Current Topics in Autism Resear & the Impact on Tarrant County

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- Who am I?
- Goals for this morning:
  - Identify prevalence and points of contact in Tarrant County
  - Discuss recent advances in research
  - Brainstorm ways to engage the Tarrant County autism community more effectively
- Stick around and tour our lab afterward!

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Prevalence in Tarrant Co.

Population of Texas in 2015 = 27.43 mil

Population of Tarrant County in 2015 = 1,982,000

Estimated number of children ages 3-21 with ASD living in Tarrant Co. in 2015 = 3,709

(Easter Seals 2014-2015 statistics report)

Population of Tarrant County in 2016 = 2,016,872

If 1 in 68 children have ASD (CDC, 2014), then an estimated **7,919 children under 18 with ASD** were living in Tarrant County in 2016

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Points of Contact

- **ECI** (0-3 years)
- **Easter Seals** (1.5-11 years)
- **PPCD** (3-5 years)
- **FWISD** (4-21 years for 504/IEP-driven supports)
- **MHMR** of Tarrant County
- **Cook Children's** network/Child Study Center
- **THHS/DARS** (3-15 years for max 24 mos of comprehensive ABA + vocational rehab and housing services for adults)
- **Private providers**

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These are just some examples…Where else?

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Crunching the Numbers

- MHMR served 1,223 people with ASD in FY 2016
  - ECI services for 65 children ages 0-36 mos
- Around 1,300* students with ASD estimated to be enrolled in **FWISD** in the prior academic year

**Extrapolated from total 2016-2017 enrollment based on 2014 CDC prevalence*

- Cook Children's network has served* 4,588 patients with ASD from 1994-present (ages 0-21)

**Children identified as at-risk in the CCMC network are referred to the Child ter for follow-up diagnostic assessment*

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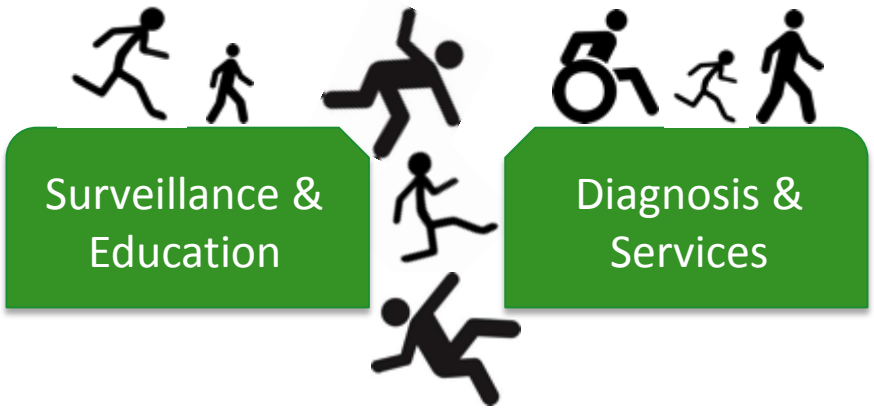
Falling Through Cracks?

- Prevalence estimates don't align with #s served, within or across organizations
- Who is falling through the cracks?
  - Can we predict it?
  - Can we prevent it?
  - Can we make up for it?



- What additional surveillance, education, or outreach efforts are needed in Tarrant Co.?

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Bridging the Gaps

- Research can help by:
  - Identifying processes/policies that place some individuals at a disadvantage (e.g., our multi-site chart review study with CCMC/CSC/UNTHSC on diagnosis & early management pathways)
  - Discovering & defining features/symptoms (e.g., our NIH- and NSF-funded studies on the use of visual processing to support movement; genetic research happening at our partner institution, UT Southwestern)
  - Determining which interventions are effective, and what frequency/dose/etc. is required (e.g., pre-clinical and clinical drug trials and intervention research happening at our partner institutions, UT Southwestern and UNT Denton/Kristin Farmer Autism Center)
  - Building science literacy in the community through outreach and education (which you are participating in right now!)

