Navigating the pathway to diagnosis and care for individuals with Autism Spectrum Disorder

Nicholas Fears, Ph.D.; Karolina Kata, M.B.S., OMS-IV; Shannon Chang, OMS-III; Monica Nguyen, OMS-II; Abhinaya Ganesh, OMS-III; & Haylie Miller, Ph.D.

July 20, 2019
Our Mission at UNTHSC:

– Partner with stakeholders in the ASD community
– Provide resources for individuals/families in need
– Study sensorimotor function in ASD
– Understand co-occurrence of ASD and other developmental disorders/conditions
What to Expect Today:

– Multiple short presentations that are all related
– Some research data, some clinical evaluation
– Lots of information in a short period of time
– Many passionate, enthusiastic young scientists!
### Social Communication & Social Interaction

- Deficits in social or emotional reciprocity
- Deficits in nonverbal communicative behaviors (gestures/expressions)
- Deficits in developing, maintaining, & understanding relationships across multiple contexts (imaginative play/friendships)

### Restricted, Repetitive Patterns of Behavior or Interests

- Stereotyped motor behaviors (hand flapping/rocking)
- Insistence on sameness/routines
- Restricted interests abnormal in intensity or focus
- Hyper- or hypo-reactivity to sensory input or unusual sensory interest

**AND…**

Symptoms present in early development, cause clinically significant impairment, and are not better explained by intellectual disability or global developmental delay.
Redefining Autism Spectrum Disorder (ASD):

– Complex set of neurodevelopmental symptoms
– Not just social or psychological – “whole body”
– Not just a two-dimensional spectrum (low/high)
Low to High Functioning
Symptom domains present or absent
Low to High Functioning

Symptom domains present or absent

Degree to which domains are affected
How components of each domain are affected
Whole-Body Disorder

• Will require a **culture shift at all levels**!
  
  – Community surveillance
  – Provider assessment and diagnosis
  – Intervention planning and outcome evaluation
  – Scaffolding to support social, healthcare, daily living, employment contexts that will all be affected by non-core symptoms of ASD
“Autism Pure” vs. “Autism Plus”

Nicholas Fears, Ph.D.
Autism is Autism Plus

- Nearly all individuals with Autism have Autism Plus
  - >95% of individuals with Autism have one or more co-occurring conditions (Soke et al., 2018, JADD)
  - Majority of individuals have 4 or more co-occurring conditions (Soke et al., 2018, JADD)

Topple®, Pressman Games
Common co-occurring conditions

- Sleep issues
- Seizure disorders
- Anxiety, depression, loneliness, aggression
- GI disturbance
- Metabolic disorders
- Immune system dysfunction
- Growth Differences
- Motor Problems
- Cognitive Differences
- Sensory Sensitivity

Heather Weston

CDC
Impact of co-occurring conditions

• Impacts both patients’ and families’ quality of life (Moyal et al., 2014, Paediatr Drugs)

• Parents experience considerable problems:
  – combining daily activities with care
  – have financial problems
  – suffered from depressive mood (Hoefman et al., 2015, JADD)
Recent changes to diagnostic criteria allow for ASD to be co-diagnosed with Developmental Coordination Disorder (DCD) (DSM-V, 2013, APA)

- 2-7% of children
- Problems with development of motor coordination
- Delays in achieving motor milestones, poor balance, coordination, and handwriting skills
  - This allows for ASD only, DCD only, or ASD+DCD.
  - Diagnoses of ASD and DCD are inconsistent, ranging from potentially 1% to 25% (Kata et al., 2019; Kopp et al., 2010)
How do children with ASD compare to children with DCD on parent reports and standardized assessments of movement?

- Developmental Motor Milestones & Developmental Coordination Disorder Questionnaire (DCD-Q)
- Movement Assessment Battery for Children (MABC-2)
- Beery Test of Visual-Motor Integration (Beery VMI)
ASD and DCD

- Discrepancies in parent reports
  - 76% of children with ASD met developmental motor milestones according to parent reports
  - 92% of children with ASD met criteria for DCD via parent report on the DCD-Q
ASD and DCD

- Similarities in standardized assessments
  - 77.88 was the mean standard score for children with ASD on the Beery VMI
  - 97.5% of children with ASD met DCD criteria (below 16th percentile) on the MABC-2
Below 16th percentile DCD Likely

DCD likely at: 5-7:11yr, 8-9:11yr, 10+yr

Haylie L. Miller, Ph.D., Gabriela M. Sherrod, B.S., Joyce E. Mauk, M.D., Nicholas E. Fears, Ph.D., & Priscila M. Caçola, Ph.D.
Impact of untreated motor deficits

