

Autism Knowledge Survey: Trends in Understanding of Autism Spectrum Disorders

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Abstract

The Autism Knowledge Survey-Revised (AKS-R) is a 20-item measure that assesses a participant's degree of agreement with several statements regarding autism spectrum disorders (ASDs) including etiology, interventions/treatments, diagnosis, and outcomes. Participants included parents and caregivers, educational personnel (i.e., educators, paraprofessionals, administrators), medical care providers (i.e., physicians, pediatricians, nurses), and licensed therapists (i.e., Ph.D., BCBA, OT, SLP). Additionally, participants were asked to report on their years of experience with ASDs (none, less than 2 years, between 2 and 5 years, or 5 or more years). Information regarding the trends in understanding of autism spectrum disorders across disciplines and years of experience are presented.

Introduction

How society perceives autism spectrum disorders (ASDs) has the potential to impact the way those with ASD are treated in the community, the amount of much research and funding initiatives devoted to it, and the types of policies developed to support those with the disorder. More importantly, those who interact on a regular basis with individuals with ASD should be knowledgeable about the cause, diagnosis, treatment, and symptom presentation. Many researchers agree that it is essential for those in the medical field (Shah, 2001) therapists (Stone, 1987), educators (Stone & Rosenbaum, 1988), and parents (Stone & Rosenbaum, 1988) to be aware of current beliefs about ASD in order to best facilitate diagnosis, treatment planning, and collaboration. Misinformation by any of the above groups can lead to delayed services, frustration, and inaccurate diagnosis or treatment planning. Additionally, it is unknown as to the extent that years of experience contributes to understanding about ASDs. To examine current trends in understanding across disciplines and years of experience with ASD, the Autism Knowledge Survey-Revised (AKS-R) was used. The AKS-R is a revision of a 23-item scale developed by Stone (1987) and is updated to assess areas of diagnosis, intervention/treatment, and outcomes for individuals with ASD. In the original use of the AKS, Stone (1987) found that misconceptions about various aspects of autism exist in all professional groups and discrepancies from specialist views were largely due to the persistence of older views that have since been challenged or refuted. Stone and Rosenbaum (1988), also used the AKS but compared parents and teachers to specialists views. Results from that study showed misconceptions to exist in both groups and differing beliefs to exist between the two groups. Taken together, the results suggest that misconceptions exist across all disciplines compared to specialists views and that these misconceptions have the potential to adversely affect service provision and system collaboration for individuals with ASDs.

Hypotheses

It was hypothesized that a majority of the sample would agree with the specialists view. Additionally, it was hypothesized that years of experience with ASDs would be positively related to the number of respondents agreeing with the ideal response, with more years of experience relating to a greater proportion of respondents agreeing with specialists views.

Information regarding differences across disciplines is largely exploratory. However, it is hypothesized that those assigning diagnoses (i.e., medical professionals and licensed therapists) would be more like specialists' views on issues related to diagnosis and symptom presentation compared to groups that do not assign diagnoses (i.e., caregivers, educators).

Methods and Participants

A sample of 502 individuals completed the AKS-R from May, 2006 to December, 2007. Participants were recruited through conferences and awareness events, email listservs, announcements on the Internet, and paper copies distributed at an autism specialty clinic. Responses were anonymous. Participants were asked to complete the survey and answer basic demographic questions (age, $M = 38.04$, $SD = 10.02$ years; gender, female $n = 429$, male $n = 59$) as well as select which discipline they most identified with (parent/caregiver, $n = 273$; medical, $n = 45$; educational, $n = 118$; therapist, $n = 45$; or other, $n = 8$). Additionally, participants were asked to report how many years of experience they had with individuals with ASD (none, $n = 20$; < 2 years, $n = 73$; 2 - 5 years, $n = 126$; or 5 + years, $n = 218$). The majority of participants were female parent/caregivers, with 5 or more years of experience with ASD.

Measures & Coding Procedures

Participants were asked to rate their agreement with a statement about autism spectrum disorders on a 6-point scale (1 = Fully Agree with the statement; 6 = Fully Disagree with the statement). Responses are compared both with other participants as well as to the model or 'correct' responses as determined by specialists at the Christian Sarkine Autism Treatment Center. Specialists included representative from medical, educational, and therapist roles, all with 5 or more years of experience with ASDs. As more research evidence in this field emerges, it is possible that some of the model responses may change making past responses obsolete. Responses were calculated as frequencies and are presented as the proportion of each categorical group that matched the ideal response. The most frequent response is also presented for each categorical group.

