

Early Intervention Outcomes for Toddlers With Autism Spectrum Disorder and Their Families

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Autism spectrum disorder (ASD) can be diagnosed as early as 18 months of age. State Early Intervention (EI) programs under Part C of the Individuals with Disabilities Education Act (IDEA) are serving increasing numbers of children with ASD; however, little is known about outcomes of these services. This study evaluated the impact of EI for toddlers with ASD ($n = 193$) and other disabilities ($n = 129$) and their families, using measures that included federal Part C outcome indicators. Children with ASD showed reduced maladaptive behaviors and improved social and communication skills on the PDD Behavior Inventory; some also made progress on the Part C child outcome indicators. Families of children with ASD reported that EI helped them achieve many outcomes identified as important to families participating in EI. Results provide a rich description of outcomes experienced by children with ASD and their families in one of the largest EI programs in the United States. Implications for results-driven accountability and future research are discussed. **Key words:** *ASD, autism spectrum disorder, child outcomes, early intervention, family outcomes, Part C*

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THERE is growing concern about the increasing prevalence of autism spectrum disorder (ASD) among young children (Lord & Bishop, 2010). According to studies conducted in the 1980s, coinciding with the adoption of the American Psychiatric Association's (APA's) criteria for autism as codified in the Diagnostic and Statistical Manual, third edition (APA, 1980), the estimated prevalence of ASD was 3.3 cases per 10,000 for children 3-18 years of age, or 3.6 cases for children 8-12 years of age (Christiansen et al., 2016). At present, the prevalence of ASD is estimated to be 16.8 cases per 1,000 children 8 years of age, based on surveillance studies conducted by the Autism and Developmental Disabilities Monitoring Network using criteria in the *Diagnostic and Statistical Manual of Mental Disorders*, Fourth Edition, Text Revision, *DSM-IV-TR* or the Diagnostic and Statistical Manual of Mental Disorders, Fifth edition (*DSM-5*) (APA, 2000, 2013; Baio et al., 2016). The magnitude of the prevalence increase is striking.

Autism spectrum disorder can be reliably diagnosed as early as 18 months of age (Boyd, Odom, Humphreys, & Sam, 2010; Johnson & Myers, 2007; Lord & Bishop, 2010; Woolfenden, Sarkozy, Ridley, & Williams, 2012). Thus, state Early Intervention (EI) programs under Part C of the Individuals with Disabilities Education Act (IDEA) are serving increasing numbers of children with an ASD diagnosis. Data on the size of the ASD population participating in state EI programs are not widely available or reported to the U.S. Department of Education (USDOE). However, according to a recent national study, 26 states recognize ASD as a diagnosed condition with a high probability of development delay, meaning that in these states, all children referred with ASD are eligible for EI services (Elie, Barger, Shaw, & Greer, 2016).

Outcomes of EI for children with ASD and their families

There is particularly high need for data on the outcomes of community EI services for children with ASD. Most studies examining

the effect of EI on young children with ASD can be characterized as efficacy studies conducted in controlled research environments (Weitlauf et al., 2014). Much less is known about the effectiveness of EI delivered by community providers across a range of settings (Lord & Bishop, 2010; Weitlauf et al., 2014), or the multiple elements of state EI programs (service coordination services, interagency collaboration, interventions that support children and families) that may impact child and family outcomes (Schwartz & Sandall, 2010). The current study was undertaken to provide states, local EI programs, policy makers, researchers, families, and other key stakeholders with a rich description of the outcomes experienced by the growing population of children with ASD and their families in one of the largest state EI programs in the United States. Outcomes for this key subpopulation of children and families are contextualized by presenting corresponding data on a comparison sample of children with other developmental delays and disabilities who likewise participated in the state's EI program.

Results-driven accountability

Child outcomes were incorporated into the federal Results-Driven Accountability (RDA) system for state EI programs in 2005, as part of new State Performance Plan/Annual Performance Report (SPP/APR) requirements (IDEA, 2004). The child outcomes indicator (Indicator 3) for toddlers exiting Part C EI programs is the percentage of infants and toddlers receiving EI services who demonstrate improvements in positive social emotional skills, including social relationships ([3A], "social-emotional skills"); acquisition and use of knowledge and skills, including early language/communication and early literacy ([3B], "knowledge and skills"); and use of appropriate behaviors to meet their needs ([3C], "behaviors to meet needs"). The accountability system also includes an indicator (Indicator 4) of the extent to which families perceived that EI helped the family: know their rights (4A); effectively communicate their children's needs (4B); and, help

their child develop and learn (4C). State performance on child outcomes has been used by USDOE to assess states' implementation of IDEA requirements since 2015; family outcomes have not yet been incorporated into this process (USDOE, 2015).

In the context of the RDA system, states' reports of their performance on the child and family outcomes indicators are intended to be representative of the entire population of children and families served in EI. Thus, the data may or may not reflect outcomes for any specific subgroup within the overall population of children and families in state EI programs. Given the significant developmental challenges faced by toddlers with ASD (Landa & Garrett-Mayer, 2006; Lord & Bishop, 2010; Myers & Johnson, 2007) and the higher level of stress experienced by families of these children compared with families of children with other developmental disabilities (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Hastings, 2008; Hastings & Beck, 2004; Hastings & Brown, 2002; Romanczyk & Callahan, 2012), there is a need for outcome data specific to this subpopulation. Data on the needs and outcomes of specific subgroups have important programmatic and policy implications for state EI programs (Elbaum & Celimli-Aksoy, 2017) and the national approach to assessing state Part C performance (Noyes-Grosser et al., 2013). Therefore, the current study addressed the following research questions:

- What are the outcomes of EI, both for children with ASD and a comparison group of children with other disabilities, related to autism symptomatology, children's overall developmental progress, and parents' perceptions of the helpfulness of EI to their child?
- What percentage of children with ASD participating in EI make "substantial progress" in each of the three federally defined outcome indicators? What percentage of children with ASD are "within age expectations," in each of the outcome indicators, when they exit EI? What are the corresponding percentages for a

representative sample of children with other delays and disabilities who participated in EI?

- What percentage of parents, both of toddlers with ASD and of children with other developmental disabilities, report that EI helped them attain each of the federal family outcome indicators? What is the level of stress experienced by parents in both groups, both on entry to EI and on exit?

METHODS

Study participants

Participants in this study were parents and their toddlers with a diagnosis of ASD and a comparison group of parents and their similarly aged children with other diagnoses or developmental delays (referred to as "disabilities" throughout). A total of 1,622 families whose toddlers had an ASD diagnosis and 1,320 families whose toddlers had other disabilities were invited to participate. Based on sample size calculations, a minimum of 105 participating families in the ASD group and 50 participating families in the comparison group were required for study objectives. A total of 351 families returned signed consent forms and 322 participated in the study (ASD group, $n = 193$ [12% of those invited]; comparison group with other disabilities, $n = 129$ [10% of those invited]). All participants were in EI for less than 1 year at the time of recruitment and exited EI during the study time frame.

