

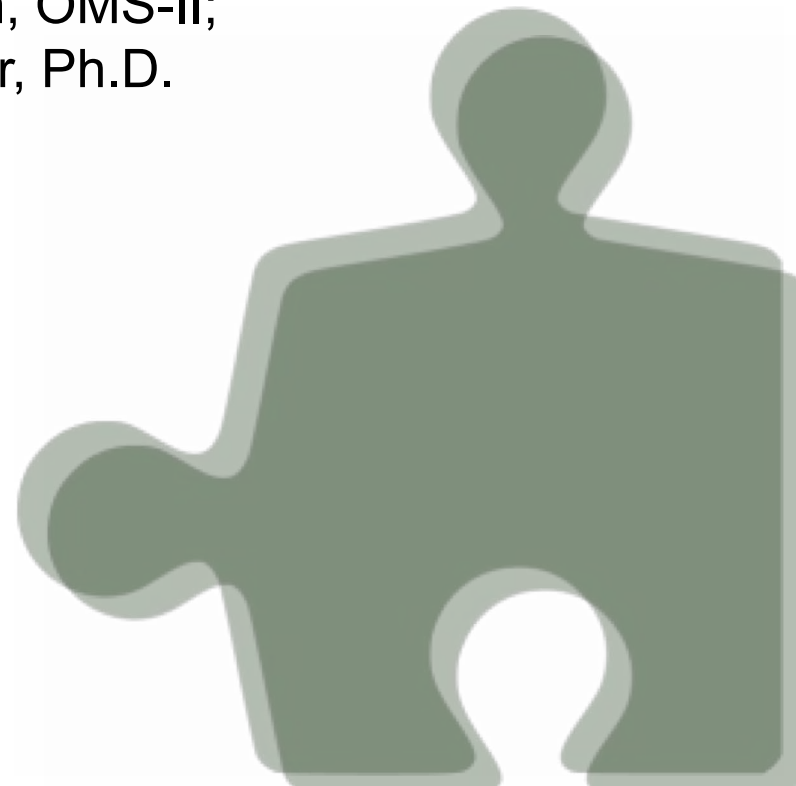
Navigating the pathway to diagnosis and care for individuals with Autism Spectrum Disorder

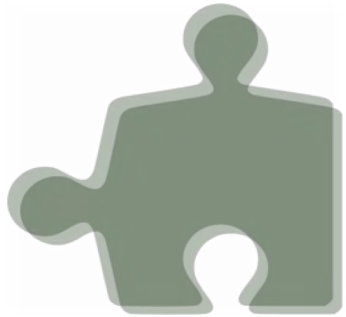
Nicholas Fears, Ph.D.; Karolina Kata, M.B.S., OMS-IV;
Shannon Chang, OMS-III; Monica Nguyen, OMS-II;
Abhinaya Ganesh, OMS-III; & Haylie Miller, Ph.D.

July 20, 2019

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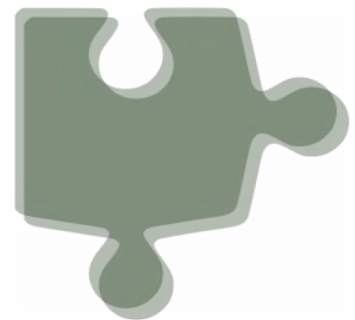
AUTISM & DEVELOPMENTAL DISORDERS RESEARCH

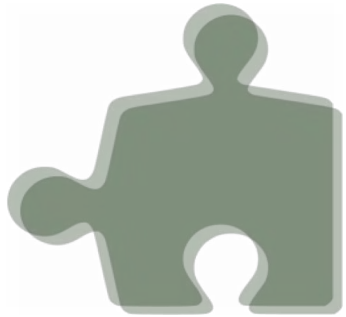




Our Mission at UNTHSC:

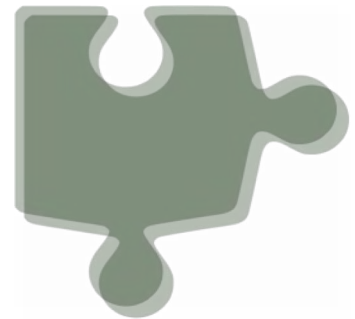
- Partner with stakeholders in the ASD community
- Provide resources for individuals/families in need
- Study sensorimotor function in ASD
- Understand co-occurrence of ASD and other developmental disorders/conditions





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!



ASD Diagnostic Criteria

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

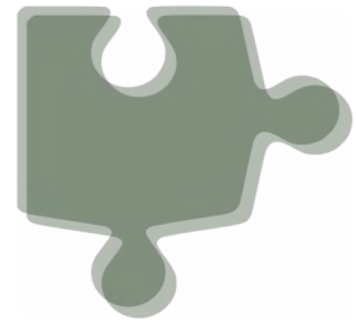
AND...

Symptoms present in early development, cause clinically significant impairment, and are not better explained by intellectual disability or global developmental delay.



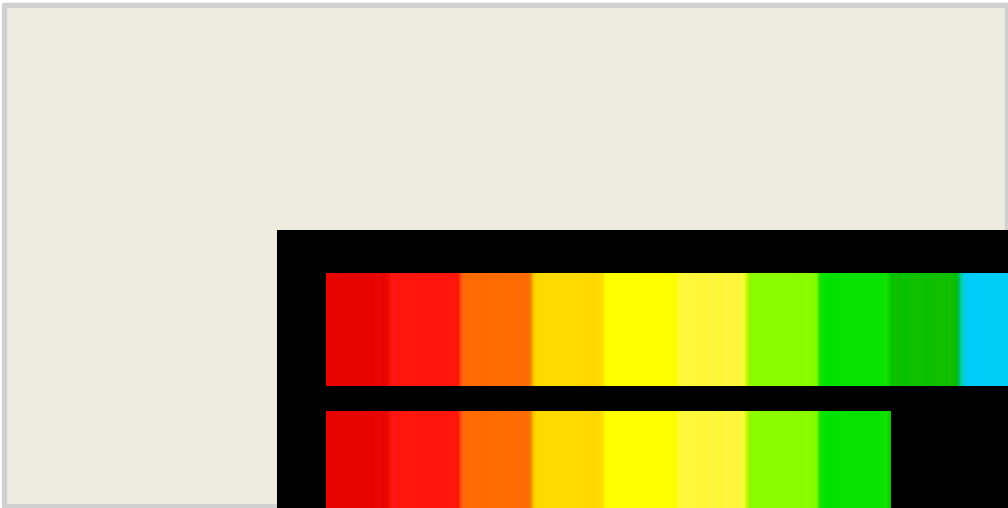
Redefining Autism Spectrum Disorder (ASD):

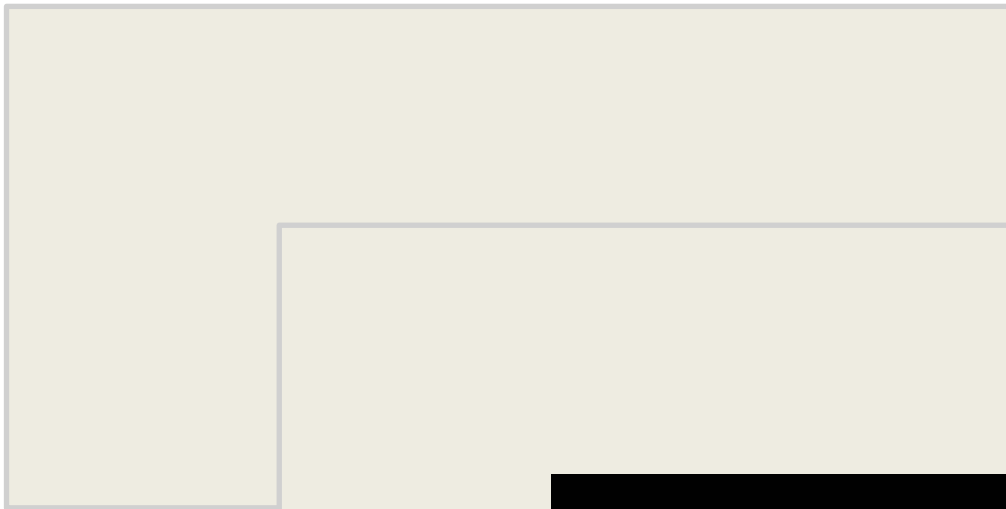
- Complex set of neurodevelopmental symptoms
- Not just social or psychological – “whole body”
- Not just a two-dimensional spectrum (low/high)

