



Research Brief

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Assessing the Needs of Individuals with Autism Spectrum Disorder in Virginia: Report of a Parent Survey

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In the summer of 2005, the Virginia Tech Autism Research Group, in conjunction with the New River Valley Autism Action Group conducted a survey for the purpose of evaluating and improving services for those diagnosed with Autism Spectrum Disorder (ASD) in Virginia. The following is a summary of our findings from this survey.

A full report of our survey can be found on our webpage at www.psyc.vt.edu/clinics/autism/

Information was received from 146 respondents, primarily of mothers (75%) of individuals with ASDs. The majority were Caucasian/ European American (89%), with a college degree or above (59%), and a household income of \$40,000 and above (67%). Most lived in Virginia (79%) and in their current county (65%) for over a decade, with approximately a third of the sample currently residing in Montgomery County (29%). With the exception of Campbell (11%), the remaining counties were fairly evenly distributed between 2-6%.

The average child described in this survey was 10 years old and had completed the 3rd grade. Ages ranged from 2-40 years old, but

the most frequent reports were for children who were 5 years old and in preschool. The majority of children were boys (83%), with a ratio of approximately 5:1.

The majority of children reported in this study have a diagnosis of Autism/Autistic Disorder. The average age at the time of diagnosis was 4 years, 9 months, but the most frequent age of diagnosis was 3 years old. Most of the children with ASD were reported to also have other diagnoses (88%), most commonly problems with anxiety, attention/hyperactivity, and digestion. A small percentage (9%) of the children with ASD also had younger siblings on the autistic spectrum. Siblings with ASD were most frequently diagnosed with Asperger's Disorder.

Most of the children (43%) described in this survey were first diagnosed by a developmental pediatrician. Although many (41-45%) of the professionals who made the diagnosis provided additional information about autism and available resources and spent some time discussing autism with the family, 18% of professionals provided no additional information beyond the diagnosis.

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Parents most often turned to the media (71-73%; internet, books, videos, etc.), conferences/workshops (42%), or other parents (42%) for additional information about ASD. Only 15-20% of parents reported obtaining this information from local healthcare, educational, or early intervention professionals. Most parents (59%) did report belonging to a parent support or advocacy group, which speaks to the importance of parents helping parents. *The relatively low percentages of information reportedly received from professionals, however, suggest that this avenue of support and information can be strengthened.*

18% of professionals provided no additional information beyond the initial diagnosis

Needs Assessment

The participants were presented with a list of services and were first asked if they had used the service. Next, they were asked to rate the current availability, general quality, and need/importance for the service to be offered within 30-40 miles of their home. They were asked to rate these qualities on a scale of 1 to 5 (1 = very low to 5 = very high).

The five services that most participants were currently using or had used in the past were Occupational Therapy (86%), Speech Language Therapy (85%), Family Services (71%), Web-Based Resource Network for Local Autism Resources (71%), and Diagnostic Services (70%).

On the other hand, the five services rated as having the lowest availability (rating of 1-2) were Autism Specialty Clinics/Centers (46%), Behavioral Treatment (42%), Social Skills Training (38%), Respite Care (34%), and Diagnostic Services (31%). Although many other services were rated as having high availability, these data demonstrate certain services are not readily available to

families.

The five services most participants rated as high need or importance (as a rating of 3-5) were Speech Language Therapy (79%), Occupational Therapy (79%), Family Services (77%), Web-Based Resource Network of Local Autism Resources (74%), and Behavioral Therapy (71%). Of services reported as high need or importance, only Behavioral Therapy was also rated as low in availability. This demonstrates that there are many services that families with a child with autism believe are needed and important to have in Virginia. *Importantly, many of these services are indeed being provided and used by families. One exception, however, is the low availability and use of behavioral interventions.*

The five services most often rated as having the lowest quality (rating of 1-2) were Occupational Therapy (23%), Behavioral Treatment (22%), Speech Language Therapy (22%), Early Intervention Services for Ages 0-3 Years (20%), and Diagnostic Services (20%). *These data demonstrate that, even when services are available to families, a large minority of users do not perceive the services to be of high-quality.* In addition, many respondents marked "Don't Know" for the availability, quality, and need of the services, which could suggest that the service is not readily available in their area and therefore they do not have knowledge about it.

Services with High Need/Importance and Low Availability

The following table reflects the top five services that were rated as **both** high in need/importance and low in availability in the respondents' local areas. Some services were rated as high in

need/importance (rating of 3-5) but were also perceived as being readily available to the participants, so they were not included here.

