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Communication Services and Supports for Individuals with Severe Disabilities: Guidance for Assessment and Intervention

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Abstract

The National Joint Committee for the Communication Needs of People with Severe Disabilities (NJC) reviewed literature regarding practices for people with severe disabilities in order to update guidance provided in documents originally published in 1992. Changes in laws, definitions, and policies that affect communication attainments by persons with severe disabilities are presented, along with guidance regarding assessment and intervention practices. A revised version of the Communication Bill of Rights, a powerful document that describes the communication rights of all individuals, including those with severe disabilities is included in this article. The information contained within this article is intended to be used by professionals, family members, and individuals with severe disabilities to inform and advocate for effective communication services and opportunities.

People with severe intellectual disabilities are more present and visible in today's society than ever before, yet these individuals continue to have significant communication support needs that remain unmet. In 1992 the National Joint Committee for the Communication Needs of Persons with Severe Disabilities (NJC) published guidelines aimed at addressing these needs. Since then, important changes have occurred in United States federal and state laws and recommended practices. An increasing evidence base about communication for individuals with severe disabilities exists. The areas of greatest change include assessment, goal selection, interventions to improve communication, interventions to improve environmental supports for communication, and service delivery. In the current document we have summarized what is still applicable from the 1992 guidelines and then updated the content to reflect findings and policy changes over the last 22 years. In addition, we have updated and included the widely cited Communication Bill of Rights, a powerful interdisciplinary statement relevant for professionals, families, self-advocates, policy makers, and peers. Although many of the guiding principles presented in the original documents remain current, this update reflects contemporary laws and new practices that have proven beneficial in promoting communication. This document is intended to guide practitioners and family members toward implementing current evidence-based practices.

What is the NJC?

The NJC is an interdisciplinary group representing nine diverse organizations that support the communication of individuals with severe disabilities (see Table 1). The purpose of the

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NJC (www.asha.org/NJC) is to advocate for individuals with significant communication support needs resulting from intellectual disability that may coexist with autism spectrum disorder, sensory and/or motor limitations. The interdisciplinary composition of this joint committee reflects the pervasive importance of communication in all spheres of human functioning and across traditional boundaries. The shared commitment to promoting effective communication by persons with severe disabilities thus provides a common ground on which the professionals across diverse disciplines can unite in their efforts to improve the quality of life for individuals with such disabilities. The members of the NJC contribute expertise in direct service for children and adults with significant communication support needs, public policy, advocacy, personnel preparation, professional development, applied research on effective communication intervention strategies, and basic research on communication and processing.

One goal of the NJC has been to promote communication services for all individuals with unmet communication needs. NJC eligibility documents (NJC, 2002, 2003) stress the need for services to be based on individual communication needs rather than arbitrary criteria (e.g. the individual is too old, too young, or too “disabled”). Furthermore, the NJC conducted a comprehensive review of the evidence for the efficacy of communication interventions (Snell et al., 2010) and found that 96% of the intervention studies reported positive change in varying degrees in the communication behavior of individuals with severe disabilities. Although there were limitations in the studies reviewed, there is strong support for the efficacy of communication interventions for persons with severe disabilities. The NJC continues to be actively engaged in efforts to inform effective practice. For example, with support from the National Institute of Deafness and other Communication Disorders, the NJC convened a research conference in 2011 (www.cas.gsu.edu/njc/con_materials.html) that summarized the results of the comprehensive review and set the stage for further research aimed at addressing measurement and design challenges that confront researchers investigating communication needs and interventions for individuals with severe disabilities (Sevcik & Romski, in preparation).

The following sections of this paper present updated guidelines for assessing communication and intervening to improve communication for persons with severe disabilities. Although assessment and intervention are often intertwined and co-occurring, with common guiding principles, we have separated the content for ease of presentation. Our intent is that this document will be a resource for advocates, including interventionists and family members. As such, it provides an authoritative source to ensure that the communication rights of individuals with severe disabilities are acknowledged, respected, and supported (insert table here).

