

Public Early Intervention and Preschool Services in a High-Resource Community Sample of Children with Autism

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Abstract

Objectives

The majority of young children with autism spectrum disorder (ASD) in the United States receive their Early Intervention (EI) and Preschool services through public intervention programs, yet there are few detailed reports of their intervention experiences. Referencing a large literature that associates demographics (geography, urbanicity, poverty, and race) with access to services for autistic children, this study examined what can be achieved in a high-resource area with demographic characteristics that should provide greater access to services.

Method

This observational, longitudinal study reports on EI and Preschool intervention experiences for 68 children with ASD who live in a such an area, using archival billing and program records (assessment reports, progress notes, and service plans) at Time 1 and follow-up parent report at school age (Time 2).

Results

Most children received a full multidisciplinary program with 15-plus weekly hours. Speech therapy, occupational therapy, and special education were the most prominent disciplines used; however, in this sample, applied behavioral analysis accounted for many hours as well. Total hours and intensity increased from EI to Preschool. Child Nonverbal Developmental Quotient predicted intensity of services in Preschool, but not in EI. Neighborhood income did not predict amount of services, suggesting that in a high-resource area, lower-income families may have equitable access to services due to proximity.

Conclusion

The results underscored the need for examining barriers to services in varying geographical, economic, and demographic areas.

Introduction

Early Intervention (EI) is critical for addressing early learning needs and mitigating later degrees of disability in children with autism spectrum disorder (ASD) (Hyman et al., 2020). The majority of autistic children in the United States receives EI services through the federal Part C Early Intervention Program and Part B preschool program, established in 1986 under the Individuals with Disabilities Education Act (IDEIA) and reauthorized as the Individuals with Disabilities Education Improvement Act of 2004. All 50 states have now adopted the law and administer it through a state-determined Lead Agency. The mandated programmatic functions include Child Find efforts, guidelines for timely and comprehensive

evaluations, service provision, periodic review and update of intervention plans, transition support services, and due process procedures.

However, comprehensive public EI service provision for young autistic children has faced two major challenges. First, the case rates of ASD have dramatically increased from when the CDC, informed by the Autism and Developmental Disability Monitoring network (<https://www.cdc.gov/autism/addm-network/uti>), which reports a current average estimate across states of 27.6 per 1,000 (one in 36) at age 8 (Maenner et al., 2023). Increased awareness of recognizing ASD symptoms in young children with ASD combined with national public health campaigns for early identification such as Learn the Signs, Act Early (e.g., CDC, 2007; Peacock & Lin, 2012), there were significantly increased service demands. Second, there is consensus that children with ASD require relatively intensive services that include several disciplines and modes of intervention (Landa, 2018) as well as year-round programming using autism-specific models (Odom, Collet-Klingenberg, & Hatton, 2010) all of which place financial pressure on the administering agencies. However, the extent to which states typically meet the demands they face in their Part C and B programs remains an open question.

Best practice amounts of intervention

These demands also raise the question of what are adequate to best-practice *amounts* of services, especially in light of the call for intensive services. In the past, the 2001 National Research Council report (NRC, 2001), recommending 20–25 h/week, was frequently cited. However, the NRC recommendations are now over two decades old and were based on research with older children, not infants and toddlers. Since then, although many more studies have been done with infants, toddlers, and preschoolers, this more recent body of research has not yielded a clear standard regarding intensity. Klintwall and Eikeseth (2013) reviewed studies of Early Intensive Behavioral Intervention (EIBI)—which by its nature implies an intense treatment schedule—and showed that high quality, controlled studies reported a range of 25 to 38 hr./week. In a systematic review of behavioral intervention for children birth-to-12 years, Weitlauf et al. (2017) suggested that effective interventions ranged from 14 to 28 hr./week (although this referred to a wide age range and the focus of the present study is on birth-to-three). A report on EI practices in Massachusetts indicated that the lead agency contracted with specialized service providers for intensive behavioral up to 27 hr./week (Henderson, 2009).

While EIBI is expected to have high intensity levels, Naturalistic Developmental Behavioral Interventions (Bruinsma et al., 2019) have risen in prominence over the last decade. There are varying models that involve working directly with the both the child and parent, and those focusing solely on parent coaching. Those that have focused on direct intervention with the child, including the seminal work by Dawson et al. (2010) and subsequent studies (Eapen et al., 2013; Estes et al., 2015; Vivanti et al., 2014), have reported a range of 15–25 hr./week.

