Using Telehealth in the Field of Autism Intervention and Research

Lindsey Burrell, PhD
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Overview

- Autism Spectrum Disorder (ASD) and empirically supported treatments
- Barriers to treatment for ASD overcome by telehealth
- Details related to telehealth programs at the Marcus Autism Center
  - Parent Training (clinic-to-clinic)
  - Brief Behavior Intervention Program (clinic-to-home)
  - Community Autism Program (clinic-to-home)
Telehealth at Children’s Healthcare of Atlanta (CHOA)

TELEHEALTH OFFERINGS
Through December 2015

- LDL, Peer Review
- Medical Visits
- Store & Forward
- Research
- Behavioral Health

<table>
<thead>
<tr>
<th>Year</th>
<th>LDL, Peer Review</th>
<th>Medical Visits</th>
<th>Store &amp; Forward</th>
<th>Research</th>
<th>Behavioral Health</th>
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Total for 2015: 2,847
Autism Spectrum Disorder

- Diagnostic Criteria
  - Difficulties in verbal and nonverbal communication
  - Functional limitations in communication, social interactions, relationships, academics, and/or occupation
  - Onset early in development

- Current Prevalence Rates of 1 in 68 Children (CDC, 2014)

- Noncore symptoms are frequent targets of treatment
  - High rate of disruptive behavior problems (≈50%)
Empirically Supported Treatments for ASD

• Parents overwhelmed by ‘treatment’ choices
  – Google search ‘Autism Treatment” = 69.6 million hits
  – Few of these are empirically supported

• Behaviorally-based parent training is one of the few evidence-based treatments for ASD
Benefits of Telemedicine

• Decreased time to first appointment

• Increased access to specialized programs available in limited locations

• Successful at accurately assessing and treating problem behavior and improving communication (Gibson, 2010; Wacker et al., 2013)
Parent Training in Autism Spectrum Disorder

- Parent Support
  - Knowledge-focused
  - Child is *Indirect* Beneficiary
    - Care Coordination
    - Psychoeducation

- Parent Implementation
  - Skill-focused
  - Child is *Direct* Beneficiary
    - Parent-Mediated Interventions for Core Symptoms
      - Social Communication, Imitation, Play
        - Primary (e.g., JASPER)
        - Complimentary (e.g., ESDM)
    - Parent Training for Maladaptive Behaviors
      - Disruptive Behavior, Feeding, Sleep, Toileting
        - Primary (e.g., RUPP PT)
        - Complimentary (e.g., Feeding Day Treatment)

A Pilot Study of Parent Training via Telehealth for Children with ASD And Disruptive Behavior

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Marcus Autism Center
Department of Pediatrics
Emory University
Parent Training for Disruptive Behaviors

AUTHORS
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Benjamin Handen, PhD  
Eric Butter, PhD  
Luc Lecavalier, PhD

Edited by Lawrence Scahill, MSN, PhD and Tristram Smith, PhD
Original Investigation

Effect of Parent Training vs Parent Education on Behavioral Problems in Children With Autism Spectrum Disorder
A Randomized Clinical Trial

Karen Bearss, PhD; Cynthia Johnson, PhD; Tristram Smith, PhD; Luc Lecavalier, PhD; Naomi Swiezy, PhD; Michael Aman, PhD; David B. McAdam, PhD; Eric Butter, PhD; Charmaine Stillitano, MSW; Noha Minshawi, PhD; Denis G. Sukhodolsky, PhD; Daniel W. Mruzek, PhD; Kylan Turner, PhD; Tiffany Neal, PhD; Victoria Hallett, PhD; James A. Mulick, PhD; Bryson Green, MS; Benjamin Handen, PhD; Yanhong Deng, MPH; James Dziura, PhD; Lawrence Scahill, MSN, PhD

Yale University          Ohio State University
Emory University         Rochester University
University of Pittsburgh  Indiana University
Parent Training (PT) for Disruptive Behavior in ASD

- Piloted manual (Johnson et al., 2007)
  - Feasibility, acceptability
- Tested in 24 Week trial of Risperidone only vs. Risperidone + PT (Aman et al., 2009)
- Adapted and piloted manual for use as a solo treatment for young children with ASD (Bearss et al., 2013)
  - Preventative
  - Recognition that many families of young children not yet open to medication
- Tested in 24 Week trial of PT vs. Parent Education (PE) (Bearss et al., 2015)
Key Points of RUBI PT Program

