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
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 ACT\(^3\) 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
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

Synchronous:
- “Live” coaching

Synchronous:
- Training without direct coaching

Non Synchronous:
- Modules, uploading videos for review
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, Fettig 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
Assessments:
- Interviews
- Structured observations

Intervention (based in Applied Behavior Analysis)
- Augmentative and alternative communication (AAC) programming
- Functional communication training

Identify Routines/contexts
Potentially communicative behavior
<table>
<thead>
<tr>
<th>Process</th>
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<tbody>
<tr>
<td>Screen</td>
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<tr>
<td>Lending technology kits to families, if needed</td>
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<tr>
<td>Manual/resources to support technology, explain process</td>
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<tr>
<td>Environmental check</td>
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<tr>
<td>Assessment</td>
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<tr>
<td>Intervention</td>
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<td>Follow up</td>
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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).
## Low-Tech AAC: Ella

<table>
<thead>
<tr>
<th>Contexts</th>
<th>Idiosyncratic Behavior</th>
<th>AAC Request</th>
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<tbody>
<tr>
<td>Snack/Drink Video Break</td>
<td>Leading Parents Tantrums</td>
<td>PECS Verbal approximation</td>
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High Tech AAC via Telehealth

- 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
Percentage of 5 block trials with correct independent responses

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

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
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
• 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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