Pennsylvania
Department of Human Services

Communication Bulletin 00-25-05

in easier to understand terms

The Purpose

Office of Developmental Programs' (ODP) policy on communication.

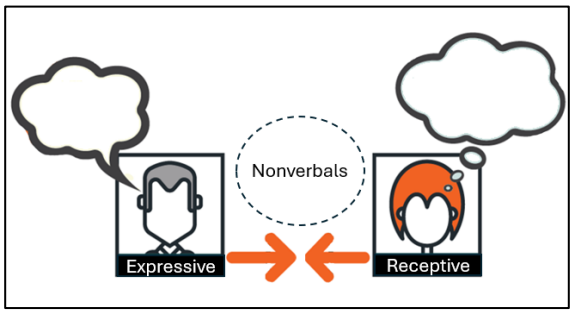
Everyday Lives: Values in Action is a guide to ODP. Individuals and their families picked areas that are important for ODP to focus on. One of those areas is communication. ODP's goal is for every person to have an effective way to communicate.

What is Communication

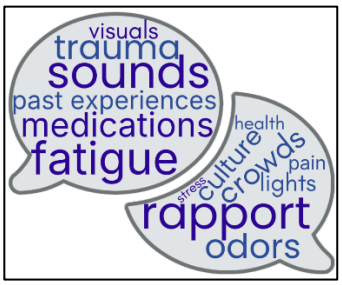
Communication is the successful exchange of ideas, feelings, and information between people. There are many ways people communicate:

- speech,
- signed language,
- gestures,
- facial expressions,
- body language,
- behavior,
- augmentative and alternative communication (different ways to support or replace speech),
- and others.

Communication is both expressive (the person who shares information) and receptive (the person who receives the information.) It is a two-way process. It is complex and includes multiple ways of communicating happening at the same time. Both people are equally important and responsible for ensuring the message is sent and received successfully.



There are many things, within a person (such as illness) and in their environment (such as smells and noises), that impact communication. Many other factors like someone's culture, their past experiences, sensory differences, stress level, and other things will also affect how they understand and respond to communication.



The Value of Communication

It is important that people are 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.

ODP's values about communication are:

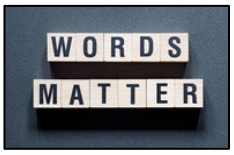
Communication is fundamental. It is the key to leading a self-determined life, being part of communities, being healthy and safe, and having meaningful relationships.

Everyone can communicate; however, not everyone has the tools to communicate effectively and in a way that is easily understood by people who don't know them. Communication is complex, flexible, and individualized. All communication should be respected.

Behavior is a means of communication.

All communication partners should consistently provide communication services and supports to help communication be effective and meaningful. A communication partner is the person with whom someone is communicating with.

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.

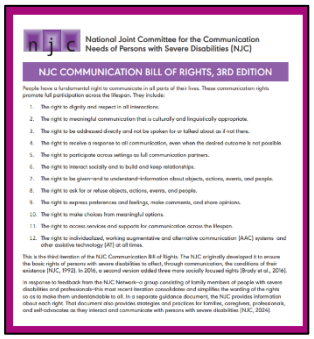


There is not one way to describe the diversity of communication. The words we use and words we avoid represent our values. Words can promote equity or inequity; how someone is described can affect how others see them. Using general terms such as "nonverbal" to describe someone should be avoided, because it may suggest 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 have a right to communication.

Beyond this, individuals have the right to:

- interact socially,
- to request and refuse,
- express preferences and feelings,
- to make choices,
- to be informed,
- to access supports, and
- to be acknowledged, responded to, and included in things involving them.


