

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

Communication Bill of Rights (3rd Edition): Guidance for Advocacy and Practice

The Communication Bill of Rights (3rd Edition): Guidance for Advocacy and Practice provides details regarding each of the rights, offers guidance on interpretation and application for advocacy and practice, and aims to serve as a practical guide with useful strategies. It is intended for families, caregivers, professionals, advocates, and organizations supporting the communication rights of people with severe disabilities.

You can use this guidance document broadly across audiences. This document provides suggested practical actions that you can take across settings. Use these actions to teach others how to uphold communication rights of people with severe disabilities. Teams may also find these actions useful as they reflect on and improve their own practices.

Guidance for Use

When using or adapting/modifying any content from the *Communication Bill of Rights*, even if you have simplified the wording further or changed representational format, be sure to use the following citation:

National Joint Committee for the Communication Needs of Persons with Severe Disabilities. (2024). *NJC Communication Bill of Rights* (3rd ed.). https://www.asha.org/njc

In order to track the reach and impact of the content—and to support ongoing refinement—we kindly ask that you share your modified version with the NJC by emailing it to Diane Paul (dpaul@asha.org).

Important Note: The current third edition of the *Communication Bill of Rights* is published as open access (i.e., no paywall). The NJC does not support monetizing the *Communication Bill of Rights* or any modified versions.

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

1. The right to dignity and respect in all interactions.

Why Is It Included?

All people have value. Everyone is worthy of being heard and accepted by others. Showing dignity and respect during interactions recognizes everyone's inherent humanity and is foundational to successful communication.

Actions You Can Take

- Ensure body autonomy and seek consent for all physical interactions (e.g., avoid acting without a cue on someone's body, equipment, or personal property—such as their wheelchair, walker, or belongings).
- > Use age-respectful communication that honors the individual, their preferences, and their choices.
- Ask about and use preferred pronouns.
- Talk with individuals rather than about them in their presence; communicate to them and with them, and encourage others to do the same (see Right #3).

Bottom Line

We must treat people with severe disabilities the way we expect to be treated.

2. The right to meaningful communication that is culturally and linguistically appropriate.

Why Is It Included?

It is important to affirm the value of multiple cultures and languages—and the fact that these can be assets to ensuring that the individual's full abilities are realized. Meaningful communication is understood, accessible, and relevant. Individuals with disabilities can be exposed to and learn more than one language. See the following resources for more information on providing culturally and linguistically responsive services:

- Service With Culturally Diverse Individuals
- Building a Thriving and Inclusive Occupational Therapy Community

Actions You Can Take

- ➤ Collaborate with families and individuals to ensure that they receive culturally and linguistically relevant services.
- Ensure that symbols and images for augmentative and alternative communication (AAC) systems reflect the individual's culture and identity.
- > Select instructional targets (e.g., vocabulary) that enhance the individual's participation in cultural values, traditions, and practices.
- ➤ Use language that is appropriate, meaningful, and relevant to the individual and their communication partners.
- > Select materials and activities that are affirming to multiple cultures.

Bottom Line

Communication is more successful when we recognize, value, and address each other's intersecting identities across languages and cultures.

3. The right to be addressed directly and not be spoken for or talked about as if not there.

Why Is It Included?

Everyone should have the opportunity to participate in communication that is relevant to them. This is especially the case when the individual is present. Talking about or for a person who is present without their consent and/or participation is disrespectful.

Actions You Can Take

- Actively acknowledge and engage the individual in the conversation.
- > Allow time for the person to participate.
- > Demonstrate how to include people in conversations that are about them.
- ➤ If exclusionary patterns of communication continue, acknowledge that the course of the interaction is leaving out the key participant, and model strategies for engaging the individual.

Bottom Line

We should strive to address people directly and include them in all of our conversations about them.

4. The right to receive a response to all communication, even when the desired outcome is not possible.

Why Is It Included?

Responding to an individual's communication is critical. Communication should be acknowledged, even when the expressed desire cannot be fulfilled at that time. Doing so ensures that an individual's communication efforts are honored and reinforced.

Actions You Can Take

- Acknowledge the communication attempt even if you're unsure of the intent or message.
- > Employ strategies seeking clarification of the individual's intent or message.
- If the desired outcome is not possible within the specific context, explain why.
- Partner with the individual to understand and communicate alternative options to meet their needs or desires.

Bottom Line

Ignoring any communication attempt can be harmful. When we acknowledge communication, it increases the likelihood of future communication.

5. The right to participate across settings as full communication partners.

Why Is It Included?

People with significant communication support needs are often excluded from full participation because of myths and misconceptions, attitudinal barriers, and barriers in the built environment. Our lives are enriched when we have opportunities to engage with a wide range of people and pursuits. These opportunities can be enhanced through (a) access to

flexible communication systems and (b) individuals willing to engage in and support communication.

Actions You Can Take

- Advocate for and promote inclusive design and practices.
- Address, call out, and eliminate barriers to participation when you see them.
- > Engage in interprofessional collaboration.
- Ensure access to effective communication systems.

