

**AUTISM AND EARLY INTERVENTION  
– WHICH FACTORS SHAPE OUTCOMES?**


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Associate Editor, *Journal of Autism and Developmental Disorders*



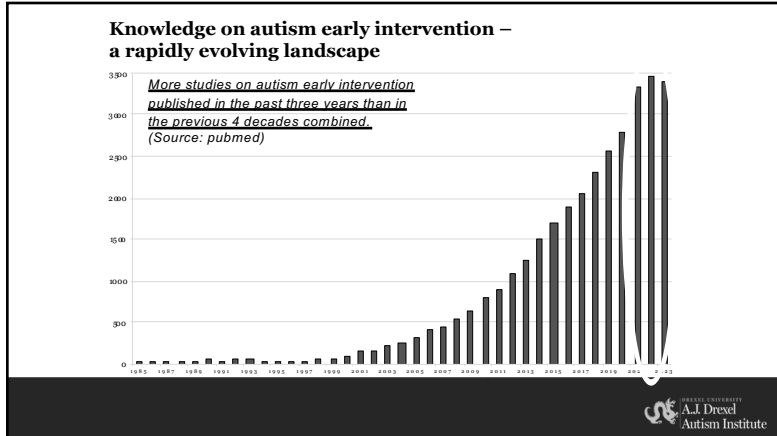
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<http://drexel.edu/autisminstitute/>



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**Autism intervention meta-analysis of early childhood studies (Project AIM): updated systematic review and secondary analysis**

80% of all RCTs published in the past decade.  
Mostly Naturalistic Developmental Behavioral Interventions

Micheal Sandbank,<sup>1</sup> Kristen Bottema-Beutel,<sup>2</sup> Shannon Crowley LaPoint,<sup>3</sup> Jacob I Feldman,<sup>4,5</sup> D Jonah Barrett,<sup>6</sup> Nicolette Caldwell,<sup>7</sup> Kacie Dunham,<sup>4,8</sup> Jenna Crank,<sup>9</sup> Suzanne Albarran,<sup>10</sup> Tiffany Wojnaroski<sup>6,9,11,12</sup>


Intervention and outcome type	Studies	Effect sizes	Hedges' g (95% CI)	Hedges' g (95% CI)
<b>Behavioral</b>				
Social communication	9	84		0.54 (-0.24 to 1.32)
Social emotional or challenging behavior	10	57		0.58 (0.11 to 1.06)
<b>Developmental</b>				
Social communication	14	123		0.28 (0.12 to 0.44)
<b>NDBI</b>				
Adaptive	11	31		0.23 (0.02 to 0.43)
Cognitive	13	48		0.18 (-0.02 to 0.38)
Diagnostic characteristics of autism	17	46		0.38 (0.17 to 0.59)
Language	26	138		0.16 (0.01 to 0.31)
Play	8	65		0.19 (0.02 to 0.36)
Restricted and repetitive behaviors	7	20		-0.01 (-0.32 to 0.31)
Social communication	32	322		0.35 (0.23 to 0.47)




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**Early intervention does not ‘remove’ autism – but can mitigate disability**

- Autism (including profound autism) can and *should* co-exist with a fulfilling life




- Physical and mental health
- Emotional well-being
- Self-reliance
- Self-determination
- Freedom from distress
- Opportunities
- ...



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**However:**

Many individuals on the autism spectrum experience **preventable** adverse outcomes



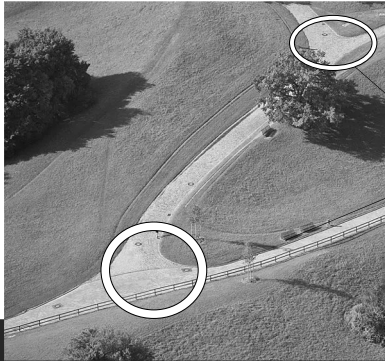
- Physical health
- Mental health
- Community participation
- Well-being
- Quality of life
- Self-reliance/ self-determination/ self-realization
- Educational opportunities
- Social opportunities
- School/ Employment

**How do we identify and address factors contributing to preventable adverse outcomes?**




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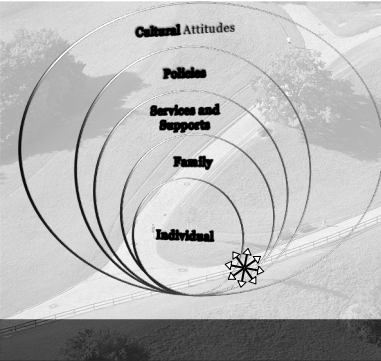
**Modifiable factors contributing to adverse outcomes – beyond child diagnosis and functioning level**



Understanding and addressing “Turning Points” leading certain children to experience adverse outcomes (perhaps years after early intervention)



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**Cultural Attitudes**

**Policies**

**Services and Supports**

**Family**

**Individual**



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### Understanding why interventions targeting spoken language do not work equally for all children – need for aggregate datasets

**The MIRA (Minimal Intervention Responders in Autism) Consortium**

NIDCD R01DC017181 – Prevalence and Profile of Treatment Non-Responders In Autism  
Early Intervention – PI: Vivanti