Thus, intensive interventions appear to be possible, presumably where the resources are available. In fact, the question of availability of resources is very relevant for state EI and Preschool programs

regarding their ability to meet the identification, evaluation, and service provision needs of autistic children. Such resources vary dramatically across and within states and are related to several demographic features. A body of literature has shown that one key is proximity to resources associated with earlier identification and availability of treatment resources, which lead to greater utilization (e.g., Kalkbrenner et al., 2011). Areas with higher population (Stahmer, 2007), including metropolitan centers, with more licensed service providers and specialized programs for autism (Lauritsen et al., 2019; Yingling et al., 2021), will generate earlier identification and service referrals (Daniels and Mandell, 2014; Kalkbrenner et al., 2011; Thomas et al., 2012), leading to earlier entry to treatment (Bradshaw et al., 2023). Families with higher SES and living in areas of higher median income utilize more services (Thomas et al., 2012; Yingling & Bell, 2020). In contrast, significant and interrelated conditions that create barriers to access include poverty, SES, and race/ethnicity (Broder-Fingert et al., 2013; Liptak et al., 2008). Racial and ethnic minority groups and children from low-income families receive fewer services compared to White families (Smith et al., 2020).

Previous research

To date, only five studies have reported on EI and Preschool services in their respective geographical areas (see Table 1). Three studies surveyed program administrators and providers on their current and intended practices, (Aranbarri et al., 2021; Downs & Downs, 2010; Stahmer, 2007), and one did not specify how data was collected (Noyes-Grosser et al., 2018). Only one focused on the children themselves (McIntyre & Zemantic, 2017), and thus the only one that could characterize demographics such as race and age of children. However, this study relied on retrospective parent report for the service amounts and duration. All studies reported averages and ranges of hours and disciplines of services, and each study also had other research questions. Only one examined child predictors of intensity, showing that lower age of starting EI and higher severity of symptoms predicted greater intensity of services (McIntyre & Zemantic, 2017). Two studies correlated county or family income with amount of services, showing that higher income was associated with higher service provision (Aranbarri et al., 2021; McIntyre & Zemantic, 2017).

Several conclusions can be drawn from this survey of literature. The first is that methods of collecting data regarding hours of services received—surveying administrators on general practices and parent retrospective report—pose questions related to accuracy. Only one of the studies used a child-focused approach, that is, collected information on children’s actual experiences rather than surveying providers’ estimates and intentions (McIntyre & Zemantic, 2017). As well, two studies (Aranbarri et al. 2021; Stahmer, 2007) included programs with at least some children with ASD in them, but also children with other disabilities; thus, their results did not reflect information only for autistic children. Finally, these studies comprise a very small but emerging literature, one that is particularly relevant to current policy. Therefore, there is a strong need for additional studies that show what eligible children actually receive from these public programs, and how closely aligned the services provided are to best practice.

Current study and aims

The current observational, longitudinal study endeavors to add to the literature in several ways. First, it is unique in that it reflects a relatively high-SES, high-resource area in which children, theoretically, would be able to receive the level of services approaching that recommended by experts. The county is proximal to a very large metropolitan area and has many of the enabling features that research has suggested will support access to identification and intervention services. It is also the first study to use EI program billing records to record the hours of services across all disciplines for each child, ensuring much more accuracy than estimates from program administrators or from parental retrospective recall. Therefore, the first aim of the study was to report the types (disciplines), hours, and intensity (hours-per week) of services received by young autistic children, as accessed through archival records and reported upon by their parents who lived in a high-resource area. Due to the data collection method, this was a more accurate accounting than previous studies. Second, the use of detailed EI records, both administrative and narrative, allowed for examination of how children received services over time, and thus the second aim of the study was to explore this feature. For the third aim of the study, we conducted a within-group analysis to examine how child level of functioning—nonverbal developmental quotient (NVDQ)—may influence different amounts of services received. The fourth aim was to explore the relationship of neighborhood income to variability of services received in the same way.

Method

Setting

County-level features

The setting was a county of approximately one million residents proximal to New York City. This county was considered high resource for the purposes of this study due to the following contextual parameters. First, the median household income of said county is USD89,968, in contrast to that in New York State (USD62,765), the New York Metropolitan Area (USD75,368) and the United States median household income (USD67,521), according to the 2020 census (www.justicemap.org). With reference to the 62 counties in New York, the study county ranks #3 in both wealth and public school quality (<http://www.usa.com/rank/new-york-state--average-education-index--county-rank.htm>).

The second set of parameters chosen was more specific to the relevant resources for children and families with ASD and developmental disabilities (DD). One important feature relates to the New York State approved EI programs, the majority of which serve children with autism, but others serve DD in general or a specific non-ASD disability. Compared to the ten most populous counties in the state, the study county ranked #1 (<https://www.health.ny.gov/community/docs>). Next, the availability of relevant professions was considered. Using ratios of one physician per 100,000 children, for the ten counties considered, the study county ranked as follows: developmental pediatricians, #2; for general pediatricians, #4 (<https://www.op.nysed.gov/professions/physicians/license-statistics>). Finally, the

number of specific disciplines available was determined by creating a ratio of # of licensed professionals in the county/county population (<https://www.op.nysed.gov/professions-index>). This county ranked as follows out of the ten most populous counties: psychologists – 2; speech pathologists – 6; occupational therapists – 5; occupational therapy assistants – 4, and physical therapists – 4. It is important to keep in mind that the number of licensees refer to the actual address of the provider—which is often an adjacent county that may have a lower cost of living, but they may practice in the study county.

