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DEPARTMENT OF HUMAN SERVICES

OFFICE OF DEVELOPMENTAL PROGRAMS BULLETIN

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SUBJECT	BY
Communication	Kristin Ahrens, Deputy Secretary for Developmental Programs

SCOPE:

Administrative Entities
Supports Coordination Organizations
Providers of Adult Autism Waiver Services
Providers of Consolidated, Person/Family Directed Support (P/FDS), Community Living Waiver Services
Private Intermediate Care Facilities for People with an Intellectual Disability (ICFs/ID)

PURPOSE:

The purpose of this bulletin is to establish the Office of Developmental Programs' (ODP) policy on communication and assure all individuals have an effective way to communicate in order to express choice and ensure health and safety.

DISCUSSION:

In accordance with ODP's *Everyday Lives: Values in Action*, individuals and their families identified several areas of importance for increasing the overall quality of their lives. One of those priorities is communication. It is ODP's goal that every person has an effective way to communicate in order to express choice and ensure health and safety. All forms of

COMMENTS AND QUESTIONS REGARDING THIS BULLETIN SHOULD BE DIRECTED TO:

The appropriate ODP Regional Program Office

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communication should consider and include the individual's language preferences and use of current technology.

I. What is communication:

Communication is the successful exchange of ideas, feelings and information between individuals. It occurs in many ways such as, but not limited to, speech, signed language, gestures, facial expressions, body language, behavior, and augmentative and alternative communication. Communication is both expressive and receptive; it is always a two-way process. It is complex and includes multiple ways of communicating occurring simultaneously. Both people involved in a communicative interaction are equally important and responsible for successful communication.

There are a variety of factors unique to each person that impacts communication, both internal (such as illness) and external (such as noise). How people understand and respond to spoken and non-spoken communication will vary depending on many things such as culture, experiences, sensory differences, level of stress, etc.

II. The Value of Communication

In accordance with ODP's *Everyday Lives: Values in Action*, it is important that individuals are being listened to and understood, and their input is respected. Individuals want their family, friends, providers, and community to listen and communicate in ways that work for each individual. In addition, the following are ODP's values about communication:

- Communication is fundamental. Effective communication is the key to individuals leading self-determined lives, being part of communities, being healthy and safe, and having meaningful relationships.
- Everyone can communicate; however, not everyone has the tools to do so effectively and in a manner that is readily understood by unfamiliar people. Communication is

complex, flexible, and individualized. All communication should be respected, no matter the method.

- Behavior is a means of communication.
- All communication partners should consistently provide communication services and supports to aid in effective and meaningful communication.
- The way people communicate is influenced by our different cultures. Our culture shapes our views, how people behave, what people believe, and how people interpret others' communication. These differences are valued.
- Words matter. There is no single, universally accepted term that describes the diversity of communication. The words chosen to be used, and words avoided represent our values. Words can foster equity or sustain inequity; how someone is described can influence others' perceptions. Generic terms such as "nonverbal" to describe someone should be avoided because it suggests that the person does not communicate. Instead, describe how that person communicates; for example, 'they communicate nonverbally, through gestures.'

In addition, ODP values the National Joint Committee for the Communication Needs of Persons with Severe Disabilities (NJC), Communication Bill of Rights. The Communication Bill of Rights says that all people with a disability have a basic right to affect, through communication, the conditions of their existence. Beyond this general right, individuals have the right to interact socially; to request and refuse objects, actions, events, and people; express preferences and feelings; to make choices; to be informed; to access supports; and to be acknowledged, responded to, and included in all daily interactions and interventions involving them. For more information, see this link to the Communication Bill of Rights.

These values should guide decisions made by, for, and about people with an intellectual disability or autism.

III. Americans with Disabilities Act (ADA)

The ADA ensures the provision of equal access for all individuals with disabilities. This law requires that “reasonable accommodations” be made to allow individuals with disabilities to participate fully in and receive all the services and benefits available to those without disabilities. The ADA uses the term “auxiliary aids and services” (“aids and services”) to refer to the ways to communicate with people who have communication disabilities. For more information about the ADA, please visit www.ADA.gov.

IV. Limited English Proficiency (LEP)

Title VI of the Civil Rights Act of 1964 requires programs providing federally funded services to provide language assistance to persons with LEP to ensure meaningful access to needed services. For procedures necessary to meet Title VI requirements, reference Bulletin 00-04-13-Limited English Proficiency or its successor.

