



Easter Seals' *Living with Autism Study*

actforautism.org

Conducted by:



Made possible by:



In cooperation with:



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Background

- Autism Spectrum Disorders are complex developmental disabilities which result in challenges in the areas of communication, socialization and restrictive/repetitive behavior.
- There are five diagnostic classifications within Autism Spectrum Disorders: Autistic Disorder, Asperser's Syndrome, Childhood Disintegrative Disorder, Rett's Syndrome and Pervasive Developmental Disorder – Not Otherwise Specified.
- Diagnosis is increasing at a higher rate of 10 to 17 percent each year and the Centers for Disease Control and Prevention (CDC) estimates the prevalence of ASD are now as many as 1 in 150 children. Males are four times more likely than females to have autism.

Objectives

- Call attention to the ongoing and critical lifetime challenges of people living with autism
- Identify financial needs for families with special needs and uncover ways for Easter Seals and Mass Mutual to address these needs
- Understand how parents and care givers prefer to access information
- Assist service providers in their roles of providing assistance
- Provide support for the need for additional funding to enhance key resources in the following areas:
 - School to work transitions
 - Employer support
 - Residential and community support
 - Financial planning

Methodology

Population Studied:	<ul style="list-style-type: none"> ▪ Are U.S. residents ▪ Are 17 years of age or older ▪ Are parents of a child age 30 or younger who either has ASD or does not have any special needs at all ▪ Received an email invitation from one of the following sources: <ul style="list-style-type: none"> – Harris Poll Online – Easter Seals – Autism Society of America
Sample Size:	<p>A total of 2569 surveys were collected</p> <ul style="list-style-type: none"> ▪ 917 parents with children age 30 or younger without any special needs ▪ 1652 parents with children age 30 or younger with ASD
Data Collection:	<p>Surveys were conducted online between June 16 and July 17, 2008.</p>
Weighting:	<p>Data received from the Harris Poll was weighted to be representative of the U.S. population on the basis of age by gender, education, region, household income, and race/ethnicity, and propensity to join an online panel.</p>
Significance testing at 95% level of confidence:	<p>Throughout the report circles (○) are used to indicate if a number is significantly higher than the corresponding number between the general population and the parents with children with ASD. Additionally, a green number indicates it is significantly higher than a corresponding red number.</p>

Sample Definitions

No Special Needs: Parents Of Children In The General Population

Autism Spectrum Disorder (ASD): Parents of Children with ASD (Autism, Pervasive Developmental Disorder – Not Otherwise Specified, Asperger’s Syndrome, Rett’s, Childhood Disintegrative Disorder, or not sure of type)

Autism: Parents Of Children With Autistic Disorder

Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS): Parents of Children with Pervasive Developmental Disorder – Not Otherwise Specified

Asperger’s Syndrome: Parents of Children with Asperger’s Syndrome

Other groups were included in this study, but were also excluded due to low base sizes.



Profile of Respondents/ Demographics

Parents of Children with No Special Needs

Demographic Profile

Gender of Child	N=917
Male	48%
Female	52%

Age of Child	N=917
1-3	13%
4-6	7%
7-12	16%
13-18	21%
19-24	18%
25-30	25%

MEAN = 16.1

Primary Residence	N=917
Suburban	54%
Rural	22%
Urban	21%
Other	2%

Parent Gender	N=917
Male	43%
Female	57%

Total Household Income	N=917
Less than \$15,000	5%
\$15,000 to \$24,999	7%
\$25,000 to \$34,999	6%
\$35,000 to \$49,999	13%
\$50,000 to \$74,999	20%
\$75,000 to \$99,999	15%
\$100,000 to \$124,999	13%
\$125,000 to \$149,999	5%
\$150,000 to \$199,999	5%
\$200,000 to \$249,999	1%
\$250,000 or more	1%
Decline to answer	9%

MEAN = \$75,258
 MEDIAN = \$56,597

Parent Ethnicity	N=917
White	72%
Black/African American	12%
Asian or Pacific Islander	1%
Native Amer. or Alaskan Native	<1%
Mixed Race	<1%
Some other race	<1%
Hispanic	11%
Decline to Answer	3%

Parents of Children with Autism Spectrum Disorder

Demographic Profile

Gender of Child	N=1652
Male	83%
Female	17%

Age of Child	N=1652
1-3	8%
4-6	26%
7-12	36%
13-18	20%
19-24	7%
25-30	3%

MEAN = 10.0

Person Who First Made Diagnosis of ASD	N=1652
Pediatrician	8%
Developmental Pediatrician	23%
Psychiatrist	10%
Neurologist	16%
General Practitioner	<1%
Psychologist	26%
Teacher	6%
Other	9%

Age of Child at Time of Diagnosis of ASD	N=1652
0	1%
1 to 2	33%
3 to 5	46%
6 to 9	12%
10 to 13	6%
14 to 17	2%
18 to 21	<1%
22 to 25	<1%

MEAN = 4.2

Primary Residence	N=1652
Suburban	59%
Rural	20%
Urban	18%
Other	2%

Parent Gender	N=1652
Male	10%
Female	90%

Total Household Income	N=1652
Less than \$15,000	5%
\$15,000 to \$24,999	6%
\$25,000 to \$34,999	7%
\$35,000 to \$49,999	12%
\$50,000 to \$74,999	18%
\$75,000 to \$99,999	15%
\$100,000 to \$124,999	10%
\$125,000 to \$149,999	5%
\$150,000 to \$199,999	5%
\$200,000 to \$249,999	2%
\$250,000 or more	3%
Decline to answer	12%

MEAN = \$82,581

MEDIAN = \$58,463

Parent Ethnicity	N=1652
White	81%
Black/African American	5%
Asian or Pacific Islander	2%
Native Amer. or Alaskan Native	<1%
Mixed Race	2%
Some other race	<1%
Hispanic	8%
Decline to Answer	3%

Parents of Children with ASD (Autism)

Demographic Profile

Gender of Child	N=874
Male	82%
Female	18%

Age of Child	N=874
1-3	9%
4-6	31%
7-12	33%
13-18	18%
19-24	6%
25-30	2%

MEAN = 9.6

Person Who First Made Diagnosis of ASD	N=874
Pediatrician	9%
Developmental Pediatrician	27%
Psychiatrist	7%
Neurologist	17%
General Practitioner	1%
Psychologist	25%
Teacher	5%
Other	10%

Age of Child at Time of Diagnosis of ASD	N=874
0	<1%
1 to 2	44%
3 to 5	46%
6 to 9	7%
10 to 13	2%
14 to 17	1%
18 to 21	<1%
22 to 25	-

MEAN = 3.3

Primary Residence	N=874
Suburban	58%
Rural	21%
Urban	19%
Other	2%

Parent Gender	N=874
Male	11%
Female	89%

Total Household Income	N=874
Less than \$15,000	5%
\$15,000 to \$24,999	6%
\$25,000 to \$34,999	8%
\$35,000 to \$49,999	11%
\$50,000 to \$74,999	18%
\$75,000 to \$99,999	14%
\$100,000 to \$124,999	10%
\$125,000 to \$149,999	4%
\$150,000 to \$199,999	6%
\$200,000 to \$249,999	3%
\$250,000 or more	3%
Decline to answer	12%

MEAN = \$83,783

MEDIAN = \$58,102

Parent Ethnicity	N=874
White	81%
Black/African American	5%
Asian or Pacific Islander	2%
Native Amer. or Alaskan Native	<1%
Mixed Race	1%
Some other race	<1%
Hispanic	7%
Decline to Answer	2%

Parents of Children with ASD (Pervasive Developmental Disorder – Not Otherwise Specified)

Demographic Profile

Gender of Child	N=398
Male	82%
Female	18%

Age of Child	N=398
1-3	9%
4-6	27%
7-12	37%
13-18	19%
19-24	6%
25-30	2%

MEAN = 9.6

Person Who First Made Diagnosis of ASD	N=398
Pediatrician	6%
Developmental Pediatrician	26%
Psychiatrist	11%
Neurologist	18%
General Practitioner	-
Psychologist	27%
Teacher	6%
Other	7%

Age of Child at Time of Diagnosis of ASD	N=398
0	1%
1 to 2	29%
3 to 5	51%
6 to 9	11%
10 to 13	5%
14 to 17	2%
18 to 21	1%
22 to 25	-

