Chapter 11: Translating Research to Practice in Prelinguistic Communication

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Abstract

Implementation of evidence-based intervention practices into every day settings in the community has been a serious challenge for researchers in the field of autism spectrum disorder (ASD). There is general agreement that a gap exists between research and practice and that this must be broached if we are to achieve the best possible outcomes for individuals with ASD. This gap is all too evident in the sub-group of prelinguistic communicators with ASD who may be even more likely to receive experimental approaches as they fail to respond to interventions that have proven effective for other sub-groups of children.

In this chapter, we explore the research-to-practice gaps associated with implementing interventions for individuals who have not progressed past the prelinguistic stage of development. In so doing, we consider the need to support professionals to engage in data-driven decision making and to provide parent and professional education that increases knowledge and use of evidence-based practices. We detail how this alone is insufficient, with unproven and disproven practices persisting in the community, despite research evidence that they are ineffective. The spread of misinformation, particularly via the internet, can be powerful and persuasive and research is needed to better understand how the use of these unhelpful practices can be prevented. Recommendations for future research into the implementation of interventions for prelinguistic communicators with ASD are discussed.

Keywords: research-practice gap, evidence-based practice, interventions, implementation, knowledge transfer

The focus of this book is on prelinguistic communication in ASD, inclusive of individuals who fail to progress beyond this stage of development and remain nonverbal throughout their lives. There has been little research conducted on this particular sub-group.

11.1 Current Research on Prelinguistic Communicators

A multidisciplinary workshop was convened in 2010 by the National Institutes of Health (NIH) to discuss knowledge about, and research opportunities for, nonverbal school-aged children with ASD (NIH, 2010). The workshop participants discussed three themes: definition, assessment, and intervention. We provide an overview of definitional issues below and then for the remainder of the chapter focus primarily on factors associated with translating knowledge of assessment and intervention practices in the community.

11.1.1 Definition

A significant challenge faced by researchers and clinicians who seek to better understand this population is how to ensure we are actually identifying and describing similar individuals. In general, there seems to be agreement about what is referred to as the prelinguistic stage of development as it relates to children under 5 years of age (see for example Chapter 2 in this volume). However, when children fail to develop functional speech by the time they reach 5 years, a variety of different terms have been applied (Tager-Flusberg & Kasari, 2013). These individuals who remain in the prelinguistic stage of development have been referred to as preverbal, nonverbal, non-linguistic, or minimally verbal.

There appears to be no consistency in use of terminology. This lack of consistency contributes to issues of definition and variability in prevalence rates, and generally undermines efforts to learn more about the characteristics of this sub-group. One of the terms used with increasing frequency is "minimally verbal". To illustrate, we conducted a comprehensive search of the PsycINFO, ERIC, ProQuest Educational Journals, CINAHL,

Medline, and SAGE databases for the periods 2006 – 2010 and 2011 – 2015 using the terms "autis*", "min* verbal", and "minimally verbal". We included only peer-reviewed articles and excluded studies where minimally verbal language was an outcome measure. The period 2006 – 2010 yielded only one publication, a case study of the impact of an intervention to enhance the communication and socialization skills of a minimally verbal child with autism (Baharav & Darling, 2008). The period 2011 – 2015 yielded 18 publications. The lack of publications involving the sub-group of individuals who are minimally verbal prior to 2011 lends weight to the claim that the estimated 30% of children with ASD who have not developed spoken language by 5 years of age have been the "neglected end of the spectrum" (Tager-Flusberg & Kasari, 2013). It may also reflect a trend in the use of the term "minimally verbal" to identify this particular sub-group of individuals.

To gain further insight into the type of research being conducted with this sub-group, we categorized each of the 18 papers identified through the comprehensive search in the period 2011 – 2015 according to the three major themes discussed at the NIH workshop. The results are displayed in Table 1. We also categorized the chapters in the current volume according to each of the three themes (see Table 1).

Table 1.

NIH Workshop Themes, Publications and Book Chapters

NIH Workshop Theme	Publications 2011 – 2015	Related Chapters in this volume
Theme 1: Who are these children? What do we know about their developmental trajectories?	Haebig, McDuffie, & Weismer (2013a)	Crais & Ogletree (Chapter 2)
	Haebig, McDuffie, & Weismer (2013b)	Braddock & Brady (Chapter 3)
	Norrelgen et al. (2015)	Iverson & Wozniak (Chapter 4)
	Tager-Flusberg & Kasari (2013)	
	Thurm, Manwaring, Swineford, & Farmer (2015)	
	Weismer & Kover (2015)	
	Woynaroski, Yoder, & Watson (2015)	
Theme 2: How can we assess their skills and knowledge across different domains, with special reference to those abilities relevant to language acquisition (e.g., verbal comprehension, sensory and motor skills, apraxia)?	Hartley & Allen (2015)	Trembath & Iacono (Chapter 5)
	Kasari, Brady, Lord, & Tager-Flusberg (2013)	Brady & Keen (Chapter 6)
	Plesa Skwerer, Jordan, Brukilacchio, & Tager-Flusberg (2015)	Sigafoos et al. (Chapter 7)