Demographic forms designed for the study were completed by 98% of participants in the ASD group ($n = 190$ of 193) and 87% in the comparison group ($n = 112$ of 129). Data for the study also included child data extracted from two statewide information systems used for state and local EI program administration. State administrative data were available for all study participants and were used to calculate children's developmental level on entry to EI (based on reported multidisciplinary evaluation data) and duration, intensity, and types of

services received by study participants. These data also served as a supplemental source of data on gender, race and ethnicity, household income, Medicaid status, and parental age and education for participants with incomplete or missing demographic forms.

Table 1 presents demographic and household characteristics of study participants. Chi-square tests were performed to examine the difference between the ASD and comparison groups on child's gender, race, ethnicity, Medicaid status, household income, maternal and paternal education, and maternal and paternal age. Overall, the ASD and comparison groups were quite similar with respect to these social-demographic characteristics, showing statistically significant differences only with respect to child gender and paternal age.

Table 2 presents children's developmental levels on entry to the EI program. As seen in the table, children with ASD were significantly more likely than children with other disabilities to have moderate to severe delays in all five developmental domains (adaptive, cognitive, communication, social emotional, and physical).

Table 3 presents data on the duration and intensity of EI services for the ASD and comparison groups, derived from state administrative EI services utilization data. Duration in EI was calculated as the number of weeks between the start date of the child's initial individualized family service plans (IFSP) and exit date from EI. Total weeks of EI services were calculated as the sum of weeks in EI when any EI services (excluding service coordination and evaluation) were received by the child or the family. Hours per week of service were calculated by dividing total hours of services by total weeks of service for each child. Total hours of EI services were calculated as the sum of hours across all EI services received by the child and the family (excluding service coordination and evaluation services). Hours of services received by the child were collapsed if the child received more than one service in the same hour (e.g., if a child received special instruction services in a group setting for 60 min and services from a speech-language

therapist for 30 min of that hour, only 1 hr was counted).

Children in the ASD and comparison groups participated in EI for a similar number of weeks overall ($M = 90$ weeks vs. $M = 86$ weeks, respectively). Children with ASD had more total weeks of therapeutic services ($M = 71$ weeks vs. $M = 62$ weeks), received more total hours of services ($M = 918$ hr vs. $M = 131$ hr), and more hours per week ($M = 13$ hr vs. $M = 2$ hr).

Table 4 presents data on the types of services received by children in the ASD and comparison groups. Higher percentages of children with ASD received special instruction services (100% vs. 52%) and occupational therapy services (85% vs. 45%). A higher percentage of children with ASD also received group services with other children (50% vs. 11%).

Procedures

Institutional review board approval to conduct the study was obtained before commencing recruitment.

Recruitment of participants

Participants were recruited for the study on the basis of EI diagnostic codes (*International Classification of Diseases, Ninth Revision [ICD-9]*) reported in the state's EI administrative data systems. The ASD participants were recruited from among all families of toddlers with an *ICD-9* code of 299 and associated modifiers (inclusive of autistic disorder and pervasive developmental disorder—not otherwise specified). Comparison group participants were randomly selected for recruitment from among families of children with other disabilities who were at least 18 months of age. All participants were recruited from 17 out of 58 localities that accounted for more than 99% of all children with reported ASD enrolled in the state's EI program during the recruitment period.

Potential participants received a study brochure and an invitation letter customized to the child's disability (ASD vs. other), accompanied by a postage-paid return postcard

Table 1. Demographic Characteristics of Study Participants

	ASD Group		Comparison Group		χ^2	<i>p</i>
	<i>N</i>	% ^a	<i>N</i>	% ^a		
Child gender					7.2	<.001
Male	144	74.6	78	60.5		
Female	49	25.4	51	39.5		
Child race					6.7	= .23
Asian	17	8.8	13	10.1		
Black	50	25.9	24	18.6		
White	115	59.6	80	62.0		
Other	11	5.7	12	9.3		
Child ethnicity					3.4	<.07
Hispanic or Latino	73	37.8	36	27.9		
Not Hispanic or Latino	120	62.2	93	72.1		
Child Medicaid status					0.6	= .43
Yes	96	49.7	70	54.3		
No	97	50.3	59	45.7		
Family household income					2.4	= .66
<\$25,000	59	30.6	36	27.9		
\$25,000 to \$50,000	43	22.3	35	27.1		
\$50,000 to \$75,000	32	16.6	15	11.6		
\$75,000 to \$100,000	19	9.8	14	10.9		
>\$100,000	40	20.7	29	22.5		
Parental education					Fisher's exact test	
Mother's education						= .18
Less than high school	14	7.8	5	4.2		
High school/GED	26	14.5	26	21.8		
Some college	33	18.4	16	13.4		
2-year college degree	15	8.4	5	4.2		
4-year college degree	49	27.4	28	23.5		
Master's degree	30	16.8	31	26.0		
Doctoral degree	6	3.3	5	4.2		
Professional degree	6	3.3	3	2.5		
Father's education						= .46
Less than high school	24	12.4	6	4.7		
High school/GED	39	20.2	29	22.5		
Some college	32	16.6	20	15.5		
2-year college degree	11	5.7	10	7.8		
4-year college degree	35	18.1	27	20.9		
Master's degree	21	10.9	16	12.4		
Doctoral degree	7	3.6	4	3.1		
Professional degree	3	1.6	2	1.5		
Parental age	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	Two-sample <i>t</i> -test	<i>p</i>
Mother's age	31.5	5.6	30.9	7.0	<i>t</i> = 0.9	= .39
Father's age	34.4	7.1	32.5	7.2	<i>t</i> = 2.2	<.03

Note. ASD = autism spectrum disorder.
^aPercentages may not sum to 100% due to rounding.

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Table 2. Developmental Domain Delays on Entry to Early Intervention^a

Level of Domain Delay ^b	ASD Group (<i>n</i> = 193)		Comparison Group (<i>n</i> = 129)		χ^2	<i>p</i>
	<i>N</i>	%	<i>N</i>	%		
Adaptive					28.8	<.001
No delay	99	51.3	104	80.6		
Moderate delay	55	28.5	13	10.1		
Severe delay	39	20.2	12	9.3		
Cognitive					35.1	<.001
No delay	31	16.1	57	44.2		
Moderate delay	50	25.9	33	25.6		
Severe delay	112	58.0	39	30.2		
Communication					39.5	<.001
No delay	12	6.2	36	28.0		
Moderate delay	17	8.8	23	17.8		
Severe delay	164	85.0	70	54.2		
Social emotional					183.5	<.001
No delay	12	6.2	97	75.0		
Moderate delay	33	17.1	22	17.0		
Severe delay	148	76.7	10	8.0		
Physical					15.4	<.001
No delay	32	16.6	45	34.9		
Moderate delay	27	14.0	19	14.7		
Severe delay	134	69.4	65	50.4		

Note. ASD = autism spectrum disorder.

^aPercentages within a category may not sum to 100% due to rounding.

^bModerate delay in a domain is defined as a 25% delay or 1.5 standard deviations below the mean. Severe delay in a domain is defined as a delay of 12 months, 33%, or a score of 2.0 standard deviations below the mean on a standardized test.