- Mental health may be negatively impacted

- Children may be more socially isolated
  - Teachers’ report children with DCD having fewer friends (Piek et al., 2005)

- Children may have lower self-esteem
  - Self-esteem may be lower due to fewer social contacts and friendships (Poulsen et al., 2008)
Impact of untreated motor deficits

- Physical health may also be negatively impacted

- Children may engage in less physical activity
  - (Cairney et al., 2011; Hamm & Yun, 2017)

- Placing them at higher risk for obesity, chronic health conditions, and reduced quality of life
  - (Hill et al., 2015)
Important complete review of ALL health systems by primary care physician to recognize ASD symptoms (Ellerbeck et al., 2015, Prim Care.)

- Treatment options:
  - physical therapy
  - gastroenterology
  - cognitive behavioral therapy
  - melatonin (sleep disturbances)
  - speech therapy

Summary of Results

• ASD is a complex condition with a wide range of variability in symptom profiles.
  – Some symptoms might be well-known (social communication) or easily noticeable (sleep and GI issues)
  – Motor problems might be “overshadowed” by other symptoms (McLeod, et al., 2017)
    • We need to assess for potential motor difficulties in ASD
    • We need to include the appropriate health professionals (OTs, PTs etc.) for developing motor abilities in ASD.
A multi-center retrospective investigation of diagnostic, referral, and early management pathways for pediatric patients with Autism Spectrum Disorder (ASD) and Developmental Coordination Disorder (DCD)

Karolina Kata, M.B.S., OMS-IV¹, Shannon Chang, OMS-III¹, Abhinaya Ganesh, OMS-III¹, Monica Nguyen, OMS-III¹, Joyce E. Mauk, M.D.², W. Paul Bowman, M.D.¹,², Laurie Bailey, Ph.D.², Tyler Hamby, Ph.D.², & Haylie L. Miller, Ph.D.¹

¹UNT Health Science Center, Fort Worth, TX, USA,
²Cook Children’s Medical Center/Child Study Center, Fort Worth, TX, USA
Diagnostic Pathways for ASD with/without Co-Occurring Conditions

Karolina Kata, M.B.S., OMS-IV
Neurodevelopmental Disorders

• Presence of motor symptoms in ASD:
  (Morris et al., 2015; Ozonoff et al., 2008)
  • Abnormalities of: gait and balance, postural instability, and incoordination (Miller et al., 2019)
  • Findings are widely documented with standardized motor function tests (Ozonoff et al., 2008)

• Current diagnostic practice does not include a systematic evaluation of motor coordination in ASD. (Caçola et al., 2017)

• DCD and ASD can be diagnosed as co-occurring (ASD+DCD). (American Psychological Association, 2013)
Motor Symptoms

Motor symptoms in ASD:

Motor difficulties significant enough to warrant a diagnosis of DCD. (Caçola et al., 2017; Miller et al. 2019)

The treated prevalence remains low and motor function is often not prioritized in treatment planning. (McLeod et al., 2017)

Early intervention and improved outcomes. (Blauw-Hospers & Hadders-Algra, 2005)
Diagnostic Pathways

• **Evidence-based medicine:**
  - No clear pattern to how a patient arrives at final diagnosis.
  - There are few published studies examining the details of pathways used for diagnosis, referral, and early management of pediatric patients with ASD, DCD, and ASD+DCD. (Caçola et al., 2017)

• **Reaching the diagnosis:**
  - Variability in the chain of clinical events leading to diagnoses of ASD, DCD, and ASD+DCD.
  - Multifactorial provider and patient centered differences → unique pathways for patients seeking care.
Key Questions

• **Diagnostic path:**
  • How does the classification of the first responsible healthcare provider influence the diagnosis?
  • How long do families wait to see a specialist?
  • What is the prevalence of ASD+DCD and which is diagnosed first?
  • What presenting symptoms are being reported?
Methods

• **Design:**
  - A multi-site retrospective chart review.

• **Population:**
  - Pediatric patients diagnosed with ASD, DCD, and ASD+DCD in the Cook Children’s Medical Center (CCMC) network, the University of North Texas Health Science Center, and the Child Study Center (CSC) in Fort Worth, Texas.