MEAN = 4.3

Primary Residence	N=398
Suburban	62%
Rural	19%
Urban	18%
Other	2%

Parent Gender	N=398
Male	8%
Female	92%

Total Household Income	N=398
Less than \$15,000	5%
\$15,000 to \$24,999	5%
\$25,000 to \$34,999	6%
\$35,000 to \$49,999	11%
\$50,000 to \$74,999	19%
\$75,000 to \$99,999	15%
\$100,000 to \$124,999	9%
\$125,000 to \$149,999	8%
\$150,000 to \$199,999	5%
\$200,000 to \$249,999	3%
\$250,000 or more	3%
Decline to answer	12%

MEAN = \$84,745

MEDIAN = \$60,296

Parent Ethnicity	N=398
White	81%
Black/African American	5%
Asian or Pacific Islander	1%
Native Amer. or Alaskan Native	<1%
Mixed Race	2%
Some other race	1%
Hispanic	8%
Decline to Answer	2%

Parents of Children with ASD (Asperger's)

Demographic Profile

Gender of Child	N=300
Male	85%
Female	15%

Age of Child	N=300
1-3	2%
4-6	12%
7-12	44%
13-18	29%
19-24	10%
25-30	4%

MEAN = 12.3

Person Who First Made Diagnosis of ASD	N=300
Pediatrician	5%
Developmental Pediatrician	12%
Psychiatrist	20%
Neurologist	11%
General Practitioner	1%
Psychologist	30%
Teacher	10%
Other	11%

Age of Child at Time of Diagnosis of ASD	N=300
0	<1%
1 to 2	6%
3 to 5	36%
6 to 9	31%
10 to 13	19%
14 to 17	5%
18 to 21	1%
22 to 25	1%

MEAN = 7.2

Primary Residence	N=300
Suburban	57%
Rural	22%
Urban	19%
Other	2%

Parent Gender	N=300
Male	8%
Female	92%

Total Household Income	N=300
Less than \$15,000	4%
\$15,000 to \$24,999	6%
\$25,000 to \$34,999	8%
\$35,000 to \$49,999	13%
\$50,000 to \$74,999	17%
\$75,000 to \$99,999	16%
\$100,000 to \$124,999	12%
\$125,000 to \$149,999	5%
\$150,000 to \$199,999	4%
\$200,000 to \$249,999	2%
\$250,000 or more	1%
Decline to answer	12%

MEAN = \$78,990

MEDIAN = \$58,872

Parent Ethnicity	N=300
White	85%
Black/African American	3%
Asian or Pacific Islander	1%
Native Amer. or Alaskan Native	1%
Mixed Race	1%
Some other race	1%
Hispanic	5%
Decline to Answer	3%

Parents of Children with ASD (Other Types: Rett's, Childhood Disintegrative Disorder, or Not Sure)

Demographic Profile

Gender of Child	N=80
Male	85%
Female	15%

Age of Child	N=80
1-3	18%
4-6	22%
7-12	37%
13-18	15%
19-24	5%
25-30	3%

MEAN = 9.4

Person Who First Made Diagnosis of ASD	N=80
Pediatrician	7%
Developmental Pediatrician	17%
Psychiatrist	12%
Neurologist	20%
General Practitioner	-
Psychologist	24%
Teacher	11%
Other	9%

Age of Child at Time of Diagnosis of ASD	N=80
0	2%
1 to 2	29%
3 to 5	51%
6 to 9	10%
10 to 13	6%
14 to 17	1%
18 to 21	-
22 to 25	-

MEAN = 3.9

Primary Residence	N=80
Suburban	61%
Rural	17%
Urban	17%
Other	5%

Parent Gender	N=80
Male	12%
Female	88%

Total Household Income	N=80
Less than \$15,000	4%
\$15,000 to \$24,999	6%
\$25,000 to \$34,999	9%
\$35,000 to \$49,999	16%
\$50,000 to \$74,999	21%
\$75,000 to \$99,999	14%
\$100,000 to \$124,999	14%
\$125,000 to \$149,999	4%
\$150,000 to \$199,999	-
\$200,000 to \$249,999	1%
\$250,000 or more	2%
Decline to answer	10%

MEAN = \$72,477

MEDIAN = \$52,694

Parent Ethnicity	N=80
White	61%
Black/African American	10%
Asian or Pacific Islander	4%
Native Amer. or Alaskan Native	-
Mixed Race	1%
Some other race	-
Hispanic	18%
Decline to Answer	6%

Snap Shot of Demographic Differences

	Parents of children with...		Parents of children with ASD			
	No Special Needs (N=917)	ASD (N=1652)	Autism (N=874)	PDD-NOS (N=398)	Asperger's (N=300)	Other Types of ASD (N=80)
Household Income		Higher average income				
Parents' race	More likely to be Black / African American	More likely to be White				
Parents' education		More likely to be college educated	More likely to be college educated	More likely to be college educated		More likely to be college educated
Parents' Marital Status		More likely to be married				
Times divorced	More likely to have been divorced					
Children's Age	16	10	10	10	12	9
Children's Gender	Half male (52%)	More likely to be male	More likely to be male	More likely to be male	More likely to be male	More likely to be male
Children's education	More likely to be college educated				More likely to be college educated	



Detailed Findings

Independence

“What will happen to my son when we are gone? Who will care for him, how will he live, who will make sure he is taken care of? He is completely dependent on us.”

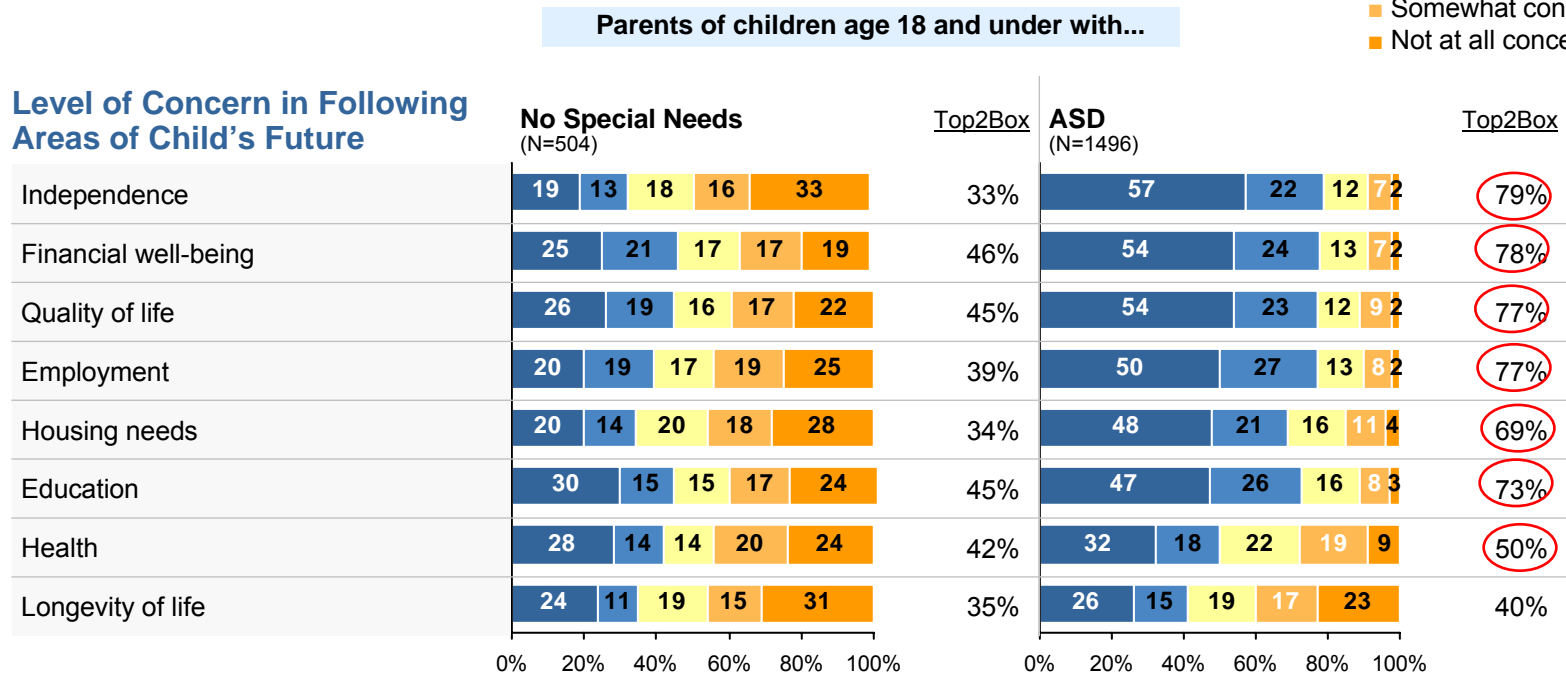
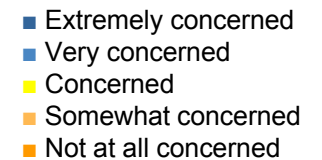
“Can children with autism grow into independent adults who are able to live by themselves and care for themselves, work and even form relationships? What can I expect in the future for my child?”

