Presidential Address, 2020—Using Technology to Deliver Services and Supports in Homes, Neighborhoods, and Communities: Evidence and Promise

Leonard Abbeduto, President, 2020–2021

The COVID-19 pandemic has led to a devastating loss of life, staggering economic losses, and untold psychological distress for people all over the world. People with intellectual and developmental disabilities (IDD) have been impacted as well and, in many ways, they are particularly vulnerable to the pernicious effects of the pandemic. Preliminary data reported in the popular press, for example, suggest that people with IDD who contracted COVID-19 have died at more than twice the rate of that of the general population. In addition, most of the services and supports required to optimize inclusion of people with IDD in their communities were severely disrupted during the pandemic. Diagnostic and developmental evaluations to determine eligibility for services, in-home behavioral services, special education and ancillary school-based therapies, and supported employment were limited or halted completely. Indeed, the vulnerability of our systems of services and supports for people with IDD to disruption by natural and human-made disasters was made abundantly clear during the past few months.

The pandemic, however, has also provided glimpses into how we could redesign services and supports for people with IDD in ways that could make them more robust and less susceptible to disruption. At the heart of this redesign is technology. At the UC Davis MIND Institute and at other academic health systems around the country, clinic visits with psychologists, psychiatrists, developmental-behavioral pediatricians, genetic counselors, and other professionals were quickly shifted to video visits through video teleconferencing technology platforms, such as Skype© and Zoom©. K-12 schools shifted to online classrooms and curricula, including for students receiving special education services. Families even took educational and fun trips to museums and zoos through virtual reality technology.

I believe that a lesson from the pandemic is that technology-delivered services should be more fully developed so as to allow us to continue to support people with IDD when the next disaster makes face-to-face contact difficult. Moreover, I would encourage the widespread use of technology-delivered services as a complement to face-to-face services even during non-disaster "normal" periods of life. Technology offers the promise of making professional expertise accessible to more people, removing barriers that create health disparities based on race, ethnicity, geography, and economic circumstances, and all while providing services in cost-effective ways.

At the same time, not every service will lend itself to technology-based delivery, or at least not without considerable adaptation. Anecdotal reports from many parents suggest that online classrooms for students with special needs, without consideration of how to support engagement and reduce challenging behaviors, have not been effective. So, rather than just assuming that every service can be delivered through technology, we must do the hard work of adapting the services and the technologies in an iterative process designed to provide evidence of efficacy, to develop procedures for individualization, and to show that the technology-delivered services can be brought to scale and be cost effective. And finally, there must be evidence that the technology-delivered services reduce rather than reinforce or exacerbate disparities in access that are common according to race, ethnicity, income, etc. If technology just makes getting care more convenient for those citizens who already have access to the best care and does not reach those citizens who are typically marginalized, we have failed as researchers and professionals.

In the remainder of this address, I will summarize some of the research conducted by my lab group to develop a distance-delivered, parent-implemented language intervention (PILI). I will

also briefly touch on a few other examples of technology-delivered services by other researchers to provide a sense of the scope of work ongoing in the field.

Distance-Delivered Parent-Implemented Language Intervention

There is considerable evidence from longitudinal correlational studies that the ways in which caregivers interact with, and talk to, children shape language development in typically developing children (Hart & Risley, 1995). Importantly, there is also evidence that the same types of parent input and interaction that optimize typical development are facilitative of language in children with developmental challenges, including those with autism spectrum disorder (ASD) or an intellectual disability (ID) associated with conditions, such as Down syndrome and fragile X syndrome (e.g., Haebig et al., 2013; Warren et al., 2010). The unique learning and behavioral challenges associated with IDD, however, make it difficult for parents and other adult caregivers to engage in these language-facilitating behaviors – behaviors toward which the adults would be naturally inclined. In no way is this to suggest that parents are at fault for their children's language problems. Instead, it is the case that the unique characteristics of the child with IDD, which slow language learning in and of themselves, also "create" an environment that is less conducive to learning than it could be. The goal of PILI is to help parents learn ways to engage their children in adaptive interactions in which the use of language-facilitating strategies is again possible. In other words, we train parents to serve as "therapists" and deliver a naturalistic intervention to their children.