Early Intervention and Preschool Intervention Programs

The structures and functions of EI and Preschool programs at the time data collection took place continue to be the same in the present. Following the framework of the federal law, and thus, regulations at the state level, the state and local agency administering the EI program is the Department of Health (DOH), which serves as the mandated single point of entry in the county. Parents contact the program and are immediately assigned an initial service coordinator, who reviews with them the structure of the program and assists with the evaluation process. A multidisciplinary evaluation then determines if the child qualifies for intervention based on degree of delay in five developmental areas, as well as presence of conditions that automatically qualify (e.g., genetic syndromes associated with developmental delay). At the IFSP meeting, evaluators, parents, and EI program representatives come to an agreement about the child's intervention program. The parents then also determine who their Ongoing Service Coordinator (OSC) will be.

The service structure is a synthesis of family-centered and medical models. Parents have roles in therapy and program selection, setting goals for intervention, reviewing service plans periodically, and requesting additional evaluations and service hours. Consistent with a medical model, individual therapies are matched directly to the delay in a given developmental area; for example, speech/language would result in speech therapy, motor delay in physical or occupational therapy. This model is also considered multidisciplinary and it contrasts with models used in other programs where there are fewer service providers available. One example of an alternate model would be a generalist, usually a special educator, working with parents on a weekly basis to carry out goals from disciplinary therapists. They (for example, a speech or physical therapist) might visit the child monthly to note progress and adjust goals to be carried out by the generalist, but not work with the child directly. This strategy would be considered transdisciplinary.

The NY DOH EI program contracts with approved agencies for evaluations, disciplinary services, early special education programs, and service coordination. In this county, there is a variety of settings available to children for intervention. There is usually a choice of at-home therapies, therapies at an agency, an EI special education program, or a combination of the these. Some children attend a private non-special education preschool program in their community and therapists visit the program to provide the therapies. There may be additional therapy sessions in the home or not. Finally, there are integrated programs wherein both typically-developing and children with needs attend. In this case, both special education and regular teachers are present.

Regarding the Preschool program in New York, as the child ages out of EI, the administration shifts from DOH to the local school district's special education department. The state agency overseeing the activities is the state Department of Education and the intervention model shifts to an educational one. Parents are guided through the transition process by their EI OSC. The school district receives all relevant documents from EI and then may conduct their own evaluation(s) or observation. Parents, evaluators, and school district personnel then attend an initial IEP meeting, during which programs and therapies are put in place. The school district often does not have their own programs; the EI placements and many EI providers are approved by the school district as well as the DOH. Thus, at preschool age, some children continue with their current programs approximately intact and others have a shift of therapists or may enter a different preschool setting. In both EI and Preschool, children may have aides in special education or typical preschool classes.

Participants

The data were originally collected for a longitudinal study of children diagnosed with/established as having ASD before age three and who received treatment through the public EI program (Part C) and local school district preschool program (Part B). Participants were parents/guardians of 68 such children. The families and their children had been involved with a University Center for Excellence in Disabilities (UCEDD) for either county EI program service coordination or for diagnostic evaluations. They did not come to the UCEDD for the purpose of the study; rather, their children received clinical or service coordination services there, as approved providers for the EI program, and their archival charts were accessed for the study. The children had birth years of 1996 to 2007 and thus were receiving services as a group from approximately 1997 to 2012.

Archival charts came from two sources and using them in the study and was a two-step process (See Procedure, below). Archival charts provided Time 1 data, although Time 1 data was supplemented in some cases by parent report at Time 2. At Time 2, parents participated in a follow-up study and filled out several questionnaires regarding their child's early intervention experiences, current school-age placements and functioning, as well as standardized autism symptom parent-report instruments (see Author, 2014, 2018). Demographics of parents suggest that many of the families included well-educated parents with higher-than-average financial resources.

Instruments and Measurements

Measurements from Early Intervention Charts (Time 1)

Child Characteristics: Gender, Age, and Developmental Level

The chronological age of the child was based on when the child was *diagnosed with* or *recognized as having* ASD. The latter designation was adopted because some children did not have a diagnosis in their agency EI chart. For example, parents may have requested that it not be specified. In other instances, evaluating providers recognized the symptoms and asked for ASD-specific programming and then arranged for a later confirming diagnostic evaluation by a psychologist (who, in New York State, is the only professional besides an MD that can diagnose ASD). In these cases, the records were examined for behaviors consistent with the DSM-IV and DSM-5 diagnostic criteria and service coordination notes were examined for when ASD-specific services were initially provided. Nonetheless, 54 (80%) of EI charts did have a definitive diagnosis of ASD in them. Sometimes this was from the supplemental psychological evaluation and other times from a pediatric neurologist or developmental pediatrician that the family had consulted privately.