“My child is 24 years old and I am looking for quality health care – and for him to be able to find a job to take care of himself one day. That would be nice.”

*A sampling of verbatims shared by survey participants

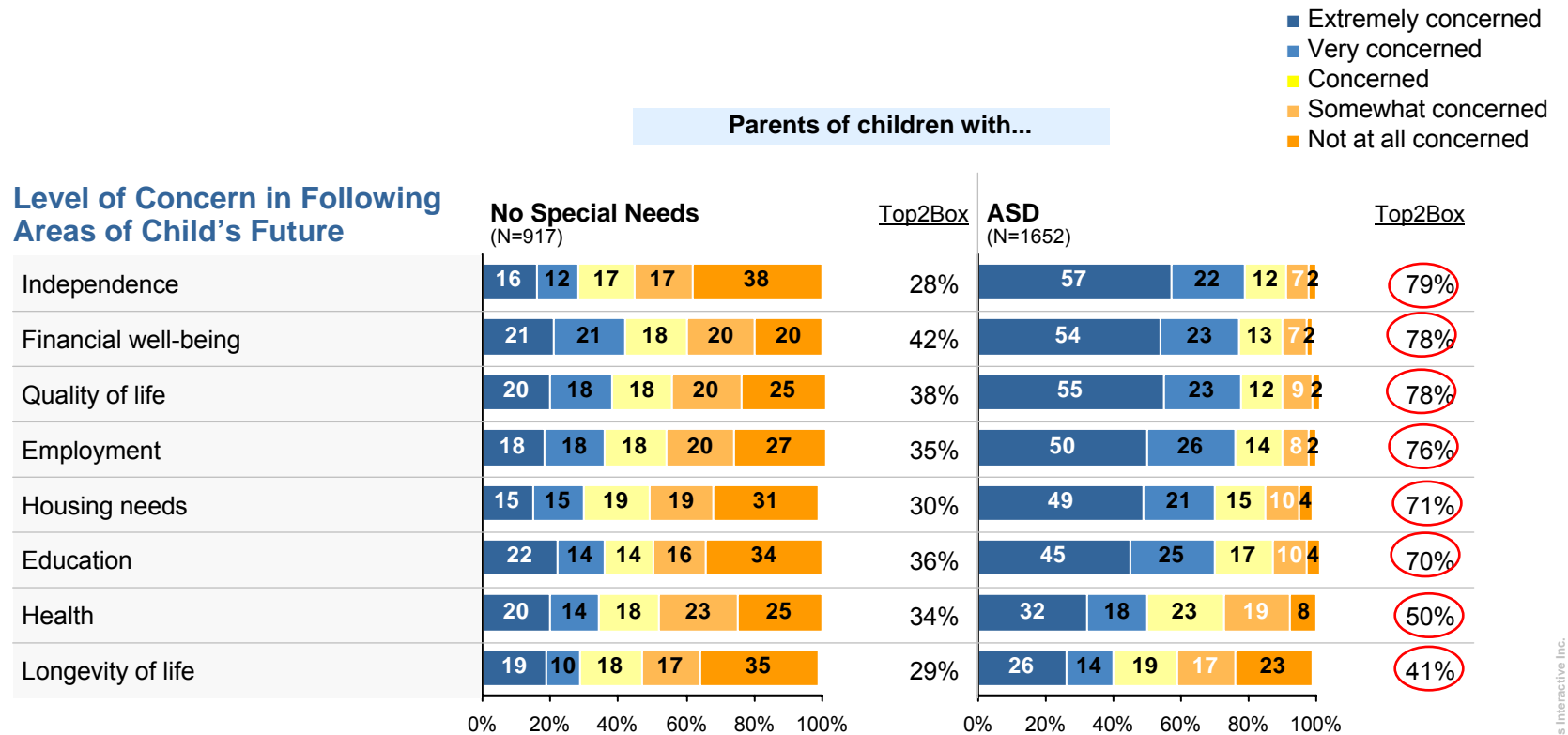
Parents of children living with ASD are more likely than typical parents to be concerned about their children's future.

- They are most concerned with their independence, financial well being, quality of life, and employment.



BASE: ALL PARENTS OF CHILDREN AGE 18 AND UNDER
 Q1500 How concerned are you for this child's future as an adult in regards to each of the following areas?

Among typical parents these concern decrease as their children reach adulthood. However, for parents of children with ASD, level of concern remains high.



BASE: ALL PARENTS

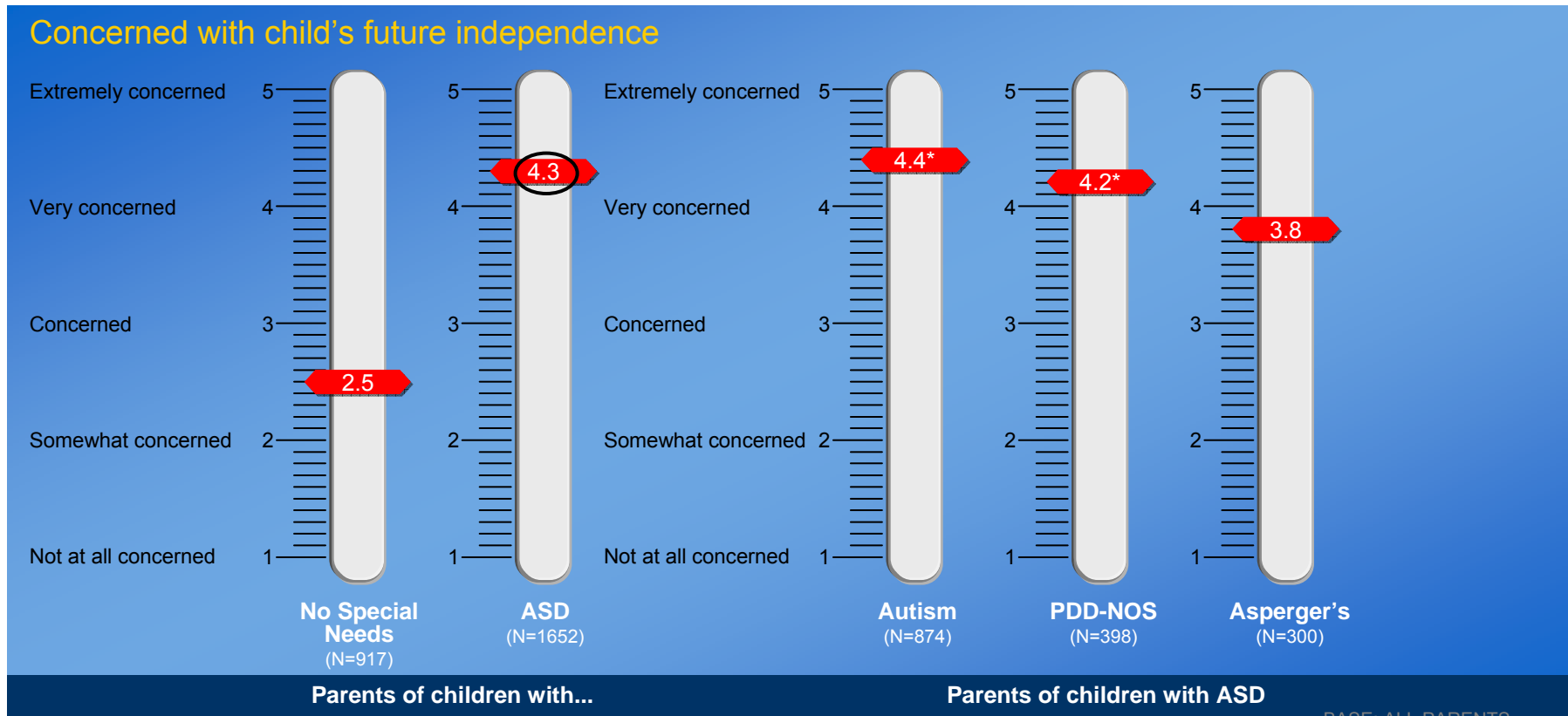
Q1500 How concerned are you for this child's future as an adult in regards to each of the following areas?