Table 3. Duration of Participation in EI and Intensity of Services Received for Study Participants

Duration and Intensity of EI Services	ASD Group (<i>n</i> = 193)		Comparison Group (<i>n</i> = 129)	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Total weeks in EI	90	38	86	42
Total hours of EI services	918	418	131	132
Total weeks of EI services	71	20	62	25
Hours per week of EI services	13	5	2	2

Note. ASD = autism spectrum disorder; EI = Early Intervention.

Table 4. Types of EI Services Received by Study Participants

EI Service Type	ASD Group (<i>n</i> = 193)		Comparison Group (<i>n</i> = 129)	
	<i>N</i>	%	<i>N</i>	%
Special instruction	193	100	67	52
Speech-language therapy	190	98	108	84
Occupational therapy	165	85	58	45
Physical therapy	81	42	58	45
Group developmental intervention ^a	97	50	14	11

Note. ASD = autism spectrum disorder; EI = Early Intervention.

^aGroup developmental intervention is a service model that involves delivery of EI services by one or more qualified personnel to two or more children, typically in a structured learning environment.

to indicate interest in the study (see Supplemental Digital Content 1 and 2 for study brochures, available at: <http://links.lww.com/IYC/A8> and <http://links.lww.com/IYC/A9>). Parents who returned the postcard received a follow-up letter detailing study requirements, accompanied by a consent form to sign and business reply envelope to return the form. Parent consent included consent to access and review the child's EI records and evaluations for the preschool special education program.

Participant data collection packets

Upon receipt of a signed consent form, an entry packet was sent by US Postal Service (USPS) to the participant to complete, accompanied by a postage-paid addressed envelope for return to study staff. Entry packets included a demographic form, the PDD Behavior Inventory (PDDBI) Parent Report Form (Cohen, 2003; Cohen, Schmidt-Lackner, Romanczyk, & Sudhalter, 2003; Cohen & Sudhalter, 2005), Parenting Stress Index Short Form ([PSI-SF], Abidin, 1983), and the Family Outcomes Survey (Bailey et al., 2006). The Family Outcome Survey was used for another phase of this study and results are not reported here.

Exit packets, accompanied by postage-paid envelopes for return to study staff, were sent by USPS to participants to complete as

their children exited EI. Exit packets included the PDDBI, PSI-SF, Family Outcomes Survey, and a version of the New York (NY) Family Survey (Noyes-Grosser & Elbaum, 2011) developed specifically for this project (Elbaum et al., 2014; Elbaum et al., 2015; Noyes-Grosser et al., 2013; see NY Family Survey, Supplemental Digital Content 3, available at: <http://links.lww.com/IYC/A10>).

Follow-up calls were made by study staff to participants who did not return consent forms or study materials within 2 weeks of each mailing. No more than three contacts were made to participants as reminders to return consent forms or instruments. Participants received two incentive payments (\$40 for completion of entry instruments and \$60 for completion of exit instruments) to compensate them for their time.

Clinical record review

Child records were obtained from local EI and preschool special education program administrators. The review and abstraction of data from child records were completed using a protocol developed for this study (see Record Review Protocol, Supplemental Digital Content 4, available at: <http://links.lww.com/IYC/A11>). Reviewers had 15 or more years of experience in reviewing child records for EI program monitoring and quality improvement. Data abstracted included

details related to child evaluations, IFSPs, provider progress notes, and, where available, preschool special education evaluations.

Three reviewers completed child outcomes summary (COS) ratings (Early Childhood Technical Assistance Center, 2017c) based on the review of children's records. Two of the COS raters also completed overall progress ratings. Reviewers were trained for 10 hr over a 5-day period in record abstraction, interpretation of evaluation reports and provider progress notes, and methods for deriving COS and overall progress ratings.

Outcome measures

Outcome measures used in this study, including the timing of data collection (entry and/or exit) and the number of participants for whom the data were available, are described below.

COS ratings (entry and exit)

The COS process was developed by the national Early Childhood Outcomes Center to provide states with a method for measuring and reporting federal child outcome indicator data (Early Childhood Technical Assistance Center, 2017c). Developers of the COS emphasize that the COS is not an assessment tool but rather a process for use by professionals, in consultation with parents, to summarize children's current developmental functioning compared with age expectations based on multiple sources of information (Early Childhood Technical Assistance Center, 2017c). Central to the COS process is use of the 7-point COS rating tool, used to rate the extent to which the child "shows age appropriate functioning, across a wide variety of settings and situations, on this outcome." The COS ratings range from "Not Yet" (rating = 1) to "Consistently" (rating = 7; Early Childhood Technical Assistance Center, 2017c).

The COS ratings were based on a review of children's multidisciplinary evaluations on entry to EI and preschool special education evaluations near exit to EI. Standardized scores on developmental assessments in the areas of social skills, cognitive and communication

skills, and adaptive/fine/gross motor skills (or alternatively, descriptive information on functional skills, age levels, and developmental status) were used by reviewers to determine COS ratings. Reviewers used reference tables for developmental assessment instruments to align standardized test scores with each of the seven COS ratings.

Among children in the ASD group, 87% ($n = 168$) had COS entry ratings, and 83% ($n = 160$) had both entry and exit ratings. Among children in the comparison group, 86% ($n = 111$) had COS entry ratings and 64% ($n = 82$) had both entry and exit ratings. Interrater reliability for the COS ratings was calculated using weighted Cohen's κ statistic and was found to be adequate, $\kappa > 0.6$.

Overall progress rating (exit)

Children's overall clinical and developmental progress and progress toward outcomes and goals in their IFSPs were rated using a scale of 1–5, where 1 = no progress; 2 = little progress; 3 = moderate progress; 4 = great deal of progress; and 5 = outcomes achieved. Indicators of overall progress, based on record reviewers' judgments, included the general course of the child's progress while in EI; clinical assessment of progress as noted by providers serving the child; change in breadth of disparity between the child's developmental levels and those of typically developing same-age peers; and effects of developmental or physical behaviors or conditions on the child's progress. Overall progress ratings were completed for 87% ($n = 168$) of children in the ASD group and 86% ($n = 111$) of children in the comparison group. Interrater reliability for the overall progress ratings was adequate, $\kappa > 0.6$.

PDD Behavior Inventory (entry and exit)

The PDDBI is a standardized rating scale of behavior-associated ASDs (pervasive developmental disorders, autism, Asperger disorder, pervasive developmental delay—not otherwise specified) designed to be completed by parents or teachers (Cohen, 2003; Cohen

et al., 2003; Cohen & Sudhalter, 2005). The measure yields age-standardized scores and is designed for use in intervention studies in which a reduction in maladaptive behaviors and improvements in adaptive, social, and communication skills is expected. Among children in the ASD group, 79% had PDDBI entry scores ($n = 152$), 78% had exit scores ($n = 150$), and 67% ($n = 130$) had both entry and exit scores. Among children in the comparison group, 76% ($n = 98$) had PDDBI entry scores, 74% ($n = 96$) had exit scores, and 64% ($n = 82$) had both entry and exit scores.

