

Autism in California

2012 Survey



Compiled by the Autism Society of California
April 2012

 **AUTISM SOCIETY**
Improving the Lives of All Affected by Autism
California

TABLE OF CONTENTS

EXECUTIVE SUMMARY	3
INTRODUCTION	7
DEMOGRAPHICS	9
OBTAINING A DIAGNOSIS	11
QUALITY OF LIFE ISSUES	13
ACCEPTANCE OF ASD IN THE COMMUNITY	16
ACCESS TO HEALTHCARE SERVICES	18
SYSTEMS OF CARE	19
TREATMENT AND THERAPIES	20
SERVICE QUALITY	22
EASE OF NAVIGATING SYSTEMS	24
HEALTH INSURANCE	26
REGIONAL CENTER	27
SCHOOL DISTRICTS	28
TRANSITIONING TO ADULT SERVICES	31
ADULTS WITH ASD	33
ADULT SERVICES	34
HIGHER EDUCATION	35
EMPLOYMENT	37
RESIDENTIAL SERVICES	39
BUDGET CUTS & LEGISLATION	41
INFORMATION AND RESOURCES	44
INDEX	45
ACKNOWLEDGEMENTS	46

Executive Summary

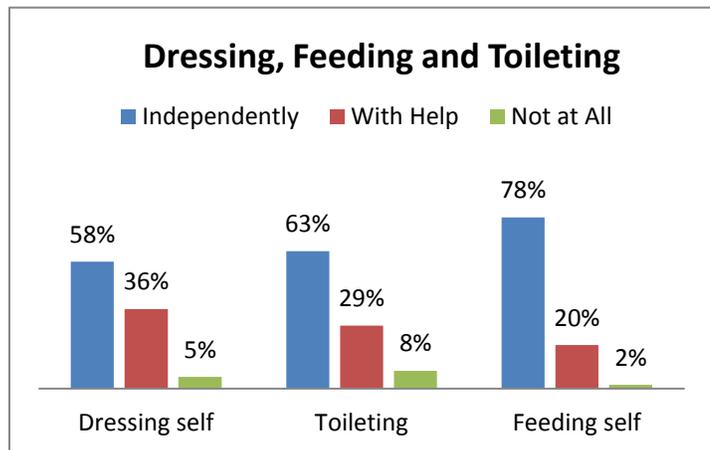
California continues to lead the nation in the highest number of individuals with Autism Spectrum Disorders (ASD). The Autism Society of California (ASC) estimates there are at least 72,000 individuals living in California with a form of ASD. As the number of individuals with ASD continues to increase, budget cuts are placing more stress on service delivery systems effecting all ages.

The Autism Society of California first surveyed the California Autism Community in 2009. In January 2012 an expanded survey was distributed in both English and Spanish to capture individuals with ASD and families' opinions on current services and needs. Over 1,400 responses were received. The Executive Summary highlights some of the findings:

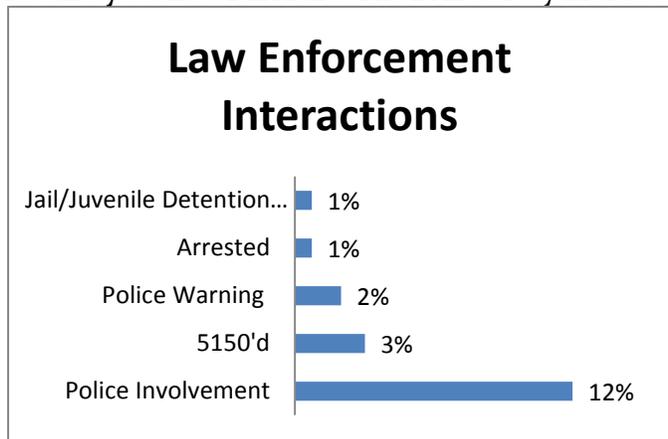
1. **The number of families recognizing symptoms and receiving a diagnosis before the age of 3 years decreased.** In 2009, 92% of parents advised they noticed symptoms by age 3, however, in 2012 only 86% parents reported noticing symptoms. In 2009, 62% of families received a diagnosis at age 3 or younger; in 2012 only 54% of families received a formal diagnosis 3 years or younger.

Recognizing Symptoms and Obtaining Diagnosis for 0-3 years		
	2009	2012
Noticed First Symptoms	92%	86%
Received First Diagnosis	62%	54%

2. **Twenty-two percent (22%) to 41% of the individuals with ASD need assistance with basic quality of life skills.** The survey showed 41% individuals with ASD need assistance dressing themselves; 37% need assistance toileting and 22% need assistance feeding themselves. Families also reported communication is an area of struggle for many of the individuals with ASD: 49% individuals can not indicate when they are sick; 29% cannot request items they need; 26% cannot request items they want.



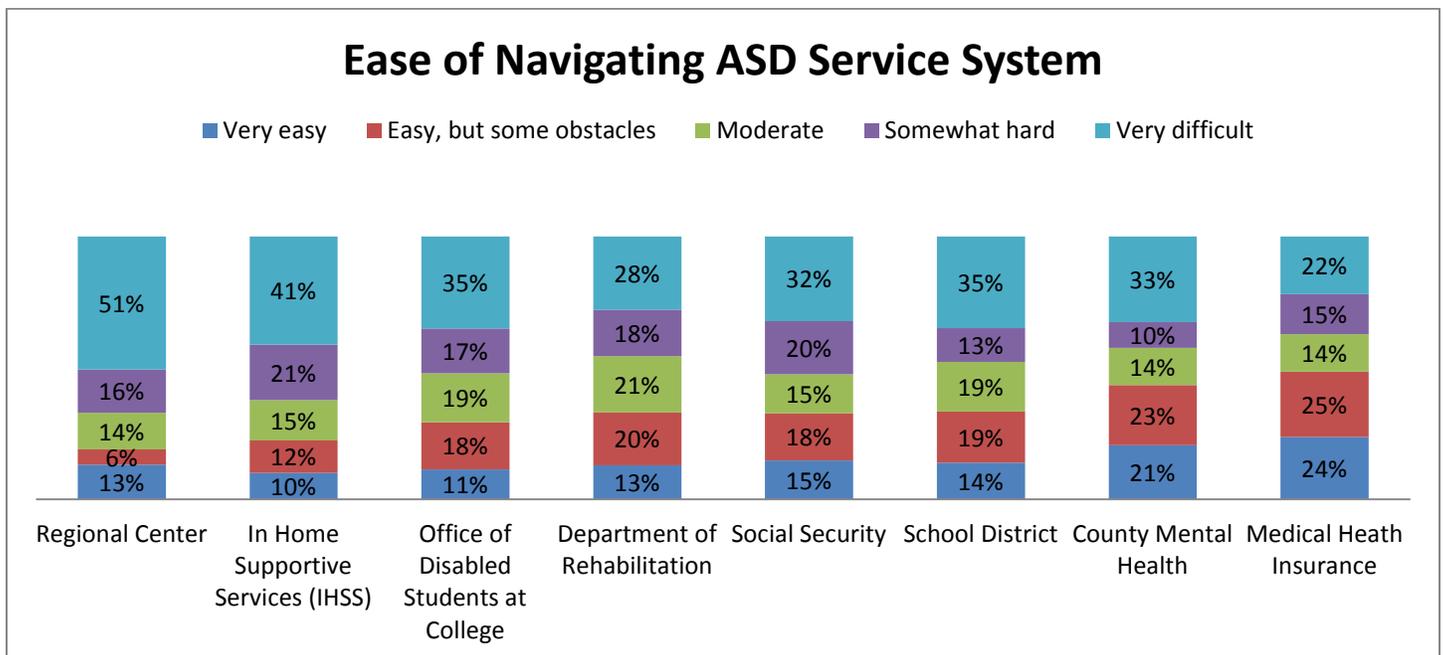
3. **The Justice System is now encountering adults and youths with ASD.** The 2012 Survey indicated 14% of families had interactions with police (including school police); 5% reported severe behavior had involved interactions with Child Protective Services (CPS), neighbors, or school personnel; 3% advised the person with ASD had been entered into a behavioral unit or 5150'd; 3% were given a warning from a Law Enforcement Officer; 1% was arrested and 1% spent time in jail or a juvenile detention center.



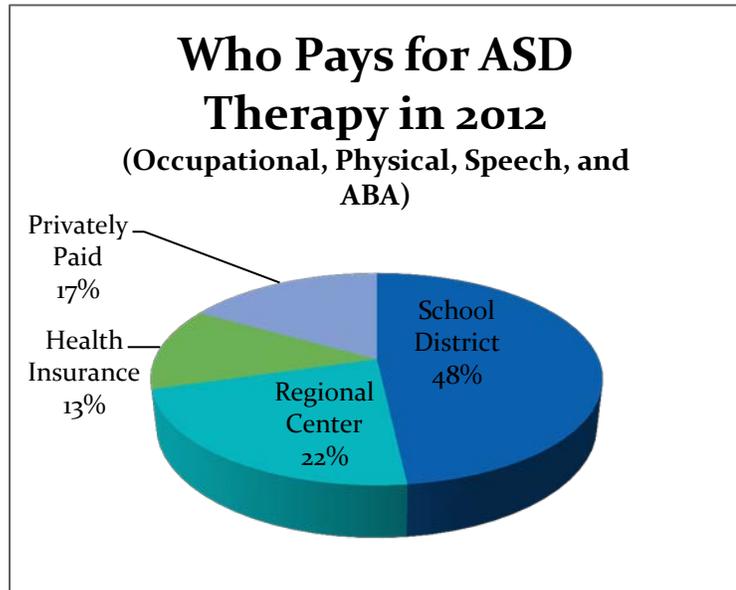
4. **The percentage of families accessing services through the Department of Developmental Services (regional centers) has decreased since 2009:** In 2009, 77% of families indicated they were regional center clients, while in 2012, 70% indicated they were regional center clients (a 7% decrease from 2009).

Regional Center Clients	2009 Survey	2012 Survey
Regional Center	77%	70%

5. **Service systems are difficult to navigate.** More than half of the parents and individuals indicated that this was another obstacle they must overcome and that all of the systems were moderate to very difficult to navigate. The regional center system was rated the most difficult to navigate with 81% of parents rating it moderate to very hard to navigate and 51% indicating the medical health insurance system moderate to very difficult to navigate.



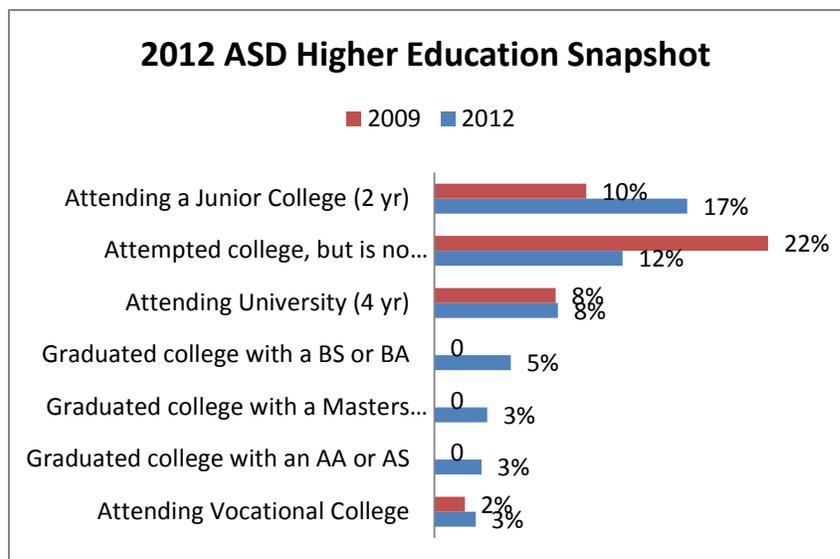
6. **Health insurance companies are currently paying for only 13% of autism therapies.** Parents report school districts are currently funding 48% of treatment (ABA, Speech, Occupational, Physical Therapies); regional centers 22%; parents are paying 17% and health insurance companies are currently paying only 13%. Even though the school districts are providing almost half of the therapy, parents report they feel the quality of the school therapies rate much worse than those provided by the regional centers, health insurance or privately paid services.



7. **More than 40% of families are not aware of the new Autism Health Insurance Law (SB946):** The 2012 Survey shows almost 44% of families are not aware of this new law and how it can benefit their loved one with ASD.

8. **The majority of transition-age families (98%) believe current adult programs are not going to meet their loved ones needs.** When we asked families with children 14 years or older and adults on the spectrum if they thought the existing Adult Service programs would meet their needs, 77% replied they were unsure and 14% indicated they felt the Adult Services they would encounter would be of low quality or would not meet their loved ones needs. Overall, only 2% of families believe current adult programs are going to meet their loved ones needs.

9. **More Students with ASD are attending community colleges and finding ways of staying in college than in 2009:** The 2012 Survey showed more students with ASD are attending community colleges (17% in 2012 compared to 10% in 2009). The survey also showed less individuals with ASD



are dropping out of college – only 12% reported no longer attending in 2012 compared to 22% in 2009. There was no or little change in the number of individuals with ASD attending a 4 year university or vocational college.

10. **The number of Adults with ASD who are employed or attending Day Programs has decreased.** Individuals with ASD and parents reported a decrease in the number of adults employed or participating in a Day Program from 2009 while the number of adults who are sitting at home with no program increased.

Does the adult with ASD attend:	2009 Survey	2012 Survey
Day Program	29%	20%
Employed	42%	25%
Still in High School	16%	17%
At home - no program or employment	13%	18%

11. **The percentage of adults with ASD accessing Adult Services has decreased.** Only 65% of the adults who participated in the survey reported they were current regional center clients compared to 90% of individuals under 18. In 2012, participants reported 39% of adults with ASD collect income from Social Security (SSI); 33% had health insurance through Medi-Cal; and 52% receive In Home Supportive Services (IHSS). Adults expressed their frustration with the quality of employment services they received from the Regional Center employment programs, day programs and the Department of Rehabilitation Employment Programs. The Regional Center Employment Programs had 57% participants rate it as poor; Department of Rehabilitation had a 53% poor rating and Regional Center Day Programs had a 42% poor rating.

Number of Adults with ASD in Adult Services		
	2009 Survey	2012 Survey
Regional Center	90%	65%
IHSS	26%	52%
Social Security (SSI)	52%	39%
Medi-Cal	51%	33%
County Mental Health	NA	7%

12. **Even with all the public awareness done over the last five years, the majority of individuals with ASD and parents report they do not feel accepted by their own families, schools and neighborhoods.** Only half reported individuals with ASD are completely accepted by extended family; 21% accepted in their own school; and 23% accepted in their own neighborhood. The 2012 Survey did bring good news. Although there still is a large number of individuals with ASD who have no friends, families reported more peer relationships than reported in 2009: 40% of families reported their child had no friends compared to 53% in 2009. As one parent voiced, *“It’s better than it was a decade ago, but there is still room for improvement. Awareness & exposure of our kids forces requires allows the ‘other people’ to see experience participate in the lives or lessons our kids live and teach. Acceptance is a general term. Tolerance is another and better still embraced is the ultimate word I’d strive for”*

Introduction

Autism Spectrum Disorders (ASD) are complex developmental disabilities which typically appears during the first three years of life and affects a person's ability to communicate and interact with others. The term "Autism Spectrum Disorders" is often used to describe disorders that currently include autism, Asperger syndrome, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). These disorders are typically characterized by social deficits, communication difficulties, stereotyped or repetitive behaviors and interests, and/or cognitive delays. Although these diagnoses share some common features, individuals with these disorders are thought to be "on the spectrum" because of differences in severity across these domains.

In December 2009, the Centers for Disease Control and Prevention (CDC) concluded the prevalence of autism had raised to 1 in every 110 births in the United States and almost 1 in 70 boys. This increase means 1% of the general population has a form of autism. On March 29, 2012, the CDC announced the rate at 1 in every 88 births showing a 78% increase in the past 10 years.

California continues to lead the nation in the highest number of individuals with ASD. We estimate there are at least 72,000 individuals living in California with a form of ASD. The California Department of Education reports there are 65,908 students as of December 2010 identified with ASD. There is no current data available from the Department of Developmental Services, however, as of 2007, DDS reported they had identified 6,000 adults with autism. We believe 72,000 is a conservative number that will include children under the age of 3 who have not received a formal diagnosis, the adults with ASD who do not qualify for DDS services, and the school-aged children on the spectrum, but do not qualify for special education services.

2012 CALIFORNIA SURVEY

On Jan 9, 2012, the 2012 California Autism Survey was released electronically through the network of Autism Society chapters and other autism organizations throughout California in English and Spanish. The survey was open to individuals on the spectrum, parents and caregivers of all ages. Answers were gathered from the experiences of over 1,500 individuals with ASD. The youngest was 1 year old; the oldest was 85 years old.

Data was collected from Jan 9, 2012, through Feb 1, 2012. A total of 1,412 participated in the survey; 1,381 in English (98%) and 31 in Spanish (2%); however 1,148 people completed all the questions. Because this survey was only distributed online, we realize the families who do not have access to the internet will not be represented.

The Survey was similar to a Survey conducted by the Autism Society of California (ASC) in 2009. The objective was to gather information on services and supports in California to determine a course of action to assist individuals and families living with ASD in California.

Comments from the survey will be highlighted in blue and italicized.

LIMITATIONS OF DATA REPORTING

Despite the Survey being available in Spanish and an outreach effort through Latino groups, we did not receive a representative sample of the Latino community.

The Latino families only accounted for 16% of the survey participants compared to 36% of the students assessed with ASD through the California Department of Education (CDE). Both the Asian community and the African American community are under represented in the survey. Only 8% of the survey participants indicated they were of Asian Ethnicity compared to the California Department of Education data showing 14% of the student population is of Asian ethnicity. While 6% of our survey participants were of African American ethnicity compared to the CDE average of 8%.

Because this survey was available only online we realize families and individuals without access to the internet or lower socioeconomic status would have been excluded.