Theme 3: What treatments/interventions are effective in improving spoken language and communication in these children (augmentative and non-augmentative methods)?	Allen, Hartley, & Cain (2015) Goods, Ishijima, Chang, & Kasari (2013) Kasari et al. (2014) Mucchetti (2013) Paul, Campbell, Gilbert, & Tsiouri (2013) Schneider & Hopp (2011) Schreibman & Stahmer (2014) Shire et al. (2015)	Shire et al. (Chapter 8) Reichle et al. (Chapter 9) Meadan & Keen (Chapter 10) Keen et al. (Chapter 11)

The least researched theme was assessment (three papers) while factors related to definition/developmental trajectories or interventions were reported in seven and eight papers respectively. It is evident that although the number of studies being published has increased in recent years, research involving this sub-group is still in its infancy, leaving many gaps in our knowledge. This contrasts with the volume of research in prelinguistic communicative development for children with ASD under 5 years of age. For example, there has been a great deal of research interest in joint attention skills for children with ASD in the early years (see for example Chapter 3 in this volume) and this research spans the three NIH workshop themes. Our knowledge base of the prelinguistic period is thus much more expansive in the

early years of development for children with ASD. Of course a considerable proportion of these children do go on to develop at least some language. There is clearly a need for ongoing research in the early years but there is also an imperative to increase our knowledge about those children who fail to develop language. It is our intention in this chapter to consider issues of translating research to practice across the lifespan and we will therefore focus primarily on issues of assessment and intervention for the remainder of the chapter.

11.1.2 Assessment

The emergence of techniques including eye-tracking and measures of brain activity have opened up new ways of investigating language development in prelinguistic communicators. Use of these techniques is in its infancy, but the techniques provide a promising line of enquiry for researchers. In practice, however, there seems to be general agreement that our ability to assess prelinguistic communicators with ASD is limited (Kasari et al., 2013). The chapter in this volume written by Trembath and Iacono provides an excellent overview of standardized assessments and highlights ways in which clinicians can make use of some of these measures despite their limitations when applied to this particular sub-group. Brady and Keen then go on to review various informal and individualized assessment approaches that can also be useful when profiling the communication skills of prelinguistic communicators. Plesa Skwerer et al. (2015) support this individualized approach, and provide useful information on the assessment of receptive language using standardized tests, eye-tracking, and the use of touch screens. These individualized approaches can help practitioners to assess communicative forms, functions, and spontaneity of social communication and to measure how different interventions affect child outcomes. This is critical in enhancing our understanding of how individual children respond to specific intervention strategies and what intervention approaches will work best for which children. Implementing these assessment

practices can be challenging for those working in the community who may lack the knowledge, skills, or time necessary to undertake this type of assessment. We shall return to these issues later in the chapter.

11.1.3 Intervention

Building our knowledge of what interventions work best for prelinguistic communicators with ASD is an important priority for researchers. In Chapter 8, Shire et al. review a large number of social communication intervention studies for children with ASD under 8 years of age. Child outcomes resulting from many of these interventions were encouraging, with most children showing improvement in skills. While this highlights that the evidence is building in relation to effective interventions targeting social communication, a number of challenges remain for enhancing the language skills of prelinguistic communicators.

First, we need to improve uptake of these interventions in the community and reduce the use of unsupported practices. Numerous studies have found that the knowledge and use of evidence-based practices by parents of children with ASD and professionals working with these children and their families are limited (e.g., Carter et al., 2011; Paynter & Keen, 2015). Furthermore, unsupported and even harmful practices are in use within the community. We examine these issues in more detail shortly. Second, we know that some children with ASD remain minimally verbal, particularly if at least single-word speech has not been acquired by 8 years of age (Pickett, Pullara, O'Grady, & Gordon, 2009). This failure to develop speech occurs for some children despite access to quality early intervention. We need to learn more about this group of children and to investigate new ways of intervening that may reduce the number of children who fail to develop spoken language. In the following section we consider intervention practices supported by research evidence, some of the barriers to their

uptake in the community, and the persistent use of unsupported practices with prelinguistic communicators.