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Advances in 2016

- The Interagency Autism Coordinating Committee (IACC) puts out a report each year summarizing advances
- The 2016 summary included 20 journal articles
- Articles were grouped into 7 priority topics/areas of investigation identified by the IACC

https://iacc.hhs.gov/publications/summary-of-a

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Question 1: When Should I Be Concerned?

- Jones et al., 2016, *Journal of Neurodevelopmental Disorders*; Miller et al., 2016, *Autism Research* (sadly…a different Miller…) ☺
- Average age of diagnosis is 4 years
- Social engagement at 6 mos is different in high-risk infants later diagnosed at 24 mos with ASD
  - Difference wasn't as big at 12 mos…so some differences may fade as children develop, making it harder to detect?
- Symptoms of concern are consistent over time for both younger and school-age children
  - Docs may say "wait and see", so this is important!

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Question 2:
What is Happening?

- Orefice et al., 2016*, Cell*; Parikshak et al., 2016, *Nature;* Werling et al., 2016, *Nature Commun.*

- In mouse models of ASD, Mecp2 and Gabrb3 affect touch sensitivity
- 584 genes responsible for regulation/maintenance of neurons had higher expression in the brain
- 558 genes expressed in neurons, which send/receive info, had lower expression in the brain
- There may be ASD-protective features in the female genome, leading to the M:F prevalence difference

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Question 3: What Caused It? Prevention?

- Eriksson et al., 2016*, Molecular Autism*; Jokiranta-Olkoniemi et al., 2016, *JAMA Psychiatry;* Zerbo et al., 2017, *JAMA Pediatrics*

- May be in utero protective effects against ASD/ADHD for girls with a male co-twin
- "Clustering" effect…greater risk for co-occurring diagnoses for children with ASD and siblings, especially if parent has a psychiatric disorder
- No significant increase in risk of ASD related to maternal flu vaccine during pregnancy (hooray!)

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Question 4: Which Interventions Help?

- Almirall et al., 2016*, J Clin Child Adolesc Psychology*; Chang et al., 2016, *JADD;* Hampton & Kaiser, 2016, *J Intellectual Disabilities Res;* Kasari et al., 2016*, J Child Psychology & Psychiatry*

- Speech-generating devices can improve communication in minimally-verbal individuals *when used in combination with development-based behavioral intervention.*
- Small-group social engagement interventions (e.g., SKILLS/ENGAGE/JASPER) can be successfully adapted to public schools & led by teachers.
- Targeted & comprehensive language interventions are effective, especially when parents are also involved
- Brain responses to biological motion predict some social intervention (PRT) outcomes

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Question 5: Where Can I Turn for Services?

- Leslie et al., 2017*, Medical Care*; Mandell et al., 2016, *JAMA Pediatrics;* Nguyen et al., 2016, *JADD*

- Medicaid HCBS waivers reduce service gaps, *especially for higher-income families*
- Treated prevalence of ASD increased in states with ASD insurance mandates, but still did not match estimated community prevalence
- Language barriers and insurance type are barriers to service utilization, especially for minority communities

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Question 6: What Does The Future Hold?

- Hirvikoski et al., 2016*, British Journal of Psychiatry*; Wehman et al., 2016, *Autism*

- Higher risk of premature mortality (53.87 yrs in ASD vs 70.20 yrs in TD), especially females.
- Co-occurring medical conditions (e.g., epilepsy in low-functioning) and suicide (high-functioning) pose greatest mortality risks.
- Project SEARCH employment training program reduced the amount of support needed by adults with ASD (90% employed at end vs. 6% in standard SpEd program, 87% kept jobs for 12 mos)

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Question 7: Infrastructure/Surveillance Needs?

- Christensen et al., 2016, *MMWR Surveillance Summary*
- 1st evaluation by 36 mos
- Delivery of services by 48 mos
- Targeted strategies for minority communities
- Empower schools to aid in early detection
- Assess impact to prevalence as a result of DSM-5 diagnostic criteria revisions

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#FakeNews

Why the Amish Rarely Get Sick or get Cancer: Things You Can Learn From Them

When we think of Amish people we think of a simple life, free of modern advancements. Most of us view them as foolish for not using the advantages of...