V. 55 Pa. Code § 6100.50: Communication

As required in 55 Pa. Code § 6100.50, “[w]ritten, oral and other forms of communication with the individual, and persons designated by the individual, shall occur in a language and means of communication understood by the individual or a person designated by the individual.” The “means of communication understood by the individual” is the individual’s preferred mode of communication. If there is question about the individual’s preferred mode of communication, the team including the individual, their family, Supports Coordinator, service providers, and others identified by the individual, should assess, support, and assist to determine the tools that the individual needs to communicate effectively. Behavior is a form of communication. It is also the provider’s responsibility to recognize there is meaning behind behavior and to assess, support, and assist the individual to determine the tools that the individual needs to communicate effectively and in a manner that is readily understood by unfamiliar people.

It is the provider’s responsibility to always ensure access to communication. For example, if the individual uses a device for communication, it is the provider’s responsibility to ensure that the device(s) is always in working order (including charged) and is readily accessible to the

individual. For individuals who have multiple providers, it is important that the team coordinate efforts to ensure access to effective communication.

If the individual's designated person(s) has different communication needs, the provider is responsible to meet both needs. For example, if the individual communicates with a picture book, and the designated person speaks Spanish, the provider must use both the picture book and a Spanish interpreter.

While Private Intermediate Care Facilities for People with an Intellectual Disability (ICFs/ID) are not required to follow 55 Pa. Code § 6100.50, it is strongly recommended that Private ICFs/ID follow the regulation.

PROCEDURE:

Policy Requirements

A. Administrative Entities

In accordance with the Administrative Entity Operating Agreement, all Administrative Entities must have a policy that assures that every individual has access to effective communication. This policy must include, at minimum, the following:

- Training protocols to equip staff with the skills necessary to be effective communication partners.
- Strategies to ensure all communication will be culturally and linguistically appropriate.
- A plan for budgeting and providing necessary accommodations, such as interpreters.
- An ongoing plan to ensure that all Individual Support Plans (ISPs) include strategies and supports for ensuring individuals have access to effective communication.

The policy should be reviewed and updated regularly to ensure effectiveness, continuity, and sustainability. It must be made available to ODP upon request.

B. Supports Coordination Organizations

All Supports Coordination Organizations (SCOs) are required to have a policy that assures that every individual has access to effective communication to demonstrate compliance with 55 Pa. Code §§ 6100.50 and 6100.222-223. This policy must include, at minimum, the following:

- A description of how the SCO will ensure that communication shall occur in the "means of communication understood by the individual" for all individuals they support.
- Guidelines to ensure ISPs include how the individual communicates (both expressively and receptively), what is needed for effective and meaningful communication, and any assessment results/recommendations.
- A description of how the SCO's monitoring process will prioritize communication.
- A description of measures that will be put into place to ensure individuals always have access to functioning augmentative and alternative communication (AAC) and assistive technology (AT) across all environments.
- Strategies to ensure all communication will be culturally and linguistically appropriate.
- Training protocols to equip staff with the skills necessary to be effective communication partners.
- A plan for budgeting and providing necessary accommodations, such as interpreters.

This policy should be reviewed and updated regularly to ensure effectiveness, continuity, and sustainability. It must be made available to ODP upon request.

C. Providers and Private ICFs/ID

To ensure compliance with 55 Pa. Code §§ 6100.50 and 6100.224 for providers of services and 42 CFR §§ 483.430(b) and 483.440(c) for Private ICFs/ID, these entities are required to have a policy that assures that every individual has access to effective communication. This policy must include, at minimum, the following:

- A description of how the provider or Private ICF/ID will ensure that communication shall occur in the “means of communication understood by the individual” for all individuals they support.
- A plan for how the provider or Private ICF/ID will assess each individual’s communication to identify the tools and supports needed for effective communication.
- When providing behavior services, how the provider or Private ICF/ID will ensure that the communicative intent behind an individual’s behavior(s) will be explored and understood before addressing the behavior itself. Effective communication will be explored as a replacement for behaviors.
- A description of measures that will be put into place to ensure individuals always have access to functioning AAC and AT across all environments where service provision by the provider or Private ICF/ID will occur.
- Strategies to ensure all communication will be culturally and linguistically appropriate.
- Training protocols to equip staff with the skills necessary to be effective communication partners.
- Training protocols to ensure staff will be trained on each individual they support communication and how to effectively communicate with each individual before providing services to that individual.
- A plan for budgeting and providing necessary accommodations, such as interpreters.

