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AUTISM SPECTRUM (A RICHDALE, SECTION EDITOR)

Supporting Children with Autism Spectrum Disorder at Primary School: Are the Promises of Early Intervention Maintained?

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Abstract Early and intensive intervention (EI) for children with autism spectrum disorder (ASD) is considered to be "best practice" to reduce the symptoms of autism and maximize the outcome for children's functioning. Many studies have established the effectiveness of, particularly, early intensive behavioral intervention, and in some cases improvements have been impressive, with children moving off the autism spectrum. However, very few long-term follow-up studies have been conducted to determine if the progress seen as a result of EI has been maintained as children with ASD continue through school. Eight long-term follow-up studies published between 1993 and 2014 are reviewed. The researchers reported that although most children had made progress in many areas as measured by standardized assessments, children in some studies had regressed. Significant difficulties in autism symptomatology, behavior, and social skills remained at follow-up for many children across studies. It appears that ongoing, uninterrupted intervention after the conclusion of early intervention is necessary to ensure gains made in EI are maintained. However, because of numerous methodological issues in the studies, these conclusions cannot be definitive, and additional longitudinal research is called for.

Keywords Autism spectrum disorder · Early intervention · Follow-up · Primary school · Developmental disorders

Introduction

Autism spectrum disorder (ASD) is one of the most common developmental disabilities, currently affecting as many as 1 in 68 individuals [1]. Diagnostic criteria for ASD include having difficulties with social interaction and social communication, along with the presence of circumscribed and repetitive behavior, although there is considerable variability in the severity of ASD symptoms among individuals [2]. Examples of the former include difficulties in initiating or maintaining conversations or friendships, difficulties in regulating social interaction through nonverbal communicative behavior, and adjusting behavior to suit the social context. Examples of the latter include the insistence on sameness and lack of flexibility in routines, stereotyped motor behavior that may include hand-flapping, unusual and intense interests, and hypo- and/or hypersensitivities to sensory stimuli [2]. Co-morbid intellectual disability is common (31 % in 2010, although this has decreased significantly over the years from 47 % in 2002) [1] as is attention deficit hyperactivity disorder, epilepsy [2], and anxiety or mood disorders [3].

The effectiveness of early intervention (EI) for children with ASD is undisputed and well supported by the literature and is currently recommended as "best practice" to optimize outcomes [4]. In his landmark 1987 study, Lovaas found that 47 % of the children ($N = 9$) in an experimental group ($N = 19$)

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receiving 40 h per week of one-to-one intensive behavioral intervention for 2 or 3 years achieved “normal functioning” and had “recovered” from autism in that they scored in the average range on IQ tests and successfully attended first grade in a public school in a regular education classroom [5]. Despite considerable criticism of some of his methods and measures, and Lovaas’ use of the term “recovered” (e.g., [6–8]), many subsequent studies over the years of early and intensive behavioral intervention (EIBI or IBI) using a variety of models in numerous countries have demonstrated its effectiveness for many children with ASD and established it as the form of EI with the best evidence base [9–15].

It is generally believed that children participating in EIBI will have a reduced need for supports and programs as they go through school, thus providing an economic rationale to “front-load” intervention [16]. As Matson and Konst [17•] point out, however, this supposition is based on the assumption that gains made in IBI will be maintained as the children age. Whether this is true or not can only be established by conducting long-term follow-up research. By far, the majority of follow-up studies to date, however, are better characterized as EI pretest/post-test evaluations (e.g., [11, 18, 19]) and only a few studies, e.g., [16, 20], would be considered “long-term,” as noted by Matson and Konst [17•] in their brief review of IBI follow-up studies. Even these studies, however, usually have few outcome measures included in their protocols. As Towle, Vacanti-Shova, Shah, and Higgins-D’alessandro [21•] point out, there is a need for studies that look at broader outcomes for children diagnosed early with ASD that focus on a variety of “meaningful behaviors” (p. 1358) rather than simply diagnostic outcome, severity of autism symptoms, and class placement. In addition, studies need to follow the children well into grade school rather than the customary 1 to 3 years [21•].

Of interest in this paper is whether the gains (oftentimes substantial) that many children make in EI programs translate into successful primary school experiences not only in terms of social, communication, and behavior skills as measured by standardized assessments, but also in terms of more “real life” outcomes such as being accepted and included in activities by classmates, positive relationships with teachers, and academic success. When children “graduate” from EI programs and are enrolled full time in school, there is often legitimate concern on the part of both parents and EI providers as to whether the skills gained in EI will be maintained as the children progress through the school system. This concern is paired with a worry that teachers do not hold high enough expectations for their students with autism resulting in children losing acquired skills [22].

Thus, the purpose of this paper is threefold. First, the extant literature is examined to determine whether skills usually targeted in early intervention—specifically communication, social reciprocity, and adaptive behavior—are maintained in primary school as evidenced in longer-term follow-up studies, and limitations of that research are identified. Secondly, recommendations for practice emerging from the research to ensure skill maintenance and enhancement as children progress through school are discussed, and finally, suggestions for future research are made.