NY Impact on Child Scale—Modified (exit)

The NY Impact on Child Scale—Modified (NYICS-M) measures families' perceived helpfulness of EI in attaining outcomes for their children. It is based on an existing measure used by the NY EI program, the NYICS (Noyes-Grosser & Elbaum, 2011), expanded to include items identified as having particular relevance to children with ASD through a concept-mapping methodology (Kane & Trochim, 2007) with stakeholders (Elbaum et al., 2015; Noyes-Grosser et al., 2013). Like the NYICS, the 83-item NYICS-M—as well as the NY Impact on Family Scale—Modified (NYIFS-M), and the NCSEAM Family-Centered Services Scale (NFCSS), described later—was evaluated for unidimensionality and coverage of a range of item difficulties through the Rasch measurement model (Bond & Fox, 2007; Wright & Masters, 1982). The instrument uses a 6-point response scale (1 = very strongly disagree to 6 = very strongly agree) in response to the common stem “EI services have helped my child . . .” Table 5 provides sample child outcome items in the NYICS-M. The NYICS-M was found to have strong reliability, Cronbach's $\alpha = 0.99$ (Elbaum et al., 2014 [see also NY Family Survey, which includes the full set of items for the NYICS-M, in Supplemental Digital Content 3 available at: <http://links.lww.com/IYC/A10J>]). The NYICS-M was available for 82% ($n = 158$) of the ASD group and 81% ($n = 104$) of the comparison group.

NY Impact on Family Scale—Modified (exit)

The NYIFS-M measures families' perceived helpfulness of EI in attaining family outcomes. It is based on a family outcomes measure already being used by the NY EI program (Noyes-Grosser & Elbaum, 2011), adapted from the Impact on Family Scale developed by the National Center for Special Education Accountability Monitoring (NCSEAM) for use by states to measure and report federal family outcome indicators (Fisher, Elbaum, & Coulter, 2012). The NYIFS-M incorporates outcomes expected of EI from families of children with ASD identified through concept mapping with stakeholders (Elbaum et al., 2015; Elbaum, Noyes-Grosser, Morgan, Yan, and Siegenthaler, 2011, Noyes-Grosser et al., 2013). The 86-item NYIFS-M (Elbaum et al., 2014) uses the same response scale and similar stem (EI services have helped my family . . .) as the NYICS-M described previously. Table 5 provides a sample of family outcome items included in the NYIFS-M. Scale reliability for the NYIFS-M was very high, Cronbach's $\alpha = 0.98$ (Elbaum et al., 2014 [see also NY Family Survey, which includes the full set of items for the NYIFS-M, in Supplemental Digital Content 3, available at: <http://links.lww.com/IYC/A10J>]). The NYIFS-M was available for 82% ($n = 158$) of the ASD group and 81% ($n = 104$) of the comparison group.

NCSEAM Family-Centered Services Scale (exit)

The NFCSS was also developed by NCSEAM for use by states for accountability and quality improvement purposes (Fisher, Elbaum, & Coulter, 2012). The scale was developed on the basis of a family-centered model of EI services. A 29-item version of the NFCSS is used by the NY EI program to measure the quality of families' experiences with the EI program and services. The NFCSS uses the same response scale as the NYICS-M and the NYIFS-M. Scale reliability for the NFCSS is very high, Cronbach's $\alpha = 0.88$ (Fisher, Elbaum, & Coulter, 2012). Table 5 provides a sample of items

Table 5. Sample Items from the NYICS-M, NYIFS-M, and NFCSS

<p>Sample items from the NYICS-M</p> <p><i>Early intervention services helped my child . . .</i></p> <ul style="list-style-type: none"> Engage in more eye contact with others. Take part more in family activities, like meal times, watching TV, or going out together. Improve his or her social skills. Learn good ways to behave. Participate in activities in the community. <p>Sample items from the NYIFS-M</p> <p><i>Early intervention services helped my family . . .</i></p> <ul style="list-style-type: none"> Do things with and for my child that are good for my child’s development. Know and understand how the early intervention program works. Communicate better with the people who work with my child and family. Be better at managing my child’s behavior. Develop a support system with other families. <p>Sample items from the NFCSS</p> <ul style="list-style-type: none"> My service coordinator was available to speak to me on a regular basis. I felt part of the team when meeting to discuss my child. Someone from the EI program asked whether the services my family received met our needs. My family was given information about ways of connecting with other families for information and mutual support. Someone from EI went out into the community with me and my child to help us get involved in community activities and services.
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Note. EI = Early Intervention; NFCSS = NCSEAM Family-Centered Services Scale; NYICS-M = New York Impact on Child Scale-M; NYIFS-M = New York Impact on Family Scale-M.

included in the NFCSS (see also NY Family Survey, which includes the full set of FCSS items, in Supplemental Digital Content 3, available at: <http://links.lww.com/IYC/A10>). The NYIFS-M was available for 82% ($n = 158$) of the ASD group and 81% ($n = 104$) of the comparison group.

Parenting Stress Index Short Form (entry and exit)

The PSI-SF is a measure of stress in the parent-child system and has extensive empirical support (Abidin, 1983). The PSI-SF consists of 36 items and yields a total stress score. Scores at or above the 90th percentile indicate areas in which parents are experiencing significant distress (i.e., clinically elevated). Numerous studies have investigated the psychometric properties of the PSI and the PSI-SF (Abidin, Zalaquett, & Wood, 1997; Bigras, LaFreniere, & Dumas, 1996; Haskett et al., 2006; Loyd & Abidin, 1985; Puura,

Guedeney, Mäntymaa, & Tamminen, 2007; Reitman, Currier, & Stickle, 2002). Among families in the ASD group, 85% ($n = 165$) had PSI-SF entry scores, 78% ($n = 150$) had exit scores, and 71% ($n = 137$) had both entry and exit scores. Among children in the comparison group, 84% ($n = 108$) had PSI-SF entry scores, 74% ($n = 103$) had exit scores, and 64% ($n = 92$) had both entry and exit scores.

Data analysis

Data collected in different formats were converted into SAS datasets. Analyses were conducted using SAS software version 9.4 (SAS Institute, 2003).

COS ratings

The COS entry and exit ratings derived by record reviewers were used to calculate progress for the ASD and comparison groups using the methodology states and are required to use for federal reporting purposes

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(Early Childhood Technical Assistance Center, 2014a). Children's COS entry and exit scores were compared to assign children to one of five progress categories used for federal reporting: (a) "children who did not improve functioning;" (b) "children who improved functioning but not sufficient to move nearer to functioning comparable to same aged peers;" (c) "children who improved functioning to a level nearer to same aged peers but did not reach it;" (d) "children who improved functioning to reach a level comparable to same age peers;" and (e) "children who maintained functioning at a level comparable to same age peers" (USDOE, 2014). Federal formulas were applied to calculate "summary statements" reported in states' APRs. Summary Statement 1 reports the percentage of children who "substantially increased their rate of growth" by the time they exit EI ["progress categories $100\% \times (c + d) / (a + b + c + d)$ "]. Summary Statement 2 reports the percentage of children "functioning within age expectations" by the time they exit the program ["progress categories $100\% \times (d + e) / (a + b + c + d + e)$ "] (USDOE, 2014).