The PILI training is largely delivered to parents individually in their homes through video teleconferencing and other digital technologies. Once trained, parents can then engage in supportive, "therapeutic" interactions with their children at home or in other settings that they experience together in daily life. There are many potential advantages of this distance-delivered approach.

- Low burden on family in that there is no need to travel to a clinic, thereby reducing costs for families and providing access to families whose children with IDD do not tolerate travel.

- Supports generalization in that the parent is learning and delivering the treatment in the natural setting of the family rather than in an unfamiliar clinic setting.
- Accessible to the majority of families as most families in the U.S. have access to the Internet, and the computer and other hardware can be provided to them if necessary.
- Enables a high dose and duration of treatment in that, in theory, parents can deliver the treatment to the child many times throughout the day and in many settings in contrast to clinician-delivered treatments, which are typically an hour or less per week.
- Cost-effective in that the technology is affordable and the lack of travel for families and clinicians saves time and money.
- Creates parent-professional alliance in that a bond is forged between the parent and the clinician teaching them the PILI strategies and parents learn a vocabulary that enables them to be more comfortable asking questions and making suggestions with other therapists in their children's lives.

The goal of PILI is to teach parents to be more "verbally responsive" and thereby more supportive of their child's language learning. A verbally responsive style of interaction entails:

- Following the child's lead (i.e., attending to, and talking about, the child's current focus of attention rather than trying to direct the child's attention elsewhere).
- Being affectively positive (i.e., being warm and supportive in tone of voice, facial expression, and action).
- Providing contingent responses (i.e., responding in ways that connect with, and help to continue, the talk or activity of the child).
- Using language that is consistent with and maybe slightly in advance of the child's current developmental level.
- Encouraging child communication by arranging the environment and interacting in ways that require, or at least make more likely, communication by the child.

Verbal responsivity provides the optimal interactive context for language learning throughout development, although the implementation will differ depending of the age and developmental capacity of the child. Verbally responsive interac-

tions between a parent and preschooler with IDD will look different in many respects from a verbally responsive interaction between a parent and an adolescent with IDD.

We have developed and tested different telehealth-delivered PILIs for people with fragile X syndrome (FXS), which is the leading inherited cause of ID and the leading single-gene cause of autism spectrum disorder (ASD). The different versions were adapted according to the ages and developmental levels of the target group. At the heart of all the interventions, however, was the goal of improving outcomes for people with FXS by teaching and supporting increased verbal responsivity of parents through technology.

PILI for Young Children With Fragile X Syndrome

We have developed and tested the efficacy of a distance-delivered PILI for 2- to 5-year-olds with FXS (McDuffie, Oakes et al., 2016; Oakes et al., 2015). The intervention was delivered in the context of dyadic play with objects. The participants were six boys with FXS and their biological mothers. The boys ranged in age from 27 to 43 months at the start of their participation in the intervention. All had IQs in the range of ID, and the language levels ranged from no productive language to the production of an occasional multiword utterance.

The primary focus of the intervention was on increasing child communication and secondarily on improving spoken language. Parents were taught three strategies. In *follow-in commenting*, the parent was to describe an object, activity, or event that was the focus of the child's attention. In *interpreting/expanding*, the parent was to respond to a child utterance with a fuller, more adult-like version and to a child nonverbal behavior with an utterance that ascribed an intention to that behavior. In *indirect prompting*, the parent was to create a need for the child to communicate by offering a choice or delaying a desired activity or object. The parent was also taught strategies to reduce child challenging behaviors.