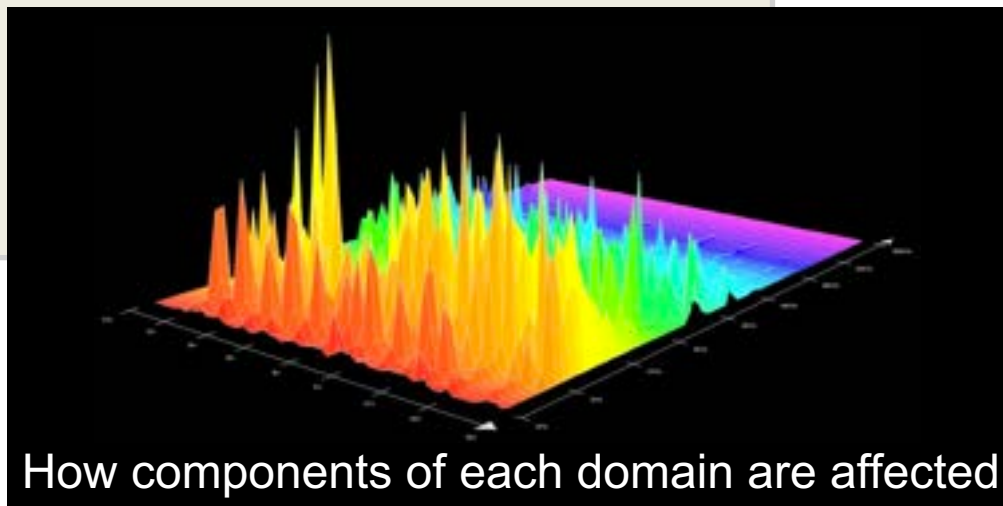
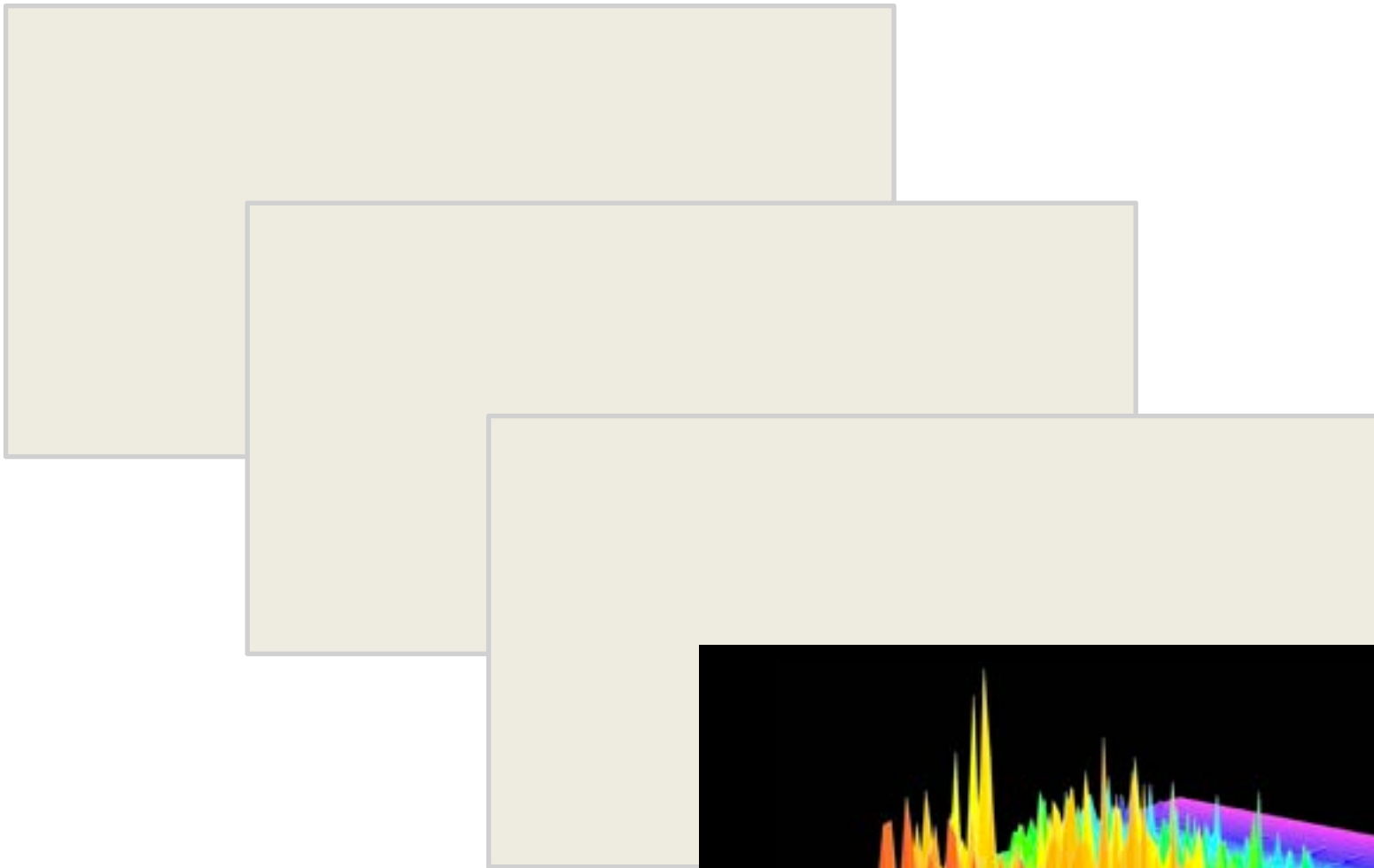




Low to High Functioning









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.

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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)



Topple®, Pressman Games

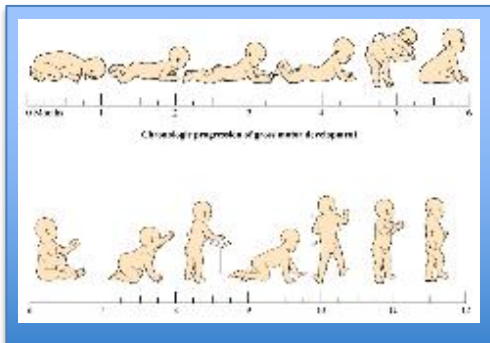
ASD and DCD

- 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)



ASD and DCD

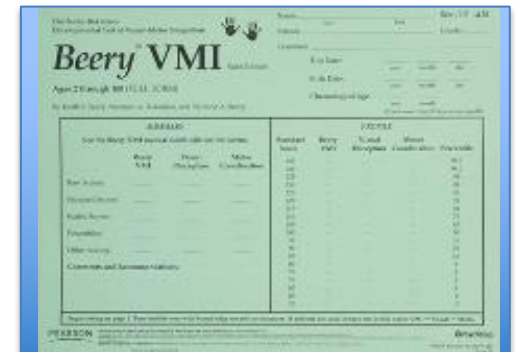
- How do children with ASD compare to children with DCD on parent reports and standardized assessments of movement?
 - Developmental Motor Milestones & Developmental Coordination Disorder Questionnaire (DCD-Q)
 - Movement Assessment Battery for Children (MABC-2)
 - Beery Test of Visual-Motor Integration (Beery VMI)