• Manualized intervention to target:
  – Noncompliance, tantrums, aggression, transition difficulties
• Based on principles of ABA
• Delivered individually to the parents
  – 60 to 90- minute sessions
• Each session contains
  – Therapist script
  – Fidelity forms
  – In session activity sheets/video vignettes
  – Homework assignments (individually tailored)
What We Learned and Where to Go

- A 24-week parent training (PT) program for children with ASD and disruptive behaviors is effective in reducing disruptive behaviors when delivered *in-person* to families.

- Goal of wider implementation:
  - 6 sites + 23 therapists + 97% fidelity = high promise
  - Increase access to more individuals
    - Group
    - Train-the-trainer model
    - **Telehealth**
Research on Treatment via Telehealth in ASD

• Boisvert et al review (2010)
  – 8 peer-reviewed papers
  – Largely single subject

• Recent studies
  – Language and joint attention (Vismara et al., 2013)
  – FCT (Wacker et al, 2013)
Current Pilot Study

• Unclear whether PT program will work when delivered via Telehealth

• This open-label pilot study focuses on the *feasibility* of delivering the PT intervention via Telehealth by therapists from the Marcus Autism Center
Telehealth Participants

• Children with ASD + disruptive behavior and their parents/caregivers
• Living near one of 4 collaborating sites
  • part of the Georgia Partnership for Telehealth (GPT) network
Inclusion Criteria

- Children between the ages of 3-8
- Diagnosis of ASD
- Score > 10 on the parent-rated Aberrant Behavior Checklist Irritability Subscale
- Stable medication/treatment
- Means of transportation to local Telemedicine site
# Modifications to PT

<table>
<thead>
<tr>
<th>Research Protocol</th>
<th>Manual</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Expand age range up to 8</td>
<td>• Remove home visits (HV)</td>
</tr>
<tr>
<td>• Reduce ABC-I inclusion score from 15 to 10</td>
<td>• Week 20 HV turned into 2\textsuperscript{nd} telephone booster call</td>
</tr>
<tr>
<td>• Remove RL &lt; 18 mo. exclusion</td>
<td>• Remove role-plays</td>
</tr>
<tr>
<td>• Accept ASD community diagnosis</td>
<td></td>
</tr>
<tr>
<td>11 CORE SESSIONS</td>
<td>SKILLS / ACTIVITIES</td>
</tr>
<tr>
<td>--------------------------</td>
<td>------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Behavioral Principles</td>
<td>Introduce treatment goals and concepts of behavioral functions, antecedents and consequences of behavior</td>
</tr>
<tr>
<td>Prevention Strategies</td>
<td>Discuss antecedents to behavior problems and develop preventive strategies</td>
</tr>
<tr>
<td>Daily Schedules</td>
<td>Develop a daily schedule and identify points of intervention (including use of visual schedules) to decrease behavior problems</td>
</tr>
<tr>
<td>Reinforcement I</td>
<td>Introduce the use of reinforcers – to promote compliance, strengthen desired behaviors and teach new behaviors</td>
</tr>
<tr>
<td>Reinforcement II</td>
<td>Teach play and social skills through child-led play</td>
</tr>
<tr>
<td>Planned Ignoring</td>
<td>Explore systematic use of planned ignoring to reduce behavioral problems</td>
</tr>
<tr>
<td>Compliance Training</td>
<td>Introduce effective parental requests and the use of guided compliance to enhance compliance and manage non-compliance</td>
</tr>
<tr>
<td>Functional Communication</td>
<td>Teach alternative, communicative skills to replace problematic behaviors</td>
</tr>
<tr>
<td>Teaching Skills I &amp; II</td>
<td>Using task analysis, chaining, and prompting, provide parents with tools on how to replace problem behaviors with appropriate behaviors, and promote new adaptive, coping and leisure skills</td>
</tr>
<tr>
<td>Generalization/Maintenance</td>
<td>Generate strategies to consolidate behavior changes and establish new skills</td>
</tr>
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</table>

