Overview

1. Dr. Goldstein – History and Timeline
2. D.D. Fritch-Levens – Overview of Telemedicine at CHOA
3. Dr. Goldstein – Clinic to Clinic Telemedicine
4. Dr. Delfs – Clinic to Home for Language and Skill Acquisition
5. Dr. Scheithauer – Clinic to Home for Problem Behavior
6. Dr. Bearss – Research and Clinical Trials

Objectives

- Define telehealth
- Provide a brief history of telemedicine
- Describe how telehealth is used in the diagnosis and treatment of children with developmental disabilities

What is Telehealth?

- Use of electronic information and telecommunications technologies to support and promote:
  - Long-distance clinical health care
  - Patient and professional health-related education
  - Public health
  - Health administration

History and Timeline of Telehealth To Help Children with Developmental Disabilities

Felissa P. Goldstein, M.D.
Board Certified Adult, Child and Adolescent Psychiatrist
Interim Medical Director

Brief History of Telemedicine

- In 1924, a radio enthusiast magazine titled Radio News described and illustrated what it termed “The Radio Doctor” - a complete bedside unit that allowed a physician to remotely examine, diagnose, and treat a patient.
A Brief History of Telemedicine

• 1964: Nebraska Psychiatric Institute began using a two-way closed-circuit TV link between the Institute itself and Norfolk State Hospital about 112 miles away. Used for education and consultation.

• 1967: A medical station was established at Boston's Logan International Airport and linked to Massachusetts General Hospital (MGH). MGH provided medical care to patients using a two-way microwave audio/video link.

• 1971: The U.S. National Library of Medicine's Lister Hill National Center for Biomedical Communication choose 26 sites in Alaska to verify the reliability of telemedicine via satellite communications.

• 1972: NASA began trial runs of its Space Technology Applied to Rural Papago Advanced Health Care (STARPAHC) program.
  – This was for people living in remote areas with limited healthcare (Arizona’s Papago Indian reservation)
  – The system used two-way microwave transmissions to link paramedical personnel located in mobile units and fixed stations with medical experts at hospitals in Tucson and Phoenix.

• 1972: U.S. Department of Health, Education and Welfare funded seven telemedicine research and demonstration projects:
  – Illinois Mental Health Institute
  – Case Western Reserve University
  – Massachusetts’ Cambrige Hospital
  – Illinois’ Bethany/Garfield Medical Center
  – Minnesota’s Lakeview Clinic in Waconia
  – Dartmouth Medical School’s INTERACT in Hanover, N.H.
  – Mount Sinai School of Medicine in NYC

• 1973: National Science Foundation funded two more telemedicine projects:
  – Boston Nursing Home project for geriatric patients
  – Miami-Dade project between Florida’s Dade County and Miami’s Jackson Memorial Hospitals

• 1977: Canada’s Memorial University of Newfoundland participated in a Canadian Space Program for distance education and medical care, using the joint Canadian/U.S. Hermes satellite

• 1984: The North-West Telemedicine project was set up in Australia
  – Pilot tested the Australian government’s Q-Network satellite communications network
  – Project’s goal was to provide health care to people in five remote towns south of the Gulf of Carpentaria

• 1989: After a massive earthquake hit the Soviet Republic of Armenia, the U.S. offered the Soviet Union, use of a one-way international telemedicine network for consultations with patients in Yerevan, Armenia and Ufa, Russia with four medical centers in the U.S.

• 1990s:
  – Development of personal computers increased options and applications in telemedicine
  – Programs difficult to sustain

• 2000s:
  – Internet and lower cost technology led to boom in the usage of telemedicine
  – Universal policies, regulations and recommendations are initiated
**Why Design a Telehealth Program for Children on the Autism Spectrum?**

“I think autism is a good illness in some respects to use telemedicine for. The kids actually interact well with technology and more naturally than they do if you’re in the room. They’re not good with social relationships and they may find it easier to find someone talking to them from a television than they do face-to-face, which might make them more anxious.” (Peter Yellowlees at UC Davis, in Terry 2009)

