SCAPE:

Administrative Entity (AE) Directors or Administrators
County MH/MR Programs Directors or Administrators
Supports Coordination Organization Directors
Providers of Mental Retardation Services
Providers of Autism Services
State Center Directors
NonState Intermediate Care Facilities for People with Mental Retardation (ICFs/MR) Directors

PURPOSE:

The purpose of this bulletin is to establish the Office of Developmental Programs’ (ODP) policy on accessing communication supports and services for people in the ODP service system.

BACKGROUND:

Communication occurs through the use of spoken language, gestures, eye contact, facial expressions, body movements, patterns of behavior, manual signs, vocalization, in writing or typing, pointing to items and pictures, and natural, synthesized, or digitized speech. Effective communication depends on both the sender of the message and the communication partners who receive the message. Effective communication is the key to leading self-determined lives, being part of communities, being healthy and safe, and having healthy relationships. Individuals whose spoken language is difficult to understand, those who do not communicate through spoken language, and those whose background or culture is such that English is not the primary language are at risk of being misunderstood or not listened to, especially in matters affecting personal choice and health and safety (for example, abuse and neglect).
According to recent data made available through the National Core Indicators project\(^1\) and Independent Monitoring for Quality\(^2\) (IM4Q), between 20 and 30 percent of people receiving mental retardation services in Pennsylvania do not use spoken language to communicate. IM4Q results also indicate that there is a formal communication system in place for only approximately one-third of those people who do not communicate using spoken language.

While most speakers supplement their spoken message with a variety of non-speech strategies like facial expressions and gestures, people with complex communication needs may also need to rely on a variety of techniques, strategies, and alternative aids to effectively communicate. These “Augmentative and Alternative Communication” (AAC) approaches are important tools to assure the ability to communicate. AAC approaches include, but are not limited to, “low tech” systems, as well as sophisticated and expensive technology. Many individuals with complex communication needs can benefit from accommodations and approaches that can be implemented using “low tech” systems (such as paper symbols and generic devices like talking photo albums), “mid-tech” specialized devices with recorded speech, or combinations of these types of aids. Some individuals with complex communication needs will be able to use and benefit from sophisticated AAC devices with speech output and many other features. In addition, many people can benefit from strategies that do not use any external aids at all, or from a combination of these strategies paired with devices or technology. Training communication partners to interpret signs, gestures, behavioral attempts to communicate (for example, grabbing staff to gain their attention), or to use gestures when communicating with the individual with complex communication needs are examples of “unaided” approaches. These “unaided” approaches should also focus, whenever possible, on developing more standardized modes so that communication can occur with unfamiliar as well as familiar communication partners.

Regardless, all AAC strategies and aids identified as necessary, preferred, and appropriate for the individual may be considered as comprising the person’s “communication system.” The most important ingredient of all is the “soft technology”; that is, the knowledge and support that ‘everyone communicates’ and all supporters have a role in assisting the person to be fully heard and respected.

**POLICY:**

ODP supports the right of all persons with communication challenges to receive needed supports and services so that they can effectively and more fully communicate. ODP also recognizes its responsibility, and that of its service system partners, to ensure that all individuals registered for and receiving services, even those with significant communication challenges, have:

- The assistance they need to improve their ability to communicate across all aspects of their life, for a variety of purposes, with different people and in different contexts.

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\(^1\) NCI Adult Consumer Outcomes Report, January 2008
\(^2\) 2006-07 IM4Q Statewide Summary Report, February 2008
• Access and choice to services that best match their current and future communication needs and interests.

Assessment and Reassessment in the Individual Support Plan (ISP)

ODP requires that all individuals registered for services with ODP have their functional communication needs assessed as part of the ISP process. Individuals enrolled in the Consolidated or Person/Family Directed Support (P/FDS) Waiver will receive as part of their assessment process a Supports Intensity Scale™ and Pennsylvania Plus (SIS™ and PA Plus) that contains information on communication and need for assistive technology. The SIS and PA Plus will be administered as per a rollout strategy developed by ODP. For non-waiver assessments, the qualified communication professional will employ the appropriate tools for communication assessment based on available standards and functional tools.

The Bureau of Autism Services will be utilizing the Scales of Independent Behavior-Revised (SIB-R) as a means to identify needs and inform service delivery in the following funding sources specific to adults with autism:

• The approved Adult Community Autism Program (ACAP).
• The approved Autism Waiver.

The SIB-R includes a section on social interaction and communication skills. In addition, the SIB-R also identifies frequency and severity of problematic behaviors. The ACAP and the Autism Waiver contain services specific to utilizing Functional Behavior Assessment (FBA) to understand the function of one’s communicative attempts and to develop a multi-component intervention plan to support the individual in getting his or her needs met. The FBA is particularly useful to address misunderstanding of communicative attempts and to cease inappropriately labeling these attempts as problematic behavior.

