

Autism Spectrum Disorders: Reasons for Treatment Referrals Across the Developmental Life Span

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As the identification of autism spectrum disorder (ASD) continues to rise and the demand for intervention increases, data on referral concerns across the life span are necessary to help community programs prepare for meeting the needs of children and families. The purpose of this study was to examine reasons for referral for treatment of 113 randomly selected children with ASD who represented one of four developmental stages (2-6; 7-11; 12-14; 15-21 years). The associations between child variables of IQ and verbal ability and types of concern were examined. Results revealed that the top three referral reasons were: (a) social skills (72.6%), (b) behavior (52.2%), and (c) speech (49.6%) concerns. Social skills and behavior concerns were evenly distributed within all four developmental stages. Speech concerns were significantly higher in the preschool stage than in any other stage ($p < .001$). An IQ below 70 was significantly associated with speech concerns ($p < .001$) and an IQ above 70 was significantly associated with social skills concerns ($p < .001$). As expected, speech concerns were significantly higher in individuals who were nonverbal. These findings provide new information for treatment providers and program administrators who are responsible for the provision of services for individuals with ASD.

INTRODUCTION

Autism spectrum disorders (ASDs) are recognized as relatively widespread and affect about more than 1% of children¹ with higher rates in boys (1 out of about 54 to 70), more prevalent than childhood cancer, diabetes, spina bifida, and Down syndrome combined.² ASDs significantly impair development of social and communication skills and

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are considered chronic disorders that typically last a lifetime. The core deficits of communication, social interaction and restricted/repetitive behaviors remain generally stable over time.³ Piven et al,⁴ however, found notable improvements in communication and social behaviors compared to repetitive behaviors, but Eaves and Ho⁵ reported the opposite finding. McGovern and Sigman³ specified that high functioning adolescents showed more improvements in social interaction, repetitive behaviors, and emotional responsiveness than their lower functioning counterparts. Matson et al⁶ found a higher incidence of challenging behaviors (ie, aggression, property destruction, and self-injurious behaviors) in children with ASD behaviors that were persistent and stable over time compared to behaviors of children with other disorders. Thus, more information is needed about the changes in symptoms over time, and particularly, what changes pose concerns for caregivers.

The goal of treatment for children with ASD is to help each child reach his/her individual

TREATMENT REFERRALS FOR ASD

potential by enhancing developmental skills, most often in the areas associated with the core deficits in autism—social, communication, and adaptive behavior skills. Research indicates that children who receive high-intensity specialized treatments (at least 25 hours weekly) when they are young are more likely to have better social, cognitive, and communication outcomes.^{7,8}

Despite the fact that children and families of autism require highly intensive services from multiple providers addressing a broad range of difficult issues, relatively little is known about the types of services parents seek in outpatient health care settings. Information on the reasons for treatment referrals can assist program administrators in designing and planning treatment programs and preparing their workforce in meeting the complex needs of children with ASD and their families in their own communities.

While changes in symptoms over time appear to be associated with the level of functioning of the individuals with ASD, it is not clear how these changes affect referral patterns and treatment needs across the life span. Further, it is not clear if parent/caregiver referral concerns are affected by individual specific characteristics such as age, intelligence level, and language skills. To begin to answer these questions three research questions were asked: (a) What are the reasons for referral for treatment? (b) Are reasons for referral associated with age? and (c) Are child variables of IQ and language associated with reasons for referral?

METHOD

A cross-sectional retrospective study of medical records of children who received

outpatient services from an autism treatment center in Kentucky, US, was conducted. The medical records of participants were randomly selected and then divided into one of four groups based on age at the time of referral to treatment. The study was approved by the Institutional Review Board.

Sample

The study sample included a total of 113 randomly selected children with an established diagnosis of Autistic Disorder, Aspergers Disorder, or Pervasive Developmental Disorder-Not Otherwise Specified (DSM-IV-TR⁹), and referred to the autism center for treatment. The initial referrals had to come from a physician or other health care provider. Approximately the first 30 children in order of date of birth were selected from 801 medical records of children who represent each different developmental stages: (a) preschool (2-6 years), (b) elementary (7-11 years), (c) middle (12-14 years) and (d) high school (15-21years). Of the 30 medical records selected in the last category (15-21 years) only 23 were available for review. Table 1 describes sample characteristics.

Data Collection and Analysis

The top three reasons for referral by caregiver or referring physician for each selected case was classified under nine broad categories (defined in Table 2): (a) social skills, (b) speech, (c) behavior, (d) sensory/motor, (e) academic, (f) anxiety, (g) depression/mood disorders, (h) adaptive functioning, or (i) other. Inter rater reliability was calculated to ensure reliable classification under the nine broad categories. Two raters independently

Table 1. *Sample Characteristics*

Developmental Stages	Number of Individuals	Female	Male	Verbal	Non verbal	IQ>70	IQ<70
Stage 1 (2-6)	30	11	19	15	15	5	25
Stage 2 (7-11)	30	2	28	22	8	19	11
Stage 3 (12-14)	30	7	23	25	5	21	9
Stage 4 (15-21)	23	1	22	18	5	16	7
Total	113	21	92	80	33	61	52

Table 2. Referral Concern and Definition.