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For these special needs parents, independence is a top concern.



- Among parents of children with the different types of Autism Spectrum Disorder, parents with children with Asperger's are less likely to be concerned than other parents.
 - Perhaps this is because children with Asperger's are more likely to be mainstreamed in school.

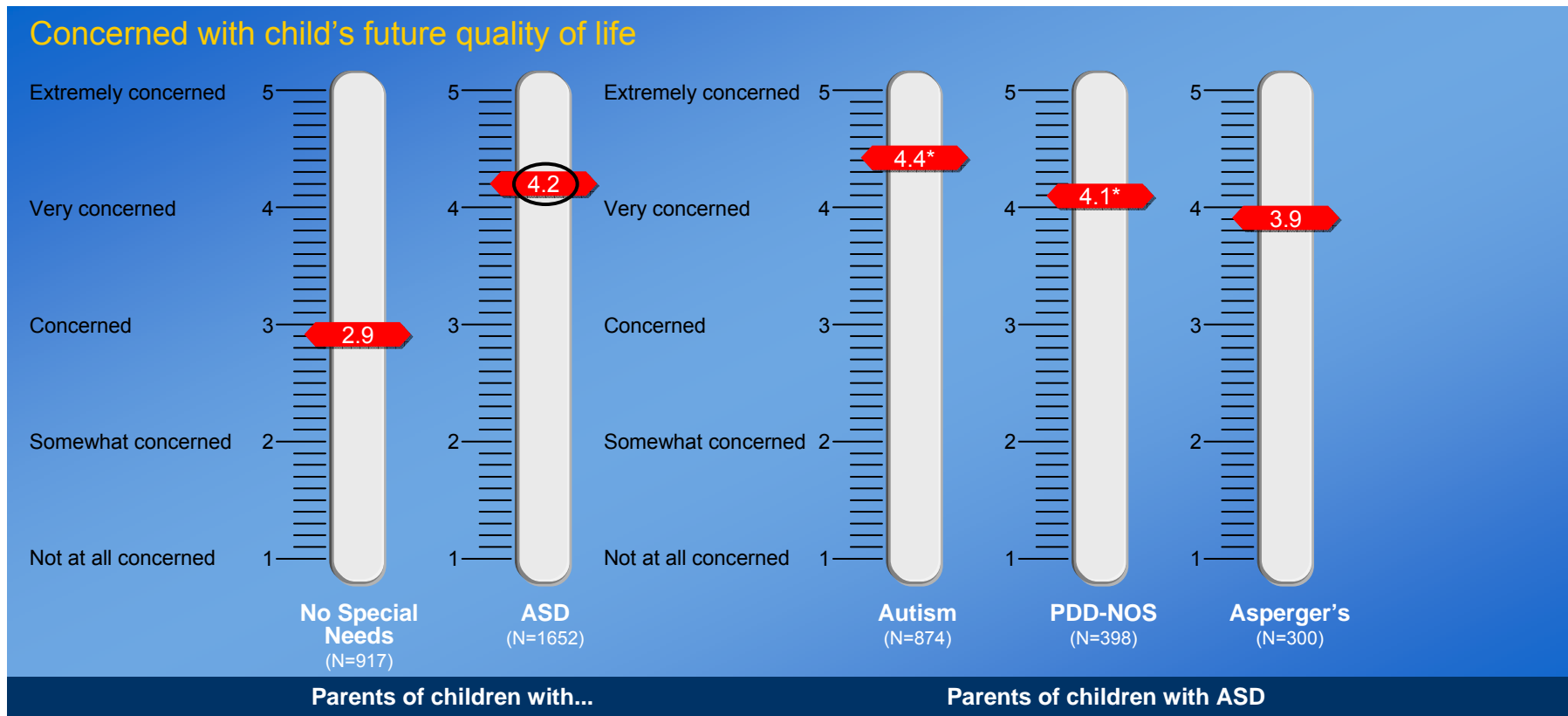


BASE: ALL PARENTS

Q1500 How concerned are you for this child's future as an adult in regards to each of the following areas?
 *NOTE: The Autism group is significantly higher than the PDD-NOS and Asperger's group. And, the PDD-NOS group is significantly higher than the Asperger's group.

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...followed by **quality of life.**



Q1500 How concerned are you for this child's future as an adult in regards to each of the following areas?
 *NOTE: The Autism group is significantly higher than the PDD-NOS and Asperger's group. And, the PDD-NOS group is significantly higher than the Asperger's group.

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They worry about their children fitting into society.

- Few parents living with autism feel that their children will be able to make his/her own life decisions, have friends in the community, have a spouse, be valued by their community, participate in activities, have strong religious affiliations, or develop age-appropriate recreation skills.

	Parents of children with...		Parents of children with ASD		
	No Special Needs (N=917)	ASD (N=1652)	Autism (N=874)	PDD-NOS (N=398)	Asperger's (N=300)
Concerned with child's quality of life – Top 2 Box	38%	78%	83%	73%	67%
% of Parents Who Agree with Statements – Top 2 Box (Very strongly agree/Strongly agree)					
	My child will...				
Have the ability to make his/her own life decisions	65%	14%	13%	12%	17%
Have friends in the community with whom he/she shares interests	57%	17%	17%	16%	14%
Have a spouse or life-partner	51%	9%	8%	7%	12%
Be valued by his/her community	50%	18%	19%	14%	16%
Regularly participate in recreational activities	50%	20%	20%	19%	15%
Have a strong religious affiliation	36%	19%	17%	19%	21%
Have developed age-appropriate recreation and leisure skills	-	16%	17%	13%	14%

BASE: ALL PARENTS

Q1500 How concerned are you for this child's future as an adult in regards to each of the following areas?

Q1510. Now, please think about the future, when you may not be around for your child.

To what extent do you agree with each of the following statements regarding your child's future?

Typical parents are much more likely than those living with ASD to say their children have bank accounts and are using electronic products, i.e. the tools of mainstream society.

- Not quite 4 in 10 parents have set-up bank accounts for their children with ASD. However, children with Asperger's are more likely to have bank accounts, which may indicate they are participating in mainstream society more than children with other types of Autism Spectrum Disorder.

