the following article:

Article 19. *Living Independently and being Included in the Community:*

State parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measure to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

(a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement (United Nations, 2006, electronic version).

In line with this philosophy, federal and state policies are currently structured in a manner that encourages the deinstitutionalization of persons with developmental delay. The State of California has already closed two developmental centers, and Agnews Developmental Center in San Jose is scheduled to be closed in 2008.

However, the deinstitutionalization of persons with severe developmental disabilities is not a one-sided issue. Proponents of an opposite viewpoint believe that state developmental centers provide a necessary level of social and medical services. It is argued that developmental centers may be the least restrictive environment possible to support the health and safety of some people with severe developmental delays who display extreme aggressive or self-injurious behavior, or who are medically fragile, or both.

The American Speech-Language-Hearing Association (ASHA) recognized the relevance of this debate to delivery of speech-language services for individuals with mental retardation and developmental disabilities in a position statement on deinstitutionalization. The 1989 position statement addressed the core disagreements regarding deinstitutionalization of severely disabled individuals as follows:

A growing number of professionals, consumers, and legislators are arguing that large institutions, by their very nature, offer inadequate environments in which to achieve developmental objectives on behalf of any person with mental retardation. There are equally vocal persons who firmly contend that facility size is not a primary determinant of program quality and therefore should not be an overriding consideration in the appropriateness of placement. These persons advocate for large facilities to remain an element of the residential continuum, both to service clients whose needs cannot be adequately met in alternative settings and to act as a back-up system, or safety net, for the overall service network (ASHA, 1989).

In the 1989 position statement, ASHA pointed out several issues surrounding deinstitutionalization that could negatively impact delivery of service to developmentally delayed people. These issues included high staff turnover, utilization of para-professionals, and lack of funding for speech-language services in community-based residential settings. ASHA also pointed out the lack of research comparing acquisition of communication skills within community versus institutional placements. Given the trend

of current practices, the committee suggests it may be appropriate for ASHA to revisit the issue of deinstitutionalization of individuals with severe disabilities. An examination of research and data available on the status of individuals who have been moved from institutions into other living situations may inform a necessary update of the 1989 position statement.

In light of the current controversy over closure of developmental centers in the State of California, the debate over the deinstitutionalization of people with developmental disabilities is not likely to be resolved any time soon. In the meantime, there are approximately 3,000 individuals residing in developmental centers who, because of the level of severity of their disabilities, are likely to require speech and language services provided by licensed speech-language pathologists (Department of Developmental Services. (2005).

Issues of Concern for Speech-Language Pathologists

There are at least two concerns of vital interest to speech-language pathologists that have been expressed by representatives of the California Association of State Hospitals – Parent Councils for the Retarded (CASH-PCR). These issues include:

- (1) The extent to which adequate and necessary speech-language services are provided to people with developmental delay who have complex communication needs in the State of California
- 2) The establishment of procedures to facilitate the valid determination of the meaning of messages that may be generated by persons with complex communication needs.

Ideally, people with complex communication needs should have access to the services of licensed speech-language pathologists who are knowledgeable in the area of augmentative and alternative communication.

Defining Augmentative and Alternative Communication

The American Speech-Language-Hearing Association (ASHA) has defined augmentative and alternative communication (AAC) as: (1) a set of procedures and processes by which an individual's communication skills . . . can be maximized for functional and effective communication, and (2) the field or area of clinical, educational, and research practice to improve, temporarily or permanently, the communication skills of individuals with little or no functional speech and/or writing (ASHA, 2002, electronic version). Alternatively, Hegde and Maul (2006) stated that augmentative methods of communication supplemented the communication of those who had limited verbal skills, and alternative methods served as the "primary means of communication for individuals who are functionally nonverbal" (p. 459). Speech-language pathologists may teach individuals with limited verbal skills to access a variety of AAC systems such as unaided systems (e.g. eye gaze, gesturing, pointing, signing, vocalizing, producing word approximations), or aided systems including no technology (e.g. PECS, communication boards, picture/photo choice books), low technology and high technology systems.