Regarding cognitive level, assessments were conducted by the licensed practitioner to which each child was referred, resulting in variability among the specific measures used. However, cognitive level for each child in the study were based on widely-used, standardized instruments, e.g. Mullen Scales of Early Development (MSEL, Mullen, 1995), or criterion-based measures, e.g., Hawaii Early Learning Profile (HELP, Parks, 1984). As is typical for community studies, we converted scores to nonverbal mental age equivalents in every case possible, and a Nonverbal Developmental Quotient (NVDQ) of MA/CA X 100 was generated. Adaptive skills were measured using the *Vineland Adaptive Behavior Scales, II* (VABS-II, Sparrow et al., 2005) or VABS-3 (Sparrow et al., 2016). An Adaptive Behavior Quotient (ABC) or other subscales from the VABS-II or VABS-3 were available from the majority of the charts (between 62–68 charts depending on the particular subscale score).

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

Demographics

On the questionnaires, parents provided their highest educational degrees obtained, place of residence, and race. Median income was calculated using the family's address and then referring to 2020 census tract data retrieved from justicemap.org.

Intervention history: EI and preschool

The responding parent/parent described program placements and all disciplinary services received—as well as sessions per week and length of sessions in hours and minutes—for EI and Preschool. The main source of this information, however, was through direct examination of Department of Health (DOH) EI records (containing billing records, IFSPs, service coordination and providers' progress notes), accessed with additional consent of the parents. Billing records were especially valuable because they reflected the services that were actually delivered, rather than based on the recorded plan made at the start of services. For example, weeks could be missed while a therapist was sought, and there were absences due to vacations, illnesses, and other cancelled sessions. For Preschool interventions, the child's

Individualized Educational Plan (IEP) was usually included in the EI record. For 31% of the children, DOH records for Preschool were not available and in this case the amount reported by parents in the follow-up questionnaires was used.

Procedure

Participant recruitment

In the preparation or feasibility phase, stored UCEDD agency clinical records for children with birthdates from 1995 to 2007 were reviewed. Children were identified as having ASD using the ASD Decision Making Protocol as developed by the first Author (see Author, 2009, 2014, 2018). Using this protocol, children were placed in categories of Confirmed ASD, Highly Probable ASD, and Possible ASD. Only Confirmed and Highly Probable designations were included in the initial pool of children, the parents of whom were the Participants. A reliability study was carried out for this coding (see Author, 2009, 2014). Another criterion for initial selection was the availability within the agency records of EI and preschool diagnostic assessments, disciplinary evaluations, Individual Family Service Plans (IFSPs), progress reports, and preschool Individual Education Plans (IEPs). This resulted in an initial pool of 229 children.

After IRB approval had been obtained, parents were then contacted to be recruited to participate in a questionnaire-by-mail follow-up study. For the initial pool of 229 potential families, 141 could be located and contacted by phone or letter (61.6%). Of these, 14 families declined to participate (9.9%). Questionnaire packets were sent out to 127 parents, of which 70 were returned, making a return rate of 51.1%. For the current study, two children were eliminated due to insufficient EI or preschool data, resulting in a final sample of 68.

Recording of services received

The first source was the authors' agency clinical charts, which were used to identify children with ASD. Within these charts were several types of documents that had been gathered for record review or service coordination available (e.g., IFSPs, progress notes). The second source was outside of the agency, at the Department of Health, from where the EI program was administered. These separate records contained billing records as well as the similar documents as the home agency's charts (e.g., IFSPs, progress notes) but often a more comprehensive set.

The parent questionnaire packet included an additional consent form to examine their child's charts housed at the county Department of Health. All parents gave this permission and thus the DOH billing records could then be accessed. As the study was done before individual electronic records were maintained, the information was available on paper. The relevant sections of the child's charts from the Department of Health were photocopied then de-identified and subject numbers assigned. A trained master's-level research assistant manually recorded the hours of therapies received across the days and weeks using a combination of billing records, progress notes, and IFSP and IEP documents. The core source of information for the specifics of hours and types of services received for each child was the billing records, while progress notes and the other documents were primarily corroborative.

Disciplinary services recorded were speech therapy, occupational therapy, applied behavioral analysis (ABA), special instruction (traditional/non-ABA), physical therapy, feeding therapy, nutrition services, and family training. Data included for each discipline was: age at which the child began receiving the service, length of time received (in weeks), total hours for the duration, and hours-per-week (intensity). We also calculated total hours and intensity of combined child-focused interventions (special instruction, ABA, speech therapy, occupational therapy, and physical therapy) for EI and Preschool separately.

In the county's service model, therapies could be provided in the home, at a clinic, or as part of EI/Preschool program. A convention was adopted to record special instruction hours when children attended EI or preschool special education programs, which ran for 2.5 h per half day. First, the time a child spent in individual therapies (speech, occupational, and physical therapy) was subtracted. Then an hour was subtracted for presumed non-instructional time such as arrival and departure activities, loosely supervised free play, recess, snack, and lunch. Thus, an hour of special instruction per half-day was recorded.

