
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.



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

<http://www.asha.org/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



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NJC History

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

30th
Anniversary



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NJC Purpose

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

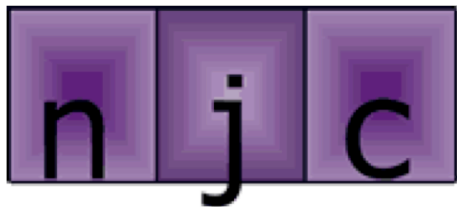


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NJC Focus

- Research
- Policy
- Practice
- Education



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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 \(USSAAC\)](#)



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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
- Judith Schoonover, MEd, OTR/L,
ATP
Loudoun County Public Schools
Ashburn, VA
- **APTA**
Lorraine Sylvester, PT, PhD
University of Oklahoma
Oklahoma City, OK



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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



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NJC Representatives

- **ATAP**

Beth Mineo, PhD, CCC-SLP
University of Delaware
Newark, Delaware

- **CEC/DCDD**

Susan Bruce, PhD
Boston College
Chestnut Hill, MA

- **TASH**

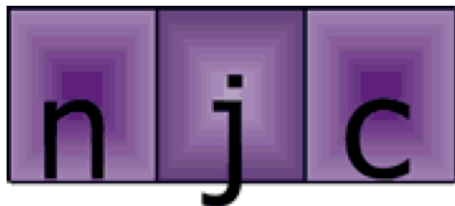
Karen Erickson, PhD
University of North Carolina
Chapel Hill, NC

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

- **USSAAC**

Rose A. Sevcik, PhD
Georgia State University
Atlanta, GA

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



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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 Ronski, Rose Sevcik, Ellin 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



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COMMUNICATION BILL OF RIGHTS

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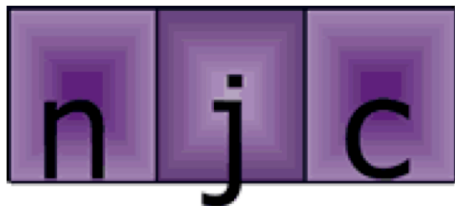
For more information, go to the NJC website at: www.asha.org/njc

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

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EBOOK
AVAILABLE

Communication Interventions *for* Individuals *with* Severe Disabilities

Exploring Research Challenges & Opportunities

Rose A. Sevcik
& MaryAnn Ronski

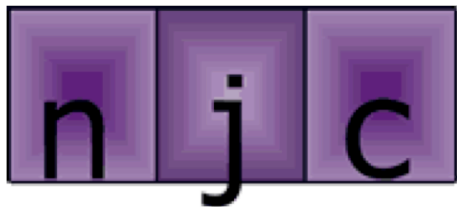
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Conference and Edited Volume

- 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.



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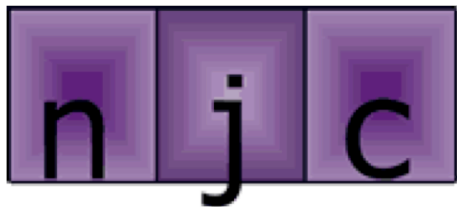
Chapter Topics

- 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.



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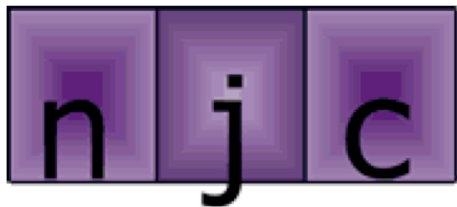
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- June 11 – 23, 2014
- “People with severe disabilities face complex communication issues, which are best met with integrated, collaborative services. After attending this conference, you’ll possess a broader context for serving this unique client while being more prepared to be an integral part of an interprofessional circle of care.”
- “This online conference will help you provide team-based 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!!