After implementation of these assessments, ISPs for individuals who have functional communication impairments need to include strategies for helping the person effectively communicate with others. These strategies can include services, technologies, or support to the individual and his or her communication partners.

Regular reassessments of the individual’s communication needs will occur to evaluate the effectiveness of the strategies, including technologies and ongoing supports provided to the person. Regular reassessments are done at least annually, or more frequently based on the individual’s changing needs. Reassessments are necessary to amend or add to the full communication support plan of the person, acknowledging first and foremost the style and the use of the person’s preferred system of communication.

For people who are deaf or hard of hearing and who use and understand American Sign Language, assessment and reassessment to determine communication strengths and needs shall be conducted by a licensed speech-language pathologist, audiologist, or

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3 Supports Intensity Scale™ 2004 AAIDD
teacher of the hearing impaired in conjunction with a registered interpreter (except where the licensed communication professional is also a registered interpreter.)

ODP expects that all waiver recipients who have functional communication impairments will have a current assessment or annual reassessment in their ISP by July 1, 2010. Non-waiver recipients will be expected to have a current assessment or annual reassessment in their ISP by January 1, 2011.

Services and Supports

ISPs must address the communication supports and services the individual needs based on the assessment and reassessment phase. In accordance with this requirement, communication supports and services, including services and technologies authorized and funded outside of the ODP service system, need to be included in the ISP. All services shall be based on an individual’s needs and preferences, and be coordinated by the individual’s Supports Coordinator. The ISP will specify the frequency and duration of communication services and supports and the persons responsible for providing these supports, including AAC devices and the services required to obtain, customize, and maintain these devices.

AAC services may include development and fabrication of communication boards or the procurement of speech-generating devices. AAC includes instruction for the individual and the communication partners in unaided approaches, such as the use of signs and gestures, and assistance in designing, implementing, and assessing the effectiveness of communication systems authorized for individuals and their communication partners. AAC also includes services such as professional evaluation and assessment, consultation, purchase or rental of supplies and equipment, repair and maintenance of devices, and instruction of staff, families, and individuals receiving services. Instruction or training is provided to family members, staff, and others involved in the individual’s life when needed to:

- Improve the opportunities for communication.
- Increase the responsiveness of communication partners across different environments.
- Ensure the implementation of any AAC and communication strategies.

Communication supports and services are developed with a qualified professional in accordance with the Pennsylvania Speech, Language and Hearing Licensing Act (Act 238 of 1984, as amended). A qualified professional is a licensed speech-language pathologist, audiologist or teacher of the hearing impaired, or a person who is employed by the Commonwealth as a speech-language pathologist, audiologist, or teacher of the hearing impaired who engages in his or her profession or occupation, if the person performs services solely within the scope of the person’s employment. For services funded through ODPs Medicaid Waivers, please see the provider qualification standards for the specific service as outlined in Appendix C of the waivers.

The qualified professional is authorized to direct the assessment and reassessment of the individual’s communication needs, progress, supports and services, in conjunction with or as part of the ISP team. The qualified professional is also authorized to provide
staff and family training and to work directly with the individual in utilizing communication supports and services, including AAC devices and strategies, as needed.

In consultation with the qualified professional, direct support professionals (DSPs), family members, and other members of the ISP team may provide communication services and support. The communication supports and services provided by a direct support professional or other member of the ISP team is considered part of the service or support the individual is authorized to provide in the ISP, not as a service provided by a qualified professional.

Progress in the implementation of communication strategies must be measured by the provider of services. Progress is to be measured on one or more of the following seven outcome indicators:

1. Expansion of communicative purposes across a variety of contexts.
2. Increased effectiveness of communication with a larger number of familiar and unfamiliar people as communication partners.
3. Expansion of repertoire of communication modes that are increasingly symbolic and more generally understood by others.
4. Increased understanding of messages sent by an increasingly large array of communication partners.
5. Increased independence in communication without reliance on assistance from others.
6. Reduction of challenging behaviors where functional communication has been substituted, where appropriate.
7. Ability to appropriately (and spontaneously) initiate, maintain, and terminate interactions.

As communication partners, all team members have responsibility for participating in the development and implementation of identified communication strategies and approaches. A communication partner’s responsibilities are documented in the ISP, and monitored on a regular basis. Direct support professionals serving individuals with communication needs must be able to demonstrate skills and techniques identified in the ISP.

Documentation and evaluation of individual progress is to be entered in a progress note as required by the funding source or program in which the individual participates. The documentation is to be made by a qualified professional when required within their scope of practice or by a direct support professional when a qualified professional is not required. Lack of progress or documentation of progress with a communication strategy based on this assessment requires an immediate reassessment as to the viability of the
device or strategy, and when necessary, the development and implementation of new measures.