Statistics

Frequencies, means, ranges, and standard deviations are reported for therapies received. For the six NVDQs not available, linear regression was used to predict NVDQ scores from Vineland Adaptive Behavior scores. For total hours of therapies received (to be used in the total intensity calculation), the non-normal distribution was addressed with Winsorization (Simplified Estimation from Censored Normal Samples, Dixon, 1960). This technique moves the outliers (those outside the 5th and 95th percentiles) closer to the more frequent observations. Total intensity of all therapies in EI and Preschool was calculated by summing the hours across the 5 therapies and then dividing by the sum of all the weeks each therapy was received. Comparisons across EI and Preschool were completed with longitudinal Winsorized regressions for continuous data and multiple logistic regressions for categorical data. All analyses were done using Stata software.

Results

Child and Family Characteristics

In terms of child characteristics, there were 58 males and 10 females (male:female ratio of 5.8:1). The average age of diagnosis or recognition of ASD was 25.3 months ($SD = 5.3$, range 15–36 months). The average NVDQ was 74.09 ($SD = 18$, range 37–106). It is important to remember that these participants were drawn from the Early Intervention, wherein all were 3 years or younger.

Table 2 shows the parent demographics for the sample. This is a relatively highly educated, White sample of parents. Family income based on the census tract information (see Method) ranged from USD49,000 to $> USD250,000$, with a median of USD134,000.

Table 2
Parent Demographics

Ethnicity	<i>n</i>	%
White	63	92.64
African American	1	1.47
Hispanic	2	2.94
Asian	2	2.94
Educational Level		
Father (n = 68)		
High School or Less	10	14.70
2–4 Years College	30	44.12
Master’s Degree or Higher	28	41.18
Mother (n = 67)		
High School or Less	3	4.47
2–4 Years College	33	49.25
Master’s Degree or Higher	31	46.26
Income Level of Based on Census Tract Data of Primary Residence ^a (USD)		
< 68,000	5	7.35
68-99K	17	25.00
100-149K	20	29.41
150-199K	13	19.12
200-249K	9	13.23
>=250K	5	7.35
^a Median income for family of four in Westchester County, NY is USD89, 968; poverty level is USD67,898.		

Description of Services Received

Table 3 shows the types of services received in EI and Preschool: the percentage of children who received each disciplinary service and the mean intensity and ranges thereof. All children in this sample who began intervention in the EI period continued to receive fairly intensive preschool services. In both EI and Preschool, speech and occupational therapy were the most common therapies received, followed by

special instruction, ABA, physical therapy, then family training. Feeding and nutrition services only occurred in EI and for relatively few hours. The largest number of hours-per-week were in the disciplines of ABA and special instruction.

Table 3
*Types of Services Received in Early Intervention and Preschool:
Percentages of Children and Intensity (N = 68)*

Discipline	n %	Intensity	
		m	Range
EI Speech Therapy	65 97.05	2.04	1.1–4.20
Preschool Speech Therapy	66 100.00	2.20	1.0–5.80
EI Occupational Therapy	61 89.71	1.49	0.5–3.50
Preschool Occupational Therapy	64 98.48	1.53	0.5–3.40
EI Special Education	52 76.47	4.09	0.75–15.2
Preschool Special Education	55 83.33	8.44	1.0–21.0
EI ABA	44 64.71	13.30	1.5–41.0
Preschool. ABA	45 68.18	15.47	1.5–33.5
EI Physical Therapy	23 33.88	1.01	0.1–3.0
Preschool Physical Therapy	29 43.93	1.04	0.5–1.5
EI Family Training	27 42.65	1.02	0.2–3.0
Preschool Family Training	29 50.00	0.86	0.2–4.3
EI Feeding	17 25.00		
Preschool Feeding	0 0.00		
EI Nutrition	1 1.47		
Preschool Nutrition	0 0.00		
Note. These results are for children who received the therapy			

Intensity of services

Intensities are used as the primary measure of use because they take into account the number of hours received across the number of weeks the therapy was received. This equalizes the metric for children who started EI later than others, and the few children who left Preschool early. Intensity also allows comparisons between EI and Preschool. Table 4A shows the number of children receiving different numbers of therapies in EI and Preschool and the average intensities summed across the services

received. By Preschool, all children received at least three therapies simultaneously. The mean intensity for preschoolers increased from EI (Wald chi-square: $X^2(1)$, 26.2, $p < .000$).

The distribution of weekly hours shown in Table 4B revealed that 74% of preschool children received over 15 hr./week of intervention. Over half (53%) of the sample received a full complement of four or five child-focused therapies. About half the children had up to 15 hr./week and half had 15 to 25 + hr./week; 5 children had more than 30 hr./week.