**Why Use Telemedicine With Children With Developmental Disabilities?**

- Neurodevelopmental disorder affects 1 in 68 individuals
- Average age of parental concern is about 13 months
- Median age of diagnosis in rural areas is about 7 years
- Due to a gap between parental concern and formal diagnosis, children do not receive interventions during key developmental years

**Benefits of Telemedicine for Children on the Autism Spectrum**

- Improved patient outcomes
  - Decreased time to first appointment
  - Earlier identification and treatment of autism spectrum disorders
  - Increased access to specialized programs for children with developmental disabilities
- Education and Support
  - Community doctors
  - Schools and families throughout the state

**How is Telemedicine Currently Used?**

- Videoconferencing
  - Psychotherapy
  - Pharmacotherapy
  - Native American children with Autism Spectrum disorders living in rural areas received psychiatric and psychological assessments by telemedicine (Savin, 2005)

- Behavioral Therapy Using Telemedicine
  - Numerous studies report the effectiveness of behavioral analysts guiding teachers in conducting functional behavioral and preference assessments, implementing treatment protocols and data collection (Barretto, 2006; Machalicek 2009 and in press)
  - University behavioral consultants trained teachers to implement functional communication training (Gibson, 2010)
  - University based clinicians guided teachers to improve their fidelity in conducting functional behavioral assessments (Machalicek, 2009)

- Data Collection
  - Behavioral imaging software brings the clinician into the home by allowing the parents to press a button and record the child’s behaviors.
  - The data is recorded for a long enough period of time that antecedents are recorded as well (Terry, 2009)
  - Dr. Christopher Smith (2012) utilized behavioral imaging technology to have families capture video during family mealtimes, playtime with peers, unstructured playtime, and problem times. Video is sent to expert who reviews videos and compares to DSM criteria to make diagnosis
How is Telemedicine Currently Used?

- **Education/ Other Interventions**
  - Educational consultants and university researchers used teleconferencing equipment to collaborate with teachers to develop and implement IEPs (Rule, 2006)
  - Using live instruction and telehealth University researchers taught parents and early intervention specialists how to use the Early Start Denver Model. The differing instruction methods were equally efficacious (Vismara, 2009)

How is Telemedicine Currently Used?

- **Diagnosis**
  - Pub med search using autism, autism spectrum disorders, telemedicine, telehealth, and telepractice shows no literature regarding comprehensive evaluations to diagnose autism via telemedicine.
  - In 2012 a meeting of experts in telehealth and autism spectrum disorders highlighted the absence of a comprehensive evaluation that could be done solely by telemedicine and would be comparable to the gold standard in person assessment.

How is Telemedicine Currently Used?

- Dr. Matthew Reese’s team at the University of Kansas (2013) compared the effectiveness of the Autism Diagnostic Interview (ADI) and a modified Autism Diagnostic Observation Schedule (ADOS) administered by videoconferencing and in person. The ADI was reliable except for sensory and the ADOS was equally effective except for pointing.
- Dr. Jamie Schutte and her team at the University of Pittsburgh (2015) determined high levels of reliability and usability of the ADOS module 4 when administered by video conferencing.

How is Telemedicine Provided for Children on the Autism Spectrum?

The need is there

How do we provide it?

Here is one example –

**Collaboration between**
- Marcus Autism Center (MAC)
- Georgia Partnership for Telehealth (GPT)

The Evolution of a Telehealth Program

- Began in collaboration with Ga. Partnership for Telehealth in 2009
- In November 2010 Marcus Telemedicine Program became a part of the Children’s Healthcare of Atlanta Telemedicine Program
- 2011 Marcus and CHOA collaborated with Cisco and Georgia Tech Research Institute to develop an ideal telemedicine system to facilitate the diagnosis and treatment of children with Autism Spectrum Disorders
Impacting the access and quality of pediatric healthcare in Georgia

Program Development

Our Program

- Children’s Telemedicine Program
- 501(c)3 – Not for Profit
- Network of Partners
- Minimal Partnership Fees:
  - Field-Based Telehealth Liaisons
  - Support for Credentialing
  - Scheduling System
  - Centralized PACS System
  - 24/7 support for network partners
  - Access to Network