11.2 Research to Practice

Research into what works best for prelinguistic communicators has not led to one single best recommended assessment or treatment. This is perhaps not surprising given the heterogeneity in the ASD population, including variability in response to treatment (e.g., Kamio, Haraguchi, Miyake, & Hiraiwa, 2015; Trembath & Vivanti, 2014). Further, strategies found to be effective for other sub-groups may not be effective for this group. As such, clinicians are advised to select interventions using an evidence-based practice (EBP) framework (e.g., American Speech Language Hearing Assocation, 2006; National Autism Center [NAC], 2015; Speech Pathology Australia, 2010). Such a framework is broadly accepted to encompass three elements: using the best available evidence; clinical expertise/judgment; and client values, preferences, and priorities to guide practice (e.g., APA Presidential Task Force on Evidence-Based Practice, 2006; Sackett, Rosenberg, Gray, Haynes, & Richardson, 1996). However, concerns raised about implementation of EBP in practice (e.g., Drake, Merrens, & Lynde, 2005) may be magnified in this area. These include a lack of consensus regarding the best available evidence and challenges of limited or absent research; a disconnect between practices used in the community and the available research; proliferation of misinformation; potential for professional bias in decision making; and challenges with balancing parental priorities and preferences that may conflict with the evidence base.

11.2.1 Best Available Evidence

There is broad consensus that when available, systematic reviews provide the highest level of evidence, followed by randomized control trials, cohort studies, controlled case studies and so forth (e.g., National Health and Medical Research Centre, 2009). Treatment guidelines for

ASD are available internationally and provide broad recommendations for interventions and treatments based on the best available research evidence across the spectrum, but do not give guidelines for prelinguistic communicators. For example the Australian, *Guidelines for Good Practice* (Prior & Roberts, 2012) provide broad recommendations for ASD intervention including using individualized programming, relevant program content, and visual supports. However, they also fail to provide explicit guidelines on what specific interventions or treatments to use, or indeed not to use. In contrast, the NICE guidelines from the UK (National Institute for Health and Clinical Excellence, 2013), although again focusing on ASD broadly, offer some specific guidance on intervention practices to use broadly (e.g., psychosocial treatments) and on treatments not to use (e.g., potentially harmful treatments such as secretin). Such guidelines are helpful in providing general guidance of components of effective interventions, but fail to give fine-grained information on intervention practices.

Systematic reviews of the literature provide more fine-grained analysis of specific practices, although again they focus on the spectrum as a whole. A number of reviews have been released recently including the National Standards Report by the National Autism Center (NAC) (2009, 2015) and reviews by Odom, Wong, and colleagues (Odom, Boyd, Hall, & Hume, 2010; Wong et al., 2013, 2015). To date, no systematic review has focused on prelinguistic communication specifically, but recent EBP reviews (NAC, 2015; Wong et al., 2013, 2015) have included analysis of communication interventions for young children that may be considered in sourcing the "best available evidence," at least for young children who are prelinguistic. There is a clear gap in reviews for older children or adults who have failed to develop spoken language. In the reviews mentioned above, the evidence base for strategies to increase communication as a whole may be included but are not specific to prelinguistic communication. For example, in the area of communication, *pivotal response training* is listed across reviews as having an evidence base for young children (NAC, 2015; Wong et

al., 2013, 2015), and would be an appropriate intervention. In contrast, *scripting* is listed in the NAC review as a suitable communication intervention for young children, but requires verbal ability and is unlikely to be suitable to this population. Thus, interpretation of these reviews for this population relies on clinical judgment that should be informed by appropriate assessment of the child, which poses its own challenges as outlined in Chapters 5-7.

A list of practices that may be appropriate to prelinguistic communicators is considered in the two recent major reviews (NAC, 2015; Wong et al., 2013, 2015)[1] and is overviewed in Table 2. It is important to note that not all practices are covered in each review (e.g., time delay, standard echoic training, and language training) and the same practices are sometimes classified differently. As shown in Table 2, the NAC has classified some practices as "emerging" (Picture Exchange Communication System, augmentative and alternative communication, and technology-based interventions) that have been classified as EBP by Wong et al. (2013, 2015). These discrepancies can be explained by the use of different classification criteria used in each review. Adding to this confusion, one intervention (joint attention-symbolic play instruction) that is a combination of two EBPs (discrete trial teaching and naturalistic intervention) is classified as having "some support" rather than as an EBP by Wong et al., raising the question of whether combining two EBPs would be considered appropriate. These changing goal posts and questions about combining interventions can be a source of confusion for professionals and parents when selecting and implementing EBPs.

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[1] Note: Wong et al. (2013) and Wong et al. (2015) include the same content.

