Communication Interventions for Individuals with Severe Disabilities
Exploring Research Challenges and Opportunities

by
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Contents

About the Editors ........................................................................................................ vii
About the Contributors ............................................................................................... ix
Foreword Author Leonard Abbeduto ............................................................................ xvii
Preface .......................................................................................................................... xix
Acknowledgements ..................................................................................................... xxiii

I. Communication Interventions for Individuals with Severe Disabilities: What Is the Evidence? ................................................................. 1

1. What Is the State of the Evidence? ................................................................. 3
   Nancy C. Brady, Martha E. Snell, and Lee K. McLean

2. Prelinguistic Communication Intervention for Young Children with Intellectual Disabilities: A Focus on Treatment Intensity ............... 15
   Tiffany G. Woynaroski, Marc E. Fey, Steven F. Warren, and Paul J. Yoder

3. Challenging Behavior and Communicative Alternatives ................... 35
   Joe Reichle and Mo Chen

4. Research on Communication Intervention for Children Who Are Deafblind ............................................................. 75
   Charity Mary Rowland and Amy T. Parker

5. Are We There Yet? Targeted and Phenotypic Communication Interventions for Children with Down Syndrome or Autism Spectrum Disorder ................................................................. 99
   Stephanie Yoshiko Shire and Connie Kasari

6. Augmented Language Interventions for Children with Severe Disabilities .................................................................................... 123
   Ashlyn L. Smith, R. Michael Barker, Andrea Barton-Hulsey, MaryAnn Romski, and Rose A. Sevcik

7. Parents as Partners in Effective Communication Intervention .......... 147
   Ann P. Kaiser, Lauren H. Hampton, and Megan Y. Roberts

8. Putting It Together: Discussion Synthesis of Communication Interventions for Individuals with Severe Disabilities ........................................... 169
   Ellin B. Siegel, Diane Paul, and Lorraine Sylvester
II. Challenges for Communication Intervention Research: Design Methods Issues .................................................................................. 187

   William J. McIlvane, Anne-Therese Hunt, Joanne B. Kledaras, and Curtis K. Deutsch

10. Randomized Controlled Trials: Do They Tell Us What We Want to Know About Interventions for People with Severe Disabilities? ............................................................................................................. 209
    R. Michael Barker and David J. Francis

    Roger Bakeman

III. Challenges for Communication Intervention Research: Measuring Outcomes ............................................................................ 233

12. Recent Innovations in the Assessment of Auditory Discrimination Abilities in Individuals with Intellectual Disabilities Who Are Nonspeaking.................................................................................. 235
    Richard W. Serna

13. The Role of Cultural, Ethnic, and Linguistic Differences.............................. 259
    Katherine T. Rhodes and Julie A. Washington

14. Measuring Communication and Language Skills in Individuals with Severe Intellectual Disabilities................................................................. 281
    Billy T. Ogletree

15. Where does Social Validity Measurement Fit into Identifying and Developing Evidence-Based Practices? ................................................................. 299
    Howard Goldstein

16. Section Discussion Summary: State of the Evidence: Research Design and Measurement Issues ................................................................. 313
    Krista M. Wilkinson, Beth A. Mineo, Diane Paul, and Christine Regiec

IV. The Future ............................................................................................................. 325

17. Communication Interventions for Individuals with Severe Disabilities: Research and Practice Gaps, Opportunities, and Future Directions................................. 327
    Rose A. Sevcik and MaryAnn Romski

Index.......................................................................................................................... 339
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Research is urgently needed to promote identification and implementation of effective communication interventions for individuals with severe intellectual and developmental disabilities (IDD). One of the long-standing goals of the National Joint Committee (NJC) for the Communication Needs of Persons with Severe Disabilities has been to promote research that will lead to additional communication resources. This chapter summarizes events leading up to this conference and the current state of the evidence regarding communication practices for individuals with severe intellectual and developmental disability (IDD).