Communication and Individuals with Severe Disabilities

Communication is both a basic need and a basic right of all human beings (American Speech-Language-Hearing Association, 2014; United Nations, 2008). Table 2 describes the Communication Bill of Rights, which extends the original NJC Bill of Rights (NJC, 1992) to reflect current perspectives. Any consideration of quality of life must take into account the degree to which individuals can effectively communicate with, and thus be full participants

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in, the community in which they live. Even individuals who may appear to demonstrate purposeful communication ("unintentional" communicators) can be perceived as potential communicators because their behavior is interpreted by the listener as communicative (Ogletree, Bartholomew, Wagaman, Genz, & Reisingner, 2012; Reichle & Brady, 2012; Sigafoos, et al., 2000).

Communication may involve conventional or unconventional signals, may take linguistic or nonlinguistic forms, and may occur through spoken or other modes. Thus, all persons do communicate in some way; however, the effectiveness and efficiency of this communication vary with a number of individual and environmental factors. The contention that all people, even those with the most severe disabilities, "communicate" suggests that every individual can, willingly or otherwise, impact others by behaviors interpreted as expressions of purpose. Some individuals with severe disabilities develop unconventional and highly individualized or idiosyncratic means to communicate. For example, an adult with severe disability who shows signs of irritation, moving her head back and forth when offered an object, can be understood by a competent communicative partner as protesting even if her behavior does not meet accepted criteria for communicative intent (e.g., persistence, alternating gaze between the object and the communicative partner, repair, or termination of the signaling once the goal is achieved (Bates, 1976). Downing and Flavey (2015) state that the assumption that all people communicate is appropriate in that it errors on the side of inclusiveness and respect for all individuals. Further, this assumption contributes to a sense of responsibility on the part of all persons who interact with individuals with severe disabilities to recognize all potential communication acts and to seek ways to promote communication effectiveness.

Evolving Definitions and Perspectives on "Severe Disabilities"

Prior to 1992, a number of legal mandates and philosophical shifts transformed the approach to services for individuals with disabilities, beginning with the *Education for All Handicapped Children Act* (PL 94-142, 1975), the *Individuals with Disabilities Education Act* (1990, amended in 1997, 2004), and the *Americans with Disabilities Act* (PL 101-336, 1990, amended in 2008). In 1992, when many of these legal mandates were already established or well underway, the NJC published its original guidelines for supporting the communication needs of individuals with severe disabilities. In the decades since that original report, however, significant changes have occurred in the recommended procedures for identifying, diagnosing, and serving such individuals--changes that reflect important shifts in philosophies concerning disability.

Definitions of "Severe Disabilities."

Important changes have occurred in the ways that severe disabilities are defined. Three organizations have classification systems that are often used in the process of defining, diagnosing, and characterizing intellectual disability: (a) American Association on Intellectual and Developmental Disabilities (AAIDD, formerly the American Association on Mental Retardation or AAMR); (b) American Psychiatric Association (APA), publishers of the Diagnostic and Statistical Manual of Mental Disorders (DSM); and (c) World Health Organization (WHO), which produces both the International Classification of Disease (the

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ICD governs recommendations about definitions and diagnosis of health conditions), and the International Classification of Functioning, Disability and Health (ICF makes recommendations for classification after diagnosis of disability conditions).

In 1992, the definition of what was then called "mental retardation" was considered by both the APA and the WHO to involve two components: onset in childhood, and presence of significant limitation in measured IQ functioning. The classification of the level of disability was based on a level of deficit and measured as *mild*, *moderate*, *severe*, or *profound*. Reflecting a widespread shift in terminology, all three organizations have moved from the term "mental retardation" to the use of some variant on "intellectual and developmental disabilities." In this same year the AAMR (now the AAIDD) introduced a fundamental shift away from a deficit-based approach to both diagnosis and classification. Under the AAMR/AAIDD definition, diagnosis required not just childhood onset and limitations in intellectual functioning, but also the presence of limitations in adaptive behaviors. In the 2002 and 2010 updates, the classification system shifted even further away from a deficit-based approach to one which reflects how competence is a situational construct, impacted by a person's communication, sensory, motor, and behavioral characteristics as well as the demands, and supports associated with the environments with which they interact.