To be included in this review, studies had to be true “follow-up” studies in that the children had been out of EI for at least 6 months prior to follow-up measures being administered. Included studies also had to report on more than simply ASD diagnosis and class placement (i.e., mainstream/inclusive setting or self-contained setting) since in the majority of Western countries, children are often placed in inclusive settings regardless of autism severity, and this is not necessarily indicative of progress made in EI. In addition, studies needed to include, at a minimum, measures of adaptive behavior and autism severity. As seen below, some studies also included various academic achievement measures and occasionally included parental perspectives on the child’s functioning. After an extensive literature search, eight studies published between 1993 and 2014 conducted in a number of countries were found that met these criteria and are described below in chronological order. The characteristics of these studies are summarized in Table 1.

Long-Term Follow-Up Studies

The first study to look at long-term outcomes for children who received EIBI was conducted by McEachin, Smith, and Lovaas [23] who returned to the participants of the original Lovaas [5] American EIBI study when the experimental group was a mean age of 13 years and had been out of treatment for a mean of 5 years, to examine whether gains made in EIBI had been maintained. The subgroup of nine experimental group children who were considered “normally functioning” had been out of treatment for 3 to 9 years (mean of 5 years). Children were administered an intelligence test (although a few children were administered a receptive vocabulary assessment as a measure of intellectual functioning), the Vineland Adaptive Behavior Scale (VABS), and a personality inventory to ascertain the presence of psychological disturbance. Examiners also completed a clinical rating scale that covered a variety of topics that included areas of difficulty that would be typical of children with ASD (e.g., friendships, ritualistic behaviors) [23].

McEachin et al. [23] found that the experimental group maintained the gains they had made in EIBI over the control group. Specifically, the experimental group scored significantly higher than the control group at follow-up on all measures including IQ, although mean scores on the VABS subscales were almost 2 standard deviations below the population average of 100. In terms of maladaptive behavior, the experimental group mean was below the clinically significant range, whereas the control group’s mean was not. McEachin et al. also

Table 1 Characteristics of long-term follow-up studies

Authors and country	*N*	Mean age at initial evaluation in months (range or SD if provided)	Measures used[b] (not all measures used with all children)	Length of EI[c] program	Mean length of time out of EI in years (range if provided)	Mean age at follow-up in years (range if provided)	Presence of control/comparison group
McEachin et al. (1993) USA	38	32[a]	WISC, VABS, PIC	2–3 years	5 (0–12)	13 (9–19)	Y
Turner et al. (2006) USA	25	31.0 (23–35)	Bayley-II, SICD-R, MCDI, K-ABC, MP, Leiter, ADOS, ADI-R, WJ-R, PPVT-3, EVT	1 year	–[d] (5–7)	9.1 (8.1–10.8)	N
Akshoomoff et al. (2010) USA	29	28.9 (SD = 2.7)	VABS, PSI, Parent Questionnaire (classroom placement, treatment services), Bayley-II, MSEL, DAS, ADI-R, ADOS	7.7 months	4 (1.1–8.4)	7.2 (4.4–12.2)	N
O'Connor and Healy (2010) Ireland	5	55 (40–72)	BAS-II, VABS, GARS-II, MSSQ, CRS-S, SDQ,PSS	3.1 years	1.10 (10 m–3.9)	11 (9.8–12)	N
Magiati et al. (2011) UK	36	40 (27–54)	Bayley-II, WPPSI-R, WISC-R, MP,VABS, BPVS, EOWPVT, ADI-R	2 years	4–5	10.3 (8–12)	N
Kovshoff et al. (2011) UK	41	35.7[f] (30–42)	SB-4, Bayley-II, VABS, RDLS-III, NCBRF, DBC, ADI-R	2 years	2	7.2 (6.5–8)	Y
Landa and Kalb (2012) USA	48	27.0 (22–33)	ADOS, MSEL, SB-5, VABS	6 months	T3[e] = 6 m T4 = 3.1	T3 = 3.5 T4 = 6	N
Towle et al. (2014) USA	80	24.9 (16–36)	ASD-DMP, VABS, CARS, GARS, VABS-II, Parent Questionnaire (Demographics, Current ASD Diagnosis, Medical History, Medications, Current Behavioral, Physical, and Social Functioning)	2 years	8.4 (5.7–13)	10.6 (7–16)	N

