ON THE ROAD OR ON THE WEB: NOVEL METHODS OF AUTISM ASSESSMENT IN RURAL APPALACHIA

Jennifer R. Bertollo, M.S.
BACKGROUND
WHEN IS AUTISM DIAGNOSED?

CAN BE RELIABLY DIAGNOSED

18-24 m

MEDIAN U.S. AGE

4y, 3m

significant lag

8y+

MANY UNDIAGNOSED

RURAL/IMPOVERISHED AREAS

(Antezana et al., 2017; Lauritsen et al., 2014; Maenner, 2020; Mandell et al., 2005; Rhoades et al., 2007; Rural Health Information, 2020; Scarpa et al., 2020)
Rural Disparities

- Reduced services in rural areas
- Later diagnosis → Missed or delayed supports
- Perceived barriers in rural Virginia:
  - Too few providers
  - Affordability of services
  - Geographic location/isolation
- Limited availability of parent training/education

(Antezana et al. 2017; Lauritsen et al., 2014; Mandell, Novak, & Zubritsky, 2005; Rhoades, Scarpa, & Salley, 2007, Scarpa et al., 2020)
VIRGINIA TECH MOBILE AUTISM CLINIC (MAC)

(Carmack, 2010; Fernandez, 2017; Guruge et al., 2010; Harris et al., 2011; Yu et al., 2017; Bertollo et al., under review)
Use of Telehealth

- Maximize time, staff, financial resources to reach more families
- Success of telehealth for ASD intervention
- Less guidance on ASD tele-assessment
- Gap: spanning childhood and adolescence

(Alfuraydan et al., 2020; Bearss et al., 2018; Dahiya et al., 2020; Fairburn & Patel, 2016; Ferguson, Craig, & Dounavi, 2019; Mazurek, Brown, Curran, & Sohl, 2016; Parmanto et al., 2013; Stone et al., 2000; Talbott et al., 2020)
Benefits of Caregiver Psychoeducation

- Psychoeducation → increased parental competence and empowerment
- Caregiver empowerment = key factor in treatment success and confidence in managing child’s care

THESIS STUDY
Pilot Study Aims

- **Aim 1**: Feasibility and acceptability of mobile and tele-assessment protocols

- **Aim 2**: Preliminary effects on caregiver ASD knowledge and empowerment
Participants

- 30 children with autism referral question
- One or both caregiver(s) of each child ($n = 34$)
## Demographics: Children

<table>
<thead>
<tr>
<th></th>
<th>Mobile Assessment (n = 15)</th>
<th>Teleassessment (n = 15)</th>
<th>Overall (n = 30)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>M=8.94 (SD=3.51)</td>
<td>M=7.92 (SD=4.22)</td>
<td>M=8.43 (SD=3.85)</td>
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<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Male</td>
<td>14 (93.3%)</td>
<td>10 (66.7%)</td>
<td>24 (80%)</td>
</tr>
<tr>
<td>Female</td>
<td>1 (6.7%)</td>
<td>5 (33.3%)</td>
<td>6 (20%)</td>
</tr>
<tr>
<td><strong>Race</strong></td>
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<td></td>
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<tr>
<td>White</td>
<td>14 (93.3%)</td>
<td>11 (73.3%)</td>
<td>25 (83.3%)</td>
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<tr>
<td>Black</td>
<td>0 (0%)</td>
<td>3 (20.0%)</td>
<td>3 (10%)</td>
</tr>
<tr>
<td>Bi-racial</td>
<td>1 (6.7%)</td>
<td>1 (6.7%)</td>
<td>2 (6.7%)</td>
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<tr>
<td><strong>Ethnicity</strong></td>
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<tr>
<td>Hispanic</td>
<td>1 (6.7%)</td>
<td>0 (0%)</td>
<td>1 (3.3%)</td>
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<tr>
<td>Non-Hispanic</td>
<td>14 (93.3%)</td>
<td>15 (100%)</td>
<td>29 (96.7%)</td>
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## Demographics: Parents