This shifting perspective is further reflected in both the fifth edition of the *Diagnositic and Statistical Manual of Mental Disorders* (DSM-5; American Psychiatric Association, 2013) and WHO ICD-11 definition and classification guidance (publication pending 2015); however, there are some important variations across the two systems. Consistent with AAIDD's definition, the DSM-5 focuses on adaptive behavior (referred to as adaptive functioning) in conceptual, practical, and social domains without specifying the age of onset (developmental period). The DSM-5 includes a severity rating and uses the phrase "intellectual developmental disorder." In contrast, reports from the working group on intellectual disability for the WHO ICD-11 suggest that it will incorporate adaptive functioning in the definition; however, it appears that the WHO ICD-11 classification recommendations may still retain terms reflecting level of deficit (mild/moderate/severe/profound) rather than a support-based system (Carulla et al., 2011; http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3188762/).

These evolving definitions, classifications, and perspectives of severe disabilities influence assessment and treatment processes, which have traditionally focused on remediating deficits identified by professionals (Breen, Green, Roarty, & Saggers, 2008) who often consider an individual's needs through the lens of their particular scope of practice. For example, the medical model, which influenced clinical perspectives and practices for so long, viewed disability as arising from the deficits secondary to an individual's medical condition or health-related diagnosis. Consequently, the focus of assessment was to identify the problems originating from the individual's condition and attempt to *cure* them, or at least reduce the negative impact of the problems on the person's functioning.

A significant driver of our evolving perspective—sometimes referred to as the "new paradigm of disability" (National Institute on Disability and Rehabilitation Research, 1999)—has been the WHO's ICF (WHO, 2001). This framework promotes much more holistic

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consideration of “disability” as the result of interactions among the person and the environments in which she or he functions. Personal characteristics such as body functions (e.g., mobility, hearing, speech production, and understanding) and body structures (e.g., limbs, mouth, larynx, brain) are considered in the context of the activities in which the individual engages (e.g., listening, singing, conversing) and the extent to which she or he is able to participate fully in those activities. In a major departure from the medical model, however, the ICF bio-psychosocial model also considers environmental factors that either hinder or facilitate participation. These factors include the design of the built environment, the knowledge, skills, and attitudes of those who interact with or have some influence on the individual, and the policy landscape. According to Simeonsson (2009), fundamental elements of this new paradigm are its (a) holistic view of the person; (b) focus on function over impairment; and (c) conceptualization of disability as a disablement process defined by a person’s interaction with the environment over time.

The influences of this new paradigm on assessment and intervention practices are game-changing. First, the new paradigm requires that assessment and intervention practices are person-centered, occurring only in the context of a particular individual’s health profile, needs, wants, preferences, goals, culture, and customary environments (including the people with whom he interacts). Culture, values, and preferences that are important to the person and the family must help to determine the design and course of assessment and intervention. Furthermore, this paradigm ensures that stakeholders consider ways that the environment poses barriers to effective communication, leading to interventions that target the environment for modification. This could involve changes to the physical environment, training of caregivers to recognize and respond to unconventional communication strategies, or advocacy to eliminate discriminatory policies regarding access to funding or opportunities for participation. Finally, it provides a common framework to which a multitude of professionals can contribute, increasing the likelihood that all will coalesce around the goal of improved function and participation. In some exciting explorations of how the ICF might directly impact service delivery, several teams have begun devising taxonomies of classification codes related to communication and applying these codes to describe participation of individuals with significant communication support needs (e.g., Pless & Granlund, 2012; Rowland et al., 2012; Simeonsson, Bjorck-Akesson, &, 2012; WHO, 2007). Further implications are implicit within the changes in assessment and intervention practices highlighted in the following sections.

Assessment Guidance

Assessments provide information leading to effective intervention planning as well as monitoring changes. Assessment that promotes the basic right to communicate begins with the implementation of procedures that inventory and describe the individual’s communication abilities, the skills, needs, culture, and behaviors of their communication partners, and the communication supports and demands presented by different environments. These efforts are accomplished best when conducted by collaborative teams that actively engage and incorporate caregivers and other significant and constant communication partners using dynamic methodologies. Assessment is structured to determine what supports are in place and what supports are still needed to maximize

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participation in meaningful activities. Optimal assessments occur in natural contexts across multiple settings, consider an individual's culture and preferences, and result in findings that identify strengths and needs of individuals and their partners (Crais, 2011; Wilcox & Woods, 2011).

