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### Designing Studies to Evaluate Parent-Mediated Interventions for Toddlers With Autism Spectrum Disorder

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Given recent advances in science, policy, and practice of early identification in autism spectrum disorder (ASD), questions about the effectiveness of early intervention have far-reaching service and policy implications. However, rigorous research evaluating the efficacy and effectiveness of intervention programs for toddlers with ASD faces a multitude of novel scientific challenges. The Autism Speaks Toddler Treatment Network (ASTTN) was formed in 2007 to provide an infrastructure for ongoing communication between the investigators of eight research projects evaluating parent-mediated interventions for toddlers with ASD. The present article describes and compares the research studies of the ASTTN; highlights specific challenges with regard to research design, participants, recruitment, eligibility criteria, enrollment, and intervention approach; and outlines practical considerations that may guide the next generation of parent-mediated intervention studies involving toddlers with ASD.

### *Keywords: clinical trial, intervention, parent, mother, family, toddler, communication, autism*

In 2006, the American Academy of Pediatrics (AAP; 2006) published a groundbreaking policy statement on early identification of children with developmental delays. Specific recommendations for surveillance and screening of autism spectrum disorders (ASD) were published as clinical practice guidelines in 2007 (AAP, 2007). According to these guidelines, all children (independent of known risk factors or parental concerns) should be screened for ASD using formal screening tests administered during pediatric well-child visits at 18 and 24 months. These practice recommendations continue to be supported by a growing body of rigorous, large- sample research studies, documenting that many children with ASD can be reliably identified as young as 18 months of age (Guthrie, Swineford, Nottke, & Wetherby, 2013). Despite advances in research and policy, many questions remain about the validity of available screening tools (Charman, 2014), the challenge of moving screeners from academic centers to the "real world" (Volkmar & Reichow, 2014), the difficulty of establishing differential diagnoses in toddlers (Camarata, 2014), and the availability of experienced clinicians (Crais & Watson, 2014).

Given the increased interest in identifying ASD in toddlers, questions about the effectiveness of early intervention have far-reaching service and policy implications. During the last decade, several focused interventions and comprehensive treatment models have been developed specifically for toddlers with ASD (Boyd, Odom, Humphreys, & Sam, 2010). However, because of the sparse research literature, practice recommendations for toddlers continue to require significant extrapolation from the existing literature on older children (Odom, Boyd, Hall, & Hume, 2010; Odom, Collet-Klingenberg, Rogers, & Hatton, 2010; Warren et al., 2011). It is worth noting that practice recommendations for preschoolers with ASD generally prescribe intervention programs that (a) require many more hours of clinician time than are typically provided as part of publicly funded early intervention programs (Wise, Little, Holliman, Wise, & Wang, 2010) and (b) often lack a sufficient familycentered focus, which is required for early intervention programs funded through Part C of the Individuals With Disabilities Education Act (IDEA).

Given the heated debate between advocates and policy makers about funding for early intervention services (Schwartz & Sandall, 2010), and given the popular bias of "hope and expectation" shared by clinicians and advocates (Green, 2011), rigorous early intervention

research continues to be highlighted as a key objective in the Strategic Plan published by the Interagency Autism Coordinating Council (IACC; 2012). Despite this emphasis, the systematic evaluation of early intervention programs faces a multitude of novel scientific challenges: (a) New intervention approaches need to be developed that meet the needs of toddlers with ASD and their families, (b) research samples need to be specified according to valid "high risk" or diagnostic criteria (Camarata, 2014), (c) the possibility that some toddlers experience regression or plateauing needs to be considered when evaluating intervention outcomes (Crais & Watson, 2014), (d) symptom heterogeneity needs to be embraced to predict *who* is likely to benefit from *what* intervention (Trembath & Vivanti, 2014), and (e) innovative research designs need to be developed that provide families with a clinical service while ensuring scientific rigor (L. K. Koegel, Koegel, Ashbaugh, & Bradshaw, 2014).

In September 2006, Autism Speaks announced a funding opportunity for research studies testing the efficacy of interventions for toddlers, younger than 24 months, at "high risk" for ASD. Due to the multitude of scientific challenges that these projects were expected to face, the Autism Speaks Toddler Treatment Network (ASTTN) was formed to provide an infrastructure for ongoing communication between the key investigators of the eight funded research projects (one project, Project V, was not funded through this mechanism but joined the ASTTN by invitation). Descriptive information on the ASTTN research projects is provided in Table 1. Throughout the funding period of these research projects (2007-2010), the ASTTN was directed by Sally Rogers and Michael Siller, and included 26 investigators who met regularly during bi-monthly conference calls and annual meetings. The present article will describe and compare the research studies of the ASTTN, highlight specific challenges with regard to research design, participants, recruitment, eligibility criteria, enrollment, and intervention approach, and propose considerations for future research.

#### **Research Design**

About a decade ago, a working group supported by the National Institute of Mental Health (NIMH) developed a methodological roadmap for validating and disseminating psychosocial interventions for individuals with ASD (Smith et al., 2007). This roadmap outlines a sequence of four steps in which the primary research goals and activities evolve from the identification of new techniques (Step 1), to manualization and protocol development (Step 2), to efficacy testing under controlled conditions (Step 3), and to evaluating outcomes in real world settings (Step 4). The goals and activities of the ASTTN projects were most closely aligned with Steps 2 and 3 of this roadmap, revealing the overall assessment (at the time when the ASTTN projects were conceived) that short-term research goals should focus on developing and testing interventions under controlled conditions. However, as time progressed, the interactions between the ASTTN researchers also revealed an increasing awareness that efficacy research may be most fruitful if the evaluated interventions are compatible with the constraints commonly faced by community early interventions are provided in an individual/group setting, whether intervention sessions are held in a