• **Inclusion criteria:**
  - Children ages 0-21 years at the time of first chart entry.
  - Documented medical or educational diagnosis of Autistic disorder, Autism, Autism spectrum disorder, Pervasive developmental disorder, Asperger’s syndrome, Developmental coordination disorder, and/or Dyspraxia

• **Data collection:**
  - Data entered into a REDCap database
Methods

- **Sample size:**
  - Data collection includes charts from 1994 to 2017, including diagnoses based on the criteria from any of the following:
    - DSM-IV (1994-2013)
    - DSM-V (2013-present)

- **Full EMR data set n=7540**

<table>
<thead>
<tr>
<th>Site</th>
<th>ASD (n)</th>
<th>DCD (n)</th>
<th>ASD+DCD (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>CCM</td>
<td>5220</td>
<td>424</td>
<td>59</td>
</tr>
<tr>
<td>CSC</td>
<td>1559</td>
<td>46</td>
<td>232</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>6779</strong></td>
<td><strong>470</strong></td>
<td><strong>291</strong></td>
</tr>
</tbody>
</table>

- **Current study data set n=209**

<table>
<thead>
<tr>
<th>Site</th>
<th>ASD (n)</th>
<th>DCD (n)</th>
<th>ASD+DCD (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total</strong></td>
<td><strong>91</strong></td>
<td><strong>51</strong></td>
<td><strong>67</strong></td>
</tr>
</tbody>
</table>
ANOVA:
F(2, 79) = 2.84, p = 0.065

Post-Hoc Tests:
ASD = ASD+DCD (p = 1.00)
DCD = ASD (p = 0.13)
DCD = ASD+DCD (p = 0.07)

ASD=91; DCD=51; ASD+DCD=67
Total=209
Age at First Concern Visit

ANOVA:
F(2, 92) = 7.22, p = 0.001

Post-Hoc Tests:
ASD = ASD+DCD (p = 0.015)
DCD = ASD (p = 0.75)
DCD = ASD+DCD (p = 0.02)

ASD=91; DCD=51; ASD+DCD=67
Total=209

34 months = ~3 years
**Age at Referral Visit with Specialist**

ANOVA:
F(2, 116) = 6.73, p = 0.002

Post-Hoc Tests:
ASD = ASD+DCD (p = 0.94)
DCD = ASD (p = 0.40)
DCD = ASD+DCD (p = 0.001)

ASD=91; DCD=51; ASD+DCD=67
Total=209
Findings are collapsed across all groups.

ASD=91; DCD=51; ASD+DCD=67
Total=209
Conclusion

- **Parental concern and visits:**
  - Greater variability in the DCD group for age of first concern.
  - DCD patients enter the diagnostic pathway nearly 3 years later than ASD and ASD+DCD groups.
  - ASD+DCD may manifest as greater functional impairment or symptom severity, prompting earlier concern.

- **Delays in motor skill acquisition:**
  - A portion of patients are labeled within normal limits of development, but receive a diagnosis of a developmental disorder at a later time.
  - Diagnostic gap in screening and/or documentation.
Implications

- **Problems with global impact across co-occurrences:**
  - Missing information about the source of diagnosis.
  - Variability in quantity and quality of supporting information for a diagnosis.
  - Limited sample size due to low treated prevalence.

- **Impact of understanding the diagnostic trajectory:**
  - Better characterization of whole body symptom profile in ASD.
  - Increased awareness to differences in the diagnostic pathways.
  - Improved diagnostic efficiency of co-occurring diagnosis.
  - Development of more appropriate, targeted, accessible interventions.
  - Optimal outcomes mean earlier, more intense interventions and less pharmacologic treatment *(Sanchack and Thomas, 2016, *Am Fam Physician*)
Future Directions and Goals

• **Clarify overlap** vs independent presentation of motor issues.

• **Systematic screening** for motor symptoms and coordination.

• **Timely diagnosis** (Bhat et al., 2014, *Rev Neurosci.*)
  - Evidence-based and cost-effective interventions (Durken et al., 2015, *Autism Res.*)
  - Smoother transitions in care (pediatric → adult services or one clinical provider → another) (Colver et al., 2018, *BMC Med.*)
ASD vs. ASD+DCD: A Case Study