Given the complex and multiple needs of individuals with severe disabilities, communication assessment is dependent upon important information about the whole individual, including information about the individual's sensory needs and abilities (e.g., vision and hearing evaluation results) and motor needs and abilities (e.g., range of motion, strength, and positioning). In the sensory realm, team members consider acuity, perception, and integration across domains of hearing, vision, and kinesthetics. Motor assessments consider strength, range of motion, tone, and the extent of voluntary control as well as the effect of positioning on these areas. Results from sensory and motor assessments may influence other areas of communication assessment. For example, results of a vision assessment may identify optimal appropriate placements of materials and communication partners. Similarly, results of motor assessments may identify optimal positions for voluntary movements. Failure to identify and accommodate for these factors during assessment and intervention may result in misinterpretations or inaccurate conclusions about an individual's communication abilities.

Procedures for assessment of communication are multifaceted, addressing both receptive and expressive communication and encompassing all modes-oral, gestural and visual. The ongoing assessment process involves multiple tools and results in data that are reliable, socially valid, and sensitive to cultural and linguistic diversity. Ethical and effective assessment relies upon the assessor's knowledge regarding current instruments and practices, including an ever-growing number of assessment instruments that adhere to the recommended principles described above. For example, Crais (2011) describes assessment processes and instruments for young children that incorporate families and meaningful activities. Brady and colleagues (2012) provide an evidence-based tool for describing both conventional and unconventional expressive communication observed during structured activities. The *Communication Matrix* (Rowland, 2011) and the *Inventory of Potential Communication Acts* (Sigafoos et al., 2000) are two tools that capitalize on the knowledge of familiar partners to obtain information about how an individual communicates in daily interactions. Assessment of the communicative functions of challenging behaviors are based on behavioral methods such as functional analysis (Hanley, Iwata, & McCord, 2003; Koegel, 2000).

Whereas formal assessments that produce standardized measures have questionable validity for persons with severe disabilities (Bruce, 2011; Venn, 2007), informal instruments and procedures are particularly valuable because they are often applied within frameworks that allow for broad-based consideration of individuals and the contexts in which they live and communicate. For example, the *tri-focus framework* organizes assessment and intervention with emphasis on the individual, communication partners, and environments (Siegel & Cress, 2002; Siegel & Wetherby, 2006). *Ecological inventories* can be used to describe how an individual with severe disabilities accesses and responds to current environments and activities, as well as to identify potential opportunities for participation by referencing the

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demands of current and future communication environments (Beukelman & Mirenda, 2013; Mohsin, 2011; Reichle, York, & Sigafoos, 1991; Snell & Brown, 2011). Tools, such as a cultural competence checklist (ASHA, 2010), may be used to determine whether service delivery addresses the needs of individuals from diverse cultural and linguistic backgrounds.

In contrast to static assessments that identify how an individual currently performs, dynamic assessments identify the individual's potential to learn new knowledge and skills when provided with appropriate support (Boers, Janssen, Minnaert, & Ruijssenaars, 2013; Overton, 2011). Dynamic assessments integrate teaching, prompting, and feedback to identify barriers to learning and instructional approaches and strategies that support the individual to be successful. As such, the quality of interactions shared between the assessor and the individual is a central focus of dynamic assessment (Crais, 2011; Olswang, Bain, & Johnson, 1992). Dynamic assessment may be a less biased form of assessment for learners who are culturally or linguistically diverse because it considers the individual's responses to different learning situations rather than static performance on standardized tasks (Kritikos, 2009). For example, in *child-guided assessment*, the assessor modulates and continually adjusts expectations according to the child's actions, responses, preferences, and level of alertness (Nelson, van Dijk, McDonnell & Thompson, 2002; Nelson, van Dijk, Oster, & McDonnell, 2009). Outcomes of child-guided assessment include information about the skills, instructional support needs, and contextual accommodations necessary to promote optimal learning.

Person centered planning (PCP) is an assessment and intervention planning process that actively engages the individual with disability in collaboration with others, to identify valued outcomes and a plan toward their achievement (Cohen & Spenciner, 2010; Reid, Everson, & Green, 1999). Grounded in values such as reducing isolation, building friendships, and promoting respect for the individual (Holburn, 2001), PCP focuses on what matters to the individual, as well as what matters to those who interact most often with the individual (i.e., those in her or his circle of support). PCP assessment approaches often involve mapping procedures, which are used to collaboratively identify preferences held by the individual with severe disabilities as well as their interaction partners (Reid, Everson, & Green, 1999). PCP assessments are highly valued by parents and professionals (Crais, Roy & Free, 2006).

