

*The Use of Telehealth to Reach Children
with Neurodevelopmental Disabilities and
Families Experiencing Barriers to Early and
Intensive Intervention*

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Partnerships

- Thank you to the families that participate in this ongoing research project



MN LEND Program

Leadership Education in Neurodevelopmental
and Related Disabilities

The importance of early intervention

- Early and intensive intervention grounded in behavioral principles is linked to improvements:
 - communication
 - IQ
 - challenging behavior, and
 - related positive child and family outcomes for children with ASD.

Intervention recommendations

- **Re-authorization of the Individuals with Disabilities ACT³ parts C (EI; birth-2) and B (ECSE; 3-5) prioritizes intervention that:**
 - Routines-based intervention
 - Occurs in natural settings (i.e., the home environment)
 - Is focused on family-centered services
- **American Academy of Pediatrics**
 - (1) begin treatment when ASD is a serious consideration, including before a formal diagnosis is given, if necessary,
 - (2) provide a minimum of 25 hours of intensive intervention per week for the full calendar year, and
 - (3) include **parent involvement, education, and training**. It is equally important that these early intervention services are delivered in **family-centered settings natural to the child**

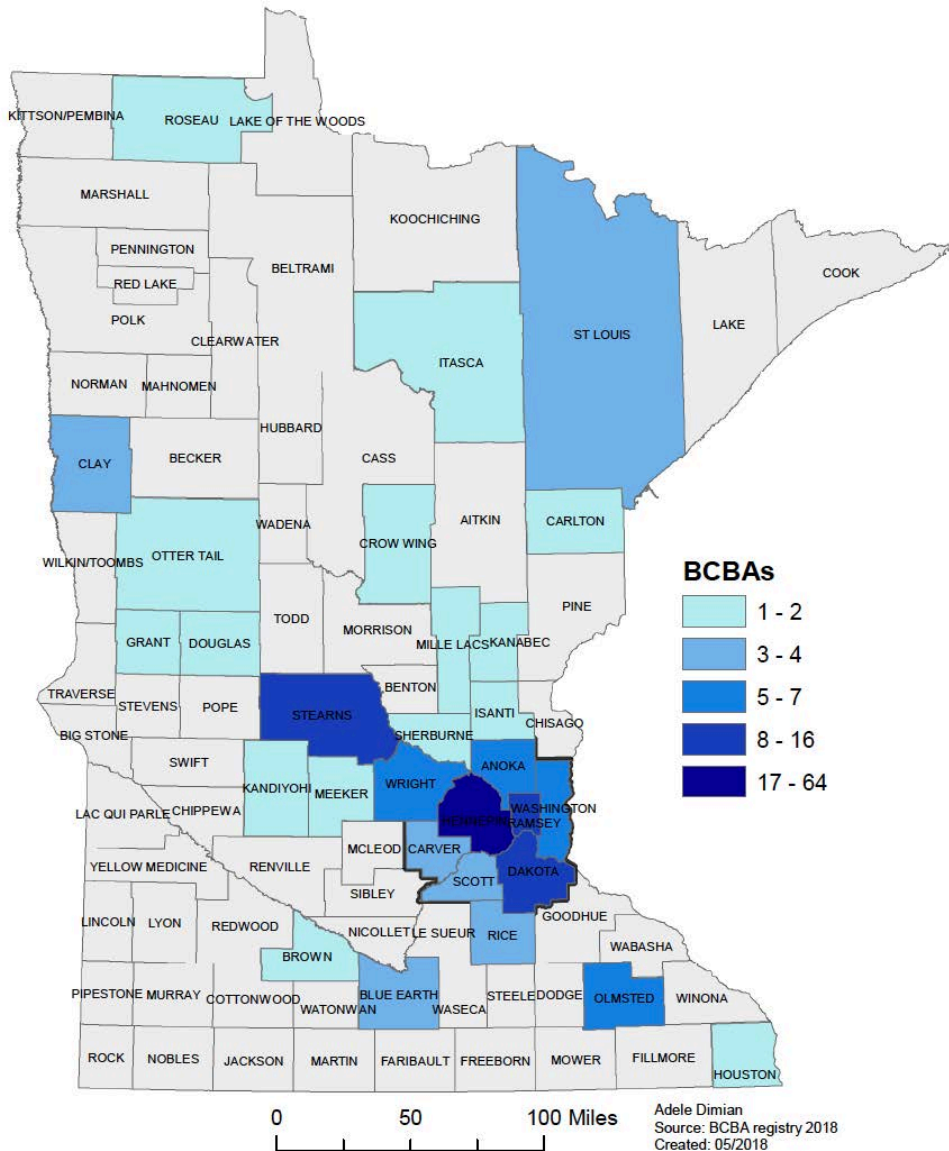
Context

- Autism spectrum disorder (ASD) prevalence
- Disparities in autism-related service access
 - Delays associated with receiving a diagnosis
 - Delays associated with starting intensive services

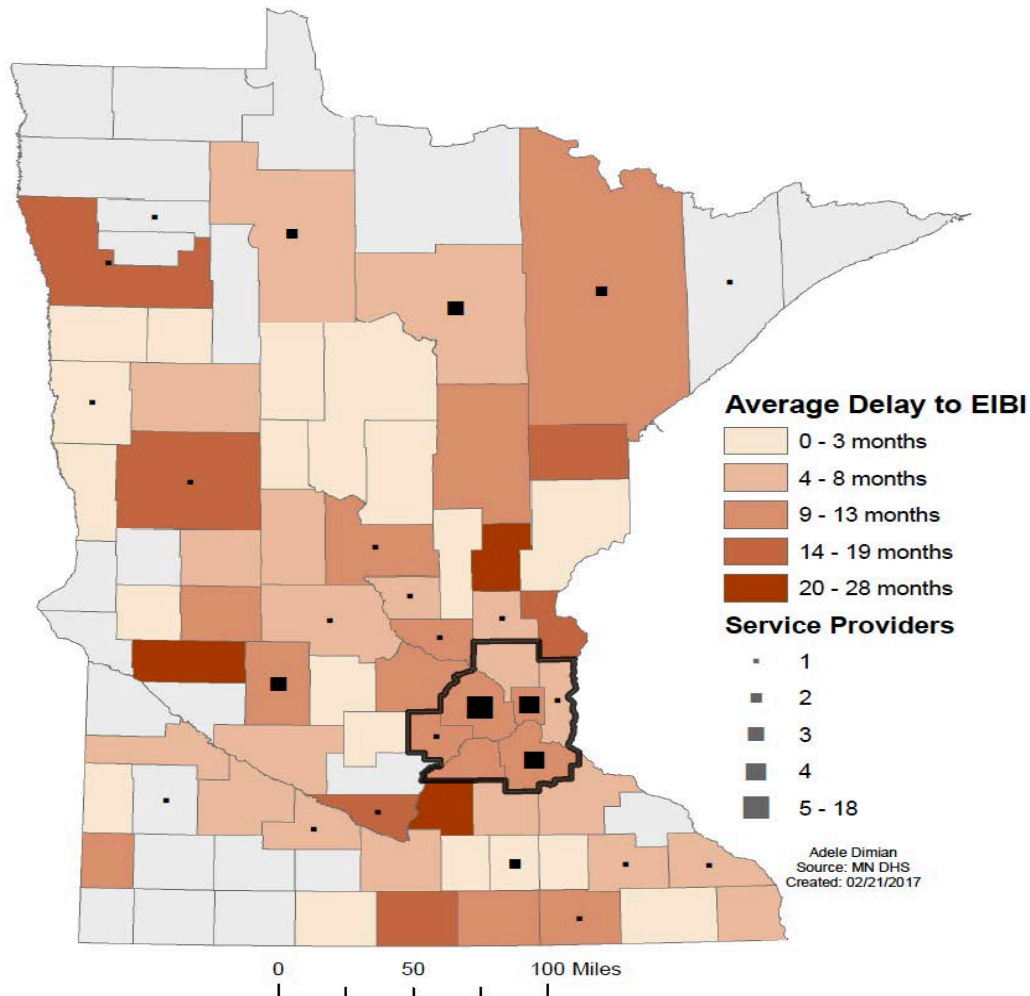
Barriers to timely service

- Waitlists
- Geographic location
- Service provider shortage

Map of BCBAs



Average Delay to EIBI



Telehealth: Overview of Modality

- The World Health Organization defines **telehealth** as including:
 - “surveillance, health promotion and public health functions. [telehealth] is broader in definition than telemedicine as it includes computer-assisted telecommunications to support management, surveillance, literature and access to medical knowledge” (WHO; December, 2015: Retrieved from <http://www.who.int/>)