Table 2

Intervention Practices for Prelinguistic Communication in NAC (2015) and Wong et al.

(2013, 2015) Reviews

	NAC (2015)	Wong et al. (2013, 2015)
Joint attention interventions	Established*	Classifies "Joint attention – symbolic play instruction" as having some support
Standard echoic training	Established*	-
Discrete trial training (DTT)	Established*	EBP
Time delay	-/Established*	EBP
Language training (production)	Established	-
Modelling	Established	EBP
Naturalistic teaching strategies/interventions (NI)	Established	EBP
Pivotal response training	Established	EBP
Augmentative and alternative communication devices (AAC)	Emerging	EBP (Technology-aided instruction and intervention)
Imitation-based interventions	Emerging	Some support
Language training (production and understanding)	Emerging	-
Picture Exchange Communication System (PECS)	Emerging	EBP
Sign instruction	Emerging	-
Technology-based intervention	Emerging	EBP (Technology-aided instruction and intervention)
Reciprocal imitation training	-	Some support
Aided language modeling	-	Some support
Facilitated communication	Unestablished	-

* Classed under "behavioral interventions" with joint attention, standard echoic training, and DTT given as examples, time delay is not explicitly mentioned, although arguably it would be classed in this category.
- indicates this practice is not discussed in the review

Adding to potential confusion, most clinical guidelines (e.g., Prior & Roberts, 2012)

and reviews (e.g., Odom, Collet-Klingenberg, Rogers, & Hatton, 2010; Wong et al., 2013,

2015) provide information on practices that have an emerging or established evidence base,

but fail to highlight those that have been shown not to work. Only the NAC highlights one

unestablished practice of relevance to prelinguistic communication, facilitated

communication (FC). This practice involves a "facilitator" using physical contact with a body

part of a person with a disability (including ASD) to support selection of a symbol (letter, word, picture etc.) on a keyboard or other augmentative and alternative communication (AAC) system, selection that is then interpreted as their communication. Lilienfeld, Marshall, Todd, and Shane (2014) highlight that high quality studies have consistently shown the facilitator rather than the person with the disability to be responsible for the communication. This has been harmful to individuals and their families in some cases, leading to life-altering accusations and court cases. The continued use of this practice, as outlined below, highlights the need to not only improve the evidence base for interventions for this population, but to also discourage and minimize the use of unproven or even harmful practices.

11.2.2 Practices used in the Community

Little is known about the frequency of use of practices in the community for the prelinguistic population specifically. However, a significant research-to-practice gap is apparent in the field of ASD broadly (e.g., Cook, Cook, & Landrum, 2013; Cook & Odom, 2013) and emerging research suggests this extends to prelinguistic communication. For example, although research suggests generally positive attitudes towards EBP by parents and professionals (e.g., Aarons, 2004; Auert, Trembath, Arciuli, & Thomas, 2012; Stahmer & Aarons, 2009), the continued use of unsupported practices including FC has been found in recent studies (Deyro, Simon, & Guay, 2014; Hess, Morrier, Heflin, & Ivey, 2008; Paynter et al., 2015).

In a study of parent interventions, Deyro et al. (2014) found FC was ranked as the eighth most commonly used intervention strategy by parents, and was used more often than other strategies that have an established evidence base in this area such as joint attention intervention (11th), naturalistic teaching (15th) and pivotal response training (17th). Only 12.7% of parent participants were aware that FC was ineffective and/or harmful and 66.7%

thought FC was an emerging or established intervention. This is consistent with research with teachers of children with ASD that has found many believe they are using EBPs, when in fact they are not (Stahmer, Collings, & Palinkas, 2005).

Thus, a challenge in translating research to practice is not only disseminating evidence of practices found to be effective, but also discouraging the use of debunked practices and combating misinformation (e.g., beliefs that FC is evidence based). A significant challenge to this is the persistence of FC in academic and institutional settings (Lilienfeld et al., 2014), as well as the spread of misinformation, particularly via the internet and social media (Hemsley & Dann, 2014).

11.2.3 Challenge of Misinformation

Recent years have seen an explosion in information available on ASD from a range of sources including popular media and the internet. However, this does not necessarily translate to accessibility of high-quality information by all stakeholders as there can be both tangible (e.g., financial, pay-walls) and cognitive (e.g., unintelligible terminology) barriers to access (Trembath, Paynter, Keen, & Ecker, in press). In contrast, low-quality information including anecdotal information, such as advice from colleagues, may be more accessible and trusted (e.g., Boardman, Argüelles, Vaughn, Hughes, & Klingner, 2005). Further, accessible sources of information such as the internet, social media, and popular media (particularly with a tendency for false balance when there is clear evidence for one side) can easily spread and maintain misinformation (e.g., Clarke, 2008; Scanfeld, Scanfeld, & Larson, 2010). Thus the quality of information accessed, including exposure to misinformation, can influence knowledge translation.