					Projects			
Descriptive information	Ι	П	Ш	IV	Λ	IV	ПЛ	VIII
Experimental Intervention Intervention brand (adapted)	R esponsive Teaching	Pivotal Response Training	Hanen More than Words	Early Start Denver Model	Achievements for Little Learners	Joint Attention Mediated Learning	Focused Playtime Intervention	The SCERTS Model
Treatment duration	6 months	3 months	3.5 months	3 months	6 months	4 to 12 months	3 months	9 months
Treatment intensity and context	36 individual sessions (home)	13 individual sessions	3 individual sessions (home); 8	12 individual sessions (clinic)	26 individual sessions (home); 52 group	17 to 52 individual sessions (home)	12 individual sessions (home)	120 individual sessions (home)
		(amon)	group sessions		SCSSIOIIS			
Parent education strategies								
Live coaching	Х	Х	Х	Х	Х	Х	Х	Х
Didactic/conceptual		х	Х	Х	Х	Х	Х	Х
Video feedback			Х		Х	Х	Х	Х
Video modeling			Х		Х	Х		
Live modeling				Х	Х		Х	Х
Performance-based feedback	X	Х	Х	Х	Х		Х	Х
Prior evidence in support of the experimental intervention	Pre-post group design <sup>a</sup>	Single-subject design <sup>b</sup>	Clinical trial with older children <sup>c</sup>	Clinical trial with older children <sup>d</sup>	Research-based model program	Research-based model Single-subject design <sup>e</sup> program	Clinical trial with older children <sup>f</sup>	Pre-post group design <sup>g</sup>

Table 1

5

I 1 mized al trial ent-as-	П						
atment sites 1 Randomized clinical trial control Treatment-as-		Ш	IV	>	IV	IIA	VIII
Randomized clinical trial Treatment-as-	7	ę	7	_	ę	5	5
Treatment-as-	group	Randomized clinical Randomized trial clinical tria	Randomized clinical trial	Randomized clinical trial	Single case and randomized clinical trial	Randomized clinical trial	Randomized clinical trial
group usual	L	Treatment-as-usual	Treatment-as- usual	Active control treatment of lower intensity	Treatment-as-usual	Active control treatment of lower intensity	Active control treatment of lower intensity
Proximal child outcomes Social Functional communication/ language; sensory social symptoms engagement	ent ;	ASD symptoms; communication	Imitation; nonverbal communication	Nonverbal and verbal communication	Preverbal social communication	Nonverbal communication	Nonverbal and verbal communication
Distal child outcomes Cognitive, Language adaptive skills, skills; ASD and ASD symptoms symptoms	s D	Cognitive, language, adaptive, and social-emotional skills	Cognitive, language, and adaptive skills	Language skills and ASD symptoms	Language, social, and Language and adaptive skills adaptive skill	Language and adaptive skills	Language and adaptive skills; ASD symptoms

Table 1 (continued)

NS: Project III. PIs: Carter, Stone, Yoder, Messinger & Mundy; Sites: (1) Nashville, TN; (2) Miami, FL; (3) Boston, MA; Project IV, PIs: Estes & Rogers; Sites: (1) Davis, CA; (2) Seattle, WA; Project IV. Note. Project I. Pls: Baranek, Watson, Turner-Brown, Reznick, and Crais; Sites: (1) Chapel Hill, NC; Project II. Pls: Bryson, Brian, Smith, Zwaigenbaum and Roberts; Sites: (1) Toronto, ON; (2) Halifax, PI: Landa; Sites: (1) Baltimore, MD; Project VI. PIs: Schertz, Odom & Baggett; Sites: (1) Chapel Hill, NC; (2) Lawrence, KS; (3) Greenley, CO (Phase 1) or Bloomington, IN (Phase 2); Project VII. PIs: Kasari & Siller; Sites: (1) Los Angeles, CA; (2) New York, NY; Project VIII. PIs: Wetherby & Lord; Sites: (1) Tallahassee, FL; (2) Ann Arbor, MI. ASTTN = Autism Speaks Toddler Treatment Network; ASD = autism spectrum disorder; SCERTS = Social Communication, Emotion Regulation, and Transactional Supports.

<sup>a</sup>Mahoney and Perales (2005).

<sup>b</sup>R. L. Koegel and Koegel (2006).

<sup>c</sup>McConachie, Randle, Hammal, and Le Couteur (2005).

<sup>d</sup>Dawson et al. (2010).

<sup>e</sup>Schertz and Odom (2007).

fSiller, Hutman, and Sigman (2013).

<sup>g</sup>Wetherby and Woods (2006).

clinic or the families' homes), the typical intervention intensity in terms of clinician time, and the available infrastructure for provider training.

#### **Intervention Intensity**

The experimental interventions evaluated by the ASTTN relied heavily on parentmediated strategies (see Table 1). In terms of clinician time, the interventions varied substantially, ranging between 12 and 120 sessions, implemented over a period of 3 to 9 months. Because parents were the primary intervention target, all projects were built on the assumptions that parents would implement the intervention strategies with sufficient intensity to produce changes in child development, and that parents would continue using these strategies after the intervention to ensure enduring intervention effects. These assumptions seemed to have face validity as all projects aimed to embed intervention strategies within children's natural environments. However, as time progressed, the ASTTN researchers became increasingly cautious about these assumptions, and discussed explicit strategies for increasing the intensity with which parents implement the acquired intervention strategies throughout the families' busy lives. For example, in Project VIII, parents were asked to keep a diary and document that intervention activities and strategies were implemented at least 25 hr per week. In addition, researchers identified the need to develop new methods for measuring the parents' day-to-day implementation of the acquired strategies. Possible promise comes from automatic data-collection methods such as Language Environment Analysis (LENA<sup>™</sup>; www.lenafoundation.org).

