Highlighting Occupational Therapy's Role on the National Joint Committee for Communication Needs of Persons With Severe Disabilities

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You?

- Who are you?
- What brings you here?
- Have you heard about the NJC before?
- Are you familiar with the Communication Bill of Rights?
- Have you used the NJC web site before?

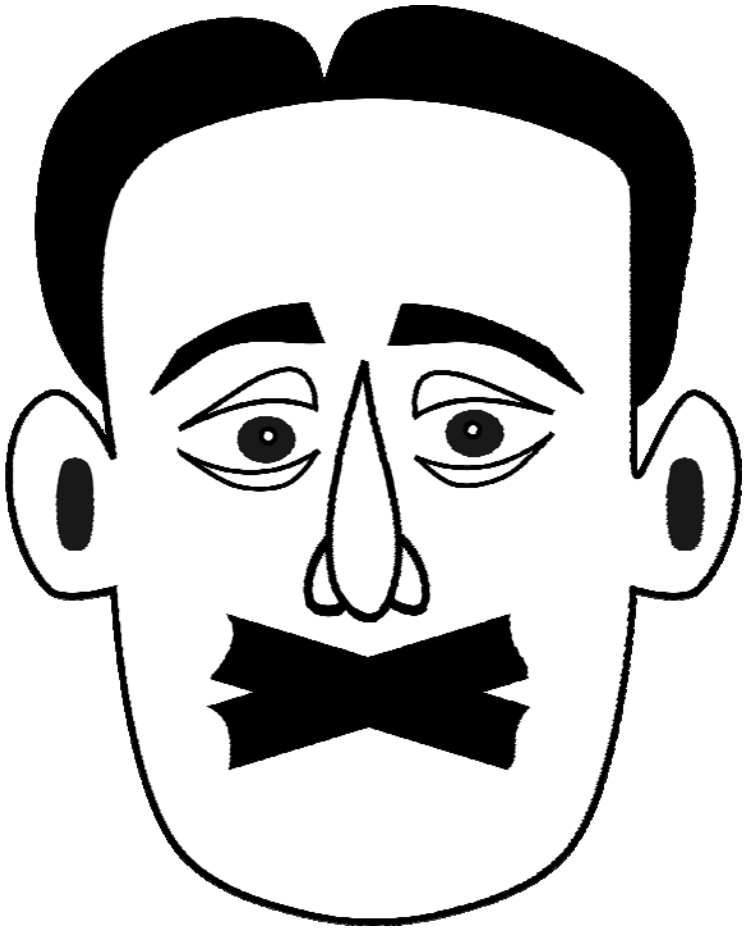


Communication: Everybody does it!



https://www.youtube.com/watch?v=_JmA2ClUvUY

But What if You Couldn't?



Think About It

"If you want to know what it is like to be unable to speak, there is a way. Go to a party and don't talk. Play mute. Use your hands if you wish but don't use paper and pencil. Paper and pencil are not always handy for a mute person. Here is what you will find: people talking; talking behind, beside, around, over under and through, and even for you. But never with you. You are ignored until finally you feel like a piece of furniture." Rick Creech

(Musselwhite & St. Louis, 1988, p. 104)



I Hate Potatoes!

"I know what it is like to be fed potatoes all my life. After all, potatoes are such good basic food for everyday, easy to fix in many different ways. I hate potatoes! But then, who knew that but me? I know what it is like to be dressed in reds and blues when my favorite colors are mint greens, lemon yellows, and pinks. I mean can you really imagine?"

Sara Brothers



"Sara's Story" Keyhole Communique 3(3), May 1989

Purpose of Today's Presentation

- Understand the mission of the National Joint Committee on Communication Needs of Persons with Severe Disabilities (NJC).
- Understand the role that occupational therapists fulfill on the NJC.
- Identify ways that knowledge about the NJC can be used and applied in clinical practice and academia.
- Identify ways that occupational therapy practitioners can contribute to the mission and work of the NJC.