PDD Behavior Inventory

The PDDBI yields age-standardized scores that provide information about problem and adaptive behaviors. Scores are reported as T-scores with a mean of 50 and a standard deviation of 10. Scores between 40 and 60 are considered within the average range for individuals diagnosed with autism; a lower PDDBI score indicates less severe ASD symptomatology. A percent child change was calculated for each child, using the formula: $100\% \times (PDDBI \text{ exit} - PDDBI \text{ entry}) / (PDDBI \text{ entry})$ to assess the magnitude of change across the wide range of scores that are possible. The ASD and comparison group entry scores were expected to cluster at different points on the scale and, therefore, percent change was conceptualized as less biased by the total initial score than use of simple numeric score change. A negative percent change score can be interpreted as an improvement in child behavior, that is, a reduction in ASD symptoms

and increase in adaptive, social, and communication skills.¹

NY Impact on Child Scale—Modified

Parents' responses to the NYICS-M were analyzed through the Rasch measurement framework (Bond & Fox, 2007; Wright & Masters, 1982; Wright & Mok, 2000), using the Winsteps Rasch measurement software version 3.70 (Linacre, 2010). Higher parent measures indicate greater perceived helpfulness of EI in attaining positive outcomes for the parent's child.

NY Impact on Family Scale—Modified

Parents' responses to the NYIFS-M were likewise analyzed through the Rasch measurement framework, using the Winsteps Rasch measurement software version 3.70 (Linacre, 2010). Higher parent measures indicate greater perceived helpfulness of EI in attaining positive family outcomes. Standards recommended by NCSEAM for use by states to calculate their percentages on the OSEP family outcomes indicators (4A, know their

¹For children 3 years and younger, informants frequently are unable to complete sections of the instrument that assess expressive language. Outcome scores affected by the inability to rate expressive language include the Semantic/Pragmatic Problems (SEMP) and Expressive Language (EXPRESS) domain scores. Importantly, these two domains are utilized to generate the overall Autism Composite. For the purposes of this study, an aggregate research score (AGS) was computed using three of the four Approach/Withdrawal Problems domain T-scores and one of the two Receptive/Expressive Social Communication Abilities domain T-scores to allow for interpretation of symptom severity aside from expressive language skills. Sensory/Perceptual Approach Behaviors, Ritualisms/Resistance to Change, and Social Pragmatic Problems T-scores were summed and the obtained T-score on the Social Approach Behaviors domain was subtracted to generate the AGS (Romanczyk et al., unpublished manuscript). Although not standardized, the AGS allows for the generation of a severity score when children's expressive language has not yet developed. The AGS should be interpreted as a severity indicator of ASD characteristics within the present sample, not confirmation of diagnostic status or comparison to the clinical sample used for standardization of the PDDBI.

rights, NYIFS-M > 539; 4B, effectively communicate their children’s needs, NYIFS-M > 556; and 4C, help their children develop and learn, NYIFS-M > 516; Elbaum, 2007; Mid-South Regional Resource Center, 2009) were applied to the study data.

NCSEAM Family-Centered Services Scale

The NFCSS was analyzed similarly to the NYICS-M and the NYIFS-M. Higher parent measures indicate greater perceived family-centeredness of EI services.

Parenting Stress Index Short Form

A total stress score was calculated for participants on the basis of responses to the PSI-SF at entry and exit. The percent change score was calculated using the following formula: 100% × (PSI-SF exit – PSI-SF entry)/PSI-SF entry. Lower stress levels experienced by a parent at exit from EI, compared with entry, yield a negative percent change score.

RESULTS

Child outcome measures

Federal child outcome indicator summary statements

Table 6 presents the percentage of children in the ASD and comparison groups who

“substantially improved their rate of growth” (Summary Statement 1) and the percent in each of these groups who were “functioning within age expectations” (Summary Statement 2) on exit from EI on each of the federal child outcome indicators (3A, “social-emotional skills”; 3B, “knowledge and skills”; and 3C, “behaviors to meet needs”). Among toddlers with ASD, 42.4% were found to have “substantially improved their rate of growth” on exit from EI in 3A, 55% in 3B, and 24.2% in 3C. Corresponding percentages for toddlers with other disabilities were 44.1% in 3A, 69.7% in 3B, and 42.5% in 3C. Very low percentages of children with ASD were found to be “functioning within age expectations” on exit from EI in any of the three federal outcome indicators (12.5% in 3A, 11.9% in 3B, and 6.9% in 3C). Corresponding percentages for toddlers with other disabilities were 45.1% in 3A, 28% in 3B, and 26.8% in 3C.

Overall progress rating

None of the children in either group were rated as having made “No Progress” on the five-point overall progress rating scale. Among children with ASD, 32% were rated as having made “little progress”; 59% were rated as having made “moderate progress”; and 9% were found to have made a “great deal of progress.”

Table 6. Summary Statement Percentages for Federal Child Outcome Indicator 3 for Study Participants

Federal Child Outcome Indicator 3	ASD Group (n = 160)		Comparison Group (n = 82)	
	%	95% CI	%	95% CI
Summary Statement 1 (% of children who substantially improved their rate of growth)				
3A. Social Emotional Skills	42.4	34.6-50.5	44.1	31.2-57.6
3B. Knowledge and Skills	55.0	47.0-62.9	69.7	58.1-79.8
3C. Behaviors to Meet Needs	24.2	17.6-31.0	42.5	30.1-54.6
Summary Statement 2 (% of children functioning within age expectations)				
3A. Social Emotional Skills	12.5	7.8-18.6	45.1	34.1-56.5
3B. Knowledge and Skills	11.9	7.3-17.9	28	18.7-39.1
3C. Behaviors to Meet Needs	6.9	3.5-12.0	26.8	17.6-37.8

Note. ASD = autism spectrum disorder; CI = confidence interval.

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None of the children with ASD were rated as having “outcomes achieved.” Within the group of children with other disabilities, 16% were rated as having made “little progress”; 47% made “moderate progress”; 23% made a “great deal of progress”; and 12% were rated as “outcomes achieved.”

PDD Behavior Inventory

Mean entry and exit scores for toddlers with ASD were $M = 107.9$ ($SD = 39.7$, 95% confidence interval [CI, 101-114.8]) and $M = 98.9$ ($SD = 38.1$, 95% CI [92.3-105.5]), respectively. Corresponding entry and exit scores for the comparison group were $M = 75.2$ ($SD = 36.4$, 95% CI [67.2-83.2]) and $M = 68.7$ ($SD = 33.8$, 95% CI [61.3-76.1]), respectively. The higher scores for toddlers with ASD at both time points suggest that these children were experiencing more problem behaviors and deficits in adaptive, social, and communication skills than children with other disabilities. Toddlers with ASD showed a reduction in their scores on the PDDBI ($M_{\text{difference}} = -5.6\%$, $SD = 26.7$, 95% CI [-10.2 to -0.9]). Toddlers with other disabilities on average showed little change in their scores ($M_{\text{difference}} = -0.7\%$, $SD = 42$, 95% CI [-9.9 to 8.5]).

NY Impact on Child Scale—Modified

The mean NYICS-M measure for parents of toddlers with ASD was $M = 551.3$, 95% CI (533.7-568.8). The mean measure for fami-

lies of children with other developmental delays and disabilities was $M = 527.9$, 95% CI (507.3-548.6). On average, families in both groups perceived EI to be most helpful for their children in improving their development and functioning and less helpful to their children in taking part in group and community activities.