Shannon Chang, OMS-III
# Case Introduction

<table>
<thead>
<tr>
<th>Case #1: ASD + DCD</th>
<th>Case #2: ASD</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>7 year old Caucasian female</strong></td>
<td><strong>7 year old Hispanic boy</strong></td>
</tr>
<tr>
<td>First seen by CCMC Pediatrics in <strong>2012</strong> with concerns of developmental delay</td>
<td>First seen by CCMC Pediatrics in <strong>2013</strong> with concerns of difficulty speaking and eating</td>
</tr>
<tr>
<td><strong>Background</strong>: low birth weight, pre-term, adopted from Russian orphanage at 18 months</td>
<td><strong>Background</strong>: uncomplicated pregnancy, consistently attended well-child visits, only speech was noticed to be delayed</td>
</tr>
<tr>
<td><strong>Past Medical History</strong>: ADHD, microcephalus, fetal alcohol syndrome, seizures, failure to thrive</td>
<td><strong>Past Medical History</strong>: ADHD</td>
</tr>
<tr>
<td><strong>Family + Social History</strong>: information regarding biological parents unknown; adoptive mother has advanced degree and works as ICU nurse</td>
<td><strong>Family + Social History</strong>: Spanish speaking household and family required translator for visits, covered by Medicaid, older brother with developmental delays and autism</td>
</tr>
</tbody>
</table>
Case #1: ASD+DCD
Clinical Timeline

2012
- Early Childhood Intervention (ECI)
- First visit to Pediatrics in Ft. Worth
  - Was administered Ages and Stages and MCHAT
  - No diagnosis
- 2nd visit to Neurology yielded DCD diagnosis
- Speech, Physical, and Occupational Therapy
  - No detailed information

2013
- Pediatrics
  - Again administered Ages and Stages and MCHAT
  - Referred to Child Study Center for evaluation

2014
- Child Study Center
  - ADOS again administered - no results available

2015
- Child Study Center
  - continued going to CSC for ADHD evaluation and treatment

2016
- Child Study Center
  - brought up possibility of fetal alcohol syndrome for patient’s "autistic-like features"

2017
- Child Study Center
  - Child Study Center – another Psych Evaluation
  - ADOS test showed "moderate level of ASD"
  - Reached ASD diagnosis

4.25 years to reach final diagnosis
Case #2: ASD
Clinical Timeline

2011-2012
- Pediatrics
- Attended 6 Well Visits from 2011-2012
- Administered Ages and Stages in late 2011

2013
- Pediatrics
- First concern regarding development
- Referred to Speech Therapy (ST)
- Speech Therapy
- Diagnosed with Developmental expressive language disorder and receptive language disorder

2014
- Pediatrics
- Referred to Occupational Therapy, Physical Therapy, Speech Therapy, and Child Study Center
- Concern for global developmental delays and autism

2015
- Pediatrics
- Well Child Visit
- Child Study Center
- Administered ADOS and Social Communication Questionnaire
- Diagnosed with ADHD, global developmental delay, and language disorder

2016
- Neurology
- Diagnosed with sleep terror disorder
- Pediatrics
- Referred to psychiatry and genetics

2017
- Genetics
- Child Study Center
- Diagnosed with ASD
- No records available

4.5 years to reach final diagnosis
<table>
<thead>
<tr>
<th></th>
<th>Case 1 (ASD+DCD)</th>
<th>Case 2 (ASD)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td>Female</td>
<td>Male</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td>Caucasian</td>
<td>Hispanic</td>
</tr>
<tr>
<td><strong>Socioeconomic Status</strong></td>
<td>Middle-High</td>
<td>Low</td>
</tr>
<tr>
<td><strong>Age of First Concern</strong></td>
<td>2 years</td>
<td>2 years</td>
</tr>
<tr>
<td><strong>First Professional Seen</strong></td>
<td>Pediatrician</td>
<td>Pediatrician</td>
</tr>
<tr>
<td><strong>Age of ASD Diagnosis</strong></td>
<td>6.25 years</td>
<td>6.5 years</td>
</tr>
<tr>
<td><strong>Age of DCD Diagnosis</strong></td>
<td>2 years</td>
<td>N/A</td>
</tr>
<tr>
<td><strong>Age of Final Diagnosis</strong></td>
<td>6.25 years</td>
<td>6.5 years</td>
</tr>
<tr>
<td><strong>Source of Final Diagnosis</strong></td>
<td>Child Study Center</td>
<td>Child Study Center</td>
</tr>
<tr>
<td><strong>Time Spent Between First Concern and Final Diagnosis</strong></td>
<td>4.25 years</td>
<td>4.5 years</td>
</tr>
<tr>
<td><strong># of Visits before Final Diagnosis</strong></td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td><strong>Recommended Interventions</strong></td>
<td>ST, OT, PT</td>
<td>ST, OT, PT</td>
</tr>
<tr>
<td><strong>Interventions Utilized</strong></td>
<td>ST, OT, PT</td>
<td>ST</td>
</tr>
</tbody>
</table>
Discussion