AOTA
Occupational Therapy
Living Life To Its Fullest®

The Communication Bill of Rights

A Shared Responsibility

All people with a disability of any extent or severity have a basic right to affect, through communication, the conditions of their existence.

share[1]
/SHer/

verb
past tense: **shared**; past participle: **shared**

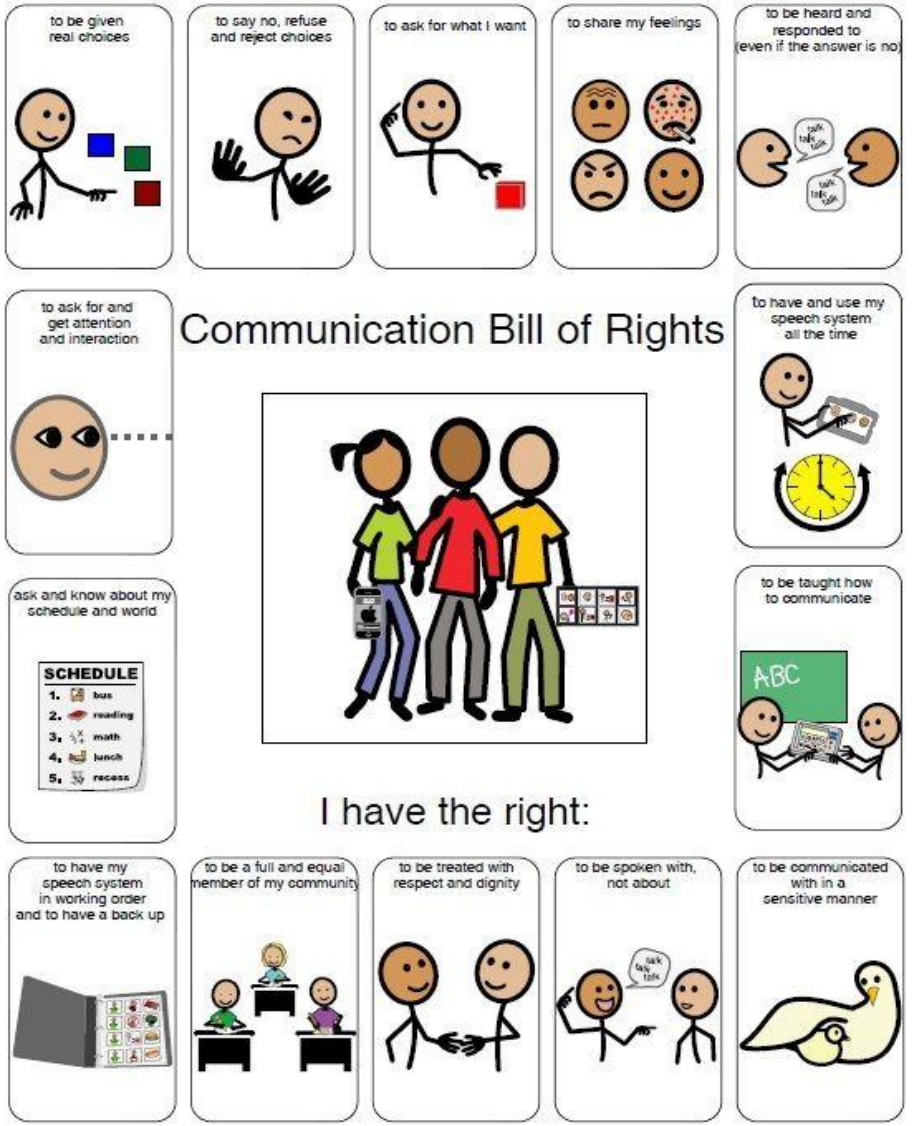
have a portion of (something) with another or others.
"he **shared** the pie **with** her"
synonyms: split, divide, go halves on; More



http://www.cbc.ca/news/technology/app-gives-voice-to-people-with-disabilities-1.1246180

Specific Rights

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.



Fundamental Rights:

To participate fully in communication interactions, each person has these fundamental communication rights:

The right to interact socially, maintain social closeness, and build relationships



The Right to Interact Socially…

Social skills: specific abilities or behaviors required to perform social tasks competently (McFall, 1982)

Social competence: ability to perform as expected on age-specific social tasks across social situations (Lim and Roger, 2008)

Social well-being: ability to demonstrate empathy, affection, and intimacy and maintaining caring relationships (AOTA, 2010).



Social Participation

- “Organized patterns of behavior that are characteristic and expected of an individual or a given position within a social system.” (Mosey, 1996).
- Very often, the ability to fully participate in a social system is dependent on the ability to use these organized patterns appropriately.
- This may be through speech, movement, postures, use of devices or other forms of support to enable participation.



Communication Influences Participation

- "Social skills often determine the quality of interaction with others." (Yun & Richardson, 2013)
- "Within the school context, the occupational therapy practitioner provides services and supports to foster development of communication skills, management of sensory needs and social skills, and facilitates adherence to rules, self regulation, and interaction with peers and adults." (AOTA, 2011)

Fundamental Rights

The right to access interventions and supports that improve communication

The Occupational Therapy Practice Framework: Domain and Process: Domain and Process

Communication and social skills are "actions or behaviors a person uses to communicate and interact with others in an interactive environment" (Fisher, 2006).