Service	Number of Participants that Rated as High Need (3-5)	Number of Participants that Rated as Low Availability (1-2)
1. Behavioral Treatment	103 (71%)	62 (42%)
2. Social Skills Training	103 (70%)	55 (38%)
3. Autism Specialty Clinics	97 (67%)	68 (46%)
4. Diagnostic Services	96 (66%)	45 (31%)
5. Sensory or Auditory Integration	90 (61%)	42 (29%)

Behavioral Treatments

Behavioral treatments are based on the idea that behaviors that are reinforced will increase in frequency and behaviors that are punished or ignored will decrease in frequency. Both Applied Behavioral Analysis (ABA) and Pivotal Response Training (PRT) are behavioral therapies that have strong empirical support for treating children with autism. Both of the therapies should be started early in the child's life (before age 5).

Social Skills Training

Children with ASD have a pervasive deficit in socialization, and Social Skills Training attempts to teach the social skills that they lack. Research has demonstrated that Social Skills Training can positively change problem behaviors of children with ASD, but there needs to be more detailed accounts of how to implement the procedures.

Autism Specialty Clinics/Centers

Autism Specialty Clinics and Centers vary in which services they offer, but could include parent training, social skills groups, and behavior therapy in addition to assessment and diagnosis. The only

way to evaluate if a clinic or center is supported by research is to see if the individual service being offered is supported by research.

Diagnostic Services

It is critical that a child with ASD be diagnosed as early as possible in their life. Several screening instruments for autism that have been shown to be effective are the Checklist for Autism in Toddlers (CHAT), the Developmental Behavior Checklist, and the Social Communication Questionnaire. To diagnose children with ASD, there should be clinical interviews with the parent or caregiver and observation of the child. The two assessment tools that are used to effectively diagnose children with autism are the Autism Diagnostic Interview- Revised (ADI-R) and the Autism Diagnostic Observation Schedule (ADOS). Other medical or psychiatric conditions should also be considered in the diagnosis of the child.

Sensory and Auditory Integration Training

Therapists who use Sensory Integration Therapy attempt to get functional responses from children through the use of different sensory activities. Auditory Integration Therapy is thought to make children with autism less sensitive to certain peak frequencies of sound by listening to electronically modified music. The use of these therapies for children with autism lacks empirical support, and so they are not currently recommended.

Conclusions

Overall, the data from this Needs Assessment Survey show that parents of children with autism in Virginia perceive that many services are of high need and yet have low availability in their local areas. Although parents rated many of these services as high need, not all

Of services reported as high need or importance, only Behavioral Therapy was also rated as low in availability.

of them are supported by current research. In general, more high quality studies need to be conducted to determine which services are most beneficial in the treatment of individuals with ASD.

Based upon the findings from this survey and available treatment-outcome research, we recommend the following services be increased in Virginia for individuals with ASDs and their families: Behavioral Therapies such as Applied Behavior Analysis and Pivotal Response Treatment, Social Skills Training, Autism Specialty Clinics or Centers, and Diagnostic Services. An ideal scenario would be a specialty clinic that incorporated evidence-based diagnostic services as well as behavioral and social skills intervention programs. Moreover, certain services are currently used and available in Virginia and should be continued. Most notably, these include Speech Language Therapy, Web-Based Resource Networks of local autism services, and Family Services such as family/sibling counseling and support groups.

Some services, even when available, were nonetheless listed as low quality by a large minority of the respondents. These included Behavior Therapy, Speech Language Therapy, Occupational Therapy, Early Intervention (0-3 years), and Diagnostic Services. In order to address this concern, we recommend that agencies carefully review the services they provide, regularly collect data on client progress, and survey parents on their satisfaction with the services provided. We also recommend that agencies rely primarily on evidence-based services that are most likely to be effective.

Lastly, a concern raised by this report is that only 15-20% of parents reported obtaining information about autism and available resources from local

healthcare, educational, or early intervention professionals. Most turn to the internet, media, and other parents for additional information. This leads to two recommendations. One is that frontline professionals (such as pediatricians and special educators) should be provided with appropriate information about ASD and the related services that are both available and recommended in their local area, and discuss this information with their patients and families. Secondly, there is a wealth of information related to ASDs in the media (i.e., internet, books, TV, etc.) and obtained from other parents. This information can be quite helpful and supportive, yet can also be overwhelming and confusing. All professionals in the field need to make a concerted effort to monitor the information parents are receiving from such indirect sources, and clarify information that may be misleading or incorrect.

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