

Autism Society of California

Key Findings of 2009 Survey

The Autism Society of California conducted an online survey to determine a course of action to assist families living with an autism spectrum disorder (ASD) in California. Online surveys were sent to over 50 California autism organizations for distribution. Families and individuals on the spectrum received an email invitation to participate in the survey from Feb 12, 2009-March 1, 2009. A total of 713 parents and 18 individuals on the spectrum participated. A total of 643 or 90% of the participants completed the survey. We realize that this is a small sample of the 45,000 families that are affected by an autism spectrum disorder; however, our hope is that this data will provide a snapshot of the needs of our families and individuals on the spectrum. This report highlights some of the key findings.



DIAGNOSIS

1. The survey results showed that the average age at which a child received a diagnosis of an autism spectrum disorder was 4.7 yrs of age. However parents first suspected something was wrong at an average of 2.3 years of age - a lag of 2.4 years.
2. Pediatricians diagnosed only 6% of the cases of ASD and Developmental Pediatricians diagnosed 13%. In contrast, Regional Centers gave the first diagnosis to over 25% of the families.

FAMILY DYNAMICS

3. Approximately 1/3 of the families (30%) indicated they had another child with special needs.



IMPACT ON THE FAMILY

4. Seventy-six percent (76%) of the families reported that they feel that their job is at jeopardy because they have a loved one with ASD. Seventy-nine percent (79%) are most concerned that they have to leave work to take care of problems and 69% felt it is the frequent meetings associated with ASD.
5. Fifty-eight percent (58%) of the families reported difficulty in finding child care.

EMPLOYMENT

6. Forty-two percent (42%) of the adults with ASD indicated they were presently employed (part-time, full-time, or volunteer) and 29% attended a Day Program. However, 57% of the respondents said they were not happy with their employment situation.
7. Families reported that school districts were not providing essential employment skills needed (i.e. completing a job application, interviewing, creating a resume, etc). Generally it was parents who provided the training or no one taught the young adults the much needed skills. Only 15% reported training was provided by the schools and 14% were assisted by Regional Centers.



HIGHER EDUCATION

8. Approximately 42% of the adults on the spectrum attempted higher education, with 64% reporting they were not successful. The majority of families and individuals reported no one had taught them the needed skills for college including asking for help, identifying what accommodations or modifications might be needed, or identifying how to navigate transportation issues.

TRANSPORTATION

9. The survey showed that transportation continues to be a barrier: 58% of adults on the spectrum said that a parent drives them, 22% use the bus system and only 9% can drive.

RESIDENTIAL

10. We asked parents of our adults if they would prefer their adult child to live somewhere other than at home; 70% of the families indicated they prefer the adult child to remain in the family home.

MEDICAL INSURANCE

11. Only 2% of the families indicated that they do not have medical insurance at this time. 38% of families indicated that their insurance company has denied coverage for an autism related treatment. Treatments which were most often denied were: speech therapy (33%), occupational therapy (21%), physical therapy (9%) and counseling/psychologist (9%).

MOST REQUESTED SERVICES

12. Social skills/groups were the most requested service families wanted to receive. Second to training of teachers/aides from school districts, first in needs from Regional Centers, and the #1 need for adults. Fifty-three percent (53%) of the families reported that their child plays with no one outside of school.

The complete copy of the survey results can be found on our website: www.autismsocietyca.org
Autism Society of California
800-869-7069