OT Needed Here?

"Augmentative Communication is often provided through Speech Generating Devices (SGDs). A wide variety of product options are available, yet all require the client to access the device itself. Access methods include direct, switch, mouse, eye gaze and more."

Webinar description:
Speech Generating Devices: Determining Access
Michelle Lange, OTR/L, ABDA, ATP/SMS



Why OT?

The Role of Occupational Therapy in Providing Assistive Technology Devices and Services

Occupational therapy practitioners' understanding of occupational needs and performance, coupled with their skills in activity analysis and focus on achieving client goals, strongly support the use of diverse types of assistive technology within models of best practice. That perspective helps identify and integrate desired features of assistive technology solutions, as well as address potential barriers to integrating assistive technology into the client's daily routines.

Developed by Beth Goodrich, OTR, ATP, PhD, and Eileen Garza, OTR, ATP/SMS, PhD, for the American Occupational Therapy Association.

OT and Assistive Technology

For 100 years, technology has been embedded as a consistent part of occupational therapy. For the next 100 years, as technology advances, occupational therapy practitioners and occupational scientists will deepen their understanding of how technology and occupation intertwine.

Roger O. Smith, OT, FAOTA
Eleanor Clarke Slagle Lecture
Technology and Occupation:
Past 100, Present, and Next 100 Years



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 History

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





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

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  Atlanta, GA

- AOTA

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- APTA

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NJC Representatives

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  Newark, Delaware

- CEC/DCDD
  Susan Bruce, PhD
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- USSAAC
  Rose A. Sevcik, PhD,
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  Georgia State University
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- 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*

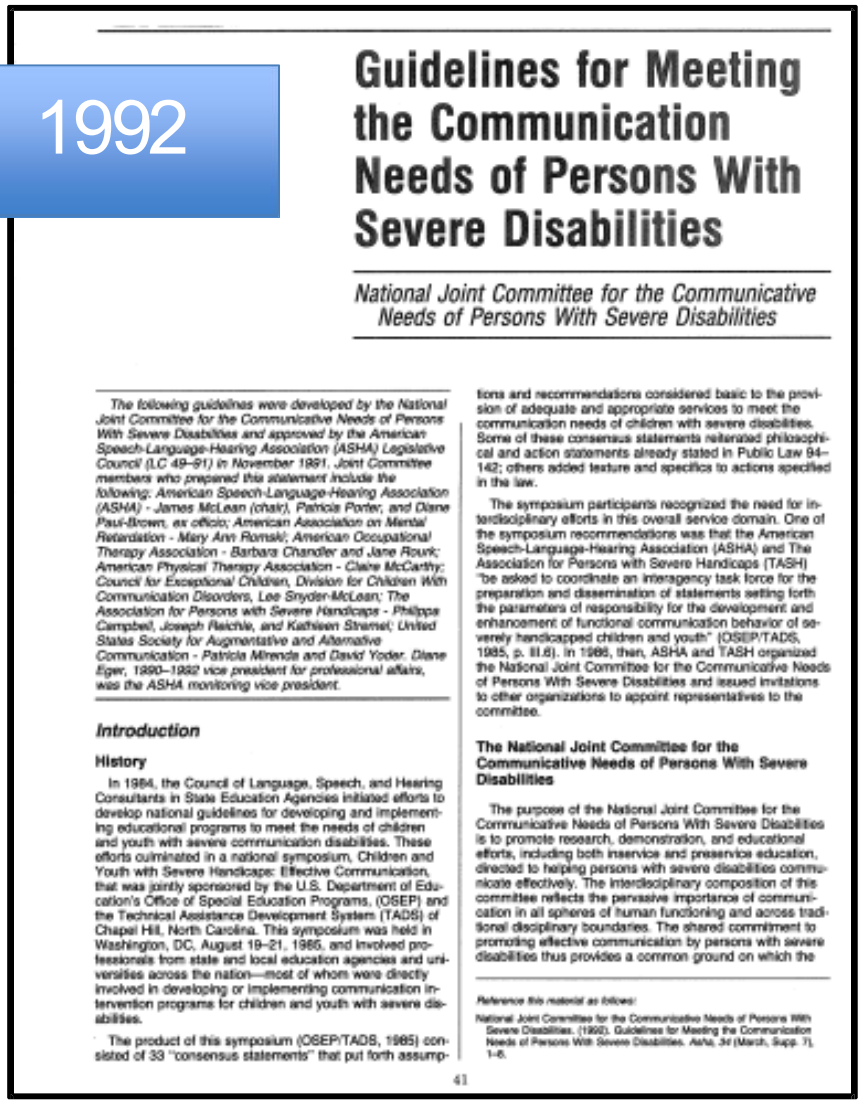
Obviously Interdisciplinary!