- Several factors lead to delayed diagnosis and intervention
Conclusions

- Need for collaborative, caregiver-mediated and child-directed intervention in ASD children
  - Physicians need to listen to caregiver concerns on symptoms and treatment strategies (Guan et al.)
  - Consider cultural differences in caregiver behaviors and associations between caregiver behaviors and clinician adherence
    - Only 47% of concerns expressed per physician visit (Guan et al.)
  - Consider socioeconomic background and feasibility of caregiver and ASD individual’s environment
Future Directions

• Early intervention results in improved functional use of:
  – Language
  – Daily living skills
  – Positive social behavior
  – Other domains playing a role in quality of life

• All these skills have long-term implications for independent living, employment, fall/injury risk, etc.

• Examples of Early Intervention
  – Routine developmental screening at every well-child visit

  – ASD-specific screening
    • Modified Checklist for Autism in Toddlers (M-CHAT)
    • Early Screening of Autistic Traits (ESAT)
    • The Screening Tool for Autism in Toddlers and Young Children

  – Genetic counseling
    • Risk is increased in siblings of children with ASD
Use of Autism-Related Services in DFW

Abhinaya Ganesh, OMS-III
Shravan Mupparapu, MPH
Haylie Miller, Ph.D.
Texas ranks as the 2\textsuperscript{nd} lowest state in the nation for community-based disability support services (\textit{The Case for Inclusion}, 2016, United Cerebral Palsy)

- An estimated \textbf{8,000 children} are living with ASD, in Tarrant County (based on census data and CDC prevalence rate)

- Only \textbf{120 BCBAs} in the DFW Metroplex (BCBA/BCaBA Registry, 2019)

\textbf{Fig. 1.} The overlap between intervention types and common symptoms in ASD.
Specific Aims

• Identify patterns of ASD service utilization in the Dallas/Fort Worth area

• Measure caregiver satisfaction with availability and quality of services

• Identify whether socioeconomic factors influence treatment choice
Methods

- **Design:** Cross-sectional analysis using a survey
- **Participants:** Caregivers of an individual with ASD or adult self-advocates with ASD in DFW
- **Sample Size:** Data collection is still ongoing
  - Planned sample size = 75 caregivers and 25 self-advocates

<table>
<thead>
<tr>
<th>Category</th>
<th>Level</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Race/Ethnicity</td>
<td>White Non-Hispanic</td>
<td>18</td>
<td>56.25%</td>
</tr>
<tr>
<td></td>
<td>White Hispanic</td>
<td>9</td>
<td>28.12%</td>
</tr>
<tr>
<td></td>
<td>African-American</td>
<td>5</td>
<td>15.62%</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>32</td>
<td>100.00%</td>
</tr>
<tr>
<td>Sex</td>
<td>Male</td>
<td>5</td>
<td>13.89%</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>31</td>
<td>86.11%</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>36</td>
<td>100.00%</td>
</tr>
<tr>
<td>Household Income</td>
<td>Low ($10,000-49,999)</td>
<td>9</td>
<td>26.47%</td>
</tr>
<tr>
<td></td>
<td>Moderate ($50,000-99,999)</td>
<td>17</td>
<td>50.00%</td>
</tr>
<tr>
<td></td>
<td>High ($100,000+)</td>
<td>8</td>
<td>23.53%</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>34</td>
<td>100.00%</td>
</tr>
</tbody>
</table>

Table 1. Demographics of current survey respondents.
Survey Variables

**Socioeconomic Factors**
- Respondent & recipient demographics
- Family characteristics
- Recipient education
- Diagnosis
- Source of diagnosis
- Clinical recommendations
- Source of information after diagnosis
- Medications

**Services**
- Type of services & programs used
- Reason for type of service used
- School programs
- Home-based interventions
- Specialists
- Payment for services
- Age of child at outset of services

**Satisfaction**
- Satisfaction with educational & support services
- Perceived results/outcomes
- Access to services through school
- Access to services through the community
- Priority of services
S1. I am very satisfied with the diagnostic services we received from our school/provider

- Strongly Disagree
- Disagree
- Neutral
- Agree
- Strongly Agree

S2. The recipient's behavioral or emotional needs are met by his/her education program

- Strongly Disagree
- Disagree
- Neutral
- Agree
- Strongly Agree

<table>
<thead>
<tr>
<th>The recipient is doing better at home</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
<th>Does not apply</th>
</tr>
</thead>
<tbody>
<tr>
<td>The recipient is doing better at school</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>The recipient's behavior is better</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>The recipient's communication is better</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>The recipient's social skills are better</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>The recipient is better able to solve his/her problems</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I have less stress</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Our family has less stress</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>Our family has less financial worry</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
Preliminary Results

• **Service Navigation**
  - Several trends in caregiver reports of the three most challenging issues following diagnosis. The most commonly-reported challenging issue was service navigation.