DAILYNOW.NET

- How do we identify it?
- How do we innoculate families against it?
- What is the danger in sensationalizing or overstating research findings?
- What is the danger in only publicizing “flashy” or significant results?
- How can we improve science literacy?

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What Can You Do?

- Participate in research
- Share your perspectives/concerns
- Be an advocate for change
  - Visibility
  - Clear messaging
  - Unity, rather than factions
  - Seek facts

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What Do We Do?

- Studies in the lab here at UNTHSC
- Studies in the community (e.g., Fort Worth Museum of Science & History, schools, libraries, clinics…)
- Chart-review/records-review studies with collaborating clinical groups/schools
- Resource hub for families/individuals

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What Are We Studying?

- People with ASD use their eyes differently
- Vision is important for balance & movement
- Movement is our first language!
- We think it is important to understand how vision + movement work together in ASD
- We call this ***visuomotor integration***

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…Visuomotor What?

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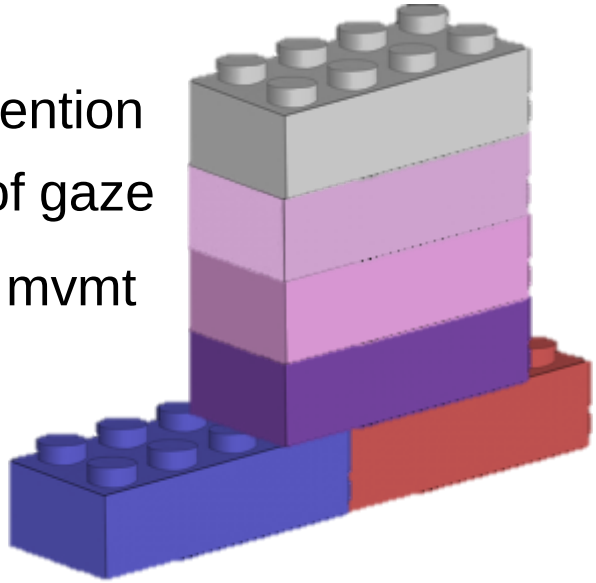
Building blocks to complex skills