National Joint Committee for the Communication Needs of Persons with Severe Disabilities (NJC)

NJC COMMUNICATION BILL OF RIGHTS, 3RD EDITION

People have a fundamental right to communicate in all parts of their lives. These communication rights promote full participation across the lifespan. They include:

1. The right to dignity and respect in all interactions.
2. The right to meaningful communication that is culturally and linguistically appropriate.
3. The right to be addressed directly and not be spoken for or talked about as if not there.
4. The right to receive a response to all communication, even when the desired outcome is not possible.
5. The right to participate across settings as full communication partners.
6. The right to interact socially and to build and keep relationships.
7. The right to be given—and to understand—information about objects, actions, events, and people.
8. The right to ask for or refuse objects, actions, events, and people.
9. The right to express preferences and feelings, make comments, and share opinions.
10. The right to make choices from meaningful options.
11. The right to access services and supports for communication across the lifespan.
12. The right to individualized, working augmentative and alternative communication (AAC) systems and other assistive technology (AT) at all times.

This is the third iteration of the NJC Communication Bill of Rights. The NJC originally developed it to ensure the basic rights of persons with severe disabilities to effect, through communication, the conditions of their existence (NJC, 1992). In 2016, a second version added three more socially focused rights (Brady et al., 2016).

In response to feedback from the NJC Network—a group consisting of family members of people with severe disabilities and professionals—this most recent iteration consolidates and simplifies the wording of the rights so as to make them understandable to all. In a separate guidance document, the NJC provides information about each right. That document also provides strategies and practices for families, caregivers, professionals, and self-advocates as they interact and communicate with persons with severe disabilities (NJC, 2024).

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.

Americans with Disabilities Act (ADA)

The Americans with Disabilities Act (ADA) ensures equal access for all individuals with disabilities.

This law requires that “reasonable accommodation” be made to allow individuals with disabilities to fully participate in and receive all the services and benefits available to those without disabilities. The ADA uses the term “auxiliary aids and services” to refer to the ways to communicate with people who have communication disabilities.

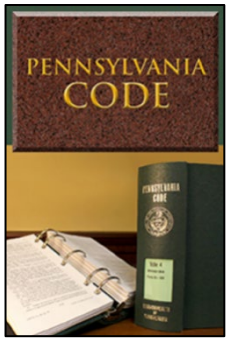
For more information about the ADA, please visit www.ADA.gov.

Limited English Proficiency (LEP)

Title VI of the Civil Rights Act of 1964 says that programs that provide federally funded services must provide language assistance to persons with Limited English Proficiency (LEP). Limited English Proficiency means the individual does not speak English as their primary language and have a limited ability to read, speak, write, or understand English.

For procedures necessary to Title VI requirements, reference Bulletin 00-04-13- Limited English Proficiency or its successor.

55 Pa. Code §6100.50 Communication



The Pennsylvania Code has rules and regulations for Pennsylvania. The 55 Pa Code section is for Human Services. Under the Human Services section, Chapter 6100 has rules and regulations for services for individuals with an intellectual disability or autism.

The 55 Pa. Code §6100.50 says, “written, 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 way to communicate. If the team doesn’t know it, the team (the individual, their family, Supports Coordinator, providers, and others picked 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 see there is meaning behind behavior and to assess, support, and help the individual identify the tools the individual needs to communicate effectively and in a way that is easily understood by unfamiliar people (people who do not know the individual).

It is the provider's responsibility to make sure the individual always has 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 working (including charged) and is accessible to the individual.

For people who have many providers, it is important that the team coordinate efforts (work together) to ensure access to effective communication.

If the individual's designated person(s), has different communication needs, the provider is responsible for meeting 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.

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

Policy Requirements

Administrative Entities

Administrative Entities (AEs) must have a policy that assures that every person has access to effective communication. This requirement comes from the Administrative Entity Operating Agreement.

This policy must at least include:

- Training procedures to provide staff with skills needed to be effective communication partners.
- Ways to ensure all communication will be culturally and linguistically appropriate (meaning all communication will consider everyone's culture and language differences).
- A plan to budget and provide accommodations, such as interpreters.
- An ongoing plan to ensure that Individual Support Plans (ISPs) include strategies and supports for ensuring access to effective communication.

This policy should be reviewed and updated regularly. It must be made available to ODP when requested.

Supports Coordination Organizations

Supports Coordination Organizations (SCOs) are required to have a policy that assures that every individual has access to effective communication. This policy will help to show that the SCO is meeting 55 Pa. Code §§6100.50 and 6100.222-223 requirements.

