A Screen-Refer-Treat Service Delivery Model for Toddlers At Risk for Autism Spectrum Disorder

Lisa V. Ibañez & Wendy L. Stone
Research in Early Autism Detection & Intervention Lab
University of Washington

Overview

The **Screen-Refer-Treat (SRT)** research study is evaluating an innovative healthcare delivery model designed to promote earlier access to specialized intervention for toddlers with suspected Autism Spectrum Disorder (ASD). The SRT model comprises **three components**: (1) universal ASD screening at 16-20 months and prompt referral to Early Intervention (EI) programs by primary care providers (PCPs); (2) expedited ASD assessments within EI programs; and (3) use of a low-cost, evidence-based ASD-specialized intervention by EI providers. Distance coaching via telemedicine will be available to EI providers to support their ASD assessment activities. This model will be implemented sequentially in four counties throughout Washington State.

Background

Numerous studies indicate that participation in early, specialized intervention is associated with significant improvements in social-communication for toddlers with ASD (Dawson et al., 2010).

Every state in the U.S. provides Early Intervention (EI) services at minimal to no cost to families of eligible infants and toddlers until the age of 3 (IDEA, 2004). However, access to early ASD-specialized intervention through EI is impeded by several factors: limited use of validated ASD screening tools by PCPs, which leads to under-detection; delays in making referrals for ASD evaluation or early intervention services; long waits for diagnostic evaluations, and lack of ASD-specialized service providers (Arunyanart et al., 2012). As a result, many children fail to receive early intervention for ASD at an age at which it is likely to be most effective (Barton et al., 2012).

The delays in obtaining ASD-specialized services during the toddler years are, in large part, attributable to the prevalence of a service delivery model that *requires a formal diagnosis* before children are eligible to receive these services.

The Screen-Refer-Treat (SRT) model examined in the current study employs a *preventative intervention* approach, in which treatment begins when early signs or symptoms are identified, in lieu of postponing treatment until ASD is formally diagnosed.

Study Aims

1. To increase the rates of ASD screening and referral at 18 months by Primary Care Providers (PCPs)

2. To increase the number of toddlers with suspected or confirmed ASD who receive ASD-specialized behavioral intervention before 24 months

3. To decrease the age at which children receive a community ASD diagnosis

4. To improve outcomes for caregivers and their toddlers with ASD or ASD risk

5. To reduce disparities in screening and diagnosis for underserved populations *(particularly for the Hispanic population)*

Method

Randomized Control Trial (RCT) Design

This study uses a stepped wedge cluster RCT to implement the SRT service delivery model sequentially in the four WA State counties ("clusters"); counties (and the PCPs and EI providers within them) are randomly assigned to the time they receive the SRT intervention. Currently, in Year 1, all counties are undergoing baseline data collection. Beginning in early 2017 (Year 2), the SRT model implementation will be initiated through training workshops for PCPs and EI providers that provide instruction on ASD-specific screening practices and intervention, followed by 3 months of technical assistance. Another period of data collection (Years 3-4) will ensue after the SRT implementation period is complete.

Two cohorts of caregivers with toddlers (16-30 months of age) with and without ASD concerns will also be recruited before and after the SRT training workshops from participating PCP practices and EI agencies; the enrollment of the first cohort is currently underway.

Providers (Within-Subjects, primarily)

	Year 1				Year 2				Year 3				Year 4				Year 5			
	1-3	4-6	7-9	10-12	1-3	4-6	7-9	10-12	1-3	4-6	7-9	10-12	1-3	4-6	7-9	10-12	1-3	4-6	7-9	10-12
C1	•x	x			•x	SRT	x	•x	•		•x									
C2	•x	x				SRT	x	•x	•		•x									
C3	•x	x			•x	SRT	x	•x	•		•x									
C4	•x	x			•x	•x	SRT	x	•x	•		•x								

● = Surveys; **X** = Screening checklists

Group	Measures
PCPs $n = 47$	• Practice Demographics • Knowledge/Practices Survey • 18-month Screening Checklist • Organizational & Implementation Climate
EI Providers $n = 59$	• Practice Demographics • Knowledge/Practices Survey • Child Intervention Checklist • Organizational & Implementation Climate

Caregivers (Between-Subjects)

