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ORIGINAL PAPER

A Longitudinal Study of Children Diagnosed with Autism Spectrum Disorder Before Age Three: School Services at Three Points Time for Three Levels of Outcome Disability

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Abstract

This study follows 70 children determined to have Autism Spectrum Disorder (ASD) before age three (Time 1). Parents filled out questionnaires and standardized measures about their child when he/she was school-aged (Time 2), including information about their children's preschool, kindergarten, and grade school educational settings. At Time 2, the researchers placed children in three diagnostic groups of No ASD, ASD-Higher Functioning, and ASD-Lower Functioning. Retrospective results showed that most children were receiving intensive services at the preschool level. In kindergarten, there was some divergence among the three groups, with more intensive services continuing for the ASD groups. At school age, classroom placement and services reflected service patterns that were consistent with these three levels of disability.

Keywords ASD · Longitudinal · Educational placement · Educational services · Adaptive behavior

Introduction

A body of literature has developed around following children diagnosed early with autism spectrum disorder (ASD) from time of diagnosis (Time 1) until later, with Time 2 or Time 3 ranging from a year or two later, to school age or early adulthood (see reviews: Kleinman et al. 2008; Woolfenden et al. 2012). Many of these studies focused on the validity/stability of early ASD diagnosis, since only relatively recently have children been diagnosed consistently below 3 years of age. The studies as a whole demonstrate that, of children diagnosed with ASD this young, the great majority will remain on the autism spectrum after various follow-up intervals. Woolfenden et al. (2012), who examined studies ranging from 1989 to 2009 from a context of methodological rigor, made a best estimate of 85–89% of children remaining on the spectrum from early childhood diagnoses. Such findings provide confidence in the reliability and validity of these early diagnoses.

While most original follow-up studies from very early childhood focused almost exclusively on diagnostic stability, more recently others have examined a variety of outcomes, such as those measured by standardized tests of specific language and information processing abilities (Anderson et al. 2009; Fein et al. 2013), IQ and adaptive functioning as represented by standardized scores (Anderson et al. 2009, 2014; Baghdadli et al. 2012; Szatmari et al. 2015), and autism severity and/or behavior problems/psychiatric co-morbidities (Barnevik-Olsson et al. 2016; Szatmari et al. 2015; Visser et al. 2017). Others have followed samples from early childhood to school age and characterized their overall outcome functioning using very general categories such as high versus low (Stevens et al. 2000), or "Very Poor" to "Very Positive" (Anderson et al. 2014). Few studies, however, have examined the children at school age with respect to more detailed, functional outcomes in addition to their follow-up diagnoses. An exception is Towle et al. (2014), who, in addition to diagnostic outcome, adaptive behavior, and other standardized scores, also reported on school-age medication use, social functioning (e.g., parent report of number of

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friends, how many birthday parties and sleepovers attended), and classroom placement and learning problems.

An area that remains particularly under-described is that of school services and placement. It would seem to be an important area to examine, given that much of epidemiologic and early intervention research with ASD implicates lifelong expenditures for educational, health, residential and vocational support, and disability services (Ganz 2007; Sharpe and Baker 2007). The majority of studies about the school placements of children with ASD are those that are using this as an outcome for a treatment study (e.g., Cohen et al. 2006; Harris and Handleman 2000; Sallows and Graupner 2005; Smith et al. 2000). In such studies, early intervention is predicted to result in differential outcomes in terms of class placement of children receiving early treatment versus those who did not. While some recent studies have focused on describing in more detail educational services per se, they address specific educational issues in relatively narrow samples. For example, Bitterman et al. (2008) reported on parent satisfaction with school services in preschoolers with ASD. Mandy et al. (2015) investigated transition from primary to secondary school in children with ASD in mainstream education in the UK. Thomas et al. (2007) surveyed parents of children up to 8 years of age in North Carolina regarding the types of autism-related services used, including special education and therapies in school as well as various types of community-based services. Finally, White et al. (2007) examined educational placement and service use in students with ASD, but included only higher-functioning children. Thus, while these studies comprise an important beginning literature on certain aspects of school outcomes, there is a paucity of basic description of educational placement, degree of segregation, and specific services for a sample of children with ASD across all ability levels. Such information is of great importance in order to understand the resources that will be necessary as increasing numbers of children with ASD enter the public school system.

Another challenge for the next generation of longitudinal outcome studies is to reflect the emerging knowledge about different trajectories of growth and outcome for children on the autism spectrum. It is widely acknowledged that there is a broad range of symptom and functioning levels in ASD; the autism "spectrum" is so-named to reflect this variation. Recent studies have shown that there are faster and slower growth curves across ages and outcome variables, as well as groups of outcome functioning levels as children mature (Anderson et al. 2009, 2014; Farmer et al. 2018; Fountain et al. 2012; Solomon et al. 2018; Szatmari et al. 2015; Visser et al. 2017). These studies inform the field that there are fairly consistent proportions of children who will have different levels of outcome. The exact number of relatively homogeneous subgroups generated from such studies—as well as the percentage of a sample that falls within the subgroups—varies depending on age of participants, participant characteristics (e.g., some studies focused on only high-functioning individuals), time span examined (age at Time 1, then at Time 2 and sometimes Time 3 and 4), the outcome variables examined (autism severity, language, cognitive level or intelligence quotient (IQ), adaptive behavior, or behavior problems), and the statistical analytic approach (cluster, latent class, growth curve, or trajectory analysis, percentages, or predefined groups such as Autistic Disorder versus PDD-NOS, or IQ > = 70–85 vs. < 70–85). Nonetheless, these investigations typically find two-to-three subgroups at outcome, primarily distinguished by higher vs. lower functioning. If other groups are found, they comprise relatively small percentages such as 5–10% (Fountain et al. 2012; Visser et al. 2017). None of these studies have followed children with ASD over time in terms of patterns of school placement and services, however, so this remains a gap in the literature.