**OPTIONAL SESSIONS**

- Toileting, Feeding, Sleep, Time Out, Imitation, Point Charts

**WEEK 16**

- Week 18 Telephone Booster: Review intervention strategies and troubleshoot new behaviors
- Week 20 Telephone Booster: Review intervention strategies and troubleshoot new behaviors
- Week 22 Telephone Booster: Review intervention strategies and troubleshoot new behaviors
# Feasibility Outcome Measures

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Benchmark</th>
<th>Rated by</th>
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<tbody>
<tr>
<td>Therapist Fidelity</td>
<td>≥90%</td>
<td>Independent Review</td>
</tr>
<tr>
<td>Parent Adherence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Treatment engagement</td>
<td>≥80%</td>
<td>Therapist</td>
</tr>
<tr>
<td>- Understanding in-session materials</td>
<td>≥80%</td>
<td>Therapist</td>
</tr>
<tr>
<td>- Homework completion</td>
<td>≥80%</td>
<td>Therapist</td>
</tr>
<tr>
<td>Parent Acceptability</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Core session attendance</td>
<td>≥85%</td>
<td>Parent</td>
</tr>
<tr>
<td>- Satisfaction (endorse competence)</td>
<td>≥80%</td>
<td>Parent</td>
</tr>
<tr>
<td>- Attrition</td>
<td>≤20%</td>
<td>Parent</td>
</tr>
</tbody>
</table>
Study Enrollment

14 families enrolled

12 Participants completed all 11 core
  10 by Week 16
  2 by Week 24
1 Participant completed 10 cores

13 participants completed the 24 Week Trial

1 dropped out with no core sessions
### Baseline Child Demographics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N = 14</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Child Demographics</strong></td>
<td></td>
</tr>
<tr>
<td>Child Age, Mean ± SD</td>
<td>5.84 ± 1.68</td>
</tr>
<tr>
<td>IQ Score, Mean ± SD*</td>
<td>69.36 ± 17.56</td>
</tr>
<tr>
<td>Gender – Males, N (%)</td>
<td>9 (64.3%)</td>
</tr>
<tr>
<td>Race, N (%)</td>
<td></td>
</tr>
<tr>
<td>White, Non-Hispanic</td>
<td>10 (71.4%)</td>
</tr>
<tr>
<td>African American, Non-Hispanic</td>
<td>2 (14.3%)</td>
</tr>
<tr>
<td>White, Hispanic</td>
<td>1 (7.1%)</td>
</tr>
<tr>
<td>African American, Hispanic</td>
<td>1 (7.1%)</td>
</tr>
<tr>
<td>Diagnosis, N (%)</td>
<td></td>
</tr>
<tr>
<td>ASD**</td>
<td>12 (85.7%)</td>
</tr>
<tr>
<td><strong>School Program, N (%)</strong></td>
<td></td>
</tr>
<tr>
<td>Regular Class</td>
<td>6 (42.9%)</td>
</tr>
<tr>
<td>Special Education</td>
<td>7 (50%)</td>
</tr>
<tr>
<td>Home School</td>
<td>1 (7.1%)</td>
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</table>
## Baseline Parent Demographics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N = 14</th>
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<tbody>
<tr>
<td>Mother Age, Mean ± SD</td>
<td>38.29 ± 8.25</td>
</tr>
<tr>
<td>Father Age, Mean ± SD (N = 13)</td>
<td>39.77 ± 10.22</td>
</tr>
<tr>
<td>Two-Parent Family, N (%)</td>
<td>12 (85.7%)</td>
</tr>
<tr>
<td>Household Income, N (%)</td>
<td></td>
</tr>
<tr>
<td>&lt; $20,000</td>
<td>4 (28.6%)</td>
</tr>
<tr>
<td>$20,000 – $40,000</td>
<td>5 (35.7%)</td>
</tr>
<tr>
<td>$40,001 – $60,000</td>
<td>2 (14.3%)</td>
</tr>
<tr>
<td>$60,001 – $90,000</td>
<td>1 (7.1%)</td>
</tr>
<tr>
<td>&gt; $90,000</td>
<td>2 (14.3%)</td>
</tr>
<tr>
<td>Maternal Education, N (%)</td>
<td></td>
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<tr>
<td>&lt; 8th Grade</td>
<td>1 (7.1%)</td>
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<tr>
<td>HS Graduate/GED</td>
<td>1 (7.1%)</td>
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<tr>
<td>Some College</td>
<td>7 (50%)</td>
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<tr>
<td>College Graduate</td>
<td>4 (28.6%)</td>
</tr>
<tr>
<td>Advanced Graduate</td>
<td>1 (7.1%)</td>
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</table>
Baseline Child Clinical Characteristics