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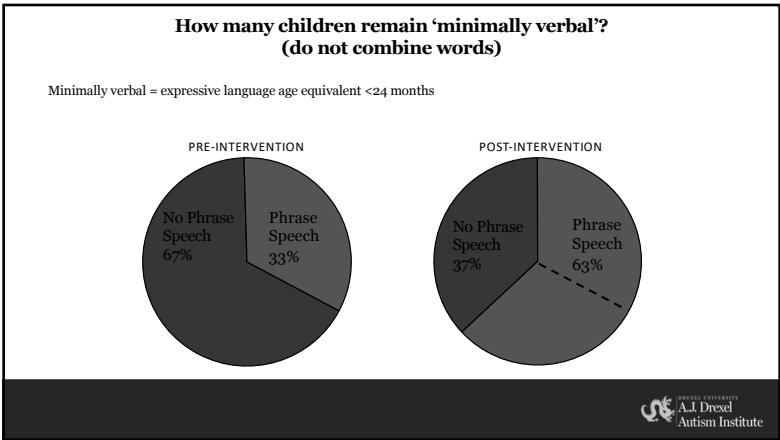
### MIRA Consortium Goals

- ❖ **Aggregate dataset (final n=707)** comprising preschoolers who had received approximately 12 months of evidence-based early intervention targeting spoken language through University-affiliated programs
- ❖ Examining the **prevalence of preverbal and minimally verbal children who did not acquire spoken language** during the intervention period
- ❖ Examining **factors that predict spoken language**

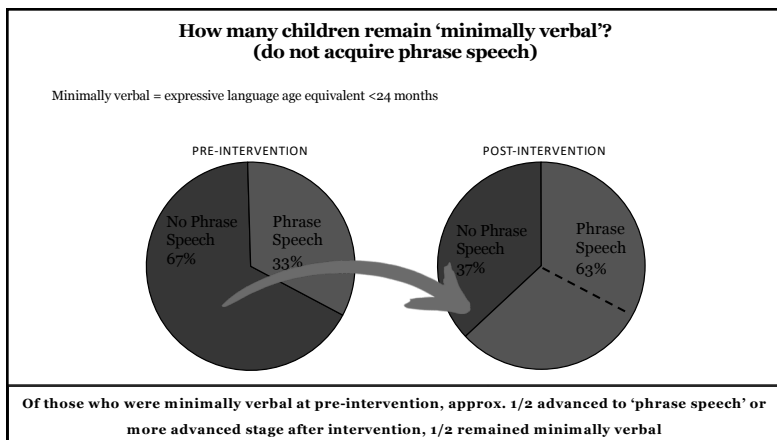
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Site	Intervention	Duration, Intensity	Setting	Format	Category	Sample
UC Davis	ESDM	12 months, 15-25 h/week	Home	1:1, therapist + parent delivered	ESDM	40
UC Davis	ESDM	12 months, 15-25 h/week	Home	1:1, therapist + parent delivered	ESDM	36
La Trobe	ESDM	12 months, 15-25 h/week	Preschool	small group, therapist delivered	ESDM	140
Cornell	NDBI	6 months, 20 h/week	Clinic, Home	1:1 + small groups, therapist delivered	Other NDBI	20
IWK	PRT	12 months, 11.2 h/week	Preschool, Home	1:1, therapist + parent delivered	Other NDBI	88
UCSD	PRT	6 months, 10 h/week	Clinic, Home	1:1, therapist delivered	Other NDBI	6
UCSD	STAR + ImPACT	12 months, 10 h/week	Clinic, Home	1:1, therapist delivered	Other NDBI	44
UNC	ASAP	7 months, 10-25 h/week	Preschool	1:1 + small groups, teacher + therapist	Other NDBI	46
MSU	EIBI	12 months, 30 h/week	Clinic, Preschool	1:1 + small group, therapist delivered	EIBI	41
Rochester	EIBI	12 months, >10 h/week	Clinic, Home	1:1, therapist delivered	EIBI	21
Rochester	EIBI	12 months, 35 h/week	Home	1:1, therapist delivered	EIBI	28
Rochester	EIBI	12 months, 18.5 h/week	Preschool	1:1, therapist delivered	EIBI	20
Rochester	EIBI	6 months, 15 h/week	Preschool	1:1, therapist delivered	EIBI	22
Rochester	EIBI	12 months, 35 h/week	Home	1:1, therapist delivered	EIBI	18
UNC	LEAP	9 months, 10-25 h/week	Preschool	small group, teacher delivered	EIBI	47
UNC	TEACCH	9 months, 10-25 h/week	Preschool	small group, teacher delivered	TEACCH	86