Johnson & Blasco, 1997, *Pediatr Rev.*



Pearson



ASD and DCD

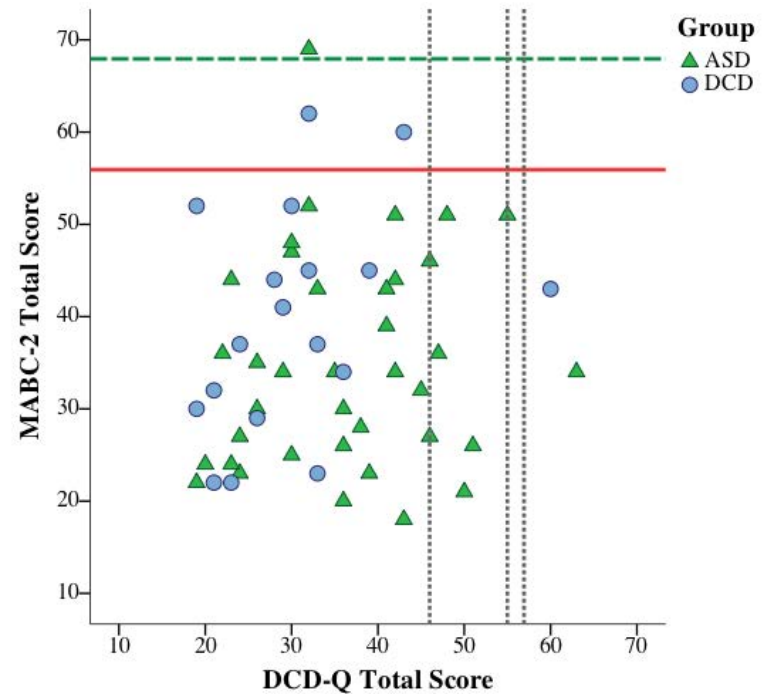
- Discrepancies in parent reports
 - 76% of children with ASD met developmental motor milestones according to parent reports
 - 92% of children with ASD met criteria for DCD via parent report on the DCD-Q

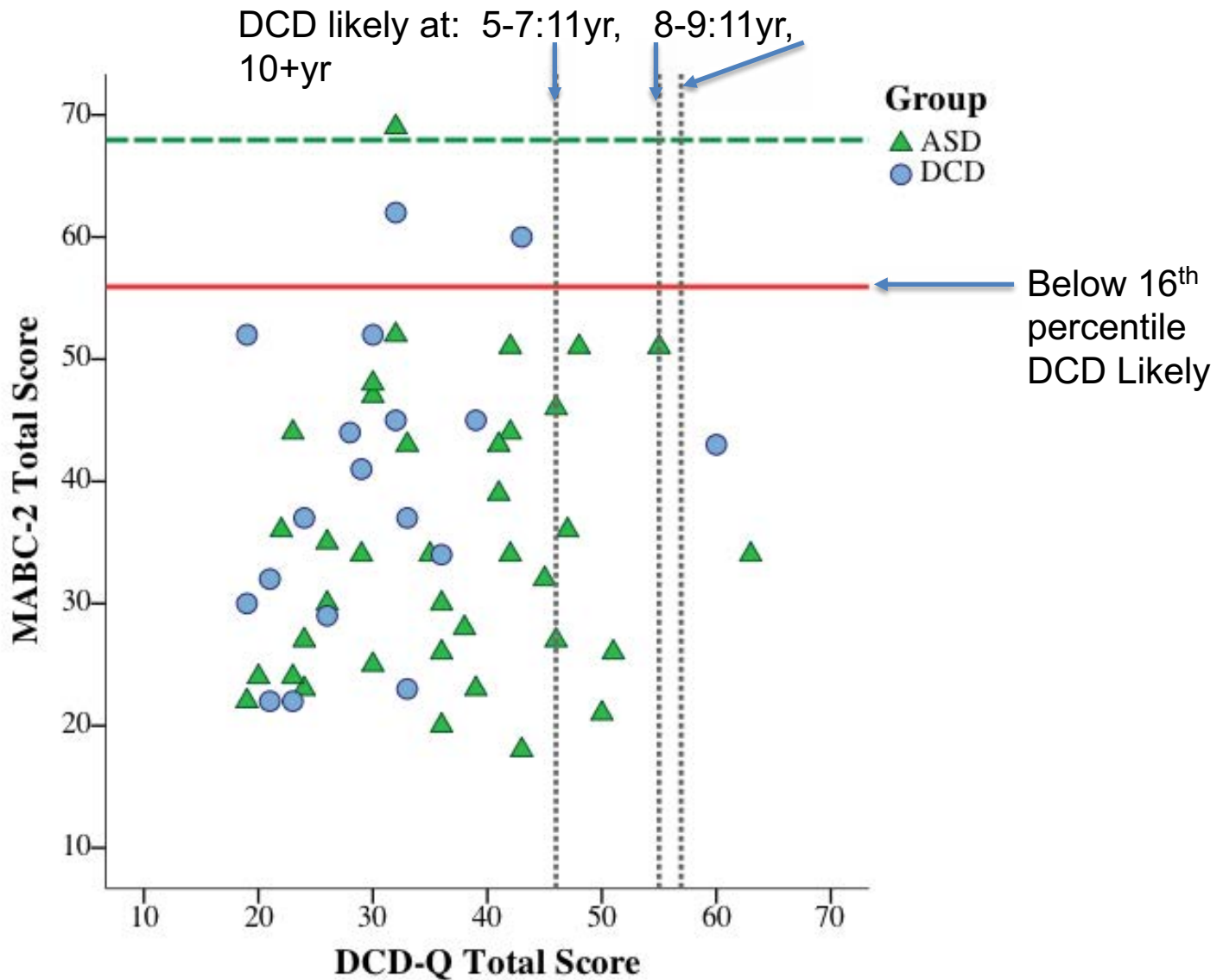


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ASD and DCD

- 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





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)



Getty Images



CDC

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)



Christopher Furlong. Getty Images



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Diagnosis & Treatment

- 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

(Vargason et al., 2019, Autism Res., Carmassi et al., 2019, Front Psychiatry, Gabis, Defense-Netrval and Fernandes, 2016, Cudas)



Moriarty Physical 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

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Diagnostic Pathways for ASD with/without Co-Occurring Conditions

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

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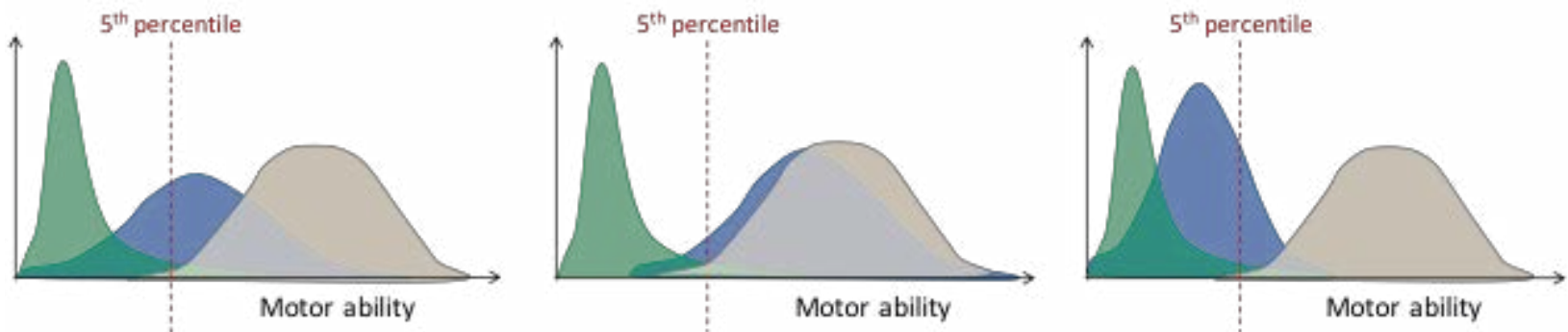
Neurodevelopmental Disorders

- 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)