Family outcome measures

NY Impact on Family Scale—Modified

Table 7 presents the percentage of families in the ASD and comparison groups who reported that EI helped them achieve the federal family outcome indicators, derived through application of national standards recommended for use by NCSEAM. The three indicator percentages for families of children with ASD were 53.2% for 4A, 45.6% for 4B, and 63.3% for 4C. The corresponding percentages for families of children with other disabilities were 41.4%, 34.6%, and 50%, respectively.

The mean NYIFS-M measures for families of children with ASD and families of children with other developmental delays and disabilities were $M = 557.3$, CI [541.1-573.4] and $M = 525.4$, 95% CI [505.8-545.0], respectively. On average, families in both groups perceived EI to be most helpful to them in understanding and improving their children’s development and less so in assisting them in finding and engaging in resources and

Table 7. Percentage of Families Achieving Federal Family Outcome Indicator 4

Federal Family Outcome Indicator 4	ASD Group (n = 158)		Comparison Group (n = 104)	
	%	95% CI	%	95% CI
Percentage of families who report that EI helped them:				
4A. Know their rights	53.2	45.4-60.9	41.4	31.9-50.8
4B. Effectively communicate their children’s needs	45.6	37.8-53.3	34.6	25.5-43.8
4C. Help their children develop and learn	63.3	55.8-70.8	50.0	30.1-54.59

Note. ASD = autism spectrum disorder; CI = confidence interval; EI = Early Intervention.

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activities in the community for their child and the family.

NCSEAM Family-Centered Services Scale

The mean NFCSS measures for families of children with ASD and families of children with other disabilities were $M = 542.7$, 95% CI [527-558.5] and $M = 522.8$, 95% CI [506.1-539.5], respectively. On average, families in both groups were more likely to agree that EI professionals were accessible and responsive in assisting them to access and participate in EI. Families were less likely to feel that someone from EI helped them solve problems or access community supports and services.

Parenting Stress Index Short Form

For families of children with ASD, mean entry and exit scores on the PSI-SF were $M = 87.3$ ($SD = 21.3$, 95% CI [83.7-90.9]) and $M = 88.0$ ($SD = 22.7$, 95% CI [84.2-91.8]), respectively. For families of children with other disabilities, the corresponding means were $M = 74.1$ ($SD = 21.1$, 95% CI [69.7-78.4]) and $M = 73.7$ ($SD = 20.7$, 95% CI [69.4-78.0]). Scores changed negligibly between entry and exit for both the ASD group ($M_{\text{difference}} = 2.9\%$, $SD = 24$, 95% CI [-1.1% to 7.0%]) and the comparison group ($M_{\text{difference}} = 2.1\%$, $SD = 24$, 95% CI [-2.9% to 7.0%]).

DISCUSSION

The primary purpose of this study was to provide a rich description of outcomes of state-provided Part C EI services for toddlers with ASD and their families. Outcomes were also assessed for a comparison group of toddlers with other developmental delays and disabilities and their families to provide important contextual information for examining and understanding outcomes for children and families affected by ASD.

Child outcomes of EI

Outcomes for toddlers in the ASD group

Evidence from randomized control and single-subject design studies suggests that

high quality, evidence-based EI can result in positive change in the development, functioning, and health of young children with ASD (Boyd et al., 2010; Chakrabati, Haubus, Dugmore, Orgil, & Devine, 2005; Corsello, 2005; Lord & Bishop, 2010; Weitlauf et al., 2014). On entry to EI, children in our study with ASD were delayed in more developmental areas and were more severely delayed than children with other disabilities. However, in line with the positive findings from clinical research, our study of community-based services delivered through the EI program found that as measured by the COS, some children with ASD had “substantially increased their rate of growth” (Summary Statement 1) on one or more of the three federal child outcome indicators. Not surprisingly, a very low percentage (at most 12%) of toddlers with ASD were found to be “functioning within age expectations” on exit from EI in any of the three federal outcome indicators.

More children with ASD in our study improved in the outcome indicators “social-emotional skills” and “use of knowledge and skills” than in “behaviors to meet needs.” Of particular interest is the finding that similar percentages of participants in the ASD and comparison groups were found to have “substantially improved their rate of growth” in social-emotional skills (3A), a particularly challenging area of development for children with ASD. It is possible that intervention strategies for children with ASD and their families focused on improvement in social skills, including social relatedness, communication and play skills, and early learning foundations and cognition. Evidence-based intervention approaches recommended for this population are increasingly focused on early social and communication skills (e.g., joint attention), play skills, and cognition (Dawson et al., 2010; Kasari, Freeman, & Paparella, 2006; Rogers & Vismara, 2008; Weitlauf et al., 2014; Zwaigenbaum et al., 2015).

Taken together, the aforementioned findings support the relevance of the child outcomes indicators to children with ASD. In particular, the findings suggest that the COS

ratings, which are used by many states for accountability reporting, are sensitive enough to capture differences between children with ASD and the broader population of children receiving EI for other developmental delays or disabilities.

In addition, most toddlers with ASD were found to have made progress toward achieving IFSP goals, as assessed by our clinical record review measure of overall progress, though none of the children with ASD achieved these goals entirely. These findings provide further support for the conclusion that participation in community-based services delivered by EI has a positive impact on children's development. At the same time, the findings also clearly indicate the need for ongoing supports and services as children transition from EI to preschool special education or other programs and services.

Results for the PDDBI, an empirically validated parent-report measure designed for use with the ASD population, showed notable improvement in the ASD group between entry to and exit from EI. These data suggest that families experienced a reduction in maladaptive behaviors and an improvement in communication and social skills in their toddlers with ASD during their participation in EI services. This finding is particularly encouraging and suggests that intervention approaches being used by community-based EI providers are appropriately including a focus on core symptoms of ASD.

Our findings on the NYICS-M indicate that overall, families perceived EI services as having helped their child with ASD accomplish a wide range of desired developmental outcomes associated with key areas of challenge for toddlers with ASD, including social skills and social relatedness, positive behaviors, self-help skills, language, and cognition.

Outcomes for toddlers in the comparison group

Early intervention outcomes for toddlers with other disabilities participating in this study provide important contextual information for understanding and examining out-

comes for toddlers with ASD. Toddlers in the comparison group were a heterogeneous group, representing the diversity of developmental delays and other diagnosed conditions with a high probability of resulting in developmental delay experienced by children in Part C EI programs and for whom states must report child outcome data.

Regardless of the variation in their diagnoses, on average children in the comparison group were functioning at higher levels in all areas of development on entry to EI than children in the ASD group. Overall, higher percentages of children in the comparison group were "functioning within age expectations" on exit from EI in all three child outcome indicator areas. The difference between groups in the severity of children's developmental delays on entry to the EI program is important to consider when examining the differences in progress made toward outcomes on exit from EI. A promising area of future inquiry is the extent to which differences in severity of developmental delay on entry to EI may impact child progress during participation in EI (cf. Elbaum, Morris, & Celimli-Aksoy, 2017).