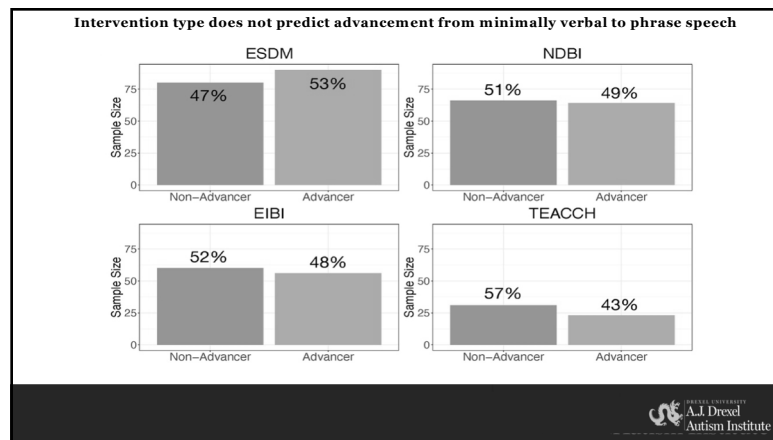
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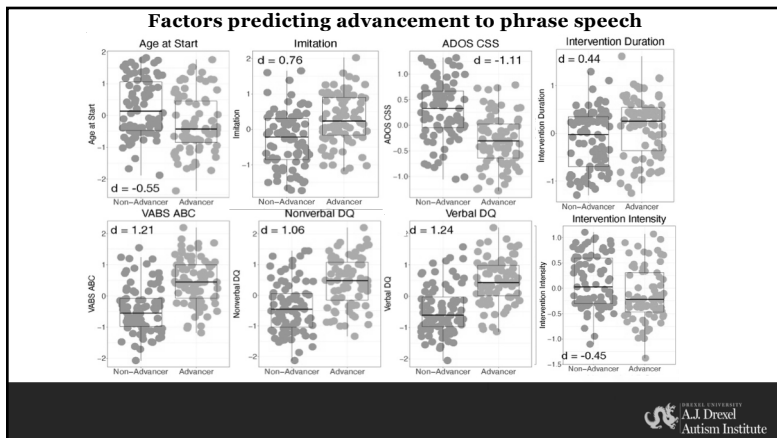
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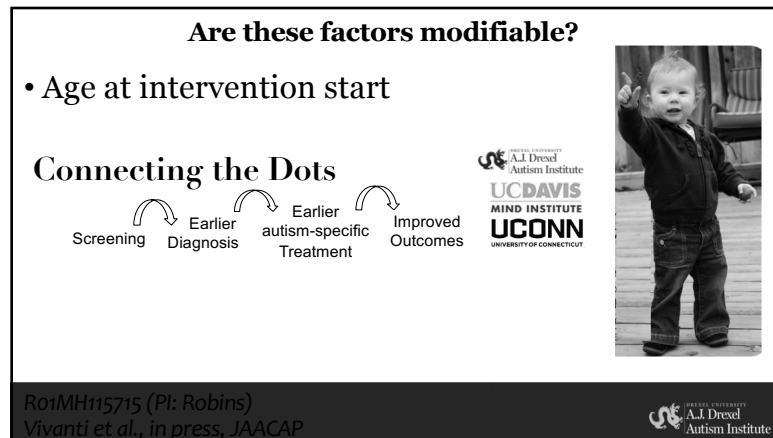
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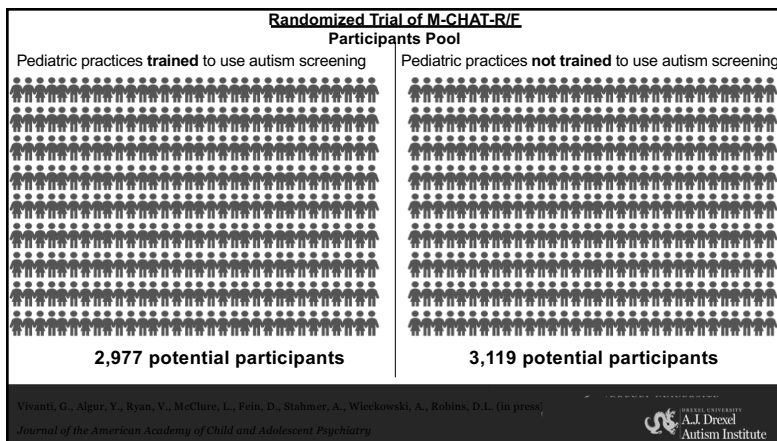
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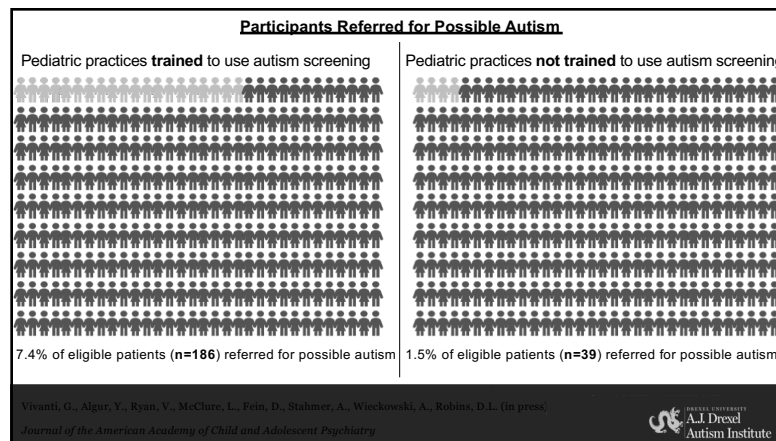
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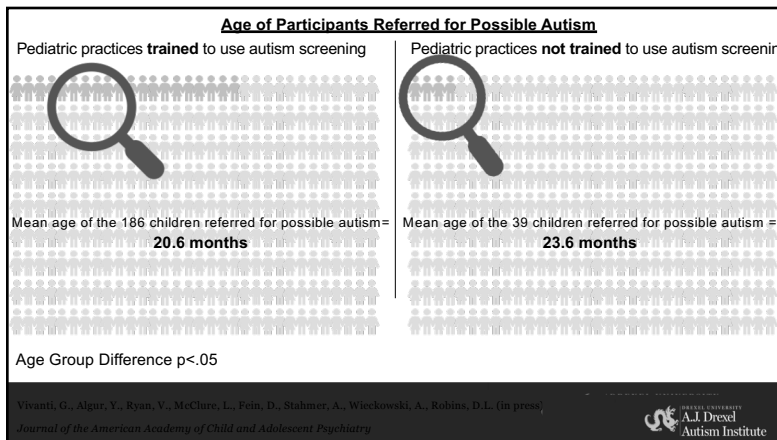
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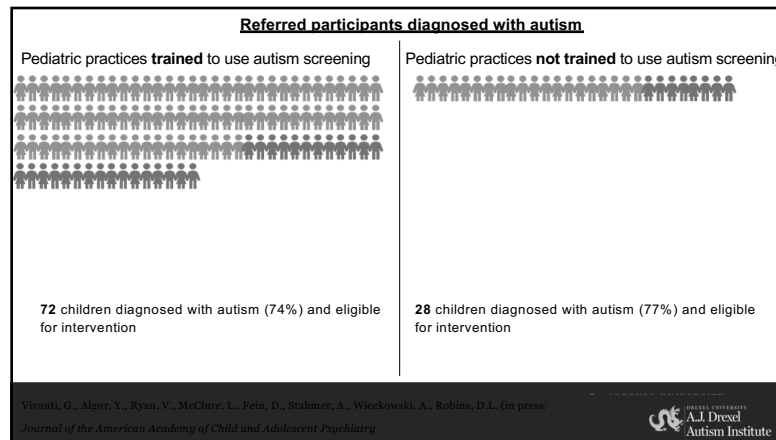