Category	Definition
<i>Social Skills</i>	concerns of social interactions including taking another's perspective, emotional responsiveness, pragmatic communication, or making friends
<i>Speech</i>	concerns about receptive/expressive language skills or statements indicating inability to use language to communicate
<i>Behavior</i>	concerns about behaviors that were not socially appropriate or acceptable such as aggression, tantrums, noncompliance, and self-injury, or self-stimulatory / repetitive behaviors
<i>Sensory or motor</i>	concerns that indicated fine/gross motor difficulties and sensory sensitivities including abnormalities in sight, sound, smell, touch or taste
<i>Academic</i>	concerns regarding competence in educational achievements pertaining to school or other institutions of learning
<i>Anxiety</i>	concern describing symptom or features of diagnostic criteria for phobias, panic attacks, post traumatic stress disorder, obsessive compulsive disorder, separation anxiety, or generalized anxiety disorder
<i>Depression or mood disorder</i>	Concerns of mood disturbances such as irritability, sadness, or mood swing
<i>Adaptive functioning</i>	concerns regarding age-appropriate behaviors necessary to live independently and to function safely and appropriately in daily life
<i>Other</i>	concerns or difficulties that could not be attributed to the other categories

sorted the concerns and an inter rater reliability of .90 was achieved for exact agreement.

Language level and IQ determination

IQ and language ability were determined from testing scores available in the medical records. Each child was classified as "verbal" if they used spoken language to communicate or "nonverbal" if they had no recognizable language and required an alternate method to communicate at time of referrals indicated in their medical record. After eliciting IQ data from medical records, children were then classified in either one of two different categories for intellectual functioning: (a) IQ >70 or (b) IQ < 70.

Data analysis

Frequencies of referral concerns were calculated for each developmental period. Data was analyzed to determine whether referral concerns were associated with different developmental stages. Nonparametric measures such as chi square were used to study the association between the top three referral concerns and child IQ/verbal ability.

RESULTS

The top three reasons for referral for the 113 cases reviewed were: (a) social skills issues (72.6%), (b) behavior issues (52.2%), and (c) speech concerns (49.6%) (See Figure 1). As noted in Figure 1, social skills and behavioral concerns were more evenly distributed

TREATMENT REFERRALS FOR ASD

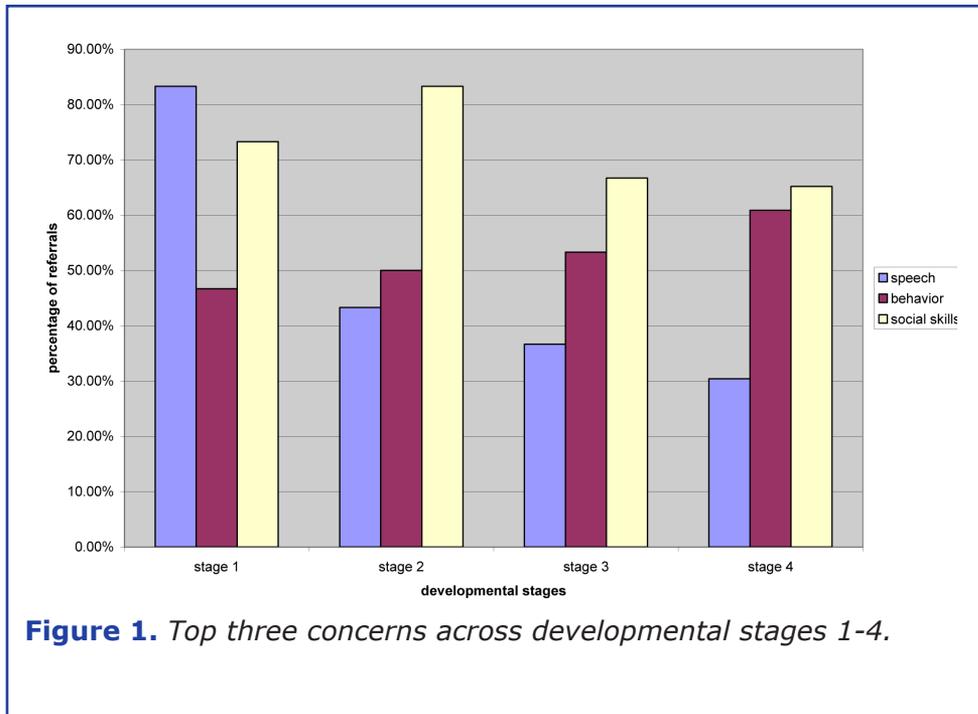


Figure 1. Top three concerns across developmental stages 1-4.

within all four developmental stages and were not differentially reported for any particular age group compared to speech concerns. Table 3 shows the results from the Chi-square analysis for each reason for referral by age, IQ, and verbal ability.