• **ABC** (mean, SD)
  – Irritability = 25.2 (9.5)
  – Hyperactivity = 26.2 (10.8)
• **Mean HSQ-ASD** = 3.6 (1.7)
• **Vineland II** (mean, SD)
  – Communication = 65.9 (13.0)
  – Daily Living = 69.9 (14.0)
  – Socialization = 68.0 (10.0)
  – Motor Skills = 77.2 (19.2)
  – Composite = 67.0 (10.6)
## Feasibility Outcomes

<table>
<thead>
<tr>
<th>Feasibility Measure</th>
<th>%</th>
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<tr>
<td>Therapist Fidelity to the Manual</td>
<td>96.7%</td>
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<tr>
<td>Parent Engagement in Treatment</td>
<td>88.4%</td>
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<tr>
<td>Parent Understanding of In-Session Material</td>
<td>91.5%</td>
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<tr>
<td>Parent Homework Completion</td>
<td>77.9%</td>
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<tr>
<td>Parent Attendance to Core Sessions</td>
<td>92.2%</td>
</tr>
<tr>
<td>Attrition Rate</td>
<td>7.1%</td>
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# Feasibility Outcomes

<table>
<thead>
<tr>
<th>Feasibility Measures</th>
<th>%</th>
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<tr>
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</tr>
<tr>
<td>Parent Homework Completion</td>
<td></td>
</tr>
<tr>
<td>Parent Attendance to Sessions</td>
<td>91.6%</td>
</tr>
<tr>
<td>Attrition Rate</td>
<td></td>
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<tr>
<td>Parent Satisfaction</td>
<td>100% recommend to others</td>
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Conclusions

• Therapists reliably administered the PT intervention via Telehealth
• Parents found it an acceptable modality of treatment delivery.
• The low attrition rate and high parent satisfaction suggest that parents enjoyed the program and found it helpful in reducing disruptive behavior in their children.
Challenges

• Conducting research at clinical sites
  – Site buy-in/engagement
  – Registration of research patient visits at clinical site
  – Availability of rooms (office/conference rooms)
• Availability of sites
  – 2 schools; closed during summer/vacations
• Technical issues
Limitations

• Open label design
• Small sample size
• Results under optimal conditions
• Reliance on parent/therapist self-report

Future Directions

• Evaluate the PT program delivered via Telehealth using a large scale randomized control trial (RCT).
Clinic-to-Home Telehealth: Problem Behavior and Ethical Concerns

Mindy Scheithauer, PhD, BCBA-D
Severe Behavior Department
Severe Behavior Clinic

- Using Telehealth in 4 distinct ways:
  1. Brief Behavior Intervention Program
  2. In-Home Observations for Day Treatment Program
  3. Intakes
  4. Evaluation of Functional Analyses
Brief Behavior Intervention (BBI) Program

- 10-week, individualized treatment program
- Focus on reduction of problematic behaviors and development of adaptive replacement behaviors:
  - Aggression
  - Self-Injurious Behavior
  - Disruptive Behavior
  - Noncompliance
<table>
<thead>
<tr>
<th></th>
<th>Home/Community</th>
<th>Clinic</th>
<th>Telehealth</th>
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<tbody>
<tr>
<td>Reactivity</td>
<td>Good</td>
<td>Poor</td>
<td>Good</td>
</tr>
<tr>
<td>Replicating Problematic Scenarios</td>
<td>Good</td>
<td>Poor</td>
<td>Good</td>
</tr>
<tr>
<td>Therapist Travel Time</td>
<td>Poor</td>
<td>Good</td>
<td>Good</td>
</tr>
<tr>
<td>Caregiver travel Time</td>
<td>Good</td>
<td>Poor</td>
<td>Good</td>
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<tr>
<td>Ease of Observation</td>
<td>Good</td>
<td>Good</td>
<td>Poor</td>
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<tr>
<td>Technology Issues</td>
<td>Good</td>
<td>Good</td>
<td>Poor</td>
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</table>
BBI Admission Summary