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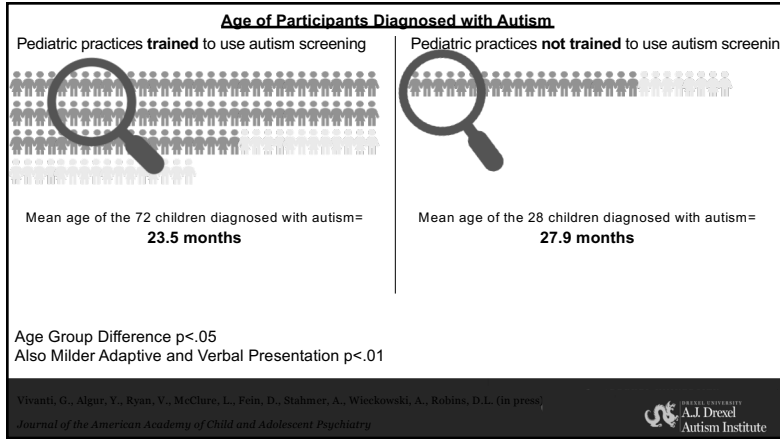
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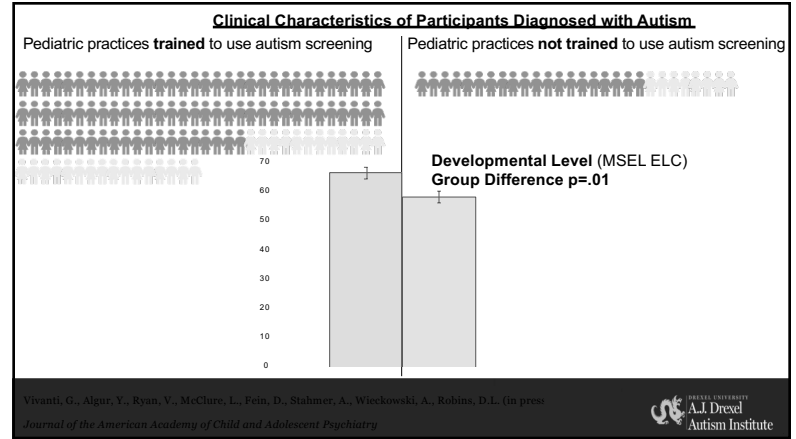
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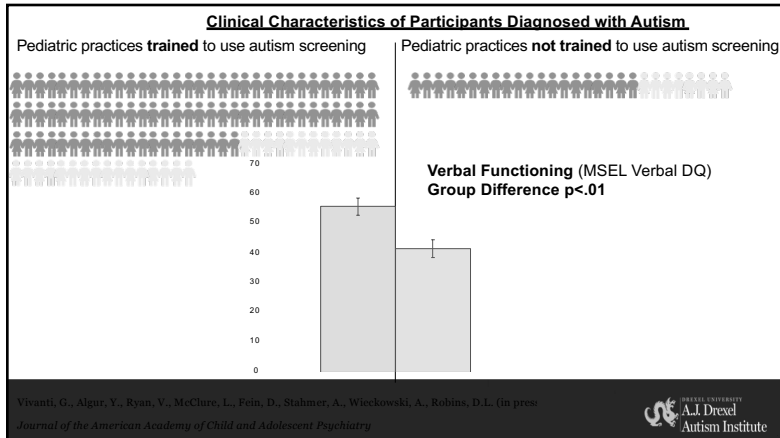
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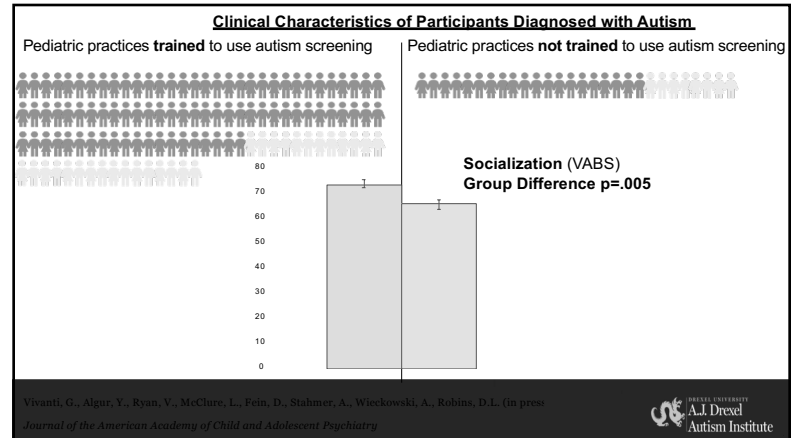
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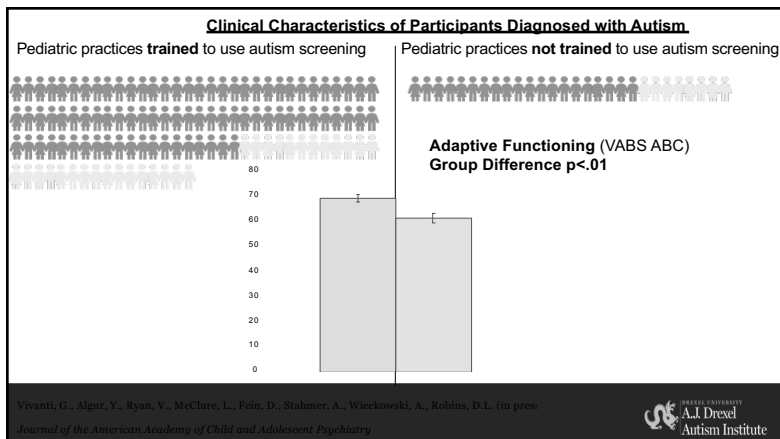
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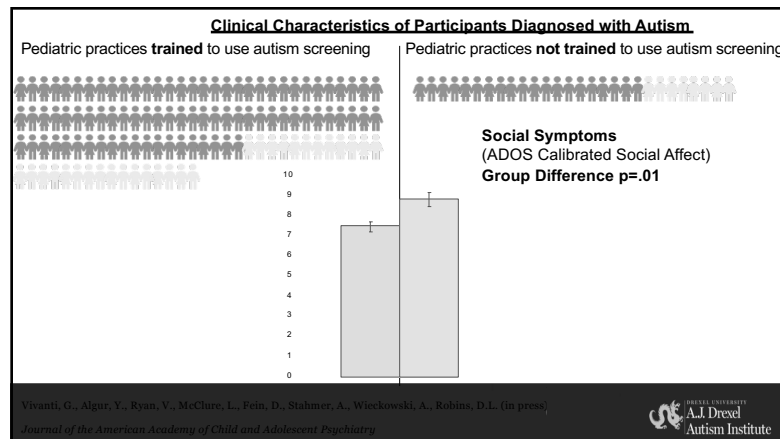
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**What about child factors?**