This policy must at least include:

- How the SCO will ensure that communication will 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 (how the individual shares information and receives information),
    - What is needed for effective and meaningful communication, and
    - Any assessment results/recommendations.
- How the SC monitoring process will prioritize communication.
- How the SCO will ensure individuals always have access to working augmentative and alternative communication (AAC) and assistive technology (AT) across all settings.
- Ways to ensure all communication will be culturally and linguistically appropriate (meaning all communication will consider everyone’s culture and language differences).
- Training procedures to provide staff with skills needed to be effective communication partners.
- A plan to budget and provide accommodations, such as interpreters.

This policy should be reviewed and updated regularly. It must be made available to ODP when requested.

Providers and Private Intermediate Care Facilities for People with an Intellectual Disability (ICF/ID)

Providers are required to have a policy that assures that every individual has access to effective communication. This policy will help to show that the provider is meeting 55 Pa. Code §§ 6100.50 and 6100.224 requirements.

Private ICF/IDs are also required to have a policy that assures that every individual has access to effective communication. This policy will help to show that the ICF/ID is meeting 42 CFR §§ 483.430(b) and 483.440(c) requirements.

This policy must include:

- How they will ensure that communication will occur in the "means of communication understood by the individual" for people they support.
- How they will assess each individual's communication to identify the tools and supports needed.
- When providing behavior services, ensure that the communicative intent behind the behavior (what the person is trying to communicate) will be explored and understood before addressing the behavior itself. Effective communication will be explored as a replacement for behaviors.
- Describe how providers and ICF/IDs will ensure individuals always have access to working augmentative and alternative communication (AAC) and assistive technology (AT) across all settings where they provide services.
- Ways to ensure all communication will be culturally and linguistically appropriate (meaning all communication will consider everyone's culture and language differences).
- Training procedures to provide staff with skills needed to be effective communication partners.
- Training procedures to ensure staff will be trained on:
    - how each person they support communicates and
    - how to effectively communicate with the individual before providing services to them.
- A plan to budget and provide needed accommodations, such as interpreters.

This policy should be reviewed and updated regularly. It must be made available to ODP when requested.

Assessment Requirements

All individuals must have their needs assessed as part of the ISP process (55 Pa. Code §6100.221(e)). This happens through the assessments required in each waiver.

Assessments are important for identifying and addressing what people need. An ongoing review of communication needs is important.

Communication continually changes. There are different things unique to each person that impact communication (how the person shares information and how they receive it). Added assessment may be needed if the individual:

- Does not use oral speech (speaking with your mouth),
- Uses oral speech but communication is not effective or is often misunderstood,
- Has a hearing loss,
- Has a vision impairment,
- Uses sign language,
- Has noticeable changes in behavior,
- Has changes in communication,
- Has changes to health and/or medication that may impact communication,
- Has changes in their environment (such as team members, location, new service, etc.), and/or
- There are concerns about how effective and meaningful communication is.

If it is decided that the individual would benefit from another assessment or a different assessment of their communication, it should be completed by a qualified professional. A qualified professional could be a Speech-Language Pathologist. Speech-Language Pathologists are experts in communication.

It is important to remember that communication changes throughout life. Assessments should not be thought of as a once and done process but rather ongoing with the team.

Individual Support Plan Requirements

Individual Support Plans (ISPs) must include strategies and supports, including assessment information, for ensuring people have effective expressive and receptive communication.

This may include but is not limited to:

- Using augmentative and alternative communication or assistive technology (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 (communication through facial expressions, gestures, body language, etc.)
- Allowing enough wait time and/or processing time
- Sensory considerations
- Services such as, but not limited to, a Communication Specialist, speech therapy, or behavioral support

Team Member Roles and Responsibilities

All team members are to participate in developing and applying the communication strategies and approaches in the ISP. This is important to ensure a full and consistent approach.
Direct support professionals (DSPs) are to provide communication support and services as part of their work responsibilities. Providers must ensure that all staff who have direct contact with the individual are fully trained in that individual's communication.