Use of Augmentative and Alternative Communication in Developmental Centers

Statistics released by the Department of Developmental Services indicated that in 2005 there were 1,695 nonverbal clients residing in the developmental centers. Of those, only 59 were reported to use a “communication aid,” defined as “all types of specialized devices which allow or facilitate communication...from the simplest device to the most complicated” (Department of Developmental Services, 2005). No information was available to indicate how many developmental center residents utilized unaided alternative communication systems.

In an effort to determine the extent of speech and language services available to developmental center residents, telephone interviews were conducted with three speech-language pathologists who were employed at two developmental centers. They indicated that none of the clients with complex communication needs on their caseloads could reliably access AAC systems, either aided or unaided, although efforts had been made to provide them with training.

Valid Interpretation of the Meaning of Messages Generated by Persons with Complex Communication Needs

The establishment of research-based procedures is needed to facilitate the valid determination of the meaning of messages that may be generated by persons with complex communication needs. This is a particularly critical issue in view of the current increased awareness of communication as a basic human right. The document resulting from the 2006 United Nations *Convention on the Rights of Persons with Disabilities* stated:

Article 21: *Freedom of Expression and Opinion, and Access to Information:*
State parties shall take all appropriate measures to ensure that persons with disabilities can exercise their right to freedom of expression and opinion, including the freedom to seek, receive, and impart information and ideas on an equal basis with others and through sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice.
(United Nations, 2006)

CSHA affirms that persons with complex communication needs have the right to fully participate and communicate in whatever language use is most accessible to them. CSHA affirms that communication is language use, including voice, gestures, periods of silence, and glances, as well as words and sentences. CSHA also recognizes the importance of accurate and sensitive interpretation of verbal and nonverbal forms of communication, especially for individuals who are “beginning communicators and have yet to develop competence in linguistic, operational, and strategic domains and thus rely on environmental supports to a greater extent and therefore will be more affected by environmental factors” (Light, Beukelman, & Reichle, 2003, p. 19).

Establishing procedures for valid determination of the meaning of messages of persons with complex communication needs, however, can be problematic. Anecdotal evidence and practical experience indicate that interpretation of the messages of such individuals is difficult, even for highly trained individuals. In one of the few systematic attempts to

research this issue, Carter and Iacono (2002) asked a group of special education teachers and speech-language pathologists to make judgments regarding the meaning of nonverbal messages conveyed by the behaviors of one typically developing child (as a control) and five children with special needs, during videotaped interactions. Judgments of the meaning of identified nonverbal messages were found to be “substantially inconsistent” with an observed tendency to “overassign intentionality” (p. 177).

Even when a system of augmentative and alternative communication is in place, there are issues to consider involving the authenticity and origin of messages generated by a person who does not read or write and has limited or no access to oral language. In such cases, aided systems of AAC commonly depend upon professionals or communication partners in the AAC-user’s environment to decide what it is the AAC-user might want to say, and then provide the symbols or computer programming for the vocabulary necessary to generate those messages. Communicative authenticity, meaning that the message conveyed is truly the message the AAC-user meant to convey, is difficult to achieve when the individual AAC-user “needs to rely on someone else (for example, the speech-language pathologists or the researcher) to select the symbols or vocabulary items that are made available to them” (Brewster, 2004, p. 168).

In short, interpretation of the communicative intent of nonverbal individuals is difficult. Even when the interpreter is a well-trained individual, and even when a system of AAC is in place, extreme caution should be used when interpreting a message having to do with a major life event, such as a request for changing residence, services, and supports. The communication partner is ultimately responsible for accurate and sensitive interpretation of messages generated by persons with complex communication needs. Seeking input from parents, caregivers, speech-language pathologists, and other qualified personnel would enhance the accuracy of that interpretation (Rogers, 1999).