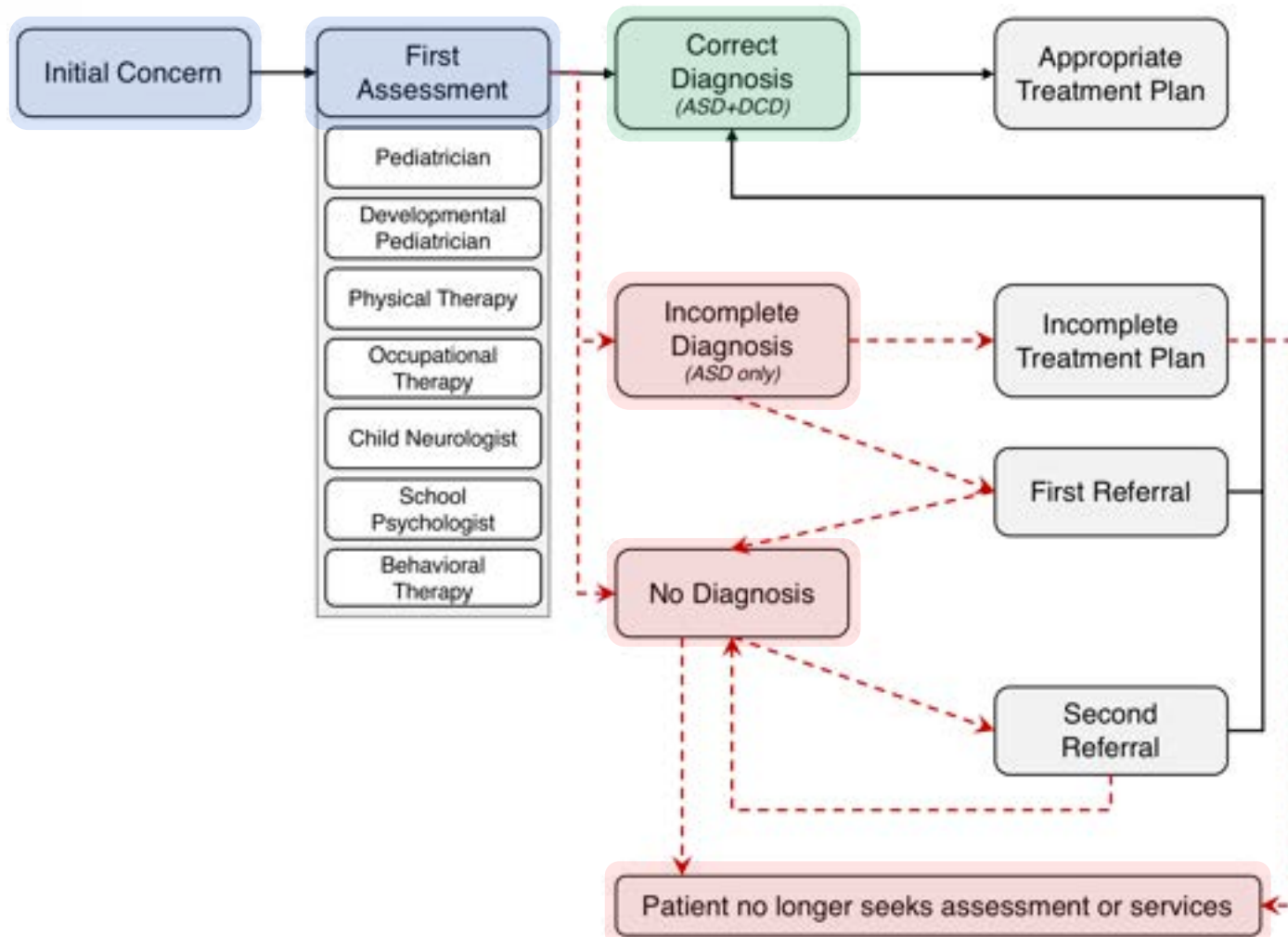
Typically Developing ASD DCD



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.

Diagnostic Pathways





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)
 - IDC-9 (1978-2015), ICD-10 (2015-present)

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

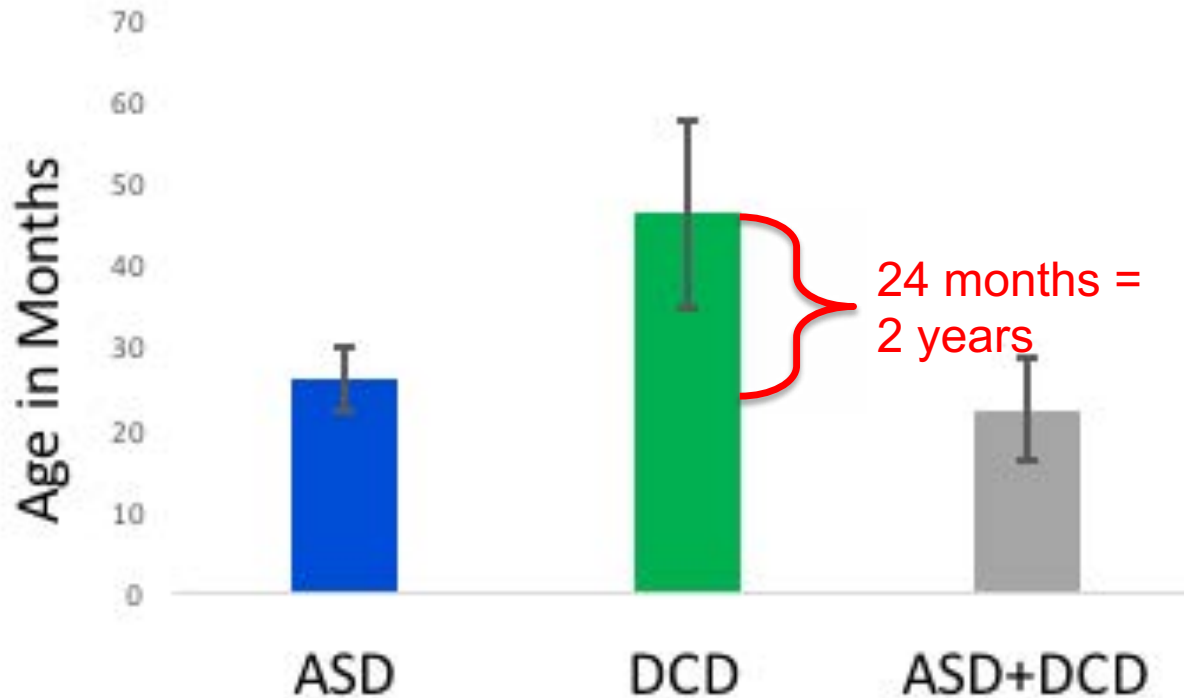
Site	ASD (n)	DCD (n)	ASD+DCD (n)
CCM C	5220	424	59
CSC	1559	46	232
Total	6779	470	291

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

Site	ASD (n)	DCD (n)	ASD+DCD (n)
Total	91	51	67



Age at First Concern



ANOVA:

$F(2, 79) = 2.84, p = 0.065$

Post-Hoc Tests:

ASD = ASD+DCD ($p = 1.00$)

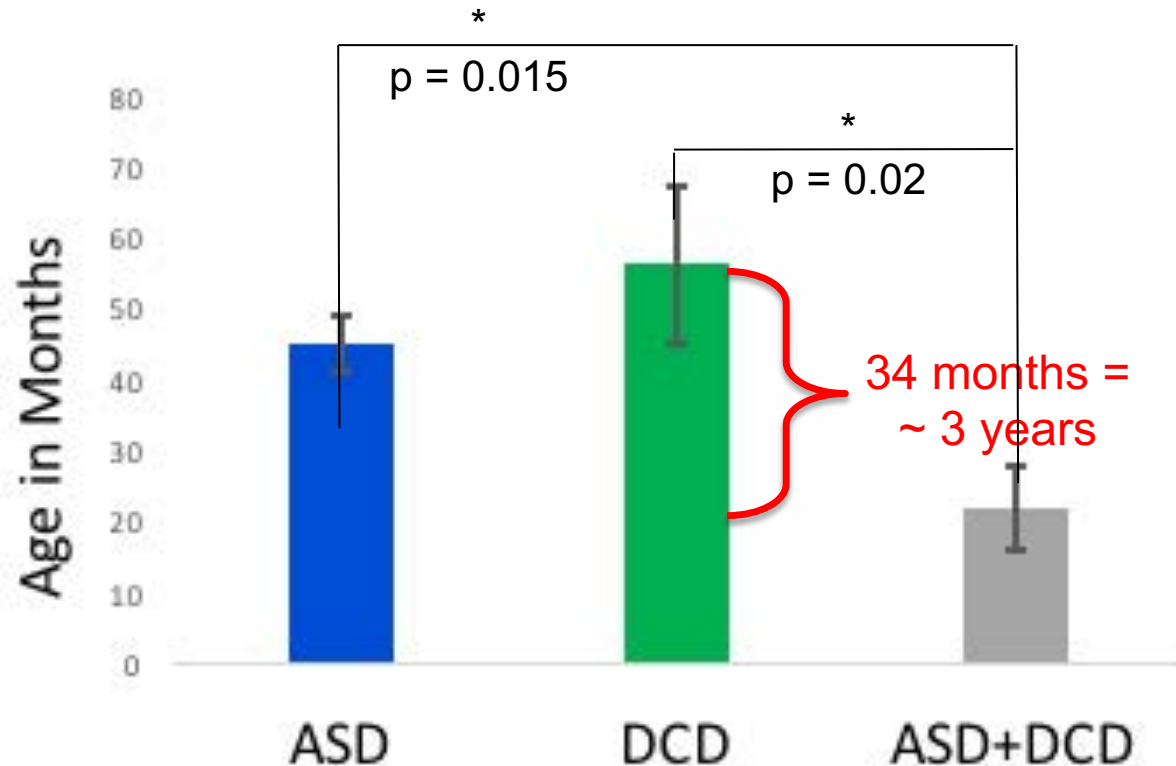
DCD = ASD ($p = 0.13$)