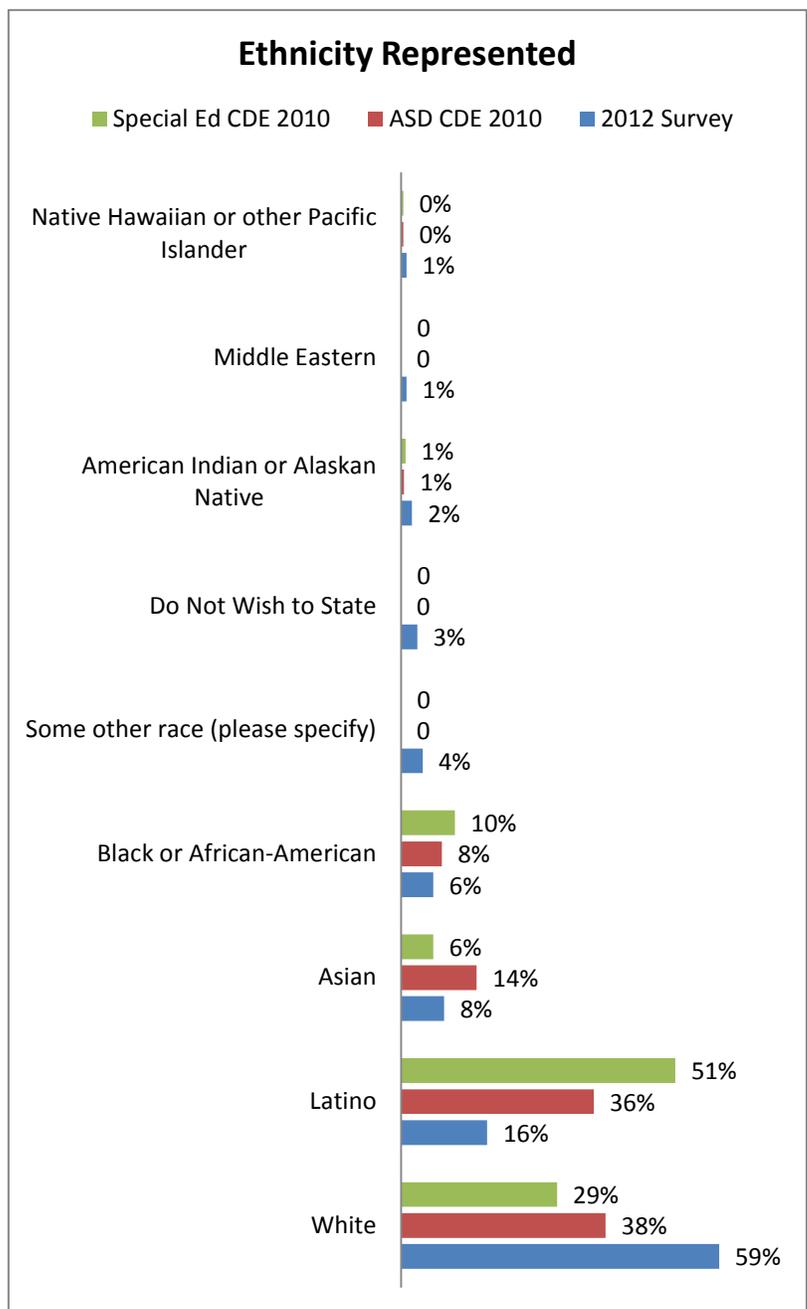


Figure 1

Demographics

ASD HOUSEHOLD DEMOGRAPHICS

Individuals from 45 of the 58 California counties (78%) participated. The reported average household size was 3.88 as compared to the California state average of 2.89 (US Census 2010). As in the 2009 Survey 1/3 of the families (33%) indicated they had another person living in the house with a special need.

The median income was inconclusive since the number of people who chose not to answer affected the data.

Individuals in Household with ASD Diagnosis		
	2009	2012
1 person	89%	89%
2 people	10%	10%
3 people	.2%	1%
4 or more	0	0%

Figure 2

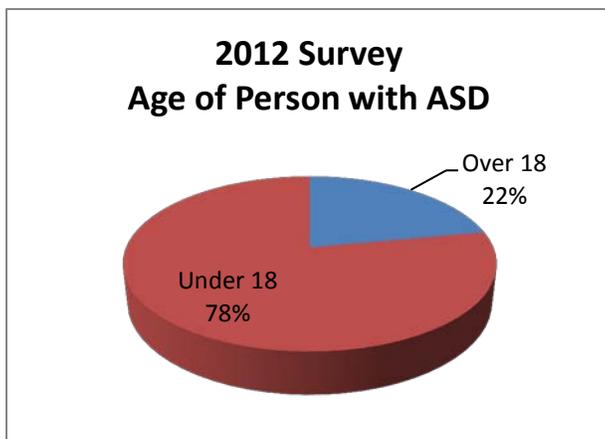
Families and individuals reported 89% of the families had only 1 person with an ASD diagnosis, consistent with the findings in the 2009 survey (Figure 1).

The majority (63%) of the families indicated that autism was the primary diagnosis; Asperger's 17%; 15% of families indicated Pervasive Developmental Disorder – Not otherwise Specified (PDD-NOS) diagnosis; and 5% indicated they had not received a formal diagnosis (Figure 2). Interestingly, the data indicates more families are receiving a PDD diagnosis.

Diagnostic Breakdown		
	2009	2012
Autism	67%	68%
Asperger's	19%	18%
PDD-NOS	10%	16%
No formal diagnosis	3%	5%

Figure 3

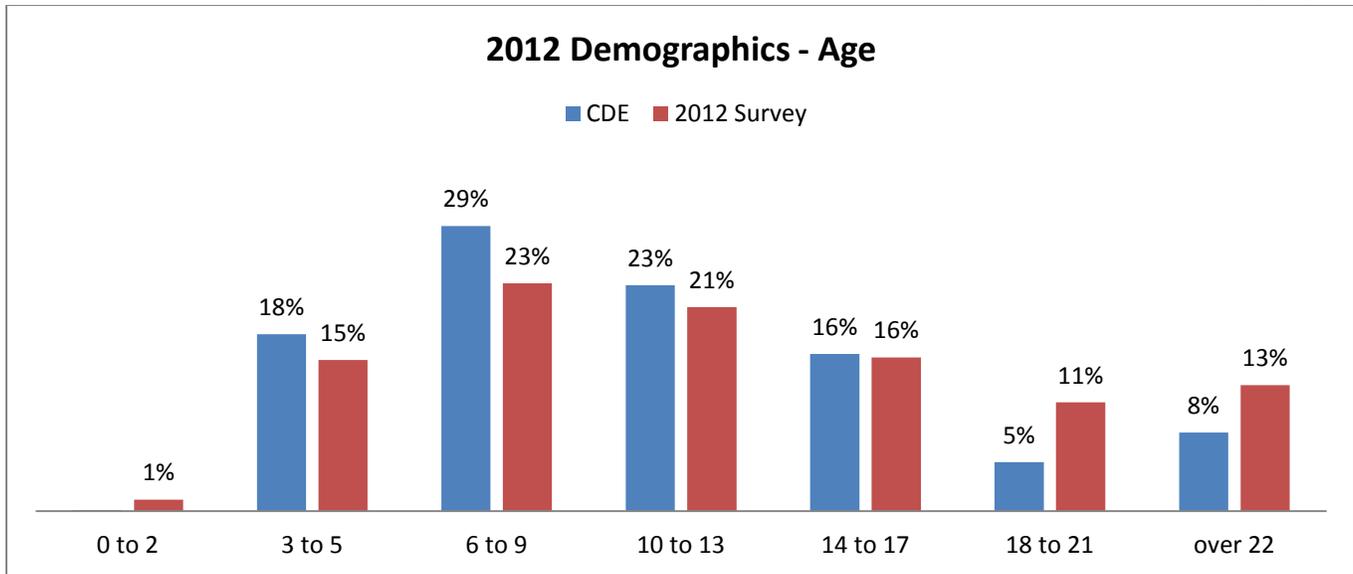
Males continue to outnumber females; 79% males to 21% females. This was the same ration we received in the 2009 Survey.



Seventy-seven percent (77% or 890) of the participants of the survey were answering for a family member under the age of 18 years, while 23% (258 individuals) of the survey were over the age of 18 years.

Figure 4

Figure 5



The average age of the person with ASD in the 2012 Survey was 15.4 years of age. Figure 5 shows the data collected in the 2012 Survey has a similar profile as the California Department of Education (CDE) data showing the number of students diagnosed with ASD in the state (DataQuest 2010). The 2012 Survey was open to all individuals with ASD, some who may not qualify for services through these agencies.

CO-MORBID CONDITIONS

In 2009 over half of the individuals (54%) indicated there was a co-morbid condition. In 2012, 87% reported co-morbid conditions. In 2009 there were only 5 conditions in which more than 10% of the families indicated a co-morbidity condition. In 2012 there were 13 co-morbid conditions over 10%. Figure 6 is not an exhaustive list but shows the co-morbid disorders with percentages higher than 10%.

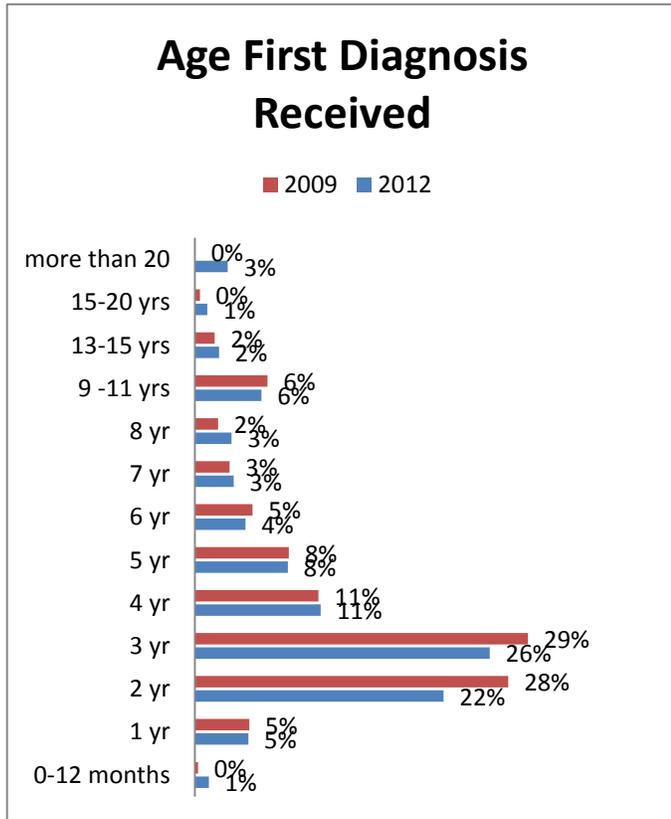
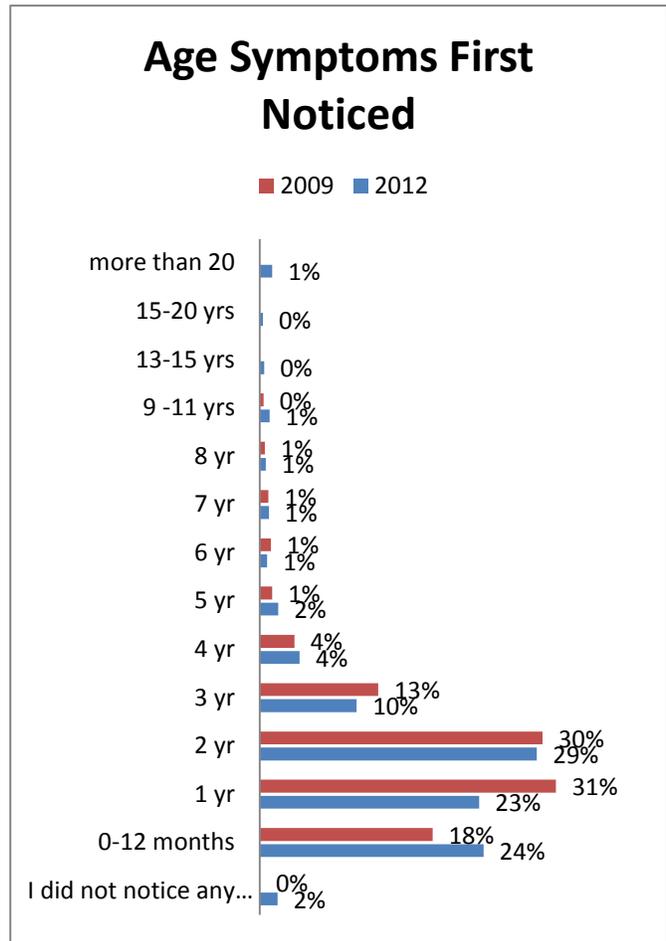
Diagnostic Breakdown		
	2009	2012
Anxiety	17%	47%
Sensory Processing	Not reported	43%
Feeding Issues/Picky Eater	30%	43%
ADD or ADHD	7%	37%
Allergies	21%	37%
OCD	13%	29%
GI Issues	Not reported	25%
Intellectual Disability	12%	23%
Executive Functioning	Not reported	21%
Learning Disability	5%	19%
Sleep Disorder	8%	19%
Depression	Not reported	15%
Seizures	8%	11%

Figure 6

Obtaining a Diagnosis

A great deal of progress has been made in identifying the earliest signs of autism and related autistic spectrum disorders (ASD). Infants can be identified as early as 12-18 months and current studies are looking for methods to identify ASD even earlier. Early Intervention services provided to children during early childhood create tools and skills to increase social opportunities throughout their lifetime, positioning them to have the best possible outcomes. Studies show with intensive early interventions around fifty percent of children with autism can succeed in the regular education classroom by first grade. Others will make gains significant enough that they will only require partial or less intensive special education services. We know early action drastically change outcomes and improve lives.

Figure 7



In 2009, 92% of parents advised they noticed symptoms by age 3. In 2012 only 86% of parents reported noticing symptoms. However in 2012, 24% of parents advised they first noticed symptoms before age 1 year compared to 18% in 2009.

Furthermore, there was a decrease in the number of diagnoses received by age 3 years. In 2012 only 54% of families received a formal diagnosis 3 years or younger compared to 62% in 2009.

Figure 8

2012 Diagnosis

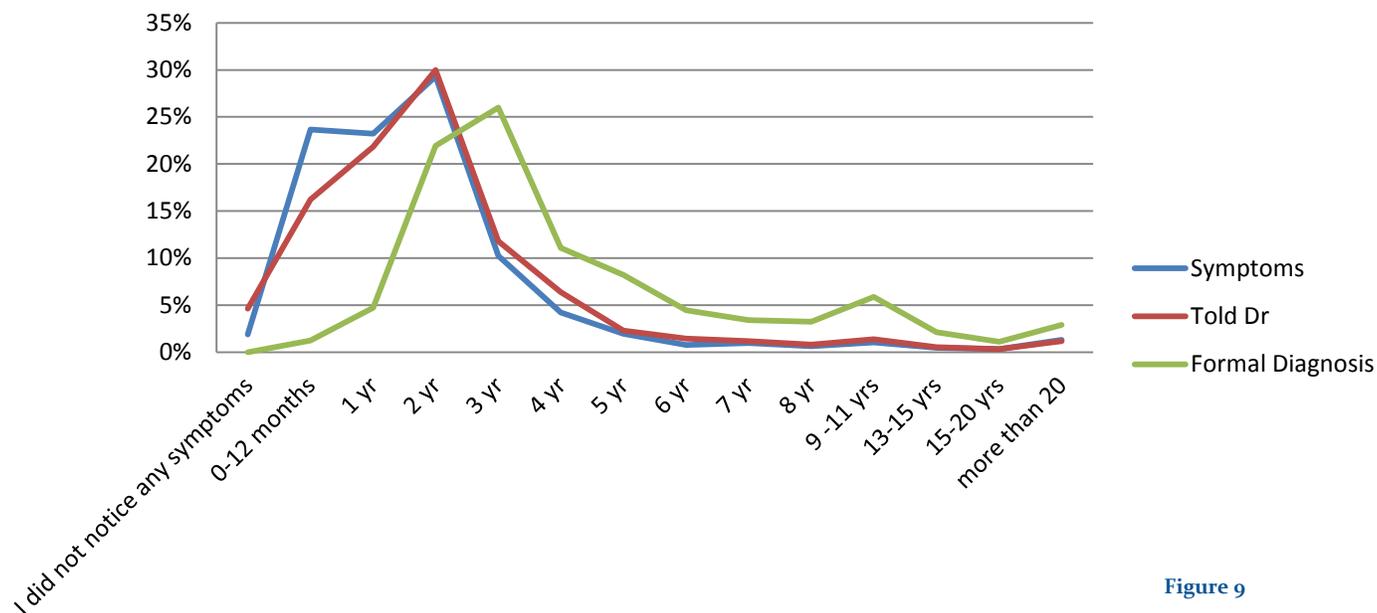


Figure 9

Figure 9 shows there is still a delay between parents receiving a diagnosis. While most parents advised they noticed symptoms and reported it to the doctor by age 2, most families did not receive a diagnosis until age 3. Another interesting note is the number of families who are reporting receiving a diagnosis after age 3 seems to have stayed consistent in the last three years.

Who Gave the First Medical Diagnosis

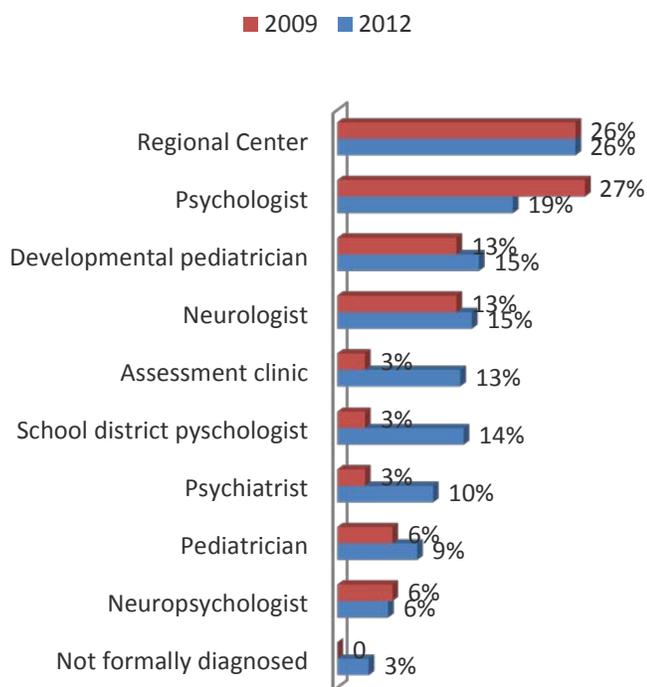


Figure 10

WHERE FAMILIES ARE RECEIVING DIAGNOSIS

The data from Figure 10 shows the change in who is providing the diagnosis to families. In 2009 parents indicated the Regional Center and psychologist accounted for more than half of the first diagnosis. While 26% of parents continue to report they received their first diagnosis from the Regional Center, families also reported relying on other professionals for diagnostic services. Here was a significant increase of parents using assessment clinics and psychiatrists. In addition, the number of school psychologists making an initial assessment increased significantly. This could indicate an increase of diagnosis of “higher functioning children.”

Quality of Life Issues

This is a new section for the Autism Survey. Improving the quality of life of people with ASD is an intrinsic part of the Autism Society's operational philosophy. The Autism Society focuses on delivering programs and information which will impact individuals with autism TODAY and continue to improve their quality of life, throughout their whole life.

In this 2012 Survey we focused on five (5) basic skills that would greatly impact an individual's ability to communicate, live, work and participate in recreational skills as independently as possible: communicating, dressing, toileting, feeding and exhibiting behavior which could be considered dangerous to themselves or others.

Reminder – the average age of this survey was 15.4 years.

DRESSING SELF

This was the skill that individuals with ASD seem to have the most difficulty with. The survey showed 41% of individuals with ASD currently need assistance to dress themselves (36% need some assistance; 5% need maximum assistance). Some parents reported issues of difficulty with buttons, snaps and zippers due to fine motor weaknesses. Other parents reported sensory issues caused children or adults to wear the same clothing. Other parents reported individuals with ASD may not be able to choose appropriate clothing for the weather or occasion.

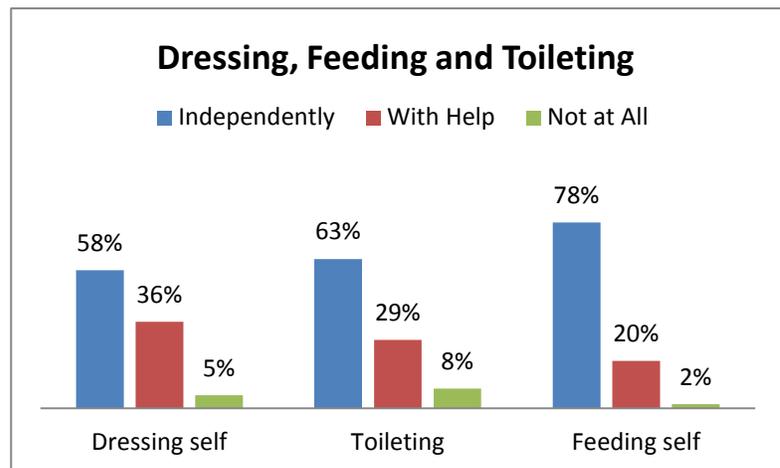


Figure 11

“Clothes are not always appropriate for the weather -- might be backwards -- belts might be twisted or not tight enough -- buttoning may be uneven -- and shoe laces are not tied tightly enough.”