Research on Telehealth Modality

- Medical literature (e.g., tele psychiatry)
- Speech-language literature (e.g., intervention for stuttering)
- Expanded to intervention for children with developmental disabilities
 - Preference assessments
 - Challenging behavior
 - Parent training (e.g., Early Start Denver Model)

Telehealth types

Asynchronous
Modules
Uploading videos
for review

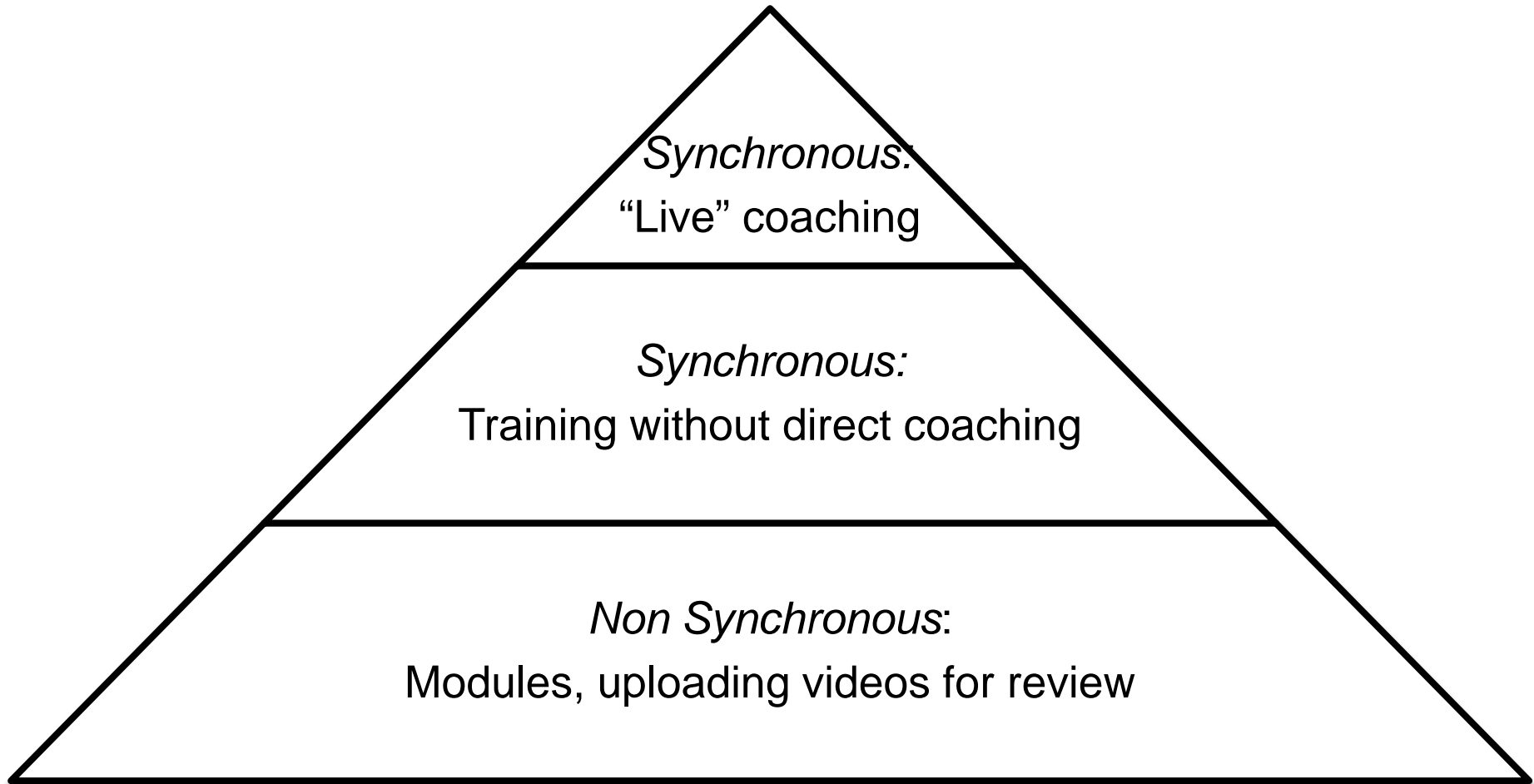


Synchronous
“Live” modules
Training w/out
direct coaching
(group or
individual)