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 ($p = 0.75$)

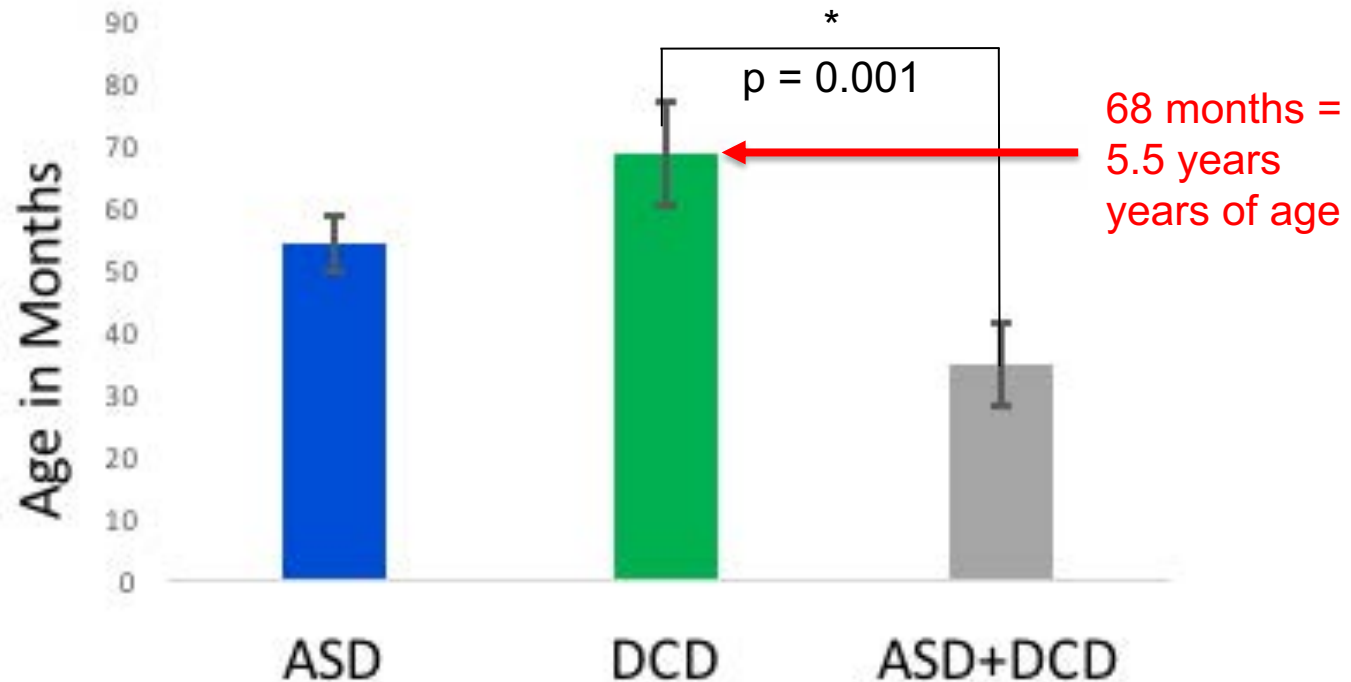
DCD = ASD+DCD ($p = 0.02$)

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

Total=209



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 ($p = 0.40$)

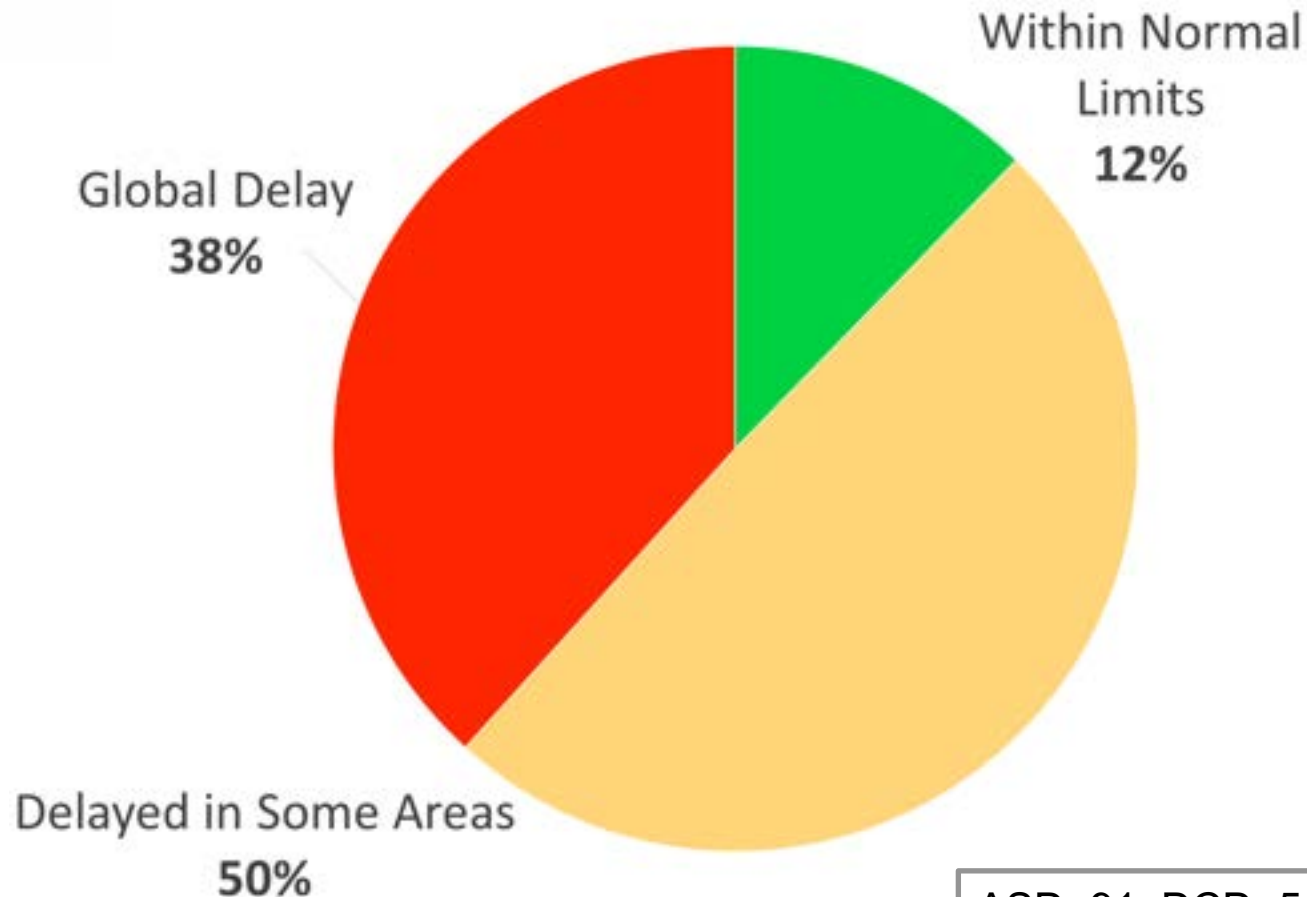
DCD = ASD+DCD ($p = 0.001$)

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

Total=209



Developmental Delay



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

Findings are collapsed across all groups.