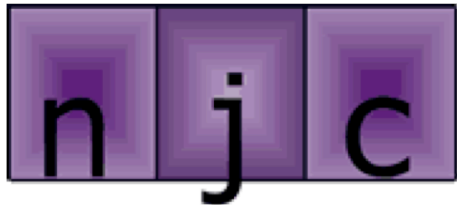


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NJC Provider/Scholar Network

Purpose: To broaden and continue
the work of the NJC

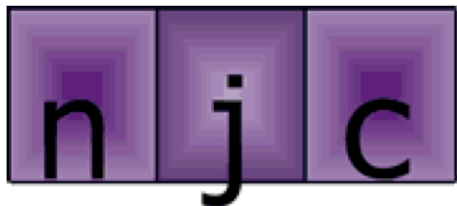


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Members will:

- 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

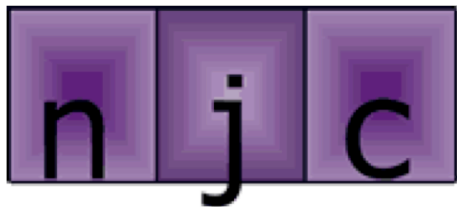


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Benefits of Joining the Network

- 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



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Join the NJC Network

<http://bit.do/b8446>

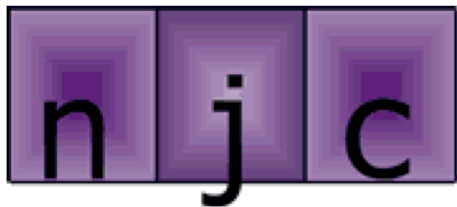


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E-Modules

- 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/b-communicators/>



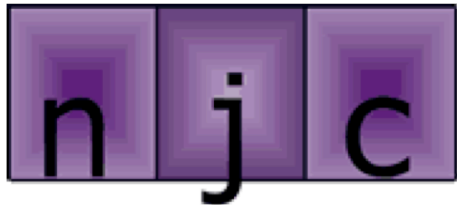
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E-Modules

- 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



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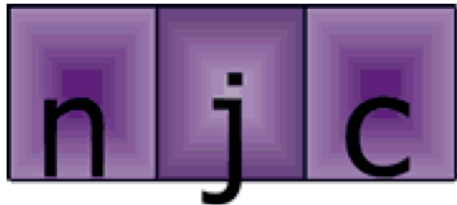
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E-Modules: Components

- Video example

<https://wcu.hosted.panopto.com/Panopto/Pages/Viewer.aspx?id=8f7690ac-54a4-41f1-b44d-bad4aedadf47>

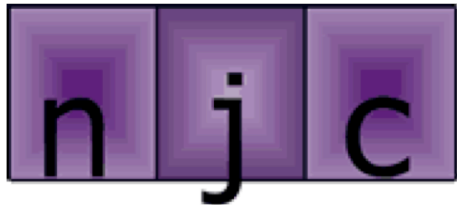
- Powerpoint
- Transcript



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AAC Myths Project

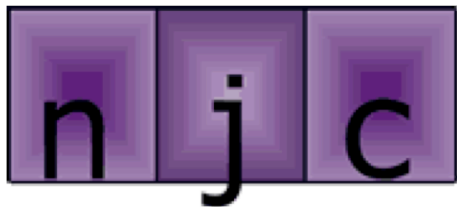


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Myths about Communication and Adults with Severe Disabilities

- 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.

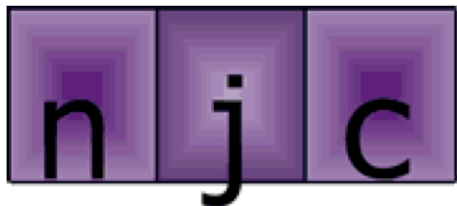


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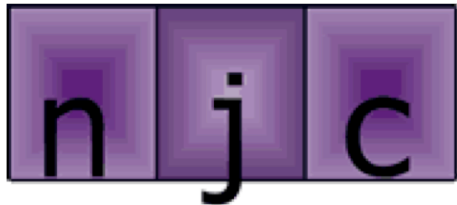
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Myths (continued)

- 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).