As discussed earlier, even the best available information can be difficult to understand for parents and professionals. In addition to needing the cognitive resources and motivation to

seek out this information, limitations in terms of time may mean it is impossible to thoroughly assess available evidence to inform decision making in the real world (Trembath et al., in press). This can lead to a reliance on poor-quality information that may be easier to understand, seems more plausible, and fits with individuals' worldviews, and may sustain the use of debunked practices such as FC (Trembath et al., in press). It should also be acknowledged that information is not the only factor that influences choice of intervention strategies in community settings, with parent priorities and professional attitudes also likely to impact on whether information from research translates to practice.

11.2.4 Parent Priorities

It is not surprising that parents want to adopt effective interventions and are interested in EBPs (e.g., Auert et al., 2012). Yet, recent research suggests that parents prioritize other factors (child's individual needs, staff attributes, ASD-specific nature of intervention, intuition) over research evidence when selecting intervention practices for their children with ASD (Carlon, Stephenson, & Carter, 2014). Consistent with this, parents of children with ASD report using a large number of different interventions, many with little or no research evidence (e.g., Carter et al., 2011; Green et al., 2006). Such interventions include FC, highlighting that this is a problem in the area of prelinguistic communication as well. Thus, it appears that in selecting interventions for their children, parents may consider a range of factors.

Recent research has suggested a behavioral economic viewpoint to understanding parent intervention choices (Call, Delfs, Reavis, & Mevers, 2015). Call and colleagues asked 18 parents to rate their knowledge of treatments and perceived effectiveness. They were then given tokens to distribute, representing allocations of resources to interventions they were currently using or would use if that were viable (e.g., financially). Finally, they were asked to

distribute tokens to hypothetical interventions where they were only given information about immediacy of outcome and empirical support. Interestingly, when resources (time, cost) were not an issue parents distributed tokens broadly, but showed a preference for empirical support over immediacy of outcomes. Call et al. interpret these findings in line with a common stock market investment approach. In this way, parents invest most of their resources in the option most likely to produce gains, but also invest a small proportion in "high risk, high reward" options. Such an approach may explain the appeal of so-called "cutting-edge" (as FC was in the 90s) or unsupported (as FC is now) treatments and the continued use of such in the face of supported treatments. This preference for eclecticism by at least some parents may pose a challenge to professionals using an EBP framework who may feel under pressure to honor parent preferences (Trembath et al., in press).

Call and colleagues' (2015) research is of interest when parents have access to or have sought out the empirical evidence for interventions; however, parents may not actively seek this out and may instead rely on other factors in informing their treatment choices. For example, Auert et al. (2012) conducted a focus group study with parents of children with ASD on their perspective on evidence-based speech-language pathology services. Parents tended to report that their priority was to find experienced clinicians who could engage with their children and showed good communication skills. They also expected speech-language pathologists to use only evidence-based interventions, and few indicated they explicitly sought information on the evidence base of the interventions provided. Similarly, Trembath, Vivanti, Iacono, and Dissanayake (2015) found that professionals reported parents tended to trust their clinical experience and knowledge of evidence and rarely asked for information on the evidence base of interventions provided. Consistent with these findings, in a large survey of 552 parents, almost half (48%) rated professionals (e.g., their child's therapist) as the most trusted source of information when selecting treatments for their children (Deyro et al.,

2014). Thus, professionals play a vital role in bridging the research-to-practice gap in supporting knowledge translation; however, this may be limited by their own knowledge and attitude towards EBP.

11.2.5 Professionals

Given that parents rely on professional's knowledge and use of evidence-based interventions, it is vital they themselves are up to date with the latest evidence. However, this is often not the case. While reviews of the research and treatment guidelines for ASD are freely available via the internet (e.g., NAC and Wong et al. reviews); these may not be widely accessed or read by practitioners. For example, in our Australian study of early intervention practitioners (Paynter & Keen, 2015), we found only 60% reported having read the Australian *Guidelines for Good Practice* (Prior & Roberts, 2012). Participants instead were more likely to have received information from internal professional development, workshops or training outside the organization, or therapists within their organization, and reported high levels of trust of this information. As discussed earlier, this can bring challenges including promotion of misinformation.