#### **Active Control Interventions**

Seven of the eight ASTTN projects chose randomized control group designs to evaluate the efficacy of the experimental intervention. For many families, the idea of being randomly assigned to one of several intervention conditions causes pause during the initial enrollment period (see the section "Enrollment") and may reduce parent buy-in and increase attrition over the course of the research study. The early months after a child's diagnosis are usually a time when the parents' knowledge, thoughts, and emotions evolve rapidly. Thus, researchers face the daunting task of implementing a rigorous research design while also providing an important clinical service to all families, including those who are assigned to a possible control condition. To meet this obligation to the participating families, all projects included follow-up visits or phone calls, often providing families with informal support and referral information. As far as the control groups are concerned, four projects compared the experimental intervention with treatment-as-usual (including any community-based services sought by the family). Across the ASTTN projects, we observed large geographical variation in the nature of services families were able to access in their communities (see the section "Treatment Studies that Incorporate Strengths and Needs of Local Communities"). Thus, the interpretation of treatment-as-usual differed substantially between treatment sites and research projects. Finally, researchers in three projects compared the experimental intervention with an active control treatment of lower intensity. For example, Project VIII included an active control intervention that was similar in content but presented in a less intense format (i.e., one weekly group session vs.

three weekly individual sessions). Alternatively, Project VII included an active control intervention that differed in content (i.e., behavioral support vs. communication strategies) and intensity (i.e., 4 vs. 12 sessions).

#### **Research Design—Considerations for Future Research**

- 1. Efficacy research is most fruitful if the evaluated interventions operate within the constraints faced by community early intervention providers.
- 2. Participation in early intervention research should provide a valuable clinical service to all families, including those assigned to a possible control condition.
- 3. Future research should incorporate strategies for increasing and measuring the intensity with which parents implement intervention techniques during everyday interactions.

#### **Participants**

Across the eight ASTTN projects, a total of 389 toddlers were enrolled: 83 under 18 months, 217 between 18 and 23 months, 79 between 24 and 29 months, and 10 over 29 months. Of these, 310 (79.7%) were boys. At baseline, seven of the eight ASTTN projects administered both the Mullen Scales of Early Learning (MSEL; Mullen, 1995) and the Social and Communication subscales of the Vineland Adaptive Behavior Scales (VABS; Sparrow, Cicchetti, & Balla, 2005). Furthermore, all projects collected information on the educational attainment of the parent participating in the study, the child's ethnic and racial background, and the intensity of the child's early intervention services when entering the study. For the purpose of the present article, each treatment site provided summary statistics (e.g., sample sizes, frequencies, means, standard deviations) for all baseline measures, broken down by age cohort. Summary statistics were aggregated across all ASTTN projects using standard statistical computations (i.e., weighted means and pooled weighted variances), and are presented in Table 2. As only 10 children entered the study at 30 months or above (M = 30.4 months, SD = 0.36), information on these children was omitted from the table and all reported analyses. To evaluate whether children's standardized scores or demographic characteristics differed between the three age cohorts, we computed a series of Analyses of Variances (ANOVAs) for continuous (e.g., MSEL) or chi-square tests for categorical (e.g., parental education) variables. One-way ANOVAs comparing the three age groups were computed based on summary statistics using the techniques outlined by Larsen and Hsu (2010). Significant main effects for age were followed with pairwise comparisons between the age cohorts, using Bonferroni adjustments to control for multiple comparisons.

#### Age of Enrollment and Measures of Global Development

Results from comparing the three age groups revealed that younger children scored higher on standardized developmental tests than older children. That is, when compared with older children, younger children scored significantly higher on the Early Learning Composite and two subscales of the MSEL (Fine Motor and Receptive Language); similarly, children who were recruited at a younger age scored higher on the Social subscale of

	А			
Item	A: < 18	B: 18-23	C: 24-29	Test statistic <sup>a</sup>
N	83	217	79	
Chronological age				
M(SD)	15.6 (2.13)	20.8 (1.54)	25.6 (1.57)	
MSEL				
Fine motor				
M(SD)	43.1 (13.56)	39.1 (11.64)	31.5 (12.31)	<i>F</i> (2,291) = 13.9***
N	71	169	54	(A B) (C)
Visual reception				
M (SD)	40.2 (12.80)	38.5 (11.83)	35.3 (14.16)	F(2,292) = 2.4
N	71	170	54	
Receptive language				
M(SD)	30.0 (11.45)	26.1 (10.82)	27.3 (12.17)	F(2,353) = 3.5*
N	80	208	68	(A) (B)
Expressive language				() ()
M (SD)	29.1 (9.18)	26.7 (9.32)	28.4 (14.51)	F(2,355) = 1.8
n	80	208	70	1 (2,000) 110
Early learning composite	00	200	, 0	
M (SD)	74.2 (16.25)	69.8 (15.76)	66.7 (19.52)	F(2,291) = 3.4*
n	71	169	54	1 (2,2)1) 5.1
VABS	/ 1	109	54	
Communication				
M (SD)	77.5 (11.64)	74.0 (13.96)	71.5 (13.57)	F(2,242) = 2.7
n	60	142	43	I(2,242) = 2.7
Social	00	142	-15	
M (SD)	85.0 (8.13)	82.7 (9.12)	76.1 (10.06)	F(2,238) = 12.7***
n (SD)	63	136	42	(A B) (C)
Maternal educational attainment	03	150	42	(A B)(C)
No college	7.8%	15.9%	13.0%	$\chi^2(4) = 14.3^{**}$
6	7.8%	25.8%	26.1%	<b>,</b> ,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,
Some college	7.8% 84.4%	23.8% 58.3%	20.1% 60.9%	(A) (B C)
College completed	84.4% 64	132	60.9% 69	
n Ethniaita (maa	04	132	69	
Ethnicity/race	12.4%	20.1%	24.0%	$x^{2}(2) = 2.7$
Hispanic/Latino White	67.9%			$\chi^2(2) = 2.7$
		58.3%	56.0%	
Asian	6.2%	6.0%	8.0%	
Black	3.7%	5.0%	2.7%	
Mixed/Other	9.9%	10.6%	9.3%	
n General de la companya	81	199	75	
Community early intervention program		10 50/	15 00/	2(4) 22 0++++
None	68.3%	43.7%	17.9%	$\chi^2(4) = 33.9^{***}$
1-4 hr/week	30.2%	39.7%	60.7%	(A)(B)(C)
5 hr/week and above	1.6%	16.7%	21.4%	
n	63	126	56	