Family outcomes of EI

Part C EI is a family-centered service delivery system, intended to ensure a high level of parent involvement in all aspects of service delivery to participating children (Bailey, 2001; Bruder, 2010; Dempsey & Keen, 2008; Dunst, 2002). Most intervention approaches for children with ASD and their families include parent training, education, and support as part of an overall, comprehensive approach to intervening with the child and the family (Dawson et al., 2010; Kasari, Freeman, & Paparella, 2006; Rogers & Vismara, 2008; Weitlauf et al., 2014; Zwaigenbaum et al., 2015). Zwaigenbaum et al. (2015) identified the active involvement of families and/or caregivers as part of intervention for young children with ASD as a "best practice," and there is an emerging evidence base for parent-mediated interventions, wherein some or all of the intervention with the child is delivered by the parent (Weitlauf et al., 2014; Wong et al., 2013).

Outcomes for families in the ASD group

Families' perceptions of the helpfulness of EI programs to the child can make an important contribution to state evaluation systems by informing stakeholders of families' views and experiences with EI as these relate to other measures of child progress (Elbaum, 2007; Fisher, Elbaum, & Coulter, 2012; Mid-South Regional Resource Center, 2009; Ziviani, Cuskelly, & Feeney, 2010). We found that higher percentages of families with ASD met the recommended national standards for achieving the outcome indicators "know their rights" and "help their children develop and learn" than for "effectively communicate their children's needs." These findings suggest that these families were more likely to attribute perceived improvements in understanding procedural safeguards and ways to facilitate their children's developmental progress to EI services.

Our findings related to the NYIFS-M indicate that families in the ASD group perceived EI as helping them achieve a broad array of family outcomes to support their children's development and communicate and collaborate with professionals assisting their child. Families in the ASD group also perceived that EI helped them find and know about resources and treatment options available in their communities; however, they were less likely to perceive EI as helping them connect or develop support systems with other families. An essential goal of EI is to help families expand and improve their access to informal support systems in their neighborhoods and communities. Our findings suggest the need for more focused attention by EI professionals in assisting families to achieve this goal.

Consistent with previous research, we found that families of children with ASD were experiencing high levels of stress both on entry to and exit from EI. Participation in EI did not appear to alleviate or diminish stress levels; indeed, our results suggest that some families had higher levels of stress on exit from EI. When planning interventions with families of toddlers with ASD, it may be important

for professionals to address parent stress levels and other factors that may affect families' ability to play an active role in their children's EI services. This may be especially important for parent-mediated intervention approaches.

Outcomes for families in the comparison group

Similar to our findings for families in the ASD group, higher percentages of families in the comparison group met the recommended national standards for achieving the federal outcome indicators "help their child develop and learn" and "know their rights" compared with the outcome "effectively communicate their child's needs." Given that lower percentages of families in both groups were less likely to perceive EI as helping them to communicate their children's needs effectively with others, our data suggest that families would benefit from an enhanced focus by EI professionals on ensuring that families understand and feel comfortable in their abilities to explain their children's strength and needs to others (e.g., extended family members, child care providers, health care professionals).

Results for the NYIFS-M suggest that families in the comparison group perceived EI as assisting them in achieving many and varied outcomes for their family related to facilitating their children's development and improving family life. Families in the comparison group were somewhat less likely to perceive EI as helping their family in outcome areas such as supporting the needs of other children in the family, coping with the emotional impact of having a child with a disability, and being better able to meet the needs of other family members—again highlighting potential areas of improvement for EI professionals.

The level of stress experienced by families in the comparison group was also elevated on entry to the study (Romanczyk et al., unpublished manuscript) and no change was observed at exit from EI. The level of parent stress observed would be sufficient to prompt practitioners to work with families to pursue additional follow-up. Future research should address factors that may contribute to

increased parent stress, such as the demands inherent in caring for children with developmental concerns (identifying and diagnosing developmental problems, scheduling of medical and services appointments, disruption of family schedules, etc.), a separate component associated with child characteristics, or an interaction of these factors. Strategies EI professionals can employ to help alleviate and reduce parent stress should also be explored.

Family-centered services

Our findings from the NFCSS suggest that families in the ASD and comparison groups had similar experiences and perceptions with respect to the quality of EI services. Families in both groups agreed that someone from EI helped them with a range of activities needed to participate in EI services (such as preparing for the IFSP meeting, informing them about parental rights, preparing for their children's transitions to preschool special education, etc.). Families in both groups were less likely to perceive EI services as helping them engage in community programs and services or connect with other families—arguably one of the central aims of EI. Families and EI providers may find achieving these outcomes challenging for many different reasons (e.g., availability of community resources for families with very young children, traveling time or transportation to access services, work schedules). This may be a fruitful area of focus for family-professional collaboration (including program administrators) to improve family outcomes of EI services.

Policy context and implications

In the past two decades, states implementing EI programs under Part C of IDEA have been impacted by two emerging trends: the rapid increase in the number of toddlers with ASD and their families referred for EI services, and federal implementation of RDA. The findings of our study have important implications in light of these trends.

Impact of increased numbers of toddlers with ASD on state EI programs

National campaigns such as “Learn the Signs. Act Early” (U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities, 2017) and efforts by the American Academy of Pediatrics and other advocacy groups to improve early identification, diagnosis, and intervention for toddlers with ASD have led to ever-greater demands on state EI programs to respond with timely evaluation, diagnostic services, and evidence-based interventions (Boyd et al., 2010; Carbone, Behl, Azor, & Murphy, 2010; Johnson & Myers, 2007; Lord & Bishop, 2010; Shattuck & Grosse, 2007). Anecdotal reports from Part C coordinators suggest that states are experiencing significant increases in the number of children with ASD and their families participating in EI, and an associated increase in costs (IDEA Infant & Toddler Coordinators Association, 2014). In New York, children with ASD and their families currently represent approximately 13% of all EI program participants.

Recent reviews of evidence-based treatments for young children with ASD (Boyd et al., 2010; Lord & Bishop, 2010; Weitlauf et al., 2014; Zwaigenbaum et al., 2015) have concluded that focused and intensive comprehensive treatment models are most effective in improving children's development and functioning. Weitlauf et al. (2014), in a systematic review of behavioral interventions for children with ASD, ages birth to 12 years of age, recently concluded that effective interventions for young children ranged in intensity from 14 to 28 hr per week, with a range in duration of 8 months to 2 years. Thus, state EI programs are challenged not only by the increasing number of children with ASD but also by the demands on resources necessary to meet the intensive service needs of these children and their families. Although our findings document that toddlers with ASD make some developmental gains while receiving EI services, it is unknown whether the intensity

of services provided to these children and their families, while markedly exceeding the intensity of services provided to children with other developmental challenges, is sufficient to attain the outcomes documented in highly resourced research interventions.

Results-driven accountability

The vision for RDA is to “target its work and investments to best support states in improving results for infants, toddlers, children, and youth with disabilities (USDOE, 2012).” Among the core principles articulated by USDOE for RDA are a system that “is transparent and understandable to states and the general public, especially individuals with disabilities and their families”; “drives improved outcomes for all children and youth with disabilities regardless of their age, disability, race/ethnicity, language, gender, socioeconomic status, or location”; “encourages States to direct their resources to where they can have the greatest positive impact on outcomes”; and is “responsive to the needs and expectations of the ultimate consumers (i.e., children and youth with disabilities and their families; USDOE, 2012).” These core principles suggest recognition, support, and anticipated differences in child and family outcomes for subpopulations in EI programs, at both the state and national levels. Results-driven accountability also represents an important shift in focus from compliance with IDEA requirements to outcomes of EI for children and their families. As such, RDA has led to the incorporation of child outcomes in annual determinations of states’ performance in meeting the requirements of IDEA (USDOE, 2015).