Suggested Guidelines for the Valid Interpretation of the Meaning of Messages Generated by Persons with Complex Communication Needs

Currently, the Department of Developmental Services has guidelines in place to determine the authenticity of a request on the part of a developmental center resident to leave the facility. The policy calls for an “interpretive conference” to be held “when there is uncertainty whether a person being served at the developmental center has made a request for release.” (DDS, 1992, policy memorandum #210). The guidelines state that:

The purpose of the conference is to decide if the person is making a request for release. At a minimum, the persons present at an interpretive conference shall include the person who may be requesting release (the client, if it is not the requestor), the Clients’ Rights Advocate, a member of the client’s IDT, and the person who has received the client’s request. Documentation of the conference shall be placed in the client’s record and shall include identification of those present, the decision made, and the reason(s) for the decision. As defined above, the only condition under which a request for release shall be determined not to have been made, is when all of those persons present at the interpretive conference agree that no request was made. (DDS, 1992, policy memorandum #210)

To provide assistance and support to the Department of Developmental Services, the California Speech-Language-Hearing Association suggests the following in reference to the interpretive conference policy:

1. DDS should determine the extent to which interpretive conferences are being held at the various developmental centers.
2. DDS should make a decision as to whether the current model utilizing interpretive conferences is a useful one. Is there a better way of systematizing the process of validating communication in individuals residing at developmental centers? If DDS determines that changes should be made, CSHA may be of further help in a consultant capacity.
3. If it is determined that the interpretive conference model is a viable one, the following revisions are recommended:
 - a. There is currently no mention of parents, caregivers, or conservators as participants in the interpretive conference. While it is understood that some individuals who reside in developmental centers may have no representation from such persons, it would nonetheless be beneficial to mention them as desired participants in the conference process, if they are present and available.
 - b. There is currently no mention of involving the speech-language pathologists who may be working at the developmental center. Speech-language pathologists would be the appropriate professional to participate in such conferences, and, in most cases, a licensed SLP can provide necessary consultation. There may be a need, in some circumstances, for consultation with a speech-language pathologist who specializes in augmentative and alternative communication. When those circumstances occur, personnel at DDS may wish to consult the websites for the American Speech-Language-Hearing Association at www.asha.org or the California Speech-Language-Hearing Association at www.csha.org for referrals.
 - c. The insistence on unanimity in making a decision against placement outside the DC presumes a bias in favor of assuming an individual would want to be placed outside the developmental center, if the individual could express that wish. This may not be consistent with the actual value system of the represented client. It is recommended that, if there is substantial doubt on the part of any one member of the interpretive conference, the doubt must be clearly included within the text of a report of the interpretive conference findings. Judicial reviews arising as a consequence of an interpretive conference writ of Habeas Corpus filing must also disclose doubts and controversies within the interpretive conference. This would be particularly important if the dissenting interpretive conference member was the parent, guardian, or conservator of the client.
 - d. Other disciplines, such as medical professionals and psychological professionals, may be of assistance in this evaluation.

Towards safeguarding the basic human right of persons with developmental disabilities when making choices, including the determination of living arrangements and full and effective participation in society, the following procedures and policies are also suggested:

1. Identify all participants in decision making – client, parents, conservators, caregivers, advocates, SLPs, and other medical and social service personnel.
2. Ensure that all participants understand and take part in the decision-making process.
3. Provide comprehensible information to the client and family including the rationale for believing the client has made a request to move, the specific location suggested, the caregivers involved, the timing of the relocation, the necessary questions to be asked, and methods to compare the advantages and disadvantages of making a move.
4. Anticipate needs and experiment with possible settings/choices of living arrangements needed to make a decision (e.g. meet persons over one to three visits to alternative sites, possibly arranging for an overnight stay with and without the present caregiver).
5. Develop and use mutually understood tools for the evaluation of the experience such as a survey of satisfaction from these visits and a time line for decision making.
6. Collaboratively determine the best course of action.
7. Create a process of appeal when any participating member dissents from the determined best course of action.

Conclusion

While this position statement is generated as a result of comments and concerns from parents and caregivers of individuals residing at developmental centers, it is recognized that difficulties in interpreting the messages of persons with complex communication needs are not unique to that particular setting or to the population of developmentally disabled people. Certainly, nonverbal and minimally verbal people who are brain-injured, or who have aphasia or various other conditions, also have difficulty communicating within home, medical, educational, and vocational settings.

It is the position of the California Speech-Language-Hearing Association that every attempt should be made to provide persons with complex communication needs with a valid, authentic system of communication. It is further the position of CSHA that caution be exercised when interpreting the messages of such individuals regarding major life decisions, and that, when there is doubt regarding the validity of those messages, the input of parents, guardians, and conservators be given priority.

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