As mentioned, longitudinal stratification studies vary in the outcome variables examined. Recent studies have focused on adaptive behavior, usually measured using the Vineland Adaptive Behavior Scales (VABS-II, Sparrow et al. 2005, 2016; current edition VABS-3), as a key feature in understanding overall functional outcome levels as children become school-aged, adolescents, and adults (Anderson et al. 2009; Bal et al. 2015; Baghdali et al. 2012; Szatmari et al. 2015). Functional outcomes include degree of independence in self-care, participating in the community, and general quality of life as related to living situation, employment, and social supports, rather than IQ or academic attainment.

Importantly, Farley et al. (2009), who followed 41 high-functioning individuals with IQs > 70, demonstrated that adaptive behavior as measured by the VABS Adaptive Behavior Composite (ABC) was most closely associated with overall functional outcome variability compared to IQ and autism severity. This was not an early childhood longitudinal study, as the mean age at Time 1 was 7.2 years, but it did examine a number of functional outcomes at adulthood, including education, employment, living setting and degree of independence, medication use, social contacts and relationships, and contact with social services and law enforcement. They also calculated a composite rating on a 5-point scale ranging from "Very Good" to "Very Poor" based on work status, residential situation, and number and quality of friendships, referencing Howlin et al. (2004). Although various cognitive and autism severity scores were significantly correlated with the global rating score, it was the VABS-II that correlated most highly.

Two recent studies demonstrated the link between executive functioning—which includes the ability to plan and organize—and adaptive behavior in ASD (Pugliese et al. 2016; White et al. 2017). White et al. (2017) concluded that their findings implicate “specific liabilities in real world executive functioning and daily living skills for females with ASD and have important implications for targeting their treatments.”

In the current study, this emerging knowledge about different subgroups based on adaptive functioning level was integral to the outcome design. At Time 2, children were first divided on the basis of whether the ASD continued to be present or not, and then those determined to be on the autism spectrum were assigned to Higher versus Lower Functioning based on the ASD group’s median split (standard score of 80) on the VABS ABC domain score.

The present report is a descriptive, longitudinal study of children who were diagnosed with ASD before age three. The goals were, first, to examine school placement and segregation level at preschool, kindergarten, and school age—for three levels of ASD and disability determined at grade school (Time 2). Second, we endeavored to provide detailed information about services and therapies received at school age in particular. Finally, the extent to which the members of the three outcome disability level groups stayed in or changed restrictive vs. inclusive settings over time was investigated. This paper is the second of three that report on a group of children diagnosed with ASD before age three, with 50% of the sample before 24 months, until ages 7–18, with an average Time 2 age of approximately 10 years (first report, Towle et al. 2014). Almost all children received relatively intense early intervention programs of service in the community (most 20+ h a week, and most with ABA services along with speech-language and occupational or physical therapy).

Method

Detailed description of the methods for the larger study can be found in Towle et al. (2014). Therefore the major points are summarized herein.

Participants and Setting

Participants were 70 children who were identified with ASD before the age of 3 years and whose parents provided information about their functioning at grade and high school age (ages 7–18 years), as well as experiences their children had in between. All families were involved with a University Center for Excellence in Developmental Disabilities in a large county outside of New York City.

Since this report focuses on educational services, it is important to note that the families were recruited from a large suburban county of about 1 million people, with 43 school districts; the participants came from 29 different districts. Therefore, some results could be influenced by varying special education policies.

Instruments and Measurements

Measurements Obtained from the Early Intervention Charts (Time 1)

Early intervention (EI) charts have extensive sets of reports and records that create an extensive cache of developmental and behavioral information about the children. They are created as part of the public early intervention system guided by federal law such that each state and municipality follows the same procedures regarding evaluations, service provision, and documentation.

Autism Spectrum Disorder Decision-Making Protocol for EI Charts (ASD-DMP, Towle et al. 2009)

A coding system to determine the presence of ASD from the materials in EI charts was used; this is described in Towle et al. (2009). The coding system is based on the DSM-IV-TR criteria for ASD.

Child Characteristics: Gender and Age

The chronological age of the child at Time 1 was based on when the child was either recognized as having OR diagnosed with ASD as long as that is when they started receiving services that reflected the diagnosis.

Preschool Setting and Services

Many, but not all, of the charts contained information about what setting and services the child participated in when they were 3–5 years old. Information was combined from the Parent Questionnaire (see below) to determine the type of setting for this age period.

Measurements Obtained from Parent-Completed Questionnaires at School-Age (Time 2)

Parent Background Questionnaire

This was created for this study and had the following components:

Demographics Parents provided their dates of birth, highest educational degrees obtained, occupations, and place of residence.

Child Medical History Any positive results for genetics or neurologic consultations, medical diagnoses, and any additional neurodevelopmental/psychiatric diagnoses such as ASD, ADHD, anxiety, or learning disability.