Judith Schoonover, AOTA; Amy Goldman, ASHA; Karen Erickson, TASH; Beth Mineo, ATAP

AOTA's History with the NJC

1992



Guidelines for Meeting the Communication Needs of Persons With Severe Disabilities

National Joint Committee for the Communicative Needs of Persons With Severe Disabilities

The following guidelines were developed by the National Joint Committee for the Communicative Needs of Persons With Severe Disabilities and approved by the American Speech-Language-Hearing Association (ASHA) Legislative Council (LC 49–91) in November 1991. Joint Committee members who prepared this statement include the following: American Speech-Language-Hearing Association (ASHA) - James McLean (chair), Patricia Porter, and Diane Paul-Brown, ex officio; American Association on Mental Retardation - Mary Ann Romski; American Occupational Therapy Association - Barbara Chandler and Jane Rourk; American Physical Therapy Association - Claire McCarthy; Council for Exceptional Children, Division for Children With Communication Disorders, Lee Snyder-McLean; The Association for Persons with Severe Handicaps - Philippa Campbell, Joseph Reichle, and Kathleen Stremel; United States Society for Augmentative and Alternative Communication - Patricia Mirenda and David Yoder. Diane Eger, 1990–1992 vice president for professional affairs, was the ASHA monitoring vice president.

Introduction

History

In 1984, the Council of Language, Speech, and Hearing Consultants in State Education Agencies initiated efforts to develop national guidelines for developing and implementing educational programs to meet the needs of children and youth with severe communication disabilities. These efforts culminated in a national symposium, Children and Youth with Severe Handicaps: Effective Communication, that was jointly sponsored by the U.S. Department of Education's Office of Special Education Programs, (OSEP) and the Technical Assistance Development System (TADS) of Chapel Hill, North Carolina. This symposium was held in Washington, DC, August 19–21, 1985, and involved professionals from state and local education agencies and universities across the nation—most of whom were directly involved in developing or implementing communication intervention programs for children and youth with severe disabilities.

The product of this symposium (OSEP/TADS, 1985) consisted of 33 "consensus statements" that put forth assumptions and recommendations considered basic to the provision of adequate and appropriate services to meet the communication needs of children with severe disabilities. Some of these consensus statements reiterated philosophical and action statements already stated in Public Law 94–142; others added texture and specifics to actions specified in the law.

The symposium participants recognized the need for interdisciplinary efforts in this overall service domain. One of the symposium recommendations was that the American Speech-Language-Hearing Association (ASHA) and The Association for Persons with Severe Handicaps (TASH) "be asked to coordinate an interagency task force for the preparation and dissemination of statements setting forth the parameters of responsibility for the development and enhancement of functional communication behavior of severely handicapped children and youth" (OSEP/TADS, 1985, p. III.6). In 1986, then, ASHA and TASH organized the National Joint Committee for the Communicative Needs of Persons With Severe Disabilities and issued invitations to other organizations to appoint representatives to the committee.

The National Joint Committee for the Communicative Needs of Persons With Severe Disabilities

The purpose of the National Joint Committee for the Communicative Needs of Persons With Severe Disabilities is to promote research, demonstration, and educational efforts, including both inservice and preservice education, directed to helping persons with severe disabilities communicate effectively. The interdisciplinary composition of this committee reflects the pervasive importance of communication in all spheres of human functioning and across traditional disciplinary boundaries. The shared commitment to promoting effective communication by persons with severe disabilities thus provides a common ground on which the

Reference this material as follows:

National Joint Committee for the Communicative Needs of Persons With Severe Disabilities. (1992). Guidelines for Meeting the Communication Needs of Persons With Severe Disabilities. *Asha, 34* (March, Supp. 7), 1–8.

41

"The level of interpersonal, interdisciplinary, and interagency cooperation required to create such facilitating and enabling communication environments and to meet personnel needs may seem, at first, to present overwhelming logistical obstacles. However, without such a commitment, there can be no true quality of life for persons with severe disabilities. This is a challenge worthy of our best efforts."