“Tactile issues - cotton Tee, basketball shorts. Good sneakers are hard to find, Will wear the same pair for a year even if they are falling apart. Doesn't understand social dressing.”

TOILETING

The survey showed a total of 37% of individuals with ASD currently need assistance toileting (29% some assistance; 8% maximum assistance). The majority of the toileting issues reported were around self-cleaning after toileting.

“Toileting for urination only. He will withhold going to the bathroom for days (making himself sick) if he is unable to use a diaper for bowel movements.”

“He is capable of urinating in the toilet by himself, but still will not have a bowel movement in the toilet. Therapists and family have been working on toilet training for almost 3 years.”

“Although she is toilet trained, she will (a few times a year) poop on the floor of her bedroom and smear the feces all over the room.”

FEEDING SELF

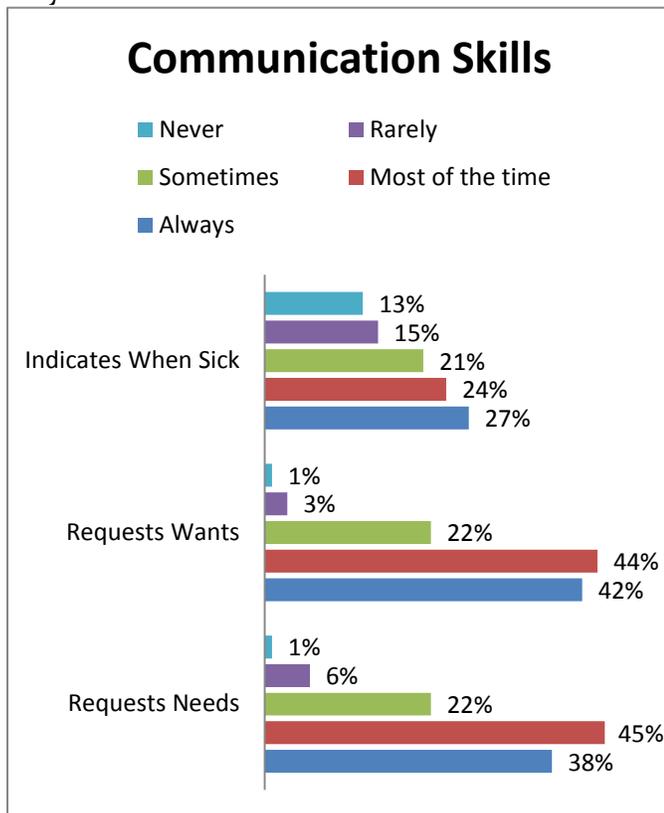
This question referred to actual feeding and not preparing or cooking food. The survey showed this area was the most successful with 22% of the respondents indicating assistance was needed (20% need assistance; 2% need maximum assistance).

“...he may need the food completely prepared, as he can use neither fork nor knife, he can use only a spoon.”

“He cannot cut food and eats too fast.”

COMMUNICATION SKILLS

Being able to communicate is one of the most basic of human needs in all stages of life. Communication is usually severely impaired in persons with autism. What the individual understands (receptive language) as well as what is actually spoken by the individual (expressive language) can be significantly delayed or nonexistent. This includes the inability to understand simple directions, questions, or request for things they want or need.



Our survey indicates communication is an area of struggle for most of the individuals with ASD:

- 49% individuals can not indicate when they are sick
- 29% cannot request items they need
- 26% cannot request items they want

Caregivers also report verbal communication is still the preferred way to communicate.

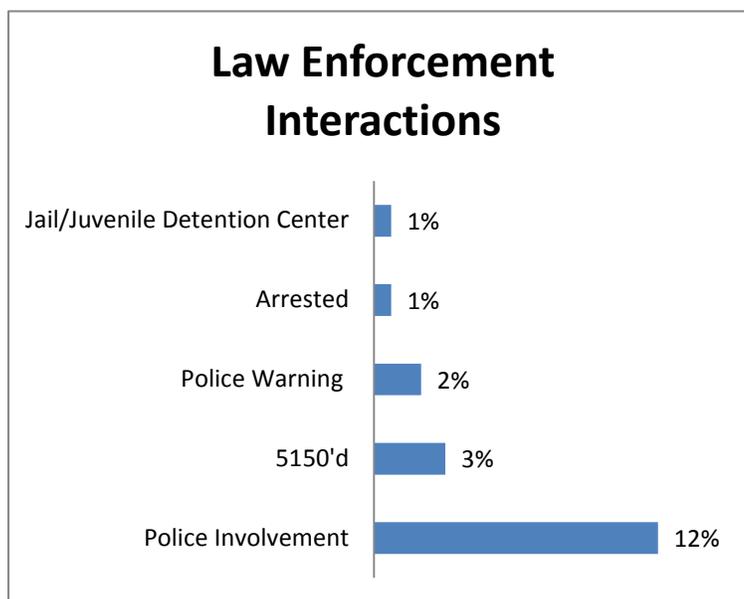
- 10% use PECS
- 8% use Assistive Technology
- 9% use writing or typing

Figure 12

DANGEROUS BEHAVIOR

Individuals with autism can often display many types of unusual behavior including repetitive behavior (such as hand flapping, making sounds, pacing) and self-injury (hand biting, head banging). Because of lack of social skills, children and adults with ASD may not understand the consequence of their words or actions (“I’m so angry I want to kill you” or walk into someone else’s house because they hear their favorite song). Children and adults with ASD may become overwhelmed and “meltdown” in public or simply wander away or bolt from a safe place (elope).

- 7% of caregivers reported they had to take the loved one with ASD to an Emergency Room for behavior
- 17% of survey participants report behavior severe enough to cause interactions with Law Enforcement, Child Protective Services (CPS), or a behavioral unit.
- Figure 13 shows the breakdown of Law Enforcement Interactions: 14% reported interactions with police (including school police); 5% reported severe behavior which had involved interactions with CPS, neighbors, or school personnel; and 3% were checked into a behavioral unit or 5150'd. Three percent (3%) of the surveyed ASD population were given a warning from a Law Enforcement Officer; 1% was arrested and 1% spent time in jail or a juvenile detention center.



“English paper on suicide prompted police call.”

Figure 13

“Ran out of our house and down the street, prompting a call to 911 because we couldn't find her, and she didn't respond well or at all to calling her name at that age (~3). Still doesn't respond well, but better than "zero.”

“She has called a neighbor to say she is being abused or has threatened to call the police to say we hit her. She heard this from another child. Her therapist gave us her business card and said have the police called her if she does make the phone call.”

“I once had a near riot at a Wendy's. One man told me that I should not take him out in public, and another woman was rude, yelled at me and raised her hand to my son when he told her not to yell at Mommy. The police were eventually called. It was HORRIBLE!”

Acceptance of ASD in the Community

ACCEPTANCE

Even with all the public awareness done over the last five years, survey participants report this is an issue for most of them. Only half reported individuals with ASD are completely accepted by extended family; 21% accepted in their own school; and 23% accepted in their own neighborhood.

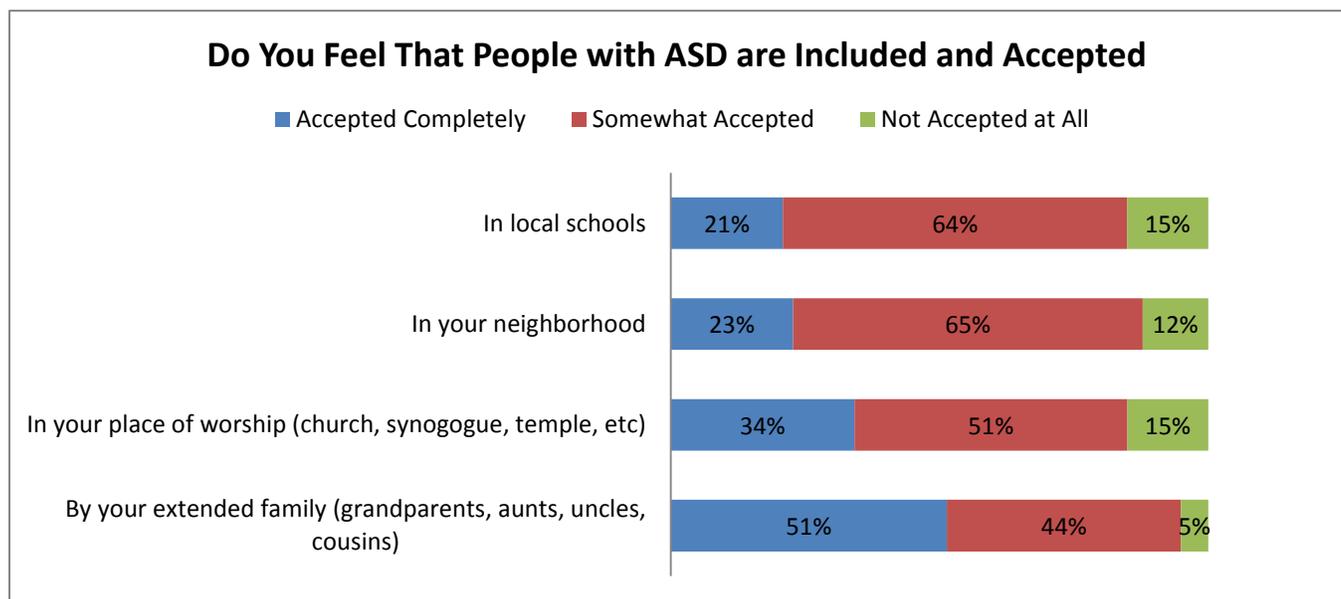


Figure 14

Individuals and families expressed their frustration of being asked not to attend family events, asked to leave private schools, churches, even their own neighborhood. Many talked about feeling that many families just stay home and don't try to socialize in the world. We were especially struck by the number of comments showing families yearn for more than acceptance:

"My son is included and has a very full life, but is also ignored by many people."

"People don't get it and many do not want to get it-- these kids are living breathing ghosts especially in every aspect of the community."

"It's better than it was a decade ago, but there is still room for improvement. Awareness & exposure of our kids forces requires allows the 'other people' to see experience participate in the lives or lessons our kids live and teach. Acceptance is a general term. Tolerance is another and better still embraced is the ultimate word I'd strive for"



FRIENDSHIP

The 2012 Survey did bring good news. Although there are still a large number of individuals with ASD who have no friends, families reported more peer relationships than reported in 2009.

Outside of School and Family, How Many Friends Does the Person with ASD Have?		
	2009	2012
No one	53%	40%
1 Friend	16%	16%
2 Friends	14%	13%
3 Friends	6%	6%
4 or more Friends	11%	18%
Online Friends	Not measured	8%

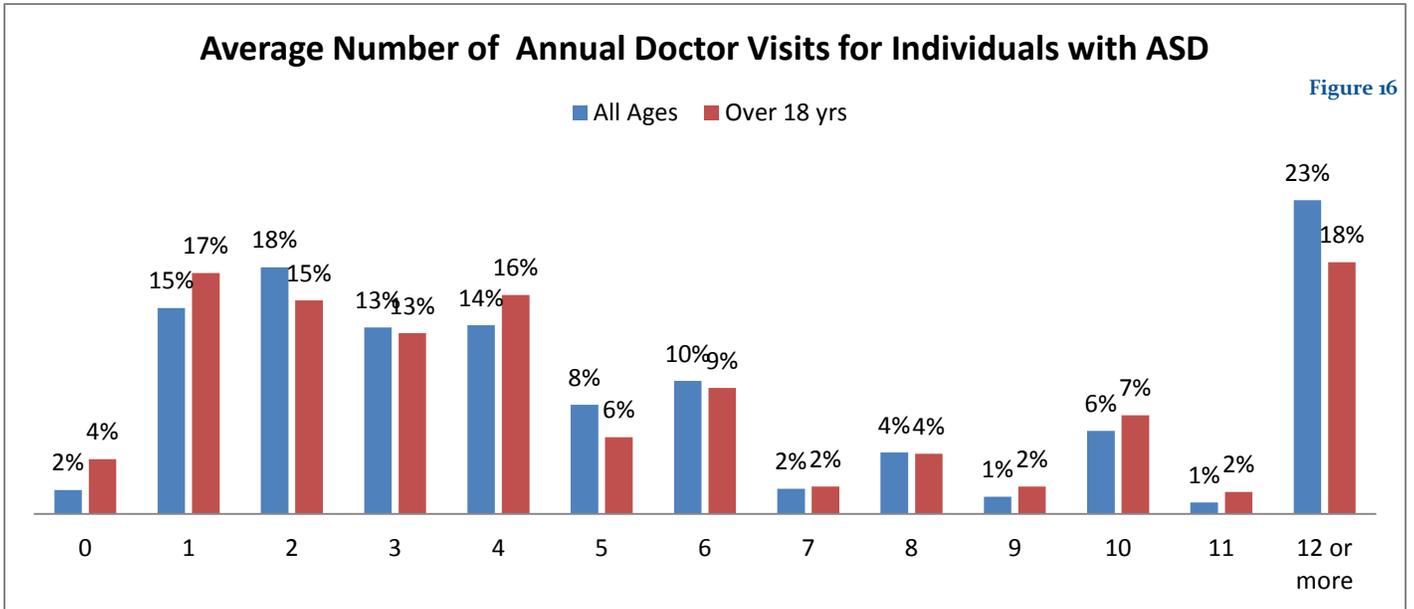
Figure 15

“He made many friends now that he attends community college with other people who are interested in music. He plays in the jazz band, orchestra and other musical groups there.”

“He thinks he has friends but they never initiate interactions. It is always us but we continue to try. If you ask him however he would tell you he has lots of friends.”

“No close friends. Just at school and occasional play dates when I can arrange them.”

Access to Health Care



Again, keeping in mind that families without access to the internet were not included in this survey, the 2012 Survey showed most people with ASD are accessing health care professionals.

Figure 17

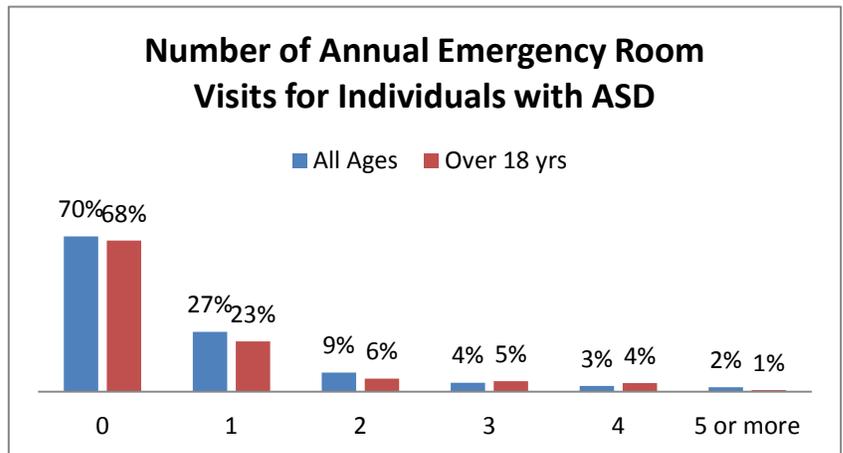
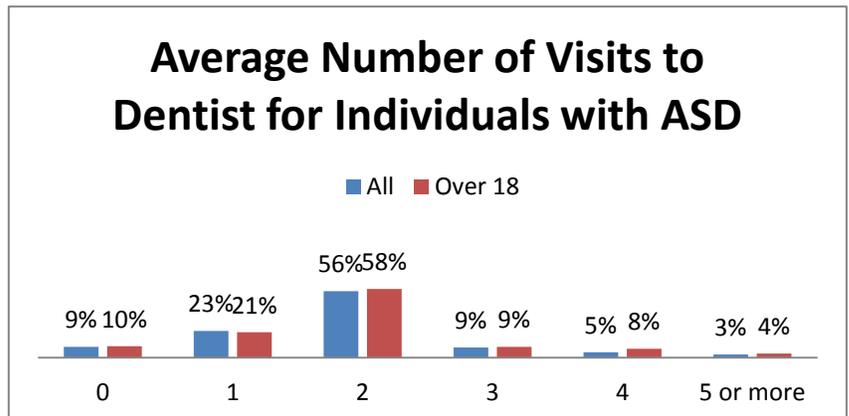
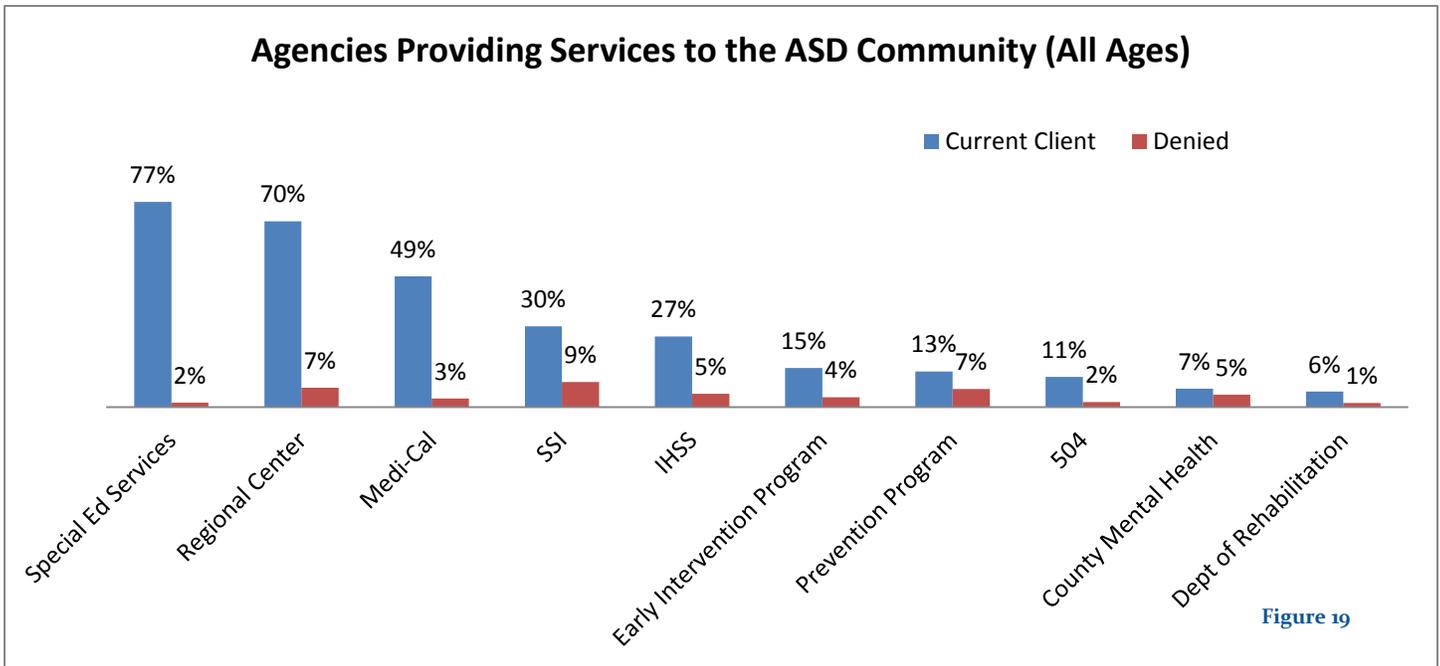


Figure 18



Systems of Care

Parents and individuals with ASD are faced with navigating many systems of care which can include medical insurance, the education system, regional centers, social security, In Home Supportive Services, Department of County Mental Health, and the Department of Rehabilitation. Each system's assessment guidelines and supports offered can vary by county or region.



