Celebrating 30 Years of the NJC: Empowering Individuals with Severe Disabilities, Families, and Stakeholders

Thursday, November 17, 2016

Session #1062

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

http://www.asha.org/njc

Disclosures

- Financial: Diane Paul, ASHA staff, participates in the NJC as part of her job duties
- Non-financial: All other members of the NJC receive no compensation for serving on the NJC.

Purpose of Today's Presentation

- Familiarize attendees with the NJC
  - NJC representatives will share
    - History
    - Recent products and actions
    - Web resources
  - Share ways attendees can network with the NJC around policy, practice and research
  - Describe an emerging scholarship opportunity for future students interested in people with severe disabilities

NJC History

- Formed in 1986 by ASHA and TASH
- First guidelines with Communication Bill of Rights in 1992
- Celebrating 30th Anniversary in 2016



NJC Purpose

- Advocate for individuals with significant communication support needs resulting from intellectual disability, that may coexist with autism, sensory and/or motor limitation

NJC Focus

- Research
- Policy
- Practice
- Education

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)

NJC Representatives

- AAIDD
  Mary Ann Romski, PhD, CCC-SLP
  Georgia State University
  Atlanta, GA
- AOTA
  Barbara E. Chandler, PhD, OTR/L, FAOTA
  Therapeutic Services and Design
  Winchester, VA
- AOTA
  Judith Schoonover, MEd, OTR/L, ATP
  Loudoun County Public Schools
  Ashburn, VA
- APTA
  Lorraine Sylvester, PT, PhD
  University of Oklahoma
  Oklahoma City, OK

NJC Representatives

- APTA
  Mari Therrien, PT, DSc, PCS
  Private Practice
  Tallahassee, FL
- ASHA
  Bill T. Ogletree, PhD, CCC- SLP
  (Committee Chair)
  Western Carolina University
  Cullowhee, NC
- ASHA
  Amy S. Goldman, MA
  CCC-SLP
  Temple University
  Philadelphia, PA

  Diane Paul, PhD, CCC-SLP, CAE (Ex Officio); ASHA Staff
  American Speech-Language-Hearing Association
  Rockville, MD

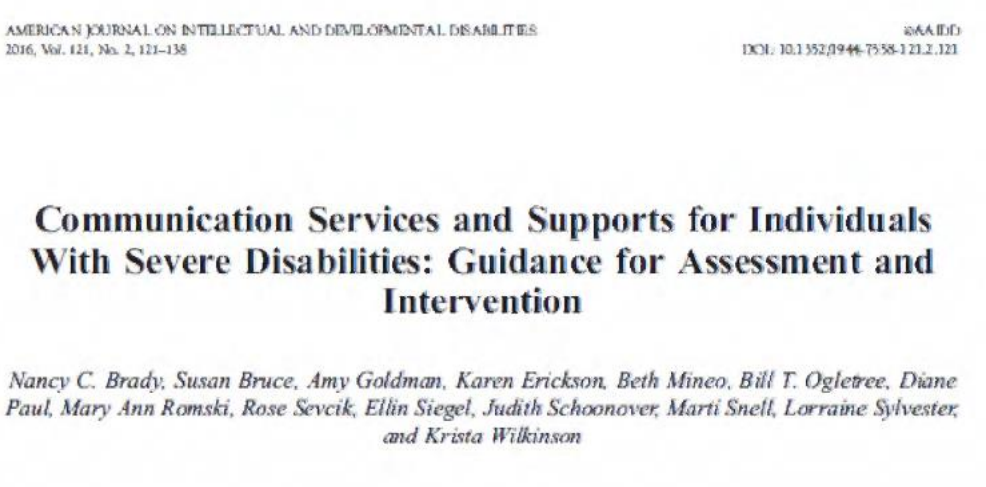
NJC Representatives

- ATAP
  Beth Mineo, PhD, CCC-SLP
  University of Delaware
  Newark, Delaware
- CEC/DCDD
  Susan Bruce, PhD
  Boston College
  Chestnut Hill, MA
- USSAAC
  Rose A. Sevcik, PhD
  Georgia State University
  Atlanta, GA
- TASH
  Karen Erickson, PhD
  University of North Carolina
  Chapel Hill, NC