Monitoring and Oversight

Providers must measure and monitor progress in communication outcomes/goals for individuals. Providers must write progress notes that document and evaluate progress. This is required in 55 Pa. Code §6100.227. Regular review is needed to evaluate if what the team is doing is effective and assess changing needs. This will help the team to know if a reassessment is needed.

Supports Coordinators must also monitor progress through their required monitoring processes.

The Administrative Entity or the Bureau of Support for Autism and Special Populations (if the individual is enrolled in the Adult Autism Waiver) and Supports Coordinators are to monitor providers.

Individuals living in an ICF/ID need to have access to communication supports and services as part of their treatment, per their plan of care. Monitoring and the ISP will be done by or with the ICF/ID's Qualified Intellectual Disability Professional (QIDP).

Communication Supports and Services

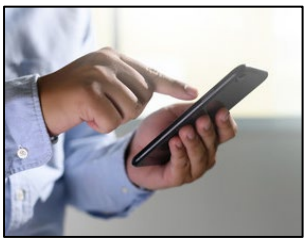
Communication supports and services are developed with a qualified professional to ensure they are most appropriate and person-centered. The qualified professional may be, but is not limited to, a Speech-Language Pathologist, a Behavioral Specialist, and/or a Communication Specialist for services funded through ODP's waivers.

To learn what the provider qualifications for the different services are, go to Appendix C of the waivers.

The qualified professional assesses communication needs, progress, supports and services with or as part of the team. The qualified professional can train the team (staff and family) to work with the individual to use communication supports and strategies.

The communication supports and services direct support professionals (DSPs) or other team members provide are a part of the service or support they are listed as providing on the ISP.

Augmentative and Alternative Communication and Assistive Technology



Augmentative and Alternative Communication (AAC) is a category of supports that improve an individual's ability to access communication.

"Augmentative" means "to add" to someone's oral speech such as gestures, pictures, or a communication board. This can make the message clearer.

"Alternative" means to be used "instead of" speech.

AAC includes all the tools and strategies a person can use to communicate when they are not able to use speech. Often, they are broken into 2 groups:

- Unaided AAC doesn't require an aid or tool beyond a person's own body. It can include facial expressions, body language, and sign language.
- Aided AAC uses tools or materials. It can be light-tech (like a paper communication board) or high-tech (like a speech generating device).

Assistive Technology is a device, equipment, or software that helps people do things.

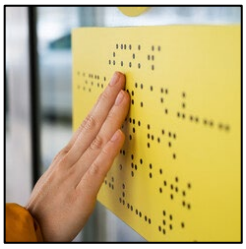
For individuals who use aided AAC or assistive technology, their ISP must include:

- A plan for regularly assessing if it is effective or not.
- If using a speech generating device; the name of the device, where to find device resources or troubleshooting guides, and technical support information.
- A plan for maintenance (upkeep) and repair. The plan must include that repairs will be made quickly and the individual will have access to an appropriate replacement device while the repairs are being completed.
- How the AAC or assistive technology will be available to the individual in all settings.
- A back-up plan to guarantee continuous access to communication in case the item breaks or is unavailable.
- How unaided communication is supplemented (or added to), such as signs or gestures.

The team must also plan for training family members, staff, and others involved in the individual's life. Training could include aided language input (modeling) and expectant pause (wait time) to ensure any AAC and communication strategies are implemented consistently.

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

Accommodation Services



Accommodation services are any change in the way things are typically done that provides an equal opportunity.

Accommodation services include a range of supports; consideration must be given to what best meets the individual's needs. It could include an interpreter, translator, captioning, large print, Braille, etc.

When accommodation services are needed, the Administrative Entity, SCO, or the provider must provide an opportunity for individuals to request the type of accommodation service they want. Primary consideration must be given to what the individual's chooses unless something different is recommended in the individual's most current assessment. It is not recommended that family members or friends act as an interpreter for the individual, even if they meet 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. These situations need to be within the limits of the ADA and for sign language interpretation, the Sign Language Interpreter and Transliterator State Registration Act of 2004 (Act 57). Using a family member or friend to act as an interpreter should be documented.