Under RDA, states report outcomes data aggregated across all subpopulations of children and families exiting the EI program. This method of reporting diminishes the potential value of child and family outcomes data for consumers—parents, service providers, program administrators, government officials, and others—for whom data on subpopulations are fundamental for funding decisions, workforce development, service planning,

quality improvement, and program evaluation. Although the need for information about outcomes for the growing population of children with ASD and their families in EI programs is particularly pressing, a strong argument can be made that such information is equally important for other subpopulations of children in EI programs for these same purposes.

Implications for future research

Need for EI program evaluation

Recent scholarly reviews and commentaries on the impact of EI on children with ASD as well as other disabilities and their families have pointed to the need for valid and reliable methods for evaluating the performance of state EI programs and community-based EI services in achieving desired outcomes for families (Conroy, 2010; Lord & Bishop, 2010; Weitlauf et al., 2014). Although the analysis of changes in children’s developmental functioning between entry to and exit from EI provides important information, this information alone does not tell us to what extent EI services contributed to children’s improved outcomes (Rosenberg, Elbaum, Robinson, Kellar-Guenther, & McManus, 2017). Thus, an important next step in understanding the impact of EI is to conduct analyses that combine data on services, outcomes, and child and family characteristics. These analyses will help us better understand what types and amounts of services provide the greatest benefit to children with ASD or other types of conditions that are often associated with developmental delays and/or disabilities.

Moreover, it is reasonable to assume that there will be only an increasing demand for rigorous research on EI child and family outcomes and the parameters of service delivery that are most associated with the attainment of desired results. Research efforts that make full use of demographic and services data collected on EI participants by states, augmented by additional measures such as those used in our study, can contribute to the evidence-base on the effectiveness of community EI

programs and help ensure the availability of EI services for future generations.

To that end, several of the resources developed through or employed in this study, including the NYICS-M and NYIFS-M, the NFCSS (see Table 6 for sample items and the NY Family Survey for all items in Supplemental Digital Content 3, available at: <http://links.lww.com/IYC/A10>), and record review protocol (see Record Review Protocol, Supplemental Digital Content 4, available at: <http://links.lww.com/IYC/A11>) can be used or adapted by state Part C programs for program evaluation purposes. Likewise, the analytic techniques used in this study for examining child and family outcomes data for the ASD and other subpopulations, using COS data and NYIFS-M data (adapted from the NCSEAM IFS), may be readily employed by other states using these or similar measures for program evaluation.

Intensity of EI services and child and family outcomes

A key factor to consider when evaluating outcomes of state EI programs is the type and intensity of services provided to individual children and their families. Commentaries by Conroy (2010) and Schwartz and Sandall (2010) pointed to the discrepancy in science-based recommendations on effective practices and the 1.5 hr per week of eclectic services provided on average to infants and toddlers with developmental disabilities in state EI programs (Hebbeler et al., 2007).

By comparison, families and their children with ASD who participated in our study were found to have received an intensive level of EI services. The number of hours of services received, as analyzed for this investigation, may in fact underestimate the intensity of resources used by families and their children with ASD, because frequently more than one service provider was involved in service delivery. Children with ASD and their families were also found to have received both more hours per week and more total hours of services than children and families in the comparison group.

Currently, there are relatively few sources of data on the intensity of services received by children and families participating in Part C EI programs (the IDEA Infant-Toddler Coordinators Association collects some data annually from member states). With the exception of ASD, there is also a relative dearth of clinical research examining the relationship between diagnosis, intensity of EI services, and child and family outcomes. There is a critical need for research in this area to help families and professionals make informed decisions about the optimal level of intervention needed to achieve desired outcomes for children and families.

Family outcomes

In our study, we found that higher percentages of families of children with ASD met the recommended national standard for achieving all three family outcome indicators than did families of children with other disabilities. We noticed a similar trend with respect to differences in families' perceived helpfulness of EI in attaining outcomes for their child as measured by the NYICS-M, their family as measured by the NYIFS-M, and their perceptions of the quality of EI services as measured by the NFCSS.

One possible reason for these differences may be the much higher level of intensity of interaction between families in the ASD group with EI service providers and the EI program. Although not unexpected, the difference in intensity highlights the very different level of ongoing interaction among children with ASD and their families and their EI service providers while participating in EI programs. Families may be more likely to attribute child and family outcomes to the helpfulness of EI services and feel more positive about the quality of their experience with the EI program and service providers, if they have more frequent contact with providers and receive more hours of EI services. A promising and important area for future research is exploration of relationships among family outcomes and attributes of community-based EI services for children with ASD and their families,

including the level of intensity and quality of family experiences with EI services. Several states, including New York, selected one or more family outcomes as the “state-identified measurable child and/or measurable result” (SIMR) for their state systemic improvement plans (SSIPs; Early Childhood Technical Assistance Center, 2017b). As part of the SSIP process, state Part C programs are collaborating with stakeholders and communities to implement strategies (or a “theory of action”) to improve their SIMRs and evaluate the extent to which improvement in outcomes is achieved (Early Childhood Technical Assistance Center, 2017a). The experiences of states in their efforts to improve family outcomes (Arkansas, Connecticut, Iowa, Kentucky, New York, and Vermont) (Early Childhood Technical Assistance Center, 2017b) may provide insight and valuable information about the characteristics of EI services that promote positive family outcomes in the future.

Limitations

Our study has several limitations. The study used state administrative data sets to identify and recruit children with ASD and the comparison group of children with other disabilities. Thus, children’s ASD diagnoses were obtained from the administrative records and were not confirmed through additional diagnostic evaluations. The COS ratings used to measure the federal child outcome indicators were based on reviewing children’s EI and preschool special education evaluations, rather than using the recommended team process for agreeing on ratings for in-

dividual children. There were differences in the availability of some measures for the two groups; most notably, COS exit ratings (which required preschool special education records to complete) were available for a smaller percentage of children in the comparison group (64%) than in the ASD group (82%). As this is one of the first studies to use a state systems approach to evaluate the outcome of EI services on families and their children with ASD, more research is needed to ascertain the generalizability of our findings to other state EI programs. When considering these limitations, it is important to note that unless very substantial external resources are made available, in-depth statewide evaluations of EI programs that differentiate across groups of children and families would likely encounter similar limitations.

CONCLUSION

This study is one of the largest studies of child and family outcomes of community-based EI services for the ASD subpopulation, with 193 family participants whose children had an ASD diagnosis. The findings presented here highlight the importance of ascertaining differences in outcomes for subpopulations of children in state EI programs, particularly for subpopulations that are growing in size and resource demands. Going forward, consideration should be given to broadening RDA to include outcomes measurement and reporting for large subpopulations, such as that of children with ASD and their families, that significantly impact state EI programs.

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