<table>
<thead>
<tr>
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<th>Mobile Assessment</th>
<th>Teleassessment</th>
<th>Overall</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(n = 16)</td>
<td>(n = 18)</td>
<td>(n = 34)</td>
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<tr>
<td><strong>Age</strong></td>
<td>$M=37.06$ (SD=10.59)</td>
<td>$M=37.78$ (SD=6.93)</td>
<td>$M=37.44$ (SD=8.71)</td>
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<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1 (6.25%)</td>
<td>2 (11.1%)</td>
<td>3 (8.8%)</td>
</tr>
<tr>
<td>Female</td>
<td>15 (93.75%)</td>
<td>16 (88.9%)</td>
<td>31 (91.2%)</td>
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<tr>
<td><strong>Relations</strong></td>
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<tr>
<td>Biological Mother</td>
<td>13 (81.25%)</td>
<td>11 (61%)</td>
<td>24 (70.6%)</td>
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<tr>
<td>Adoptive Mother</td>
<td>0 (0%)</td>
<td>4 (22.2%)</td>
<td>4 (11.8%)</td>
</tr>
<tr>
<td>Biological Father</td>
<td>1 (6.25%)</td>
<td>1 (5.6%)</td>
<td>2 (5.9%)</td>
</tr>
<tr>
<td>Adoptive Father</td>
<td>0 (0%)</td>
<td>1 (5.6%)</td>
<td>1 (2.9%)</td>
</tr>
<tr>
<td>Grandmother</td>
<td>2 (12.5%)</td>
<td>1 (5.6%)</td>
<td>3 (8.8%)</td>
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</table>
Current Study Procedures

Pre-COVID:
- Mobile Assessment
- In-person Feedback
- Three psychoeducation conditions:
  - In-Person Sessions
  - Telehealth Sessions
  - Informational Materials (paper)

During COVID:
- Tele-assessment
- Zoom Feedback
- Two psychoeducation conditions:
  - Telehealth Sessions
  - Informational Materials (emailed)
EVIDENCE-BASED AUTISM ASSESSMENT

- Observation-based measures (ADOS-2)
- Caregiver interview of development and social/communication behaviors (ADI-R)
- Best results when used in combination

(Lord et al., 2012; Risi et al., 2006; Rutter et al., 2003)
OBSERVATION MEASURES:

**ADOS-2**
45-60 MINUTES
FACILITATED IN-CLINIC
BY STUDY CLINICIAN

**CARS-2 OBSERVATION**
15-20 MINUTES
FACILITATED BY CAREGIVER AT HOME

MOBILE ASSESSMENT
TELEASSESSMENT

(Lord et al., 2012; Rutter et al., 2003; Schopler et al., 2010)
Procedure – Assessment

**Mobile Assessment**
- Session 1 (4 hours, in-person)
  - Caregiver: ADI-R
  - Child: cognitive, language, ADOS-2
- Session 2 (2 hours, phone)
  - Select ADIS-P Modules

**Tele-assessment**
- Session 1 (3 hours Zoom)
  - Caregiver: ADI-R
- Session 2: (2 hours Zoom)
  - Child: cognitive, language, CARS-2 Observation
- Session 3: (2 hours Zoom)
  - Select ADIS Modules
Week 1
• ASSESSMENT SESSIONS

Week 2

Week 3
• FEEDBACK SESSION

Week 4
• PSYCHOEDUCATION 1

Week 5
• PSYCHOEDUCATION 2
Caregiver Outcome Measures

- **Recurrent:**
  - Family Empowerment Scale
  - Autism Stigma and Knowledge Questionnaire

- **After Psychoeducation Only:**
  - Satisfaction Survey
Analysis Plan

- Feasibility and acceptability:
  - Index reasons for ineligibility, attrition, and adherence to scheduled sessions
  - Independent sample $t$-tests to compare caregiver satisfaction of mobile and tele-assessments
Analysis Plan

- Caregiver Outcomes: mixed factorial 2 X 2 X 3 repeated measures ANOVA for each outcome
  - Between-subjects:
    - Psychoeducation condition (i.e., sessions or materials)
    - Assessment type (i.e., mobile or teleassessment)
  - Within-subjects:
    - Time (intake, post-feedback, post-psychoeducation)
- Due to small sample size, examined effect sizes
  - Partial eta-squared ($\eta^2$): small=0.01, medium=0.06, large=0.14
Hypotheses

1. Service models will be feasible & acceptable
   - Low attrition, high compliance with study schedule, high caregiver satisfaction

2. Caregiver empowerment & ASD knowledge will improve with diagnosis and education
   - Will be greater for education sessions than materials
THESIS RESULTS
CONSORT Diagram: Enrollment