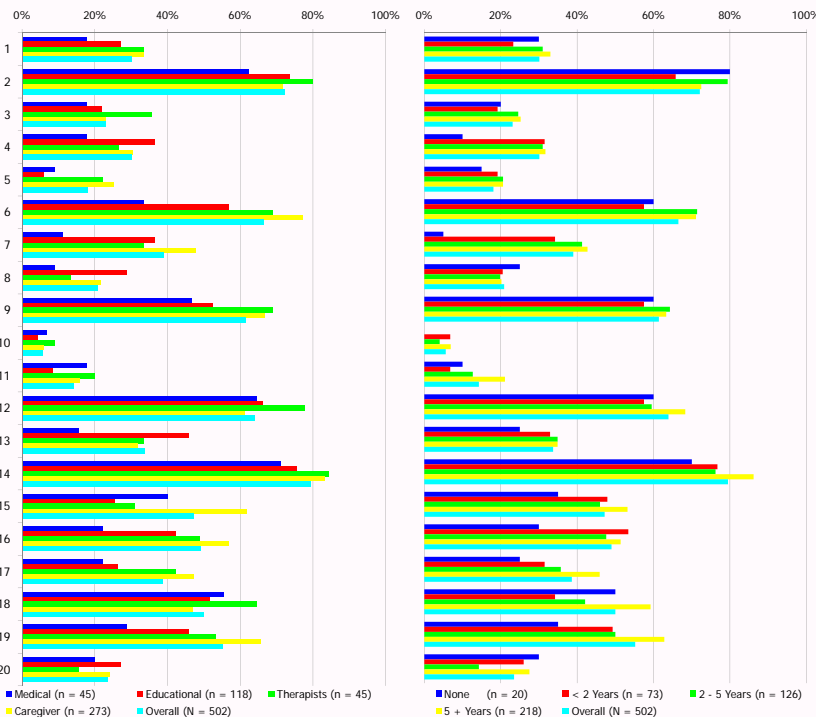


Table 1. Most frequent responses to each item by years of experience and discipline.

Item	Ideal	None (n=20)	< 2 Years (n=73)	2 - 5 Years (n=126)	5 + Years (n=218)	Medical (n=45)	Educational (n=118)	Therapists (n=45)	Caregiver (n=273)	Overall (N = 502)
1 Autism is an emotional disorder.	FD	FD	SA	FD	FD	MD	SA	FD	FD	FD
2 Early intervention can lead to significant gains in children's social and communication skills.	FA	FA	FA	FA	FA	FA	FA	FA	FA	FA
3 All children with autism display poor eye contact.	FD	SA	SD	SA	FD	SD	SD	FD	SA	FD
4 Children with autism typically perform better when tasks are presented visually than when tasks are presented verbally.	FA	MA	MA	MA	MA	MA	MA	MA	MA	MA
5 Problems with social relatedness that are present in autism are different from social problems seen in other psychiatric conditions.	FA	SA	SA	MA	MA	MA	MA	MA	MA	MA
6 Autism is more frequently diagnosed in males than in females.	FA	FA	FA	FA	FA	FA	FA	FA	FA	FA
7 Children with autism do not show attachments, even to parents/caregivers.	FD	MA	FD	FD	FD	MD	FD	MD	FD	FD
8 Research indicates that sensory integration therapy is an effective treatment for autism and its symptoms.	FA	MA	MA	MA	MA	SA	MA	SA	MA	MA
9 Children with autism are deliberately uncooperative.	FD	FD	FD	FD	FD	FD	FD	FD	FD	FD
10 Most parents/caregivers of children with autism report their first concerns were related to the child's social behavior.	FD	MA	SA	MA	MA	MA	MA	MA	MA	MA
11 Autism tends to run in families.	FA	SA	SA	SA	SA	SA	SA	SA	SA	SA
12 We now have treatments that can cure autism.	FD	FD	FD	FD	FD	FD	FD	FD	FD	FD
13 Children with autism can grow up to live independently.	FA	MA	FA	FA	FA	MA	FA	FA	FA	FA
14 There is one approach/program that works for all children with autism.	FD	FD	FD	FD	FD	FD	FD	FD	FD	FD
15 It is important that all children diagnosed with autism receive some form of special education services at school.	FA	FA	FA	FA	FA	FA	MA	FA	FA	FA
16 Autism occurs more commonly among higher socioeconomic and educational levels.	FD	FD	FD	FD	FD	SD	FD	FD	FD	FD
17 Autism can be diagnosed as early as 18 months.	FA	MA	MA	FA	FA	MA	MA	FA	FA	FA
18 With the proper treatment, most children diagnosed with autism eventually outgrow the disorder.	FD	FD	FD	FD	FD	FD	FD	FD	FD	FD
19 Children with autism do not show affection.	FD	FD	FD	FD	FD	FD	FD	FD	FD	FD
20 The need for routines and sameness is one of the earliest behavioral features of autism.	FA	MA	MA	MA	MA	MA	MA	MA	MA	MA

NOTES: FA = Fully Agree, MA = Mostly Agree, SA = Somewhat Agree, FD = Fully Disagree, MD = Mostly Disagree, SD = Somewhat Disagree. Blue text indicates responses in the opposite direction of the ideal response. Red text indicates responses in the same direction but not to the same degree as the ideal response.

Results

Results suggest a slight trend for individuals with more experience and licensed therapists to better match specialists' views about ASDs. Those with 5 or more years of experience were more like the specialists' views on 65% of the items. Therapists were more like the specialists on 45% of the items and parents were more like specialists on 35% of the items. Items with at least 50% agreement by all groups (items 2, 12, and 14) all concerned issues relating to treatments and interventions. Items relating to diagnosis and associated symptoms (i.e., items 1, 7, 10, and 20) appear to be the most variant from the specialists' views. Furthermore, these misconceptions appear to be consistent across disciplines and years of experience. Item 10 appears to be the most disparate from the specialists' views. There does not appear to be any difference between items with the ideal response being a disagreement and those with the ideal response being an agreement.

Conclusions & Future Directions

The results above suggest that issues relating to intervention and treatment may be more easily understood compared to more complex issues concerning diagnosis and symptom presentation. Therapists and those with five or more years of experience are more likely to match specialists' views compared to other groups and those with less years of experience. Item 10 appears to be a common misconception as participants across all groups and all years of experience reported a majority of responses in the opposite direction of the specialists' views. There are several limitations to the study. It could be that responding to either agree or disagree is more a matter of personal preference as opposed to a true degree of agreement or disagreement to the statement. A second concern is in the specific specialties in each role category. For example, educational may include educators, paraprofessionals, or administrators. This wide range of training backgrounds may make comparisons across groups more difficult.



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