Intervention History, Preschool, and Kindergarten Placement The responding parent was provided with forms to describe placements and check off related services received in terms of disciplinary services. For early and preschool intervention, the form queried sessions per week and how long the sessions were (e.g., speech therapy 2 × 45 min). For kindergarten, the parent was asked to describe in narrative form what type of class the child went to, and if they continued to receive services and/or be supported with an aide.

Current School Placement and Services Received This part of the questionnaire inquired about current grade and school placement, specifying the type of classroom (regular classroom in a public school, regular classroom with services, integrated/included or team-taught classroom, special classroom in a public school, segregated school building for special education, private special education school, and residential placement). In addition, a checklist of services was provided that included all the disciplines a child would typically use for related services, as well as whether the child had an aide, received 504 accommodations (a legal entitlement that supports those with demonstrable learning needs such as extra testing time, preferential seating, and note-taking) and if they had a Behavior Plan in place. A Behavior Plan is created for a child by school personnel if they have an adjustment or behavior problem that interferes with learning, participating in the classroom, or school attendance.

Current Behavioral and Social Functioning Questionnaire A checklist of items related to the three symptom domains from the DSM-IV criteria had a “yes” versus “no” endorsement. This checklist was intended to tap into school-aged behaviors that may be relevant to children with milder presentations of ASD, and as a functional check on the diagnostic information the parent might provide and the Gilliam Autism Rating Scale scores (see below).

Current Diagnosis/es Parent was asked: if the child had received an ASD diagnosis when young (and if so, when), if they agreed with it, which specific diagnoses had been assigned to the child, what were the current (Time 2) diagnoses, and if the parent considered their child to be “on the spectrum” currently. In actuality, very few children had received recent diagnostic evaluations, so current diagnostic status was determined through a procedure described below.

Gilliam Autism Rating Scale, First and Third Editions

Gilliam Autism Rating Scale first edition (GARS, Gilliam 1995) contains 56 items divided into four 14-item subscales of Stereotyped Behaviors, Communication, Social Interaction, and Developmental Disturbance. A 4-point Likert scale ranging from 0 (*Never Observed*) to three (*Frequently Observed)* is used to rate the items on the first three subscales. A dichotomous scale (yes or no) is used to score the items on the Developmental Disturbance subscale, which addresses behaviors and milestones in the first 36 months of life. Each subscale can be computed into a standard score and then tabulated for a total score, the Autism quotient (AQ).

The Gilliam autism rating scale-3 (Gilliam 2013) is the third edition of the scale. It has six subscales: restricted/repetitive behaviors (RRB), social interaction, social communication, emotional responses, cognitive style, and maladaptive speech.

Both editions supply an overall Autism Quotient, which was used; the AQ has an average of 100 and a standard deviation of 15. Since the GARS was standardized *only* on individuals with ASD, the mean of 100 indicates that a child has symptoms similar to the average child with autism and a lower score indicates fewer symptoms than the average child with autism.

Vineland Adaptive Behavior Scales-II (VABS-II, Sparrow et al. 2005)

The VABS-II is a semi-structured parent interview instrument that is the commonly used adaptive behavior scale. Items are rated on a 3-point scale. There are separate standard scores for the Communication, Socialization, and Daily Living Skills domains, and there is an Adaptive Behavior Composite (ABC) as well. These domain and composite scores have a mean of 100 and a standard deviation of 15.

Procedure

Participant Pool, Recruitment, and Data Collection

Stored service coordination and evaluation charts for children with birthdates from 1995 to 2006 were reviewed. The ASD Decision-Making Protocol was applied to identify children who fit conservative criteria for ASD. This resulted in an initial pool of 229 potential participants, of which 141 could be located and contacted (61.6%). Of these, 14 families declined participation (9.9%). Packets were sent out to 127 parents, of which 70 were returned, making a return rate of 51.1%. Therefore, the final participant count was 70.

When contact information was functional, parents were called and recruited into the study by the first author, whose position at the agency allowed her access to these records. If parents consented to participate, a consent form and the set of questionnaires and measures were mailed to them with a stamped, addressed return envelope. The study was reviewed and approved by the first author's academic Institutional Review Board.

Determining Time 2 Diagnosis

Before the study began, we made the incorrect assumption that most families would have had up-to-date diagnostic evaluations for their school-age children. In fact only five out of the 70 reported that this was the case.

Therefore, an initial method was developed to designate a Time 2 Diagnosis for each study participant so that they fell into one of three categories: ASD-Lower Functioning, ASD-Higher Functioning, and No ASD/LD (in other words, the child does not have ASD, but can have a learning disability or ADHD). The materials reviewed to place a child in one of these three categories were: statements made by the parent during the phone interview; responses on the *Current Behavioral and Social Functioning Questionnaire;* current school placement and services being received, and GARS scores.

Reliability Studies

Two sub-studies were undertaken to examine the reliability of placement into this tripartite diagnostic classification system. The first is described in Towle et al. (2014), and is based on interrater reliability using only parent information (verbal parent information, parent questionnaire, and GARS). When the weighted kappa was computed according to the method of Cicchetti et al. (2006), overall agreement was "very good" ($k_w = 0.83$). After reliability was established, all of the subsequent data charts were reviewed by the two evaluators and if a disagreement occurred, it was resolved through discussion.