Forty percent received a combination of special instruction or ABA and speech and occupational therapy. Another 15% received these four therapies plus physical therapy. Of those receiving three therapies together—25%—five different combinations occurred.

We suspected that the largest intensity totals were due to having ABA services included in the assemblage of services. This was confirmed by a significant result comparing the trimmed (Winsorized) mean intensity between those who had ABA in their therapies and those who did not. For EI: (No ABA ($n = 24$), $M = 6.28$ h, $SD = 4.75$ hr.; Yes ABA ($n = 44$), $M = 21.13$ hr., $SD = 8.08$ hr.; $t(66) = -8.24$, $p < .000$). For Preschool: (No ABA ($N = 21$), $M = 11.49$ hr., $SD = 5.28$ hr.; Yes ABA ($N = 45$), $M = 26.52$ hr., $SD = 6.18$ hr.; $t(6) = -9.62$, $p < .000$).

Age of diagnosis and age of starting therapies in EI

The age at which children started their EI services and patterns of adding and accumulating therapies was documented. Not all children began a full multidisciplinary program at a given point in time. Instead, they often arrived at a more intensive assemblage of therapies from a cumulative process. Figure 1 shows the relationships between increasing age (x-axis) and the different disciplinary therapies received (y-axis). The peak of new diagnoses (gray bar) was between 19 and 24 months of age, with declining numbers from 25–36 months. Over time, speech and occupational therapy consistently increased. ABA and special instruction were less frequent before 24 months and increased after that. Family training was not received until all children in the sample were 24 + months and stayed at the same level over the 25- to 36-month periods.

Prediction from child nonverbal cognitive level and neighborhood income

We examined the relationship between the child functioning level (NDVQ) and average intensity of services. The correlation coefficient for EI not significant; in Preschool, it was significant ($r(66) = -0.31$, $p = .01$). The lower the NVDQ, the higher the intensity of services. For neighborhood income as predictor, using both correlational and group comparisons, no analyses were significant for average intensity of services received.

Discussion

Hours, individualized programs, and therapy disciplines

This study revealed a heterogeneous landscape of interventions that young autistic children received through the public EI and Preschool (Part C and B) programs services during the years 1997 to 2012. Billing records and parent report showed that families residing in this high-resource county proximal to a major metropolitan area accessed a relatively large number of hours and multiple therapy combinations. The most frequently utilized therapies were speech therapy, occupational therapy, and special instruction, followed by ABA. These disciplines retained their prominence from the EI to the preschool period. Previous studies also have shown these therapeutic disciplines to be the main ones in EI (Bilaver et al., 2016; McIntyre and Zemantic, 2017; Noyes-Grosser et al., 2018), including several studies reflecting the same time period as the current one (Anaberri et al., 2021; Downs & Downs, 2010; Stahmer, 2007). This consensus should inform administrators and policy makers about the specific professional resources needed for children with ASD. One difference in the current study, however, was the prominence of ABA use, while this was not the case for the other studies.

Intensity of programming

There are two issues to consider here: how this sample compares to others who have reported similar data on autistic children, and how these numbers compare to best practice as represented in the literature in general. Regarding the first, for the EI period, Noyes-Grosser et al. (2018) reported the average hr./week for children in New York State as 13 hr. ($SD = 5$). Stahmer (2007) reported on children in two California counties (surveying 80 agency directors or supervisors) and the average hr./week was estimated by administrators as approximately 10 hr. (as estimated by the graph presented). McIntyre and Zemantic (2017) calculated 3.2 hr. ($SD = 1.6$) for children in a community outside of Seattle. The current finding of an average of 16.1 hr. ($SD = 8.6$, range 4–46 hr.) appears higher than the other locales. The intensity distribution in the current study showed that about half the children had up to 15 hr./week, about half had 15–25+, and five children had more than 30 hr./week. Regarding treatment intensity for preschoolers, the following was reported: Stahmer: $M = 15.6$ hr., McIntyre and Zemantic: $M = 13.2$ hr. ($SD = 4.7$). Our finding of $M = 23.4$ hr. ($SD = 9.36$; range 4.3–42.5) for Preschool also appears higher.

Higher intensity in our study was associated with ABA in a child's program, both in EI and Preschool—a logical finding because behavioral intervention is associated with intensive treatment approaches. Regarding treatment intensity for preschoolers, children received more weekly hours than children in EI, which is consistent with the two studies that have examined this issue (McIntyre & Zemantic, 2017; Stahmer, 2007).

As mentioned earlier, currently a definitive consensus on best practice intensity of services for young children with ASD is not available. However, the results of our study suggest that the children and families in this area are close to the recommendation by several studies that they will benefit from 15 or more hours-per-week of combined child-focused services.