Synchronous
“Live”
coaching/training
Implementation is
occurring during
sessions

Individualization of the Modality



Settings

Outpatient/Clinic

(Cooper et al., 1990; Harding et al., 1994; Millard et al., 1993; Northup et al., 1991; Wacker et al. 1994)



Home-based

(Wacker, 1998)



Telehealth in Satellite Centers and Schools

(Wacker et al., 2007; Machalicek et al., 2009)



Telehealth in homes

Suess et al., 2014; Wacker et al., 2013, Fetting et al., 2016, Lindgren et al., 2016; Fewell et al., in press)

ICI Telehealth Lab

- University of MN, Institute on Community Integration (ICI)
- Expand research and technical assistance on telehealth to decrease barriers experiences by people with developmental disabilities
- UMN Leadership in Neurodevelopmental Disabilities (LEND) program

Intervention Model

Involves remote coaching from research staff via video conferencing with parents/caregivers and children in their home environment

- Caregiver-implemented (with researcher/interventionist coaching) assessment and intervention for challenging behavior
- Caregiver-implemented assessment and intervention to increase communication within home routines

Identify contexts of challenging behavior or potential communicative behavior

Caregiver-implemented functional communication intervention

Assessments:

Interviews

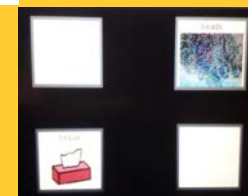
Structured observations

Identify
Routines/
contexts
Potentially
communicative
behavior

Intervention (based in Applied Behavior Analysis)

Augmentative and alternative
communication (AAC)
programming

Functional communication
training



Process

- Screen
- Lending technology kits to families, if needed
- Manual/resources to support technology, explain process
- Environmental check
- Assessment
- Intervention
- Follow up

Routines-based Communication Intervention via Telehealth

- Parent-coaching communication intervention provided via telehealth for three young children with neurodevelopmental disabilities
- First, three routines identified with potentially communicative behavior (e.g., leading, reaching)
- Next, FCT implemented to teach aided AAC
- All children acquired the targeted communication (requests)

J Autism Dev Disord (2017) 47:744–767
DOI 10.1007/s10803-016-3006-z

ORIGINAL PAPER

Communication Intervention for Young Children with Severe Neurodevelopmental Disabilities Via Telehealth

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Published online: 16 January 2017
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Abstract Young children with neurodevelopmental disorders such as autism spectrum disorders (ASD) and Rett syndrome often experience severe communication impairments. This study examined the efficacy of parent-implemented communication assessment and intervention with remote coaching via telehealth on the acquisition of early communication skills of three young children with ASD (2) and Rett syndrome (1). Efficacy of the intervention was evaluated using single-case experimental designs. First, functional assessment was used to identify idiosyncratic/potentially communicative responses and contexts for each child. Next, parents implemented functional communication training (FCT). All of the children acquired the targeted communication responses. The findings support the efficacy of telehealth as a service delivery model to coach parents on intervention strategies for their children's early communication skills.


Introduction
Early intervention targeting communication and other critical developmental domains is strongly recommended to promote optimal outcomes for children with autism spectrum disorder (ASD) and related neurodevelopmental disabilities (American Academy of Pediatrics 2007; Individuals with Disabilities Education Act [IDEA] 2004; National Research Council 2001; Satcher 2000). Further, early and intensive intervention grounded in behavioral principles is linked to improvements in communication (Cohen et al. 2006; Sallows and Graupner 2005), IQ (Sheinkopf and Siegel 1998; Sallows and Graupner 2005; Cohen et al. 2006; Eldevik et al. 2006), challenging behavior (Wacker et al. 2013a, b), and related positive child and (Harris and Handleman 2000) family outcomes (Remington et al. 2007) for children with ASD.