BACKGROUND
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 August 19–21, 1985, in Washington, D.C. 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 consisted of 33 consensus statements that put forth basic assumptions and recommendations to the planning and provision of appropriate services to meet the communication needs of children with severe disabilities. Some of these consensus statements reiterated philosophical and action statements in the Education for All Handicapped Children Act of 1975 (PL 94-142); others added texture and specifics to actions detailed 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) coordinate an interagency task force for the preparation and dissemination of statements that set forth the parameters for the development and enhancement of functional communication for severely handicapped children and youth (terminology used in original documents). In 1986, ASHA and TASH organized a joint committee to focus on the communicative needs of children and adults with severe disabilities and issued invitations to other organizations to appoint representatives to this new NJC for the Communication Needs of Persons with Severe Disabilities.

The purpose of the NJC is to advocate for individuals with significant communication support needs resulting from intellectual disability and often coexisting with autism and sensory and/or motor limitations. The committee consists of representatives from ASHA, American Association on Intellectual and Developmental Disabilities (AAIDD), American Occupational Therapy Association (AOTA), American Physical Therapy Association (APTA), Association of Assistive Technology Act Programs (AATAP), Council for Exceptional Children Division for Communication Disabilities and Deafness (CEC-DCDD), Rehabilitation Engineering and Assistive Technology Society of North America (RESNA), TASH, and the United States Society for Augmentative and Alternative Communication (USSAAC). The interdisciplinary composition of this 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 people with severe disabilities provides a common ground on which the disciplines represented by the member organizations can unite in their efforts to improve the quality of life for all.

The first task of the NJC was to translate basic assumptions and recommendations reflected in the consensus statements issued by the OSEP/TADS 1985 symposium into a set of practice guidelines. The NJC identified the specific focus of these guidelines as pertaining to all people with severe disabilities, including people with severe to profound intellectual disabilities, autism, and other disorders, that result in severe socio-communicative and cognitive-communicative impairments. Representatives from all the constituent associations of the NJC met and worked together for several years to arrive at meaningful guidelines that reflected the 1985 consensus statements, including current values, intervention practices, and knowledge bases specific to the treatment of communicative impairments among people with severe disabilities. The practice recommendations presented in these guidelines reflected what were then considered best or recommended practices. The resulting document was then submitted to all constituent organizations for review (including widespread peer review by their members). After review and endorsement by all members, these guidelines were published in 1992 (ASHA, 1992) and has recently been updated (Brady et al., in press). The NJC included a Communication Bill of Rights, which has since been disseminated as a free-standing and powerful statement used by individuals and organizations to advocate for communication rights and services, as a part of these guidelines (see Box 1.1). The Communication Bill of Rights also has been updated (Brady et al., in press).

The committee underscored the need for such guidelines by stating that there were approximately 2 million Americans who were unable to speak or who demonstrated severe communication impairments. That figure would climb to more than...
Box 1.1. 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. All people have the following specific communication rights in their daily interactions. Each person has the right to

- Request desired objects, actions, events, and people
- Refuse undesired objects, actions, or events
- Express personal preferences and feelings
- Be offered choices and alternatives
- Reject offered choices
- Request and receive another person’s attention and interaction
- Ask for and receive information about changes in routine and environment
- Receive intervention to improve communication skills
- Receive a response to any communication, whether or not the responder can fulfill the request
- Have access to augmentative and alternative communication (AAC) and other assistive technology (AT) services and devices at all times
- Have AAC and other AT devices that function properly at all times
- Be in environments that promote one’s communication as a full partner with other people, including peers
- Be spoken to with respect and courtesy
- Be spoken to directly and not be spoken for or talked about in the third person while present
- Have clear, meaningful, and culturally and linguistically appropriate communications


3 million based on estimates of 1% of the population having this degree of impairment. In light of this steady increase in population, there is a shortage of trained personnel to serve individuals with complex communication needs. Few personnel preparation programs address the communication needs of people with severe disabilities (Costigan & Light, 2010).