Our Network Partner

- Georgia TeleHealth Partnership
- Children’s Telemedicine Program
- 501(c)3 – Not for Profit
- Network of Partners
- Minimal Partnership Fees:
  - Field-Based Telehealth Liaisons
  - Support for Credentialing
  - Scheduling System
  - Centralized PACS System
  - 24/7 support for network partners
  - Access to Network

Current Sites

Participating with 43 presenting sites throughout Georgia*

10 specialties with 21 physicians

*Map and site list are included in Children’s Telemedicine Working Together for Better Care

Our Suites

- Healthcare Organizations
- Private Practices/Clinics
- Community Health Sites
- Schools
- Public Health Departments
- Child Advocacy Centers
How it Works

- Primary care physician sends Telemedicine Referral Form
- Telemedicine Scheduler coordinates Children’s provider, patient and presenting site schedules
- Patient arrives at presenting site on the day of the appointment, checks in and is escorted to the telemedicine room
- Nurse assists Children’s provider with the exam
- Prescriptions and orders are faxed to the presenting site; the presenter assists the patient in finding lab locations
- All lab results are sent to the Children’s provider and progress notes are sent to the referring provider

Billing

- Providers receive professional fee at same rate as in-person visits
- Presenting site receives a facility fee and any ancillary service charges (i.e. labs, etc.)
- Children’s does not receive any compensation

Clinical Services Offered

Current Specialties and Number of Physicians:
- Aerodigestive (1)
- Autism (1)
- Child Protection (3)
- Concussion/Neurosurgery (1)
- Endocrinology/non-diabetes (1)
- GI/RD (1)
- Hepatology/Transplant (2)
- Interventional Radiology (1)
- Hepatology (1)
- Psychology/Autism (2)
- Pneumology (2)
- Sports Medicine/Concussion (1)

Other Services Offered

- Research
  - Utilizing telehealth to deliver Autism research protocols
- Training
  - Provider and caregiver training through the Marcus Autism Center
- Education
  - Monthly long distance learning offerings on various pediatric topics for providers
- Collaboration
  - De-identified child protection cases reviewed by and with peers

Offerings

Current Technology
Telemedicine Consult

Telemedicine: Working Together for Better Care

Collaboration: Project Echo

• Multidisciplinary team from Children’s provide a series of education initiatives on a selected disease states
  +
• Community providers share de-identified cases
  • Community providers sign up for sessions that apply to them and their need
  • 3-5 providers participate and each shares a de-identified case

Project Echo

• Modeled after Project ECHO
• Started in 2003 in New Mexico for Hepatitis C patients
• Presenters and community providers can be Physicians, Nurses, Social Workers, Nutritionists, Child Life Specialists, Others
• Benefits
  • Increased access to quality care for patients
  • Relieve capacity constraints on specialties at Children’s
  • Improve the proportion of clinically relevant patients seen by Children’s specialists
  • Deliver more high-quality care to children in their community
  • Educate providers and their practices

Technology

• Cisco TelePresence MX700
• Dual cameras
• Voice tracking camera technology
• Sound mitigation
• Interactive white board
• Multiple use cases

Impact

For the patients:
• Pediatric knowledge within their community
• Accessibility of providers within their community
• Decrease travel expenses, increase days in school, decrease workdays missed

For our system:
• Support and access to program benefits and offerings
• Decrease the need/expense of bricks and mortar /travel

For the community:
• Local support to enhance pediatric knowledge and availability of pediatric specialist when needed
• Support workforce and school attendance