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

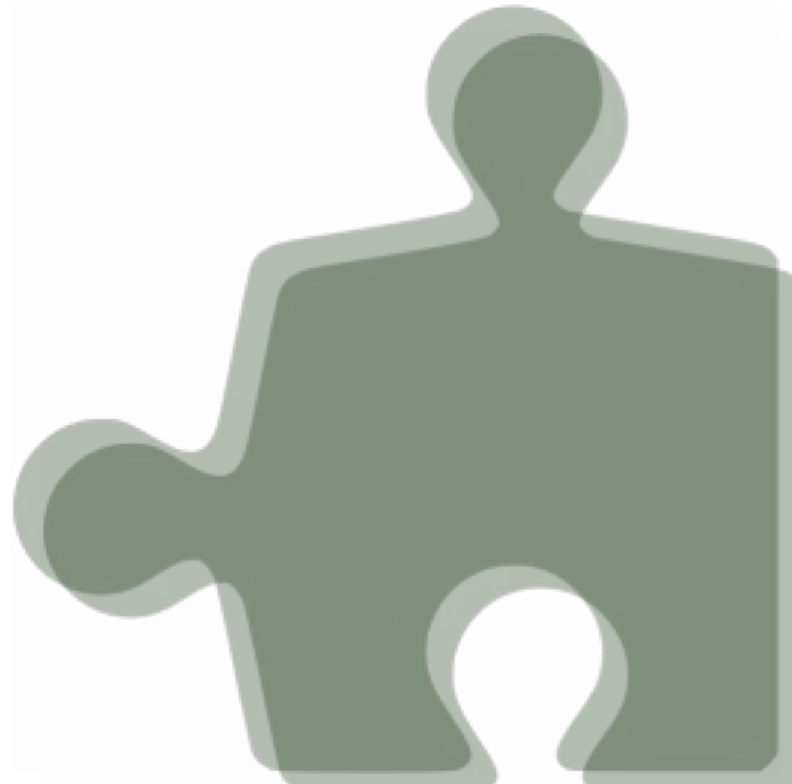
- **Clarify overlap** vs independent presentation of motor issues.
- **Systematic screening** for motor symptoms and coordination.
- **Timely diagnosis** (Bhat et al., 2014, *Rev Neurosci.*)
 - Evidence-based and cost-effective interventions (Durken et al., 2015, *Autism Res.*)
 - Smoother transitions in care (pediatric → adult services or one clinical provider → another) (Colver et al., 2018, *BMC Med.*)
 - Coordination and sharing of information between sectors (education, health, social care) (Walsh et al., 2017, *J Autism Dev Disord.*; Goodson et al., 2016, *J Ark Med Soc.*)

ASD vs. ASD+DCD: A Case Study

Shannon Chang, OMS-III

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Case Introduction

Case #1: ASD + DCD

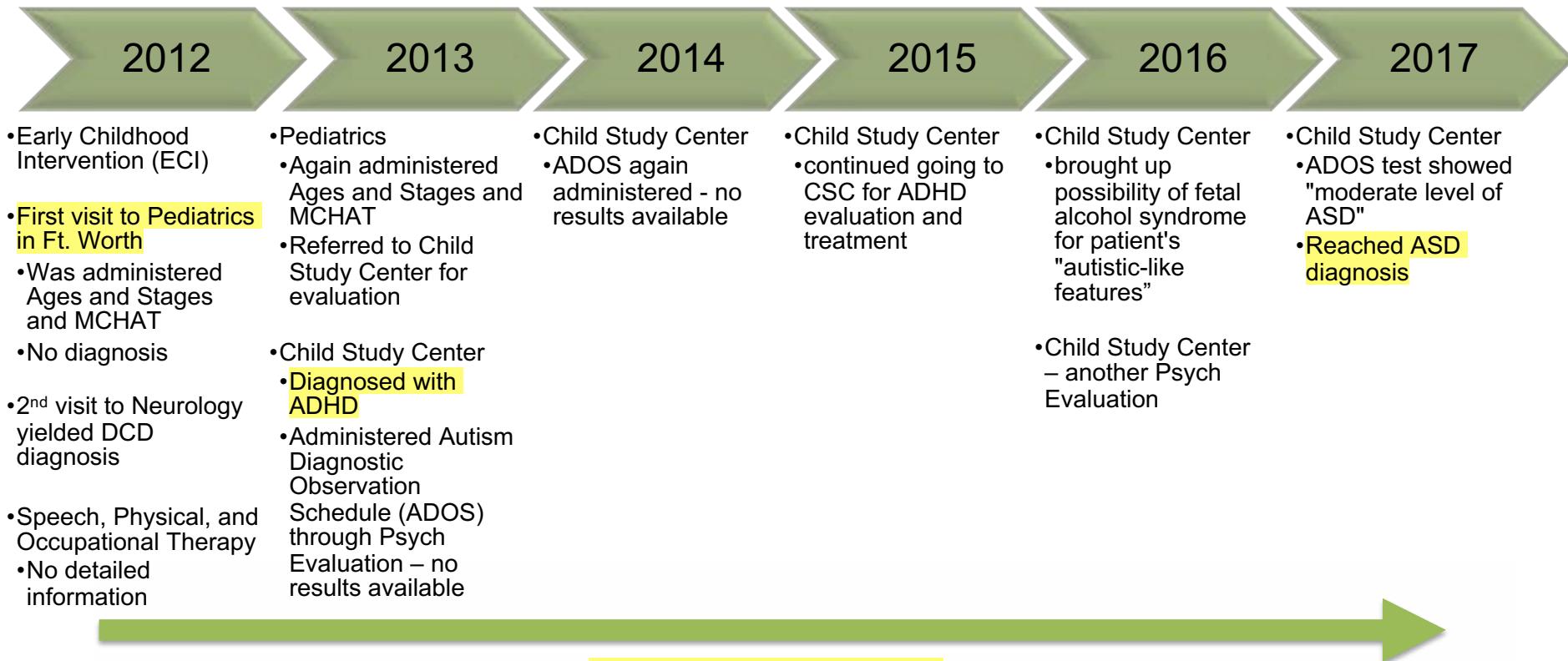
- 7 year old Caucasian female
- First seen by CCMC Pediatrics in **2012** with concerns of developmental delay
- **Background:** low birth weight, pre-term, adopted from Russian orphanage at 18 months
- **Past Medical History:** *ADHD*, microcephalus, fetal alcohol syndrome, seizures, failure to thrive
- **Family + Social History:** information regarding biological parents unknown; adoptive mother has advanced degree and works as ICU nurse

Case #2: ASD

- 7 year old Hispanic boy
- First seen by CCMC Pediatrics in **2013** with concerns of difficulty speaking and eating
- **Background:** uncomplicated pregnancy, consistently attended well-child visits, only speech was noticed to be delayed
- **Past Medical History:** *ADHD*
- **Family + Social History:** Spanish speaking household and family required translator for visits, covered by Medicaid, older brother with developmental delays and autism