Paying for Accommodation Services

Administrative Entities

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

AEs must pay for needed accommodation services for:

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

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

Supports Coordination Organizations

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

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

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

Providers

Providers must provide any needed accommodation services shown in the ISP when providing services to individuals.

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 10 calendar days and participate as needed to revise the ISP.When providing services to individuals who use ASL and the individual does not have the 'ASL – English Interpreter service' on their ISP, providers are required to provide staff fluent in ASL or ASL interpretation.

Private Intermediate Care Facilities for Individuals with an Intellectual Disability

Intermediate Care Facilities for Individuals with an Intellectual Disability (ICFs/ID) are a Medicaid State Plan service. It is required that accommodation services 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.

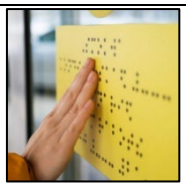
Obsolete Bulletins:

The bulletins below are no longer in use:

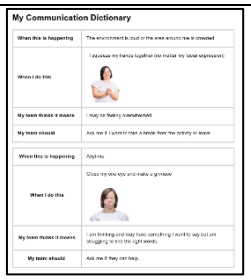
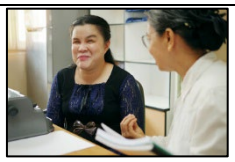
- Office of Developmental Programs 00-14-04, Accessibility of Intellectual Disability Services for Individuals Who Are Deaf
- Office of Developmental Programs 00-08-18, Communication Supports and Services

Communication Definitions

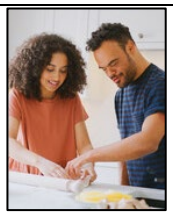
This section defines terms related to communication.

Accommodation Services	Any change in the way things are typically done that provides an equal opportunity to an individual with a disability. Accommodations may include but are not limited to interpreters, translators, captioning, large print, Braille, etc.	
American Sign Language (ASL)	A formal language with its own semantics (word meaning) and grammar, beginning in the United States and used also in English-speaking parts of Canada. It is a language that has the same linguistic (language) properties as spoken languages, but with grammar that differs from English.	
Artifacts, Tactile Cues, and/or Objects of Reference	A physical object or texture that is used to represent a person, place, object, or activity. The artifacts, textures, and objects are individualized to the person using them.	

Augmentative and Alternative Communication (AAC)	AAC means all the ways that someone communicates besides speech. “Augmentative” means “to add” to someone’s oral speech such as gestures, pictures, or a communication board. This can make the message clearer. “Alternative” means to be used “instead of” speech. AAC incorporates all the tools and strategies a person can use to communicate when they are not able to use speech. Often, AAC is broken into 2 groups: Unaided AAC and Aided AAC. • Unaided AAC doesn’t require an aid or tool beyond a person’s own body and can include facial expressions, body language, and sign language. • Aided AAC uses tools or materials and can be light-tech (like a paper communication board) or high-tech (like a speech generating device).	
Braille	A form of written language for people who are blind. Letters and symbols are represented by patterns of raised dots that are felt with the fingertips.	
Communication Access Realtime Translation (CART)	Also known as CART, real-time captioning, and human captioning. CART is a service performed by a hired professional to caption.	

Communication Dictionary	A person-specific document that helps communication partners learn about an individual's unique behavioral signals, signs, etc. to interpret them correctly, and respond to the communicator's intent in a way they will understand.	
Communication Partner	The person with whom someone is communicating. They can help make the conversation more successful, inclusive, and effective for everyone.	
Communication Passports	A person-centered document that describes the individual's most effective communication, including information from past and present (from many people who know the individual). The passport is carried by the individual and shared with communication partners.	
Eye Gaze	Looking at an object, symbol, or person for an extended period to communicate an interest or desire for interaction.	
Foreign Sign Language	Any sign language from another country, such as British Sign Language, French Sign Language, etc. These are different languages than American Sign Language and are unique to each country.	
Haptics / Touch Cues	A tactile (touch) sensation that represents an incoming signal received by the somatic (body) system, or a relationship between tactile sensations which can be used to understand a higher level of information. Visual, environmental, or emotional information can be provided through touch.	