[a] Mean age of experimental group

[b] WISC and WISC-R = Wechsler Intelligence Scale for Children (and Revised); VABS and VABS II = Vineland Adaptive Behavior Scales (and 2nd edition); PIC = Personality Inventory for Children; Bayley II = Bayley Scales of Infant Development—2nd edition; SICD-R = Sequenced Inventory of Communicative Development-Revised; MCDI = MacArthur Communicative Development Inventory; K-ABC = Kaufman Assessment Battery for Children; MP = Merrill Palmer Scale of Mental Tests; Leiter = Leiter International Performance Scale; ADOS = Autism Diagnostic Observation Schedule; ADI-R = Autism Diagnostic Interview-Revised; WJ-R = Woodcock-Johnson-Revised; PPVT-3 Peabody Picture Vocabulary Test—3rd edition; EVT = Expressive Vocabulary Test; PSI = Parenting Stress Index; MSEL = Mullen Scales of Early Learning; DAS = Differential Ability Scales; BAS II = The British Ability Scales: 2nd Edition; GARS and GARS-2 = The Gilliam Autism Rating Scale (and Revised: 2nd Edition); MSSQ = The Mainstreaming Social Skills Questionnaire; CRS-R = Conner's Rating Scales-Revised; SDQ = The Strengths and Difficulty Questionnaire; PSS = Perceived Stress Scale; WPPSI-R = Wechsler Pre-school and Primary Scale of Intelligence; BPVS = British Picture Vocabulary Scales—2nd Edition; EOWPVT = Expressive One Word Picture Vocabulary Test; SB-IV and SB-V = Stanford-Binet Intelligence Scales—4th edition (and 5th edition); RDLS-III = The Reynell Developmental Language Scales—3rd Edition; NCBRF = The Positive Social Subscale of the Nisonger Child Behavior Rating Form; DBC = Developmental Behavior Checklist; ASD-DMP = Autism Spectrum Disorder Decision-Making Protocol for EI Charts; CARS = Childhood Autism Rating Scale

[c] EI = Early Intervention

[d] Mean not given

[e] T3, T4 = Time 3 follow-up, Time 4 follow-up

[f] Mean age of intervention group

specifically examined the results of the nine children considered “normally functioning” at the conclusion of EIBI. All except one of these children had average IQ and scored within normal limits on all measures, and all but one were able to “hold their own in regular classes” (p. 368) although no measures of academic achievement were included. However, three of these “best outcome” children scored in the clinically significant range in terms of maladaptive behavior.

The findings of McEachin et al. [23] are interesting in that follow-up studies conducted in subsequent years have not achieved the same lasting results, as described below. It is possible that this is a consequence of a number of methodological issues and differences as elucidated by Kovshoff, Hastings, and Remington [16], such as assessment of the children at different ages and after they had ceased EIBI for differing time periods, lack of a time-limited intervention, and the comparison of “best outcome” children to a new group of typically developing children.

Turner, Stone, Pozdol, and Coonrod [24], in their follow-up study of children with ASD at age 9 who had been diagnosed at age 2, included academic assessment (Woodcock-Johnson-Revised [WJ-R] subtests on reading, math, and written language) in addition to cognitive, diagnostic, and language assessment. Although not specifically designed to measure long-term effects of EI, Turner et al. divided the children at time 2 into three global outcome groups: “higher outcome” (based on high cognitive ability and high language ability defined as achieving in at least the average range on the cognitive *and* language measures), “mixed outcome” (*either* high cognitive *or* high language), or “lower outcome” group (neither high cognitive nor high language ability) to determine the predictors of overall outcome. All of the children in the higher outcome group completed the academic assessment with means varying between 92 and 100 on the subtests (with scores of 90–110 being “average”), while only 7 of the 11 children in the lower outcome group did so, achieving means between 33 and 59 on the academic assessment. A specific question of interest was whether the amount of intervention in terms of hours of speech-language therapy and “educational therapy” (not operationally defined) the children had received between age 2 and 3 was predictive of their outcome group.

Although diagnosis remained relatively stable over time, Turner et al. [24] found that children in the higher outcome group at age 9 had been diagnosed earlier, had higher cognitive and language skills at age 2, and had received more hours of speech-language therapy than children in the lower outcome group. Interestingly, the number of hours of educational therapy was not predictive of group outcome. Why this should be so cannot be definitively determined, but the authors suggest that the intensity of one-to-one language intervention and the focus on social-communicative deficits in some programs may account for this.

Although Turner et al. [24] included academic assessment in their measures, academic achievement was not explored explicitly in terms of effects of EI. In addition, Turner et al. did not include any measures of social competence to determine outcome group, and, as they acknowledge, this is a crucial aspect of effective functioning. Nor did they consider the influence of educational programming in school *after* early intervention among children in their sample (essentially ages 4 or 5 years to 9 years of age).

Akshoomoff, Stahmer, Corsello, and Mahrer [20] also conducted a follow-up study of 29 children in the United States who had been diagnosed with ASD and began a 7-month inclusive early intervention toddler program at a mean age of 28.9 months. At follow-up, the children ranged in age from 4 to 12 years. While some children had only finished the early intervention program 6 months earlier and were in either special education preschool classes or kindergarten at follow-up, other children were enrolled in grades 1 through 6. In addition to standardized measures of cognitive functioning, diagnostic measures, and adaptive behavior, a measure of parent stress and a questionnaire regarding current classroom placement and other treatment services being used was also administered to parents [20].

Significant differences were found in nonverbal IQ and verbal IQ over time between EI entry and exit, along with a significant gain in verbal IQ between exit and follow-up. Similarly, significant improvements were found in communication and daily living skills from EI entry to exit and exit to follow-up for the former, and from exit to follow-up for the latter. However, there were no differences in Socialization scores as measured by the VABS over time. Diagnosis remained consistent over time for 70 % of the children from exit to follow-up, but where there was a change, it was most commonly from Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) to Autistic Disorder. At the time of follow-up, 63 % of the children in kindergarten through 6th grade were in general education classrooms. Not surprisingly, children with more severe autism symptoms received more services both in and out of school [20]. Unfortunately, Akshoomoff et al. did not analyze the results by length of time since exiting the EI program, so it is impossible to know the effect of length of time in school on the results.