Intervention Guidance

Communication intervention is any systematic effort to improve how individuals understand the communication of others and express themselves. In the following paragraphs, themes of continuing importance from the original NJC guidelines (1992) are reinforced and extended to reflect recent research and evidence-based practices aimed at improving communication within naturally occurring contexts. Over the past 20 years, intervention approaches have evolved with regard to who intervenes, what is targeted, where intervention occurs, and how to measure progress. However, a lingering concern is that few interventions address the role of comprehension as well as production (Brady, 2000; Sevcik & Romski, 2002; Snell et al., 2010). Interventions are needed to improve an individual's ability to understand communication in various forms, within a variety of contexts, and from a variety of

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communication partners. However, due to a lack of research focus in the area of comprehension, the following discussion is limited to interventions aimed at improving expressive communication.

Who provides intervention?

As emphasized in the 1992 NJC Guidelines, communication assessment and intervention must involve significant people and meaningful contexts across multiple environments. It is critical that those supporting an individual with severe disabilities share a common perspective on communication behavior. This can be an outgrowth of inter-professional education (IPE) provided in either pre-service or in-service instructional formats. IPE is described by Barr, Koppell, Reeves, Hammick, and Freeth (2005) as instruction that transcends discipline-specific methodologies through learning alongside and from representatives of other disciplines. Systematic reviews of IPE have been generally supportive, reporting training benefits such as increased knowledge specific to collaborative practices, fewer clinical errors, improved care management, the generation of positive and collaborative treatment cultures, and improved patient satisfaction (Hammick, Freeth, Koppel, Reeves, & Barr, 2007; Lapkin, Levett-jones, & Gilligan, 2013; Reeves, Zwarenstein, Goldman, Barr, Freeth et al., 2010). Although IPE is appealing, it presents specific challenges. Constraints related to time, costs, scheduling conflicts at the pre-service level, and the matching of participants by skill/knowledge level have all been raised (Abu-Rish, Kim, Chloe, Varplo, Malik, et al., 2012; Ogletree, in submission). In spite of potential challenges, IPE should be considered as an innovative vehicle to prepare all providers to address communication needs of individuals with severe disabilities. For example, Sonnenmeier, McSheehan, and Jorgensen (2005) developed a collaborative team model in which members work together to identify needed supports and strategies aimed at improving communication and increasing participation within the general education classroom.

As instruction has moved to more natural contexts, the individuals within those contexts have gained increasingly important roles as instructors and partners. Generalization is promoted when multiple communication partners are involved as intervention agents (Koegel, 2000; Schlosser & Lee, 2000; Snell, Lih-Yuan, & Hoover, 2006). Thus, the strategies outlined in the previous paragraph about IPE are critical for promoting instruction and communication facilitation with multiple “teachers” and across multiple environments. Classroom teachers and school personnel have become more effective communication partners (Douglas, Light & McNaughton, 2012; Kent-Walsh & McNaughton, 2005; Kent-Walsh, Stark, & Binger, 2008). Studies have also shown that parents, siblings, and caregivers can be effective communication partners and teachers across the lifespan (Cheslock, Barton-Hulsey, Romski, & Sevcik, 2008; Skotko, Koppenhaver, & Erickson, 2004).

Intervention targets

Historically, intervention approaches put more emphasis on communication forms than communication functions and provided intervention in isolated settings (for a review and analysis see Snell et al., 2010). More recent research has further documented the effectiveness of various procedures for teaching initial functional communication repertoires

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to individuals with severe disabilities including autism (e.g., Duffy & Healy, 2011; Kasari et al., 2014; Olsson & Granlund, 2002; Reichle, Cooley Hidecker, Brady, & Terry, 2003; Sigafoos et al., 2008; van der Meer et al., 2014). While the approaches taken by these research studies reflect different philosophies and teaching strategies, they all emphasize an important aspect of communication intervention-establishing a repertoire of communication responses.