Thank you, Jane Davis Rourk

NATIONALLY SPEAKING

Roles for School-Based Occupational Therapists: Past, Present, Future

Jane Davis Rourk



The occupational therapy specialty area of school practice was relatively unknown before 1975 when the Education of All Handicapped Children Act (Public Law 94-142) was enacted. School practice consisted of a few therapists working primarily in special schools for children with orthopedic impairments, mental retardation, and blindness or deafness. These facilities were usually residential institutions organized on a medical model of services that focused on curing and training the residents. The educational services in these facilities were often inferior to those offered in public schools.

The Education for All Handicapped Children Act provided funds to assist state and local educational agencies in educating students with disabilities, resulting in increased employment opportunities for occupational therapists in school systems. Now, 20 years later, approximately 18.7% of occupational therapists provide services in school settings either as salaried employees or through contractual arrangements (American Occupational Therapy Association [AOTA], 1995).

The passage of the Education for All Handicapped Children Act produced a diverse public school population that resulted in new conceptualizations and practices for special educators and school-based occupational therapists. As well, both professional groups faced new roles, responsibilities, and colleagues. This legislation was amended in 1990 by the Individuals With Disabilities Education Act (IDEA, Public Law 101-476).

The first occupational therapists working in school systems brought with them the practice approaches they had used in hospitals and rehabilitation facilities. These were usually individual, one-on-one, direct treatment approaches that used a medical orientation of curing or fixing the student's deficit (the weak performance component), such as visual–motor problems, that prevented him or her from successfully performing a task, such as handwriting. Additionally, therapy services of the past tended to be provided in isolated or special locations away from the classroom. In fact, a therapist new to school practice often requested that a separate room be provided in which he or she could administer assessments and provide treatment. In some settings, the space made available was not the well-equipped therapy room envisioned, but a broom closet, the auditorium stage, the hallway, or a corner of the cafeteria or gymnasium.

School-based therapists soon recognized that this medically oriented approach, as well as their pull-out delivery of services, was interfering with rather than supporting the educational process. Removing students from the classroom not only fragmented the school day, but also did little to aid the student to benefit from special education as mandated under IDEA. Lessons and educational instruction missed while out of the classroom for therapy could put students at additional academic risk. New approaches to service delivery were required that focused not only on the remediation of performance component deficits, but also on assisting students to function successfully in the school environment.

School-based therapists also recognized that in writing individualized education programs (IEPs), which are required by IDEA, they had to shift from including therapy goals and objectives that would develop or remediate performance components to using those that were educationally relevant. This was a challenging task because most pediatric standardized and criterion-referenced tests focused on identifying the deficits or underlying causes that prevented a student from accomplishing a task. Therapists felt caught between the

Jane Davis Rourk, OTR/L, FAOTA, is Clinical Associate Professor, Occupational Therapy Division, University of North Carolina at Chapel Hill, CB #7335, Trailer 49, Chapel Hill, North Carolina 27599, Consultant for Occupational Therapy Services, Exceptional Children Division, North Carolina Department of Public Instruction, Raleigh, North Carolina, and is Guest Editor for this special issue on school-based practice.

This article was accepted for publication July 29, 1996.

As a member of the NJC in 2004, developed a set of frequently asked questions for consumers/parents and professionals related to communication services and supports for persons with severe disabilities (available on the NJC website).

Updated

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

Nancy C. Brady, Susan Bruce, Amy S. Goldman, Karen Erickson, Beth Mineo, Billy T. Ogletree, Diane Paul, MaryAnn Romski, Rose A. Sevcik, Ellin Siegel, Judith Schoonover, Lorraine Sylvester, Mari Therrien, and Krista Wilkinson

COMMUNICATION BILL OF RIGHTS

1992



- NJC publishes the Communication Bill of Rights
- Supports rights of all individuals as effective communicators
- Widely used to advocate for communication services and supports for persons with severe disabilities

Revision Descriptions

- Clearer, simpler statements
- Broader range of potential communication abilities (comments, opinions)
- More inclusive of communication used to promote socialization

2015



- NJC revises the Communication Bill of Rights
- Reflects contemporary perspectives on communication and disability

Uses for Practitioners

- Advocate for communication services and supports
- Promote inclusive opportunities
- Encourage broader community acceptance

