

# Communication Resources: The National Joint Committee on the Communication Needs of Persons with Severe Disabilities

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# Disclosures

- **Nonfinancial:**
  - Sevcik and Ronski are members of the National Joint Committee on the Communication Needs of People with Severe Disabilities and advocate for communication services and supports for people with severe disabilities including dispelling myths
  - Sevcik and Ronski have published a number of the studies/books that they discuss in this webinar.

# WEBINAR OVERVIEW

- Introduction
- NJC and Its Purpose
- History of the NJC
- NJC Activities
- Questions and Comments

“If all of my possessions were taken from me, I would choose to keep the ability to communicate because with it I would win back all the rest.”

(attributed to Senator Daniel Webster)

## *COMMUNICATION....*

- ❑ Provides a window into our inner selves
- ❑ Permits a person to express...
  - ❑ Basic wants, needs, and desires
  - ❑ Thoughts and feelings
  - ❑ Knowledge
- ❑ Provides a basis through which others perceive who we are

# Communication Is Critical To Self-Determination ...

- Children and adults must have adequate opportunities, including supports and accommodations, to be the causal agents in their own lives, to make choices, and to permit self-determination.
- An essential accommodation for self-determination is being able to communicate.
- And, it is often by using Augmentative and Alternative Communication (AAC) Systems.
- AAC encompasses all forms of communication
  - *Unaided* forms of communication
    - simple gestures
    - facial expressions
    - manual signs and sign language (e.g., ASL, BSL)
  - *Aided* forms of communication
    - picture communication boards
    - dedicated computer-based devices that can speak in words and sentences
    - computers, tablets, and smartphones







# Need

- Shortage of trained personnel
- Need for guidance/guidelines for interdisciplinary teams and other stakeholders
- Need to develop foundational beliefs (grounded in evidence) to guide practice



# PURPOSE OF THE NJC

- Advocate for individuals with significant communication support needs resulting from intellectual and developmental disability, that may coexist with autism, sensory and/or motor limitation.
- *Focus: Research, policy, practice and training*



# NJC Member Organizations



American Association on Intellectual and Developmental Disabilities (AAIDD)

American Occupational Therapy Association (AOTA)

American Physical Therapy Association (APTA)

American Speech-Language-Hearing Association (ASHA)

Association of Assistive Technology Act Programs (ATAP)

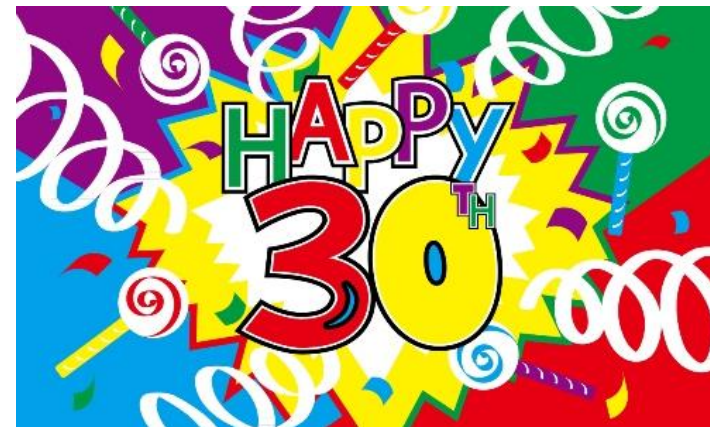
Council for Exceptional Children/Division for Communicative Disabilities and Deafness (CEC/DCDD)

TASH

United States Society for Augmentative and Alternative Communication (USSAAC)

# HISTORY OF THE NJC

- 1984 – Council of State Consultants in Speech, Language and Hearing convened to develop guidelines
- 1985 – OSEP Consensus Conference; issued 33 recommendations re: education of children with severe disabilities
- 1986 – NJC formed in 1986 by ASHA and TASH after a OSEP Conference
- 1992 -- First Guidelines including the Communication Bill of Rights NJC
- 2016 -- Revised Guidelines and Communication Bill of Rights
- 2016 -- Celebrated 30<sup>th</sup> Anniversary



# NJC Resources: Guidance Document

AMERICAN JOURNAL ON INTELLECTUAL AND DEVELOPMENTAL DISABILITIES  
2016, Vol. 121, No. 2, 121–138

©AAIDD  
DOI: 10.1352/1944-7558-121.2.121

## **Communication Services and Supports for Individuals With Severe Disabilities: Guidance for Assessment and Intervention**

*Nancy C. Brady, Susan Bruce, Amy Goldman, Karen Erickson, Beth Mineo, Bill T. Ogletree, Diane Paul, Mary Ann Ronski, Rose Sevcik, Ellin Siegel, Judith Schoonover, Marti Snell, Lorraine Sylvester, and Krista Wilkinson*