The second, more recent, reliability study involved bringing a sample of 20 subjects into the clinic for a best estimate diagnosis (BED) using a combination of "gold standard" instruments (ADOS-2, brief Wechlser or Leiter IQ, VABS-II, GARS-3, and ADI-R for questionable cases) and clinical judgment. The 20 subjects were included either by newly recruiting subjects [new subjects were those whose birthdates from the stored files now put them in the 7–12 year-old category (n = 14) or by re-recruiting previous subjects (n = 6)]. Two experienced clinicians conferred to reach the BED. A third rater, blind to the BED, placed each substudy child in a diagnostic category by reviewing only the materials used for the questionnaire-by-mail phase of the study. In other words, the third rater reviewed the four pieces of information detailed above, but did not have available the ADOS, IQ, or direct observation information. The resulting weighted kappa was 0.65, which represents "substantial" agreement (Viera and Garrett 2005).

The decision was then made to divide the children determined to have ASD into the Higher versus Lower Functioning group based on VABS Adaptive Behavior Composite (ABC). The range of the ABC scores was examined and there was a clear median split at 80, so that 80 and above was considered Higher Functioning and below 80 as Lower Functioning. This resulted in four children changing groups (all moving from Higher Functioning ASD to Lower Functioning). The agreement with the blinded rater improved to 0.70, which reflects "substantial" agreement (Viera and Garrett 2005).

There were 20 children, however, who did not have Time 2 VABSs completed for them. In this case, the assignment reverted to the original judgment about what category the child should be in. Although 20 out of the 70 did not have VABS to determine the grouping, the previous clinician-judgment method had been shown to be reliable as well.

Data Analyses and Missing Data

Data were managed and analyzed using the Statistical Package for the Social Sciences (SPSS) software. There was opportunity for uneven sets of data as a result of the different level of participation of the recruited parents-primarily whether the VABS-II could be administered at Time 2, but also because inconsistency in how some parents responded to specific questions. When data was missing, only cases with the variables coded were included.

Results

Participant Characteristics

Of the final sample, 60 of the children were male and 10 were female, resulting in a male:female ratio of 6:1. Table 1 shows child participant characteristics in terms of gender and of age (of ASD recognition) at Time 1 and age at Time 2.

Table 2 presents parent demographics variable of education, showing that this was a somewhat highly educated group as a whole.

Time 2 Diagnostic Outcomes

Table 3 shows Time 2 Diagnostic status distribution, with 57.1% falling in the ASD-Lower Functioning category,

Table 1 Mean child ages at Time 1 and Time 2

	M	*SD*	Range
Time 1 age	25.24 months	5.5 months	13–36 months
Time 2 age	10 years	27 months	7 years, 1 month–18 years, 5 months

Time 1 = age at ASD recognition/diagnosis

Time 2 = age of child when parents filled out packets of questionnaires

Table 2 Parent demographics

Education level	Mother		Fathers	
	N	%	*N*	%
High school or less	3	4.4	10	14.4
2–4 years college	34	49.0	30	33.5
Master's degree or higher	31	45.8	29	43.1
Total	68	100.0	69	100.0

27.5% in the ASD-Higher Functioning category, and 17.1% in the No ASD/LD category.

The GARS Total scores across the three-category ASD groups were consistent with the functioning levels of ASD-Lower Functioning, ASD-Higher Functioning, and No ASD/LD diagnosis, as were the Time 2 VABS-II adaptive behavior composite (ABC) scores. A one-way analysis of variance showed that there were meaningful differences among the groups for both the GARS total (*F* (2, 64) = 37.41, p = .000) and the Vineland ABC *(F* (2, 47) = 86.62. p = .000). The large, significant difference for the Vineland would be expected because the groups were divided on the basis of the VABS-II ABC score. A Tukey's test for pair-wise comparisons determined that each group was statistically significantly different from the others on both of these variables at the p < .001 level or smaller.

School Placement, Parent-Reported Learning Problems, and Services Received

Once the children were placed in their Time 2 groupings, their previous educational settings were reviewed to understand the trajectory over time. Table 4 presents the preschool placements for the Time 2 groups. The placements were categorized first into the following four categories:

- Regular (non-special education) class placement with no services or one service
- Regular class placement with two or more services (children had IEPs and were in special education administra-

Table 3 Distribution of Time 2 Diagnosis for children at school age, GARS total scores and Vineland-II Adaptive Behavior Composite (ABC) Scores

Measure	Time 2 Diagnosis								
	ASD Lower Functioning			ASD Higher Functioning			No ASD/LD		
	N = 40 (57.1%)			N = 18 (25.7%)			N = 12 (17.1%)		
	N	*M*	*SD*	*N*	*M*	*SD*	*N*	*M*	*SD*
GARS total score	*31*	93.23^{a}	15.90	*17*	*70.88^{b}*	11.17	*10*	54.60^{c}	8.59
Vineland ABC	*28*	61.14^{a}	10.53	*11*	85.45^{b}	5.03	*10*	104.60^{c}	10.44

Means with different superscript letters are significantly different from each other (across rows) at the p < .001 level

ASD Autism spectrum disorder, *LD* Learning disability, *GARS* Gilliam autism rating scale.