	Year 1				Year 2				Year 3				Year 4				Year 5			
	1-3	4-6	7-9	10-12	1-3	4-6	7-9	10-12	1-3	4-6	7-9	10-12	1-3	4-6	7-9	10-12	1-3	4-6	7-9	10-12
C1	•	•	•	•	SRT	•		•	•	•	•	•	•							
C2	•	•	•	•		SRT	•	•	•	•	•	•		•						
C3	•	•	•	•		SRT	•		•	•	•	•	•							
C4	•	•	•	•	•	SRT	•	•	•	•	•	•	•							

Group	Measures
Caregivers/Toddlers Pre-SRT ($n = 280$) Post-SRT ($n = 280$) (Projected)	• Family Demographics • Child Health History (includes dx and services) • Parenting Stress (PSI-SF) • Parenting Efficacy (MES) • Quality of Life (WHOQOL-BRF) • Service Satisfaction (MPOC-20) • Child Social Communication Behavior (PIA-CV)

Components of Multi-System SRT Model

Health Care System (PCPs)

- Conduct Level 1 ASD screen at ALL 18 month well-child visits using a validated tool (M-CHAT-R/F)[1]
- Refer positive screens immediately to Part C Early Intervention (EI) program

- Training in use of the M-CHAT-R/F to screen
- An online version of the M-CHAT-R/F to reduce time burden

Early Intervention System (EI Providers)

- Conduct Level 2 interactive ASD screen/expedited assessment (STAT)[2]
- If indicated:
  - provide a cost-effective, evidence-based ASD intervention (RIT)[3]
  - refer for further assessment/diagnosis
- Communicate back to PCP

- Training in use of the STAT + caregiver interview
- Telemedicine coaching for the expedited assessment
- Training in providing RIT intervention & coaching parents in its use
- Training in use of a standard form for referral & communication

- [1]The Modified Checklist for Autism in Toddlers-Revised, With Follow-Up (M-CHAT-R/F; Robins et al, 2014) is a validated Level 1 screening tool, comprising 20 parent-report items and prescribed follow-up questions, developed for use in primary care settings with toddlers 16-30 months old.

- [2]The Screening Tool for Autism in Toddlers (STAT; Stone et al., 2004) is an interactive Level 2 screener with 12 items designed to elicit social-communicative behaviors within a 20-minute play-based interaction with a trained examiner/provider.

- [3]Reciprocal Imitation Training (RIT; Ingersoll, 2008; Ingersoll & Schreibman, 2006) is a low-cost, evidence-based intervention that uses a naturalistic behavioral approach to teach object and gesture imitation to young children with ASD within a play-based context.

Preliminary Findings

At the 18-month well-child visit, **64% of PCPs** reported that they used the M-CHAT as a universal screen for ASD risk. However, only **39% of PCPs** reported always using the M-CHAT follow-up questions after an initial positive screen.

When autism is suspected at the 18-month well-child visit, **88% of PCPs** reported that they almost always immediately refer to EI, but **50% of PCPs** also indicated that they sometimes wait until the next visit to see how the child is developing before taking action.

For children in their caseload, **57% of EI providers** reported rarely/never using ASD screening tools and **48%** reported that they did not typically have ASD concerns until a child is 2 years or older.

34% of EI providers reported that they had not received any training on specific intervention approaches for children with ASD.

28% of EI providers reported that they always communicate about assessment results and/or intervention progress with the PCPs of children in their caseload.

Conclusion

The SRT model provides a coordinated and cost-effective approach to early identification and intervention by involving both medical and EI providers, and represents a practical and sustainable strategy for bridging the gap between ASD concerns and ASD intervention. Preliminary findings from baseline data collection indicate that there is considerable room for improvement for: (1) integrating the M-CHAT-R with follow-up questions in primary care, which can help minimize false positives; (2) increasing ASD-specialized services available through EI programs; and (3) increasing communication between EI providers and PCPs. This model aligns with the efforts of the Help Me Grow WA Partnership, which unites several state agencies—including the Department of Health, Department of Early Learning, the WA Chapter of the American Academy of Pediatrics—to collect data on screening and referral practices, increase universal screening using validated tools, and ensure subsequent referrals and optimal care coordination.