## Table 2 Descriptive Information on the Participants of the Eight ASTTN Projects at Study Entry

*Note.* For example, (A) (B, C) indicates that Group A differs significantly from Groups B and C. Project III did not administer the VABS and used only the two language scales of the MSEL. Projects II and VII did not provide information on children's community early intervention program at baseline. MESL = Mullen Scales of Early Learning; VABS = Vineland Adaptive Behavior Scales. <sup>a</sup>Age groups (A, B, C) that differ significantly at p < .05 are separated by brackets.

the VABS than children recruited at an older age. Results from pairwise comparisons revealed that children enrolled below 18 months scored significantly higher on the Receptive Language subscale of the MSEL than children between 18 and 23 months. Similarly, children enrolled between 24 and 29 months scored significantly lower on both the Fine Motor subscale of the MSEL and the Social subscale of the VABS than children enrolled below 24 months. Given the descriptive nature of the current data, the exact interpretation of these group differences is unclear. Alternative explanations include (a) the possibility that standardized assessments are less sensitive to problems at earlier ages; (b) an underlying regressive course characteristic for some toddlers with ASD (Crais & Watson, 2014); (c) a greater degree of diagnostic instability or misidentification in younger than in older children; (d) differences between research sites with regard to recruitment, screening, and eligibility criteria; and (e) geographic differences in identification and service practices.

#### Age of Enrollment and Community Services

Results also revealed significant age-related differences with regard to children's enrollment in community early intervention services. Only 31.7% of children enrolled below 18 months received community-based early intervention services when entering the ASTTN research projects. This percentage increased sharply for children enrolled between 18 and 23 months and between 24 and 29 months (56.3% and 82.1%, respectively). Age-related differences in children's access to early intervention services likely reflect current early identification practices. In turn, the majority of children who entered this research below 18 months were enrolled in projects that used a community-wide screening protocol to identify eligible participants (e.g., Projects I and VIII). Furthermore, early intervention services received by children below 18 months were usually not directly related to concerns about ASD. For example, one participant enrolled in Project I received services from a feeding specialist when entering the study, and the nature of the child's early intervention services focused only on communication as delays in this area became more apparent.

#### Age of Enrollment and Family Diversity

Compared with most research on ASD, the studies of the ASTTN were quite successful at enrolling diverse groups of families. Data from the 2010 CENSUS for the United States reveal that about 50% of children younger than 5 years were minority. The percentage of minority children in the ASTTN projects ranged between 32% in children enrolled younger than 18 months and 44% in children enrolled between 24 and 29 months. Although children's ethnic or racial background did not differ significantly based on the age when children were enrolled, results revealed that children who entered the studies below 18 months were significantly more likely to have a parent who completed college (84.4%) than children who entered the study between 18 and 23 months (58.3%) or between 24 and 29 months (60.9%). These age-related group differences are consistent with research that demonstrates that children from disadvantaged backgrounds receive ASD diagnoses up to a year and a half later than children with more privileged family backgrounds (Mandell,

Novak, & Zubritsky, 2005). It should be noted, however, that significant group differences may also be attributed to geographic differences in early identification practices and differences in sampling biases across research sites.

## Treatment Studies that Incorporate Strengths and Needs of Local Communities

Descriptive information collected across the network also revealed considerable geographical differences in children's utilization of early intervention services. That is, among children who entered the study between 18 and 23 months, the percentage receiving 5 or more hours weekly of early intervention services in the community ranged across treatment sites between 0% and 44% (M = 16.7%). To design experimental interventions that complement available community resources, researchers implemented several strategies. First, projects that anticipated low levels of community services tended to evaluate experimental interventions with a broader focus, addressing children's needs across various developmental domains (e.g., Project VIII). In contrast, projects conducting research in locations with high levels of community services tended to evaluate experimental interventions with a narrower focus (e.g., Project VII). In addition, Project VIII evaluated an experimental intervention that required 3 hr of clinician time weekly, an amount of service quite commonly received by toddlers with ASD in this geographical region. Finally, Project IV evaluated an experimental intervention that was limited in duration to 3 months. This duration was chosen based on the experience that, at least in this geographical region, most families experience about a 3-month delay between the time when families first look for early intervention and when the Individual and Family Service Plan (IFSP) is established and community services can start.

#### Participants—Considerations for Future Research

- 1. To avoid age-related confounds (e.g., global development, access to community services), future research should recruit participants within a narrow age window.
- 2. Targeted recruitment strategies should be implemented to reach parents with low educational attainment (e.g., partnerships with local Head Start programs or Women, Infants, and Children [WIC] centers).
- 3. Experimental and control interventions should be designed to fill important gaps in available community resources.

#### Recruitment

Despite advances in science and policy related to early identification, the majority of children with ASD continue to be diagnosed well after 4 years (Centers for Disease Control and Prevention [CDC], 2012). As a result, most ASTTN projects reported that participant recruitment required significantly more time and resources than anticipated. Notable exceptions were three projects that were concurrently engaged in community-wide screening projects (Projects I and VIII) or prospective studies of infant siblings of children with

				Pro	ject			
Design feature	Ι	II	III	IV	V	VI	VII	VIII
(a) Recruitment strategies								
Municipal early intervention program administration			Х	Х		Х	Х	
Early intervention provider agencies			Х	Х	Х	Х	Х	
Primary and secondary medical care providers		Х	Х	Х	Х	Х	Х	Х
Community-wide mailings of a screening instrument	Х							
Families of children with ASD with younger siblings		Х	Х		Х			
Other community organizations and resources								
Day care centers						Х	Х	
Online research registries and websites			Х	Х	Х	Х	Х	
Conferences for parents and/or professionals				Х	Х	Х		
Support groups for parents of children with ASD					Х	Х		
(b) Questionnaire-based screening measures								
ESAC								Х
ESAT				Х				
FYI	Х							
ITC				Х				Х
M-CHAT				Х		Х	Х	
(c) Observational measures of autism symptoms								
ADOS		Х			Х	Х		
ADOS-T	Х			Х				Х
AOSI	Х	Х						
CSBS	Х				Х		Х	Х
STAT			Х					
Structured home observation								Х
(d) Eligibility determination								
Was eligibility based on diagnostic classifications?	No	Yes	Yes	Yes	Yes	Yes	No	Yes
Was clinical judgment considered?	No	Yes	Yes	Yes	Yes	Yes	No	Yes
Were multiple sources of information aggregated?	Yes	Yes	No	Yes	Yes	Yes	No	Yes