Recommendations based on research findings indicate that early intervention should be delivered as an intensive, individualized, and specialized service (American Academy of Pediatrics 2007; Rogers 1998; National Research Council [NRC], 2001). The American Academy of Pediatrics issued the following 2007 guidelines for children with ASD: (1) treatment should begin when ASD is a serious consideration, including before a formal diagnosis is given, if necessary, (2) a minimum of 25 h of intensive intervention per week for the full calendar year should occur, and (3) parent involvement, education, and training (retrieved from pediatrics.aappublications.org) need to be a part of treatment. Equally important is that services are delivered in family-centered settings natural to the child (AAP 2007; Horn et al. 2002; IDEA 2004; NRC 2001).

Keywords Communication intervention · Telehealth · Idiosyncratic responses · FCT

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Low-Tech AAC: Ella

	Contexts	Idiosyncratic Behavior	AAC Request
Ella	Snack/Drink Video Break	Leading Parents Tantrums	 PECS Verbal approximation

High Tech AAC via Telehealth

Advances in Neurodevelopmental Disorders
<https://doi.org/10.1007/s41252-018-0055-7>

ORIGINAL PAPER



Teaching Communicative Responses with a Speech-Generating Device Via Telehealth Coaching

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Abstract

Caregivers need support with teaching augmentative and alternative communication (AAC). The purpose of this study was to coach caregivers via telehealth (i.e., live video conferencing with Google Hangout) to implement communication assessments, functional communication training (FCT), and/or navigation training to address either idiosyncratic or problem behavior exhibited by two young boys with developmental delay (age 5.5 years) and autism (age 7 years) who were non-verbal. An adapted multiple probe design and a multiple probe design across three contexts (play, break from demands, help) were used to evaluate acquisition of communicative requests using high tech aided AAC on a speech-generating device (SGD; a Tobii Dynavox T10 device). A forward chain was also introduced to teach symbol selection and navigation on the SGD. Both children acquired the communicative alternatives across each context. Caregiver implementation fidelity was measured with procedural checklists and was acceptable across baseline and intervention sessions for both children. Children with developmental disabilities face many barriers to accessing needed communication intervention and may not have access to interventionists with the expertise in AAC with a SGD. Our findings have potential research implications for the use of telehealth to improve access to expertise in high tech aided AAC communication assessment and intervention.

Keywords Alternative and augmentative communication · Speech generating device · Telehealth

Many individuals with neurodevelopmental disabilities (NDDs) have complex communication needs and as a result require alternative and augmentative communication (AAC) strategies to augment or replace the use of spoken utterances (Johnston et al. 2012). When learners do not have intelligible conventional communicative means, they are at risk for developing a communicative repertoire that consists of idiosyncratic behavior that may evolve into problem behavior (Johnston et al. 2012; Reichle and Wacker 2017). This, in turn, can contribute to reduced participation in social opportunities

and affect quality of life. It is therefore important for individuals with NDDs to have access to AAC strategies to increase their communicative repertoires.

Aided communication systems, a type of AAC, play a prominent role in establishing a beginning repertoire of communicative behavior among persons with significant NDDs (Johnston et al. 2012). Reichle and Drager (2010) characterized an aided communication system as one that requires the use of materials that extend beyond an individual's own physiological means of producing a communicative output (e.g., vocalizations, verbalizations, or gestures). Within aided communication systems, there are low-, mid-, and high-tech options. Low-tech options do not involve the application of electronics (e.g., the Picture Exchange Communication System; Bondy and Frost 1994). Mid- and high-tech aided AAC options involve a continuum of devices typically with a limited number of speech-recorded messages (e.g., mid-tech devices include the BIGmack® and Go Talk® series;