Table 4 Preschool placements for Time 2 Diagnostic groups

Setting	Time 2 Diagnosis					
	ASD Lower Functioning (*N* = 37)		ASD Higher Functioning (*N* = 16)		No ASD/LD (*N* = 11)	
	N	%	*N*	%	*N*	%
Regular class w/no or 1 service	0	0	0	0	1	9.1
Regular class w/2 + services	3	8.1	3	18.7	4	36.4
Inclusion class w/services	3	8.1	2	12.5	2	18.2
Self-contained class	31	83.8	11	68.8	4	36.4
Total	37	100.0	16	100.0	11	100.0

ASD autism spectrum disorder

tively, or had 504 accommodations, but were placed with nondisabled peers)
- Inclusion class with services (all participants had IEPs and were in special education adminstratively, but were in classes with a mix of children with and without disabilities, often team-taught by a regular and special education teacher)
- Self-contained class (all participants had IEPs and were in special education adminstratively and in physical placement)

For the two ASD groups, all children were in preschool special education (had IEPs), either in a regular classroom with a number of services or in inclusion or segregated settings, also with a number of services such as speech and occupational therapy. For the eventual No ASD/LD group, all children but one were also receiving many services, but a smaller proportion were in self-contained classes.

Table 5 presents the kindergarten placements for the different groups. To be in the last three settings—regular class with 3+ services, inclusion class, or special education class—are roughly equivalent in terms of intensity of services and level of support. In each of these cases children will be in special education administratively by virtue of having IEPs. Sometimes the difference reflects the school system philosophy and choices regarding models of special education, and other times the child being in different settings reflects parents' efforts at keeping the child in a least restrictive setting with typically-developing peers.

In kindergarten, the majority of the two ASD groups received two or more services, but now a smaller percentage in the ASD-Higher Functioning group was exclusively in self-contained settings. However, members of the eventual No ASD/LD group now were in slightly less restrictive settings, and over half had no to three services.

Table 6 presents the Time 2 placements for the different groups. The placements were categorized first into seven categories that range from least restrictive and fewest services to the most restrictive environment and most services.

This table shows that by school age, 89.7% of the ASD-Lower Functioning group were in special education highly restricted settings. For the Higher Functioning group, 47.0% were in regular public school settings with services, whereas 47.1% were in more restrictive settings, but none in residential care. For the No ASD/LD group, however, half the children were in regular classes with typically developing peers, and the rest were in a variety of low-restriction settings.

In Table 7 is shown the parent-reported learning and academic challenges they perceived their children as having. Across all groups "learning" had the highest endorsement. For the ASD groups, "social functioning" was the next highest for the two ASD groups, whereas for the No ASD group, it was in the lowest third for parental endorsement. In general, the two ASD groups were similar to each other in terms of the pattern of percentage endorsement for the various learning problems while the No ASD group had a different learning problem hierarchy. The average percentage of children endorsed for any given learning problem was in line with the disability levels of the groups.

Finally, Table 8 shows the types of services that the children in the three disability level groups received at school age. Speech therapy was the most frequent service for all groups, followed by special instruction, occupational therapy, and social skills group.

Special instruction most likely has different meaning for the different groups. Since parents were asked simply to check it off as a service (along with all the others on the list), details were not available. Since 100% of ASD-Lower Functioning group received it, this most likely indicates that special education teachers are using specialized strategies to instruct challenged learners. In the No ASD group, this usually means that the child receives either limited time in a resource room at some point in the week, or that they receive some time in class with a special education teacher for an

Table 5 Kindergarten placements for Time 2 Diagnostic groups

Setting	Time 2 Diagnosis					
	ASD Lower Functioning		ASD Higher Functioning		No ASD/LD	
	(*N* = 35)		(*N* = 17)		(*N* = 12)	
	N	%	*N*	%	*N*	%
Regular class w/ no or 1 service	0	0	2	11.8	4	33.3
Regular class w/2 services	1	2.8	0	0.0	3	25.0
Regular class w/3+services	3	8.6	3	17.6	2	16.7
Inclusion class w/services	2	5.7	5	29.4	2	16.7
Self-contained class	29	82.8	7	41.2	1	8.3
Total	35	100.0	17	100.0	12	100.0

ASD autism spectrum disorder

Table 6 School-age placements for Time 2 Diagnostic groups

Setting	Time 2 Diagnosis					
	ASD Lower Functioning		ASD Higher Functioning		No ASD/LD	
	N = 35		*N* = 17		*N* = 12	
	N	%	*N*	%	*N*	%
Regular public school class with no or one service	0	0.0	1	5.9	6	50.0
Regular private school	0	0.0	0	0.0	3	25.0
Regular public school class with two or more services	4	10.3	8	47.0	3	25.0
Special education class (self-contained) in a public school building	26	66.7	7	41.2	0	0.0
Special education private school for learning disabilities (e.g., dyslexia)	0	0.0	1	5.9	0	0.0
Special education private school	7	17.9	0	0.0	0	0.0
Residential setting	2	5.1	0	0.0	0	0.0
Total	39	100.0	17	100.0	12	100.0

ASD autism spectrum disorder

Table 7 School-age learning and academic problems reported by parents for Time 2 Diagnostic groups

Parent reported problems	Time 2 Diagnosis					
	ASD Lower Functioning		ASD Higher Functioning		No ASD/LD	
	N = 40		(*N* = 17)		*N* = 11	
	N	%	*N*	%	*N*	%
Learning and social problems						
Learning	30	100.0	15	88.2	6	5.54
Social	37	92.5	12	70.6	2	18.2
Language	35	87.5	12	70.6	4	36.4
Attention deficit	31	77.5	11	64.7	2	18.2
Gross motor	18	45.0	3	17.6	2	18.2
Nonverbal or few words	10	25.0	0	0	0	0
Academic problems						
Writing (compositional)	33	82.5	6	35.9	3	27.3
Reading	39	75.0	10	58.9	1	9.1
Handwriting	25	62.5	8	47.0	5	45.4
Behavior problems						
Behavior problem	25	62.5	2	11.8	1	9.1

ASD autism spectrum disorder

area of instruction such as reading, writing, or math. For the ASD-Higher Functioning, this could mean any of those three strategies.