As Akshoomoff et al. [20] point out, there is evidence that initial gains made in the EI program were maintained and continued in a variety of areas. The authors note that given the lack of improvement in Socialization scores and diagnostic stability, it is evident that despite improvements in intellectual and adaptive functioning, many children experienced continuing difficulties in the social domain, although the nature of these was not explored in this study. Akshoomoff et al. [20] conclude that since no control group was included and the nature of the services the children received both in and out of school after leaving the EI program is not known, “it is not possible to adequately test the hypothesis that initial gains or maintenance of progress in cognitive and communication functioning in this group of children is due specifically to their participation in an early intervention…program" (p. 251). It is also important to note the brief nature of the EI program—only 7 months–so it may be particularly difficult to attribute lasting improvements specifically to the EI program.

In a study in Ireland, O'Connor and Healy [25] examined the outcomes for five children ranging in age from 9 years 8 months to 12 years (mean age 11 years) who had participated in early intensive behavioral intervention beginning between ages 3 years, 4 months, and 6 years. At the time of first assessment, the children's IQ level ranged between 14 months and 98 on the British Ability Scales II. The children had made significant gains in EI and had been in a mainstream school placement for a mean of 1 year, 10 months, having entered school at ages ranging from 7 years, 10 months to 10 years, 11 months. Four participants had full-time assistance in the mainstream placement while one participant had part-time assistance. A number of standardized assessments were administered to measure severity of autism symptoms, adaptive and problem behavior, cognitive functioning, together with a social skills questionnaire and a measure of parental perceived daily stress at follow-up.

O'Connor and Healy [25] found that while four of the five participants were able to cope with the academic demands of the classroom (albeit with the help of an educational assistant [EA]), all of them continued to have difficulties with social skills, inattention, daily living skills, and difficulties with hyperactive behavior and anxiety that in some cases were quite pronounced and of concern. Two of the participants had not maintained skills gained in EI, and adaptive behavior scores and IQ had decreased since the end of EI. In addition, there was an apparent increase in autism severity in one of these individuals. Stereotyped behaviors had also increased for four of the five participants and were considered "high intensity" for two participants and of "low intensity" for the other two. Only one of the participants (one whose post-EI skills had not been maintained) continued to have challenging behaviors [25].

This study is interesting in that it presents information about individual participants at follow-up. Evidently, not all children maintain skills acquired in EI and some problems continue across the board such as socialization and attention skills as found by Akshoomoff et al. [20] and Towle et al. [21•] (see below). However, O'Connor and Healy's [25] results must be interpreted cautiously for a number of reasons: (a) the particularly small sample size and no control group, (b) the fact that the children tended to be somewhat older than those in other studies when they began EI, (c) the older age at which the children entered school, (d) the fact the children had only been in their placements for a mean of just under 2 years is not really a long-term follow-up despite the authors' characterization of the study as such, and (e) the fact that all of the children had the assistance of an EA—a point we shall return to later. What the study highlights, however, and what O'Connor and Healy [25] point out, is the need for ongoing intervention throughout children's school years to maximize and maintain gains made in EI.

In a prospective study of the long-term effectiveness of early intervention in the UK, Magiati, Moss, Charman, and Howlin [26] followed 36 children who had participated in one of two specific behavioral early intervention programs (an intensive EIBI program or a pre-school nursery "eclectic" program) for at least 15 h per week between the ages of 2 and 4.5 years. Children were assessed at program intake (T1), after 2 years in the program (T2) and then again 4 to 5 years later (T3; mean age of 10.3 years). Children were assessed on cognitive ability using a variety of measures dependent on child ability, adaptive behavior, language comprehension and expression, and severity of autism symptoms. Overall, the children were fairly low functioning at T1 with a mean IQ of 64.4 (range 16–137.5). At T1, 72 % of the children failed to score above the basal level on the language comprehension assessment, and 81 % of the children failed to score above basal on the language expression assessment, requiring raw scores, rather than standard scores, to be used (mean of 5.1 and 2.6 for comprehension and expression, respectively).

At T3 follow-up, 35 of the children were in full-time primary school, and one child was in school part-time. Only six children (17 %) were in mainstream/inclusive settings, and five of those children had individual support 15 to 30 h per week. The rest of the children were in "specialist units" in mainstream schools, or in autism-specific schools or schools for children with moderate to severe intellectual disabilities [26].

Not surprisingly, given the variability of the children at T1, large individual differences were seen at T3, with some children showing fairly large gains, and others showing limited progress in terms of the measures used. Magiati et al. [26] found that for many children, while raw scores and age equivalent scores on cognitive functioning, language, and adaptive behavior measures had significantly increased both between T1 and T2 and between T2 and T3, standard scores remained stable or decreased (indicating the rate of progress was not within developmental norms). The children's autism symptoms remained relatively stable between T2 and follow-up. However, only total Autism Diagnostic Interview-Revised (ADI-R) and VABS scores are provided so exactly where improvements were observed is unknown. Almost 50 % of the children had functional phrase speech by T3. Magiati et al. [26] conclude that about half of the children made "reliable improvement" not only between T1 and T2 but also between T2 and T3—the period of particular interest for this discussion—while 13 % made improvement only between T2 and T3 (with 17 % making reliable improvements only between T1 and T2), thus demonstrating the effectiveness of the early intervention programs and the potential for many children to not only maintain gains made during early intervention but to capitalize on them and continue to show gains as time went on.