The most commonly used services in the ASD community were special education services through the local school district. This survey showed approximately 77% of the ASD population is currently enrolled in special education, with another 11% on 504 Plans. Roughly 88% of the ASD population is being served in some capacity by school districts while only 70% are being served by the regional center system. Our 2009 Survey showed 77% of families were being serviced by the regional center system – a 7% decrease in 3 years.

Treatment and Therapies

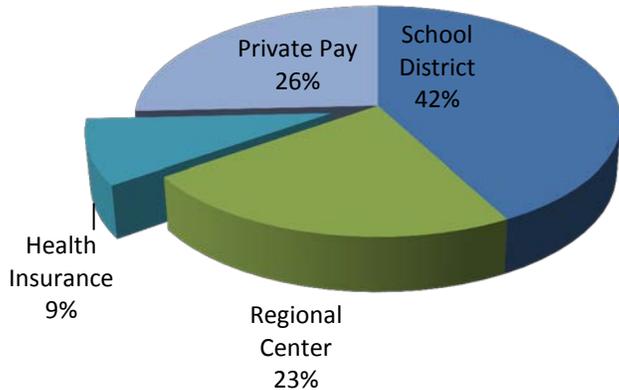
Figure 20, below, illustrates there seems to be a lot of confusion or desperation to try multiple agencies to fund therapies and services. For example, participants reported asking for funding for Camps through the School Districts, Regional Center and even Health Insurance. One parent reported they had an “after-school program provided by Superintendent of Schools, funded by Regional Center.” Another, “Speech Therapy was denied by health insurance after 3 years old because it was not medical necessary. After many appeals it was denied, so it was private pay after insurance stopped paying.”

The most requested service was speech and language therapy (93%). Parents pursued this service through a variety of service systems including school districts (74%), regional centers (17%), health insurance (23%) and private pay (21%).

Services Attempted Since Receiving Diagnosis								
	Did not request	Received through the School District	School District denied	Received through Regional Center	Regional Center denied	Received through your Health Insurance	Health Insurance denied	Privately Paid (cash, check, credit card)
Speech/language Therapy	7%	69%	5%	13%	4%	15%	8%	21%
Occupational therapy	12%	56%	8%	14%	5%	15%	7%	17%
Summer School/Extended School Year (ESY)	18%	59%	5%	1%	1%	0%	1%	5%
Social Skills Training or Groups	22%	22%	4%	20%	7%	5%	4%	23%
Behavioral (ABA, Pivotal Response, Discrete Trial)	23%	26%	7%	41%	5%	5%	6%	11%
Social Recreation Programs (Classes like art, music, theater, karate, sports)	24%	7%	2%	8%	7%	0%	2%	44%
Respite	27%	1%	1%	49%	5%	1%	1%	6%
Adaptive Physical Education (APE)	36%	40%	7%	2%	2%	0%	2%	1%
Mental Health Services	43%	7%	1%	3%	3%	17%	3%	12%
Camps	44%	1%	1%	10%	6%	0%	1%	24%
Physical Therapy	44%	13%	4%	7%	3%	8%	4%	7%
Assistive Technology	45%	18%	9%	2%	2%	1%	2%	8%
Floortime/Play Therapy/RDI	48%	5%	1%	10%	5%	3%	3%	9%
Biomedical Treatment	53%	0%	1%	0%	2%	4%	6%	19%
Vocational Training	58%	9%	1%	3%	1%	0%	0%	1%
Transportation Training	59%	8%	1%	3%	1%	0%	1%	2%
Sexual Health Training	61%	5%	1%	2%	2%	0%	1%	2%

Figure 20

Who Has Funded Treatment



Of particular interest was the data showing the distribution of which agencies are providing treatment services to the ASD community.

Parents report school districts are currently funding 42% of all treatments (See Figure 21), regional centers 23%, parents are paying 26% and health insurance companies are currently paying only 9%. Health insurance had the highest rate of denials – 39% of claims submitted through health insurance were denied compared to 24% regional centers and 15% for the school district.

The most denied services overall were Assistive

Technology (9%) and Occupational Therapy through the school district (8%); and Speech/Language Therapy through Health Insurance (8%).

Figure 21

If we focus on the four most commonly used treatments and therapies for ASD: Applied Behavior Analysis (ABA), occupational, physical and speech therapy, the 2012 survey shows health insurance companies were funding the least amount of services. Health insurance had the highest rate of denials for these four therapies – 36% of claims submitted through health insurance were denied compared to 19% regional centers and 12% for the school districts.

Funding and Denials of ABA, Speech, OT, and Physical Therapy

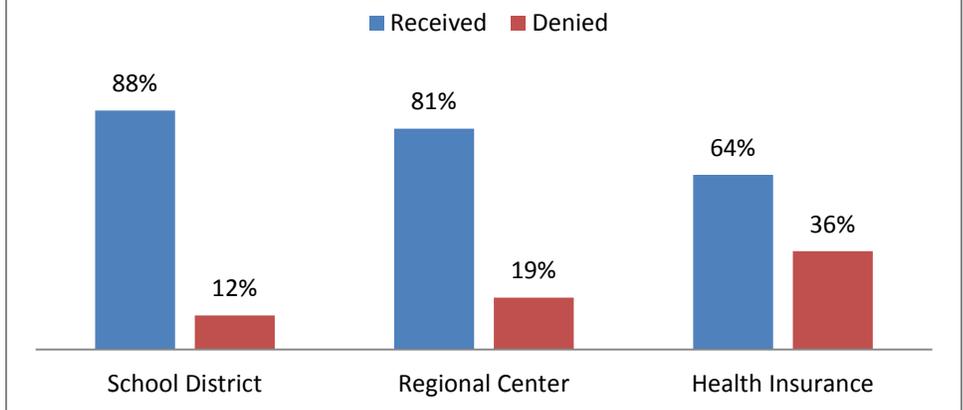


Figure 22

Service Quality

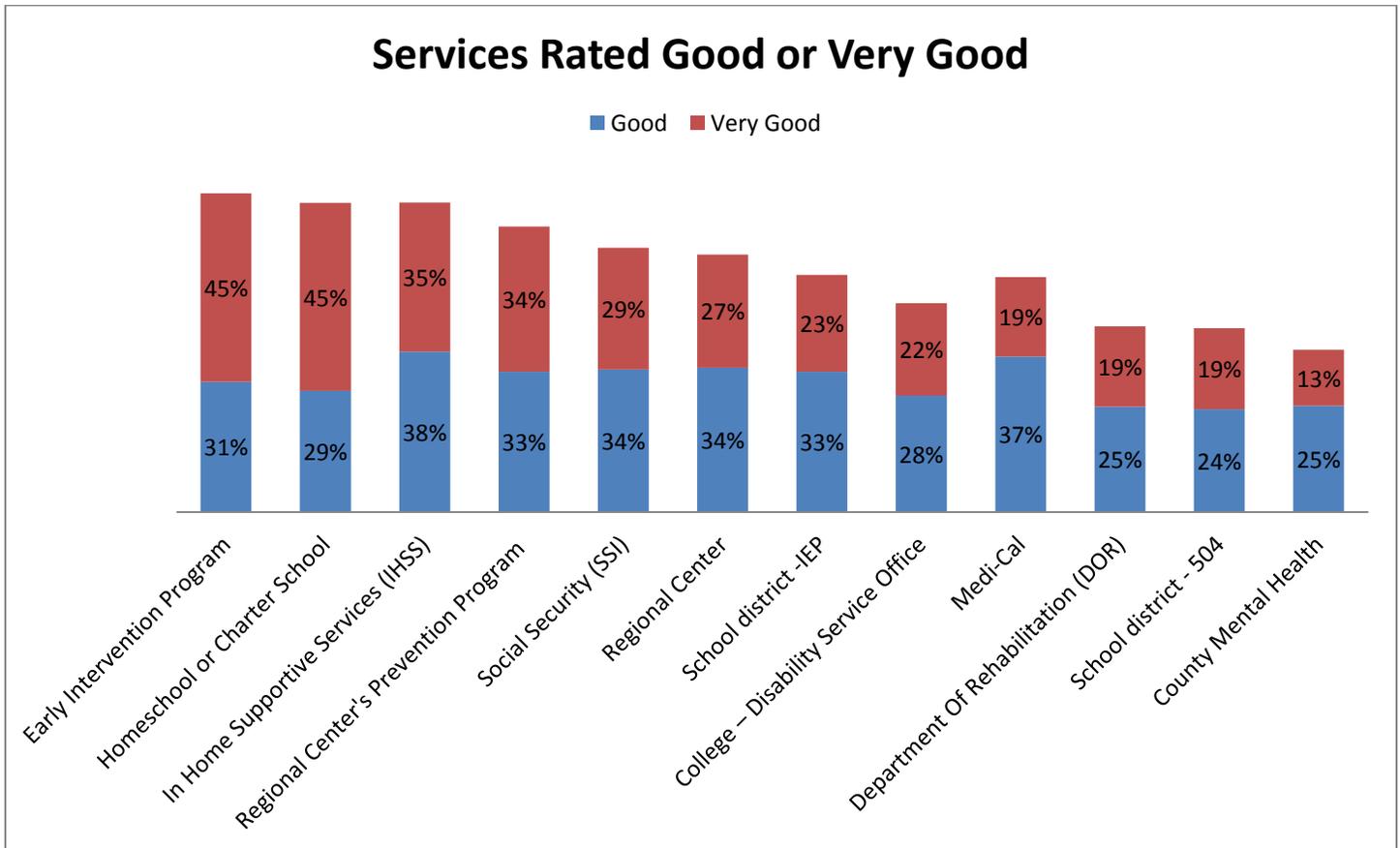


Figure 23

Participants rated 12 different service agencies. Only one agency – Early Intervention programs had more than 75% of participants rate services good or very good. Fifty percent of the participants rate 8 of the 12 agencies good or very good (See Figure 23 above). Four agencies were rated poor or fair overall: College Disability Service Offices, Department of Rehabilitation, School District’s 504 Plans and County Mental Health.

The survey also shows a disparity between services offered through various systems across the state. The biggest disparity between qualities of services is speech and language services. Figure 24 shows a 19% gap in quality of services between services received through health insurance or have been privately paid and regional centers providing them and a 35% gap between health insurance/private pay and school district services.

Figures 25 and 26 continues to show the disparity in quality in Occupational Therapy and Physical Therapy services with a 14% gap in health insurance/private pay versus regional center services. There was a 37% gap between health insurance/private pay and school district occupational therapy services and 22% gap between physical therapy provided by health insurance/private pay and school district services.

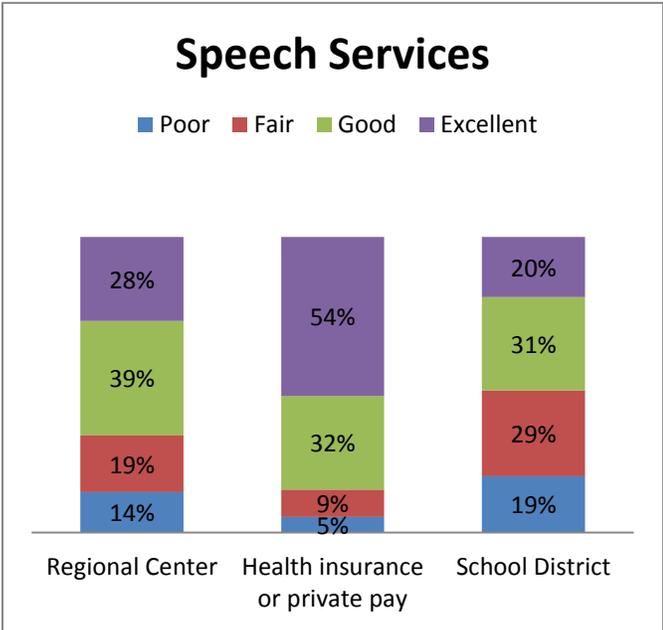


Figure 24

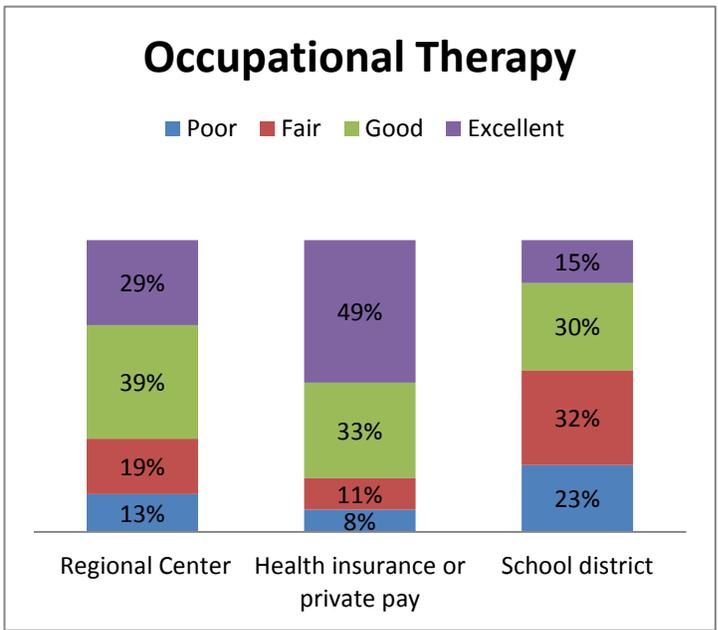


Figure 25

Speech Services: 86% rated health insurance or privately paid speech services as excellent or very good compared to 67% speech services provided by regional centers and 51% school districts.

Occupational Therapy: 82% rated health insurance or privately paid occupational therapy services as excellent or very good compared to 68% of services provided by regional centers and 45% provided by the school districts.

Physical Therapy: 70% participants rate services paid through health insurance or privately paid as excellent or very good compared to 64% to regional centers and 48% school districts.

Behavioral Therapy: 70% participants rated Behavioral Therapy provided by health insurance or privately paid as excellent or very good compared with 67% for regional center services, 61% outside consultants for school districts and 41% for school district employees.

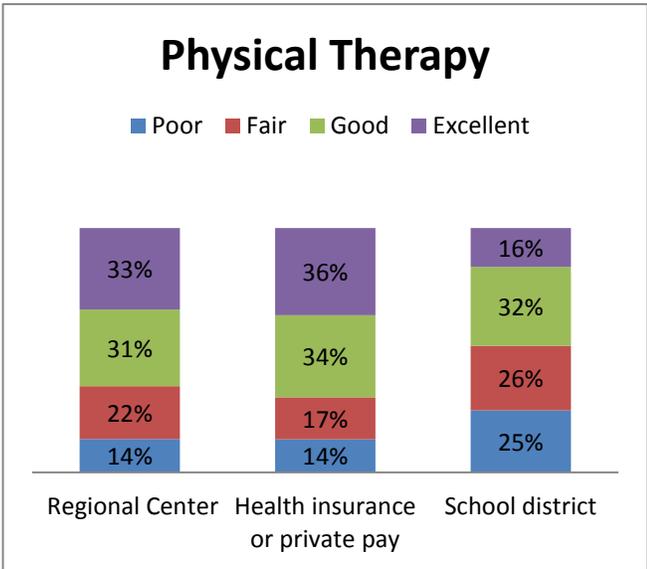


Figure 26

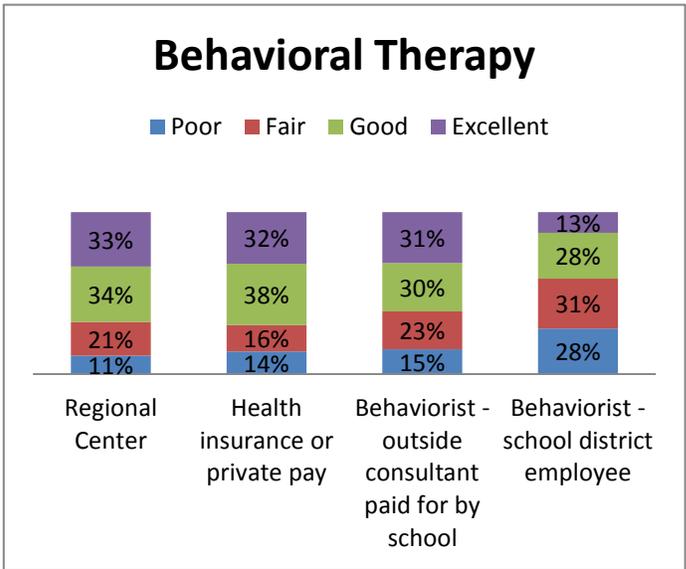


Figure 27

Ease of Navigating Systems

Parents are faced with obtaining a diagnosis, researching what services and therapies are most appropriate, and then navigating through various systems. The 2012 survey identified 17 different services provided through eight different systems. Almost 1,200 people rated the various systems in California on how easy they were to navigate. More than half of the parents and individuals indicated that this was another obstacle they must overcome and that all of the systems were moderate to very difficult to navigate. The regional center system was rated the most difficult to navigate with 81% of parents rating it moderate to very hard to navigate and 51% indicating the medical health insurance system moderate to very difficult to navigate.

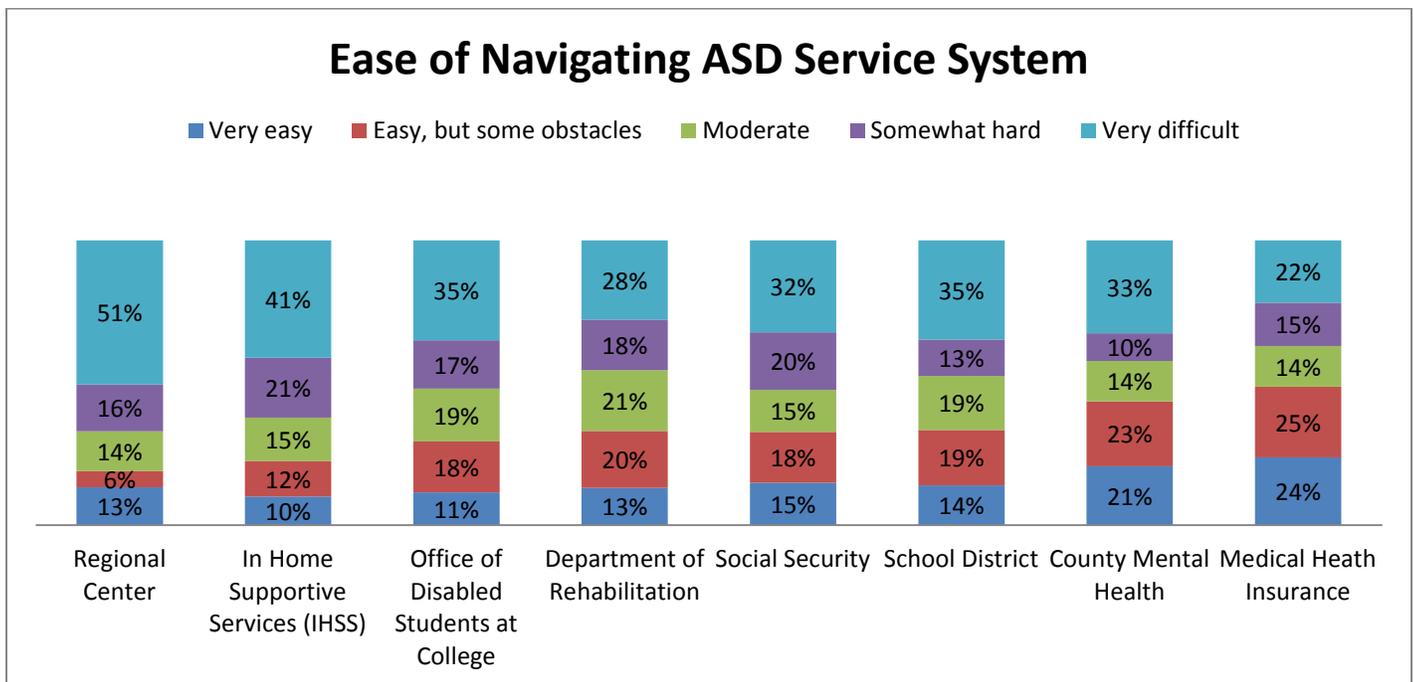


Figure 28

WAITING LISTS

Twenty-nine percent (29%) of survey respondents advised they have had to wait for assessment services or intervention services. Of the parents that reported waiting, the average time was 9 months. Regional Center services had the highest number of parents reporting wait lists (40%).