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

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NJC Guidance

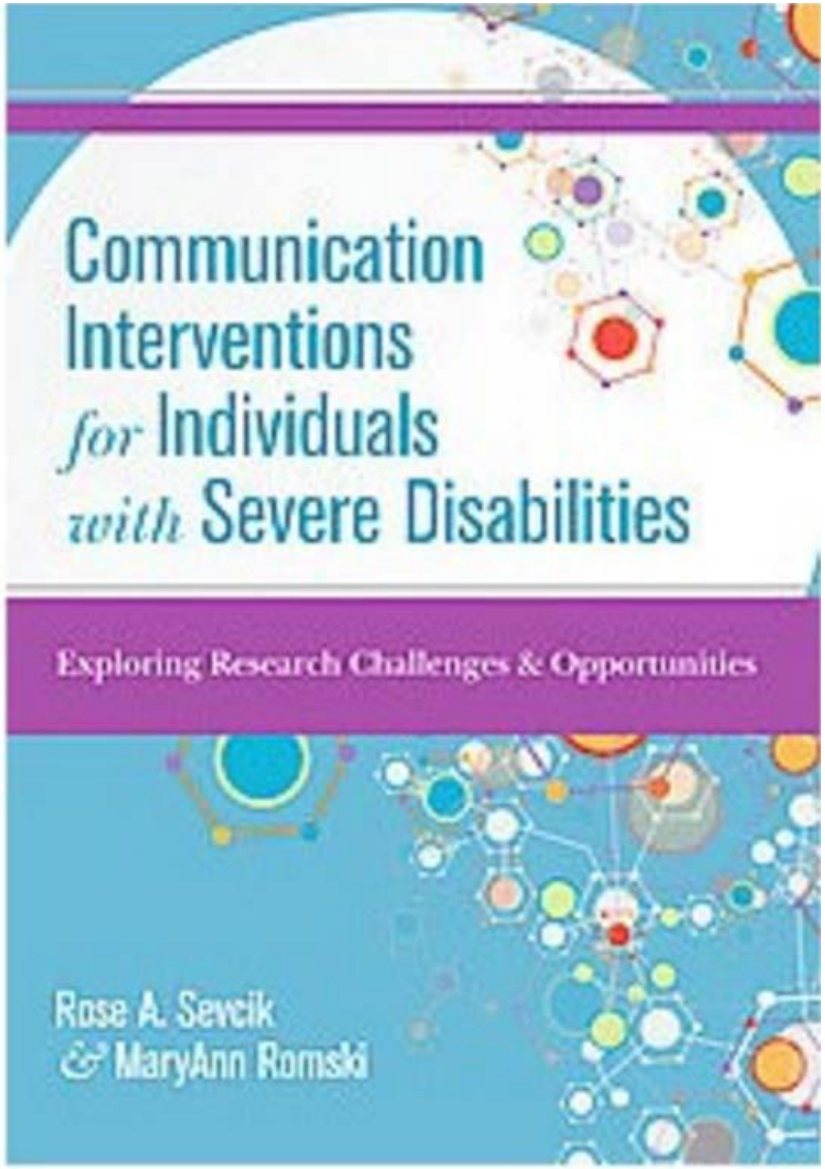
AMERICAN JOURNAL ON INTELLECTUAL AND DEVELOPMENTAL DISABILITIES
2016, Vol. 121, No. 2, 121–138

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

New book from Brookes Publishing



- Prelinguistic communication Interventions
- Challenging behavior and communicative alternatives
- Interventions for children who are deafblind
- Augmented language interventions
- Parents as partners in communication intervention
- Role of cultural, ethnic, and linguistic differences
- Targeted and phenotypic communication interventions for children with Down syndrome or ASD
- Research study design issues (sample size, randomized controlled trials, and integrating single-case and group designs)
- Assessment and measurement of communication and language skills

Conference and Edited Volume

- Research Conference (6/2011) funded by the National Institute on Deafness and Other Communicative Disorders (NIDCD).
- Resulted in an interdisciplinary book
  - 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 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.



- June 11 – 23, 2014
- People with severe disabilities face complex communication issues, which are best met with integrated, collaborative services.
- Online conference geared toward the development of 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!



E-Modules



- Support 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/beginning-communicators/

E-Modules

- Focus on people (all ages) with IDD with severe disabilities *and their communication partners*
- New opportunity to access assessment and intervention content:
  - Non-symbolic communicators
  - Emergent symbolic communicators
  - Symbolic communicators
  - Literacy

E-Modules: Components

- Narrated, online, on-demand via NJC web site
- Includes video examples
- Access materials to facilitate or deliver the training yourself:
  - PowerPoint
  - Transcript
  - Movie files

NJC Myths Project

- 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

What's new?