There is extensive evidence in support of teaching requesting in the literature (e.g., Ganz & Simpson, 2004; Lancioni et al., 2007), while fewer studies have documented strategies to teach other functions such as commenting, greeting, or asking information (Duffy & Healy, 2011). In a number of descriptive studies, Brady and colleagues reported that participants with severe disabilities infrequently commented or greeted during assessments, even when specific opportunities were provided (Brady et al., 2012; Brady, McLean, McLean, & Johnston, 1995; Brady, Steeples, & Fleming, 2005). Johnson, Reichle and Evans (2004) concluded that a preponderance of requesting is due to differences in the reinforcing values of consequences for requests versus comments. Thus, teaching commenting and other social functions is more difficult and the need remains for more research in these areas to promote communication of multiple functions.

For individuals with severe intellectual disabilities and autism, early intensive behavioral intervention has been particularly successful in establishing initial communication repertoires (Howard, Sparkman, Cohen, Green, & Stanislaw, 2005; Warren et al., 2011). Intensive interventions often encompass 30 or more hours of direct instruction per week. One strategy that has been proposed for promoting generalization of communication forms and functions acquired through intensive behavioral interventions to other more natural contexts is to use strategies that are similar to the intensive interventions, but at reduced intensity (or dosage) within the new contexts (Reichle & Johnston, 2012).

A recent statement put forth by the American Speech and Hearing Association acknowledged the importance of blending different intervention approaches such as intensive interventions aimed at developing skill sets with partner-focused interventions to promote skill usage (Blosser, et al., 2012). Inteventions that aim to build communication skill sets should be blended with interventions that reflect the growing recognition that these skills undergird inclusion in the community and across the lifespan (Bornman, Sevcik, Romski, & Pae, 2010; Mueller, Singer, Carranza, 2006). For example, pivotal response intervention is described as an approach that blends strategies such as environmental arrangement into daily routines, with the goal being accelerated acquisition and use of the target behaviors within the context of family and school interactions (Koegel, Koegel, Harrower & Carter, 1999).

Ultimately, intervention targets should build communication skills that effectively support self-determination through self-advocacy and problem solving (Avant, 2013; Wehmeyer, 1996). For example, literacy, which is recognized as critical for learning, health, well-being, employment, and functioning in society, is one important component of communication that supports self-determination (Erickson, Hanser, Hatch & Sanders, 2009). Targeted literacy

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skills such as choosing a book using eye gaze or touch have been blended into a shared story activity within the classroom (Browder, Lee, & Mims, 2011).

In terms of symbolic targets, it has been suggested that initial vocabularies meet communication needs across learning, employment, living, and community contexts including health care settings by selecting common core vocabularies across these contexts (Banajee, DiCarlo, & Stricklin, 2003; Bryen, 2008; Williams, Beukelman, & Ullman, 2012). A core vocabulary consists of words common to the vocabularies of peers, is based on the language inventories of typically developing peers and does not change across environments or between individuals (Banajee et al., 2003). The core vocabularies identified in Banajee et al.'s study of preschool age children were I, no, yes/yeah, want, it, that, my, you and more. In addition, intervention targets that enable an individual to express multiple functions such as greeting, commenting, and requesting will facilitate social interactions, and help to establish and maintain relationships (Blackstone & Hunt-Berg, 2012; Light, Parsons & Drager, 2002). Research on Functional Communication Training (FCT) demonstrates evidence-based methods for identifying functions of existing behaviors (Brady & Halle, 1997; Martin, Drasgow, Halle, & Brucker, 2005; Schmidt, Drasgow, Halle, Martin, & Bliss, 2014). In cases where the existing behavior is deemed inappropriate, FCT aims to replace the inappropriate behavior with a new target behavior that serves the same communicative function (Kurtz, Boelter, Jarmolowicz, Chin, & Hagopian, 2011). Further discussion of challenging behaviors is presented later in this manuscript.

Building communication skills that enable individuals with severe disabilities to establish and maintain social relationships with a variety of individuals will support them in achieving their rights and meeting their needs. Instruction in social interactions should involve natural routines and a range of communication partners, particularly those chosen by the person being taught (e.g., Goldstein & Morgan, 2002; Odom, et al., 1999). Interactions between children with and without disabilities may not occur naturally. The teacher, SLP, or others may have to encourage children with severe disabilities and typically developing peers to communicate with each other (Katz & Mirenda, 2002a, 2002b). Social interaction is also important beyond the classroom. Success in employment and community living is enhanced when individuals have the knowledge and skill to engage in social exchanges with friends, co-workers, merchants, and other members of the community (Johnson, Douglas, Bigby & Iacono, 2012; National Core Indicators, 2014).