• **Service Ranking**
  - When participants were asked to rank different types of services (speech therapy, occupational therapy, counseling, respite care, etc.) from 1 through 8, all 8 services averaged at about a 4. This shows that participants find all of the services equally necessary.

• **Satisfaction Rates**
  - Overall, 55% of participants were dissatisfied with available services/providers, though most were satisfied with school-sponsored services.

Fig. 2. Caregivers reported the top 3 challenges in identifying & obtaining services; responses clustered into 6 categories.
Summary of Results

<table>
<thead>
<tr>
<th></th>
<th>First Service Used</th>
<th>Other Services Used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alternative Therapies</td>
<td></td>
<td>26</td>
</tr>
<tr>
<td>Speech Therapy</td>
<td>8</td>
<td>23</td>
</tr>
<tr>
<td>Occupational Therapy</td>
<td>3</td>
<td>21</td>
</tr>
<tr>
<td>ABA</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>Early Childhood Intervention</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Counseling</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Social Support</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Physical Therapy</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>Sensory Therapy</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>Cognitive Behavioral Therapy</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Play Therapy</td>
<td></td>
<td>1</td>
</tr>
</tbody>
</table>

- Identify why participants are not using the services they ranked as important
- Issues of access or availability in the community?

Table 2. Frequency of services used (# affirmed)
Application to Real Life

• A successful treatment plan is tailored to match the child’s age and the severity of the disability. In order to make community- and state-level policy recommendations to address this issue, it is important to understand the specific landscape of met and unmet needs of individuals with ASD.

• By identifying gaps in service availability and use of services, policymakers, healthcare providers, and community advocates will be better equipped to design programs that facilitate access to appropriate and timely interventions.
Take-Home Points

– ASD is a whole-body disorder, and requires multiple approaches to assessment and intervention
– Culture shift needed at multiple levels to prevent ASD with a co-occurrence from being misdiagnosed
– Mismatch between parents’ perceptions of intervention efficacy and use/availability
How Can You Help?

– Raise awareness of non-core symptoms of ASD
– Raise awareness of common co-occurring conditions
– Prioritize “building block” skills (e.g., motor control) in intervention before targeting higher-order behaviors
– Support families in navigating a complex landscape of services, providers, and (mis)information
– Encourage families to participate in research, regardless of whether the individual with ASD has a co-occurring condition
Many people to thank…

**Mentors & Collaborators**
- Nicoleta Bugnariu, PT, Ph.D. (UNTHSC)
- Priscila Caçola, Ph.D. (UT Arlington)
- Mary Hayhoe, Ph.D. (UT Austin)
- Matt Mosconi, Ph.D. (Univ. of Kansas)
- Rita Patterson, Ph.D. (UNTHSC)
- Joyce Mauk, M.D. (Cook Children’s)
- W. Paul Bowman, M.D. (UNTHSC)
- UNTHSC TCHD program faculty
- UT Southwestern Center for Translational Medicine/CTSA KL2 program faculty

**Team Members**
- Autism & Developmental Disorders Research and Human Movement Performance Lab staff/students
- Community partners: Autism Treatment Center, Cook Children’s Medical Center, Hope Center, Dallas Children’s Theater, Amon Carter Museum, Fort Worth Museum of Science & History, Fort Worth Library, Fort Worth ISD, Keller ISD, Hill School

**Funding & Resources**
- NIMHD/Texas Center for Health Disparities (U54-MD006882)
- Autism Speaks (Local Impact Grant)
- NIMH (K01-MH107774)
- NCATS/UT Southwestern CTSA (KL2-TR001103)
- NSF SBE Directorate (SMA-1514495)
- UNTHSC Research Seed Grant

*Most importantly, our thanks to the amazing families who give time & effort so generously to advance our understanding of ASD!*
UNT Health Science Center
Autism & Developmental Disorders Research

Facebook: @UNTHSCautism
Web: www.unthsc.edu/autism
Phone: 817-735-2312
Email: autism@unthsc.edu