Unfortunately, Magiati et al. [26] did not include any measures of academic achievement. Magiati et al. also noted that they did not know the specific nature of the intervention the children received either when in EI, from other service providers (e.g., speech therapy), or once the children were at school, thus limiting interpretation of the study. Like most other studies reviewed here, Magiati et al. did not include a control group.

Kovshoff et al. [16] conducted a 2-year follow-up study of 23 children in the UK who had completed a 2-year EIBI program in either a university-supervised group ($N=14$) or a "parent-commissioned" group ($N=9$) where intervention teams were hired and managed by parents, compared to a "treatment as usual" (TAU) group ($N=18$) where children received a variety of eclectic interventions provided by the local education department. Children were between 2.5 and 3.5 years of age at EIBI onset and presumably between 6.5 and 8 years of age at follow-up although the specific age range is not given. A variety of measures was used to compare the groups at follow-up including, as in other studies, measures of intellectual functioning, adaptive skills language, behavior rating scales, and a measure of autism severity.

At follow-up, significantly more children who had been in the two EIBI groups were in mainstream school settings compared to the TAU group (60 vs. 22.2 %). However, all of these children except one had some level of individual support in the classroom. Contrary to findings in most studies of EIBI, there were no significant differences on any of the measures at follow-up between the intervention groups and the comparison group. When the data were disaggregated and follow-up data for each EIBI intervention group was considered separately, mean IQ of the university supervised group had significantly *declined* since post-intervention measures, while that of the parent commissioned group stabilized at post-intervention levels (having significantly increased from baseline measures). The same pattern was true for the remaining measures as well; specifically, children in the parent-commissioned group scored significantly higher than those in the university-supervised group although the differences were not always significant. Other than IQ (which remained stable across all three time periods), follow-up results of the TAU group are not reported [16].

Kovshoff et al. [16] conclude that results of their study indicate some support for long-term maintenance of skills acquired during EIBI, although initial gains on a number of measures were not maintained for many children, and children who had EIBI were more likely to be in mainstream education. However, as Kovshoff et al. report, numerous methodological issues confound the results including the fact that the university-supervised group was generally lower functioning than the parent-commissioned group with lower initial IQ and more severe autism, and had fewer total hours of intervention over the 2 years than the parent-commissioned group. Follow-up autism severity scores are not reported, however, and it is not known how each intervention group compared to the TAU group at follow-up. Thus, it is hard to draw much in the way of conclusions regarding the long-term effectiveness of EI, although it is possible that higher initial functioning, the intensity of intervention, and the EI model used all contributed to better outcomes for some children.

In an effort to determine the long-term outcomes resulting from short-term (6 month) evidence-based EI, Landa and Kalb [27•] conducted a follow-up study with 48 children who began intervention that included behavioral techniques at a mean age of 2.3 years. Children were assessed at four different points: pre-intervention (T1), post-intervention (T2), 6 months post-intervention (T3), and, finally, when the children were a mean age of 6 years (T4) using a measure of autism symptom severity, IQ, and the Communication Domain of the VABS. Prior to intervention, 81 % of the children had IQ scores less than 70, as did 58 % of the children on the Communication measure. Between T2 and T4 (the end of EI and final follow-up, respectively), IQ had increased significantly to a mean of 81.5. Similarly, scores on the Communication domain of the VABS also increased significantly between T2 and T4 to a mean of 82.4 (for both of these measures the significant difference occurred only between T3 and T4). Contrary to this, however, although there was a significant decrease in autism symptoms between T1 and T2, there was a subsequent significant *increase* in the number of ASD symptoms both between T2 and T3, and T3 and T4, and by T4 autism symptoms were at pre-EI levels [27•]. The reasons behind both the improvement in IQ and Communication, but the worsening of autism symptoms needs to be considered in light of the fact that by 6 years of age (T4), the children were enrolled in school, and what they may (or may not) have been receiving at school at that point may have played a role in the maintenance, or lack thereof, of gains made in EI. Landa and Kalb [27•] conclude that the concerning increase in autism symptoms highlights the need for on-going intervention that specifically targets core ASD symptoms.

As with the other studies reviewed here, conclusions regarding the long-term effectiveness of EI must be tentative. No control group was included, and the number of measures used was very limited both in terms of breadth and depth, and no socialization or behavior measures were included. Thus, definitive statements about the school functioning of the children post-EI cannot be made.