The AE or County Program is responsible to monitor this process with providers of community-based mental retardation services. ICFs/MR are expected to monitor this process internally. Documentation of communication methods and effectiveness needs to be included in written progress notes. Monitoring is expected to occur at least once every six months for all persons who are identified with a communication need.

Communication services and supports authorized by a qualified AAC provider and specified in the ISP can be discontinued only in consultation with the authorizing professional, independent licensed speech-language pathologist, or qualified employee of the Commonwealth employed as a speech-language pathologist, audiologist, or teacher of the hearing impaired.

**Communication Profile**

Individuals with significant communication needs, including persons who do not speak, need to have a documented communication profile as part of their ISP that describes:

1. How the individual communicates (including all the ways the person is already communicating “yes” and “no”, and their basic needs and concerns).

2. How communication partners communicate effectively with the individual through strategies and systems utilized across different environments.

The communication profile is expected to:

1. Inform assessment and reassessment as well as the need for communication supports and services identified in the ISP.
2. Be updated annually or as the individual’s needs and communication abilities change.
3. Reflect new communication modes, approaches, and instrumentation, as required.
4. Be developed as part of the ISP team process and shared with the individual, family, friends, and communication partners to facilitate use of effective communication systems across different settings and situations.
5. Be included in the communication section of the ISP, with copies available to direct support personnel, families, and other communication partners.

**Instruction and Technical Assistance**

AEs, County Programs, Supports Coordination Organizations, ICFs/MR and other service providers need to ensure that individuals, families, and people working with individuals with complex communication needs have access to relevant resources available for instruction, technical assistance, and other information for the provision of communication services and support. All Direct Support Professionals are expected to complete training on the person’s communication needs, at a minimum, and provide services and supports to meet those needs.
Training opportunities, including technical assistance and information related to communication services in the ISP, is to be provided to family members and other communication partners. This training includes assistance to communication partners in implementing all aspects of the individual’s communication system, including, but not limited to, communication aids, supports, and devices. ODP will continue to provide training and technical assistance and monitor the implementation of this bulletin to ensure continuous improvement of communication outcomes across the state. Independent Monitoring for Quality will continue to be the primary method of monitoring whether people who need communication supports and services have an effective communication system in place.

**Cost Effectiveness Considerations**

To ensure cost effectiveness of services, all programs need to consider the appropriateness of the full range of augmentative and alternative communication approaches, including devices with varying features and complexity, as well as strategies that do not involve the use of external aids. In the case of speech-generating devices, cost effectiveness considerations include the provision of services under the direction of a qualified professional, and the use of trials to test and identify ACC devices and strategies that work best for the individual.

Cost effectiveness is also promoted when collaboration occurs across and among identified team members, the individual, and others directly involved in the person’s life who may already be knowledgeable or have been trained to provide such services.

**Funding**

Communication services can be provided by ODP pursuant to the waivers or ACAP, in accordance with service definitions established by the Department. Communication services cannot be funded through the Consolidated Waiver, P/FDS Waiver, Autism Waiver, or base allocation when funding for these services is available through other relevant funding sources such as the individual’s school district, Medical Assistance State Plan, private insurance, or, the Office of Vocational Rehabilitation under the Rehabilitation Act of 1973, as amended, for people who would receive services at their place of work or supported employment site,

The supports coordinator is responsible to ensure that other relevant funding sources have been exhausted prior to funding communication services through the Consolidated or P/FDS Waiver. This documentation must be maintained in the individual’s file by the Supports Coordinator, as part of the ISP in the outcomes section, and as a service note in HCSIS.

Individuals living in Intermediate Care Facilities for Persons with Mental Retardation need to have access to communication supports and services, including AAC devices and services, as part of their active treatment, pursuant to their approved plan of care. Monitoring and ISP documentation shall be done by or in coordination with the ICF/MRs qualified mental retardation professional.
Repairs to communication devices and equipment are to be completed expeditiously. Access to an appropriate replacement device must be assured during the repair period, if necessary. A new communication device is to be requested when the individual’s ISP team has documented the need for the new device based on a new written assessment or reassessment.

Communication services and supports provided by a direct supports professional do not require any additional funding except where the DSP requires paid time to participate in specialized training and technical assistance in order to support an individual with complex communication needs. Direct support professionals are expected to provide communication support and services as part of their routine work responsibilities, not as a separate billable service that would require additional funding.

Equipment that is no longer being utilized can be reutilized through the Recycled and Exchanged Equipment Partnership (information on this program may be found at http://disabilities.temple.edu/programs/assistive/leep/), or similar programs, or made available to other individuals served by ODP for exploration, assessment, or long-term use. For more information about donating or obtaining used devices, contact the Institute on Disabilities at Temple University at 1-800-204-7428 or call the ODP HOTLINE at 1-888-565-9435.