“We have to pay out of pocket than wait because waiting defeats the purpose of early intervention.”

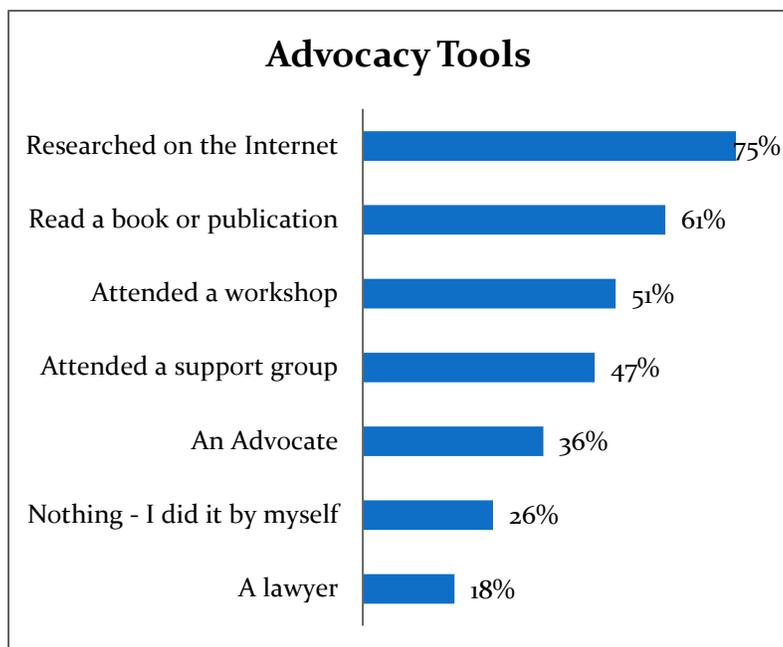


“Waitlists for appointments with SLPs, OTs etc. through private insurance due to overwhelming caseloads of ASD clients: Children's Hospital Outpatient Clinics, Waitlist for Regional Center provided PRT, also at Children's Hospital.”

“Regional center - still on waiting list, also waiting for my son to see a medical approved neurologist for about a year.”

“Regional Center ~ 3 months for intake and another ~3 to get panel team appointment for diagnosis. Medical it has been over a year that we have been waiting since we applied.”

ADVOCACY TOOLS



Only 26% of individuals indicated they were able to navigate systems with no help. Parents continue to feel frustrated as evidenced by a sample of the comments shown below.

The most common tools families turned to was the internet (75%).

Figure 29

“The school district staff lies and does everything they can to not provide services. I feel sorry for all the children who need help, aren't getting it, and the parents can't win with the school district. We pulled our son out of school and have him a private school where the teachers actually care about helping our son both academically, socially, and emotionally.”

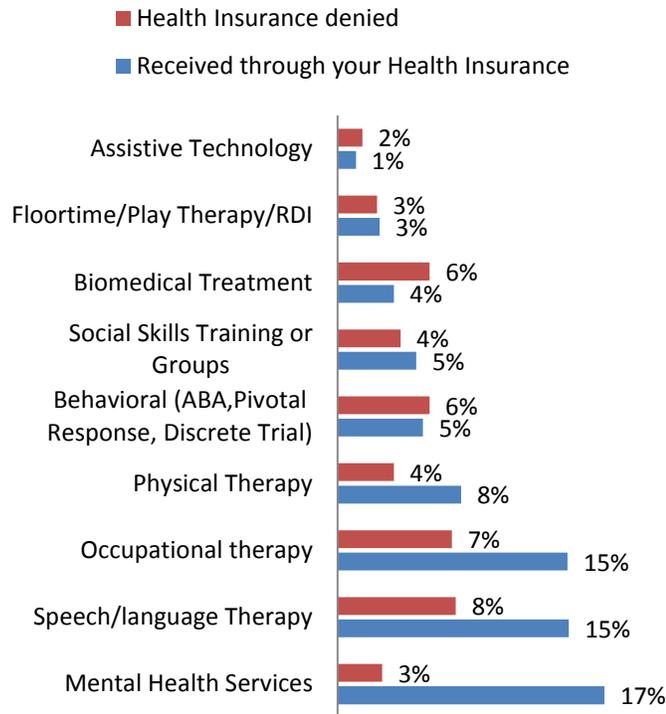
“Initial interactions with school district and regional center were hard, subsequent relationship has been very collaborative. Medical insurance rules change with every new person who speaks to you, even after getting prior authorization every claim is denied and has to fought for, sometimes with letters that point out that the insurance company is acting illegally.”

“Student in college now and Office of Disabled Students ~ not effective or helpful”

“The people at Mule Creek State Prison have fought with me about everything. If I get told one more time that they don't send Autistic people to prison I might scream.”

Health Insurance

Services Requested Through Health Insurance



Health insurance services provided the highest quality of services, but also funded the least amount of services – 9% compared to 23% Regional Center, 26% private pay and 42% school district funding (see Figure 30).

The most commonly requested service through health insurance was mental health services - 17% of families requested this service through their health insurance at one time. This was followed by speech and language therapy and occupational therapy (tied 15%).

The health insurance system has the highest rate of denial for services compared to regional centers and the school districts (Figure 22), but also has the highest rate of quality of services (Figure 31).

Figure 30

Rating of Health Insurance Services Received

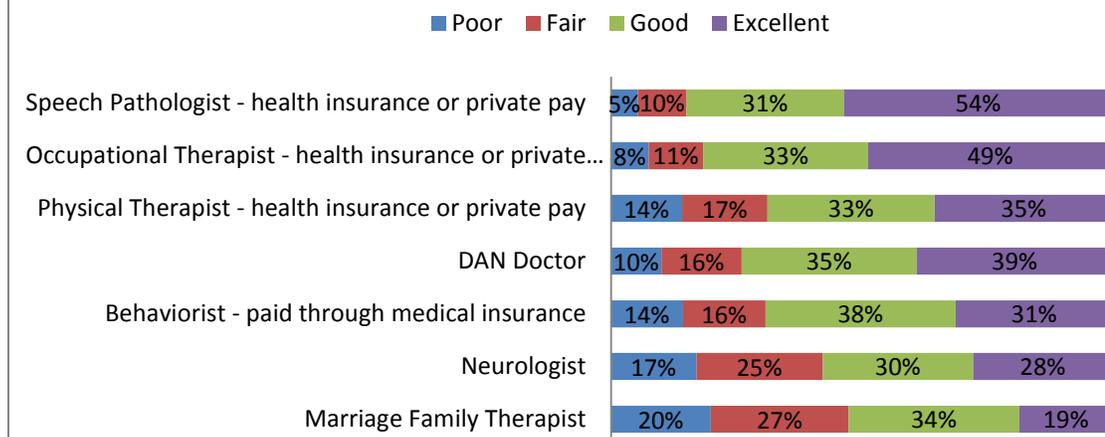


Figure 31

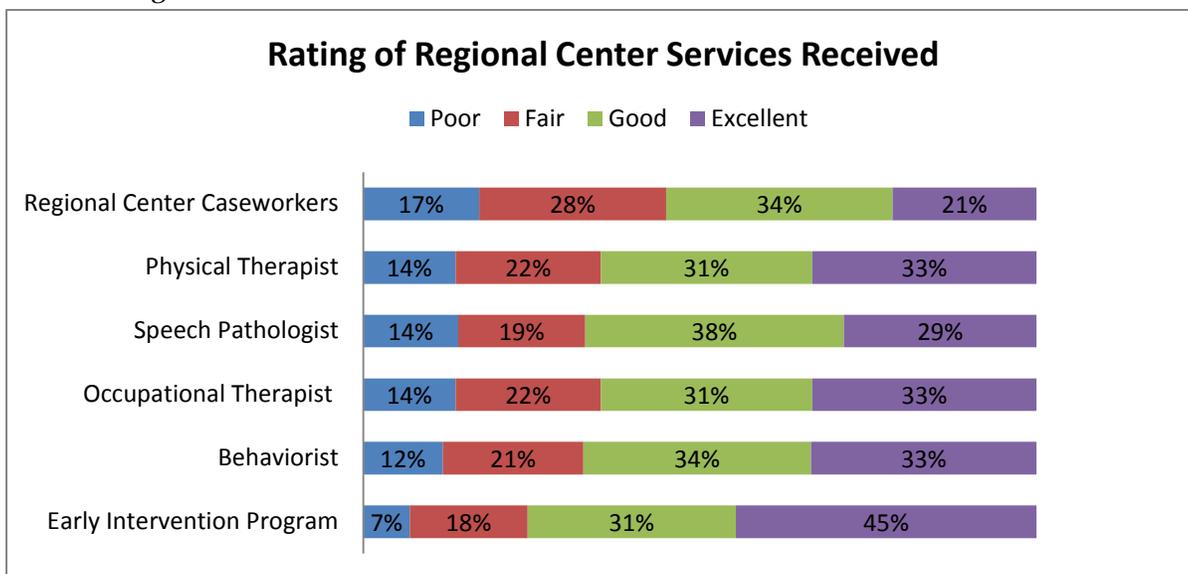
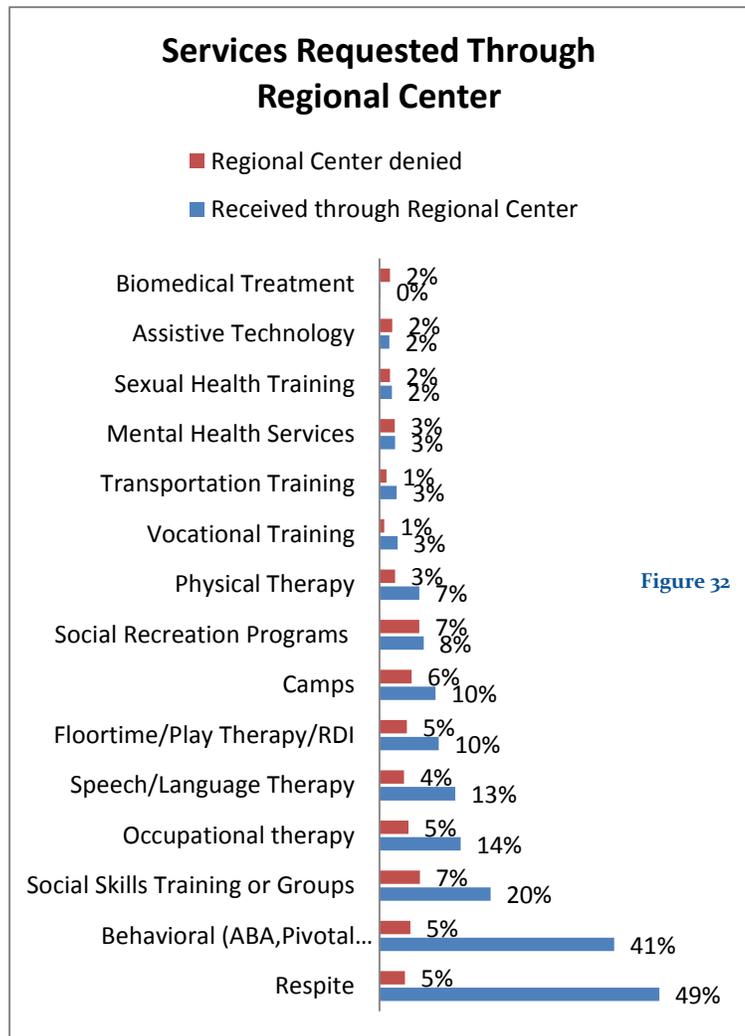
Regional Center

Seventy percent (70%) of the families indicated they were currently a regional center client, with 7% saying they had been denied services. This is down from our 2009 Survey when 77% families were members.

There are currently 21 Regional Centers contracted by the Department of Developmental Services in California to provide a variety of services. Each regional center has the ability to interpret the guidelines for admission and services.

The most commonly received service is respite with 49% of families having received this service at some time, followed by 41% of families receiving behavioral therapy. In 2009, 55% of parents indicated they were receiving ABA services through regional centers.

More than 60% of the parents reported the speech, physical therapy, occupational therapy or behavioral services received through regional center were rated good or excellent; 55% of parents rated caseworker services as good or excellent.



School Districts

Figure 34 shows approximately 77% of students with ASD are enrolled in special education; 11% are on 504 Plans, leaving 12% of students with no formal services through the school district.

Participants advised 11% of the ASD student population is currently enrolled in a Charter School or are homeschooled. This is up from 8% reported in the 2009 ASC Survey.

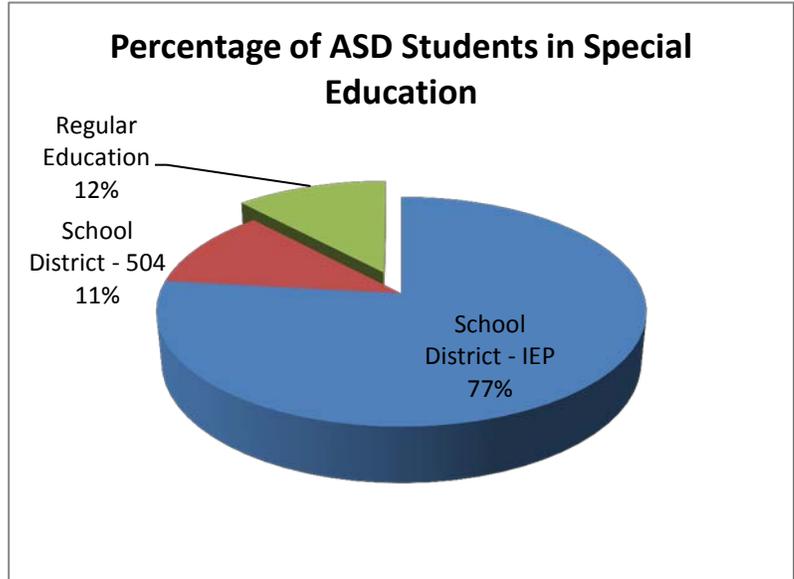


Figure 34

Services Requested Through School Districts

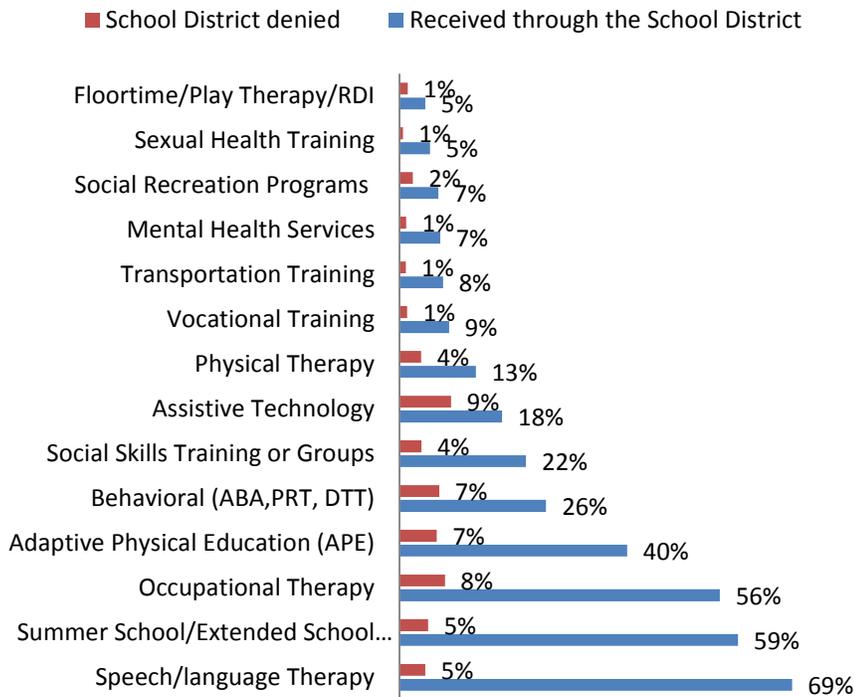
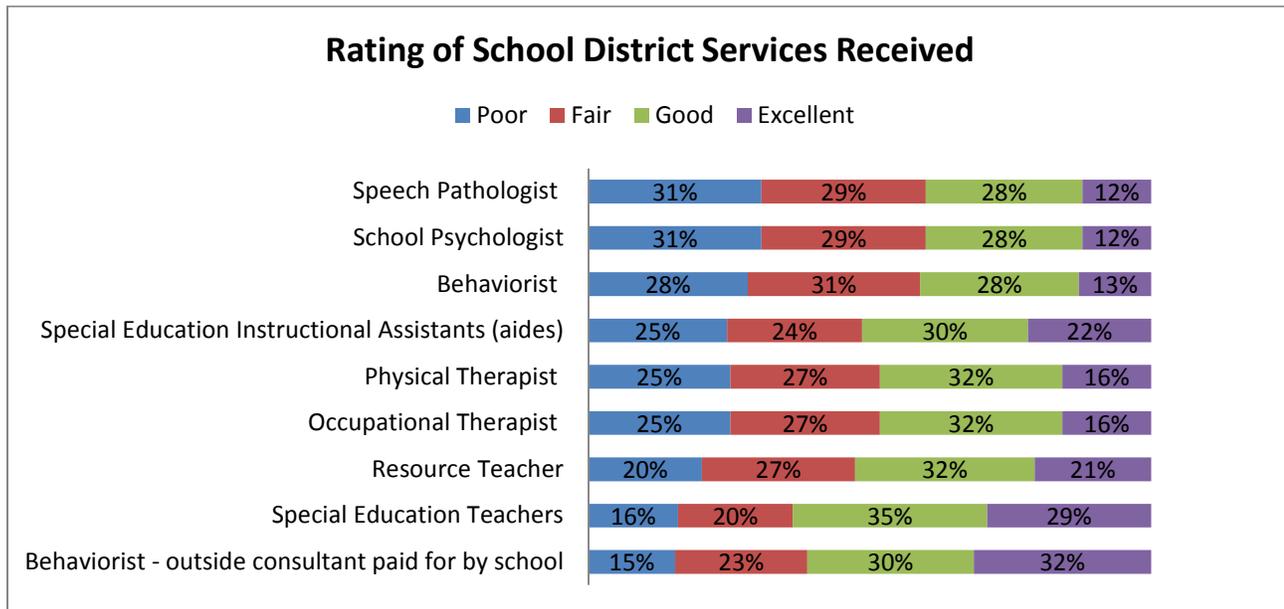


Figure 35

Figure 35 shows the most commonly funded and denied services through the school districts. These numbers have increased dramatically from the 2009 Survey. In 2009, 17% of ASD families reported speech therapy; 13% - occupational therapy; 12% - aide support; and 11% behavioral support through the school district.