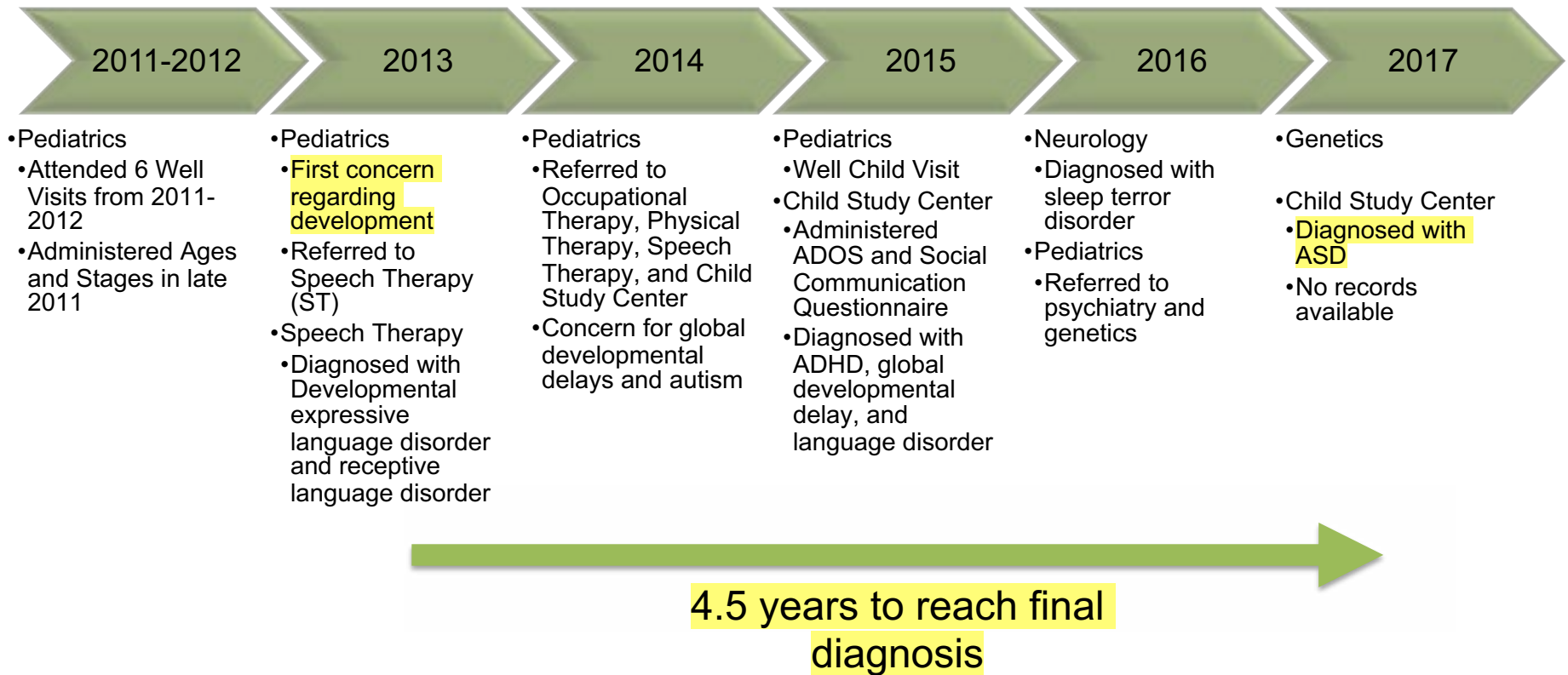
Case #1: ASD+DCD Clinical Timeline



4.25 years to reach
final diagnosis



Case #2: ASD Clinical Timeline



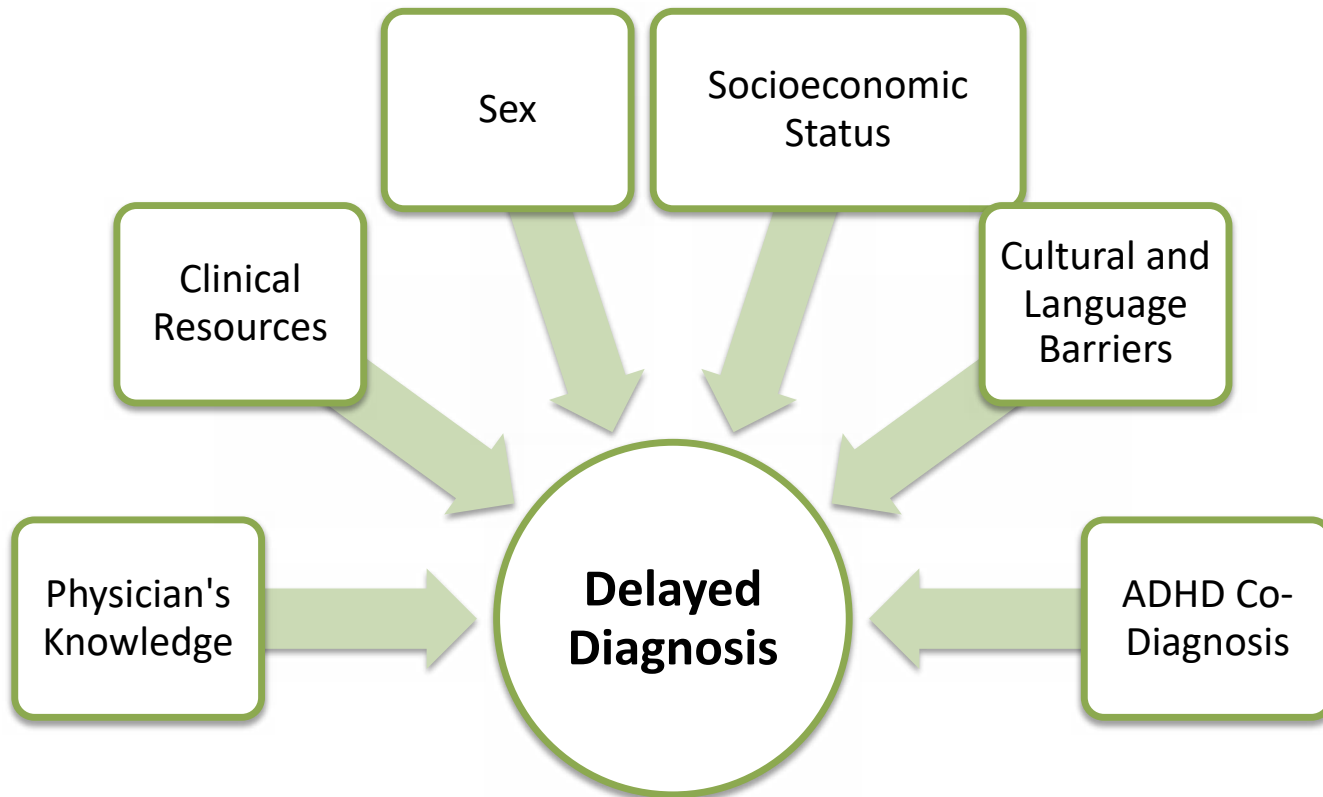


Summary of Results

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

Discussion

- Several factors lead to delayed diagnosis and intervention





Conclusion

- **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.

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Availability of Services in DFW

- **Texas ranks as the 2nd lowest state in the nation for community-based disability support services** (*The Case for Inclusion*, 2016, United Cerebral Palsy)
 - An estimated **8,000 children** are living with ASD, in Tarrant County (based on census data and CDC prevalence rate)
 - Only **120 BCBA**s in the DFW Metroplex (BCBA/BCaBA Registry, 2019)

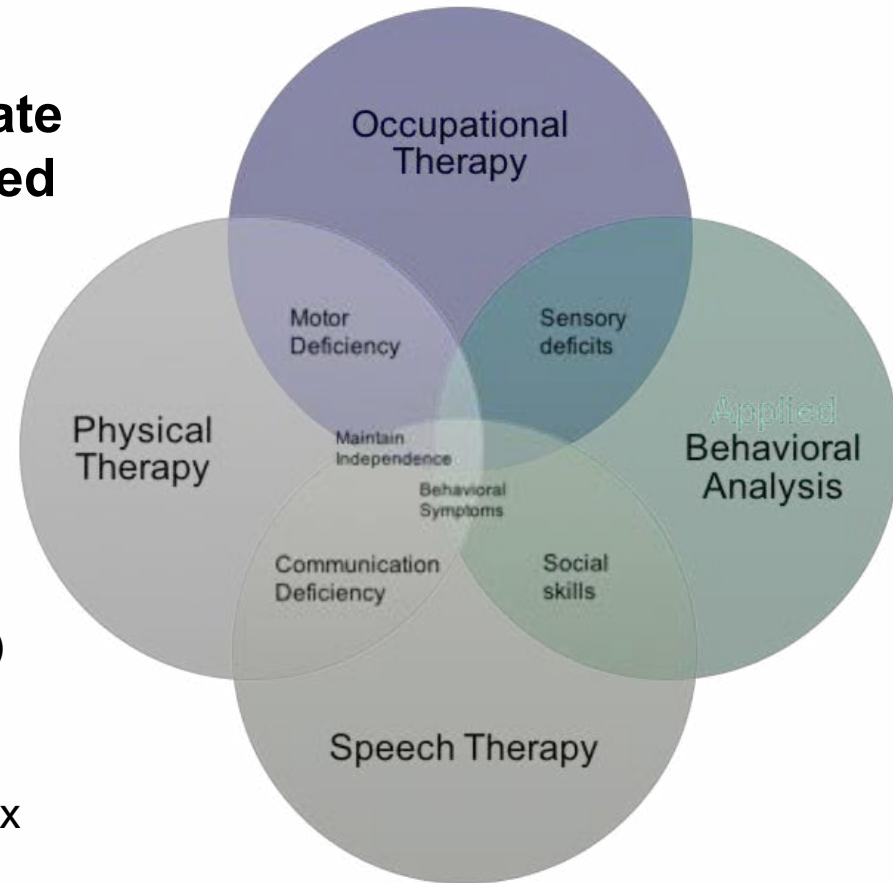


Fig. 1. The overlap between intervention types and common symptoms in ASD.