Our Community…

<table>
<thead>
<tr>
<th>2014 Statistics...Per visit:</th>
<th>Median (Range)</th>
<th>Range (Mean)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Miles Saved</td>
<td>362 (72 - 504)</td>
<td>72 - 504</td>
</tr>
<tr>
<td>Cost of miles saved</td>
<td>$199 (39 - $277)</td>
<td>$39 - $277</td>
</tr>
<tr>
<td>Hours Saved Traveling</td>
<td>6 (2 - 9)</td>
<td>2 - 9</td>
</tr>
<tr>
<td>School days</td>
<td>67% of our patients would have missed school to travel to Atlanta</td>
<td></td>
</tr>
<tr>
<td>Work Days Missed</td>
<td>72% of our parents would have missed a full day of work to travel to Atlanta</td>
<td></td>
</tr>
<tr>
<td>Patients served live in</td>
<td>78 of Georgia's 159 counties</td>
<td></td>
</tr>
<tr>
<td>49% of all counties</td>
<td>90% outside of the Metropolitan Statistical Area (MSA)</td>
<td></td>
</tr>
<tr>
<td>78% of our patients are covered by Medicaid (CMO's)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall cost of miles saved: $161,686 (203,785 x 0.55/mile)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Future State

- Expansion of specialty visits
- Sharing resources within the system
- Utilization of Children’s internal network
- Technical integration at the bedside
- Increase utilization for research and education

Program Growth and Opportunities

- Emergency Room Nursing Education
- Technological Integration at the Bedside
  - Virtual Scheduling
  - Indicators for Family Vital Signs
  - Access to Education, Child Life, Interpreters, Other Ancillary Services
- Sideline Presence
- Children’s Presenting Sites
- Complex Care Visits
- Isolation Visitation
- Remote Patient Monitoring / Care Coordination

Program Details

Telemedicine: Working Together for Better Care

- State of the art technology
- Integration of Telemedicine patients with in-person patients
- Management of the credentialing process
- Participation at national and regional conferences
- Distance Learning

Training and Support:

- Established processes, protocols and forms
- Training and support for clinic coordinators

Partnerships:

- Promotion and marketing through a partnership with the Children’s physician liaison team
- A highly valued partnership with a statewide network of presenting sites and liaisons
- Advocates for legislative, regulatory and compliance issues

Telemedicine Education and Readiness Tool (TERT)

- Research on:
  - Patient Satisfaction
  - Provider Satisfaction and Usability
  - Symptom Outcome
  - Accuracy of Assessment
  - Quality of Care
  - Cost Avoidance
- Use Cases of Telemedicine in Pediatrics
- Financial Analyses based upon four different models of delivering telemedicine
- Reimbursement and Regulatory Documents
- Implementation Barriers
- Onboarding Process

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Clinic-to-Clinic Telehealth To Help Children with Developmental Disabilities

Felissa P. Goldstein, M.D.
Board Certified Adult, Child and Adolescent Psychiatrist
Interim Medical Director
Marcus Autism Center

Marcus Child Psychiatry Telemedicine Program

- Over 2400 encounters since inception
- MAC serves as a specialist site
- Clinic is a part of the Children’s Healthcare of Atlanta (CHOA) Telemedicine Department
- I am the highest provider of telemedicine services in the state of GA
- Patients have been seen at over 40 different sites through our network partner Georgia Partnership For Telehealth

What Do You Need To Have A Telemedicine Program?

- Patient at one site
- Specialist at other
- Coordinator at specialist site to handle scheduling, billing, script refills, and mailing out paperwork
- Coordinator at rural site to handle scheduling, managing equipment, taking patient’s vitals and bringing patient to office

What Do You Need To Have A Telemedicine Program?

- One of two types of telehealth equipment
  - Standard grade
    - secure, point-to-point transmission of high-bandwidth (>386 kbits/sec) and monitor resolution (>30 frames/second) signals over satellite or fiberoptic (“T1 lines” or integrated services digital networks) systems that provide high-definition video and audio signals
    - Standard grade has a higher bandwidth and better quality audio and video
  - Consumer-grade
    - applications are provided over the internet using software that encrypts the transmission and that can be readily loaded onto personal computers; therefore, they are much more accessible, and many options exist
    - Consumer grade application companies sign a business agreement attesting that they are HIPAA compliant
    - Tech support
      - Know who provides it
      - Ensure it is easy to access

What To Think About When Designing Your Program?