Challenging behaviors

Individuals with severe disabilities frequently demonstrate challenging behaviors that may serve a variety of communication purposes (Mirenda, 1997; Rojahn, Wilkins, Matson, & Boisjoli, 2010). A robust literature has emerged over the past 30 years demonstrating that functional communication training (FCT) is an effective method for determining the function of challenging behaviors and treating the challenging behaviors through communication interventions (e.g., Carr et al., 1994; Donnellan, Mirenda, Mesaros, & Fassbender, 1984; Durand, 1990; Petty, Allen & Oliver, 2009). Findings show that challenging behaviors can have the functions of requesting tangible objects (Richman, Wacker, & Winborn, 2001), escaping tasks (Hagopian, Wilson, & Wilder, 2001), requesting

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attention (Radstaake, Didden, Oliver, Allen, & Curfs, 2012), or have multiple functions (Braithwaite & Richdale, 2000). Interventions treat the challenging behaviors by either changing the environments or demands that trigger the behaviors (Carr, Robinson, & Palumbo, 1990), replacing the behaviors altogether with more conventional communication forms (Bambara & Kern, 2005), or both (Kelley, Lerman, & Van Camp, 2002). FCT is most successful when attention is paid to the functional equivalence between challenging behaviors and replacement behaviors, response efficiency, and overall effectiveness (Beukelman & Mirenda, 2013; Johnston, 2006).

Recent research has further addressed lingering concerns in functional communication training by addressing such topics as, avoiding resurgence of problem behaviors that often occurs after functional communication training (Lattal & Pipkin, 2009; Volkert, Lerman, Call, & Trosclair-Lasserre, 2009; Wacker, Hartding & Morgan, 2013), and appropriate use of specific communicative alternatives to problem behaviors under particular conditions (Cammilleri, Tiger & Hanley, 2008; Hanley, Iwata & Thompson, 2001). However, these strategies, frequently are not considered by intervention or rehabilitation teams. Hence, greater emphasis on translational research is needed to broaden results and increase usage by intervention teams in schools and other contexts.

Where and how instruction occurs

The importance of conducting interventions within meaningful contexts originally highlighted in the 1992 Guidelines remains strong today (e.g., Calculator & Bedrosian, 1988; Halle, 1988; MacDonald, 1985; Musselwhite & St. Louis, 1989; Romski, Sevcik, & Pate, 1988; Siegel-Causey & Guess, 1989; Warren & Rogers-Warren, 1985; Yoder & Villarruel, 1988). Over the last twenty years additional research has bolstered our position that communication intervention should occur in real-world, interactive, social contexts with responsive communication partners (Mancil, Conroy, & Haydon, 2009; Smith, Warren, Yoder, & Feurer, 2004; Tager-Flusberg et al., 2009). Intervention provided in the context of familiar daily life experiences leads to communication within functional contexts and fosters maintenance and generalization of newly learned communication skills in similar contexts in the natural environment (e.g., Mancil et al., 2009).

Treatment plans for individuals with severe disabilities will involve a significant amount of environmental engineering or management (Calculator & Black, 2009). This includes careful arrangement of physical environments as well as attention to interpersonal environments and cross-cultural differences. Elements of the physical environment include the physical arrangement of the environment (e.g., placement of other individuals and furniture), lighting, sound levels, temperature, degree of clutter, and environmental distractions that might impact the communication and learning of specific individuals. Also important is the familiarity of the environment and whether the intervention environment is enjoyed and relevant to the daily routine.

The individual's preferences for activities, materials, and people (based on preference assessments) should also shape the development of activities and routines that serve as the context for interventions (Kashinath, Woods, & Goldstein, 2006; Snyder-McLean, Solomonson, McLean, & Sack, 1984; Woods-Cripe & Venn, 1997). Routines can be

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developed as part of everyday events, such as meal preparation, recreation and leisure activities, and academic or other school-based activities. Such contexts can scaffold communication by capitalizing on the anticipation of predictable events that builds during the routine.