Figure 36



This section of the survey brought some heated comments from parents and others remarked that services varies from year-to-year or school-to-school. We had a range of comments from grateful parents who found one person at the school that made the difference to other parents frustrated with an entire system:

“The teachers, adies and the admisistrative through (our) School District have been the most helpful, resourceful, have applied and gotten grants. They have iPads in the classroom, he is just beginning to work with the vocational program, starting to work the START program. He is currently taking guitar lessons three days a week at school. He loves guitars, and they initiated the lessons.”

“Last year's teacher would rate "poor," this year's would rate "good".

“We held my son back into an 8th grade program specifically designed for children with autism. He thrived and the teacher was incredible. Unfortunately, there was not an equivalent program available.”

“The special education aides have to only be US citizens and 18 yrs old. No formal training and they are left alone with our children!”

“The resource teacher at the public high school accused him of faking a disability because he was "smart enough to do the work." He is now in a district-paid NPS for kids with autism and everyone there "gets it.”

“School district experts may be knowledgeable but their recommendations are constrained by the school district administration, i.e. they are not allowed to freely provide their honest opinion. I have had good Special Ed teachers tell me discreetly: "I'm sorry but my hands are tied.”

HIGH SCHOOL COMPLETION

The 2012 Survey shows 60% of individuals with ASD graduated from High School, while 37% received a Certificate of Completion and 3% dropped out of High School.

Families with loved ones with ASD between the ages of 14-21 (transition-age) reported similar expectations. Families projected 55% would graduate from High School, 49% would receive a Certificate of Completion or Age out, and 6% of the students may drop out.

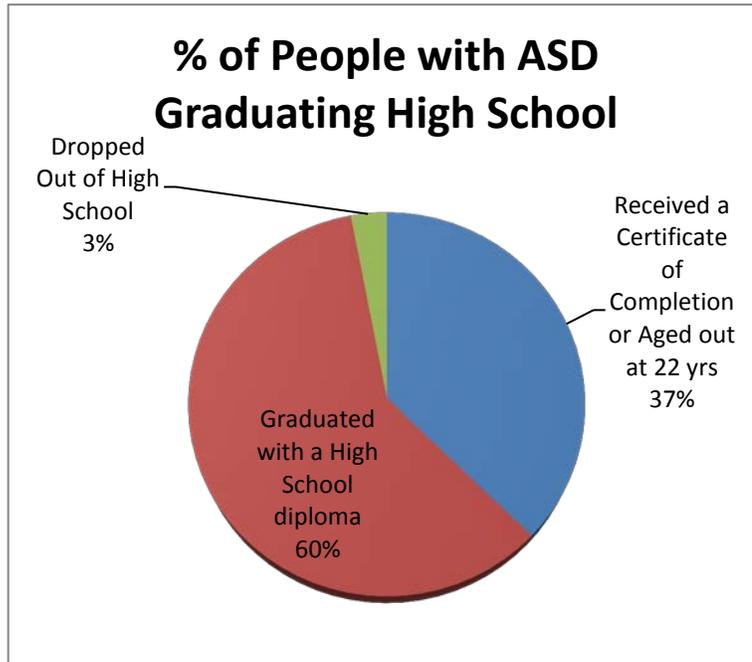


Figure 37

Families with children under the age of 14, the projection is also similar: 63% project their loved will graduate with a High School Diploma, 23% age out, and 3% may drop out.

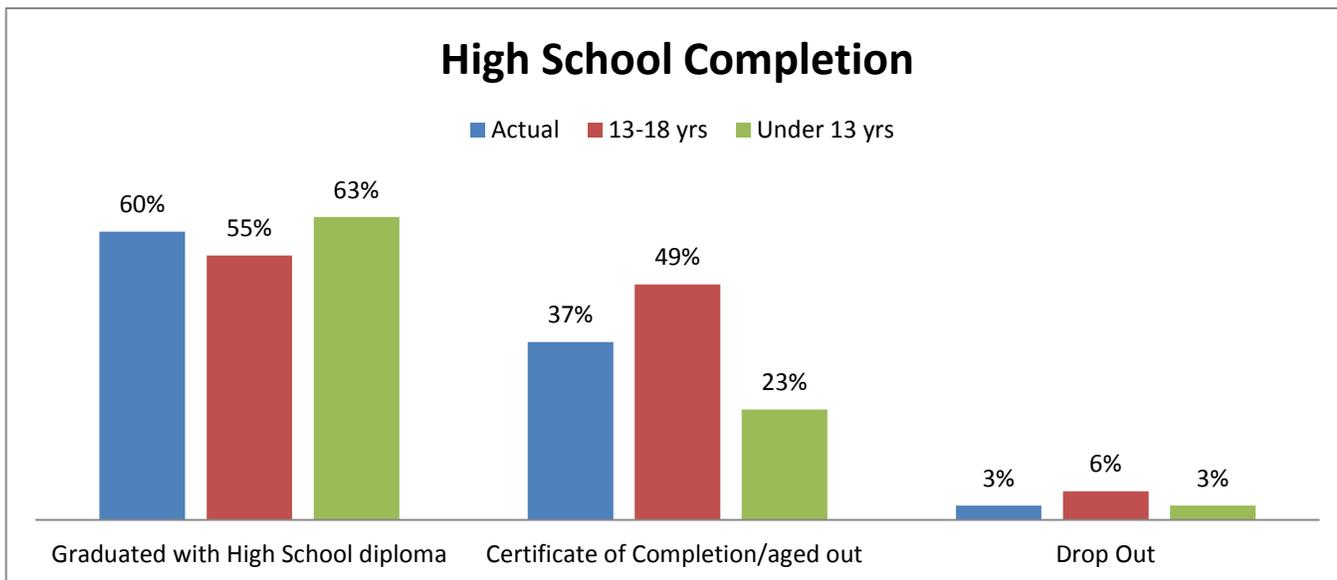


Figure 38

Transitioning to Adult Services

When we asked families with children 14 years or older if they thought the existing Adult Service programs would meet their needs, 77% replied they were unsure. Some families indicated they were not able to get information on these programs while their child was still in High School. Others commented they were just trying to get through the week and couldn't think that far ahead. Overall, only 2% of the transition-age parents (14yrs and older) believe these programs are going to meet their loved ones need.

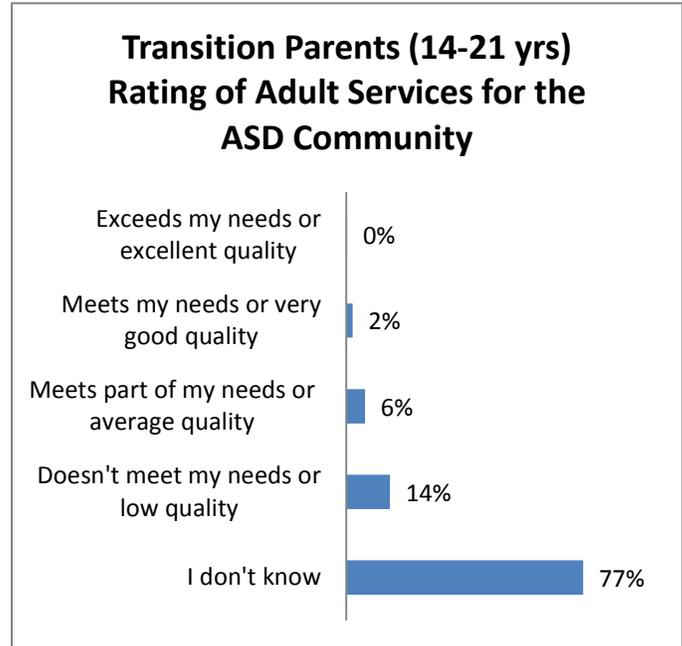


Figure 40 shows the breakdown by specific programs. Only Medi-Cal had 1% of families rate it as excellent. No other service providers were rated as excellent.

Figure 39

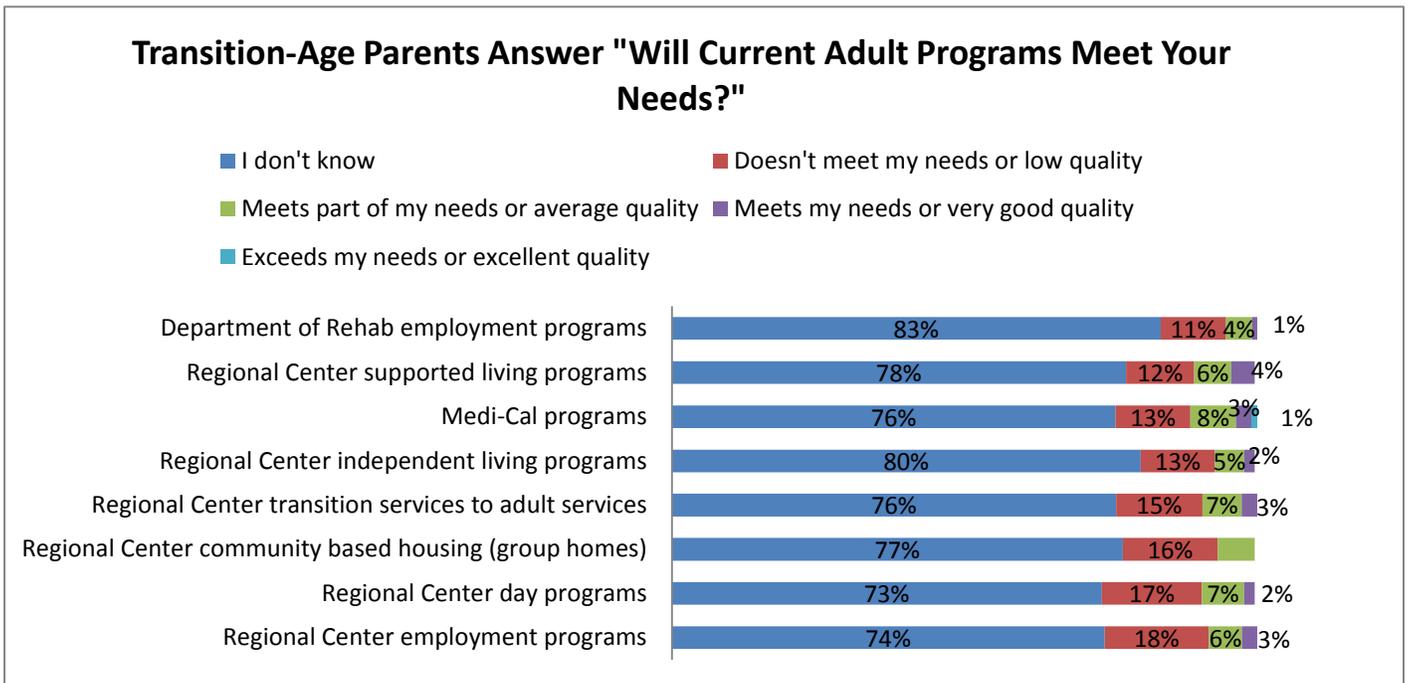


Figure 40

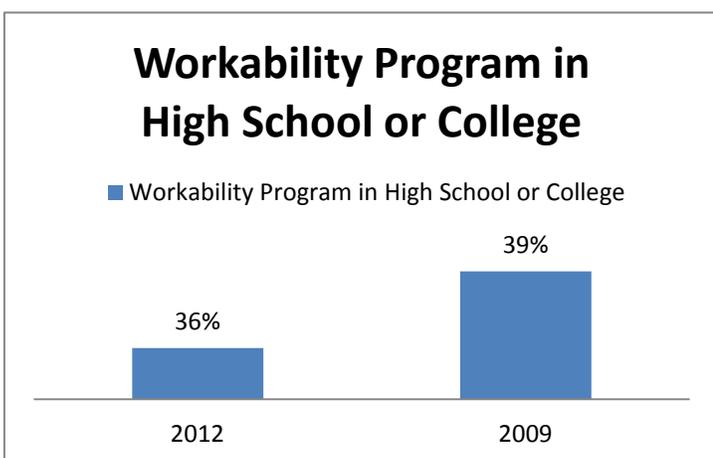
Seventy-five percent (75%) of parents clarified their expectations of what they want Adult Services to look like and common themes appeared:

- Range of options to fit person's needs
- Meaningful work opportunities and support ranging from quality day programs to the ability to work independently
- Appropriate housing and supports for a range of options including living at home, supported living or living independently
- Access to proper medical care including quality mental health services
- Safety - Someone to look out for each person's best interest; security to know that funding is in place

“Safety concerns, social opportunities, anti-discrimination, adequate transition planning before adulthood, and overall funding for providing services to the disabled, educating families what supports and services are available.”

“More opportunities for supported work for people with ASD. For those kids who have had workability opportunities, after graduation or age out of high school transition programs, there really isn't anything that will continue to put what the person has learned in motion. The adult programs need to work on actually integrating the people with ASD into the community and life. Seems from what I have recently viewed, there is a lot of baby sitting going on. Not what I am looking for my son.”

“Staged levels of living arrangements allowing individuals to develop independent living skills and graduate to their most functional level of independent living. Static living conditions don't seem to be the answer.”

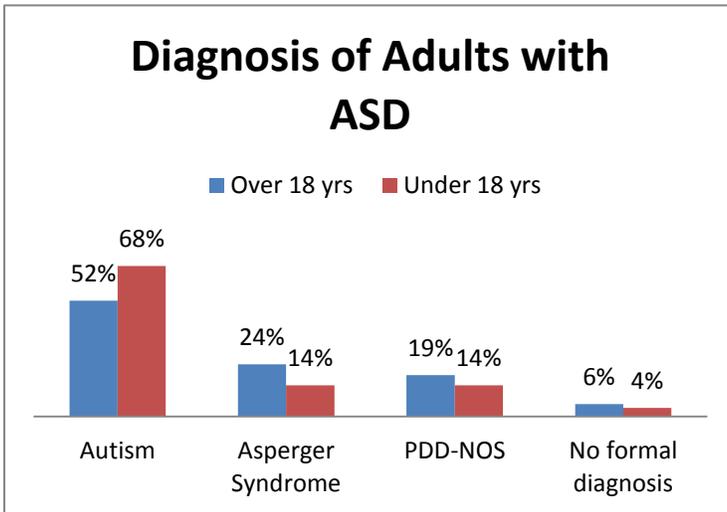


WORKABILITY

Families reported a slight decrease in how many individuals with ASD participated in a High School or College Workability or Transitional Partnership Program (TPP) compared with the 2009 Survey.

Figure 41

Adults with ASD



The 2012 Survey looked at the diagnostic labels given to individuals with ASD. Less adults were diagnosed with autism (52% compared to 68% of children) and more were diagnosed with Asperger's and PDD-NOS.

Figure 42

Figure 43 shows adults with ASD were reported to have a higher rate of mental health disorders compared to children with the largest discrepancy being depression (15% under 18 compared to 28% over 18). Figure 44 highlights the reported differences for health disorders. The largest discrepancy for health disorders between the two age groups was feeding issues that saw a decrease of occurrences (43% of children under 18 compared to 30% of adults over 18 yrs).

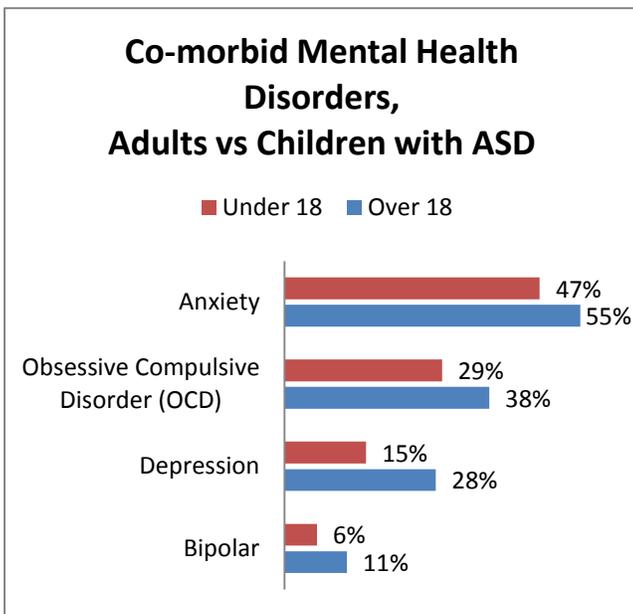


Figure 43

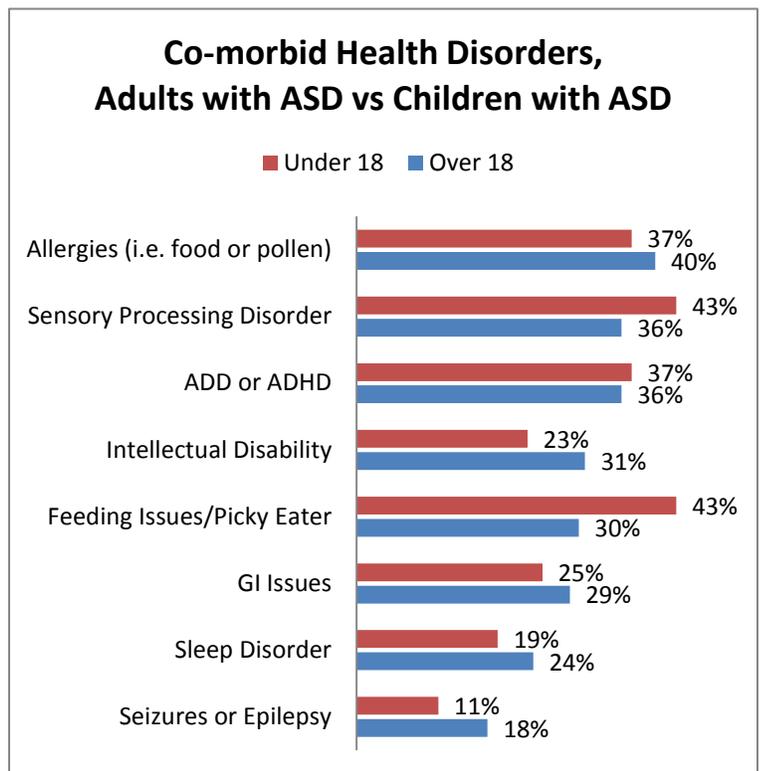


Figure 44

Adult Services

Only 65% of the adults who participated in the survey reported they were current regional clients compared to 90% of individuals under 18. In 2012, participants reported 39% of adults with ASD collect income from Social Security (SSI); 33% had health insurance through Medi-Cal; and 52% receive In Home Supportive Services (IHSS).