Parents were taught these strategies over a period of 17 weeks. The dyads visited the clinic once per month. In these clinic visits, the clinician presented the rationale for the strategies to be learned, along with video examples. This didactic session was followed by real-time coaching by the clinician as the parent played with the child. In addition to the clinic visits, there were weekly real-time dyadic play coaching sessions delivered into the home by the clinician through video teleconferencing. Parents were given a laptop computer equipped with a webcam for these in-home sessions. There were also weekly distance observation sessions for the purpose of taking data on the dyad's progress with no coaching or feedback provided. Finally, pre- and post-treatment assessments of play interactions without coaching were conducted in the clinic. Throughout the intervention, the clinician encouraged the parent to use the targeted strategies in naturally occurring interactions throughout the day.

We used a multiple baseline design in which the length of the baselines varied and the initiation of the intervention was staggered across participants so that we could be more certain that changes in parent and child behavior were due to participation in the intervention. The primary data for evaluating the efficacy of the intervention came from the observation sessions. In terms of parental behavior, the frequency of use of the targeted strategies increased during the intervention relative to baseline. In fact, there was minimal overlap for most parents in terms of their frequency of use of the strategies between baseline and treatment, although there was variability across parents in the magnitude of change. In terms of child behavior, the frequency of communication acts was greater in treatment than in baseline. This was true in general both for prompted and spontaneous acts of child communication. Increased communicativeness is important because its leads to longer and more satisfying interactions for parent and child and creates opportunities for parents to provide the child with information about the language being learned, thereby creating a positive developmental cascade.

Post-treatment surveys and interviews indicated that parents found the intervention to be helpful and felt that their interactions with their children were more positive and fulfilling as a result. These latter findings are important because positive parental attitudes are likely to be a prerequisite for the continued use of the targeted strategies after participation with the clinicians and the study has ended.

PILI for Adolescents With Fragile X Syndrome

We have developed and tested the efficacy of a parent-implemented language intervention for

preadolescents and adolescents with FXS in three studies, one a series of three single-case analyses (McDuffie, Machalicek et al., 2016), the second a small-scale randomized controlled trial (RCT; McDuffie et al., 2018), and the third an RCT of a medication with all participants also receiving distance-delivered PILI (Thurman et al., 2020). Across the studies, the participants with FXS ranged from 10 to 17 years of age, most were male, and all had IQs in the range of ID. The language skills of the people with FXS ranged from largely single-word and only occasional multiword speech to frequent use of multiword utterances, with all participants well below age-level expectations as regards language.

Parents were taught to use verbally responsive language strategies; however, because of the ages of the youth with FXS, the intervention was embedded in the context of shared story telling using wordless picture books rather than play with objects. The book functioned to provide a shared conversational topic for the dyad. In contrast to the study with young children, the focus was on building language skills. The intervention was delivered entirely into the family home through video teleconferencing, with no clinic-based instructional component. The intervention began with two parent education sessions that described the rationale for the targeted strategies and video examples. The intervention then continued for 12 weeks with four types of activities each week.

- A real-time coaching session as the parent and adolescent engaged in the shared story-telling activity.
- The parent video recorded a homework session in which he/she practiced the targeted strategies in a shared story-telling activity with the youth with FXS, later sending the video to the clinician for review.
- The parent and clinician discussed the homework via video teleconference, with the clinician emphasizing correct uses of the strategies as well as missed opportunities for strategy use.
- The clinician video recorded a story-telling session between the parent and youth with FXS, but without coaching, for subsequent analysis of parental strategy use and adolescent language behavior.

A different book was used each week so that the youth with FXS was not simply learning how to tell a specific story but was instead gaining more generalized language skills. The books were digitized and presented on an iPad.

Parents were taught three strategies. The first was to use open-ended wh-questions, such as, "What is the boy doing?" and "How is the boy feeling?" These questions tend to elicit a verbal response and thus, draw the youth with FXS into the conversation and allow him/her to practice new language skills. The second strategy was to use expansions, which entail the parent providing a fuller, more mature version of the youth's utterance and thereby an opportunity to learn new words and syntactic forms. The third strategy was the use of fill-in-the-blank statements in which the parent started a sentence but through a rising intonation and pause conveyed the expectation that the youth with FXS was to complete the sentence. Fill-in-the blank allowed the youth with FXS to participate in the conversation in way that increased the chances of communicative success.