- Imitation might facilitate spoken language by enabling gestural and **social routines foundational to communication** development
- Might also reflect motor difficulties impairments that affect gesture and oral motor execution/ speech production in some children
- Autism characteristics do play a role in phrase speech acquisition
- Options for non-advancers: **dose escalation**, intervention augmentation “treating the constraints”

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**Predictors of Expressive Language Change for Children with Autism Spectrum Disorder Receiving AAC-Infused Comprehensive Intervention**


Veronica Rose<sup>1,2,6,7</sup> · Jessica Paynter<sup>3</sup> · Giacomo Vivanti<sup>4</sup> · Deb Keen<sup>5</sup> · David Trembath<sup>1</sup>

- Group of children receiving AAC-infused intervention (pictures and other visually-based instructional techniques)
- Children who developed phrase speech at T2 visually attended significantly more to AAC pictures at pre-treatment than those who remained minimally verbal ( $p = .01$ ,  $d = 1.42$ )

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### Does Treatment Fidelity of the Early Start Denver Model Impact Skill Acquisition in Young Children with Autism?

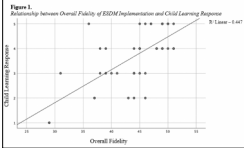
Ashley Zitter<sup>1</sup>, Hezekiah Rinn<sup>1</sup>, Zofia Szapuova<sup>2</sup>, Vanessa M. Avila-Pons<sup>3</sup>, Kirsty L. Coulter<sup>3</sup>, Aubyn C. Stahmer<sup>4</sup>, Diana L. Robins<sup>1</sup>, Giacomo Vivanti<sup>1,5</sup> 

**Fidelity matters. A lot.**

- Even within highly resourced settings, the degree to which interventions are implemented as intended varies
- Children with better outcomes → those whose therapists implement the intervention to a higher degree of fidelity

Variable	1	2	3	4	5	6
1. Child Learning Response	57**	49**	49**	49**	49**	49**
2. Overall Fidelity	57**	49**	49**	49**	49**	49**
3. Child IQ (Mullen)	14	19	20*	21**	21**	21**
4. Data in Standard (MSE)	20	24	24	24	24	24
5. Vineland ABC (SD)	88	81	80*	80*	80**	80**
Mean	1.00	80.00	29.00	110.00	79.00	72.00
Standard Deviation	1.18	1.00	6.00	18.00	18.00	22.00
Range	1.00	20.00	20.00	8.00	80.00	80.00

Figure 1. Relationship between Overall Fidelity of ESDM Implementation and Child Learning Response.  $R = .58, n = 147$