Number of Adults with ASD in Adult Services		
	2012 Survey	2009 Survey
Regional Center	65%	90%
IHSS	52%	26%
Social Security (SSI)	39%	52%
Medi-Cal	33%	51%
County Mental Health	7%	NA

Figure 45

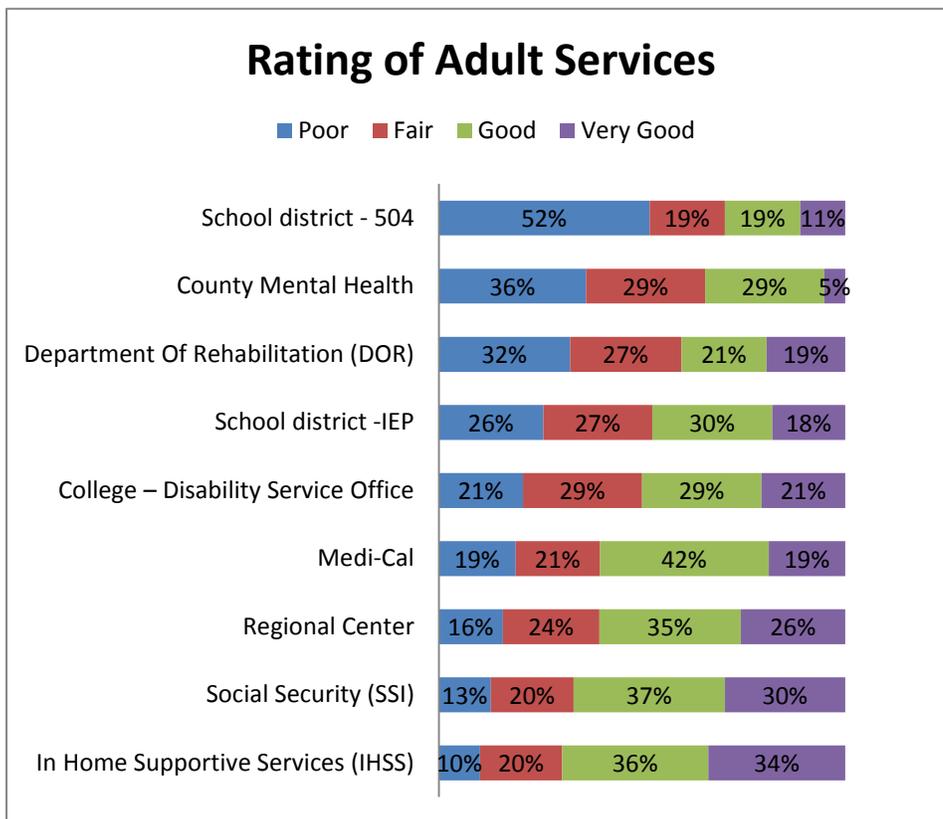


Figure 46

QUALITY OF ADULT SERVICES

Individuals with ASD over the age of 18 years and parents with adults completed this portion of the survey. In Home Supportive Services received the highest rating with 70% of individuals rating it good or very good. County Mental Health had the lowest rating with a 30% rating of good or very good.

Higher Education

The 2012 Survey showed more students with ASD are attending junior colleges. The survey also showed less individuals with ASD are dropping out of college – only 12% reported no longer attending in 2012, compared to 22% in 2009.

Families shared tales of success and of the challenges faced:

“Dropped out and went back with a lot of support received a BSW in Social Work.”

“He is taking a break this semester from college. He had a panic attack first day of school and decided to take the semester off.”

“He got an AA degree and has been taking class at a University.”

“He is taking classes at the Orange Empire Railroad Museum in hopes he can become a Train Engineer.”

“Tried to attend college 3 different times. he was overwhelmed with the number of people, homework and the number of classess. Several agencies promised to give him a social coach to go with him and assist him during the transition period. Nothing ever happened and when I called to ask about what happened I got reemed by the supervisor. I was just trying to follow through and get the services promised. Nothing ever happened and he eventually dropped out. He now has \$20,000 in debt for college loans and he probably has 9 units to show for it. Not fair!”

The survey also showed transition-age parents (14-21 yrs) and younger parents are optimistic about Higher Education possibilities for the future.

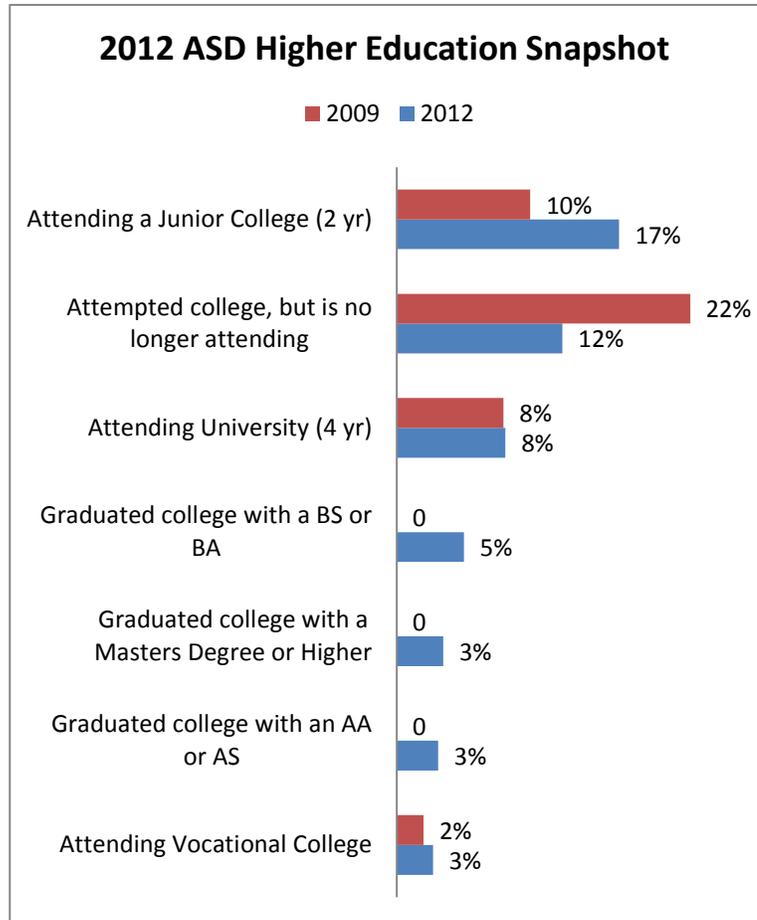


Figure 47 the



Figure 48 shows transition-age parents and parents of children under 13 years of age are setting their sights on a variety of college options.

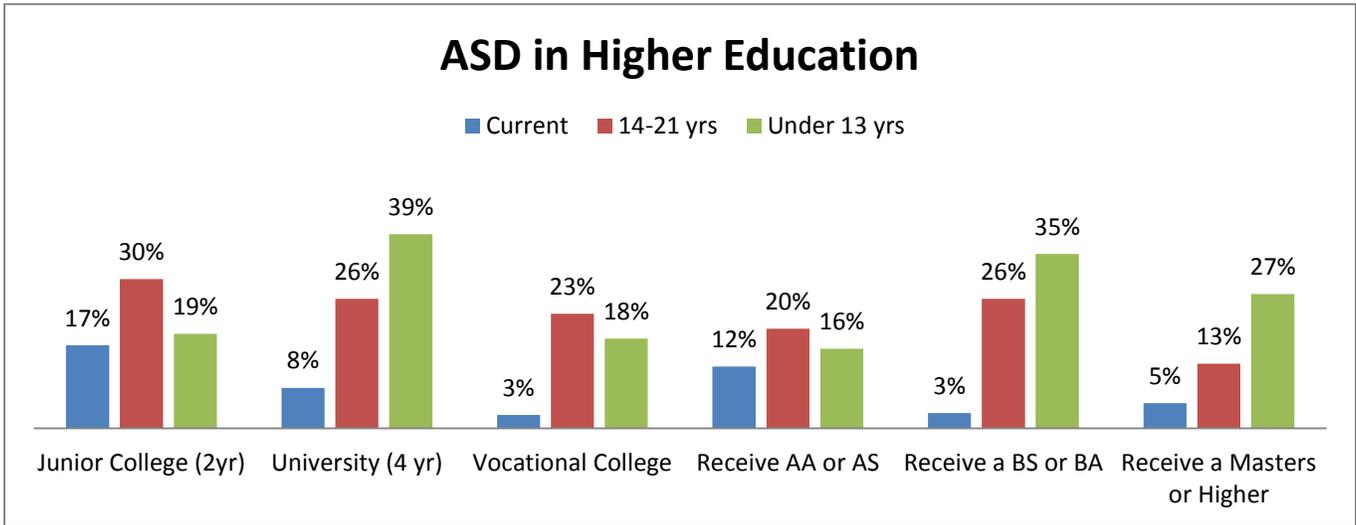


Figure 48

DISABILITY STUDENTS OFFICE

Of those attending an institution of higher learning, approximately 83% indicated they have accessed services through the Disability Students Office. Only 50% rated the services they received from the Disabled Students Office as good or very good.

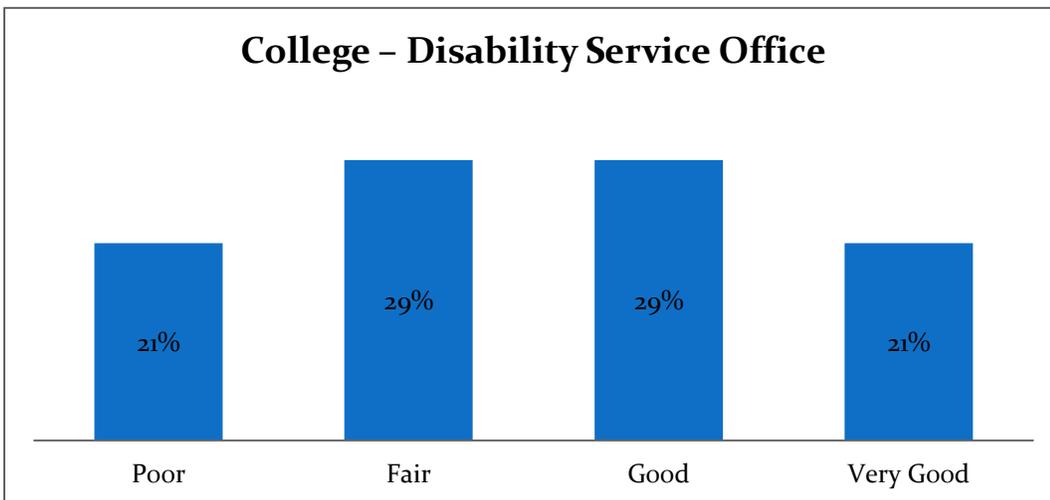


Figure 49

Employment

The employment picture continues to be bleak for adults with ASD. The 2012 Survey showed many adults with ASD are trying different options and programs. It was very common for an adult with ASD to have tried a mix of different options. An adult may have taken one or two college classes, started in supported employment, and then moved to independent employment or a Day program.

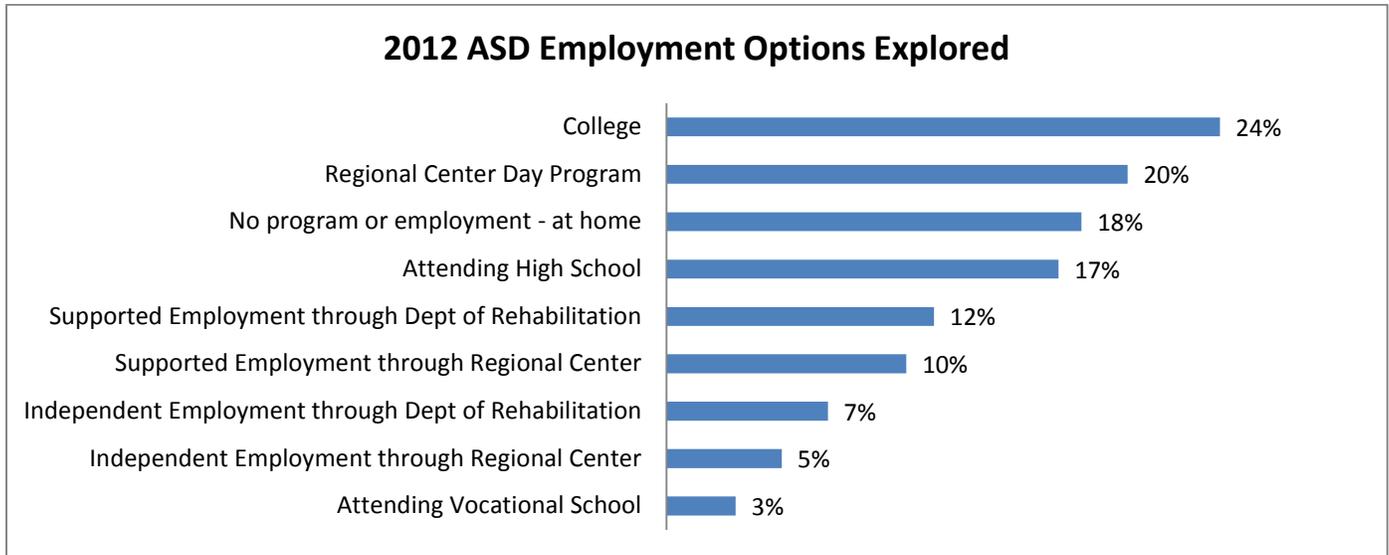


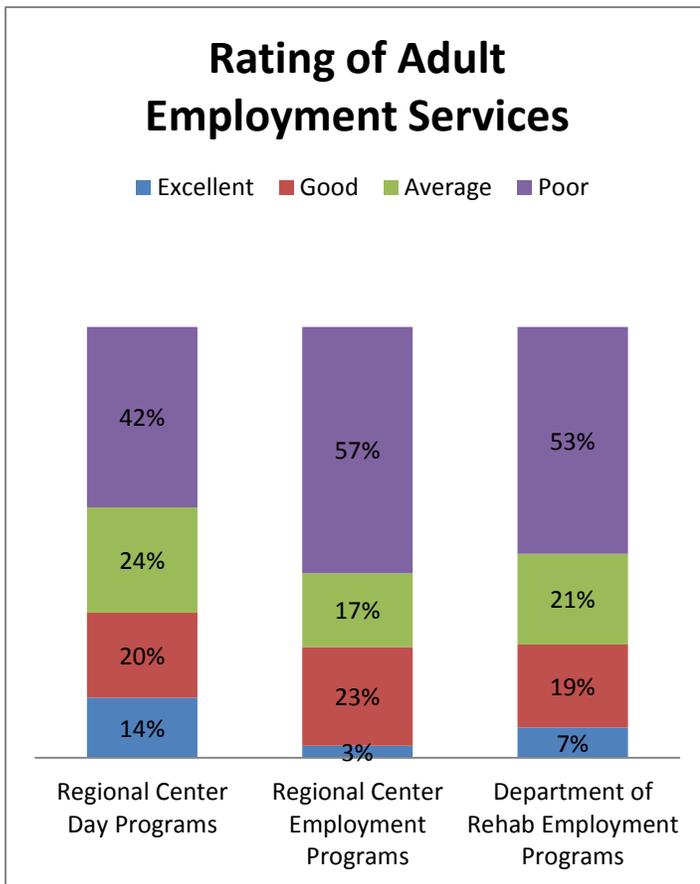
Figure 50

Unfortunately, these explored options do not seem to be translating into successful employment for adults with ASD. Individuals with ASD and parents reported the number of adults who are employed or participating in a Day Program decreased from 2009, while the number of adults who are sitting at home with no program increased.

Does the adult with ASD attend:	2009 Survey	2012 Survey
Day Program	29%	20%
Employed	42%	25%
Still in High School	16%	17%
At home - no program or employment	13%	18%

Figure 51

Figure 52



Adults expressed their frustration with the quality of employment services they received from the Regional Center employment programs, day programs and the Department of Rehabilitation Employment Programs. The Regional Center employment programs had 57% participants rate it as poor, Department of Rehabilitation had 53% rate it as poor, and Regional Center day programs had 42% rate it as poor.

Employment continues to be a prominent issue in the ASD community and many parents expressed their frustration:

“Our son was working at Wal-mart and was told by a manager he was a hard worker, was probably smarter than anyone there, but had a hard time getting along with others. After 6 months he quit.”

“In researching options for after leaving high school at age 22, I find it quite difficult to find even volunteer opportunities in our area. I am politely told we can't use them here.”

“Half way through a work adjustment program through DOR not going well. Has been a Regional Center client since August, 2011 has no Case Manager and we have received nothing from them.”

“He is in an internship program 6 hours a week. the rest of the time he spends in his room playing video games or watching t.v. My son looks capable, but what people don't realize is the amount of anxiety he experiences if he tries to leave the house, converse with people, or drive to a job, etc. We do not know if the internship will result in a job. I have to drive him to work, wake him up on time, etc. He is not independent even at 21.”

“Works thru a workshop; with job coach in a regular job; working 16 to 20 hours a week as a courtesy clerk at local supermarket. The company makes effort to hire one to two disabled in their company per store.”

“He is under the umbrella of regional center, but receives no support from them at present. In college on a reduced schedule, wants to write or sportscast. He is physically awkward and his ADHD sometimes gets in his way. He tried to mow his Grandmother's lawn and she fired him.”

Residential Services

Like employment services, residential services can offer a continuum. Adults may move from one service to another over their lifetime. For instance, an adult with ASD can live at home as an adult, may transition to supported living and then eventually live independently.

A recent DDS report indicated 75% of clients of the regional center system live in their family home. The 2012 Survey asked individuals and their families where they wanted to live.

Fifty-one percent (51%) of individuals and parents with adults over the age of 18,

and 62% under the age of 18 years, expect the individual with ASD to live at

home in the future. Some parents indicated in the comment section they had planned for the adult to live in their home for the rest of their life, while others

indicated they hoped this would be a process where the person with ASD would live at home, transition to living with some sort of support, and some to independent living.

Some parents expressed they were hoping after college, the adult with ASD would be better equipped for independent living. Other parents expressed their disappointment that more options were not available:

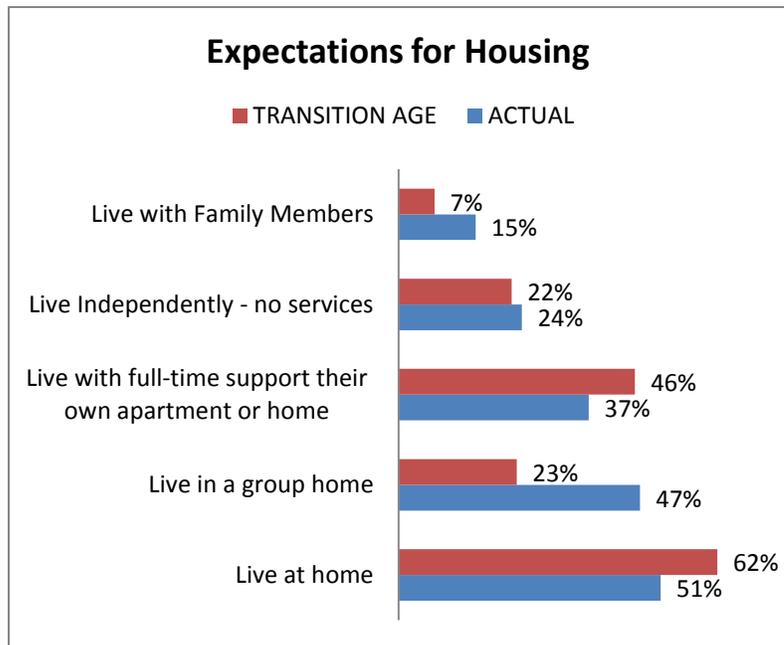


Figure 53

“He is currently living at home but gets very lonely. I would like to find an appropriate group home for him with other high functioning autistics, which has been very difficult.”

“Hopefully can remain in family home with support after parent's death.”

“He is on list for Supported Living, but no guarantees. He says he is not ready yet.”

“We are hopeful he will be to live away for college.”



The majority of individuals with ASD and parents using residential services felt the services in place rated poor in the area of Housing: 57% rated Regional Center Community Based Housing (group homes) as poor; 52% rated the Regional Center Independent Living Programs as poor; and 51% rated Regional Center Supported Living programs as poor.