## Table 3 Comparison of Key Research Design Features Between the Eight Research Projects Participating in the Toddler Treatment Network

*Note.* ASD = autism spectrum disorder; ESAC = Early Screening for Autism and Communication Disorders (Wetherby et al., 2009); ESAT = Early Screening of Autistic Traits (Swinkels et al., 2006); FYI = First Year Inventory (Baranek, Watson, Crais, & Reznick, 2003); ITC = Infant Toddler Checklist (Wetherby & Prizant, 2002); M-CHAT = Modified Checklist for Autism in Toddlers (M-CHAT, Robins, Fein, Barton, Green, 2001); ADOS = Autism Diagnostic Observation Schedule (Lord, Rutter, DiLavore, & Risi, 1999); ADOS-T = Autism Diagnostic Observation Schedule–Toddler Module (Lord, Rutter, DiLavore, Risi, & Gotham, 2012); AOSI = Autism Observation Scale for Infants (Bryson, Zwaigenbaum, McDermott, Rombough, & Brian, 2008); CSBS = Communication or Symbolic Behavior Scales (Wetherby & Prizant, 2002); STAT = Screening Tool for Autism in Toddlers (Stone, Coonrod, Turner, & Pozdol, 2004).

ASD (Project II), and in turn able to leverage resources across multiple projects. As indicated in Table 3a, the remaining five projects used a broad range of recruitment strategies. To document successes and challenges faced during recruitment for these five projects (11 treatment sites), Principal Investigators (PIs) were asked to complete a detailed questionnaire. Completed questionnaires were returned for 8 of the 11 treatment sites (4 out of the 5 projects). On average, PIs reported that the largest proportions of participants were recruited through partnerships with the early intervention administration and respective service provider agencies (M = 34%; range = 12%-66%) as well as primary and secondary medical care providers (M = 20%; range = 0%-45%). The PIs' experiences in establishing and managing these partnerships are described in detail below. In addition, research participants were recruited through a range of other community providers, including day care centers, psychologists, and speech pathologists (M = 17%; range = 0%-36%), research registries (M = 14%; range = 0%-32%), word-of-mouth (M = 4%; range = 0%-10%), and community mailings (M = 2%; range = 0%-14%).

#### Early Intervention Administration and Provider Agencies

Four of the seven PIs who completed the recruitment survey reported efforts to engage representatives of the local Part C lead agency, responsible for managing the early intervention program. In two instances, these representatives were willing to distribute information about the study to the directors of approved early intervention provider agencies, and in one instance to publish information about the study in an early intervention newsletter. In no instance was the municipal early intervention program willing or able to contact families directly about this research. In addition, all PIs reported some success in working with individual service provider agencies. This being said, four of the seven PIs emphasized that these kinds of recruitment efforts were successful only if embedded in ongoing collaborative relationships with the provider agencies. For example, many groups scheduled meetings to provide the agency directors or staff with information about the study, provided free continuing education seminars, or consulted on children's diagnostic evaluations. Despite successful recruitment partnerships, the number of participants referred by any individual agency tended to be rather small. Thus, all PIs reported partnering with a large number of provider agencies, requiring a large amount of time and resources. For example, one PI reported partnering with about 40 provider agencies, delivering one or two talks to staff and/or parents at each agency. Finally, research groups reported substantial variation in the structure and culture of provider agencies, emphasizing that developing strong working relationships typically required an internal champion who recognized the importance of rigorous treatment research (e.g., some agency directors failed to see the value of randomly assigning families to different treatment conditions) and who was convinced that the project was of value to families and did not compete or interfere with services offered by the provider agency.

#### **Primary and Secondary Medical Care Providers**

All seven PIs reported partnering with primary (e.g., family physicians, pediatricians) and secondary (e.g., developmental pediatricians, neurologists) medical care providers to recruit participants for this research. Working with primary care providers raised similar issues as working with early intervention provider agencies (i.e., resource intensive recruitment efforts with relatively low yield). Moreover, despite the increased focus on the importance of early

identification of ASD, research groups noticed considerable variability in the extent to which primary care providers implemented ASD-specific screening measures, and how concerns about ASD were communicated to families (Siller, Morgan, Swanson, & Hotez, 2013). Generally, projects were more successful in recruiting participants from hospital-based clinics than community-based primary care offices. Arguably, hospital clinics may be more effective partners for recruitment because of a higher volume of patients, closer affiliations with medical schools, and increased access to medical specialists (e.g., developmental pediatricians).

#### **Recruitment**—Considerations for Future Research

- Community service providers are reluctant to share information about a study for toddlers with ASD unless (a) they are comfortable discussing the diagnosis with eligible families, (b) they are convinced that parents directly benefit from participation, and (c) they appreciate the benefits of rigorous research designs (e.g., manualization of interventions, random assignment of participants). Successful recruitment partnerships generally require ongoing education of provider staff about these issues.
- 2. Establishing and maintaining recruitment partnerships with community service providers is time and resource intensive; leveraging recruitment resources across multiple research projects may be necessary to secure adequate funding.

#### Eligibility

To determine eligibility to participate, the projects of the ASTTN administered a broad range of questionnaire-based screening measures and observational measures of autism symptoms in toddlers. Results from these assessments formed the basis for decisions about the families' eligibility to participate. In making these determinations, research projects differed in (a) whether or not diagnostic classifications were determined, (b) whether clinical judgment was considered, and (c) whether multiple sources of information were aggregated. These key research design features are shown in Table 3.