- Physical Arrangement
  - Optimize eye contact
  - Avoid distractions in background
  - Eliminate natural light to prevent camera distortion
  - Space for observers
  - Soundproof against ambient noise and to ensure privacy
  - Use audio equipment that facilitates good sound quality

What To Think About When Designing Your Program?

- Provider Needs
  - Emergency plan
  - Communication plan for sharing bad news
  - Community Connection
  - Champions
  - High energy
  - Availability
  - Licensure and credentialing
Summary

- Videoconferencing is a great modality to use to work with children with developmental disabilities
- Marcus Autism Center collaborates with Georgia Partnership for Telehealth to provide patient care throughout rural Georgia
- Telemedicine is a means to educate and support community physicians, caregivers, and school personnel about developmental disabilities
- Telemedicine systems must take into account confidentiality, system design, physical layout, emergency plans, and rapport

Questions???

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Clinic to Home

- Benefits
  - No transportation required
  - In Home/Natural setting
  - No others present for sessions
  - Can include observation of behaviors that may not occur in other settings
  - Can incorporate other family members
- Clinical Services at MAC
  - Language and Learning Clinic
  - Severe Behavior Clinic

Language and Learning Clinic

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

- 12-week, structured caregiver training program
- Focus on building skills across a variety of areas:
  - Increasing language and functional communication
  - Social skill development
  - Building independence
  - Pre-academic skills
  - Developing routines

Community Autism Program – Referral Process

- Marcus E-take form or internal referral to LLC
- Complete LLC screening packet
- LLC Intake (if needed)
- CAP referral
  - Determine appropriate service delivery model:
    - In Home
    - In Clinic
    - Telehealth

Community Autism Program – Service Delivery and Staffing

- Scheduled to see almost 200 families each year
- Over 10 staff trained to work with these families
  - 10% Telehealth
  - 60% in home
  - 30% in clinic
- Outcomes:
  - Change in parent behavior:
    - Scores increased 56% on observation tasks (N=105, p<0.001)
  - Significant reduction in parental stress:
    - Using PSI (N=44, p<0.03)
  - Program Satisfaction:
    - 94% Satisfied or Highly Satisfied (N=155)

Community Autism Program – Initial session

- Requirements: 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
- Practice session
- Begin CAP Goals Worksheet
- Weekly practice assignment

Community Autism Program – Additional sessions

- Requirements: In home, child present, technology available, backup technology identified
- Review goals with caregivers

CAP Goals Worksheet (rev 2.13.15)

<table>
<thead>
<tr>
<th>Situation</th>
<th>OK as is</th>
<th>Some change</th>
<th>Great change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communicating: requesting, labeling, conversing</td>
<td>1 2 3 1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communicating: Following Instructions, identifying objects</td>
<td>1 2 3 1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Completing tasks</td>
<td>1 2 3 1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Following routines</td>
<td>1 2 3 1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transitioning</td>
<td>1 2 3 1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Getting dressed</td>
<td>1 2 3 1 2 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meal times</td>
<td>1 2 3 1 2 3</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Community Autism Program - Additional sessions

- Select appropriate curriculum and order to address goals

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

Community Autism Program

- Plans for Telehealth expansion
  - Currently see over 150 families each year in CAP
  - Now have 5 slots dedicated to Telehealth each week, with plans to expand
- Upgrade technology
  - Ongoing collaboration with Cisco to leverage use of technology for this clinical purpose (i.e., utilize WebEx to connect with families from the convenience of their home)

Augment to LLC Direct Services

- Direct observation of Home-based sessions
  - 20 clients in LLC: HB
  - 10 staff out in community every day
  - Uses:
    - To provide supervision and coaching to staff
    - To train on new protocols and procedures
    - To view child behavior in the moment
  - Benefits:
    - Decreases distractions for client
    - May decrease reactivity in staff
    - Recording built-in
    - Reduces drive time/mileage reimbursement
- Consultation or Follow up sessions after discharge
  - Over 80 clients in LLC (1:1, dyad, HB)