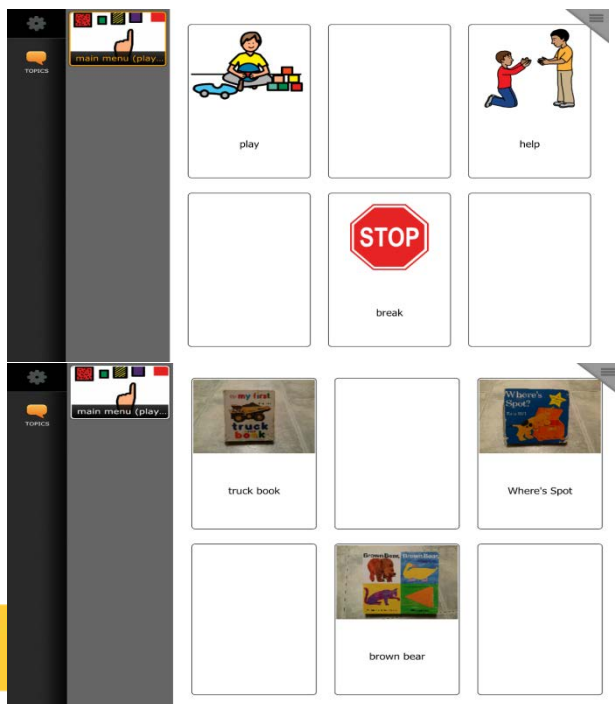
Electronic supplementary material The online version of this article (<https://doi.org/10.1007/s41252-018-0055-7>) contains supplementary material, which is available to authorized users.

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- Parent-coaching to teach high tech AAC (e.g., Proloquo2go) requests for two children with multiple disabilities.
- First, identified routines with potentially communicative behavior
- Next, taught requests using the high tech AAC devices
- For one of the participants, expanded across multiple page selections including navigation skills.