When the "best available evidence" is accessed, it may be difficult to interpret in the context of prelinguistic communication as discussed above in terms of practice guidelines and reviews. Specific information on prelinguistic communication is somewhat limited and is generally published in academic journals not necessarily accessible to practitioners, who may lack the resources (e.g., access, cost, time) or ability to interpret and understand a wide array of information. Additionally, the EBP framework approach requires professionals to have a detailed understanding of an individual's strengths and needs in order to individualize treatment (Volkmar, Reichow, & Doehring, 2011). Limitations of both informal and formal

assessments as discussed earlier (see also Chapters 7-9) present additional challenges to identifying these individual strengths and needs.

In addition to challenges with accessing accurate information, practitioners are subject to a range of organizational and attitudinal factors that may affect their use or non-use of EBPs in practice. For example, they may feel EBPs are incongruent with the everyday realities of practice (Kratochwill & Stoiber, 2002) and/or may place more weight on clinical judgement (e.g., Wilson, 1996a, 1996b), posing a challenge to knowledge translation. In our own research we found attitudes towards EBP and organizational factors were significantly linked to reported use of EBPs in early intervention for children with ASD (Paynter & Keen, 2015).

Paynter and Keen (2015) completed questionnaire measures with 99 professional and paraprofessional staff across a statewide early intervention service in Australia. They found that although staff reported attitudes generally supportive of EBP, the use of unsupported practices including FC, albeit less frequently than EBPs, persisted. Perhaps not surprisingly, greater knowledge of EBPs was linked to greater use; however, a range of attitudinal and organizational factors were also linked to levels of use of EBP. This study suggested that greater vulnerabilities to the use of unsupported practices may be found in regional areas, among paraprofessionals (e.g., teaching assistants) as opposed to professionals (e.g., therapists), and when individuals have an attitude that is not supportive of EBP, or perceive their workplace culture does not support EBP.

We found similar results in a follow-up study that collected data across a range of ASD early intervention organizations (Paynter et al., 2015). It is worth noting that participating organizations provided services across the autism spectrum, but did include children with ASD who were prelinguistic communicators. Consistent with the EBP framework, participants reported the child's strengths and needs, family values, professional

judgement, and research evidence were somewhat or very important factors to consider in making intervention choices. However, a challenge to knowledge translation may occur, as has been seen in the case of FC when the family values using strategies that are unsupported by evidence.

In summary, there is an increasing amount of research into interventions in ASD; however, there is a need for further study and reviews of interventions specific to prelinguistic communication in ASD. Current reviews consider communication interventions as a whole, rather than linking interventions specifically to the sub-group of prelinguistic communicators. Differences in classification systems between clinical guidelines and treatment reviews may further complicate the decision-making process with apparently conflicting information available between reviews published in the same year. Parents and professionals tend to endorse the EBP framework; however, the use of practices that lack empirical support such as FC persist in the community. Parents tend to trust clinicians to use EBPs, but may value eclecticism in their treatment selection and seek to "hedge their bets" by using a range of practices simultaneously. In the face of limited research for this population, clinicians may struggle to access specific information, and balance what may be competing priorities of parents, limited research, and their own clinical judgment. Knowledge translation may be impeded by the reliance on practitioners who trust anecdotal or less reliable sources of information such as other practitioners, professional development events, and training, and are guided by their own attitudes to EBP and the culture of their organization. Finally, a challenge exists in not only disseminating accurate information, but also dispelling misinformation that is prevalent (e.g., FC, complementary and alternative medicines), particularly in the time of "balanced reporting" and proliferation of information on the internet and social media, and relative silence in treatment reviews on "what not to do".

11.3   Implications for Research and Practice

Given the challenges, how should clinicians, educators, and parents proceed in their efforts to support the learning, independence, and participation of prelinguistic communicators? Clearly, a narrow approach to assessment will be inadequate; relying solely on research evidence to select interventions is problematic; and an assumption that parents and professionals will select only evidence-based interventions would be inaccurate. Instead, the facts presented throughout chapters in this book make the case for the need for a sophisticated, thoughtful, data-driven approach to identifying, understanding, and addressing the communication needs of prelinguistic communicators. The sophistication and thought must come from human minds – from parents, partners, and professionals who are dedicated to meeting this challenge – working within a framework for scientific decision making.

While "research evidence" is commonly cited as the first central tenet of the EBP framework, Sackett et al. (1996) emphasized the essentiality of *individual clinical expertise*, defined as "the proficiency and judgment that individual clinicians acquire through clinical experience and clinical practice" (p. 71). They noted that "Without clinical expertise, practice risks becoming tyrannized by evidence, for even excellent external evidence may be inapplicable to or inappropriate for an individual patient" (p. 72). Yet ironically, to date, initiatives to support EBP in the disability field have focused on (a) increasing the amount and quality of scientific research, and (b) making this research evidence accessible, with far less regard to nurturing the development and sharing of clinical expertise. Arguably, all practice is research, or at least can be, with the right training and commitment, enabled by creative thinking and technology.