The ASD-Higher Functioning group was characterized by having a higher percentage with Section 504 accommodations when compared to the other groups. These accommodations are an entitlement from the Rehabilitation Act of 1973 rather than that of the Individuals with Disabilities Education Act (IDEA) and provides for supports such as extra time for tests, taking tests in a separate setting, preferential seating, provision of notes, and so forth. The ASD-Lower Functioning group has the most behavior plans and aides assigned them.

The three groups were compared in terms of number of therapies they were receiving at school age. As seen in Table 9, the ASD groups did not differ from each other, but both differed from the No ASD/LD group. For the one-way ANOVA, there was a significant effect (F (2, 66) = 11.77, $p < .000$). A Tukey's test post-hoc comparison showed that both the ASD-Lower Functioning group and Higher Functioning group were significantly different from the No ASD/LD group, but the two ASD groups were not significantly different from each other.

Table 8 School-age special education therapies and supports for Time 2 Diagnostic groups

Therapies and supports received in grade school	Time 2 Diagnosis		
	ASD Lower Functioning	ASD Higher Functioning	No ASD/LD
	N = 40	*N* = 17	*N* = 12
	N (%)	*N* (%)	*N* (%)
Therapies			
Speech-language therapy	39 (97.5)	15 (88.2)	5 (41.7)
Special instruction	28 (70.0)	19 (73.1)	2 (16.7)
Occupational therapy	33 (40.0)	12 (70.6)	3 (25.0)
Social skills group	17 (42.5)	10 (58.8)	3 (25.0)
Physical therapy	7 (17.5)	3 (17.6)	1 (8.3)
Other supports			
Aide, part- or full-time	24 (60.0)	5 (29.4)	0 (0)
504 accommodations	9 (22.5)	13 (76.5)	2 (16.7)
Behavior plan	13 (32.5)	2 (11.7)	0 (0)

ASD autism spectrum disorder

To consider the progress of these children over time, their progression between least to most restrictive educational setting, and from the most to least services, was recoded in the following way. For preschool and kindergarten, the settings were reduced to three in the following way:

1. Regular (non-special education) class with one or no services = low level of segregation and/or intensity of services,
2. Regular (non-special education) class with two or more services OR inclusion class with services = medium level of segregation and/or intensity of services.
3. Self-contained class—high level of segregation.

At school age, the coding was as follows:

1. Regular class with one or no services, OR non-special education private school (e.g., religious school) = low level of segregation and/or intensity of services
2. Regular class with 2 + services OR inclusion class with services = medium level of segregation and/or intensity of services
3. Self-contained class OR private school for learning disabilities OR private school for autism = high level of segregation
4. Residential setting = highest level of segregation

Each child was coded for preschool, kindergarten, and school-aged setting according to the above categories, and then further grouped as follows

- Decreased segregation, or started and stayed in the least restrictive environment (e.g., 111, 321, 322, 332)
- Stayed in the same level of segregation from preschool to school age (to avoid too many groups), if a child had the same setting level in preschool and then grade school, but changed in kindergarten, it was still considered staying the same (e.g., 222, 212, 232)
- Increased segregation, or started and stayed in a segregated settings (e.g., 233, 223, 323, 333)

The frequency counts of these longitudinal patterns are presented in Table 10. The ASD-Lower Functioning group overwhelmingly progressed to the most segregated settings, and the No ASD/LD group did so for the least restrictive. In comparison, the ASD-Higher Functioning group had the most varied longitudinal pattern, although half started and stayed in the most segregated placements.

Discussion

The goal of this study was to follow children who were diagnosed with autism spectrum disorder early (before the age of three, and many before 24 months) into school age, examining in particular the types of school settings the children attended at different points in time. The diagnostic outcomes

Table 9 Mean number of educational therapies and services received at school age across Time 2 Diagnostic groups

	Time 2 Diagnosis					
	ASD Lower Functioning		ASD Higher Functioning		No ASD/LD	
	N = 40		N = 17		N = 12	
	M	*SD*	*M*	*SD*	*M*	*SD*
Mean number of therapies/interventions	3.20^a	1.1	3.00^a	1.5	1.25^b	1.4

Means with different superscript letters are significantly different from each other (across rows) at the p < .01 level

Table 10 Children who decreased, stayed the same, or increased segregation level and/or intensity of services from preschool, to kindergarten, to school age across Time 2 Diagnostic groups

	Time 2 Diagnosis					
	ASD Lower Functioning		ASD Higher Functioning		No ASD	
	N = 34		*N* = 16		*N* = 11	
	N	%	*N*	%	*N*	%
Decreased segregation or started and stayed in the least restricted environment	2	5.9	4	25.0	10	90.9
Stayed in the same level of segregation from preschool to school age	0	0	4	25.0	1	9.1
Increased segregation or started and stayed in a segregated setting	32	94.1	8	50.0	0	0

ASD autism spectrum disorder

at school age were very similar to other longitudinal studies: 17% were determined to no longer have ASD, compared to the best estimate of approximately 15% going "off the spectrum" found by Woolfenden et al. (2012) based on a literature review. The current study, however, endeavored to distinguish between Lower and Higher Functioning outcomes for those who continued on the autism spectrum. As diagnostic criteria changes have resulted in one continuous spectrum, it will be important to distinguish between disability and functioning severity levels, based on cognitive, adaptive, and communication outcomes.