Materials to help guide instruction on assessments and interventions for people with severe IDD are needed, even when training programs exist. One of the goals
for the NJC has been to develop tools that can help support interventions that reflect the NJC guidelines. After a 1992 OSEP symposium on effective communication for children and youth with severe disabilities, the NJC recognized the need to translate its guidelines into a functional tool—a communication supports checklist that programs could use to improve communication supports and services for people with severe disabilities (McCarthy et al., 1998). Although out of print, the communication supports checklist was used by many teachers and therapists to identify and implement interventions that reflected the NJC guidelines. The NJC developed additional educational materials that included conference presentations and an ASHA videoconference promoting communication assessments and interventions. Members of the NJC presented a webinar specifically about working with communication partners to promote communication (http://www.asha.org/Events/aac-conf/default). The organization’s web site also contains a section on topics under the themes of Accessing Services and Intervention Issues and Practices (http://www.asha.org/njc).

The NJC also addressed inappropriate practices by publishing a position paper and discussion paper refuting restrictive eligibility policies and practices (NJC, 2003; Snell et al., 2003). The NJC made clear that there is no evidence to support restricting communication services based on achieving either cognitive or language milestones. Rather, it is the view of the NJC that evidence supports providing communication services based on communication needs. If an individual demonstrates a need to improve communication in order to improve his or her functioning within current and likely future environments, then he or she should be considered eligible to receive services.

Most of the materials presented were based on ideals and a limited set of research studies, usually based on small numbers of participants. Since the mid-2000s, numerous calls for increased use of evidence-based practices have been issued across all types of communication disorders (Dollaghan, 2007; Nippold, 2011; Whitmire, Rivers, Mele-McCarthy, & Staskowski, 2014). These reports described how to document or demonstrate that interventions met standards of evidence-based practices (e.g., Kratochwill et al., 2013), with a goal of facilitating practitioners’ abilities to identify evidence-based practices in the literature and then implement these interventions in practice. Like all areas of communication intervention, there is a need to identify and promote evidence-based practices for individuals with severe disabilities. In addition, it is necessary to consider innovative research strategies to provide this evidence because of the extremely low incidence of the most severe IDD (which, in turn, makes it more difficult to find sufficient participants for most formal analyses). Members of the NJC realized that an examination of the existing research was necessary in order to strengthen its positions regarding services for individuals with severe ID and promote innovative research strategies.

**EVIDENCE SUPPORTING INTERVENTIONS FOR PEOPLE WITH SEVERE INTELLECTUAL AND DEVELOPMENTAL DISABILITIES**

The NJC published an article in 2010 that summarized intervention research completed over the previous 20 years with individuals with severe IDD (Snell et al., 2010). The committee members applied six criteria in conducting the literature search; articles that qualified 1) were published in peer-reviewed journals between 1987 and 2007, 2) were written in English, 3) had participants with severe IDD, 4) constituted
intervention studies addressing language or literacy outcomes, 5) contained original data, and 6) were not case studies. The authors used four steps to locate research articles meeting these six criteria. The initial step used 13 electronic databases, and 31 search terms were applied to locate articles with a general focus on intervention, participants with severe disabilities, and treatment addressing communication performance. Next, the authors created and applied 47 expanded search terms with the same focus. Third, the authors searched the reference lists of relevant articles, scanning for additional studies. Fourth, authors searched publications authored by NJC committee members. The search yielded a pool of 269 potentially relevant articles.

**Data Entry Instrument**

The NJC developed a research evaluation instrument that consisted of four sections—reviewer and article information, the criteria for including a study in the review (see following section), description of study, and evaluation of the quality of evidence—in order to summarize the characteristics of research identified in the review. During the development process, NJC members read and coded randomly selected articles from the search, compared ratings, discussed differences, and made decisions about improving the instrument. This read-code-and-compare process was repeated three times by different subsets of the NJC at meetings and by conference call until all committee members were satisfied with the instrument and its informal reliability. The final version of the instrument had 39 coding items in four sections, 32 of which concerned the content of the research: 1) article/reviewer information (2 items), 2) inclusion criteria (5 items), 3) study description and characteristics (29 items), and 4) summary of evidence quality (3 items). The latter items made use of a rating system developed by the National Research Council (2001) that addressed internal validity, external validity, and generalization. Reviewers were required to make a single choice on slightly more than half of the items, whereas 44% of the items asked that reviewers check all of the 4–8 options that were relevant to a given study. Although the instrument had 32 items addressing content, the items with multiple options meant that each study was coded on 104 items. Committee members then converted the instrument into an electronic version and placed it on a web-based survey platform (http://www.zoomerang.com) so that the six NJC members who conducted coding could efficiently code and compare articles without physically being in the same location.