#### Was Eligibility Based on Diagnostic Classifications?

During the last decade, the confidence of clinicians and researchers to diagnose ASD in toddlers younger than 24 months has evolved rapidly. In fact, when Autism Speaks first announced the mechanism that funded most ASTTN projects, the Request for Applications (RFA) specifically invited applications that evaluated interventions for toddlers who are "at risk for developing autism." As a consequence, the eligibility criteria of two ASTTN projects were based on quantitative indicators of ASD-related risk, as compared with diagnostic classifications.

#### How Was Clinical Judgment Considered?

Standardized diagnostic measures of ASD became first available during the 1990s (e.g., Autism Diagnostic Observation Schedule [ADOS]; Lord, Rutter, DiLavore, & Risi, 1999) and revolutionized autism research in that they created the opportunity to more clearly define

research samples. Despite these important advantages of standardized measures, recent research found that the judgment of experienced clinicians, trained on standardized instruments, consistently added to the results of standardized diagnostic measures (Guthrie et al., 2013). The added value of clinical judgments may be particularly important when establishing diagnostic classifications for toddlers. In turn, all projects that determined diagnostic classifications used standardized diagnostic measures in combination with the diagnostic judgment of clinicians who were experienced in diagnosing ASD in toddlers. For example, in Project III, eligibility was determined based on the clinical judgment of an experienced licensed psychologist. Similarly, in Project VIII, a best estimate diagnosis was established by consensus among the members of an interdisciplinary diagnostic team using the diagnostic criteria for Autistic Disorder or Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) defined in the Diagnostic and Statistical Manual of Mental Disorders (4th ed., text rev.; DSM-IV-TR; American Psychiatric Association [APA], 2000). Thus, in rare instances, children who missed the diagnostic cutoff on a standardized measure (often by one or two points) may have been determined eligible to participate based on the clinicians' diagnostic judgments. Similarly, children who met diagnostic cutoff scores may have been excluded from participating if the clinicians' judgments did not confirm the diagnosis. Although exact data were not collected across the ASTTN projects, disagreements between the results of standardized diagnostic measures and clinical judgment were the exception, not the rule.

#### How Were Multiple Sources of Information Aggregated?

Independent of whether clinical judgment played a role in determining eligibility, some research projects based their decisions entirely on observations from a single measure. For example, in Project III, toddlers were eligible to participate if they screened "at risk" on the Screening Tool for Autism in Toddlers (STAT; Stone, Coonrod, Turner, & Pozdol, 2004), and a licensed psychologist determined a clinical diagnosis of ASD. In contrast, to determine eligibility for Project VIII, an interdisciplinary team with experience in early diagnosis of ASD and other developmental disabilities completed a comprehensive battery of assessments that included a standardized diagnostic measure, a comprehensive developmental history, standardized assessments of cognitive and adaptive functioning, and a home video to provide an additional context to observe and evaluate features of ASD.

#### **Eligibility—Considerations for Future Research**

- 1. Decisions about eligibility have broad implications for recruitment, enrollment, intervention content, and interpretation of study findings.
- During recent years, diagnostic measures for toddlers below 24 months have become more widely available (ADOS-2 Toddler Module; Lord, Rutter, DiLavore, Risi, & Gotham, 2012). The diagnostic judgment of an experienced clinician adds valuable information to the results of standardized observations.
- According to the DSM (5th ed.; DSM-V; APA, 2013), researchers and clinicians are encouraged to include clinical specifiers (e.g., severity) when giving a diagnosis of ASD. A shared metric for establishing severity in toddlers with ASD would be helpful for defining eligibility criteria and interpreting intervention outcomes.

#### Enrollment

Despite popular enthusiasm about the possible benefits of early intervention, families who met the studies' eligibility criteria often hesitated to enroll. For many families, hesitation was related to the parents' strong emotional reaction when prompted to consider that their child may have ASD. Vignettes illustrating three typical parent reactions (i.e., consensus, uncertainty, disagreement) are presented in Text Box 1. In addition, the degree of family hesitation seemed to be influenced by the child's age, family support, and the availability of time and resources. Please note that our discussion of enrollment challenges is based on informal observation of the ASTTN investigators.

#### Text Box 1

#### Vignettes illustrating three typical reactions when parents learned that their child was eligible to participate in early intervention research: consensus, uncertainty, and disagreement

#### Consensus-Karen

Karen's parents, Susan and Daniel, began expressing concern to their pediatrician when Karen was 12 months of age. They had observed their daughter to display temper tantrums and engage in repetitive behaviors. At the pediatrician's office they completed a questionnaire regarding Karen's development and were referred for a face-to-face evaluation at the local university clinic. During the initial assessment, the clinician observed a number of repetitive behaviors in Karen's play, difficulty coordinating attention between people and objects, and very limited use of gestures. The clinician discussed these observations with Karen's parents, explained that these behaviors are red flags for ASD, and recommended a more comprehensive evaluation. She also referred Karen's family to early intervention and let them know that there was a research study for which they might be eligible. Although Susan and Daniel were quite shaken up by this experience, they agreed that it would be best to gather more information and consented to complete the full evaluation. An ADOS-T was scheduled for the following week. Following the ADOS evaluation, the diagnostician informed Susan and Daniel that although she needed to score the assessment carefully and complete a written report, her observations of Karen were consistent with a diagnosis of ASD. Two weeks later, the family met with the PI of the project. They came equipped with articles they had read about ASD, as well as a number of questions about the disorder. At the end of the meeting, Susan and Daniel, although worried and frightened for their daughter, seemed to have a clear understanding of why Karen was given a diagnosis of autism and the urgent need to begin intervention efforts. When they were invited to participate in a toddler treatment study, they were ready to get to work.