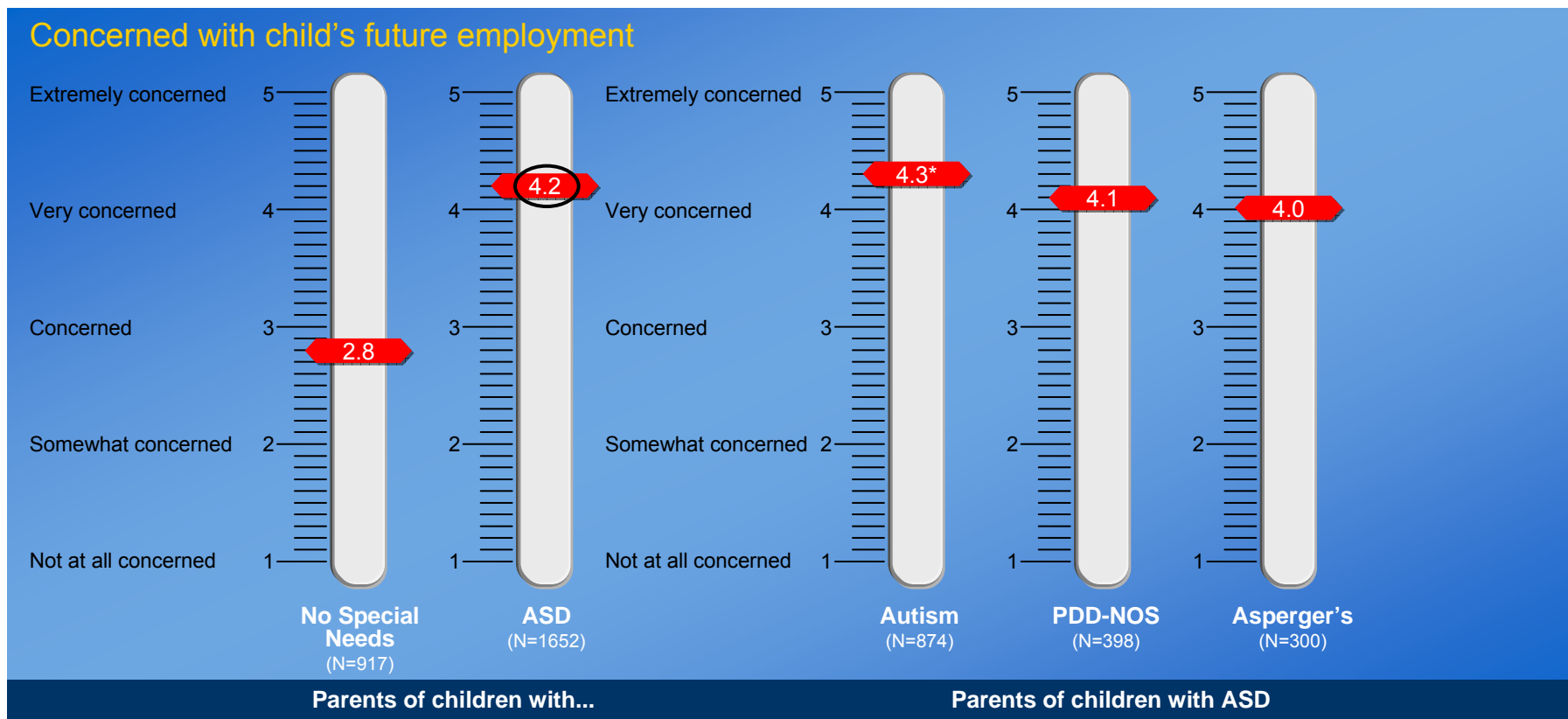
% Yes, child has...	Parents of children age 18 and under with...		Parents of children age 18 and under with ASD		
	No Special Needs (N=504)	ASD (N=1496)	Autism (N=796)	PDD-NOS (N=367)	Asperger's (N=260)
Bank account	55%	37%	33%	39%	46%
Cell phone	41%	9%	4%	8%	24%
Personal computer	40%	44%	42%	43%	54%
MP3 player	49%	23%	18%	20%	41%
Credit card	6%	1%	<1%	1%	-

BASE: ALL PARENTS OF CHILDREN AGE 18 OR UNDER(Q1605/1-3)
Q1545. Which of the following items does your child have?

Employment ranks as the 4th highest concern.



- Regarding future employment, parents of children with Autism are more concerned (4.3) than parents of children with any other type of Autism Spectrum Disorder.



BASE: ALL PARENTS

Q1500 How concerned are you for this child's future as an adult in regards to each of the following areas?

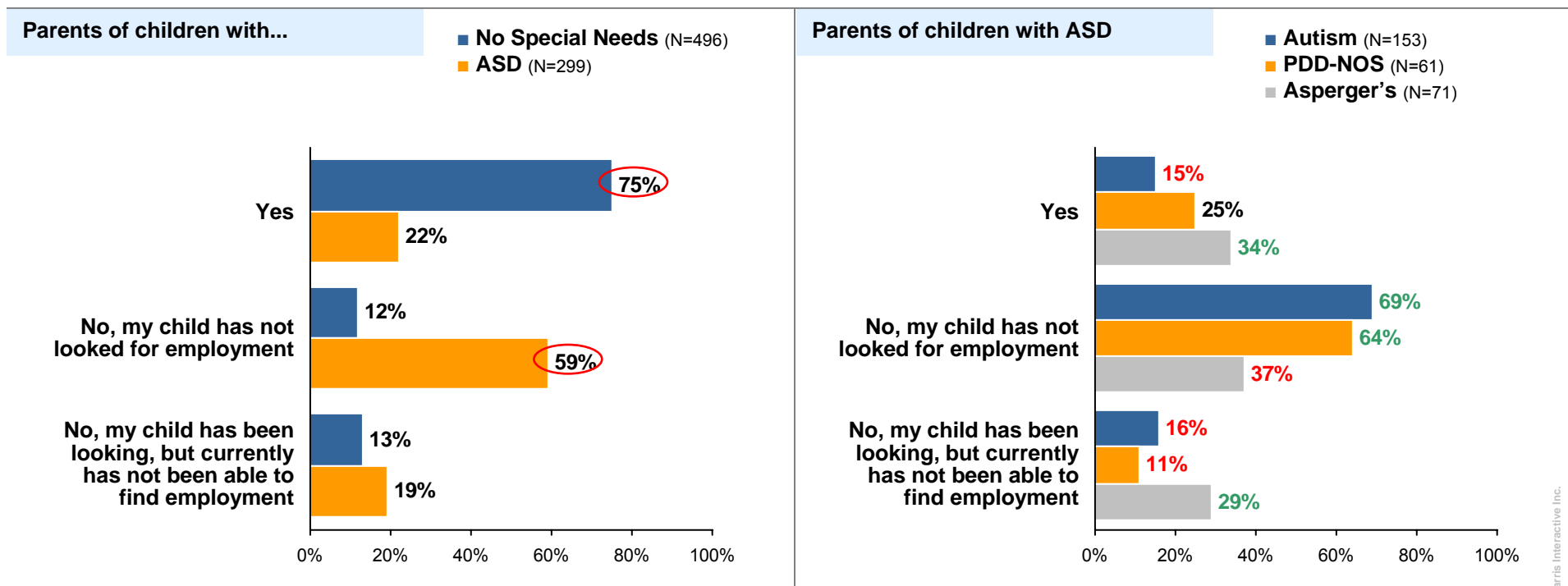
*NOTE: The Autism group is significantly higher than the PDD-NOS and Asperger's group.

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About 6 in 10 of those children with Autism Spectrum Disorder aged 16 or older have not looked for work, yet 75% of typical children are already working.

- Those with Asperger's are more likely than those with other types of Autism Spectrum Disorder to look for work or to be working.

Child Currently Engaged in Paid Employment

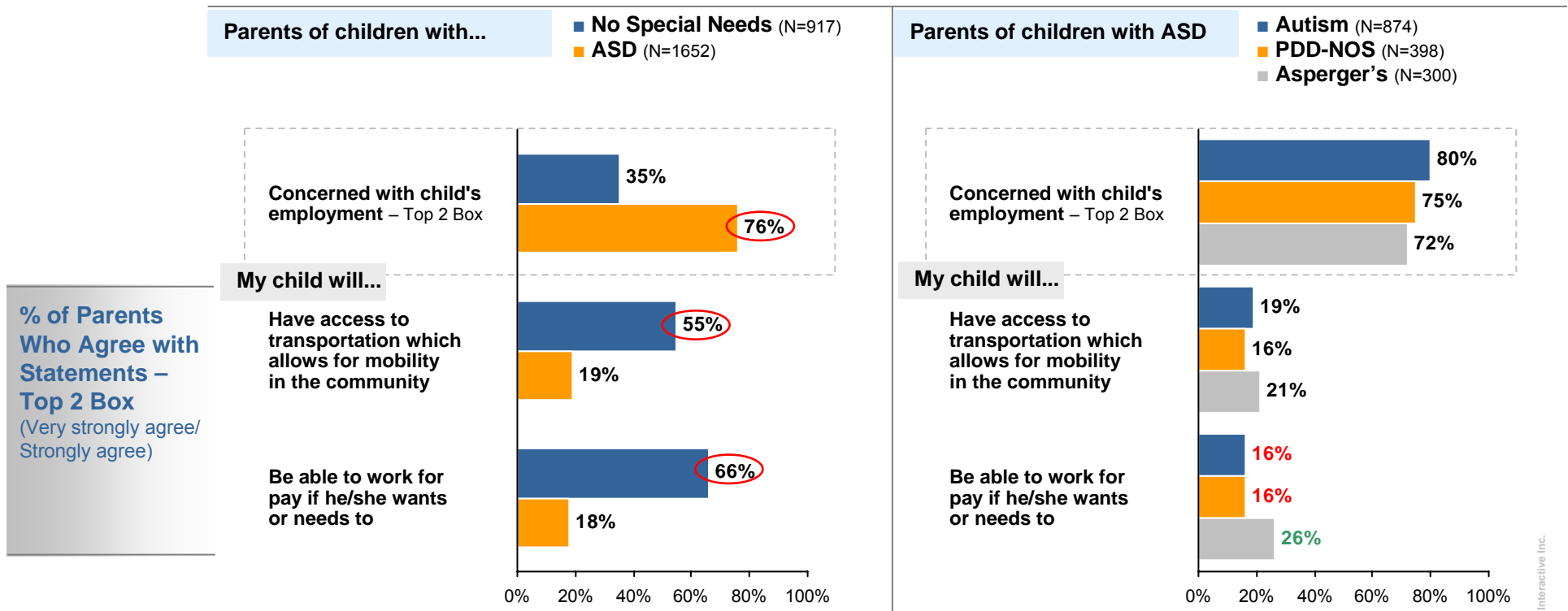


BASE: ALL PARENTS WHOSE CHILD IS AGE 16+
Q1540. Is your child currently engaged in paid employment?