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 1. Demographics of current survey

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



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

REDCap Survey

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

	Strongly Disagree	Disagree	Agree	Strongly Agree	Does not apply
The recipient is doing better at home	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The recipient is doing better at school	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The recipient's behavior is better	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The recipient's communication is better	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The recipient's social skills are better	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The recipient is better able to solve his/her problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have less stress	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Our family has less stress	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Our family has less financial worry	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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.

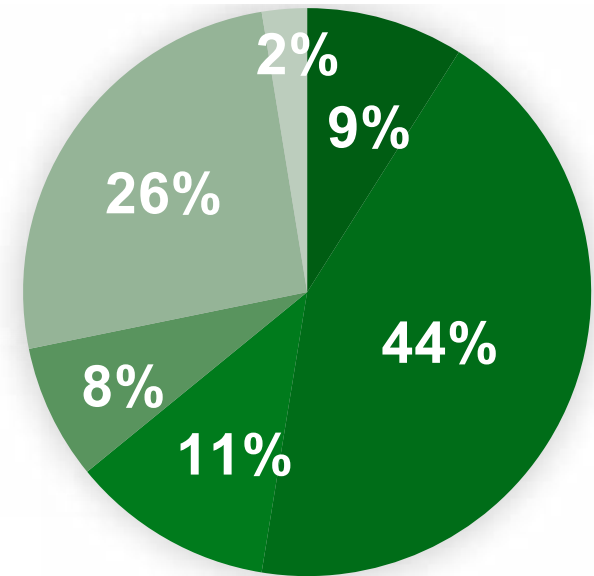
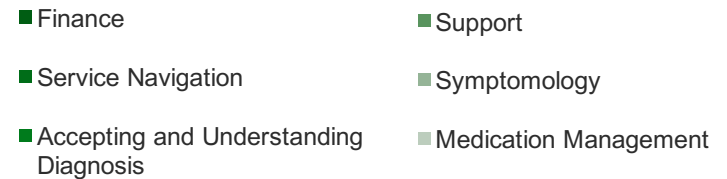


Fig. 2. Caregivers reported the top 3 challenges in identifying & obtaining services; responses clustered into 6 categories



Summary of Results

	First Service Used	Other Services Used
Alternative Therapies		26
Speech Therapy	8	23
Occupational Therapy	3	21
ABA	7	10
Early Childhood Intervention	4	4
Counseling	1	3
Social Support	1	3
Physical Therapy		2
Sensory Therapy		2
Cognitive Behavioral Therapy		1
Play Therapy		1

- 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)

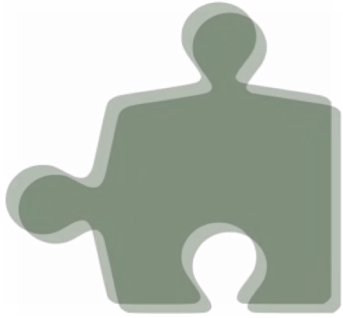


Application to Real Life

- 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.

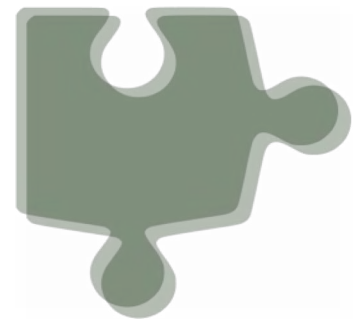


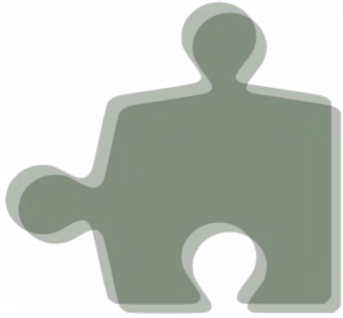
Making changes
to policies!



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



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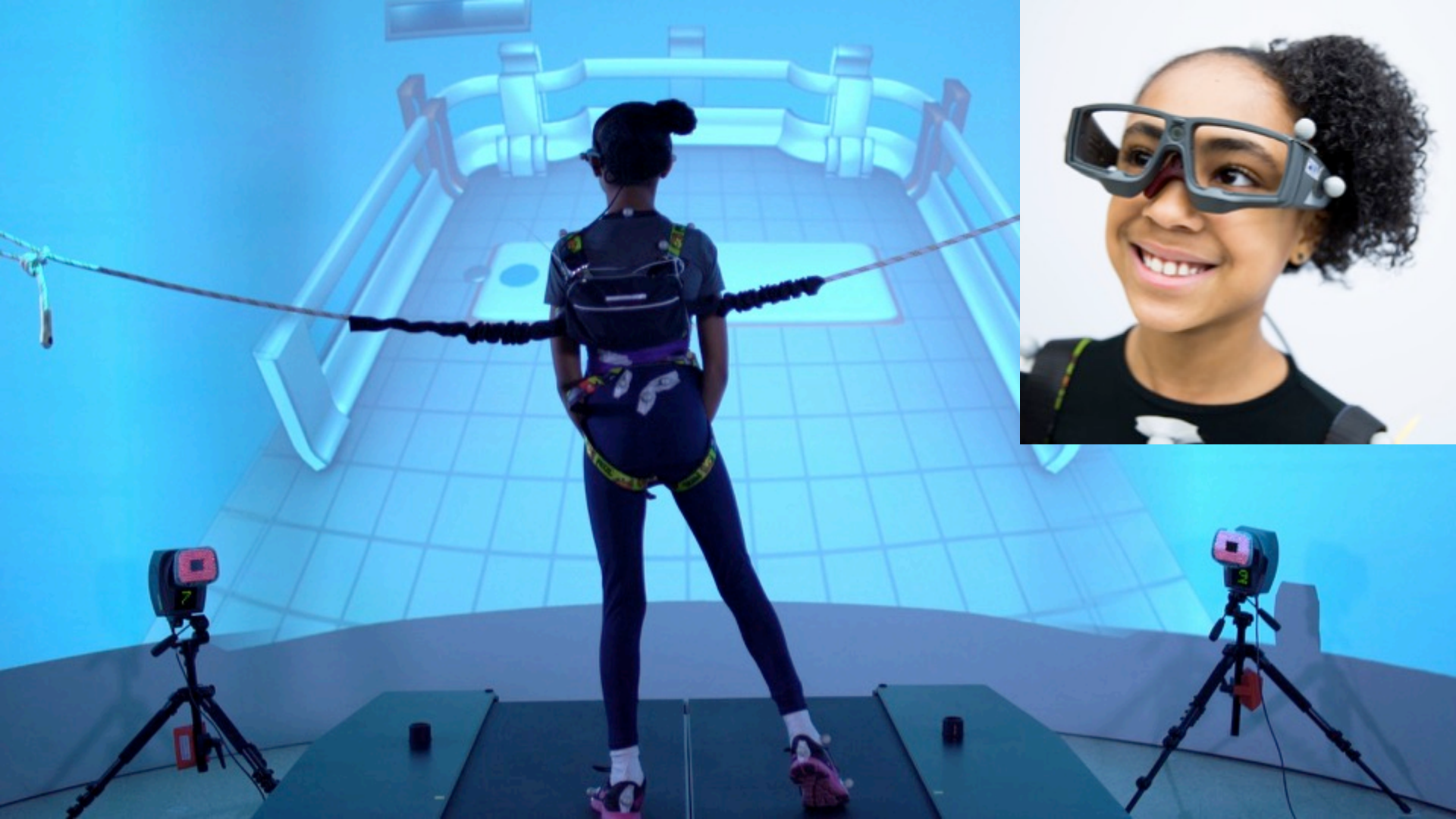
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