Three inclusion criteria against which committee members judged all 269 articles yielded by the search procedure were that articles 1) presented results from an intervention study, 2) included one or more participants with severe disabilities, and 3) applied an intervention addressing one or more areas of communication performance. Committee members determined that 116 studies of the 269 potentially relevant articles (43%) met all inclusion criteria; this group constituted the qualified database that received additional review on the 32 content items.

**Interrater Agreement**

The NJC committee members conducted interrater agreement at two levels—inclusion criteria and content items. *Inclusion criteria* reflected agreement about which articles met our criteria to be included in the review, and *content criteria* reflected agreement for answers to the 32 content-related questions.
Inclusion Criteria  First, the committee assessed members’ reliability in determining whether to include an article in the analysis. Only articles that included participants with severe disabilities and that focused on communication were included. Members used a broad definition of severe disability that included several characteristics. If an IQ score was provided, then a cutoff of 44 or below was needed; if no IQ scores were given, then a description of “severe disabilities” sufficed. If there was no IQ or severe disabilities label, then members used language-age guidelines aligned with chronological age to judge whether participants had severe disabilities. A language age that was half the chronological age or less was required for participants who were 5 years old or younger; a language age of 30 months or less was required for those older than 5 years (receptive or expressive language age, or both). The criterion for communication focus required that the research outcomes include one of the following:

learning to understand and/or produce communication messages to a communication partner, using any mode (graphic, natural gestures, sign language, speech, picture symbols, etc.), and addressing one of the following functions: requesting, commenting, protesting, conveying social niceties, answering questions, repairing after a breakdown.” (Snell et al., 2010, p. 367)

Committee members calculated agreement on the inclusion criteria by comparing two coders’ independent ratings of a group of 71 articles (26.4%) randomly selected from the 269 potentially relevant articles identified in the search. Ratings were compared on a point-by-point basis and scored for agreement or disagreement; members used the following formula to obtain an agreement percentage—total agreements divided by the total number of agreements plus disagreements and multiplied by 100. Interrater agreement on each inclusion criterion was 1) 84.5%: investigator(s) includes one or more participants with severe disabilities; and 2) 81.7%: treatment addresses one or more areas of communication performance.

Content Items  The committee used different procedures to assess reliability for the 32 content-related questions. The committee first randomly selected 35 studies from the qualified database of 116 studies that met inclusion criteria. This sample of qualified studies was independently rated by two reviewers on both inclusion criteria items and content items; ratings were compared using the same interrater reliability formula that was used with the inclusion criteria. Agreement was moderate to strong for most of the content items (81.3%- 95.8%) However, 12 subitems on the content-related questions fell below 70% agreement and were omitted from additional analysis; only information from the items with greater than 70% agreement was included in the committee’s findings.

Findings  The information gleaned from this literature review is comprehensively described in the original research report (Snell et al., 2010) but will be summarized here in two sections—characteristics of the research and nature and quality of the evidence. Overall, the findings from this systematic examination of 20 years of communication intervention research with individuals having severe disabilities showed that “positive changes in some aspects of communication were reported in nearly all of the studies in the database” (p. 373). Naturally, this data set is susceptible to publication bias because interventions that fail to work are seldom reported.
The committee’s aim, however, was to point out the many successes that have been demonstrated.