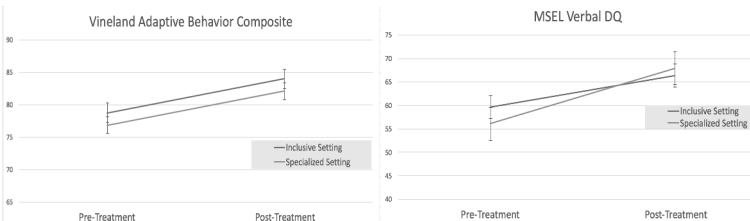
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### Outcomes of children receiving Group-Early Start Denver Model in an inclusive versus autism-specific setting: A pilot randomized controlled trial

Giacomo Vivanti<sup>1,2</sup>, Cheryl Dissanayake<sup>3</sup>, Ed Duncan<sup>4</sup>, Jessica Feary<sup>5</sup>, Kristy Capes<sup>6</sup>, Shannon Upson<sup>1</sup>, Catherine A Bent<sup>7,8</sup>, Sally J Rogers<sup>9</sup> and Kristelle Hudry<sup>2</sup>; the Victorian ASELCC Team

58 children (15-30 mo) randomized to receive the Group-ESDM intervention in either specialized or mainstream classrooms for 1 year. No overall group differences in gains.



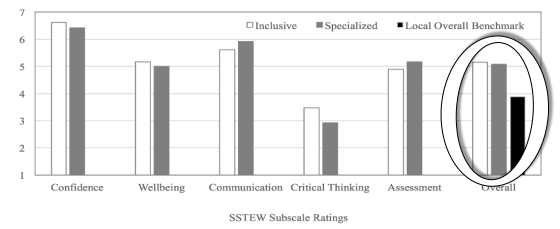
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Giacomo Vivanti<sup>1,2</sup>, Cheryl Dissanayake<sup>3</sup>, Ed Duncan<sup>4</sup>, Jessica Feary<sup>5</sup>, Kristy Capes<sup>6</sup>, Shannon Upson<sup>1</sup>, Catherine A Bent<sup>7,8</sup>, Sally J Rogers<sup>9</sup> and Kristelle Hudry<sup>2</sup>; the Victorian ASELCC Team

Implementation of G-ESDM resulted in higher quality education for all children – including “typical children” – Sustained Shared Thinking and Emotional Well-Being scale (SSTEW; *Straig et al. 2015, UCL Institute of Education*)



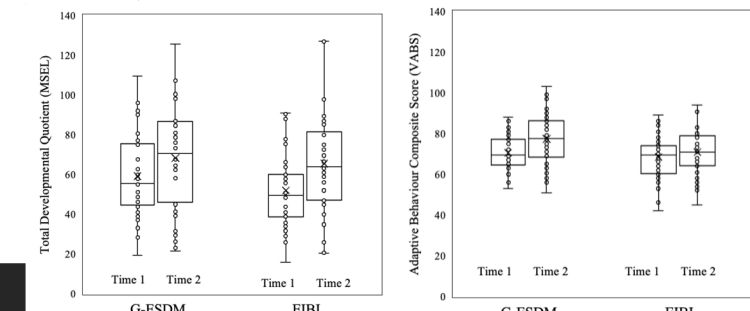
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### Predictors of Developmental and Adaptive Behaviour Outcomes in Response to Early Intensive Behavioural Intervention and the Early Start Denver Model

Catherine Bent<sup>1</sup>, Susan Glasziou<sup>2</sup>, Karen McKinnon<sup>3</sup>, Kristelle Hudry<sup>4</sup>, Cheryl Dissanayake<sup>5</sup>, The Victorian ASELCC Team - Giacomo Vivanti<sup>6,7</sup>

Outcomes for toddlers receiving Group-ESDM (n = 46) versus 1:1 EIBI



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**Autism Research**  
 Characteristics of children on the autism spectrum who benefit the most from receiving intervention in inclusive versus specialized early childhood education settings  
 DOI: 10.1002/aur.2815


**Who are the children who benefit the most from receiving intervention in inclusive versus specialized early childhood education settings?**

**Outcome Measures**

- Spontaneous Vocalizations via Language ENvironment Analysis (LENA) automated data extraction
- Social Interaction via M-COSMIC

**Putative moderators**

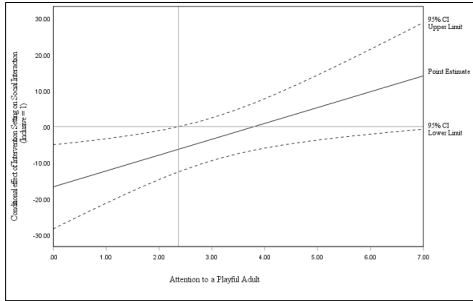
- Social interest via eye-tracking
- Developmental Quotient (MSEL)



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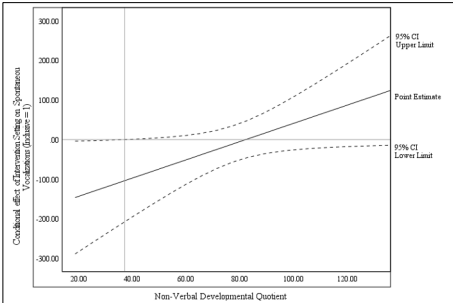
Social attention (eye-tracking) associated with Social Interaction outcomes for children in inclusive classrooms ( $b=2.84, p=.02$ ) but not for those in autism-specific classrooms ( $b=-1.56, p=.22$ ).  
 Children who attended to the person in the video for <2.37 seconds (out of 10) had lower outcomes