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

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

BBI - Locations

- Home/Community
  - High reactivity in the clinic
  - Inability to replicate antecedents/consequences in the clinic
  - Problem behavior can be reliably evoked and safely managed in the home
  - Within 50 miles
- Clinic
  - Limited reactivity in the clinic
  - Inability to consistently evoke or manage problem behavior in the home
  - Able to travel to the clinic
- Telehealth
  - Outside of 50 miles (cannot travel to clinic)
  - Caregiver can safely manage problem behavior
  - Technology and internet requirements

BBI Numbers

- 6 Board Certified Behavior Analysts
  - Case loads of 8-9 clients
  - Started with 1 telehealth spot in March
  - Increased to 2 in May
  - Plan to increase to 6 spots
- Weekly 2-hour appointments
- Approximate 10 week admission length

BBI Admission Summary

- First appointment in clinic – similar to CAP
  - Parent target problem
  - Indirect measures (parenting stress, checklist for problem behavior, parent target problem narrative)
- Remaining appointments in home
  - Functional analysis with caregiver acting as therapist
  - Function-based treatment package
  - Extinction
    - 3-step guided compliance
    - Differential reinforcement
    - Token systems
    - Behavioral contracts

Outcomes

- Since March, four clients have had full telehealth admission
  - Two clients have successfully discharged (met treatment goals identified by caregiver)
  - 1 client discharged early due to funding issues and 1 due to health issues
- Four additional clients have completed their admissions via telehealth
  - Two transferred due to transportation instability and two due to reactivity
- Two clients are completing follow-up from day treatment via telehealth
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

• Day 1 – In home observation
  - Probes of most problematic situations for caregivers based on goals
• Assessment phase
  - Functional analysis – determine what the patient likes, dislikes, and why problem behavior occurs
• Treatment phase
  - Develop a function-based treatment to reduce problem behavior
  - Often requires intensive intervention components that are gradually reduced to increase the generalizability of treatment
• Generalization and training phase
  - Adapt the treatment to increase feasibility in naturalistic settings including novel areas of the treatment environment
  - Train the caregiver to implement the treatment in a variety of settings
• Post discharge follow-up
  - Adapt treatment to the changing needs of the child and family
  - Train new caregivers
  - Address novel goals that emerge as the child develops
  - 12 appointments across the first 6-months, with annual follow-up for the remainder of the client’s childhood

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

• R01 multisite grant evaluating the necessity of functional analyses in the treatment of problem behavior
• Participants will be randomly assigned to a multielement functional analysis and also to a more general structured observation
  - Compare based on behavior reduction following functional communication training and acceptability
• 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)

Barriers

• Families are required to have internet and electronic device
• Technological difficulties
  - Video/audio freezes or skips
  - Can be difficult to coach caregiver during real-time error correcting or responding to problem behavior
• Technology failure on client’s end
  - Little that you can do to help the caregiver if he/she is not very savvy
• Active children
  - Difficult to keep the child in the frame
Ethical Concerns

- 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
  - Difficult to move distractions from instructional setting
  - Inability to remove potentially dangerous items before a tantrum
- Technology error during an emergency
  - Important to get emergency contact
- Turning away families without internet or devices
  - Likely the same group that does not have transportation to get to the clinic

Ethical Concerns - 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
  - The Ethics Committee recommends that psychologists follow Standard 1.04c, Boundaries of Competence, which indicates that “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.”

Presentation Objectives

- Describe the background research on parent training (PT) for children with ASD and disruptive behaviors
- PT Program contents
- Therapist training qualifications/procedures
- Present background research on use of telehealth in ASD
- Present findings from a recent pilot study of PT delivered via telehealth

Good News, Bad News

- Better at identifying children with ASD
- Few evidence-based treatments
- Parents overwhelmed by ‘treatment’ choices
  - Google search ‘Autism Treatment’ = 69.6 million hits
    - (up from 37 million last year, 9 million two years ago!!)
    - 6.7 million when you add ‘evidence based’

Autism Spectrum Disorder

- Current Prevalence Rates
  - 1 in 68 children [CDC, 2014]
  - 6 per 1,000 children worldwide [Elsabbagh et al, 2012]
- Broadening case definition
- Increased public awareness
- Better tools for measurement
Added Challenges of Treatment

- Most EBTs are costly, time- and personnel-intensive
  - Challenge to wide-ranging dissemination and implementation
  - Hard for families to access
- There is a pressing need for trials that will expand the availability of empirically supported, time-limited, cost-effective treatments for ASD

Parent Training

- Traditionally a time-limited approach
  - Few hours per week
- Emphasizes role of parents as the agent of change
  - History as established EBT in child mental health

Why Target Families?