**Characteristics of the Research** The qualified database of 116 studies contained a total of 460 individuals with severe IDD; of this group, 62% were males and 38% were females. The 116 studies included a mean of four participants with severe disabilities, while the range varied from 1 to 41. The participants were categorized into five chronological age groups: 44% were between 0 and 5 years, 36.2% were between 6 and 11 years, 28.4% were between 12 and 17 years, 19.8% were between 18 and 20 years, and 25% were 21 years or older. Disabilities identified in participants included intellectual disability (79.3%), autism (45.7%), multiple disabilities (34.5%), cerebral palsy (18.1%), a specific syndrome (16.4%), sensory impairment (15.8%), and behavior disorder (7.8%).

A majority of the participants (66.4%) were described prior to intervention as having prelinguistic abilities, in that they had no real words in any mode and/or had expressive language ages of less than 18 months; 51.7% were described as having emergent communication (e.g., language age between 18 and 30 months); only 6% were considered to use multiple, nonecholalic words; and 9.5% were identified as being echolalic. Participants’ communication mode prior to intervention was reported as speech (49.1%), augmentative and alternative communication (AAC) (30.1%) (unaided [17.2%], aided [8.6%], aided with speech output [4.3%]), gestures/vocalizations (59.5%), and other (21.6%), which included problem behavior. Finally, most researchers did not report on participants’ receptive communication ability or give their receptive language age (RLA; 53.4%). When reported, this ability was minimal—not responsive (RLA 9 months or younger), simple directions (RLA 9–18 months), single words (RLA 18–30 months), and grammar/syntax (older than 30 months).

**Dependent Variables** Improvement in expressive communication (81%) was the most frequently targeted outcome variable, followed by progress in interaction or conversation (23.3%). Speech was the most commonly targeted mode for communication (41.4%) in these studies, followed in frequency by AAC device with no speech output (36.2%), AAC device with speech output (25%), and unaided AAC (21.6%). More than one mode was measured in 43.5% of the studies, with a range from 1 to 4 modes. For the most part, researchers neither targeted nor measured receptive communication in any mode as an outcome of intervention. But researchers who assessed receptive abilities focused on how well participants came to understand a partner’s spoken speech. Regulating the behavior of others (53.4%) (e.g., requesting and/or rejecting objects or events) was the communication function that was most frequently targeted in this database. Eighteen percent of studies targeted multiple communication functions. The interaction or conversation targets addressed in these studies included turn-taking (11.2%), joint engagement (9.5%), and imitation (6.9%). Participants’ challenging behavior was measured before and during intervention and reported in addition to communication outcomes in 10.8% of the studies.

**Independent Variables** Committee members assessed each study for its specific intervention characteristics, including context for the intervention, instructional methods, and who delivered the intervention. Interventions often took place...
in multiple contexts; thus, the following percentages add to more than 100. Intervention in most of the 116 studies took place in the classroom (44%). Other settings included therapy or experimental rooms (34.5%), other school contexts (e.g., playground, cafeteria, empty classroom; 29.9%), home (27.6%), and community (5.2%). Close to 33% of the research used more than one of these settings.

Most research provided intervention on a one-to-one basis, although group intervention occurred in 10% of the studies. Teaching trials were distributed across sessions or activities in 45.7% of the studies, rather than massed into a short time period. Intervention was provided in decontextualized settings in 39.6% of the reviewed studies; that is, settings that were removed from natural communication environments and that had conditions (e.g., time, setting, individuals present) that were intentionally manipulated. More than one individual provided intervention to participants in 35.3% of the studies. An experimenter delivered intervention in a majority of the studies (51.7%), but others also participated as interventionists, including teachers (35.3%), others (e.g., graduate student, occupational therapist, unspecified; 19.8%), parents (16.4%), paraprofessionals (12.1%), peers (9.5%), and speech-language pathologists (6%).

**Nature and Quality of the Evidence** Not surprisingly, because only published studies were reviewed, the committee members determined that 95.7% of the studies reported both positive and immediate results in the target skill after intervention. Multiple criteria were used in making these determinations. For example, committee members visually examined graphs in single-subject design studies. Committee members relied on significant tests and effect sizes (ES) for the small number of group studies.