All the reasons for the findings of individualized, multidisciplinary, high-intensity service provision in this sample cannot be known without systematic comparison with other areas differing in the ways that have

been shown to influence access to services. However, the county fits the enabling parameters of high SES, availability of programs and professionals, high population, and proximity to a metropolitan area. As well, Zablotsky et al. (2019) found that among various geographic areas in the U.S, autistic children in the Northeast utilize the greatest number of specialty services. This sample is 90.0% White, and many studies have shown racial and ethnic minority groups and children from low-income families receive fewer services compared to White families (e.g., Smith et al., 2020). The sample had mostly (but not all) high SES families, and research has shown that such families use more services (Yingling & Bell, 2020). Finally, these families accessed specialized evaluation services in a UCEDD, suggesting that they could navigate the EI system to their advantage.

Another little-discussed characteristic is an administering region's experience with litigation (<https://caselaw.findlaw.com/court/us-7th-circuit/1136834.html>; https://www.wrightslaw.com/law/art/winkleman.pwanalysis.htm#google_vignette). Such history could influence patterns of service provision, especially if the judgments were in favor of the parents.

Building a therapeutic program over time in EI

Our findings about the cumulative process of adding therapies during EI gives additional insight into the children's experiences. In practice, these adjustments reflect requirements from the EI intervention law, specifically, that every IFSP is reviewed at regular intervals. At IFSP reviews, disciplinary progress reports from the previous quarter are considered and programmatic changes are a result of collaborative conversations among parents, providers, and EI program representatives.

Our data also show that children who eventually have ASD diagnoses often first enter the system because of developmental delays such as global developmental delay or specific language delay. As a result, many children began to receive some combination of motor, communication, and cognitive (special instruction) therapies in their second year and sometimes before 18 months. In the first author's experience, as social-communication symptoms as well as repetitive behaviors associated with ASD become more evident toward 24 months and after, ASD is more likely to be diagnosed and then therapies intensified and/or ABA added. This interpretation would be consistent with the data. Previous studies have also shown that children with ASD are often identified through the public EI system before they are diagnosed, and that children who are already in the system are more likely to be diagnosed than those who are not (Monteiro, 2019; Yingling, 2019).

Predictors of service received

NVDQ predicted total intensity of services in preschool (lower NVDQ was associated with a higher level of service). This is consistent with previous research (Bilaver et al., 2016) as well as with the logic that children with more needs require more services. It also suggests that, in this case, the public program is responsive to the child's needs, consistent with the EI law intent that services be individualized for each child and family. The second predictor examined was demographic. Although the county is generally high-income, there are large cities within that are not, and our sample varied in this way sufficiently to

explore the relationship between income and services received. Neighborhood income did *not* predict total intensity of services. This is in contrast to what two other studies found—that lower income was associated with fewer services (Aranbarri et al., 2021; McIntyre & Zemantic, 2017). A tentative conclusion is that being proximal to resources enables more equitable access in spite of family income.

Age of the data

The fact that the data were collected a number of years ago warrants discussion. The data were collected between 2011 and 2019; however, the children's EI and preschool experiences occurred from 1997 to 2012. A key issue is legislation for which the intent is increased access to evaluations, treatment, and systems coordination, and what effect this would have on differences in access to, and amounts of, services available to families and children. At the federal level, the Combating Autism Act (https://www.everycrsreport.com/reports/R42369.html#_Ref302119774), which was enacted contemporaneously with much of the study's data collection period, funded the Leadership Education in Neurodevelopmental Disabilities programs, one of which was in the study county. This program included training in autism including early identification. However, most key legislation affecting state and local entities were operative after the study period and into the present. In 2010, The Combating Autism Act funded a State Implementation Grant in New York. This grant trained pediatricians and general practitioners in early screening and identification of ASD, increasing awareness of ASD and referrals the EI program. The Autism Insurance act (Autism Insurance Law (§§ 3216(i)(25), 3221(l)(17), and 4303(ee))), took effect in New York in 2012. This and the consolidated Medicaid waiver act, enacted in New York in 2019, significantly contribute to EI funding in New York. In 2014, the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act continued to fund LEND programs, as well as development of comprehensive, coordinated state systems of care for ASD and other DDs. All these policy and initiatives would theoretically *increase* availability of services and thus data from the past should not be an over-estimate for the present, but this remains to be shown empirically.

A final factor is a local development: in the last 10 years at least four new agencies that contract with both the EI program and school districts have opened in the county. Three of the four focus primarily on behavioral intervention and ABA services in particular. This development adds to the enabling feature of resource availability in the region.

Limitations of the study

Limitations need to be considered. Since the intent of the study was to investigate public EI and Preschool intervention experiences in a high-resource area, obviously results do not represent those regions with fewer advantageous features. As well, the degree to which results would be similar to other high-resource areas is not known. Finally, the age of the data limits the generalizability to current samples, although as explained above, subsequent policy changes would not necessarily decrease the amount of services available.

Another limitation is that some key variables were not available in the data set in the same way as for a prospective study. Many of the children were not evaluated by the authors, and a strategy was devised to determine each child's ASD diagnosis from archival records. As well, cognitive level came from mixed sources in the records. Therefore, the NVDQ was derived by creating a MA/CA X 100 quotient based on nonverbal mental age equivalents and thus was not a standardized score.