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Non-Verbal DQ positively associated with language (LENA) outcome for children in inclusive classrooms ( $b=2.34, p=.013$ ), but not those in autism-specific classrooms ( $b=0.04, p=.10$ ). Children with Non-Verbal DQ <37 had lower outcomes



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Behavior Analysis in Practice (2021) 14:230–239  
<https://doi.org/10.1007/s40617-020-00474-3>

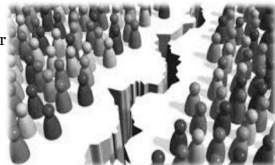
**ABA I**  
 Association for Behavior Analysis International

**Can the Early Start Denver Model Be Considered ABA Practice?**

Giacomo Vivanti<sup>1</sup> • Aubyn C. Stahmer<sup>2</sup>

**Disagreements on what count as ABA or ‘evidence based’ affects perception and eligibility for intervention coverage**

- Different reviews/agencies classify different interventions according to different conceptual categories, including whether they can be considered “ABA”, affecting funding eligibility
- Arbitrary inclusion/exclusion criteria in different categories lead again to different results on “evidence-based” status by different reviews and agencies




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### The Reach and Accuracy of Information on Autism on TikTok


Diego Aragon-Guevara<sup>1</sup> · Grace Castle<sup>2</sup> · Elisabeth Sheridan<sup>2</sup> · Giacomo Vivanti<sup>2</sup>



**How people perceives dx and diagnosis recommendations is increasingly affected by social media influencers**

**TikTok - social media platform with over 1.7 billion active users in 2023.**

**#Autism hashtag 9th most viewed health-related hashtag on TikTok**



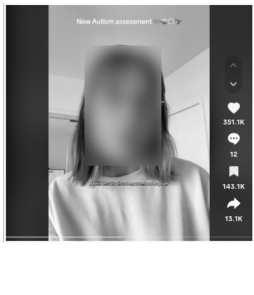
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### Tik Tok “operationalization” of autism and intervention


**you might be autistic if you...**

- have a strong sense of social justice
- have ideas that you think are genius but nobody else seems to think they're genius
- often feel confused and overwhelmed
- listen to the same song on loop

**Influencers discouraging/ encouraging interventions might be a turning point in the life of autistic children**



*From Luz, 2023, Psychology Today*



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### The Reach and Accuracy of Information on Autism on TikTok


Diego Aragon-Guevara<sup>1</sup> · Grace Castle<sup>2</sup> · Elisabeth Sheridan<sup>2</sup> · Giacomo Vivanti<sup>2</sup>

The #Autism hashtag on TikTok had 11.5 billion views as of July 2022. 'Informational' videos nearly 200 million views

73% of content inaccurate or overgeneralized.

Inaccurate or overgeneralized information 'liked' and viewed as frequently as accurate information

Accurate information and misleading information coexist on TikTok with similar perceived levels of authority.



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### The prevalence and incidence of early-onset dementia among adults with autism spectrum disorder

Giacomo Vivanti<sup>1</sup> | Sha Tao<sup>1</sup> | Kristen Lyall<sup>1</sup> | Diana L. Rubin<sup>2</sup> | Lindsay L. Shea<sup>1</sup>

30–64 year-old adults who were Medicaid beneficiaries and had a diagnosis of

- **ASD only** (n = 12,648), **ASD + ID** (n = 26,168), ID without ASD (n = 406,570),
- or no ASD nor ID diagnoses (n = 798,828)


**TABLE 3** Cox regression Hazard ratio comparing the incidence of early-onset dementia in the two ASD groups (ASD only and ASD + ID), and the ID only group relative to the general population

	Crude model		Adjusted model <sup>a</sup>	
	Hazard ratio	95% CI	Hazard ratio	95% CI
Any ASD	2.20	2.04 - 2.37	2.62	2.40 - 2.85
ASD only	1.81	1.57 - 2.08	1.96	1.69 - 2.28
ASD + ID	2.34	2.16 - 2.53	2.89	2.62 - 3.17

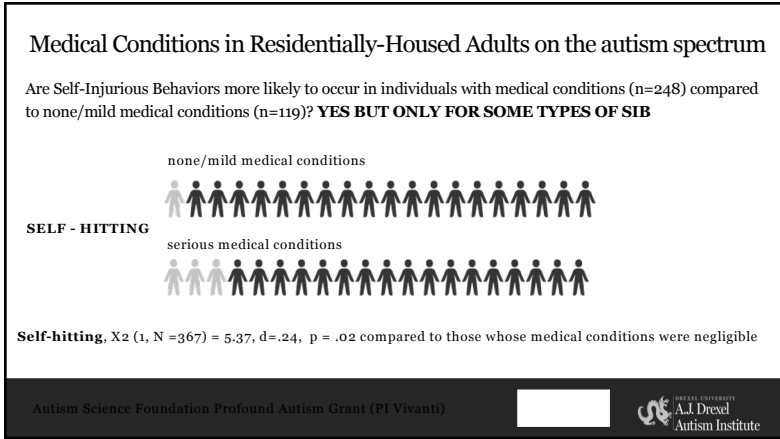
<sup>a</sup>Adjusted for: age, sex, race/ethnicity, urbanicity status, Medicaid eligibility category (poverty, disability, other), a diagnosis of depression, a diagnosis of any other psychiatric condition, cardiovascular disease risk factors and state.