The results across the three studies were generally consistent in supporting the efficacy of the intervention. In assessing treatment-induced changes, we examined story-telling interaction with previously unseen books with the parent at home and in the clinic, as well with an examiner in the clinic. In terms of parent behavior, participation in the treatment led to increases in the use of all three targeted strategies. In terms of the behavior of the youths with FXS, participation in the treatment led to sizable increases in a measure of expressive vocabulary (i.e., the number of different words used). The intervention also led to an increase in the length of the dyadic story-telling sessions both in time and number of story-related utterances. It was also found that changes in youth vocabulary were correlated with changes in parental behavior; that is, the more progress the parents made learning the strategies, the more progress the youth with FXS made. Finally, the same pattern of findings was observed for measures derived from parent-youth interactions at home and in the clinic and some non-targeted language skills (e.g., inferential language) also improved (Nelson et al., 2018). These data suggest that the intervention promoted growth in both mother and child behavior that was not specific to a single story or setting but more general to the dyadic shared story-telling context.

At the same time, however, there were limitations in the efficacy of the intervention.

First, no consistent differences related to treatment were found in the expressive syntax of the youth with FXS. This suggests the possibility that more direct and explicit instruction may be needed to improve syntax in this population. Second, the gains observed for the youth with FXS in vocabulary in their interactions with their mothers did not generalize to their interactions with the examiner in the clinic context. We believe that this lack of generalizability to the examiner-led interaction reflects the fact that unlike the scaffolding that parents were providing through their use of verbally responsive strategies, the examiner by design minimized his/her participation and provided minimal scaffolding. Thus, it may be that the vocabulary skills of the youth with FXS were still forming and not sufficiently developed so as to be used without considerable support

Next Steps

In summary, a training program for parents delivered into the home through telehealth technology can lead to improvements in communication and language for people with ID across a wide age range. At the same time, however, not all aspects of language seem to benefit from the intervention in its current form and generalization of gains may be limited to highly scaffolded contexts. We plan to address these limitations in future research. We also are exploring whether the coaching can be reduced and supplemented with self-guided online modules to make the intervention more cost effective.

More Examples of Technology-Delivered Services and Support

Telehealth technology is arguably the most widely used form of technology to deliver behavioral and mental health services to people with IDD. These uses extend beyond treatment delivery of the sort I have described above to in-home assessments and evaluations. No doubt there will be an explosion of examples of other technologies and uses post-pandemic. Here are just a few examples of technologies being tested now.

- Virtual reality is being used to address a variety of challenges in several populations, including to improve eye gaze during social interaction with youth with ASD (Kim & Mundy, 2012; Seo et al., 2019) and provide practice in job skills for adults with IDD (Newbutt et al., 2016).
- Computer games are being used to improve attention, learning in memory in people with a variety of IDD conditions (Benyakorn et al., 2018; Hessl et al., 2019).
- Artificial intelligence algorithms are being used to derive patterns from a host of different types of data, including video recorded parent-child interactions, as a means of screening for IDD conditions such as ASD (Nag et al., 2020).
- Wearable technologies are being used in both diagnostic and therapeutic interventions in ASD (Voss et al., 2019).
- Robots are being used to model and reinforce social skills for youth with ASD (van den Berk-Smeekens et al., 2020; Zheng et al., 2020).

Conclusions

As we move out of the pandemic and achieve some return to "normal" life, it is imperative that we not forget the lessons we have learned over the past several months. We desperately need a more robust and equitable system of services and supports for people with IDD. Evidence-based, technology-driven approaches to delivery of services will be an important part of the solution. However, additional resources and stronger government policies that lead to more and better coordinated systems are also needed. I know that AAIDD will help lead the way forward to improve choice and quality of life for people with IDD and their families.

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