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Parents are concerned about their children's' ability in the future to work for pay and access transportation.

- On the other hand, parents of children with Asperger's are more likely than parents of children with Autism or Pervasive Developmental Disorder – Not Otherwise Specified to strongly agree that their children will be able to work for pay in the future if he or she wants to work.



% of Parents Who Agree with Statements – Top 2 Box
(Very strongly agree/ Strongly agree)

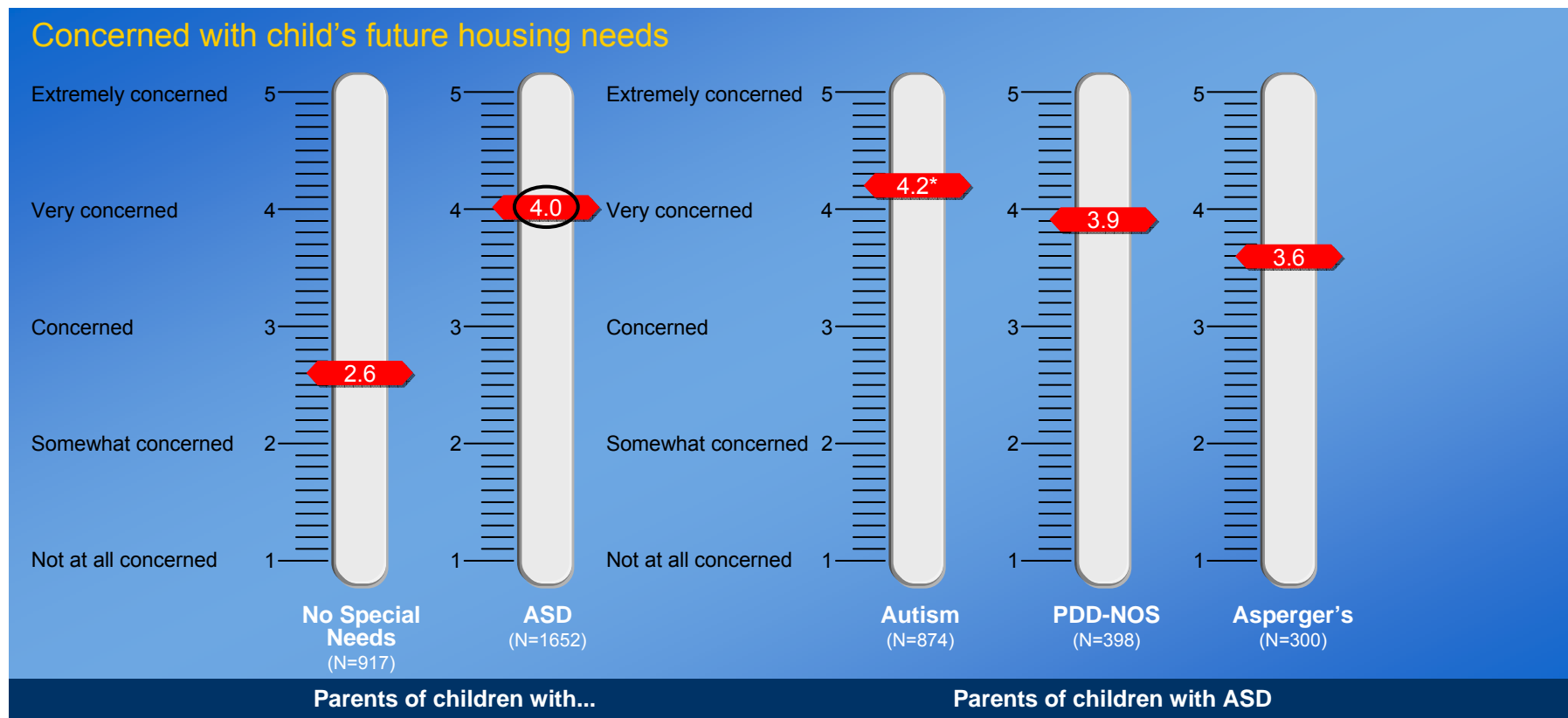
BASE: ALL PARENTS

Q1500 How concerned are you for this child's future as an adult in regards to each of the following areas?
Q1510. Now, please think about the future, when you may not be around for your child.
To what extent do you agree with each of the following statements regarding your child's future?

Housing, the 5th highest concern among parents living with ASD, is a stronger concern for them than for typical parents.



- However, parents living with Autism have a higher level of concern (4.2) than those with children with Pervasive Developmental Disorder – Not Otherwise Specified (3.9) or Asperger’s (3.6).



BASE: ALL PARENTS

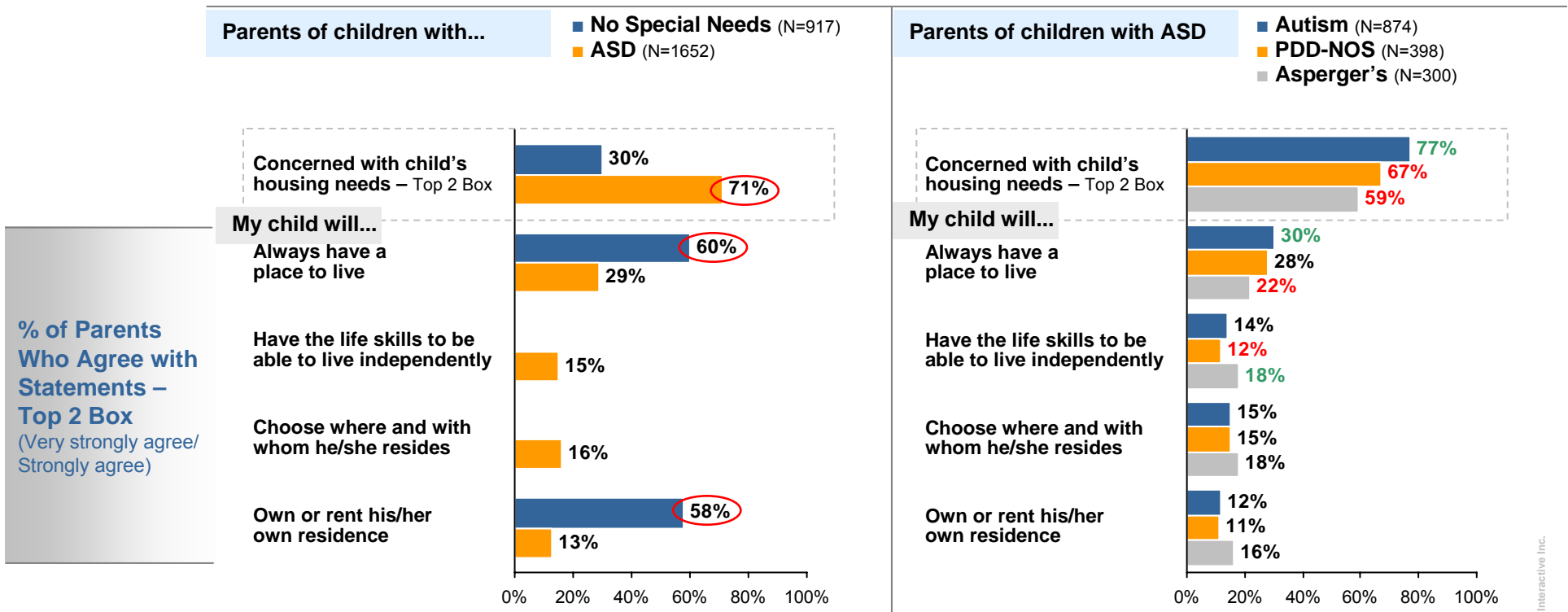
Q1500 How concerned are you for this child’s future as an adult in regards to each of the following areas?