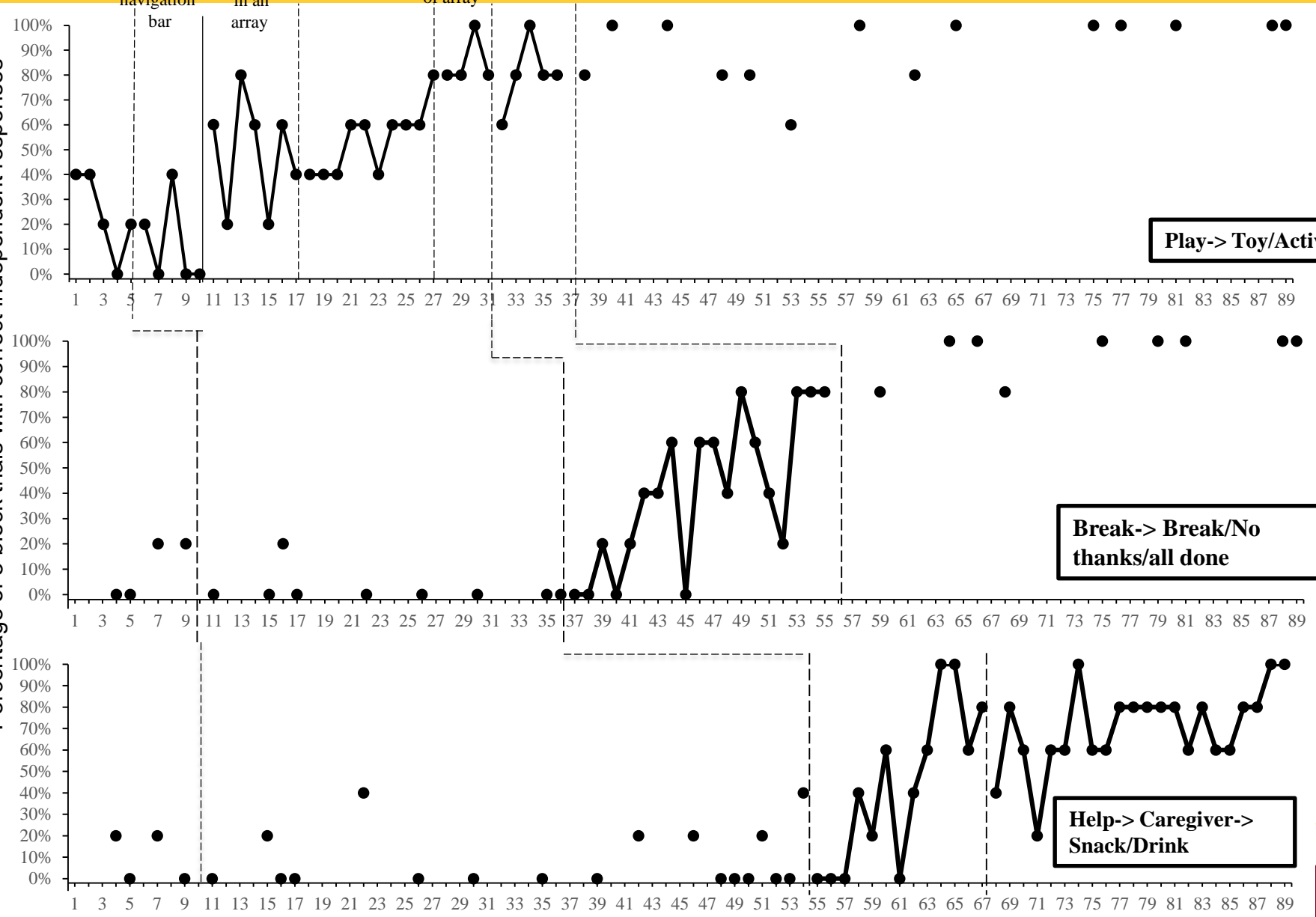
High Tech AAC: Tim

- High technology AAC (synthesized speech output devices; e.g., Tobii; Proloquo2go)
- Requires many skill sets
 - Selection response, discrimination, navigation



Baseline: superordinate symbols on navigation bar
Intervention: superordinate symbols on navigation bar
Baseline: superordinate symbols in an array
Intervention: superordinate symbols in an array
 Middle symbol moved to bottom row of array
 Symbol position randomized
 Maintenance

Percentage of 5 block trials with correct independent responses



5 block trial sessions

Current/future research

- Naturalistic Developmental and Behavioral Interventions (NDBI)
- Expanding train-the-trainer model with LEND fellows
- Identify needs and barriers for provider agencies, including telehealth implementation
- Partnership with UMN Autism Clinic to expand telehealth
- Estimating cost-benefit

NDBI TELEHEALTH PROJECT



Estimation of saved costs

- ***Wacker, Lee, & Colleagues (2013)*** estimation of weekly cost comparison
 - FA w/ interventionist
 - In home \$335.09
 - Via telehealth \$57.95
- ***Lindgren, Wacker, Suess & Colleagues (2016)***
 - 3 models service delivery (in home, tele-clinic, tele-in home)
 - Both tele models FAR less costly, without degradation in outcomes

Limitations

- Telehealth may not be appropriate for certain situations
 - Severe/dangerous forms of challenging behavior
 - *Can* be impacted by Internet quality
 - Privacy (e.g., bath time, potty training, others in home/area who are on video)
 - Community/outside
 - Elopement/child who is moving around a lot
- Though it is a billable service through some funding in MN, not yet widely adopted
- Still being investigated, many future directions

MN: THE STATE OF TELEHEALTH FOR INTERVENTION WITH CHILDREN WITH AUTISM

Early Intensive Developmental and Behavioral Intervention (EIDBI) Benefit

“As of Jan. 1, 2016, Medical Assistance (MA) covers medically necessary *telemedicine services and consultations.*”

WHO:

Physician, Nurse practitioner, Clinical psychologist, Clinical social worker, Speech therapist, Physical therapist, Occupational therapist, ***Mental Health Practitioner**

WHAT:

- Comprehensive multi-disciplinary evaluation
- Coordinated care conference
- Family/caregiver training
- Intervention observation and directions

Policy

- 48 state Medicaid programs have some type of live-video reimbursement
- Minnesota is one of six states that covers in home telehealth services (Center for Connected Health Policy, 2017)

MN Legislation: SF 562 - Autism

Bill Number: [SF 562](#)

Sponsor: Sen. Abeler

Summary: Modifies certain provisions governing autism early intensive intervention benefit, and requires coverage when delivered through telemedicine, the same as it would be if it were delivered in person.

MN Partnership targeting Telehealth

- University of MN, ICI partnering with Department of Human Services to advance telehealth for autism assessment and intervention in MN.
- Identifying needs of families and providers and current provider telehealth practices
- Identifying means to use telehealth to help address provider shortage

Thank you

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