  Ellin Siegel, PhD
  University of Nebraska-Lincoln
  Lincoln, NE

Past members contributing to 2015-16 activities: Krista Wilkinson; Nancy Brady

NJC Guidance



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 Romski, Rose Sevcik, Elin Siegel, Judith Schoonover, Marti Snell, Lorraine Sylvester, and Krista Wilkinson

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Communication Bill of Rights

Table 2
Revised Communication Bill of Rights

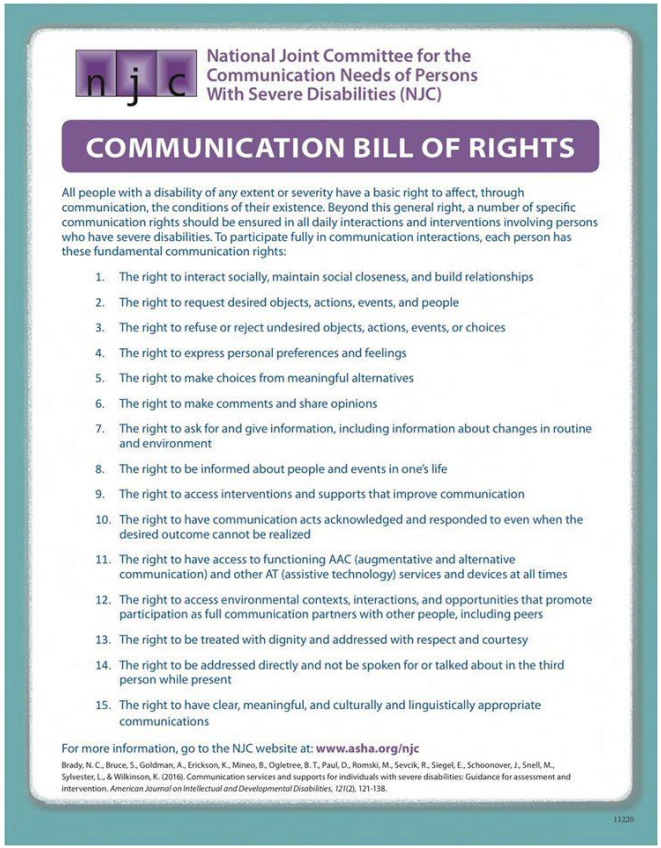
Communication Bill of Rights
All people with a disability of any extent or severity have a basic right to affect, through communication, the conditions of their existence. Beyond this general right, a number of specific communication rights should be ensured in all daily interactions and interventions 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



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Communication Bill of Rights



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

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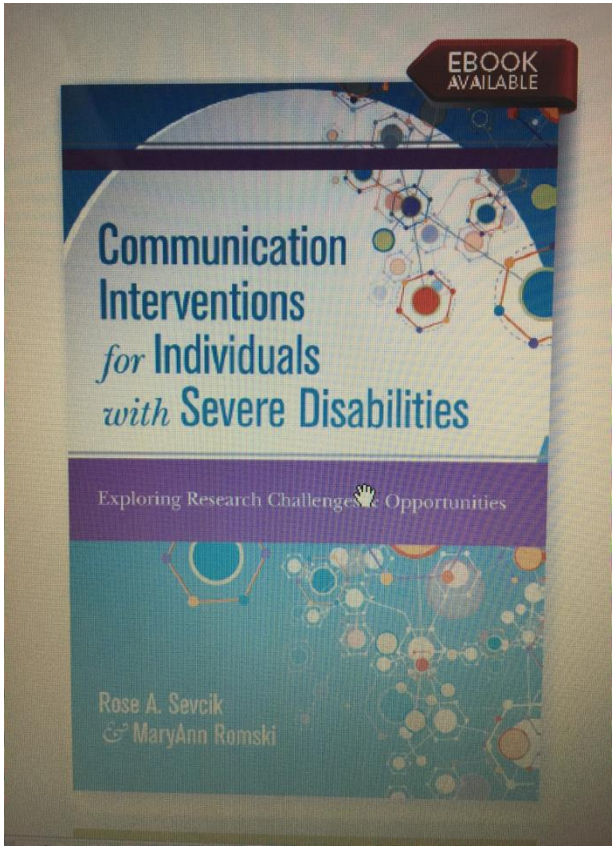
For more information, go to the NJC website at: **www.asha.org/njc**

Brady, N. C., Bruce, S., Goldman, A., Erickson, K., Mineo, B., Ogletree, B. T., Paul, D., Romski, 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.