Quality Indicators

Your thoughts?



MYAPE

McLean Yoder Award for Professional Excellence (MYAPE)

Exemplifying high quality professional service to individuals with severe disabilities

- 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

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

The purpose of the NJC is to advocate for individuals with significant communication support needs resulting from intellectual disability, that may coexist with autism, sensory and/or motor limitation. The NJC is made up of representatives from eight member organizations, and focuses on research, policy, practice, and education. Read the history of the NJC.

Announcements

NJC Network
The NJC Network is a group of professionals with a common interest in enhancing communication effectiveness for individuals with severe disabilities. Joining the network doesn't involve cost or any specific obligation. You'll hear about NJC networking opportunities. Join the NJC Network!

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

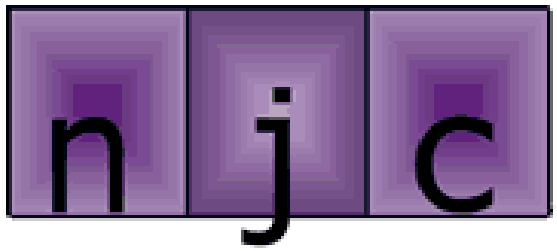
- NJC HOME PAGE
- HISTORY OF THE NJC
- NJC ORGANIZATIONS
- CONTACT INFORMATION
- NJC FEEDBACK FORM

http://asha.org/njc

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: Drilling Down

Accessing Services

Relation of Age to Service Eligibility

On This Page

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

Return to the NJC Topic List

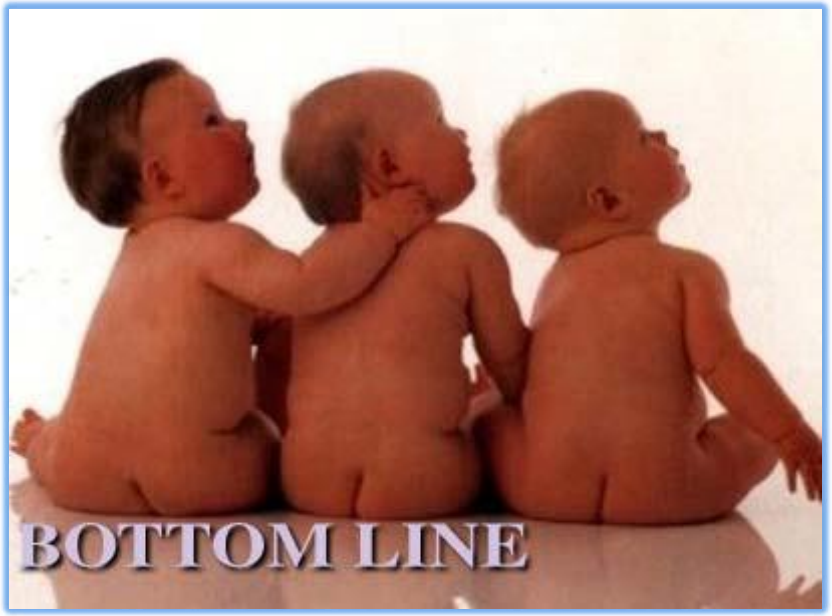


Topic Area: Relation of Age to Service Eligibility

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.

Services Birth-to-3



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 Areas

Intervention Issues and Practices

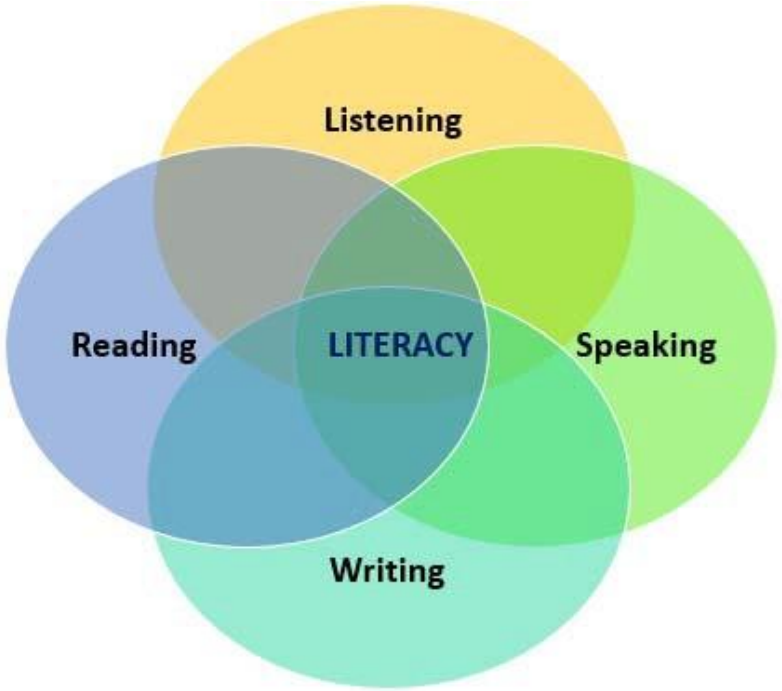
- Applied Behavior Analysis and Communication Services
- Assessment and Teaming
- Augmentative and Alternative Communication
- Challenging Behavior as Communication
- Definition of Communication and Appropriate Targets
- Evidence-Based Practice
- Inclusion and Interactions with Friends Without Disabilities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