Children of Different Outcome and Ability Levels Diverge in School Placement Over Time

Examining school placement and services at three points in time longitudinally was revealing. Through a combination of chart information and parent report, preschool settings were characterized in terms of how segregated and restricted vs. integrated and normalized they were, primarily reflecting special education needs on the part of the children. Kindergarten and school-age settings were also characterized in terms of numbers and types of services they received as reported by parents on the study questionnaires. Results showed that even in a group where 17% of the children would eventually have negligible ASD symptoms, almost all children required a high level of educational remediation and support at preschool level, and most still did so in kindergarten.

Specifically, at preschool placement (3–5 years of age), the majority of the children who would eventually be in the ASD-Lower Functioning group and ASD-Higher Functioning group were in self-contained classes (84 and 69%, respectively). The remainder was in regular or inclusion classes with services. In contrast, only 36% of the children who would eventually be in the No ASD/LD group were in such settings, but 55% were still in inclusion classes or regular preschools classes with two or more services (such as speech-language and occupational therapy and having a special educational teacher part of the time to assist them). One child in the No ASD/LD group was in a regular class with only one type of service (speech and language) by preschool age.

Two years later, at kindergarten age, larger differences between the groups emerged. For the children who would eventually be in the ASD-Lower Functioning group, 83% were still in self-contained classes, with the remainder receiving several services. In contrast, more of the children who would eventually be in the ASD-Higher Functioning group had left a self-contained class; about 40% remained there and 47% were in regular or inclusion classes with multiple services, but two children were now in a regular class with one service (11.8%). For the children who would eventually lose the ASD diagnosis, however, approximately 33% were in regular classes with no or one service, another about 30% had 2+ services, but only one child (~ 10%) was in a self-contained class.

By school age, all of the No ASD/LD children were in regular classes, half with no or one service, and about 25% with some services. Twenty-five percent were in private schools, usually a religious school or one that similarly afforded smaller classes with more individual attention. For children with ASD who were determined to be Higher Functioning at school age, slightly less than half (42.9%) were still in self-contained classes, one was in a private school for learning disabilities, one was in a regular class with one service, and the remaining 47.6% were in regular classes with two or more services. For the ASD-Lower Functioning group, about two-thirds (63.6%) were in self-contained classes, 20% were in private schools specifically for ASD, and two children (5.7%) were in residential placements. Two children (5.7%) were in regular classes with multiple services.

To further examine patterns of change, each child was characterized in terms of their restrictiveness of placement over the three points in time sampled. The extent to which children decreased restrictiveness, stayed the same, or increased restrictiveness of setting from preschool to school age showed a clear pattern. The majority of children with ASD who were in the Lower Functioning ASD group, as determined by Time 2 VABS ABC score, either started in self-contained classrooms or moved to such by school age. The children who were determined to no longer be diagnosable with ASD by school age showed the opposite pattern. The Higher Functioning children with ASD showed a mixture of the three patterns.

These results show that children with different severity trajectories diverge from each other, in terms of educational settings, in predictable directions over time. They also demonstrate that the full picture of functioning may not be apparent until a child is into the grade school years. This underscores the importance of longer follow-up times for longitudinal studies in ASD.

That children with greater levels of need—either from symptom severity or lower developmental skill levels—remain in special rather than regular education, and more often in self-contained settings, has been a common finding in previous literature (Eaves and Ho 1997; Harris and Handleman 2000; White et al. 2007). White et al. (2007) found educational placement to be relatively stable over time, and that children who began in special education stayed in special education. Their report, however, started tracking at school age (first grade), not taking into account earlier childhood placements. The current study shows that preschool settings and even kindergarten settings may *not* reflect eventual placement for some children.

Woodman et al. (2016) performed a longitudinal analysis for 364 individuals with ASD that included inclusiveness of educational settings among variables predicting change patterns over 10 years. They found that being in more inclusive settings was associated with the group with better outcomes and greater growth in skills compared to a group with lower skill outcomes. As in the current study, it is not possible to determine the extent of causality in these relationships.

Children of Different Outcome and Disability Levels Have Differential Learning Challenges and Use Different Educational Therapies and Supports

The current results also provide a number of details about the learning challenges that the different groups of children faced when they reached grade or high school. Parents reported "learning problems" in the great majority of their children across the two ASD severity groups, but still at a rate of 50% in the No ASD outcome group. A similar result was found for "language problems," but with slightly lower percentages. The two ASD groups (Higher and Lower Functioning) diverged from the No ASD/LD group in the case of "attention deficit" and "social problems" in that the two ASD group children were reported to have very high levels of these while the No ASD/LD group children had more moderate levels as a group (37% attention, 25% social). For other educationally related problems—reading, handwriting, compositional writing—the ASD-Lower Functioning group was reported to have relatively high levels while the Higher Functioning and No ASD/LD groups were more similar to each other with low to moderate levels.

Finally, the educational therapy services reported by parents reflected the above-described types and degrees of challenges and offered additional detailed information about the levels of supports their children were receiving. Speech-language therapy services closely corresponded to the percentages reported above as having learning and language problems. Occupational therapy was frequent among all three groups, as well, in slightly lower percentages. 25–60% of children in all three groups received some type of social skills group.