#### Uncertainty-Landon

At his 15-month well-baby check Landon's father, Martin, was encouraged to take him to the University speech and hearing clinic to have his communication evaluated. Although he was not overly concerned about Landon's lack of speech, Martin took him to the clinic. Martin was taken by surprise when the speech-language pathologist referred him to a University research project for further evaluation. When the research team's diagnostician suggested that Landon was at risk for autism because he was not yet pointing or showing and because he did not consistently respond to his name, Martin was confused and a little offended. Although his little boy was not using words yet, he was very affectionate and smiled at Martin often. Autism did not seem like an accurate description of Landon. Although he was hesitant, Martin agreed to participate in an intervention study for children at risk for autism. Martin considered/reasoned that even if the assessment team was wrong about Landon's diagnosis, the intervention described and offered by the researcher could not hurt. Martin enjoyed participating in the parent-mediated intervention and learned new ways to play with Landon but bristled every time the clinician mentioned autism. Toward the end of the study, Martin became involved in a community toddler play group. At this time, it began to dawn on him that Landon was

different from other children his age. At Landon's exit meeting from the study, Martin demonstrated a new openness during the discussion of final testing results. When the diagnostician described the features of ASD that she had observed in Landon, Martin concurred by giving examples of the same behaviors he had seen at home. Intervention staff felt confident that Landon's father left the project with a solid understanding of his son's ASD and with the tools he would need to pursue further resources for his son.

Disagreement—Wesley

Wesley was the first-born child of well-educated, professional parents. Confident that he was meeting his expected developmental milestones, Jennifer enrolled Wesley in a study that followed the language development of young children. During his third visit to the research program at 18 months of age, the clinician commented to Jennifer that Wesley's emerging language tended to be repetitive and had unusual intonation. She also noted that his play with blocks was unusual in that it was highly sophisticated compared with other children his age. As Jennifer did not note these differences as problems, she initially refused the offer of a more extended evaluation. One month later, Jennifer called to schedule a full diagnostic evaluation after talking about it with her husband. When the diagnostic feedback meeting was held, Jennifer and her husband jointly disagreed outright about the diagnosis of ASD being made by the clinician. They indicated that their son could not possibly have autism and that Jennifer's two younger brothers were quite similar to Wesley at the same age. The researcher described the nature of the intervention and the research project in great detail, encouraged the parents to ask whatever questions they might have, and offered to take whatever time they needed to decide whether or not to participate. Through much discussion, the family ultimately agreed to participate in the intervention project with the caveat that autism would not be the focus of the intervention sessions, that the word "autism" would not be mentioned around the nanny or extended family members, and that they would not be referred at this time to community services. Throughout the duration of the study, the project staff experienced challenges with Jennifer's participation. Jennifer often canceled intervention sessions, neglected to complete weekly data collection, and demonstrated limited transfer of the play and communication strategies she had been taught. Although Jennifer expressed satisfaction with participation in the intervention project, research staff were concerned that, due to the lack of consensus, Landon and his family did not benefit maximally from their experiences.

#### Child Age

Researchers involved with ASTTN observed that families of children younger than 24 months often were less eager to participate in treatment research than families of older children. Some families may not have been concerned about their child's development when they learned about the possibility of participating in this research. Other families may have noted some general concerns such as speech delays but lacked certainty regarding their child's diagnosis or the need for additional services. Research projects that established clinical diagnoses reported that certainty about the diagnosis may have raised the families' level of urgency in pursuing treatment. Similarly, families who had both an older sibling with ASD and emerging concerns about their toddler, were often highly motivated to participate.

#### **Family Support**

It often takes parents a considerable amount of effort and time to come to an agreement about their child's diagnosis and need for services. Similarly, grandparents and other extended family members may or may not share or immediately validate the parents' concerns. Prior to enrolling in this research, many families sought advice from community

professionals. For example, a parent may have called the child's pediatrician to get a "second opinion" on the researchers' concerns about their child's development. Other families currently enrolled in early intervention may have sought the opinion of service coordinators or intervention providers. At times, members of the child's early intervention team discouraged families from participating in this research. Possible reasons for this included (a) the belief that community early intervention services were sufficient and met the child's needs, (b) concern about a possible lack of coordination between the research project and community services, and (c) doubts regarding the potential benefits to the family of participating in a research study (e.g., when the early intervention provider's theory of change was not consistent with the research project's theory of change).

#### **Time and Resources**

Parenting any toddler involves a delicate balance between the child's rapidly changing needs, the parents' professional and financial obligations, complex child care arrangements, and often a very lively family system that includes extended family members, older siblings, and frequently, newborns. Moreover, many families of young children experience poverty, marital transitions, and illness. Thus, when concerns about ASD first enter the families' world, many parents already manage rather complex family systems. Adjusting to an ASD diagnosis may be difficult for some families. Parents may learn about autism, modify family routines, negotiate a complex system of public services and regulations, and manage their child's early intervention team. Despite the great personal benefits that parents may derive from participating in early intervention research, the first months after a child's ASD diagnosis may be a particularly difficult time for parents to commit to repeated assessment sessions or to entertain the possibility of being randomly assigned to different intervention conditions (Wachtel & Carter, 2008).

#### **Enrollment—Considerations for Future Research**

- 1. To successfully enroll a broad range of families, early intervention research needs to support families during the diagnostic process and offer supports for parents who have strong emotional reactions and/or struggle to establish consensus about the child's diagnosis and/ or need for services between family members (e.g., mother, father, grandparent), friends, and trusted community professionals (e.g., physicians, teachers).
- 2. Early intervention research should include tangible short-term outcomes that make dayto-day family life more manageable.

#### **Supporting Families**

As reviewed in Table 1, the experimental interventions of the ASTTN shared a strong emphasis on parent-mediated strategies. During the past decades, parent education has shifted away from a narrow focus on skill attainment and moved toward a more holistic approach that aims to enhance the capacity of families to meet the needs of their children. Based on a review of the literature, Woods and Brown (2011) identified four global strategies to support family capacity building: (a) addressing the families' informational needs, (b) using their natural environments as the intervention context, (c) engaging parents to be active participants in the intervention process, and (d) supporting caregivers' reflection and self-evaluation. Across the ASTTN, researchers developed many creative strategies to enhance the capacity of families to meet the needs of toddlers with ASD.