In the final study to be considered, Towle et al. [21•] used chart abstraction procedures to examine the outcomes of 80 children who had been diagnosed with ASD over a 10-year period between 1995 and 2005 at a mean age of 24.9 months. The children had been enrolled in a particular early intervention program for 2 years, and at the time of follow-up were between 7 and 16 years of age. The authors [21•] first examined the participants' original early intervention records, using a previously developed protocol for determining the presence of autism, and by applying the VABS and the Childhood Autism Rating Scale (CARS) to the time 1 records. At time 2, parents completed a number of questionnaires to determine the child's current diagnosis and level of functioning in a number of areas, and an extensive background questionnaire. Among other things, the parents were asked about the challenges their children still experienced, their school placement and any services their children received, as well as information regarding more general physical coordination, involvement in team sports, and to what extent their children had friends and were involved in such social activities as sleepovers and birthday parties. These latter questions are particularly interesting as they reflect more "real life" social functioning in terms of day-to-day experiences. However, no questions or measures tapped into the academic achievement of the children or whether parents felt that gains made in early intervention were maintained through grade school [21•].

Although Towle et al. [21•] found that about 20 % of the participants had moved off the ASD spectrum at time 2, even this "optimal outcome" (p. 1367) group ("No ASD" group) still had significant learning, language, social, or behavioral difficulties, or an ADHD diagnosis. Not surprisingly, a much higher percentage of children who remained on the ASD spectrum with mild or moderate/severe ASD at time 2 experienced considerably more difficulties in these areas. Dramatic differences were evident between the groups at time 2 in terms of social functioning in that those children still on the spectrum rarely participated in birthday parties or sleepovers, while those who had moved off the spectrum engaged in these activities at typical levels. In terms of class placement, the entire "No ASD" group was in general education classrooms with two thirds having no, or no more than one, related service (e.g., speech therapy), and one third receiving more than one related service. Slightly less than half of children in the Mild ASD group were in self-contained special education classes with the other children placed in general education classrooms and receiving a range of services, while 90 % of those in the Moderate/Severe ASD group were in a variety of self-contained special education settings [21•]. However, as pointed out earlier, it is hard to gauge children's improvement or level of functioning by relying on school placement given inclusion policies of many school boards and districts.

The Towle et al. [21•] study is helpful in that it provides long-term follow-up information on a variety of measures including "real life" social situations of a group of children who received early intervention. However, it is also limited in its usefulness in that it is not known from the information given, the severity of autism symptoms of the children at time 1 versus the autism severity category of the children at time 2, or the age at which children began EI. For example, were children who were diagnosed and began early intervention at 16 months of age (the youngest age) more likely to be in the "No ASD" group manifesting the least severe challenges at time 2? On the other hand, did the children diagnosed at the younger age manifest more severe autism symptoms as is generally the case [28], and were these children more likely to be in the Moderate/Severe category at time 2? In addition (and endemic to all the studies discussed), it is unknown what kind of educational programs the children received once in school or the effect these programs may have had on the children's functioning level. Thus, it is difficult to know precisely the long-term impact of (a) the early intervention received, (b) the educational program of the children once in school, or (c) the combined effect of early intervention and school programming.

Limitations of Extant Research As can be seen, very few EI follow-up studies specifically examine the maintenance of gains made in EI and numerous methodological weaknesses of the studies reviewed here limit conclusions that can be made regarding the maintenance of skills as children progress through primary school. Firstly, none of the studies was a randomized control study, and only two included any control or comparison group at all.

Secondly, sample sizes in all of the studies were small. Given this, and the heterogeneity of children with ASD, it would be difficult to ensure group equivalency even if some form of control group was used [29], and without control groups the internal validity threat of maturation cannot be controlled for.

Thirdly, apart from McEachin et al.'s [23] and O'Connor and Healy's [25] studies, no individual child data are provided, so it is unknown whether children who made gains in one domain also made gains in other domains. It is impossible to tell from mean effects whether the children who made gains by the end of EI were the same ones who maintained those gains as they continued through school. In addition, only O'Connor and Healy [25] and Towle et al. [21•] included what Burgess and Gutstein [30] term "functional" measures to determine how the children are actually "doing" at school (e.g., do the children have friendships that result in birthday party invitations). These are extremely important to include when looking at long-term outcomes of EI. While many children may maintain or improve skills measured on instruments such as the VABS post-EI, such instruments will not necessarily capture children's ability to capitalize on these skills in functional ways in the school context and are not predictive of satisfactory "quality of life" [30]. Similarly, increased IQ scores achieved by many children after EI do not necessarily translate into academic achievement, nor does academic achievement necessarily translate into school success [31]. Rather, research has suggested that social and communication skills are more predictive of academic and, more general, school success [31, 32•]. While it is important to include measures of academic achievement (rarely done in the studies reviewed here) when looking at long-term EI outcomes, it is equally important to include parent and teacher reports of student ability [17•, 30, 31, 32•] to get a complete picture of long-term EI outcome.

Finally, looking at Table 1, it can be seen that there is tremendous variability among the studies in a number of aspects. These include age at initial evaluation, start of EI, its length and the methods used, the number and types of measures used in the studies, class placement once in school (i.e., inclusive setting or self-contained program), the types of other programs and therapies the children may have been receiving (i.e., [20, 21•]), and the amount of classroom support the children received once in school among other things (i.e., [16, 25, 26]). The latter point raises the question as to whether children who had full- or part-time assistance and apparently maintained skills gained in EI were able to do so *because* of the extra assistance received. Were the assistants able to structure the environment in a way that enhanced the success of the children so that they were able to demonstrate the skills they had acquired? All of these aspects make it impossible to determine whether perceived maintenance or improvement of skills can be attributed to having received EI.