11.3.1 Practice is Research

Practicing clinicians and educators, in an ordinary month, may potentially work with more individual clients than there are participants in the largest randomized control trials relevant

to prelinguistic communicators. Often, they provide these services to the same clients over a number of years, while intervention trials rarely extend beyond one year. Thus, practicing clinicians and educators have the capacity to generate an astonishing amount of knowledge and clinical expertise, for the benefit of their own clients and of other prelinguistic communicators. Capitalizing on the lessons that can be learned from this natural experiment requires clinicians and educators to operate in a deliberate, systematic, and individualized approach with each client, consistent with the recommendations of preceding chapters.

In research, single case experimental designs (SCEDs) are highly regarded designs for evaluating intervention outcomes for heterogeneous populations, such as prelinguistic communicators (Horner et al., 2005; Kazdin, 2011). They involve the experimental manipulation of an independent variable (i.e., the intervention) to examine its effect on one or more dependent variables (i.e., the skills or behaviors we are seeking to increase, decrease, or modify). SCEDs are ideal for testing the safety of new interventions and are thus considered Level 1 (highest) evidence in treatment decision making by the Oxford Centre for Evidence-based Medicine (Howick et al., 2011). That is, they are ideally suited to monitoring the effects of (a) interventions for which there is little or conflicting research evidence (i.e., the majority of interventions for prelinguistic communicators), (b) interventions which are supported by research but which must be delivered in an adapted form due to client factors (e.g., different age group to those studies) or contextual constraints (e.g., decreased intervention intensity due to financial constraints), as well as (c) interventions derived from creative clinician practices that may ultimately prove worthy of formal research evaluation. Thus, SCEDs provide a framework for consistently and scientifically measuring the effects of an intervention for a particular individual as the basis for data-driven decision making about whether to continue, stop, modify, or switch interventions.

The process of using SCEDs to support clinical decision making when working with prelinguistic communicators (and other clinical populations) involves a series of important steps. First, the clinician or educator works with the client, his or her family, and significant others to identify an intervention goal. For a prelinguistic child, a goal might be to make requests using a symbolic form of communication. For a minimally verbal adult, a goal might be to choose between two real objects (e.g., swimming goggles and movie ticket) to select a preferred recreational activity. The goal needs to identify the specific behavior that will be measured (e.g., handing a picture to an adult to request a preferred snack item; touching the goggles or movie ticket to request the preferred activity) to ensure progress towards achieving it can monitored. Second, an intervention (independent variable) needs to be selected. In the case of the child, and with reference to the key EBP guidelines (NAC, 2015; Wong et al., 2015) the Picture Exchange Communication System (PECS) could be selected. The fact that PECS is classified as "emerging" by the NAC (2015) report, but as "evidenced based practice" by Wong et al. (2015), highlights the imperative to monitor outcomes for each individual client. In the case of the adult, the choice-making intervention could be broadly described as AAC (emerging according to NAC, 2015; EBP according to Wong et al., 2015). Yet here, the exact tailored method used for this client is unlikely to replicate a previous intervention exactly, let alone draw from an unequivocal evidence base, again highlighting the need to carefully monitor his or her response to the intervention.

The third step in using SCEDs is to establish the context in which the intervention will be trialed, and to measure the client's skills before, and after, the intervention is delivered. The measurement prior to intervention is referred to as "baseline", and can occur as soon as the target behavior is identified, while the team is making decisions regarding which intervention to implement. The clinician, educator, parent, or significant other monitors the child's or adult's behavior over time (e.g., each time the opportunity to make the

request occurs). Typically, the information is charted on a graph so that the individual's pattern of behavior, before and after the intervention, can be observed. Various experimental design elements and manipulations (e.g., targeting the same behavior across multiple contexts, or multiple goals in the same context), naturalistic reliability and validity checks, and methods for visual and statistical analyses can be incorporated.