Enrolled
(n = 30 families)

Mobile Assessment
(n = 15 families, 16 caregivers)
- Psychoeducation
  (n = 13 families, 13 caregivers)
- No ASD Dx
  (n = 2 families, 3 caregivers)

Tele-assessment
(n = 15 families, 18 caregivers)
- Psychoeducation
  (n = 15 children, 18 caregivers)
- No ASD Dx
  (n = 0)
Feasibility: Timeline Adherence

- Everyone who started an assessment completed!
- **Mobile Assessment**: Estimated within 5 weeks
  - Top reasons for rescheduling: weather, family/work
  - 10 of 13 families (76.92%) completed on time
- **Tele-assessment**: Estimated within 6 weeks
  - Top reasons for rescheduling: work/family emergency, clinical staff delay
  - 11 of 15 families (73.33%) finished in planned time
Comparative caregiver satisfaction of in-person mobile vs. teleassessment services.
# Caregiver Empowerment

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<th>Partial Eta Squared</th>
<th>p-value</th>
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<td><strong>Empowerment: Family</strong></td>
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<tr>
<td>Time</td>
<td>7.686</td>
<td>.235</td>
<td>.003*</td>
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<tr>
<td>Time X Psychoeducation</td>
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<td>Time X Assessment</td>
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<td>.295</td>
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<td>1.090</td>
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<tr>
<td><strong>Empowerment: Services</strong></td>
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<tr>
<td>Time</td>
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<td>.052</td>
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<tr>
<td>Time X Psychoeducation</td>
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<td>Time X Psychoeducation X Assessment</td>
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<td><strong>Empowerment: Community</strong></td>
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<tr>
<td>Time</td>
<td>6.140</td>
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* $p < .05$, $+ < .10$
# Caregiver ASD Knowledge

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<td></td>
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<td><strong>Autism Knowledge: Total</strong></td>
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<tr>
<td>Time</td>
<td>5.160</td>
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<td><strong>Autism Knowledge: Diagnosis</strong></td>
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<td>Time</td>
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<td><strong>Autism Knowledge: Etiology</strong></td>
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<td>Time</td>
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<td><strong>Autism Knowledge: Treatment</strong></td>
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<tr>
<td>Time</td>
<td>3.207</td>
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<td>2.538</td>
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<td>.089+</td>
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<tr>
<td>Time X Psychoeducation X Assessment</td>
<td>.142</td>
<td>.006</td>
<td>.868</td>
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DISCUSSION
Key Take-Aways

1. Both novel delivery methods for ASD assessment highly feasible and satisfactory

2. Assessment and psychoeducation improved caregiver ASD knowledge and empowerment comparably across formats
Limitations and Future Directions

- Small sample size
- Could not detect small-to-medium effect sizes
- Single site limits generalizability
- Unique clinical context of COVID
- Remote observation lacks validation
DISSERTATION
CARS-2 OBSERVATION
15-20 MINUTES
FACILITATED BY
CAREGIVER AT HOME

ADOS-2
45-60 MINUTES
FACILITATED IN-CLINIC
BY STUDY CLINICIAN

ONLINE VISIT: VIA ZOOM FROM HOME
IN-PERSON VISIT: LIVE, IN-CLINIC

(Lord et al., 2012; Rutter et al., 2003; Schopler et al., 2010)
IMPLICATIONS OF DISSERTATION PROJECT

- Will inform validity/utility of efficient remote observation
- Goal to refine and disseminate free training materials to community and university clinics
- Necessary to ensure consistency in training and practice during pandemic and beyond
Clinical and Research Implications

- Inform delivery methods to overcome financial, geographic, availability barriers
- Clinical utility of mobile assessment for rural areas, telehealth more broadly (crisis, weather)
- Need novel data collection tactics for follow-up
- High success in rural, under-resourced region
- Capitalize on strengths of each method/tool
FUNDING ACKNOWLEDGEMENT

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Autism Speaks Local Impact Grant
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Hulick Serving Spirit Award
iTHRIV Scholar Partnership Research Project

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Institute for Society, Culture and Environment (ISCE)
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- **Clinical Supervision:** Dr. Angela Scarpa
- **Outreach Coordinator:** Jennifer Pollard Scott
QUESTIONS?