Technology

In the past two decades there has also been tremendous change in the technologies that we harness to support the communication of individuals with significant disabilities. Technology is now so ubiquitous that communication devices have become just one more means by which we support or enhance human function via technology. Mainstream consumer technologies (e.g., tablets, telecommunications tools, enhanced displays and display functions, and speech output options) afford much greater flexibility, portability, affordability, and acceptability. Technological advances have enabled new options for AAC system design and features as well as device control (for example, eye gaze, brain waves, and other methods requiring minimal voluntary movement). In addition to impacting communication, technology innovations have also created new options for mobility, sensory enhancement, independent navigation, activities of daily living, and social interaction.

Although there have been substantial gains in securing payment for technology through public and private insurance, early intervention, K-12 and higher education, and vocational rehabilitation mechanisms, there are ongoing challenges that need to be addressed to ensure that payment sources are respectful of consumer choice and enabling in terms of the conditions under which payment will be approved. For example, medical insurance typically pays only for devices that can withstand repeated use, are customarily used for a medical purpose, and are generally not useful to a person in the absence of an illness, injury, or disability. As the lines between assistive technology and mainstream technology become increasingly blurred, however, this long-standing practice becomes problematic. A traditional AAC device, comprised of proprietary software housed within a customized case, meets the criteria for funding, but a tablet device with downloadable software (or app) does not—because the tablet can be useful to anyone in the household for a multitude of non-medical reasons. Consequently, we find ourselves in the nonsensical position of being able to secure funding for a traditional AAC device that costs $6,000 but not a device with comparable functionality—the mobile device with downloadable software—that costs $600. One solution has been to “lock down” the device so that it can only run the communication software, but that is not a satisfying solution. Mainstream technologies enable people with and without disabilities to learn, work and engage with their communities using email, the internet, and countless other applications. To prevent someone with a communication disability from accessing the full functionality afforded by a mainstream product—as a condition of access to a reasonably-priced AAC device—does not seem to be in anyone’s best interest. The solutions, however, appear to lie not in intervention practices, but in the policies that dictate the types of assistive devices that will be approved for insurance reimbursement.

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Conclusion

The past two decades have brought advances in assessment and intervention that have benefited individuals with significant communication needs. Yet, individuals continue to have unmet communication support needs. The main principles highlighted in this article may be used to guide a research and practice agenda that can propel further advances into the next decade for individuals with significant disabilities. Efforts start by increasing awareness of the fundamental need for effective communication for all individuals through widespread adoption of the Communication Bills of Rights in our society (See Table 2). In addition to promoting these rights, practitioners, educators, and researchers can help to integrate inclusive practices, build awareness, guide research, and inform effective clinical practice in the following critical areas:

1. Continue to move beyond intellectual limitations and embrace a definition of intellectual disabilities that includes adaptive functioning.
2. Conduct assessments and interventions that are more tied to the ICF framework, incorporating personal characteristics and environmental factors.
3. Continue to increase knowledge about different cultures and adapt assessment and intervention approaches to benefit each individual.
4. Extend use of dynamic assessment procedures that recognize contextual variables and value cultural differences
5. Conduct research on ways to work most effectively with communication partners (including peers) in different environments
6. Extend the focus on meaningful contexts and routines in assessment, goal setting, and intervention.
7. Move beyond “requesting” as a target for research and clinical practice to expand the use of a variety of communication forms and functions.
8. Include standards-based and functional goals in classroom settings
9. Conduct research to fill an extensive research gap in the area of comprehension and consider ways to better assess and treat comprehension deficits.
10. Determine better instructional practices for building individuals skills to promote effective communication and literacy skills.
11. Incorporate technological advances in clinical practice to advance augmentative and alternative communication systems.
12. Integrate IPE and IPP in preservice and clinical settings, moving beyond discipline-specific boundaries to improve teamwork and collaboration.

The NJC continues to assert that all people have the right to communicate. It is our purpose to synthesize and disseminate information that informs policy, practice, and research. This article advances the field with respect to knowledge about assessment and intervention practices. We recognize that more research and advocacy is needed.to actualize the

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principles embodied in this article. These principles are not static concepts, but continue to evolve based on emerging research findings and their translation into policy and practice.

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Table 1

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

The NJC consists of members from the following organizations:

- American Association on Intellectual and Developmental Disabilities
- American Occupational Therapy Association
- American Physical Therapy Association
- American Speech-Language-Hearing Association
- Association of Assistive Technology Act Programs
- Council for Exceptional Children Division for Communicative Disabilities and Deafness
- TASH
- United States Society for Augmentative and Alternative Communication

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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