• Appointment 1: Collect initial information and test technology

• Appointments 2 – 3: Functional analysis conducted by caregiver with therapist as coach
  – Determine why problem behavior is occurring
  – Set-up scenarios most likely to evoke problem behavior
  – Example: to gain access to an iPad or to avoid brushing teeth
• Appointments 4-5: Test treatment strategies
  – Work with the caregiver to implement treatment “sessions”
  – Starting with time intensive strategies that ensure initial success
  – Example: praise every 30 seconds or a break after each homework problem completed
  – Caregiver practices daily between sessions
BBI Admission Summary

- Appointments 6-10: Generalize treatment strategies
  - Work with the caregiver to decrease intensity of treatment
  - Treatment is implemented all day
  - Test treatment in novel situations (example: grocery store or park)
  - Teach novel caregivers the treatment (example: grandparents or teachers)
  - Teach the primary caregiver to train others in the treatment
Outcomes Across 9 Months

9 clients completed program

- 6 (75%) successful admissions: Similar to Traditional Admissions
- 2 (25%) DC due to funding issues: Higher than Traditional Admissions (2%)
- 1 (12.5%) DC due to caregiver buy-in issues: Similar to Traditional Admissions
Day Treatment Clinic

- Most intensive service in severe behavior
- All kids are at imminent risk of harm to themselves or others
- Admission includes 6 hours a day, 5 days a week appointments
- Approximate admission length of 3 months
- Staffing of 3:1 during admission with extensive caregiver after development of a successful treatment package
Day Treatment Clinic – Typical Admission

- In home observation
- Assessment
- Treatment development
- Generalization and caregiver training
- Post discharge follow-up
Intakes

- Severe behavior offers a continuum of services
- Important for a trained clinician to observe problem behavior to determine the appropriate placement
- Referrals come from all across the country
  - Distance often increases the importance of an appropriate referral
    - Scheduling requirements across time zones
    - Relocation based on severity
    - Identification of local resources
Telehealth Research

• Wacker & Colleagues at Iowa
  – Functional analysis of problem behavior followed by functional communication training
  – Conducted with no trained personnel in the home

• Resulted in an average reduction of problem behavior of 94% (N=20)
  – Similar reduction rates when compared to accounts of in-clinic cases
Telehealth Grant

• Multisite grant evaluating the necessity of functional analyses in the treatment of problem behavior

• Participants are randomly assigned to a treatment including a functional assessment of problem behavior or a less structured observation

• All sessions will take place via Telehealth (no face-to-face contact)
  – Allows for a larger sample more representative of different regions (e.g., rural)
Clinic-to-Home Barriers

- Families are required to have internet and electronic device
- Technological difficulties
- Active children
  - Difficult to keep the child in the frame
Telehealth Barriers

• We are not there to manage problem behavior or follow-through with prompts
  – Could be potentially detrimental if caregiver “gives in” during instruction or treatment

• Cannot fully survey environment

• Excluding families without internet or devices or the ability to learn through this mode
  – Likely the same group that does not have transportation to get to the clinic
Ethical Concerns – American Psychological Association (APA)

- APA licensure across states
  - Only 3 states have implemented specific guidelines for Telehealth

- Evidence-based nature of interventions when delivered via a different modality

- APA Statement
  - "In those emerging areas in which generally recognized standards for preparatory training do not yet exist, psychologists nevertheless take reasonable steps to ensure the competence of their work and to protect patients, clients, students, research participants, and others from harm."