Conclusions and Future Research

This study represents one of the few detailed descriptions of public EI and Preschool service provision for children with ASD in the United States, the only one that used billing records for more accurate data, and the only one focusing on a high-resource area that may reflect outcomes when the recommended services can in fact be provided. Results showed that under these circumstances, intense services and a full multidisciplinary program—individualized for each child—can be achieved for young children with ASD. Future research is important to obtain current information about service patterns for young autistic children in public EI and Preschool programs. Continuing this type of research specifically within different geographical regions and with varying demographics can contribute to practice and policy addressing equal access to essential services across communities.

Declarations

Ethical Approval: This study was approved by the Institutional Review Board of the New York Medical College. Informed Consent was obtained from the parents of the children studied.

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Table 1,4

Table 1,4 are available in the Supplementary Files section.

Figures

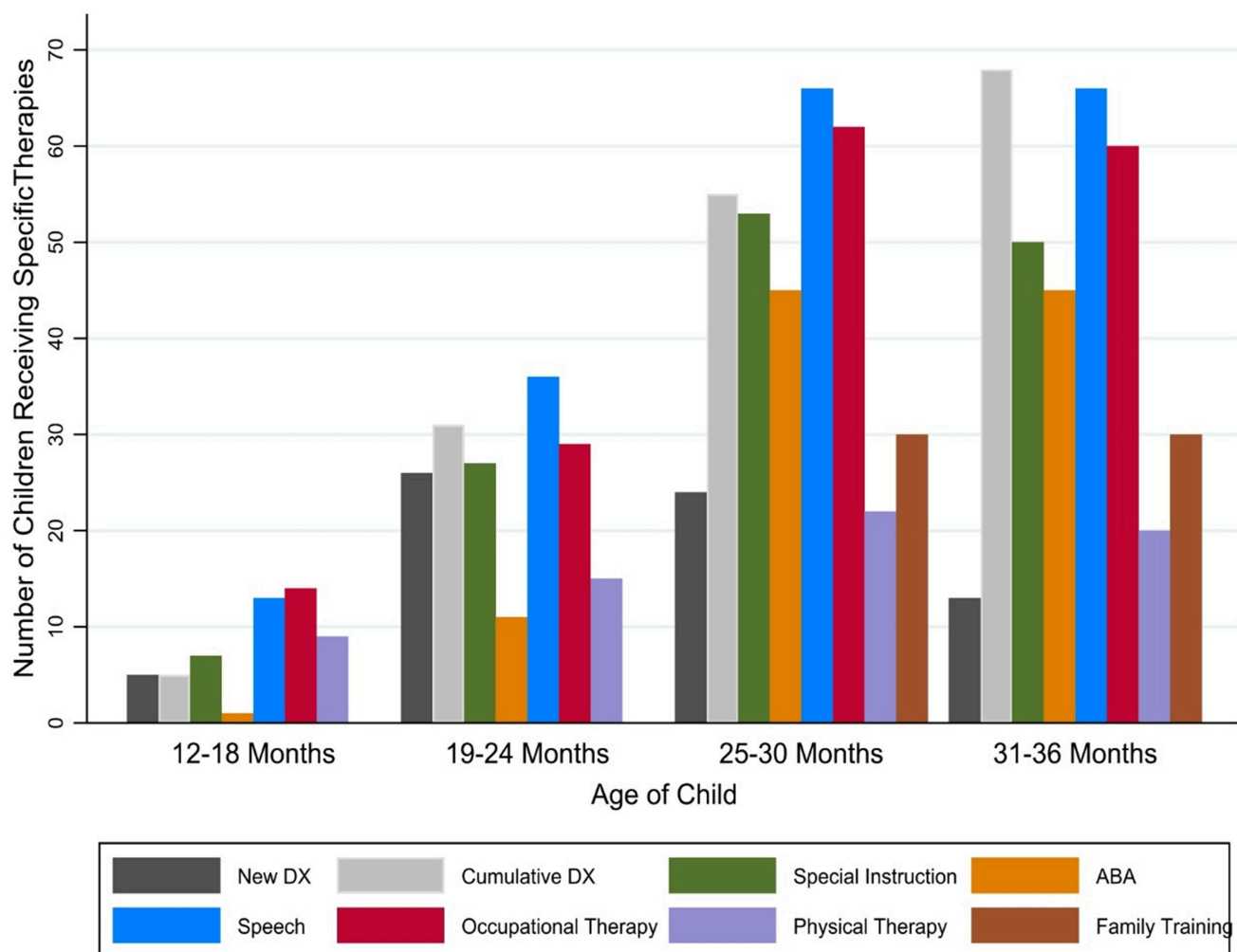


Figure 1

Disciplinary Therapies Received Over Time and Cumulative Numbers of New Diagnoses

Supplementary Files

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