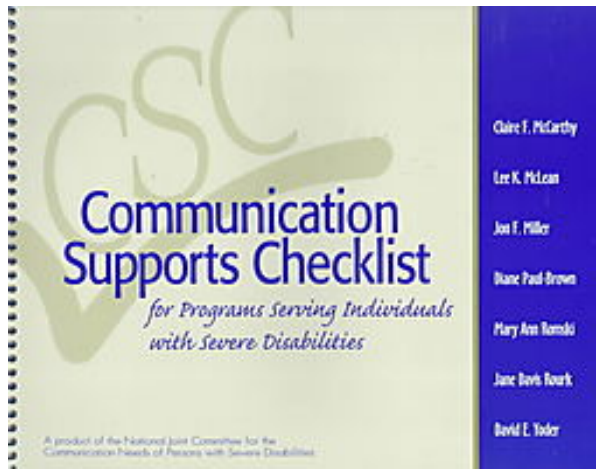


Birth of a New Tool?



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1998

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



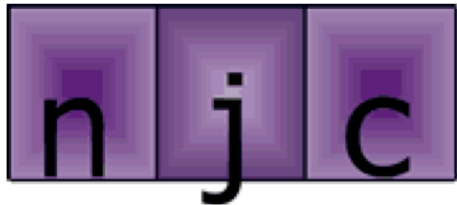
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Quality Indicators

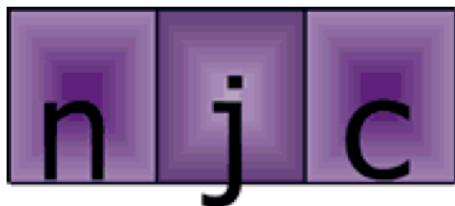


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YOUR THOUGHTS?



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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



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NEW NJC Website

WWW.ASHA.ORG/NJC



dreamstime.com



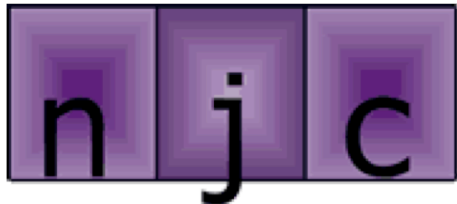
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Topic Areas

Accessing Services

- [Relation of Age to Service Eligibility](#)
- [Relation of Developmental Skills to Service Eligibility](#)
- [Decision Making in Termination of Services](#)
- [Funding for Services](#)



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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](#)



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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.



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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](#).



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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.



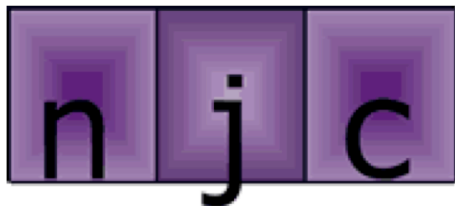
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Topic Area

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.
- Ronski, M. A., & Sevcik, R. A. (1996). *Breaking the speech barrier: Language development through augmented means*. Baltimore, MD: Brookes.



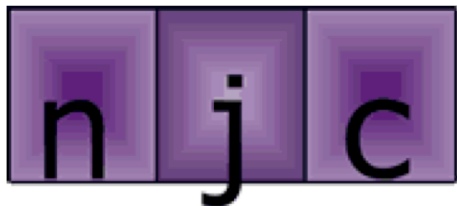
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Topic Area

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.



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Other Activities of the NJC

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



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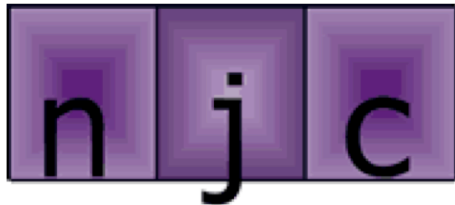
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Learn More - Join the Network

Saturday, November 19th

Noon – 1:00 PM

Room 307, Philadelphia Marriott
Downtown.



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