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Conference and Edited Volume

- Research Conference June 9-11, 2011 funded by the National Institute on Deafness and Other Communicative Disorders (NIDCD).
- Shaped by the conference, this interdisciplinary book
  - includes contributions from more than 30 top scholars from diverse fields, including psychology, special education, and speech-language pathology.
  - investigates the effectiveness of today's communication interventions,
  - synthesizes evidence from current studies, and
  - Identifies urgent research directions for the future.
- Chapters give readers 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.

Chapter Topics

- prelinguistic communication intervention for young children with intellectual disabilities
- challenging behavior and communicative alternatives
- interventions for children who are deafblind
- augmented language interventions for children with severe disabilities
- parents as partners in communication intervention
- the role of cultural, ethnic, and linguistic differences
- targeted and phenotypic communication interventions for children with Down syndrome or ASD
- issues related to research study design, including sample size, the effectiveness of randomized controlled trials, and integration of single-case and group designs
- assessment and measurement of communication and language skills

Next Steps

This book offers powerful insights about today's communication interventions—and sets a clear agenda for tomorrow's groundbreaking research.



- June 11 – 23, 2014
- “People with severe disabilities face complex communication issues, which are best met with integrated, collaborative services. After attending this conference, you’ll possess a broader context for serving this unique client while being more prepared to be an integral part of an interprofessional circle of care.”
- “This online conference will help you provide teambased services that lead to the greatest and most socially valid therapeutic gains for individuals with severe disabilities.”

More on Interprofessional Services

- In 2014-15, the American Journal on Speech Language Pathology contacted the NJC regarding its interest in dedicating a clinical forum issue to the topic of interprofessional practice and severe disabilities
- The issue is slated for publication in 2017 – look for it!!

NJC Provider/Scholar Network

Purpose: To broaden and continue the work of the NJC

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Members will:

- 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

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

Join the NJC Network
http://bit.do/b8446

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E-Modules

- Supports stakeholders who wish to promote communication with people with severe disabilities
- Based on the Dynamic Learning Maps Consortium with support from a grant from the US Department of Education, Office of Special Education Programs
  http://dlmpd.com/beginningcommunicators

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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

E-Modules: Components

- Video example
  https://wcu.hosted.panopto.com/Panopto/Pages/Viewer.aspx?id=8f7690ac-54a4-41f1-b44dbad4aedadf47
- Powerpoint
- Transcript

AAC Myths Project

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Myths about Communication and Adults with Severe Disabilities

- The 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 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.

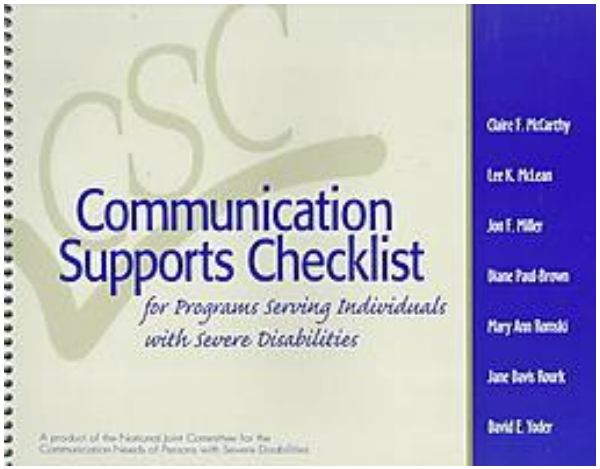
Myths (continued)

- The perception is that they are too old to improve their language and communication skills (Cheslock, Barton-Hulsey, Romski, & 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 & Romski, 2016).