Topic Area

Literacy in Individuals with Severe Disabilities:

A variety of research and development efforts over the past two decades confirms that individuals with the most significant disabilities can learn to read and write.

- Emergent Literacy
- Reading and Writing
- Assessing Literacy
- Literacy Instruction



Literacy and OT



The Pittsburgh AAC Language Seminar Series provides the help you need to support language development with children and adults using Minspeak systems.

With almost 25% of occupational therapists working in early intervention and school settings (AOTA, 2015), their role of facilitating literacy (e.g., reading, writing, speaking and listening) is critical. Occupational therapy practitioners support the development and growth of literacy at the system, home or school, and individual levels.

The occupations of literacy: Occupational therapy's role
Gloria Frolek Clark PHD, OTR/L, SCSS, BCP, FAOTA
Journal of Occupational Therapy, Schools, & Early Intervention
Volume 9, 2016 - Issue 1: Focus On: Pre-Literacy and Literacy

Other Activities of the NJC

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





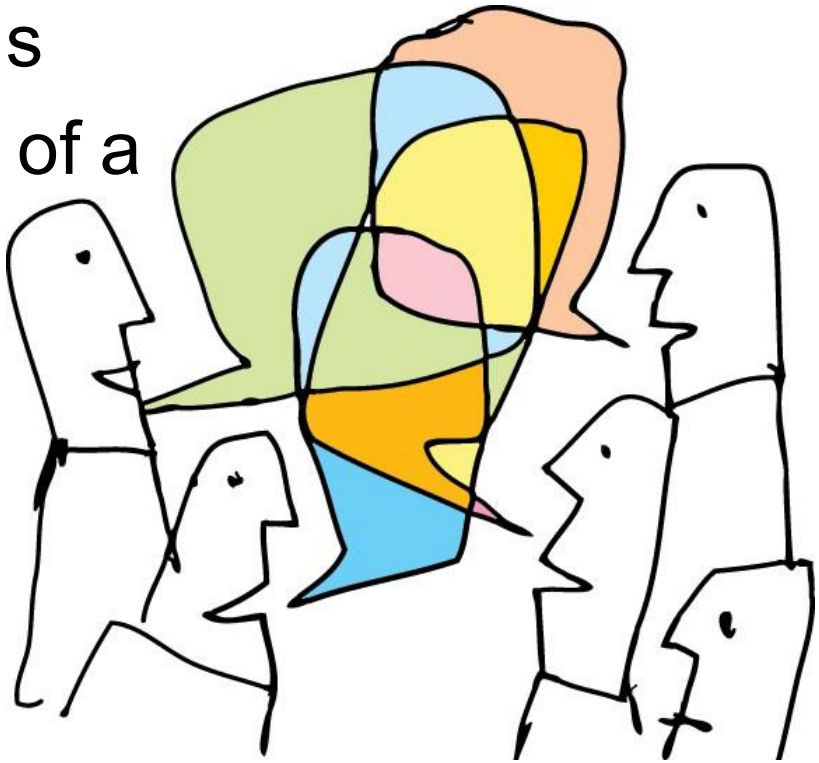
Join the Network

The purpose of the **NJC Network** is to build a network of researchers, clinicians, and other professionals who are interested and engaged in work addressing the communication needs of persons with severe disabilities in order to broaden and continue the work of the NJC.

http://bit.do/b8446

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



Why AOTA should have a place at the table?

Occupational engagement is an important aspect of daily life. Individuals whose circumstances challenge their ability to engage in the occupations of daily life and with other individuals can benefit from the perspective, skills and efforts of occupational therapy practitioners to promote engagement in the community of people.



Can We Talk?



njc

Thank You for Attending!