*NOTE: The Autism group is significantly higher than the PDD-NOS and Asperger’s group.

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.. and parents are most worried that their children may not always have a place to live and be independent.

- Among all parents of children with Autism Spectrum Disorder, parents of children with Autism or other types of Autism Spectrum are more concerned than parents of children with Pervasive Developmental Disorder – Not Otherwise Specified or Asperger’s Disorder that they will always have a place to live.



% of Parents Who Agree with Statements – Top 2 Box
(Very strongly agree/ Strongly agree)

BASE: ALL PARENTS
 Q1500 How concerned are you for this child's future as an adult in regards to each of the following areas?
 Q1510. Now, please think about the future, when you may not be around for your child.
 To what extent do you agree with each of the following statements regarding your child's future?

Most children under 30 with ASD live at home.

- More than nine-in-ten (96%) of parents with children age 30 or younger with Autism Spectrum Disorder have their children living with them, versus not even seven-in-ten (69%) of parents with children 30 or younger and without any special needs.

Current Residence of Child	Parents of children with...		Parents of children with ASD		
	No Special Needs (N=917)	ASD (N=1652)	Autism (N=874)	PDD-NOS (N=398)	Asperger's (N=300)
With parent(s) or guardian	69%	96%	97%	96%	95%
Independently, either with or without a spouse or partner	26%	<1%	<1%	1%	1%
With other family member(s)/spouse/partner	4%	1%	<1%	2%	1%
Supported residence for individuals with special needs	-	2%	2%	2%	1%
Other	2%	1%	1%	<1%	2%
Level of Professional Assistance at Supported Residence	(N=0)	(N=27)	(N=15)	(N=7)	(N=3)
24/7 care	-	84%	87%	100%	-
Less than 24/7 care	-	16%	13%	-	100%

BASE: ALL PARENTS
 Q1515. Where does your child currently live?
 BASE: IF CHILD HAS ASD OR SPECIAL NEEDS AND LIVES IN RESIDENCE FOR SPEC NEEDS
 Q1520. What level of professional assistance is at this residence?

...and children with ASD are more likely to still be living at home after high school.

- Children with Asperger's appear to be more likely than those with other diagnoses to be living outside the home.

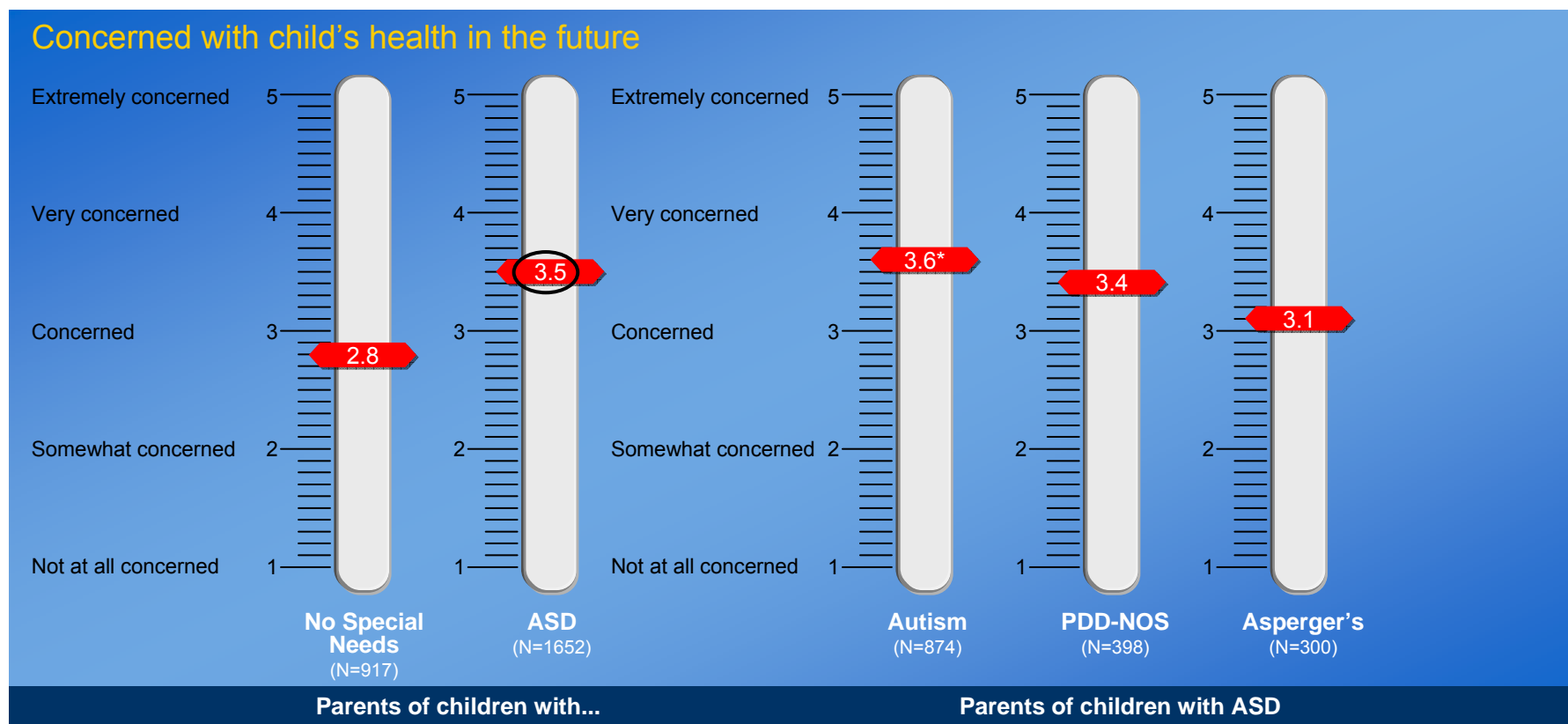
Current Residence of Child	Parents of children with...		Parents of children with ASD		
	No Special Needs (N=413)	ASD (N=156)	Autism (N=78)	PDD-NOS (N=31)	Asperger's (N=40)
With parent(s) or guardian	32%	79%	81%	84%	71%
Independently, either with or without a spouse or partner	58%	4%	3%	3%	9%
With other family member(s)/spouse/partner	7%	2%	-	3%	5%
Supported residence for individuals with special needs	-	12%	14%	10%	7%
Other	3%	3%	2%	-	7%

BASE: ALL PARENTS WITH CHILDREN AGE 19 to 30
Q1515. Where does your child currently live?

Parents living with ASD are again more concerned for their children's **Health** than are parents with children without special needs.



- Level of concern is again higher among parents of children with Autism than it is among parents of children with Pervasive Developmental Disorder – Not Otherwise Specified or Asperger's.



BASE: ALL PARENTS

Q1500 How concerned are you for this child's future as an adult in regards to each of the following areas?

*NOTE: The Autism group is significantly higher than the PDD-NOS and Asperger's group.

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Parents living with ASD need more support from health professionals, have a harder time finding physicians and obtaining health insurance that will meet their needs than typical parents.

- Parents of children with Autism have more difficulty obtaining health support than do parents of children with Pervasive Developmental Disorder – Not Otherwise Specified or Asperger’s.

Concerned with Following Aspects of Child's Life in Future – Top 2 Box (Extremely concerned/Very concerned)	Parents of children with...		Parents of children with ASD		
	No Special Needs (N=917)	ASD (N=1652)	Autism (N=874)	PDD-NOS (N=398)	Asperger's (N=300)
Health	34%	50%	55%	47%	39%
Longevity of life	29%	41%	46%	39%	24%
Independence	28%	79%	84%	78%	65%
% of Parents Who Agree with Statements – Top 2 Box (Very strongly agree/Strongly agree)					
	My child will...				
Need professional behavioral support	9%	42%	46%	36%	36%
Need paid professionals to provide daily care, vocational support or assistance with recreational activities	-	37%	47%	27%	15%
Have a primary care physician that understands his/her needs	47%	23%	24%	19%	21%
Exercise regularly	44%	20%	21%	19%	15%
Have health insurance that adequately covers his/her needs	42%	18%	19%	18%	14%

BASE: ALL PARENTS

Q1500 How concerned are you for this child's future as an adult in regards to each of the following areas?
 Q1510. Now, please think about the future, when you may not be around for your child.
 To what extent do you agree with each of the following statements regarding your child's future?