There were numerous intervention approaches represented in the articles reviewed (e.g., functional communication training, Picture Exchange Communication System [PECS], systematic social interactive training). Committee members could not compare the relative effectiveness or efficiency of these different intervention approaches due to the wide variability in the variables reported, participant characteristics, and outcome measures. Instead, they focused on summarizing the available evidence supporting currently recommended practices and identified gaps in that evidence base to be addressed in future intervention research. As previously noted, the published studies that were reviewed reported positive outcomes with at least some participants. Several areas were identified, however, that needed further research to provide more reliable, valid, and replicable evidence regarding the effectiveness of specific intervention approaches to achieve important outcomes that will contribute to improved communication functioning for participants outside of the intervention context. These gaps and needs are discussed later in this chapter.

**Quality Indicators of the Research** The database was also judged by experimental design, validity, and intervention effectiveness. In terms of design, 67.2% of the studies used experimental single-subject research designs, whereas 19% used quasi-experimental design, 9.5% used qualitative designs, and 3.4% used experimental group design. When the database was examined for its measurement of stimulus or response generalization, slightly more than half of the research (51.3%) used some measure of skill generalization, such as transfer to new partners or settings. Stimulus generalization appears to have been facilitated by the fact that
intervention was frequently delivered by more than a single person and in more than a single setting, and the classroom was the most commonly used setting for intervention. By contrast, the studies less often reported any information on skill maintenance postintervention. Only 25.2% of the researchers measured maintenance of effects 3 or more months after intervention was ended.

In terms of reliability, 89.5% studies reported interrater agreement, whereas only 2.6% reported measuring intrarater agreement (i.e., measurement of consistency in raters over time). Fidelity of treatment, or the evidence that the experimental conditions were implemented as described, was measured in 32.2% of the research. Social validity, or any measure of social acceptability or benefit of the intervention from the perspective of experts or users, was assessed only in 16.8% of the studies.

Of the four characteristics of quality research (generalization, maintenance, fidelity of treatment, social validity), only 2.6% of the studies measured all four characteristics, whereas any three of these were measured only 7.8% of the time, and any two of the four were measured 32.8% of the time, with the assessment of generalization and treatment fidelity being the most frequently assessed.

Implications for Future Research

As previously described, the state of the evidence base in severe disabilities is a case of the glass being viewed as half full or half empty. Although it is important to recognize that there is a substantial amount of published research that demonstrates positive effects for numerous communication outcomes, it is equally important to acknowledge the need for new research that will strengthen and expand the existing evidence base.

The committee members’ aim was to document positive outcomes across a number of different interventions without comparing results across different interventions. Indeed, it is difficult to compare approaches when they are represented by only a few studies, most with small numbers of participants. A few studies, however, have directly compared different interventions. For example, Tincani (2004) compared the effects of PECS and sign language training for two children with autism. The outcome measures in this study were independent demands (requests/protests) and vocalizations. Interestingly, one child showed more gains with sign language and the other child showed greater gains with PECS. In a similar study, Beck, Stoner, Bock, and Parton (2008) compared PECS to use of a speech-generating device (SGD) in terms of ease of learning and effects on verbalizations. Again, the results varied by child and outcome. These studies illustrate how difficult it can be to compare effects across children when there is so much individual variability within this very low incidence population. The most feasible approach to comparison may be to conduct meta-analyses within specific intervention types (e.g., Flippin, Reszka, & Watson, 2010) and then compare ES across different meta-analyses. Such a meta-analysis is difficult, however, given the great variability found in how investigators conduct, evaluate, and report their intervention research. Specific areas to improve on in future research were identified in the articles that were reviewed. These areas are reliability, treatment fidelity, generalization and maintenance data, and procedural detail—including participant descriptions. Greater consistency in reporting these details is essential to conduct meta-analyses across multiple studies on the effectiveness of particular interventions and research on implementation of
the interventions in real-world environments. The following sections offer some suggestions for moving the science forward by addressing these needs.