While providing training in the application of these elements is beyond the scope of the current text (see Kazdin, 2011), the examples briefly outlined illustrate several advantages of using SCEDs over other methods for assessing outcomes when working with prelinguistic communicators. First, using SCEDs provides an integrated framework for making and documenting clinical decisions, from the point of goal selection during the assessment process (see Chapters 4 and 5) to intervention selection, implementation, and evaluation. Second, the focus on ongoing monitoring of clinically relevant client behaviors means that the individual's progress can be observed and discussed, and changes made in a timely fashion, in order to maximize intervention outcomes. Third, unlike the use of pre-post measures that leave uncertainty about whether the intervention or other factors led to change in behavior, SCEDs enable clinicians to account for these other factors (e.g., maturation in young children). Finally, the use of a consistent method for evaluating client outcomes, that is relevant for use with individuals across the lifespan, with individual goals, receiving a variety of interventions, can create a common platform on which clinicians can share information about intervention successes, and otherwise, to improve assessment and intervention practices.

11.3.2 Sharing and Progress

Traditionally, clinicians, researchers, clients, and caregivers have shared information through informal consultations (e.g., colleagues talking, parents talking to other parents), semi-formal

meetings (e.g., conferences), and formal publication of data (e.g., research publications). Yet, as noted earlier, the advent of social media and the infusion of technology into practice is opening new pathways for the creation and sharing of information, that will have bearing on future research and practice relating to assessment and intervention for prelinguistic communicators. In some instances, technology will influence, and in some cases re-define, traditional modes of information sharing. For instance, parents and colleagues can now share information through social media rather than meeting face-to-face. The use of webinars and online conferences is reducing financial and geographical barriers to accessing the latest research evidence and practice innovations from around the globe. Traditional paper-based research publications are being replaced with online, in some cases open-access (no cost to view) digital versions. In other cases, technology will create new ways to create and share information, which will open the door to new and possibly more effective assessment and intervention practices.

With regards to assessment of prelinguistic communicators, a seemingly obvious application for existing technology, and the infusion of future technology, is in the assessment of comprehension. In Chapter 6, Brady and Keen outlined how eye tracking, conducted in research settings, has been used to assess speech comprehension in 14 children with ASD. In a separate study, Trembath et al. (2015) examined the relationship between visual attention to AAC and task performance in a group of children with ASD, a number of whom were minimally verbal, during simulated teaching scenarios presented using eye tracking. At the same time, publishers are releasing web-based administration, scoring, and reporting packages for standardized language assessments (e.g., Wiig, Semel, & Secord, 2013), and eye tracking is now a common feature in AAC devices and is anticipated to enter the consumer market within years (Olson, 2014). It takes little imagination to foresee the future integration of these technologies, leading to a portable eye-tracking-based assessment

of comprehension skills in prelinguistic communicators, delivered by a consumer-grade smart phone or tablet PC, with the data automatically scored, stored, and shared with permission on a cloud-based platform.

Similarly, technology is set to further influence, and hopefully enhance, the delivery and evaluation of interventions. Implementing interventions with fidelity is a key challenge to engaging in EBP, and the increasing availability of online video demonstrations of intervention practices, combined with the use of inbuilt cameras to record and then review implementation, bodes well for improving clinician and parent skills in this area. With regard to monitoring intervention progress, automated language sampling and analysis systems (e.g., Language Environment Analysis [LENA]) with automated measures of vocalizations, turn taking, and environmental conditions (e.g., partner communication, noise, television) have the potential to track the emergence of language in children across multiple contexts, and increase the efficiency and coverage of highly ecologically valid language sampling. A logical next step will be for these systems to be integrated into wearable technology, and for automated measurement, analysis, and sharing of language (and other social-communicative behaviors) to be achieved as easily as occurs for exercise data with the advent of wearable fitness devices.

11.4   Conclusion

Taken together, the implementation of a systematic, clinically-relevant approach to monitoring intervention outcomes, combined with new and existing technology, has the potential to improve assessment and intervention practices for prelinguistic communicators. Such approaches are consistent with Sackett et al.'s (1996) emphasis on the importance of *individual clinical expertise* and thus avoidance of "cook book medicine" involving the non-

critical selection and use of interventions based solely on their research evidence. After all, as Sacket et al. affirmed:

> External clinical evidence can inform, but can never replace, individual clinical expertise, and it is this expertise that decides whether the external evidence applies to the individual patient at all and, if so, how it should be integrated into a clinical decision. (p. 72)

A positive future for research and practice in supporting prelinguistic communication relies upon the integration of all key elements of EBP, and the thoughtful and creative use of current and emerging technologies. Efforts to support EBP must attend equally to (a) the need for a stronger and broader evidence base, and (b) nurturing the development and sharing of clinical experience. Such an approach is most likely to result in the selection of appropriate goals based on appropriate comprehensive assessment and individualized goal and intervention selection. Indeed, such an approach will ensure measurement of progress towards these goals, to recognize, understand, and celebrate the steps, whether they are big or small, one or many at a time, that each person makes towards greater learning, independence, and participation.

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