#### Addressing the Families' Informational Needs

When working with parents of newly diagnosed children, parents often raise a broad range of questions that usually go far beyond the scope of the evaluated experimental interventions. For example, parents ask questions about the causes and etiology of ASD (e.g., "What caused my child to have this?"), the child's prognosis (e.g., "Will my child have to be in a special education classroom?"), or what the diagnosis means for other family members (e.g., "How do I explain my child's diagnosis to his grandparents?"). To address the parents' questions, Project VIII offered monthly consultation sessions to all families. Parents were provided with a menu of possible topics and invited to choose a topic according to their own needs. Also, families were invited to involve extended family members in these sessions.

#### Using the Families' Natural Environments as the Intervention Context

To ensure that the intervention activities were infused throughout the families' natural environment, Project VIII implemented a routines-based interview designed to identify a broad range of everyday activities. Furthermore, during the last third of the intervention period, weekly community outings (e.g., grocery store, community playgrounds) were added to expand the intervention context even more. Embedding the intervention strategies within the families' natural environment fostered the density of treatment hours, facilitated generalization across activities, and expanded opportunities for families and children to participate together in meaningful everyday activities.

#### **Engaging Parents to Be Active Participants in the Intervention Process**

To encourage the parents' active participation in the planning of the intervention sessions, Project I used a routine-based interview to identify activities that parents perceived as challenging, and to collect information on the parents' concerns and goals. This interview allowed parents and interventionists to establish connections between everyday activities and the content of the intervention and to relate functional outcomes to pivotal behaviors, discussion points, and intervention strategies.

#### Supporting Parents' Reflection and Self-Evaluation

Project VII utilized video feedback to teach parents the observational tools necessary to monitor their child's attention, activities, and behaviors and to evaluate how children's social engagement and communication is influenced by parents' interactive behaviors and strategies. Interactions between parent, child, and interventionist were video-recorded during each intervention session. To scaffold the parents' reflection and self-evaluation, the interventionist carefully chose video examples to illustrate specific activities, adult behaviors, or child responses, encouraged the parent to comment on the child's behaviors and reactions, and provided specific and concise feedback on the parent's actions (accentuating positive contributions).

#### Supporting Families—Considerations for Future Research

- 1. Parents of toddlers with ASD have many different kinds of questions. Early intervention research should provide a context for addressing the parents' spontaneous questions.
- 2. To effectively embed intervention strategies within natural environments, parent and interventionist should develop an accurate understanding of family routines and activities.
- 3. Early intervention should engage parents in collaborative problem solving, empowering them to continue evaluating interactive strategies beyond the intervention period.

#### **Conclusion and Future Directions**

The past and continued collaboration between the investigators of the ASTTN highlights how rapidly the field of early identification and intervention has evolved during the last decade. Moreover, geographical differences between the research sites bring into focus how deeply individual research projects are embedded within their local communities. That is, participant recruitment builds on close collaborative relationships with community partners; local early identification and referral practices influence which families choose to participate; the cultural, economic, and educational background of the participating families as well as the availability of community interventions shapes the design of the evaluated intervention protocols; and the availability of private and public funding constrains the research questions that can be investigated. To date, three of the eight ASTTN projects have published initial results (Carter et al., 2011; Rogers et al., 2012; Schertz, Odom, Baggett, & Sideris, 2013). Arguably, the most robust finding from this research is that, on average, parents can be effectively taught to implement a broad range of intervention strategies. However, the emerging evidence also suggests that not all parents (a) acquire the same level of proficiency in using the targeted strategies, (b) maintain the use of these strategies over time, and (c) implement the acquired strategies with sufficient intensity to effect children's long-term outcomes.

Intervention research in ASD is only beginning to identify family characteristics that predict parent buy-in or moderate treatment efficacy (Siller, Hutman, & Sigman, 2013; Siller, Reyes, Hotez, Hutman, & Sigman, 2014). Similarly, little is currently known about how to best support parents with different backgrounds, values, goals, concerns, or learning styles. Impetus for this important area may come from research on other high-risk populations, including children who experience socioeconomic disadvantages. For example, Oppenheim and Koren-Karie (2002) set out to capture the parents' ability to describe their child's thoughts, feelings, and behaviors in a rich, nuanced, and accepting way (i.e., parent insightfulness). This ability may be necessary to fully engage in an intervention that targets the parents' reflection and self-evaluation and uses strategies such as video feedback (Siller, Hutman, & Sigman, 2013). At the same time, parents who consider their child's mental states in a rich and nuanced way may be less engaged if interventions are more

structured and rely on traditional behavioral approaches. Similarly, researchers have emphasized individual differences in the parents' motivation for change (Gardner et al., 2009; Wachtel & Carter, 2008). Importantly, a parent's limited motivation for change may stem from a limited understanding of the child's problem, strong emotional reactions, concerns about diagnostic labels, and/or cultural stigma, as well as a range of contextual risk factors (e.g., unemployment, marital transitions, several children, lack of education, parental depressions). Motivational interviewing may provide an excellent tool for identifying areas of strengths as well as areas of risk, and help establish consensus between parent and clinician about intervention goals (Miller & Rollnick, 2013).

During the last decade, intervention research in ASD is gradually recognizing the need to identify child characteristics that predict intervention outcomes. A greater understanding of individual differences in children's treatment response may offer an empirical rationale for matching children with promising intervention programs, guide our attempts to individualize specific intervention strategies, and refine intervention approaches to meet the needs of all children. The research of the ASTTN highlights the need to pay equal attention to parent or family characteristics that may predict or influence the parents' engagement during parent-mediated interventions. Just as it is unlikely that one intervention meets the needs of all children, it is equally unlikely that all parents share the same needs and learn in identical ways.

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