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

## COMMUNICATION BILL OF RIGHTS

All people with a disability of any extent or severity have a basic right to affect, through communication, the conditions of their existence. Beyond this general right, a number of specific communication rights should be ensured in all daily interactions and interventions involving persons who have severe disabilities. To participate fully in communication interactions, each person has these fundamental communication rights:

1. The right to interact socially, maintain social closeness, and build relationships
2. The right to request desired objects, actions, events, and people
3. The right to refuse or reject undesired objects, actions, events, or choices
4. The right to express personal preferences and feelings
5. The right to make choices from meaningful alternatives
6. The right to make comments and share opinions
7. The right to ask for and give information, including information about changes in routine and environment
8. The right to be informed about people and events in one's life
9. The right to access interventions and supports that improve communication
10. The right to have communication acts acknowledged and responded to even when the desired outcome cannot be realized
11. The right to have access to functioning AAC (augmentative and alternative communication) and other AT (assistive technology) services and devices at all times
12. The right to access environmental contexts, interactions, and opportunities that promote participation as full communication partners with other people, including peers
13. The right to be treated with dignity and addressed with respect and courtesy
14. The right to be addressed directly and not be spoken for or talked about in the third person while present
15. The right to have clear, meaningful, and culturally and linguistically appropriate communications

For more information, go to the NJC website at: [www.asha.org/njc](http://www.asha.org/njc)

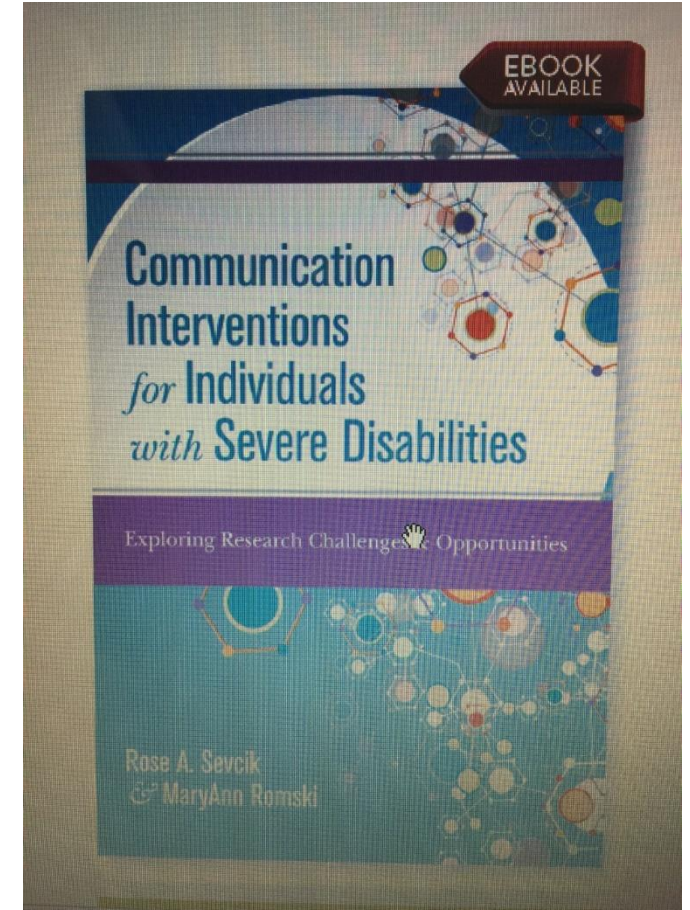
Brady, N. C., Bruce, S., Goldman, A., Erickson, K., Mineo, B., Ogletree, B. T., Paul, D., Ronski, M., Sevcik, R., Siegel, E., Schoonover, J., Snell, M., Sylvester, L., & Wilkinson, K. (2016). Communication services and supports for individuals with severe disabilities: Guidance for assessment and intervention. *American Journal on Intellectual and Developmental Disabilities*, 121(2), 121-138.

## • Communication Bill of Rights



# NJC Research Conference funded by the National Institute on Deafness and Other Communicative Disorders (NIDCD)

- Resulted in an interdisciplinary edited volume
  - contributions from more than 30 scholars from diverse fields
  - effectiveness of today's communication interventions,
  - synthesizes evidence from current studies, and
  - Identifies urgent research directions for the future.
- Chapters provide a brief summary of research studies on
  - a key intervention topic,
  - insights on research design and measurement challenges,
  - thoughts on future advances, and
  - real-world clinical and educational recommendations.



# THE NJC WEBSITE: AVAILABLE MATERIALS <http://asha.org/njc>

- **Previous Publications and Presentations**
- **Topic Area Materials**
  - **Accessing Services**
  - **Intervention Issues & Practices**
- **Resources on COVID-19 and Telepractice**





## McLean Yoder Award for Professional Excellence (MYAPE)

Honoring interprofessional teams that exemplify high quality professional services to individuals with severe disabilities.