Referral for speech concerns was associated with all three child variables of age, IQ, and verbal ability. Speech concerns were reported more frequently for the preschool stage (84%), compared to any other stage ($\chi^2 = 19.51, p = .000$). Also, individuals referred with an IQ below 70 were more likely to be referred for speech concerns (74%) compared to individuals with an IQ above 70 ($\chi^2 = 26.8, p = .000$). Speech language requests were higher in individuals who were nonverbal (88%; $\chi^2 = 27.38, p = .000$).

Referrals for social skills revealed associations with IQ and verbal ability, but not with age. Caregivers of individuals with IQs above 70 (85%; $\chi^2 = 12.79, p = .00$) and with verbal ability (65%; $\chi^2 = 25.77, p = .00$) were more likely to express social skills concerns.

Lastly, referrals for concerns of behavior showed no associations with any of the child factors of age, verbal ability, or IQ.

DISCUSSION

The purpose of this study was to provide new information on the reasons that parents and caregivers seek referral for outpatient services on behalf of their children with ASDs. Such information is helpful for program developers and administrators responsible for providing community-based services.

Of the eight possible reasons for referrals, caregiver concerns fell most frequently within

the domains of social skills, behavior, and speech, respectively.

When the reason for referral is examined by age, caregivers of the preschool population were most concerned about speech. But as children get older there is a drop in referrals for speech services. Possible reasons include that children may develop verbal skills as they get older or already have an established means of communication using an alternate method of augmentative communication. Another reason is that other concerns may take preeminence as children with ASD get older. Many studies have shown that there are age-related changes in social and communication behaviors in high IQ autistic individuals. For the most part, the changes are in the direction of improvement.⁴

Mesibov et al¹⁰ also reported decreases in autistic symptoms in a group of 89 children who participated in North Carolina's TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children) program. Analysis revealed a significant decrease in mean CARS (Childhood Autism Rating Scale¹¹) scores in adolescence indicating improvement over time in 9 of 15 areas. A similar trend is seen in this sample,

Table 3. Association between Age, IQ, and Verbal Ability and Primary Concerns.

Variable	Developmental Concern		
	Speech	Social Skills	Behavior
Age ¹			
Chi Square	19.51	2.90	1.14
Significance	0.00	0.41	0.77
IQ ²			
Chi Square	26.8	12.78	2.67
Significance	0.00	0.00	0.10
Verbal Ability ²			
Chi Square	27.38	25.77	2.44
Significance	0.00	0.00	0.12
¹ df = 3; ² df = 1			

as children have progressed from developmental stage 1, speech concerns have significantly decreased.

But unlike speech, caregiver concerns with behavior and social skills persist through the different developmental stages in this sample. Similar to the findings by Eaves and Ho⁵ of 76 children followed over 4 years to early adolescence, our results suggest that social relatedness continued to be an ongoing issue regardless of verbal ability and age. Matson et al⁶ in their cross sectional study of children 3 through 14 years of age also found no differences between the three age groups (young childhood, child, and young adolescent) in terms of challenging behaviors. They concluded that challenging behaviors in children with ASD tend to be persistent and stable over time.

Also in this sample referral concerns were associated with IQ and verbal ability. The focus for children with an IQ above 70 and who were verbal were in the direction of improving their social interactional skills. These findings, as mentioned earlier, suggest that the social skills impairments remain stable regardless of age and IQ and significantly impact adaptive functioning.¹² In their follow-up study of 16 high-functioning individuals who had received a diagnosis of autism in early childhood, Szatsmari et al¹³

found 12 of these individuals in adulthood were living with their parents, had some form of employment, but were hardly dating and not involved in any long-term relationships. Most of these individuals had been determined to have an IQ higher than 80, and yet, while they could maintain some level of employment, they were still having difficulties in their social functioning, a finding echoed by others.^{10,14}

In addition to providing information for program administrators and clinicians who are planning services and anticipating needs by the age of referred children, research on referral concerns is also important for helping clinicians assess caregivers' top concerns. In a recent study by Weisz et al,¹⁵ analyses of top problems reported by caregivers and youth referred for psychotherapy in outpatient settings resulted in the Top Problems measure that provided a clinically relevant assessment that could be used to identify and monitor treatment response repeatedly. The information gathered from the psychometrically sound instrument complemented standardized assessment measures, but it also added specificity. Such a measure for identifying and assessing response to treatment in autism spectrum disorders would be valuable.

A limitation of this study is that the sample selected was restricted to referrals

TREATMENT REFERRALS FOR ASD

received to one outpatient clinic in Kentucky, and may not be representative of referral concerns in other regions. Yet results obtained from this analysis tend to be consistent with outcome data of the few longitudinal studies attempted in the area of Autism Spectrum Disorders.

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