- High rates of stress/depression in caregivers
- Parent inclusion in treatment is not common
  - Difficulties with skill generalization
    - "no problems at school"
- High rate of accommodation
  - "Walking on eggshells"
  - E.g., dressing child, mashing food

Why Target Families?

- High rate of disruptive behavior problems (~50%)
  - Aggression, noncompliance, SIB, property destruction
  - Communication deficits = DBP
  - Requires skillful responses from parents
- Adaptive skills deficits
  - Resistance in learning new skills or performing acquired skills
  - DBP/Noncompliance negatively impacts DLS growth
  - E.g., Getting dressed in the morning

Why Target Families?

Parents need specific instruction on techniques to:

- Improve core symptoms
- Reduce challenging behaviors, and
- Improve adaptive functioning in their children

Need for PT EBTs in ASD

- NIMH Ad Hoc Committee (Smith et al. 2007; Lord et al., 2005; NIMH, 2004)
- Recognized limitations of current research
- Outlined steps to move the field forward
  - Develop a manualized intervention
  - Collect feasibility data
    - Can therapists reliably deliver the treatment?
    - Do parents show up? Do they stay in treatment?
    - Can they do it? Do they like it?
- Implement large-scale, multi-site, randomized clinical trials
- Disseminate treatments
Key Points of PT Program

- Targets challenging behaviors
  - 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)

Program Structure

- Week 1-16
  - 11 Core Sessions
  - 1 Home Visit
  - Up to 2 Optional Sessions
    - toileting, feeding, sleep, time out
  - Week 17-24
    - 1 Home Visit
    - 2 Booster Sessions
    - Up to 6 dyad coaching sessions

Manual Development

- No ‘off the shelf’ parent training manual available
- Pittsburgh Consultants
  - Cynthia Johnson and Ben Handen
- Development of a PT program that:
  - Decreases Behavioral Problems
  - Increase Adaptive Skills

Program Structure

- Week 1-16
  - Each session contains
    - Delivered individually to the parents
    - Based on principles of ABA
- Targets challenging behaviors
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Research Units in Behavioral Intervention (RUBI) Autism Network

- Lawrence Sciallih, M.S.N., Ph.D.
- Karen Bearss, Ph.D.
- Emory University
- Cynthia R. Johnson, Ph.D., BCBA-D
- University of Florida
- Tristram Smith, Ph.D.
- University of Rochester

Website: www.rubinetwork.org

Manual Development

<table>
<thead>
<tr>
<th>SESSIONS</th>
<th>SKILLS/ACTIVITIES</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Basic Behavioral Principles</td>
</tr>
<tr>
<td>2</td>
<td>Prevention Strategies</td>
</tr>
<tr>
<td>3-4</td>
<td>Daily Schedules</td>
</tr>
<tr>
<td>5-6</td>
<td>Reinforcement 1</td>
</tr>
<tr>
<td>7-10</td>
<td>Reinforcement 2</td>
</tr>
<tr>
<td>11</td>
<td>Ignoring</td>
</tr>
<tr>
<td>12</td>
<td>Compliant Ignoring</td>
</tr>
<tr>
<td>13</td>
<td>Compliance Tracking</td>
</tr>
<tr>
<td>14</td>
<td>Functional</td>
</tr>
<tr>
<td>15</td>
<td>Communication Training</td>
</tr>
<tr>
<td>16</td>
<td>Teaching Skills 1</td>
</tr>
<tr>
<td>17</td>
<td>Teaching Skills 2</td>
</tr>
<tr>
<td>18-19</td>
<td>Reinforcement &amp; Maintenance</td>
</tr>
<tr>
<td>20-21</td>
<td>Emotional Development</td>
</tr>
<tr>
<td>22-24</td>
<td>Telephone Booster</td>
</tr>
</tbody>
</table>