Discussion

There is some evidence in the studies reviewed above that gains made by some, but not all, children with ASD are maintained over the long term as children continue through school. However, there is also evidence in the studies reviewed that many children still had considerable difficulties in specific areas of behavior, socialization, and ADHD even if they were generally succeeding academically. However, what, exactly, the children were provided in terms of their school program is not mentioned in any study. Numerous researchers commented on this, and the need for ongoing intervention through the school years. For example, Towle et al. [21•] questioned why the number of speech-language therapy hours children in their study received was associated with better outcome but educational therapy hours was not, and pointed out the importance of identifying the elements of successful therapy.

In noting the accelerated development in children between T3 and T4 (short- and long-term follow-up, respectively) in their study, Landa and Kalb [27•] speculated that the involvement of children in full-day school may be linked to the surge. However, given the increase in autism symptom severity by T4, Landa and Kalb emphasized the need for ongoing, uninterrupted intervention that focuses on these symptoms. Similarly, Akshoomoff et al. [20], in finding continuing autism symptomatology and lack of change in VABS socialization scores upon follow-up, pointed out that despite placement in general education classrooms and improved adaptive and intellectual functioning, continuing support appears necessary.

Finally, O'Connor and Healy [25] also found increased socialization difficulties and autism symptomatology at follow-up compared to the end of EI for most participants. Because all of the participants were included in general education classrooms, they were not eligible to receive any specialist intervention, as this was available only for students in special education settings. As O'Connor and Healy conclude, "[t]his study highlights the need for the support and intervention from a specialist multidisciplinary team to address a broad range of issues including social skills training, daily living skills training, communication training, behavioral intervention and support, psychological and psychiatric support and intervention" (p. 602). Clearly, from the studies reviewed here, EI, while essential, is not sufficient to ensure optimal long-term outcomes, and ongoing intervention is necessary [33].

Research has shown that effective transition to school from EI is crucial for future school success for all children, including those with ASD [34–37], and it is important that comprehensive transition plans view transition as a process rather than "an event." Such plans need to include the families and the EI team, in addition to the receiving teachers and schools: a comprehensive collaboration that is frequently lacking [22, 38, 39]. Lack of such a process can result in unprepared teachers having low expectations of the children, insufficient resources, and a failure to transfer successful techniques begun in EI to the school classroom. In turn, this may result in skill regression and parents being called to take their children home because of behavioral outbursts [22, 40].

A second crucial component needed to ensure the maintenance of skills acquired by children with ASD as they proceed through primary school and beyond is teacher education concerning the nature of ASD and evidence-based interventions. This call has been made repeatedly for decades by researchers from many countries (e.g., [4, 22, 41–46]), but still has not been sufficiently heeded.

It makes intuitive sense that evidence-based educational programs provided by knowledgeable teachers with appropriate resources will better maintain gains that *are* made by children with ASD in EI than programs lacking these aspects. However, the research is absent. As noted, many of the long-term studies of the effect of EI on the educational outcomes of children with ASD suffer methodological problems. On the one hand, many outcome variables related to a child's academic and social functioning are not analyzed. On the other hand, many studies lack proper control groups, and the intervention may contain several distinct treatments (i.e., different types of EI) thus precluding causal inferences. Future research would benefit from taking a potential outcomes framework [47, 48] that explicates the set of possible treatments. In many circumstances, there may be more than simply two types of "treatments" (e.g., EI, No EI). For example, as discussed above, children may start EI at different ages or receive EI of differing intensities. In addition, children may receive different levels of support once they begin school (e.g., some children may receive an EA while others may not).

An example will help clarify some of these issues. Suppose, for simplicity, that there are three time periods, 0, 1, and 2. At time 0, a decision is made as to whether or not a child receives EI. Let EI be a variable that equals 1 if a child receives EI at time 0 and, equal 0 if s/he does not. At time 1, just after EI ends but before formal schooling begins, a behavioral outcome of the child is measured (Y_1) and a decision is made as to whether or not the child should have an EA in school. Let EA be a variable that equals 1 if a child receives an EA, and equal 0 if s/he does not. Finally, after the child receives some amount of formal schooling (time 2), a behavioral outcome Y_2 (possibly different from Y_1) is measured.

Assume that, on average, Y_1 is greater for children receiving EI. That is $E[Y_1|1] > E[Y_1|0]$ where $E[Y_1|1]$ represents the expected value of Y_1 given $EI = 1$ and $E[Y_1|0]$ is the expected value of Y_1 given $EI = 0$. Now Y_2 may depend on both EI and EA. Let $E[Y_2|EI, EA]$ be the average value of Y_2 given that EI and EA take on some values. For example, $E[Y_2|1,0]$ is the average value of Y_2 given that $EI = 1$ and $EA = 0$. We also assume that if EA is held constant, receiving EI increases Y_2 on average ($E[Y_2|1,0] > E[Y_2|0,0]$ and $E[Y_2|1,1] > E[Y_2|0,1]$) and, that holding EI constant, having an EA increases Y_2 on average ($E[Y_2|0,1)] > E[Y_2|0,0]$ and $E[Y_2|1,1] > E[Y_2|1,0]$). For a complete list of the terms and their definitions used in this illustrative example, see Table 2.