Clinic-to-Home Telehealth: Language and Skill Acquisition

Caitlin Delfs, PhD, BCBA-D
Language and Learning Clinic
Language and Learning Clinic

- Overview of LLC
Language and Learning Clinic

• Using Telehealth in 3 distinct ways:
  1. To augment Language and Learning Clinic direct services
     • Consult or Follow-up with parents
     • Observation of clients/staff
  2. Mand Training - Telehealth grant
  3. Community Autism Program
Parent Training Taxonomy

1. Augment to LLC Direct Services

- 20 of our 85 families receive services in their homes
- Includes direct services, parent training, and generalization to new settings and people
  
  20 clients receiving services +
  10 direct care staff +
  3 supervisors =

Lots of driving for staff
Reactivity in staff when supervisors are present
Reactivity/distractions for clients when others are there
Extra technology required
1. Augment to LLC Direct Services

• How we use Telehealth:
  – To provide supervision and coaching to staff
  – To train on new protocols and procedures
  – To view child behavior in the moment
  – To provide parents with coaching and guidance
  – To provide follow up, generalization training, and crisis management services to parents

• Benefits:
  – Decreases distractions for client
  – May decrease reactivity in staff
  – Recording built-in
  – Reduces drive time/mileage reimbursement
2. Mand Training Telehealth grant

• A Pilot Study to Train Caregivers to Increase Functional Expressive Language in Children with Autism Spectrum Disorder: An Evaluation of Telehealth Services
  – Emory University Junior Faculty Focused Award; through the Center for Clinical and Translational Research
  – 15 caregiver/child dyads
  – Preverbal phase of Spoken language
  – Initial request training
  – 12 weeks (up to 24 visits)
  – **All** assessments and evaluations will be completed via Telehealth
3. Community Autism Program

• 12-week, structured caregiver training program
• Developed for families who have received a recent diagnosis of autism and are interested in training and education
• Utilizes Behavioral Skills Training
  – Includes didactics, coaching, immediate and delayed feedback, live and video modeling, observational data
• Focus on building skills across a variety of areas:
  – Increasing language and functional communication
  – Social skill development
  – Developing routines
3. Community Autism Program

- Referral Process
  - Complete LLC screening packet
  - Complete LLC face-to-face Intake appointment (if needed)
- Scheduled to see almost 200 families each year with about 10 staff
  - 10% Telehealth
  - 60% in home
  - 30% in clinic
3. Community Autism Program

- **Initial Session:**
  - In clinic, child present, technology available
  - Consents and Program description
  - Pre-admission measures (parent report of language, problem behavior, level of stress, quality of life)
  - Review of technology
    - How to set up account
    - Troubleshooting tech issues
  - Establish goals through CAP Goals Worksheet
    - Parents identify situations that are difficult for them
    - Identify specific terminal goals for the admission
Community Autism Program

- Select appropriate curriculum and order to address goals

<table>
<thead>
<tr>
<th>Training Topics</th>
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<tbody>
<tr>
<td>Autism &amp; ABA</td>
<td>Pairing</td>
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<tr>
<td>Early Communication</td>
<td>Antecedent Strategies</td>
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<tr>
<td>Social Skills</td>
<td>Compliance</td>
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<tr>
<td>Teaching New Behavior</td>
<td>Community Outings</td>
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<td>Verbal Operants</td>
<td>IEP Meetings</td>
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<tr>
<td>ABCs of Behavior</td>
<td>Developing Routines</td>
</tr>
<tr>
<td>Define Behavior</td>
<td>Function</td>
</tr>
<tr>
<td>Toilet Training</td>
<td>Consequences</td>
</tr>
</tbody>
</table>
3. Community Autism Program

• Face-to-face outcomes:
  – Parents increased knowledge (N=??)
  – Parents increase performance (N=105, \( p < 0.001 \))
  – Significant reductions in parental stress (N=44, \( p < 0.03 \))
  – High levels of program satisfaction (N=155, 94% Satisfied or Highly Satisfied)

• CAP Telehealth outcomes:
  – ?
3. Community Autism Program

• CAP Telehealth Outcomes
Ethical Concerns – American Psychological Association (APA)

- APA licensure across states
  - Only 3 states have implemented specific guidelines for Telehealth

- Evidence-based nature of interventions when delivered via a different modality

- APA Statement
  - "In those emerging areas in which generally recognized standards for preparatory training do not yet exist, psychologists nevertheless take reasonable steps to ensure the competence of their work and to protect patients, clients, students, research participants, and others from harm."

References


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