This policy should be reviewed and updated regularly to ensure effectiveness, continuity, and sustainability. It must be made available to ODP upon request.

Assessment Requirements

Per 55 Pa. Code § 6100.221(e), ODP requires that all individuals have their needs assessed as part of the ISP process. This occurs through the assessments required through each waiver.

Assessments are crucial for identifying and addressing the needs of individuals. Communication is fluid and ever changing as there are a variety of factors unique to each person that impacts communication, so ongoing review of communication needs are important. Further assessment of the individual's communication may be needed if the individual:

- Does not use oral speech,
- Uses oral speech but communication is not effective or is frequently misunderstood,
- Has a hearing loss and/or a vision impairment,
- Uses a signed language,
- Displays noticeable changes in behavior,
- Demonstrates changes in communication,
- Experiences changes to health and/or medication that may impact communication,
- Experiences changes in their environment (such as team members, location, new service, etc.), and/or
- The individual or a team member expresses concern about the effectiveness and meaningfulness of communication at any time.

If it is determined that the individual would benefit from further assessment of their communication, an assessment should be completed by a qualified professional, such as a Speech-Language Pathologist.

It is essential to remember that communication changes throughout the lifespan. Assessments should not be considered as a once and done process but rather an ongoing and collaborative process.

ISP Requirements

ISPs must include strategies and supports, including assessment information, for ensuring individuals have effective expressive and receptive communication.
Communication strategies and supports may include but are not limited to:

- Using AAC or AT such as speech generating devices, objects, or print or symbol systems
- Using visual aids, such as schedules/calendars
- Using communication dictionaries or passports
- Visual gestural communication and/or sign language
- Teaching social skills
- Recognizing and understanding nonverbal communication
- Allowing adequate wait time and/or processing time
- Sensory considerations
- Services such as, but not limited to, a Communication Specialist, speech therapy, or behavioral support

A. Team Member Roles and Responsibilities

All team members are responsible for actively participating collaboratively in the development and implementation of the communication strategies and approaches identified in the ISP to ensure a comprehensive and consistent approach.

Direct support professionals are expected to provide communication support and services as part of their routine work responsibilities. Providers of service are responsible for ensuring that all staff with direct contact with the individual are fully trained in that individual's communication.

B. Monitoring and Oversight

Providers are required to measure and monitor their progress in the implementation of communication outcomes/goals for individuals receiving services. Ongoing documentation and evaluation of progress is required to be included in the provider's progress notes for individuals as outlined in 55 Pa. Code § 6100.227. Regular review of the individual's communication to evaluate the effectiveness of the strategies and assess changing needs

through completion and review of progress notes will help determine if a reassessment is needed. Supports Coordinators are also required to monitor progress through required monitoring processes.

The Administrative Entity or the Bureau of Support for Autism and Special Populations, and Supports Coordinators are responsible for monitoring providers of home and community-based services.

Individuals living in an ICF/ID need to have access to communication supports 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/ID's Qualified Intellectual Disability Professional (QIDP).

C. Communication Supports and Services

Communication supports and services are developed with a qualified professional to ensure they are the most appropriate and person-centered. Depending on the individual, the qualified professional may be, but is not limited to, a Speech and Language Pathologist, a Behavioral Specialist, and/or a Communication Specialist for services funded through ODP's waivers. Please see the provider qualification standards for the specific service as outlined in Appendix C of the waivers.

The qualified professional is to direct the assessment 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 on working directly with the individual to utilize communication supports and strategies.

The communication supports and services provided by a direct support professional or other member of the ISP team are considered part of the service or support that person is authorized to provide in the ISP.

D. Augmentative and Alternative Communication and Assistive Technology

AAC is a category of communication supports that improve an individual's ability to access communication.