**Reliability and Validity** The committee members’ review noted that interobserver reliability is frequently addressed and intraobserver reliability is sometimes addressed, but procedural reliability, also called fidelity of implementation, was seldom addressed. It is critical for intervention research that researchers indicate how accurately and consistently an intervention is administered. It is recommended that an objective rater who is not one of the experimenters document the fidelity with which the intervention procedures are followed. For example, Romski and colleagues (2010) implemented a treatment fidelity checklist that was completed by independent observers in their randomized control group study demonstrating vocabulary gains with AAC. Important steps for the intervention were listed, and the observers documented whether each of these steps was followed. Similar procedures were used by Tincani and colleagues in their single-subject research on PECS (Tincani, Crozier, & Alazetta, 2006). Regarding validity, the greatest need identified was in the area of social validity. Only one sixth of the articles reviewed included a social validity measure. There is a need to include information about how consumers—including family members, community members, and friends—evaluate communication changes following treatment. This information is extremely valuable for evaluating the overall effectiveness of an intervention. For example, Stanton-Chapman and Snell (2011) evaluated the social validity of a social-communication intervention by asking preschool teachers who were not affiliated with their research to indicate if the intervention procedures were acceptable and if the behavior changes being reported were socially important. The preschool teachers watched videotapes of participants at baseline and after the intervention in order to make these determinations.

**Generalization and Maintenance** Effective interventions have meaningful outcomes outside of the immediate treatment context; therefore, it is necessary to measure outcomes in different contexts and with different communication partners. This statement is true for all of communication research (Whitmire et al., 2014) but even more true for research with individuals with severe IDD. People with severe IDD frequently struggle with generalization (Snell, Lih-Yuan, & Hoover, 2006). Although the importance of measuring and teaching generalization and maintenance of communication behaviors has been recognized for decades, the committee members’ review still found that generalization was assessed in only half of the articles, and maintenance was only measured less than 25% of the time. Teaching communication partners to carry out part or all of the intervention is one strategy that has been implemented to increase generalization. For example, parent responsiveness is often included as part of an intervention package to promote generalization of communication skills in parent–child interactions (Paul, Campbell, Gilbert, & Tsiouri, 2013; Warren, Yoder, & Leew, 2002). Teaching within the natural environment is another strategy. To illustrate, Schmidt, Drasgow, Halle, Martin, and Bliss (2014) taught three individuals with severe IDD to use functional communication behaviors as replacements for challenging behaviors within natural contexts. Additional probes indicated that two of the individuals also generalized their communication to other natural contexts and maintained their new communication skills over at least three additional sessions past the end of treatment.
Identify Specific Effects of Intensities and Durations  The intensity and duration of an intervention are variables that are likely to influence outcomes and affect the ability to implement interventions across natural environments. Several articles have examined the key components to consider in terms of treatment intensity (Fey et al., 2013; Warren, Fey, & Yoder, 2007; Yoder, Fey, & Warren, 2012). For example, the frequency with which interventions are applied (dose frequency), as well as spacing of teaching episodes, interact with child characteristics to influence results (Yoder et al., 2012). Complex models are needed to adequately interpret these interactions, usually requiring data from large numbers of participants. Thus, creative new approaches to examining the effects of different intensities and durations within and across studies with these participants are needed.

CONCLUSION

The suggestions presented for improving the evidence base in severe IDD are not all new and include the need for more consistency in how intervention research is conducted and reported if the goal is to evaluate and demonstrate treatment effectiveness through comparative effectiveness research and meta-analyses. The fact that better research methods were suggested, despite the fact that most of these studies were completed by capable individuals, attests to the difficulties faced when conducting intervention research. Trying to maintain experimental controls while operating in the real world poses numerous logistic and ethical challenges. One purpose of the research conference was to convene experts in severe IDD with methodological experts in order to openly discuss better methods to advance the science in communication research for individuals with severe IDD. The remaining chapters further elaborate on how to address many of the identified needs for improved research on communication interventions for individuals with severe IDD.

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