Therapist Training

- Training
  - Master’s degree or higher
  - Didactic training
    - Video review of one case to fidelity (80%) by expert therapist
- Supervision
  - Weekly site supervision
  - Monthly cross-site teleconferences
- Fidelity
  - Detailed therapist scripts for session
  - Fidelity checklists
    - Integrity check on a 10% random sample of sessions
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. PE (Bearss et al., 2015)

RESULTS: Feasibility and Efficacy

- PT delivered with high fidelity within/across therapists
  - <90% across 4 trials
- Intervention is acceptable to parents
  - High satisfaction; low attrition rates (10-12%)
- Significant reductions in parent reported DBP
  - Medication + PT superior to medication alone
  - Children also received lower doses of medication
  - PT superior to PE (70% + response rate)
- Improvements in DLS
  - 6 point improvement in DLS

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

The Telehealth Suite in Action...

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

PT Telehealth Sites

(2 Schools; 2 Medical Centers)

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 2nd 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>
</tbody>
</table>

### Feasibility Outcome Measures

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Benchmark</th>
<th>Rated by</th>
</tr>
</thead>
<tbody>
<tr>
<td>Therapist Fidelity</td>
<td>≥90%</td>
<td>Independent Review</td>
</tr>
<tr>
<td>Parent Adherence</td>
<td>≥80%</td>
<td>Therapist</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></td>
<td></td>
</tr>
<tr>
<td>Parent Acceptability</td>
<td>≥85%</td>
<td>Parent</td>
</tr>
<tr>
<td>- Core session attendance</td>
<td>≥80%</td>
<td></td>
</tr>
<tr>
<td>- Satisfaction (endorse competence)</td>
<td>≤20%</td>
<td></td>
</tr>
<tr>
<td>- Adherence</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Study Enrollment

- 14 families enrolled
- 1 dropped out with no core sessions
- 12 Participants completed all 11 core sessions
- 10 by Week 16
- 2 by Week 24
- 1 Participant completed 10 core
- 8 participants completed the 24-week trial
- 5 on track to finish by August 2015

### Baseline Child Demographics

- Mean Age = 5.2y (SD=1.7)
- Mean IQ = 69.4 (SD=17.6)*
- 64% Males
- 79% Caucasian, 21% African-American
- 15% Hispanic
- 86% ASD**
- 50% Regular Class, 43%; Special Ed; 7% Home School

*3 participants (21.4%) had a receptive language below 18 months
**2 participants did not meet ASD criteria on the ADOS but held a community diagnosis of ASD

### Baseline Parent Demographics

- 86% Two-parent family*
- Mean Mother Age = 38.3 (SD=8.3)
- Mean Father Age = 39.8 (SD=10.2)
- Family Income
  - 29% <$20,000
  - 36% $20,000-$40,000
  - 21% $40,000-$90,000
  - 14% >$90,000
- Maternal Education
  - 14% HS/GED; 50% some college
  - 29% college; 7% advanced degree

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

**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
  - no control for time, attention
- Small sample size
  - impacts the generalizability of findings
- Results under optimal conditions
  - well-trained therapists
- Reliance on parent/therapist self-report

**Future Directions**

- Evaluate the PT program delivered via telehealth using a large scale randomized control trial (RCT).

**References**

- Facts for Families –American Academy of Child and Adolescent Psychiatry
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- [http://www.dana-farber.org/can/dictionary](http://www.dana-farber.org/can/dictionary)
- [http://www.dsmivtr.org/index.cfm](http://www.dsmivtr.org/index.cfm)
- [http://www.hrsa.gov/ruralhealth/about/telehealth/glossary.html](http://www.hrsa.gov/ruralhealth/about/telehealth/glossary.html)
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