If you are on - or know of - a great multidisciplinary team that exemplifies inter-professional practices (IPP) - consider nominating them for the MYAPE.

This year's deadline has been extended to **June 30, 2020.**

See <https://www.asha.org/NJC/McLean-Yoder-Award/> for the application and more information.



The CHIME Charter School,  
2019 MYAPE Winners

# The NJC Network

- The NJC Network is a group of professionals and scholars with a common interest in enhancing communication effectiveness for individuals with severe disabilities.
- Its goal is to broaden and continue the work of the NJC.
- Joining the network doesn't involve cost or any specific obligation.
- Members:
  - Promote the Communication Bill of Rights
  - Support development of online instructional models supporting evidence based practice
  - Gather success stories from the field
  - Share challenges and concerns
  - Contribute to the development of a data clearinghouse
  - You'll hear about NJC networking opportunities.

# Benefits of Joining the Network

- Interact with leaders in the field
- Impact policy
- Help set priorities at the national level
- Enhance your professional network
- Receive early access to NJC resources
- Increase potential for future membership on the NJC

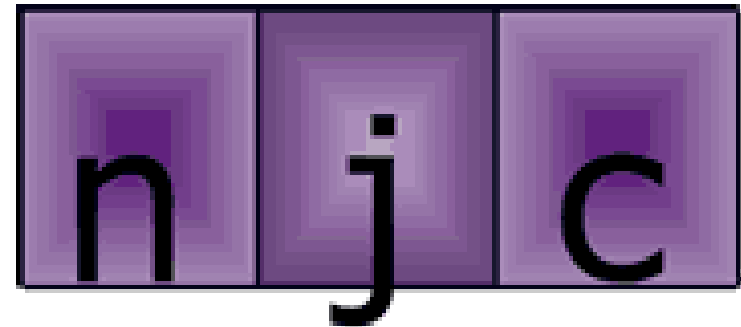
The NJC Network --.

<http://bit.do/b8446>



# Other NJC Activities

- Presentations at national and international conferences (e.g., AAIDD, ATIA, ASHA, AOTA, CEC)
- Advocacy (e.g., ASHA AAC specialty certification)
- Next Generation Scholarship: McLean Yoder Schiefelbusch Fund
- Social Media



# Coming Soon!

# E-Modules

- Focus on people (all ages) with IDD with severe disabilities *and their communication partners*
- New opportunity to access assessment and intervention content:
  - ✓ Nonsymbolic communicators
  - ✓ Emergent symbolic communicators
  - ✓ Symbolic communicators
  - ✓ Literacy
- Narrated, online, on-demand via NJC web site
- Includes video [examples](#)
- Access materials to facilitate or deliver the training yourself:
  - Powerpoint
  - Transcript
  - Movie files



# Interviews with the NJC: Video Introduction

- This video was developed specifically to encourage students and practitioners to think about the particular challenges faced by individuals with severe disabilities across the lifespan.
- The NJC members would like to thank the Katherine Brewer Smith Professorship at Western Carolina University for its generous support of this project.
- Each video has a set of discussion questions (e.g., transition to adult services) and
- Additional readings to generate further discussion and in-depth study on the specific topics has been compiled.

# Myths about Communication and Adults with Severe Disabilities

- The National Joint Committee on the Communication Needs of Individuals with Severe Disabilities (NJC) is spearheading a new initiative to address myths about communication and adults with severe disabilities.
- For adults with IDD who do not speak, the literature recommends that interventions include augmentative and alternative communication (AAC) to improve communication and interactions with others (Snell, Brady, McLean, Ogletree, Siegel, Sylvester, et al., 2010).
- Some adults with IDD exhibit limited functional speech and are often overlooked as candidates for AAC interventions because they do have some speech abilities.
- The perception is that they are too old to improve their language and communication skills (Cheslock, Barton-Hulsey, Ronski, & Sevcik, 2008).
- In truth, many adults with severe disabilities have been denied access to appropriate communication supports and services limiting the possibility of the development of new skills.
- Because recent research supports that communication interventions have been effective with this population regardless of age, these services must be available across the lifespan (Sevcik & Ronski, 2016).

# Realities about Communication and Adults with Severe Disabilities

- Adults with IDD may benefit from services and supports directed toward communication even though they are past the typical window for language and communication development.
- SGD devices offer an opportunity that opens the world of communication to adults who have a broader range of presenting speech and language characteristics than originally thought.



**THANK YOU**  
**Questions and Comments?**

# References

- Brady et al (2016). Communication services and supports for individuals with disabilities: Guidance for assessment and intervention. *American Journal on Intellectual and Developmental Disabilities*, 121 (2), 121-138
- Sevcik, R.A. & Ronski, M.A. (2016) *Communication Interventions for Individuals with Severe Disabilities: Exploring Research Challenges and Opportunities*. Baltimore, MD: Paul H. Brookes.