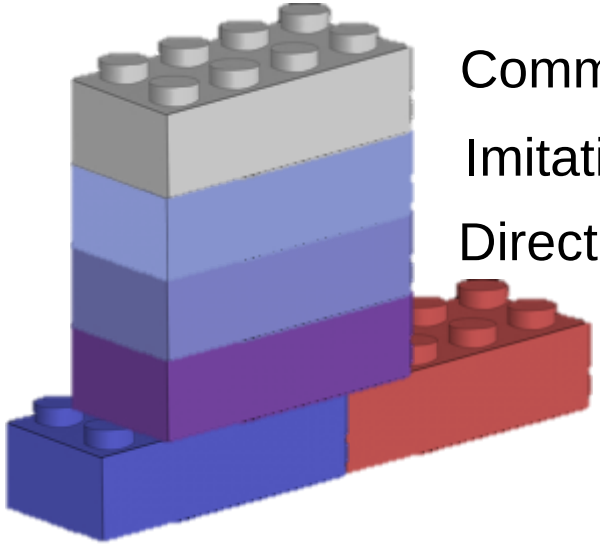
Joint attention

Social use of gaze

Directed eye mvmt

Visual info processing

Motor planning



Communicative gesturing

Imitation

Directed body mvmt

Visual info processing

Motor planning

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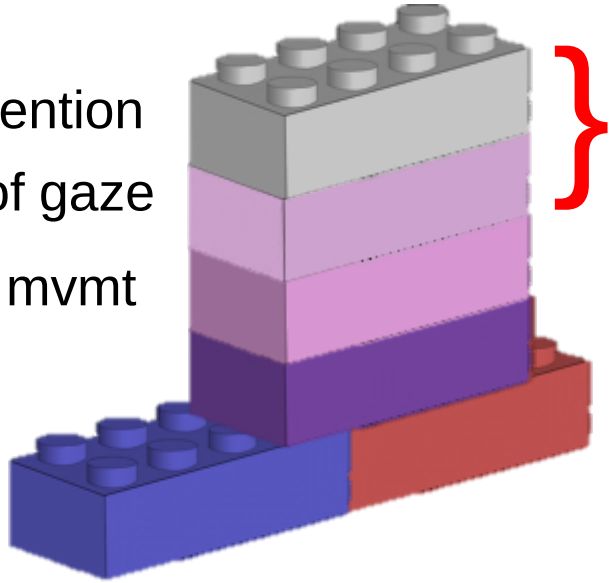
Building blocks to complex skills



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Social use of gaze

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Commonly studied

Visual info processing

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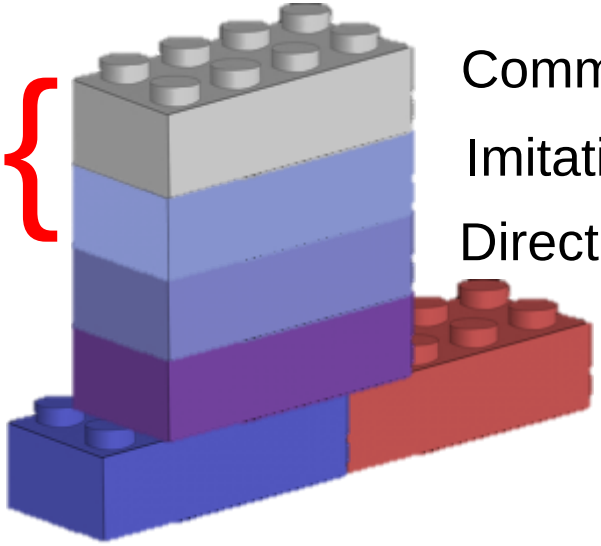
Commonly studied



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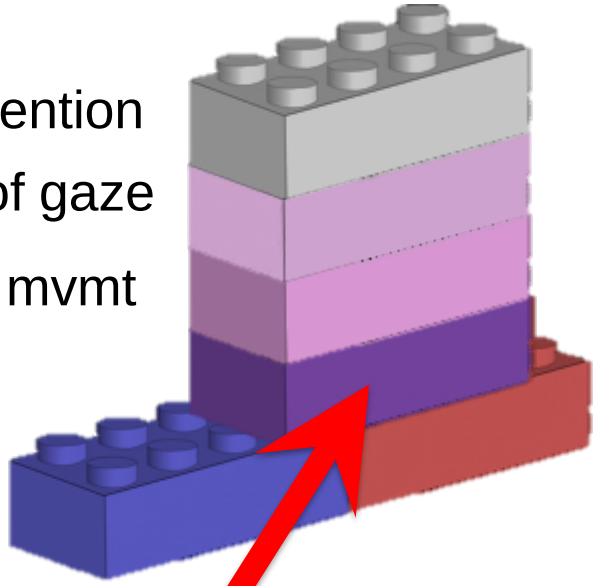

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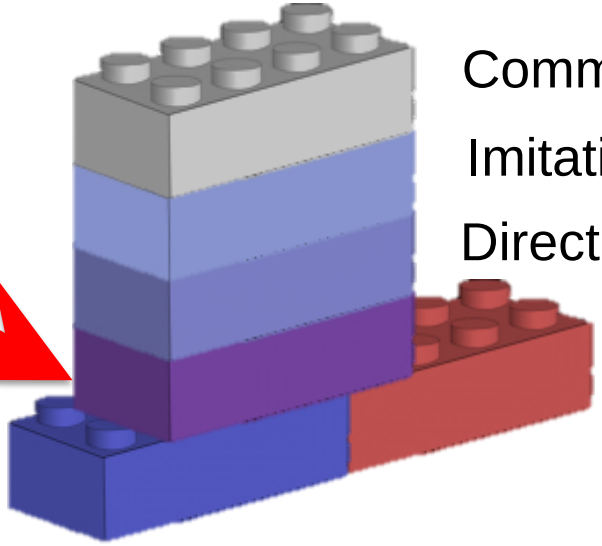

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What Does Our Research Look Like?