Bottom Line

We all need opportunities to participate meaningfully everywhere we go.

6. The right to interact socially and to build and keep relationships.

Why Is It Included?

Communication is at the core of how we engage with the world around us. Communication is essential in building and maintaining relationships and is central to the human experience. Relationships and friendships are connected with well-being.

Actions You Can Take

- Ensure access to messaging that nurtures interpersonal communication.
- > Support communication partners to maximize their responsiveness.
- Advocate and provide support to others in the setting who may not be knowledgeable about communication needs.
- ➤ Promote, teach, and practice skills that enhance social competence.
- > Support the identification of mutual interests as the basis for healthy friendships.

Bottom Line

We build and keep relationships through communication.

7. The right to be given—and to understand—information about objects, actions, events, and people.

Why Is It Included?

Everyone has the right to be informed about what impacts their lives. Information is not meaningful without comprehension and is critical to navigating our world. Denying information to someone about what impacts their lives is disrespectful.

Actions You Can Take

- ➤ When sharing information—whether positive or difficult—do so in a way that allows the person to comprehend the message.
- When sharing information, consider culture, vocabulary, symbol system, modality, wait time, and appropriate pace of communication.
- ➤ Offer opportunities for the person to ask for clarification or more information.
- > Provide information about daily schedules, other events, and social interactions.
- Ensure that the person can make their own choices about participation.

Bottom Line

Having information respects our right to be informed and included more fully in the world.

8. The right to ask for or refuse objects, actions, events, and people.

Why Is It Included?

Communication helps us get what we want or avoid what we don't want, rather than having others decide for us.

Actions You Can Take

- Ensure that the person communicating is the one in control of their wants and desires.
- Remind others that the person communicating is in control of their wants and desires.
- > Respect communication attempts.
- > Provide experiences and information that broaden communication opportunities.
- Acknowledge communication—whether or not you agree.
- > Avoid censoring communication.
- > Teach and provide access to vocabulary that the person can use to ask and refuse.

Bottom Line

Each of us has the right to determine when and how they communicate what they want or don't want.

9. The right to express preferences and feelings, make comments, and share opinions.

Why Is It Included?

Communication is essential in expressing one's unique identity, interests, and experience—including personal thoughts, feelings, ideas, and opinions. This expression fosters connection and relationships with other people.

Actions You Can Take

- > Provide a rich array of experiences and opportunities so that people can develop interests, preferences, and opinions.
- Ask about a person's preferences and opinions.
- ➤ Teach and provide access to vocabulary that the person can use to express preferences, communicate feelings, make comments, and share opinions.
- Ensure there are opportunities for people to communicate about preferences, feelings, and opinions.
- Recognize that preferences and opinions may change over time and across settings.

Bottom Line

By conveying thoughts, feelings, ideas, and opinions, we let people know who we are and what's important to us.

10. The right to make choices from meaningful options.

Why Is It Included?

Choice-making is central to having control over our lives.

Actions You Can Take

- > Develop and recognize the ways that the person communicates their choices.
- > Be aware that lack of a response may indicate a choice.

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- ➤ Give the person time to make a decision and express it.
- Take the person's profile (i.e., sensory, motor, linguistic) into account when presenting choices to them.
- Ensure that a person is familiar with the options and their representations (e.g., gestures, symbols).

Bottom Line

Authentic choice-making requires us to have experiences that help us understand and select preferred options presented to us in accessible ways.

11. The right to access services and supports for communication across the lifespan.

Why Is It Included?

Access to services and supports should exist across a person's life. People, technology, and interventions change over time. People should have the opportunity to experience new and different approaches for communication across settings.

Actions You Can Take

- Learn about and advocate for access to services and supports that exist across the lifespan.
- ➤ Document services and supports in the short and long term to ensure continuity during periods of transition.
- ➤ Provide services and supports that are responsive to changes in the individual across the lifespan.
- As device features expand, consider their potential to enrich communication experiences.
- > Provide services and supports that promote active participation across settings.

Bottom Line

Our communication needs and abilities evolve over the course of our lives. Access to appropriate services and other supports—including technology—enables successful communication.

12. The right to have individualized, working augmentative and alternative communication (AAC) and other assistive technology (AT) at all times.

Why Is It Included?

Individualized forms of AAC meet the person's strengths and needs across contexts and support participation. People need consistent access to a variety of tools and strategies that support their participation and ensure their successful communication.

Actions You Can Take

- ➤ Individualize and personalize AAC services and supports.
- Avoid removing or adjusting AAC as a form of punishment or behavioral management.
- ➤ Work with familiar communication partners—including family members and caregivers—to identify the ways an individual communicates.
- ➤ Gain input on the selection of AAC from family members or other caregivers.
- Ensure that all team members know where, what, and how to support access to working AAC and AT at all times and across settings.

Bottom Line
Communication happens throughout the day—in all settings and with diverse people. Individualized supports need to be available in all of those contexts.