For individuals who use aided AAC or AT, their ISP must include the following:

- A plan for regularly assessing ongoing effectiveness.
- If using a speech generating device, the name of the device, where to find device resources/troubleshooting guides, and technical support.
- A plan for maintenance and repair. The plan must include that repairs will be made to communication device(s) and equipment expeditiously and the individual will have access to an appropriate replacement device during the repair period.
- How the AAC or AT will be available to the individual in all settings.
- A contingency plan to guarantee continuous access to communication in case an item breaks or is unavailable.
- How unaided communication approaches are supplemented, such as signs or gestures.

The team must also consider and plan for training family members, staff, and others involved in the individual's life. Training may include instruction on techniques like aided language input (modeling) and expectant pause to ensure consistent implementation of any AAC and communication strategies.

For individuals who may benefit from aided AAC or AT, their ISP must include a plan for an AAC evaluation to be completed.

Accommodation Services

Accommodation services encompass a range of supports; consideration must be given to what best meets the individual's needs.

When a need for accommodation services is identified, the Administrative Entity, SCO, or the provider must provide an opportunity for individuals to request the type of accommodation services of their choice. Primary consideration must be given to the choice expressed by the individual unless something different is recommended in the individual's most current assessment.

It is not recommended that family members or friends fulfill the interpreter role, even if they meet the criteria to interpret. Individuals have the right to interact directly, and family and friends also have the right to focus on their role. There are some situations, however, when it may be acceptable to use a family member or friend as an interpreter within the limits of the ADA and for sign language interpretation, the Sign Language Interpreter and Transliterator State Registration Act of 2004 (Act 57). The use of a family member or friend to act as an interpreter should be documented.

Paying for Accommodation Services

A. Administrative Entities

Each Administrative Entity is required to provide accommodations to any individual registered or registering with an Administrative Entity while performing their administrative functions.

Administrative Entities are required to pay for necessary accommodation services for the following purposes:

- Engaging in any of the activities required through the Mental Health and Intellectual Disabilities Act of 1966. This includes, but is not limited to, enrolling and determining eligibility for the individual to receive intellectual disability and/or autism services through ODP; and
- Engaging in any of the activities required by or related to the Administrative Entity Operating Agreement, including when the Administrative Entity delegates or purchases any administrative functions from another entity.

Administrative Entities may utilize waiver administration funds to cover accommodation service costs (including costs incurred by SCOs) and are responsible for ensuring that contracted providers that provide base funded services meet applicable ADA requirements.

B. Supports Coordination Organizations

SCOs are required to provide accommodation services when providing supports coordination.

- For spoken language interpretation and sign language from other countries: The SCO may request funding for an interpreter needed for supports coordination services from the Administrative Entity. SCOs providing services to individuals in the Adult Autism Waiver are required to fund these services.
- For American Sign Language (ASL) interpretation: Beginning January 1, 2025, individuals enrolled in the Consolidated, P/FDS, Community Living, or Adult Autism Waiver, may have ASL – English Interpreter service authorized on their ISP and utilized at the same time as Supports Coordination services.

Targeted Support Management (TSM) is a Medicaid State Plan service. As such, it is required that accommodation services be provided for individuals who need them while receiving TSM. Administrative Entities may utilize base funds to cover these costs for TSM.

C. Providers

Providers of services are required to provide any necessary accommodation services as indicated in the ISP when rendering services to individuals. If specific accommodation services are indicated in the ISP (for example, Spanish speaking staff), providers must provide that assistance. If the provider becomes aware of a need that has not been included in the ISP, the provider must contact the individual's Supports Coordinator within ten calendar days from the date the provider becomes aware of the need and must participate as needed to amend the ISP.

When rendering services to individuals who utilize ASL and do not have an interpreter service authorized on their ISP, providers of services are required to provide staff fluent in ASL or ASL interpretation.

D. Private ICFs/ID

ICF/ID services are a Medicaid State Plan service. As such, it is required that accommodation services must be provided for individuals who need them while receiving ICF/ID services. Communication assistance can be reimbursed for people receiving ICF/ID services by building them into the ICF/ID interim per diem rate as a direct or indirect cost.

ATTACHMENTS:

Attachment 1 - Communication Definitions. This attachment defines terms related to communication.

OBSOLETE BULLETINS:

Office of Developmental Programs 00-14-04, Accessibility of Intellectual Disability Services for Individuals Who Are Deaf

Office of Developmental Programs 00-08-18, Communication Supports and Services