Birth of a New Tool?



A tool guiding teams in assessing their own practices in supporting those with complex communication needs…



1998

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Quality Indicators



YOUR THOUGHTS?

McLean Yoder Award for Professional Excellence (MYAPE)

Exemplifying high quality

professional service to individuals

with severe disabilities

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MYAPE

- Named after Drs. James McLean and David Yoder, preeminent research scientists in the area of communication and intellectual impairment.
- Judged according to the NJC's published quality indicators specific to communication assessment, goal setting, and program implementation.
- Next deadline: May 31, 2017
- Application available at www.asha.org/njc

NEW NJC Website

WWW.ASHA.ORG/NJC



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Topic Areas

Accessing Services

- Relation of Age to Service Eligibility
- Relation of Developmental Skills to Service Eligibility
- Decision Making in Termination of Services
- Funding for Services

Topic Areas

Intervention Issues and Practices

- Applied Behavior Analysis and Communication Services
- Assessment and Teaming
- Augmentative and Alternative Communication
- Challenging Behavior as Communication
- Definition of Communication and Appropriate Targets
- Evidence-Based Practice
- Inclusion and Interactions With Friends Without Disabilities
- Intervention With Special Populations
- Literacy in Individuals With Severe Disabilities
- Service With Culturally Diverse Individuals
- Transitions/Generalization of Skill
- Types of Service

Topic Areas

Relation of Age to Service Eligibility

Services in Birth-to-3

Increasingly, service provision occurs well before 2 years of age. For individuals with the most significant disabilities, the need for some type of communication services is usually evident before the child's second birthday. Those involved in care for these individuals should conduct a comprehensive, interdisciplinary assessment of the child's receptive and expressive communication skills, as well as related areas of cognitive and social development, use valid and reliable assessment instruments—including those designed for general use with infants and toddlers or for specific use with children with severe disabilities, and provide information that can be used to design an appropriate, individualized intervention plan for the child and family.

Topic Areas

On This Page

- Services in Birth-to-3
- Services to the School-Age Population
- Services to Adults

Return to the NJC Topic List.

Topic Areas

Bottom Line: Communication services should be started as soon as a communication delay or disorder is diagnosed. A professional evaluation can determine if a child is developing appropriately. If not, an intervention program can be designed to help the child develop age-appropriate or functional skills.

Topic Area

Resources on Services to Young Children

- American Speech-Language-Hearing Association. (2004). Roles of speech-language pathologists in the neonatal intensive care unit [Technical report]. Available from www.asha.org/policy.
- American Speech-Language-Hearing Association. (2008). Roles and responsibilities of speech-language pathologists in early intervention [Guidelines]. Available from www.asha.org/policy.
- Cress, C. J. (2002). Expanding children's early augmented behaviors to support symbolic development. In J. Reichle, D. Beukelman, & J. Light (Eds.), Exemplary practices for beginning communicators: Implications for AAC (Vol. 2). Baltimore, MD: Brookes.
- Romski, M. A., & Sevcik, R. A. (1996). Breaking the speech barrier: Language development through augmented means. Baltimore, MD: Brookes.

Topic Area

Resources on Services to Young Children

- Romski, M. A., Sevcik, R. A., & Forrest, S. (2001). Assistive technology and augmentative communication in early childhood inclusion. In M. J. Guralnick (Ed.), Early childhood inclusion: Focus on change (pp. 465–479). Baltimore, MD: Brookes.
- Romski, M. A., Sevcik, R. A., & Pate, J. L. (1988). The establishment of symbolic communication in a person with severe retardation. Journal of Speech and Hearing Disorders, 53, 94–107.
- Rowland, C., & Schweigert, P. (2000). Tangible symbols, tangible outcomes. Augmentative and Alternative Communication, 16, 61–78.

Other Activities of the NJC

- Presentations at national conferences (ATIA, ASHA, AOTA for example)
- Advocacy
- Social Media
- Scholarship: McLean Yoder Schiefelbusch Fund

Learn More - Join the Network

Saturday, November 19th

Noon – 1:00 PM

Room 307, Philadelphia Marriott Downtown.

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