- People with ASD ages 7-50
- Short (unpaid, 15 min) study
- Longer (paid, 3-4 visits) studies
- We track how the eyes and body move
- It’s like playing a life-sized video game!

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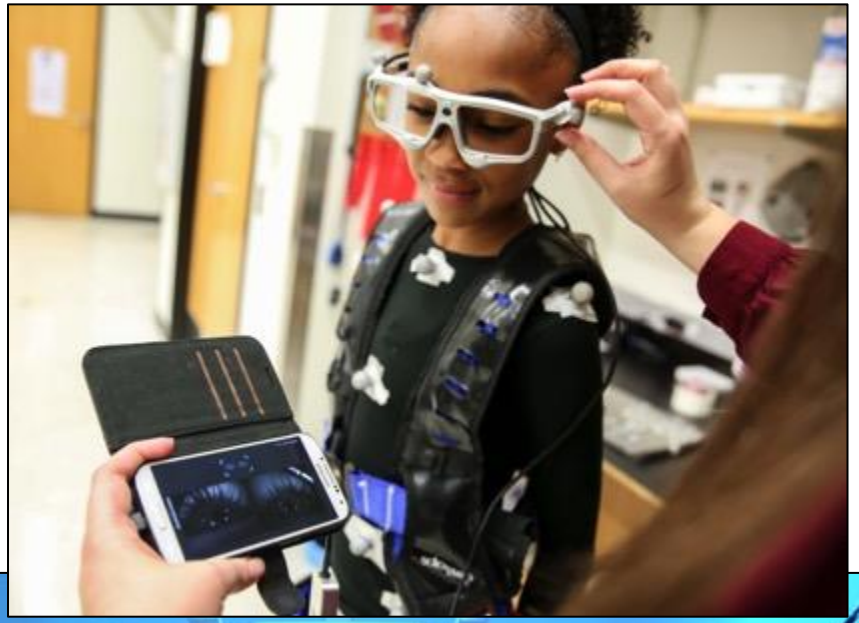
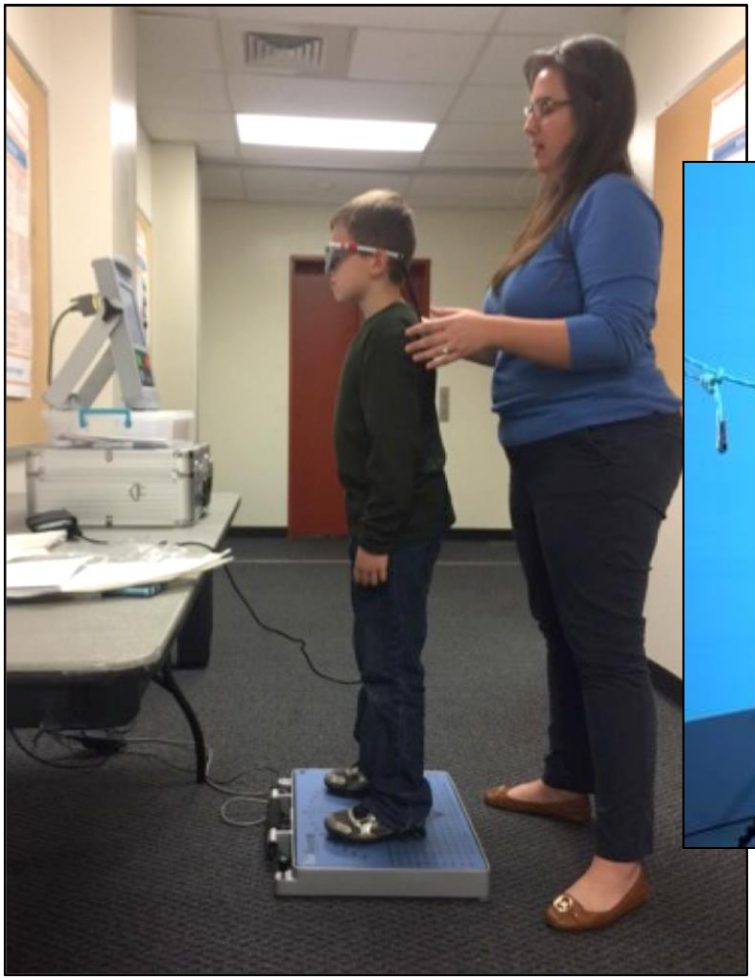
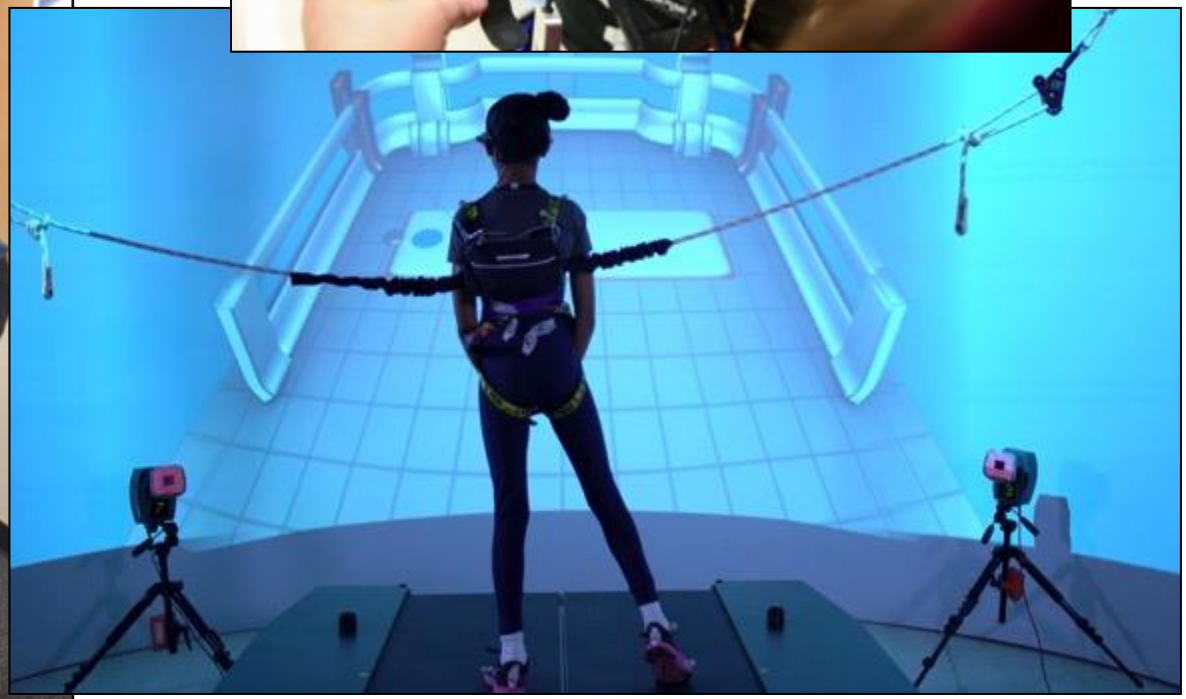
Study Examples







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Where To Learn More*

*In my opinion, these sites generally publish reliable, evidence-based information. You may have other sources, and if so, we'd love to know about them!

- Autism Science Foundation
- Autism Speaks
- Centers for Disease Control
- Interactive Autism Network
- Kennedy Krieger Institute
- National Autism Association

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Local Resources

- FEAT-North Texas
- IDD Council of Tarrant Co.
- MHMR of Tarrant Co.
- Easter Seals
- Autism Speaks – DFW Chapter
- TCC Southeast ASD Program
- Our lab on Facebook (@UNTHSCautism)
- Our lab website (unthsc.edu/HMPLab/autism)
- *Many* private service providers!

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AUTISM & DEVELOPMENTAL DISORDERS RESEARCH

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