**Mean dementia dx age in ASD in this sample**  
ASD only 49.3 ASD + ID 47.5 (much earlier than ID and general population, p < .0001)

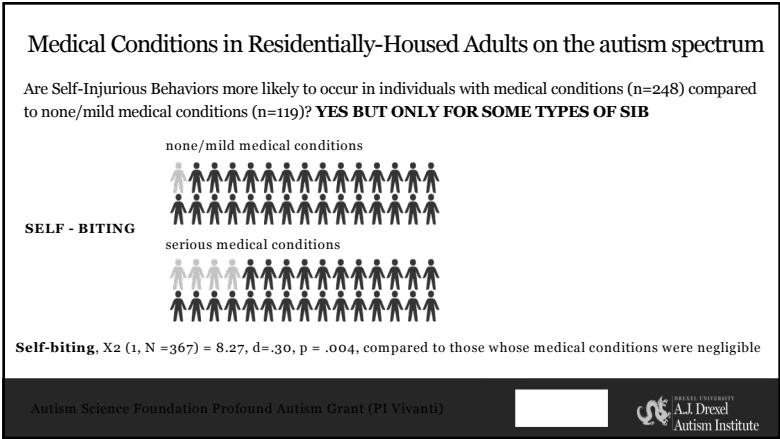
**In those older than 65**  
ASD and ASD+ID approx. 1 in 3 (1 in 9 in general population)



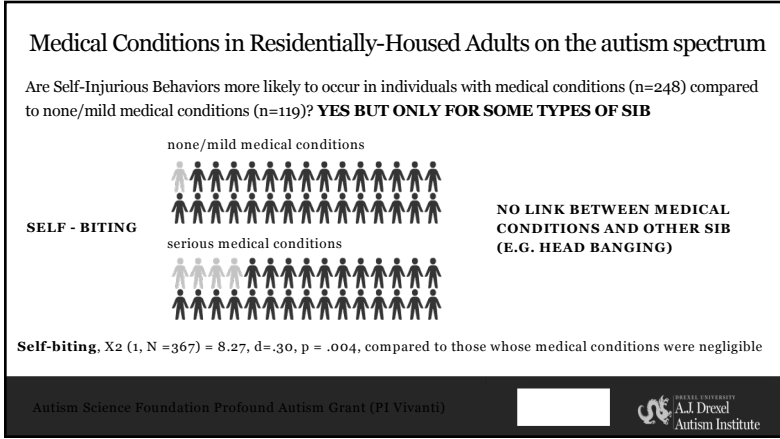
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Implementing and Evaluating Early Intervention for Children with Autism: Where Are the Gaps and What Should We Do?  
 Giacomo Vivanti ©, Connie Kasari, Jonathan Green, David Mandell, Melissa Maye, and Kristelle Hudry

To improve outcomes (and affirm rights) we need to move **from a linear to cyclical research process informed by end-users' experiences**

- **Discovery** (documenting phenomena, generating testable hypotheses)
- **Testing** (testing hypotheses/predictions, evaluating interventions)
- **Translation/Dissemination/Implementation** Community/services/policy

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Applying a public health approach to autism research: A framework for action  
 Diana Schindel © | Anne M. Ryan © | Elizabeth McChes Haycock\* | Kirsten Lyall © | Emily Steel © | Giacomo Vivanti © | Andrea Trabasso Wackowski © | Craig Newschaffer © | Diana L. Rubin ©

**From Linear to Cyclical Process via Examination of Experiences**

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**'Evidence-based' status, 'best practices', 'ABA' status, 'NDBI' status – not the end point!**

Human Development  
 Early Learning in Autism as an Atypical Balance between Assimilation and Accommodation Processes  
 Giacomo Vivanti<sup>1\*</sup>, Sally J. Rogers<sup>3</sup>, Patrick Dwyer<sup>4</sup>, Susan Rivera<sup>3,1,4</sup>

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**TOWARDS A NEURODIVERSITY-AFFIRMING MODEL OF EARLY LEARNING AND EARLY INTERVENTION IN AUTISM**

Early intervention practices informed by this model emphasize

- **Agency** - construction of new knowledge from child's self-initiated behavior
- Learning through **positive interactions** that are built on the **learner's motivation/goals**
- Promoting engagement in novel schemas through well calibrated variations on **familiar** schemas
- Alternating between familiar schemas and variations allows for **interplay of comfort and challenge** and for management of **anxiety** in the face of novelty



Vivanti, Rogers, Dwyer & Rivera, 2022, *Human Development*

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### Conclusions

- Knowledge on intervention is advancing at an unprecedented pace
- However this knowledge does not readily translate into improved outcomes for those on the autism spectrum
- Most factors contributing to positive vs suboptimal outcomes **are potentially modifiable**
- These include age of diagnosis, teaching prerequisite skills, assigning children to interventions and contexts based on "best-fit" algorithms, fidelity of implementation, addressing perception/misinformation
- Addressing these factors requires a public health framework that contextualizes the challenges and opportunities associated with autism within cyclical processes of knowledge generated by rigorous science and end-users experiences.



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### Thank you for your attention!

The MIRA Consortium, Victorian ASELCC team, OTARC team and Drexel EDI team

- Diana Robins
- Sally Rogers
- Cheryl Dissanayake
- Tristram Smith
- Joshua Plavnik
- Cathy Lord
- Ann Kaiser
- Sophy Kim
- Isabel Smith
- Aubyn Stahmer

All the children who took part in their research and their families !



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