Individual	A person registered with an Administrative Entity; enrolled in a waiver program (Consolidated, Community Living, P/FDS or Adult Autism Waiver); or who receives base-funded services, Targeted Support Management, or services from facilities that must comply with 55 Pa. Code Chapters 2380, 2390, 6400, 6500, or 6600.	
Individual Support Plan (ISP)	An organized description of person-centered activities, including services and supports for an individual.	
Interpretation	Interpreting is the process of conveying English in grammatically correct American Sign Language or another language such as Spanish and vice versa. Interpreters maintain the role of a facilitator of communication rather than the focus or initiator of communication.	
Limited English Proficiency (LEP)	Individuals who do not speak English as their primary language and have a limited ability to read, speak, write, or understand English.	
Paralanguage	The non-lexical (not words) component of communication by speech, that adds meaning to what is said. This can include tone of voice, speed of speaking, hesitation noises, gestures, and facial expressions.	
Picture Exchange Communication System (PECS)	A specific system with a protocol (procedure) for teaching expressive use of pictures to communicate. The protocol includes 6 phases of teaching and official program materials.	

Pidgin Signed English (PSE)	A grammatically simplified combination of American Sign Language (ASL) and English that was developed by hearing individuals who became deaf or hard of hearing during adulthood. The main difference between PSE and Signed Exact English (SEE) is that PSE still mainly follows ASL sentence structure such as the dropping of determiners, suffixes, and articles but is signed in English word order. SEE has its own set of accepted signs for all parts of English including determiners, prefixes, suffixes, and articles.	
Print Systems	Used to support the development of communication either instead of or with text, speech, sign language, or objects of reference. Print systems are typically less complex than PECS, are homemade (not a part of the PECS official program materials), and may be meant for individuals who have some degree of vision loss. Symbols can vary from concrete (such as a real-life picture of a house to represent “home”) to abstract (such as an arrow representing “up”).	
Provider	The person, entity, or agency that is approved to deliver a service to the individual.	

Service (paid caregiver or agency)	An activity, assistance, or product provided to an individual that is paid through a program administered by ODP. Service includes Supports Coordination (Targeted Support Management or base funded SC services), and vendor goods and services, as well as services provided through an organized health care delivery system, agency with choice, or vendor fiscal/employer agent financial management services model.	
Sign Language	A general term describing any type of gestural communication in a visual-spatial modality.	
Signed Exact English (SEE)	A system of manual communication that aims to be an exact representation of English vocabulary and grammar. It is not considered a language of its own but a manually coded form of English.	
Speech	Speech is how sounds and words are said. Speech includes articulation, voice, and fluency.	
Spoken Language	A language produced by articulated (spoken) sounds; a systematic means of communicating using sounds. This includes all spoken languages such as English, Spanish, Chinese, etc.	
Support (unpaid caregiver)	An unpaid activity or assistance provided to an individual that is not planned or arranged by a provider.	

Supports Coordination Organization (SCO)	An organization that delivers Supports Coordination (SC) services through the Consolidated, Community Living, P/FDS, and Adult Autism Waivers; Targeted Support Management (TSM); or base-funded SC.	
Symbol Systems	Used to help people with complex disabilities, including those who are DeafBlind, to: • understand what is being communicated to them, • to anticipate an event or activity, • to express themselves, and • to make choices. Types of symbol systems include objects of reference, symbolic objects, photos, pictures, line drawings and written text that can be used independently or with other communication methods, as part of a total communication approach. Many definitions in this document are considered part of the general category called “symbol systems”.	
Tactile Sign Language	A means of communication used by people with both a sight impairment and hearing loss (DeafBlindness). It is based on a sign language or other system of manual communication. "Tactile signing" refers to signing using touch.	
Visual Gestural Communication (VGC)	A method of communication that does not use vocabulary and grammar rules of a language. Instead it involves gestures, facial expressions, and body language use and analysis.	

Voice Output Device (or a speech generating device)	Electronic Augmentative and Alternative Communication (AAC) used to add to or replace speech or writing for individuals with severe speech impairments, enabling them to communicate in a way that can be heard.	