One way in which the ASD-Higher Functioning group stood out was that over three-quarters (76.5. %) had Section 504 accommodations, whereas in the Lower Functioning group, 22.5% had them. These are accommodations for extra time for tests, preferential seating, note-taking, etc., and are given outside of an IEP. It is possible that at milder levels of ASD symptoms and disability, this type of support allows a child to be in a less restrictive setting rather than a full special education designation and/or setting. Section 504 accommodations were reported for the other two groups, but at lower rates (21.7% for ASD-Lower Functioning and 18% for No ASD).

A distinction of the ASD-Lower Functioning group was that over half was assigned a part- or full-time aide (60%). Less than one-third of the children in the ASD-Higher Functioning group had this support (29.4%), whereas none in the No ASD/LD group had an aide. Both use of aides and presence of a behavior plan signals behavior management needs that often drive the restrictiveness of setting—and represent higher expenditure per student—and these characterized the school-age ASD, groups whereas none of the children in the No ASD/LD had such supports.

In the current study, many parents who said their child no longer had ASD did describe persisting learning disabilities. In the previous report on these same children, some of the diagnoses obtained from community providers were attention deficit hyperactivity disorder (ADHD), language processing disorder, nonverbal learning disability, and language-based learning disability (Towle et al. 2014). The presence of lingering learning and social problems in otherwise "recovered" children is consistent with previous literature in this area (Fein et al. 2005; Kelley et al. 2006; Helt et al. 2008).

How Should Children of Different Ability Levels Be Grouped?

This study also demonstrated that it is useful to look at different functioning groups to ascertain differential school service patterns. Similarly, Towle et al. (2014) demonstrated differential patterns in medication used in similar subgroups from the same data set. There is a strong motivation by researchers and clinicians to identify homogeneous subgroups within the very heterogeneous autism spectrum, but at this point, there is little agreement about how to do this. Traditionally, high- and low-functioning has been defined at two standard deviations below the mean of an IQ test (70); however, there is considerable variability across studies in that some choose 80 or 85 as a cut-off (e.g., Mayes and Calhoun 2011; Watkins et al. 2015; Wong et al. 2012). As described earlier, trajectory and latent class analyses have become popular, but each study has its own set of measurements, participant features, and time course.

With the recent emphasis on using adaptive skills as a more functional view of outcome functioning, the current study, in the absence of available IQ scores, used VABS composite scores. Two recent studies have investigated trajectories of adaptive scores in children with ASD. Farmer et al. (2018), with a sample of 105 children assessed with the Vineland ABC four times between 3 and 8 years of age, also found a low group of 73% and a moderate group of 27%. In the current study, of the children retaining an ASD diagnosis, 68.9% were in the Lower Functioning group and 31.1% in the Higher Functioning group, and thus there appears to be agreement between the current study and the Farmer study in the general proportions of a higher and lower group based on composite adaptive behavior scores. Baghdadli et al. (2012) plotted VABS individual domain age equivalent scores at three points in time (about 5, 8 and 15 years of age) for 152 children. For two domains—communication and socialization skills—there was a two-group solution, a low functioning stable group and a Higher Functioning improving group. The proportion was 72.4% low/stable, 27.6% higher/improving for Communication and 68.1–31.9% for Socialization. Therefore, across three studies the proportion of individuals in the lower- versus higher-ability group is fairly consistent.

Limitations

The first limitation of the study is that for the most part the children were not examined in person to determine their ASD diagnosis. A chart abstraction method was used to determine ASD at Time 1 (although 81% of the children designated as "ASD" did have an early ASD diagnosis recorded in their chart; see Towle et al. 2014) and Time 2 Diagnosis (ASD or not) was generated from a judgment rating based on parent information, outside of 20 subjects that were evaluated in person for the reliability study. Reliability studies concurrent with the research did demonstrate substantial agreement between raters and in relation to a best estimate diagnosis. As well, use of more indirect means of case ascertainment enables studies to be done for less expense and takes advantages of widely available repositories of information on children, such as early intervention, school, and medical records. The second limitation was that the participating parents were of relatively high education and socioeconomic status, and thus the outcomes may not be representative of a larger demographic of parents with children with ASD.

Conclusions and Future Research

This study has shed light on details and patterns of school placement and educational service provision for children with ASD that have not been available heretofore. Following children over time showed that children who ended up requiring fewer services by school age did have relatively intense services early on, including those who lost the ASD diagnosis. In terms of longitudinal follow-up periods, the study results also suggest that the full picture of functioning for preschoolers with ASD may not be apparent till much later. In other words, of groups of children who were functioning quite differently at school age, there was least amount of difference in educational setting and services in preschool, more differences in kindergarten, and the most differences at grade school. Grouping children by three outcome disability levels also showed the groups had somewhat different courses over time. At school age, the disability level of the groups showed differential pattern of support strategies and resources, e.g., the use of aides and 504 accommodations. Therefore, for school administrators anticipating the allotment of resources for children with ASD, there will be different needs depending on disability level. It also appeared that distinguishing differential levels of functioning based on overall adaptive skills could be a useful approach to subgrouping, but it will be important to continue to explore ways to characterize more homogeneous subgroups for individuals with ASD when investigating both basic and practical questions in the field. Future reports from this data set will investigate how early childhood characteristics and early intervention experiences predict later outcomes.

Author Contributions POT conceived of and designed the study, directed data collection, performed the statistical analysis, and drafted the manuscript. KVS collected data and participated in measurement and data analysis. AA and CR collected data and participated in

manuscript writing. All authors reviewed the manuscript critically and approved the final version.

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