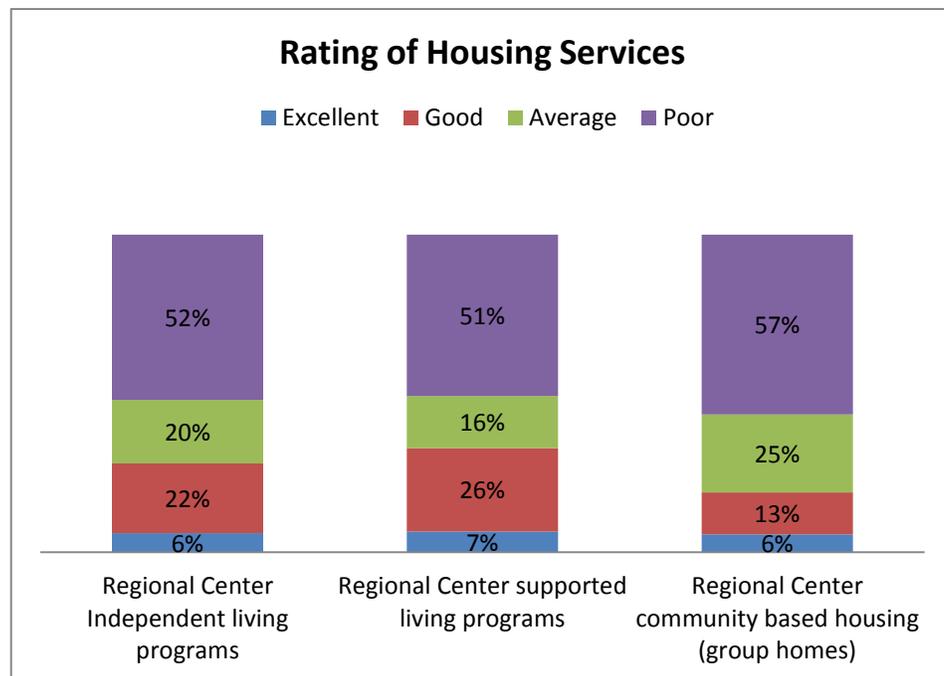


Figure 54

Parents again expressed their frustration:

“We have asked Regional Center to show us supported living situations (for the past 5 years) but they never do. The adult day program is basically a field trip a day and does nothing to prepare her for independence or work. We are disgusted -- this is not where we ever wanted to be or expected to end up.”

“Supported living failed due to untrained staff in autism and Positive Behavioral Supports”

“He will need assistance of some kind in future. Life expectancy of father is 4 years at most. Mother will be unable to provide for him. His brother will be making his own way, probably with a family. He will need some help in future or he will be on the street, I believe.”

“I am scared to death about what will happen to my son when I am not able to care for him.”

Budget Cuts & Legislation

A large number of services that impact the disabled population have been affected by budget cuts, especially, the Department of Developmental Services (DDS), schools, IHSS, social security, and Medi-Cal. More than 25% of the total ASD population has been impacted by budget cuts in four different areas: cancellation of Extended School Year classes, reduction of Medi-Cal benefits, elimination of camps and reduction of respite hours. Survey participants (50%) reported that they have been most affected by reduction of respite hours. Over 200 families responded to this section of the survey with heartbreaking comments:

“I have to transport my child to his day program in the summer as the state cannot pay for a trip. This leads to him being absent more frequently.”

“While his Special Ed class was not cancelled, others were which meant his class was more impacted and kids with problem behaviors were lumped into his class when they shouldn't have been.”

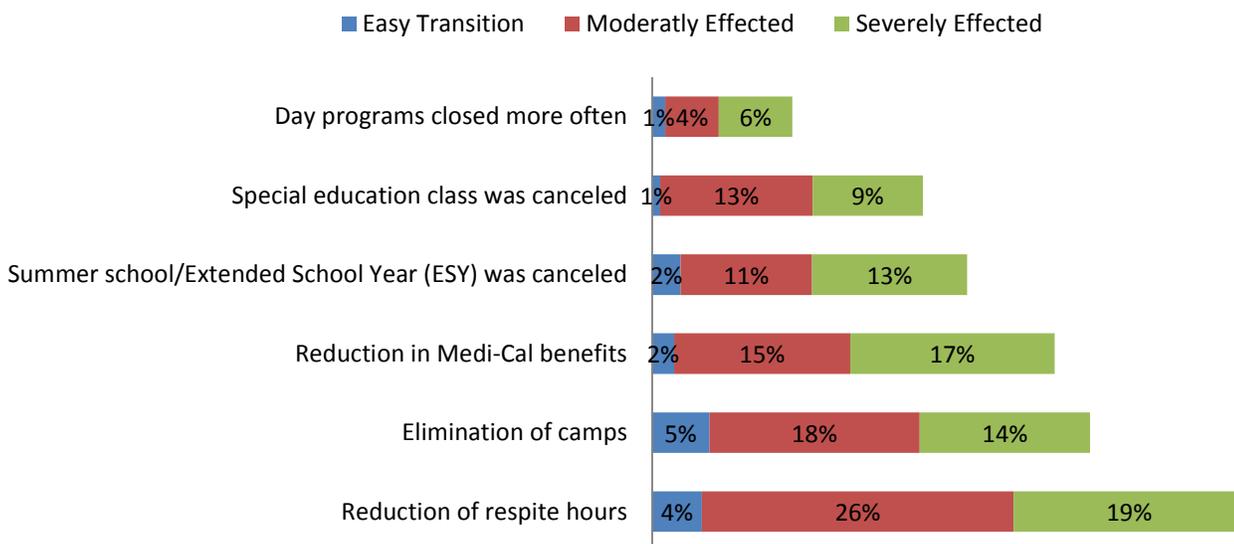
“No day programs available. School ESY so minimal I had to leave my job to cover.”

“Lower hourly rate for respite workers makes it impossible to find someone to do this hard work for only \$8/hr.”

“My son aged out of Early Prevention before the budget cuts kicked in, so we saw no impact with him. However, our second son (now 2 1/2) has a speech delay and other behavior concerns for which we cannot receive any services.”

How Have Budget Cuts Impacted Your Family

Figure 55



IMPACT OF FUTURE CUTS

ASD families are concerned about possible cuts to additional services. More than 25% of families indicated that five proposed areas will impact them, and 3 out of the 5 areas would be severely impacted. Many families indicated that the change in health care laws that allow adult children to stay on private health insurance has helped them avoid Medi-Cal issues.

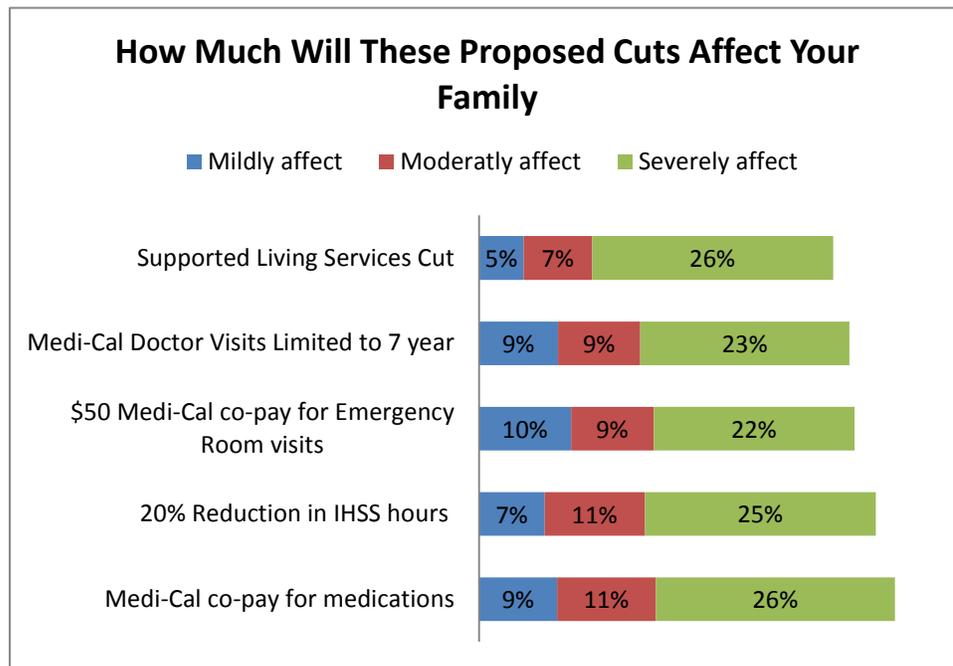


Figure 56

NEW CALIFORNIA AUTISM HEALTH CARE LAW

SB946 (Steinberg), the Autism Health Insurance Bill was signed into law in 2011 and takes effect July 1, 2012. This law states that California State regulated health care plans (also known as fully funded or fully insured plans) fall under the guidance of the new Autism Health Insurance Law. Those plans that provide hospital, medical, or surgical coverage shall also provide coverage for behavioral health treatment for pervasive developmental disorder or autism. Behavioral health treatment includes applied behavior analysis (ABA) and other evidence-based behavior intervention programs. This law does not apply to health care plans that do not deliver mental health or behavioral health services to enrollees, to participants in the Medi-Cal program, the Healthy Families Program or the Public Employees Retirement System (CalPERS). The 2012 Survey shows that almost 44% of families are not aware of this new law and how it can benefit their loved one with ASD.

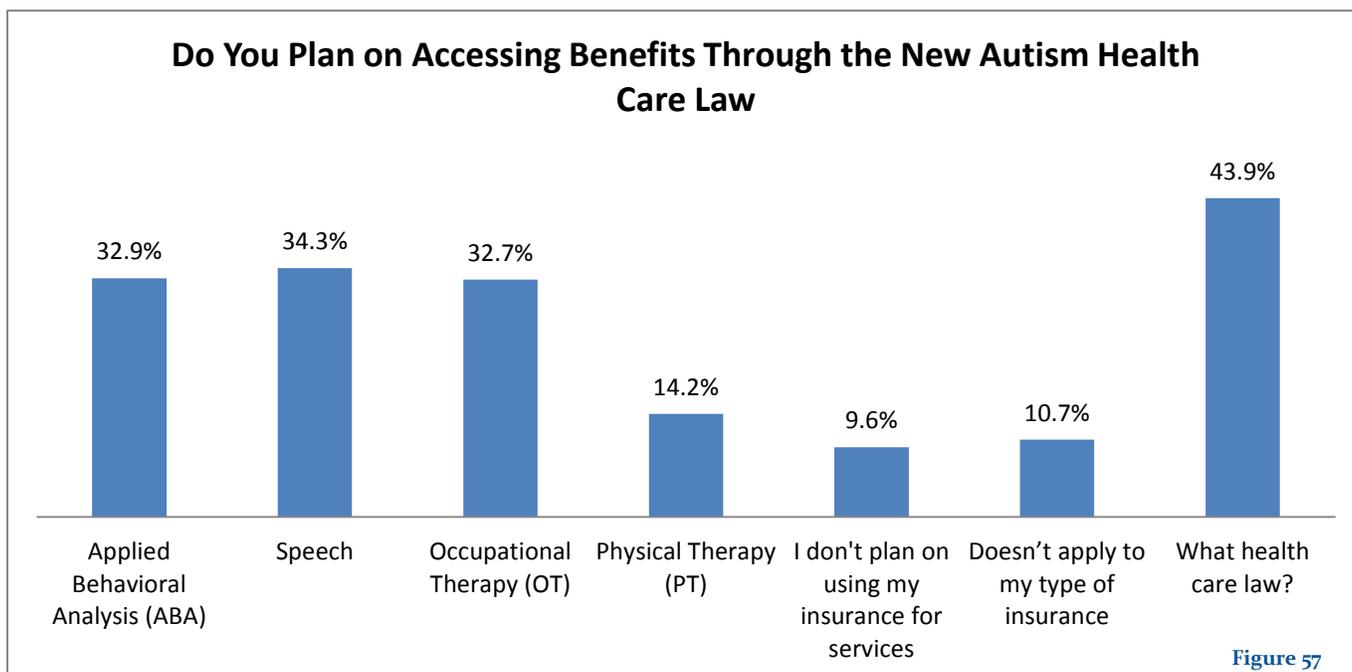


Figure 57

ADULT SERVICES CUTS

Figure 58

Forty-seven percent (47%) of our adult families indicated that they were impacted by IHSS and DDS cuts to staffing; 29% of the families indicated that they are not able to find staffing at the current rates.

Are you Able to Hire Staff with Current DDS and IHSS Rates?

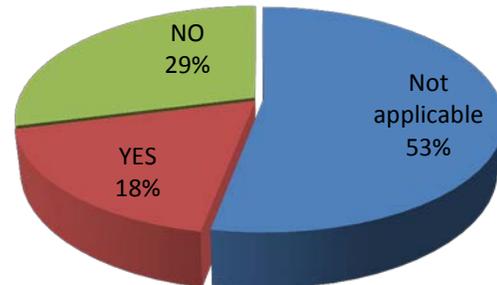
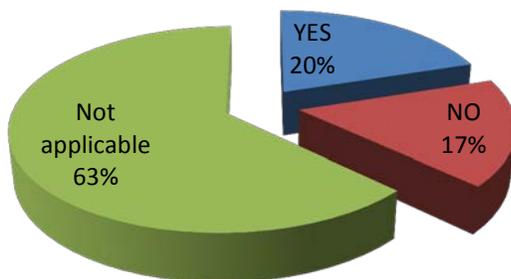


Figure 59

Do You Have to leave Work to Care for Your Adult Child When There is No Day Program?



Thirty-seven percent (37%) of the adult ASD families advised they are impacted by cuts requiring Adult Day Programs to close more often. Twenty percent (20%) of the adult families indicated it required a parent to take the day off to ensure the adult with ASD is safe.

Figure 60 shows families expressed concerned about possible cuts to adult services and how it will impact the family.

2012 Proposed Cuts to Adult Services

■ Will mildly affect our family ■ Will moderately affect our family ■ Will severely affect our family

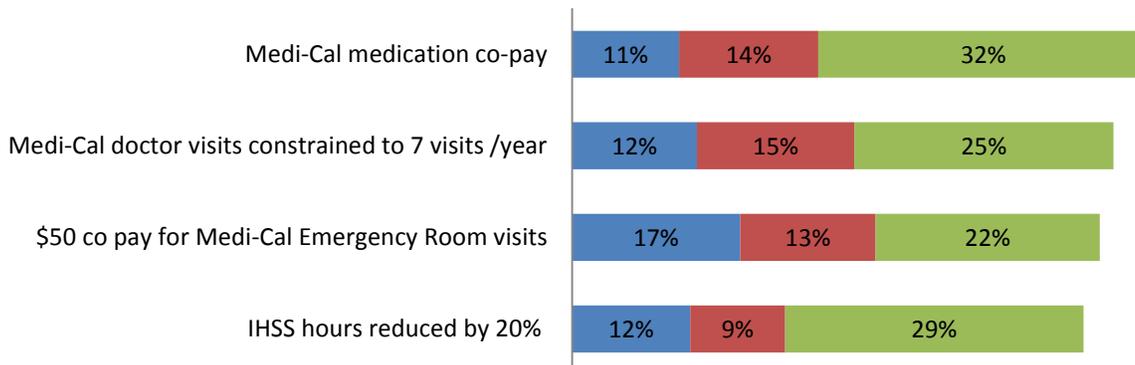


Figure 60

Information and Resources

Parents and individuals with ASD continue to want information, resources and training. Eighty-two percent of individuals and families indicated that electronic newsletters (82%) are the most preferred way to receive information. There was a significant increase in the number of people who wanted to attend conferences and support group meetings, but comments indicated that cost and time would be factors in these modes.

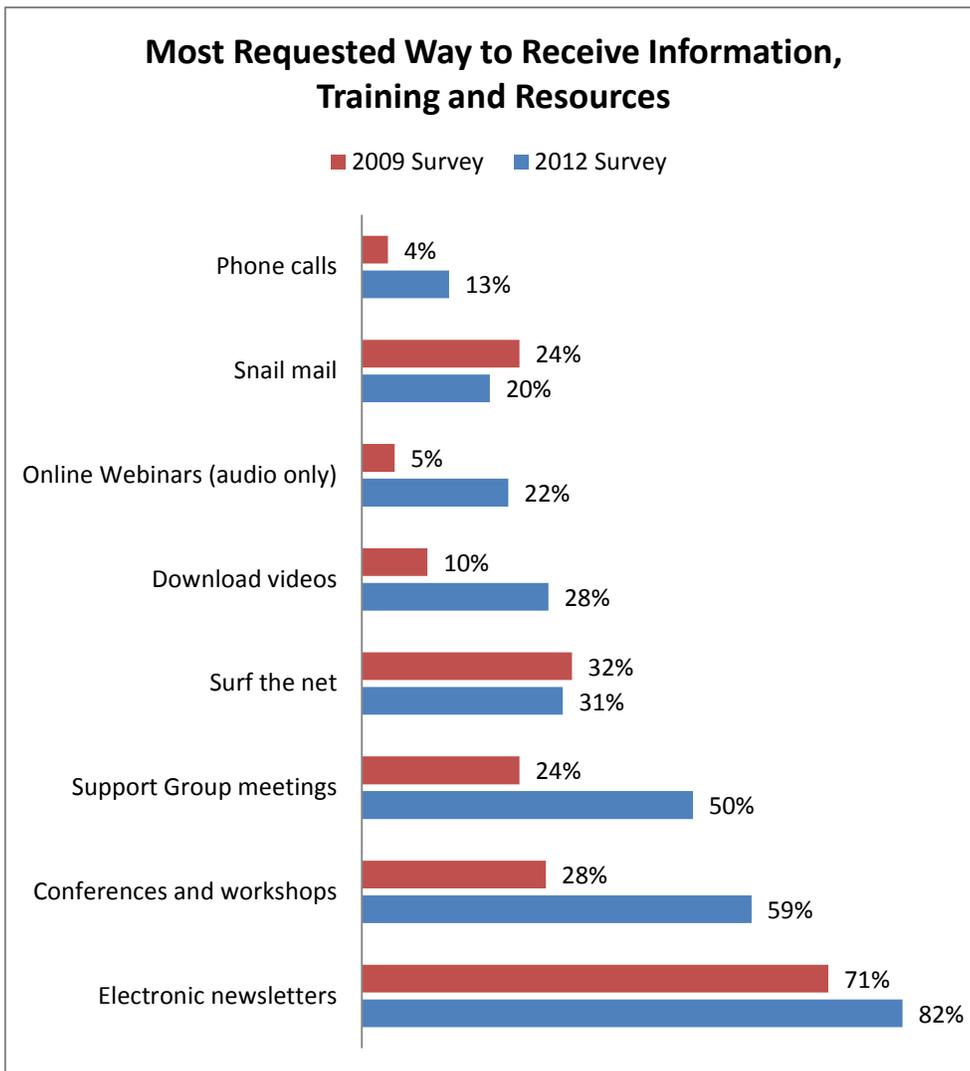


Figure 61

INDEX

- acceptance, 16
- Access to Health Care, 18
- Adult Services, 34
- adult services cuts, 43
- Adults with ASD, 33
- advocacy tools, 25
- ASD household demographics, 9
- Budget Cuts, 41
- communication skills, 14
- co-morbid conditions, 10
- dangerous behavior, 15
- Disability students office, 36
- dressng self, 13
- Ease of Navigating Systems, 4, 24
- Employment, 37
- Executive Summary, 3
- Feeding self, 14
- friendship, 17
- Health Insurance, 26
- high school completion, 30
- Higher Education, 35
- impact of future cuts, 42
- Information and Resources, 44
- Law Enforcement Interactions, 4, 15
- Legislation, 41
- new california autism health care law, 42
- Obtaining a Diagnosis, 11
- quality of adult services, 34
- Quality of Life Issues, 13
- Regional Center, 27
- Residential Services, 39
- School Districts, 28
- Service Quality, 22
- Systems of Care, 19
- toileting, 13
- Transitioning to Adult Services, 31
- Treatment and Therapies, 20
- waiting lists, 24
- where families are receiving diagnosis, 12
- workability, 32

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1st Vice-President Autism Society of California

For more information on autism spectrum disorders in California, visit the Autism Society of California website at www.autismsocietyca.org