In this example, there are four alternative treatments that a child could receive: No EI–No EA, EI–No EA, No EI–EA, and EI–EA. Short of a randomized control trial that randomly assigns children to one of the *four* possible treatment states, issues of selectivity bias may arise which can lead to misinterpretations of the results. To see this, suppose that children are randomly assigned to either receive EI or not at time 0 and assume that children who score lower on outcome Y_1 are more likely to receive an EA when they begin school. On average, children who had EI are less likely than children who did not have EI to have an EA in school. If we simply compare average values of Y_2 between children who received EI and those who did not (as in the studies described above), the difference will incorporate the fact that more children who did not receive EI received an EA in school. In fact, it can be shown that the average difference between those who received EI and those who did not,

$$
\begin{aligned}
&\mathrm{E}\left(\mathrm{Y}_2\middle|1\right)-\mathrm{E}\left(\mathrm{Y}_2\middle|0\right)\text{, is } \left\{\mathrm{E}\left(\mathrm{Y}_2\middle|1,0\right)-\mathrm{E}\left(\mathrm{Y}_2\middle|0,0\right)\right\}\\
&\quad+\{E(Y_2|1,1)-E(Y_2|1,0)-[E(Y_2|0,1)-E(Y_2|0,0)]\}\ \Pr(EA=1|1)\\
&\quad+\{E(Y_2|0,1)-E(Y_2|0,0)\}\{EA=1|1-\Pr(EA=1|0)\}.
\end{aligned}
$$

Table 2 Definitions of terms in illustrative example

Term	Definition
EI	Equals 1 if child receives early intervention, 0 otherwise
EA	Equals 1 if child receives educational assistant, 0 otherwise
Y_1	Behavioral outcome after early intervention
Y_2	Behavioral outcome after formal schooling
$E[Y_1\|1]$	Expected or Average value of Y_1 given $EI = 1$
$E[Y_1\|0]$	Expected or Average value of Y_1 given $EI = 0$
$E[Y_2\|1]$	Expected or Average value of Y_2 given $EI = 1$
$E[Y_2\|0]$	Expected or Average value of Y_2 given $EI = 0$
$E[Y_2\|1,0]$	Expected or Average value of Y_2 given $EI = 1$ and $EA = 0$
$E[Y_2\|0,0]$	Expected or Average value of Y_2 given $EI = 0$ and $EA = 0$
$E[Y_2\|1,1]$	Expected or Average value of Y_2 given $EI = 1$ and $EA = 1$
$E[Y_2\|0,1]$	Expected or Average value of Y_2 given $EI = 0$ and $EA = 1$
$Pr(EA = 1\|1)$	Probability that $EA = 1$ given that $EI = 0$
$Pr(EA = 1\|0)$	Probability that $EA = 1$ given that $EI = 0$

The difference in the first set of curly brackets is the average effect of receiving EI conditional on not receiving an EA. The second term measures the difference in the expected gain of receiving an EA between those who received EI and those who did not, multiplied by the probability of receiving an EA conditional on having received EI. The last term is the difference in the average increase in Y_2 for those having an EA when they did not receive EI, multiplied by the difference in the probability of receiving an EA between those who received EI and those who did not (which we have assumed is negative). If the value of having an EA is equal to or more beneficial for those who did not receive EI than for those who did, then the average difference in Y_2 outcomes between children who received EI and those who did not is smaller than the difference between those who received EI and those who did not conditional on not having an EA. Thus, it may appear that the effects of EI are decreasing over time when in fact what is happening is that the probability of a *future* intervention (EA) depends on whether or not a child had a previous intervention (EI). The forgoing is a stylized example with only four treatment possibilities. In reality, however, given the number of educational decisions that are made for a child with ASD over time, the number of "treatments" and their possible effect on long-term outcomes may be considerably larger.

If randomization across all treatments is not feasible, one way forward would be to apply multi-treatment propensity score matching methods [49] to compare schooling outcomes among the different treatment groups. Of course, these methods presume that selection into the different treatments groups is as good as random once the groups have been balanced on a number of observed variables.

Conclusion

It is evident that numerous problems with the extant research prevent definitive conclusions regarding the long-term effectiveness of early intervention. Research has shown that most children with ASD who participate in evidence-based EI make gains in many areas of functioning. What is now needed are well-designed longitudinal studies using causal-inference methods to determine whether skills that *are* acquired in EI will be maintained over the long run.

Given current rates of autism and philosophies of inclusion, it is inevitable that teachers will have students with ASD in their classrooms. Needless to say, parents are anxious that gains made in EI not only transfer to primary school and are maintained but also continue to be fostered and improve in succeeding years to ensure optimal outcomes for their children. Thus, identifying the conditions under which those optimal EI outcomes are realized (e.g., effectiveness of transition to school, amount of EA support, amount and kind of teacher education, content of educational programs) is of paramount importance.

Compliance with Ethical Standards

Conflict of Interest Elizabeth M. Starr, Svetlana Popovic, and Brian P. McCall declare that they have no conflict of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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