Autism-specific intervention therapy is most common among children with Autism, with half receiving this therapy.

- In most cases, when intervention therapy is received, it is paid for by the public school system.

Parents of children with...		Parents of children with ASD		
	ASD (N=1652)	Autism (N=874)	PDD-NOS (N=398)	Asperger's (N=300)
Child receives autism-specific intervention therapy				
Yes	47%	54%	46%	30%
No	53%	46%	54%	70%
Hours of intervention therapy child receives per week	(N=765)	(N=467)	(N=182)	(N=90)
Less than 1 hour per week	9%	8%	8%	19%
1 to 3 hours per week	Mean 5.5 33%	Mean 6.1 28%	Mean 5.3 34%	Mean 3.0 55%
4 to 6 hours per week	20%	19%	23%	14%
7 to 9 hours per week	7%	7%	9%	2%
10 or more hours per week	31%	38%	25%	9%
Who pays for child's intervention therapy	(N=765)	(N=467)	(N=182)	(N=90)
Public school system	54%	55%	54%	43%
Private school system	3%	2%	3%	3%
Health insurance	33%	29%	34%	46%
Personal payment	45%	45%	50%	43%
Public program	21%	24%	16%	11%
Other	8%	9%	8%	6%

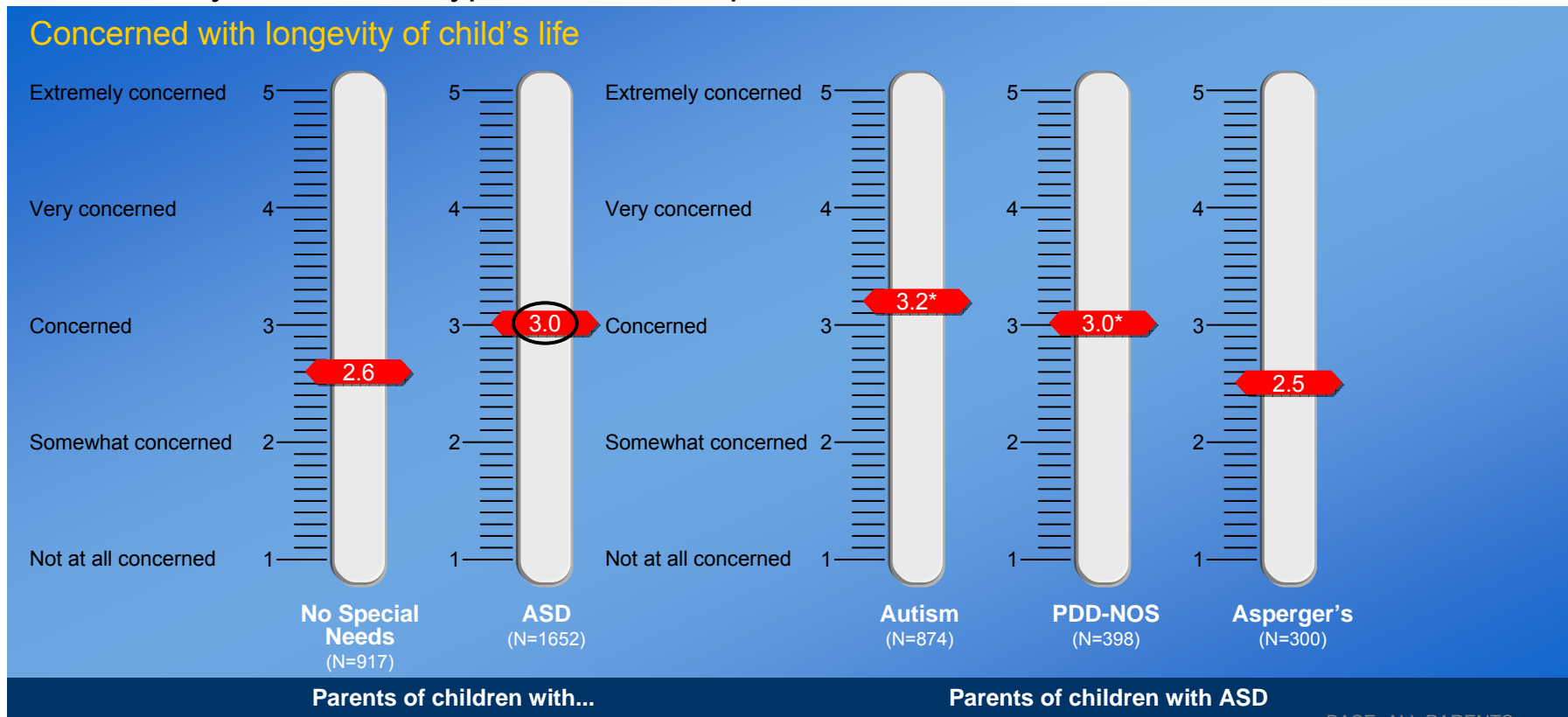
BASE: PARENTS WITH A CHILD WITH ASD
Q640. Does your child receive autism-specific intervention therapy?

BASE: USES INTERVENTION THERAPY
Q650. How many hours of intervention therapy does your child receive per week?
Q655. Who pays for your child's intervention therapy? Please select all that apply.

Although Longevity of Life ranks last on the list of concerns, they are still more concerned than typical parents.



- Consistent with all other areas of concern for their children's future, parents of children with Asperger's are less likely to be concerned than parents with children with any of the other types of Autism Spectrum Disorder.



BASE: ALL PARENTS

Q1500 How concerned are you for this child's future as an adult in regards to each of the following areas?

*NOTE: The Autism group is significantly higher than the PDD-NOS and Asperger's group. And, the PDD-NOS group is significantly higher than the Asperger's group.

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Detailed Findings

Family Life

“Help us find a way to help him. We can’t do it ourselves.”

“I worry about his future, my future and the future of his younger brother who will be required to oversee his needs when I’m gone.”

“How do I keep my sanity? How do I care for his typically developing siblings and preserve my marriage?”

*A sampling of verbatims shared by survey participants

Families with autism are more likely to eat dinner at home five days a week.



- Parents of children with Autism Spectrum Disorder are more likely than those with children without special needs to report having sit-down meals as a family more than five nights per week.

Number of nights per week have family sit down meals	Parents of children with...		Parents of children with ASD		
	No Special Needs (N=917)	ASD (N=1652)	Autism (N=874)	PDD-NOS (N=398)	Asperger's (N=300)
Less than 1	14%	9%	10%	9%	7%
1 or 2 nights per week	17%	15%	16%	15%	14%
3 to 5 nights per week	31%	30%	28%	30%	36%
More than 5 nights per week	32%	44%	45%	46%	42%
Not applicable	5%	1%	1%	1%	1%
MEAN	2.9	3.1	3.1	3.1	3.1

BASE: ALL RESPONDENTS
 Q1415. During an average week, how many nights per week do you sit around a table and eat dinner with at least one other family member?

However, their day-to-day routines are more time consuming.

- It takes children with Autism Spectrum Disorder significantly more time to get ready for each day as well as more time to prepare for bed each night than it takes children without special needs.

	Parents of children with...		Parents of children with ASD		
	No Special Needs (N=917)	ASD (N=1652)	Autism (N=874)	PDD-NOS (N=398)	Asperger's (N=300)
 Time it takes to get ready in the morning					
Less than 15 minutes	1%	1%	1%	1%	-
About 15 minutes to a 1/2 hour	13%	10%	10%	10%	10%
About a 1/2 hour to 1 hour	35%	46%	47%	46%	43%
About 1 hour to 1 1/2 hours	10%	32%	31%	34%	34%
More than 1 1/2 hours	2%	5%	5%	3%	4%
No children in household attending school	40%	6%	5%	6%	8%
MEAN (minutes)	46.3	55.0	54.8	54.6	56.1
 Time it takes to get ready for bed					
Less than 15 minutes	14%	7%	7%	6%	7%
About 15 minutes to a 1/2 hour	24%	25%	25%	25%	25%
About a 1/2 hour to 1 hour	23%	38%	38%	40%	36%
About 1 hour to 1 1/2 hours	7%	18%	18%	19%	20%
More than 1 1/2 hours	2%	8%	9%	7%	7%
No children in household attending school	29%	3%	3%	2%	5%
MEAN (minutes)	34.7	46.3	46.1	46.1	46.2

BASE: ALL RESPONDENTS

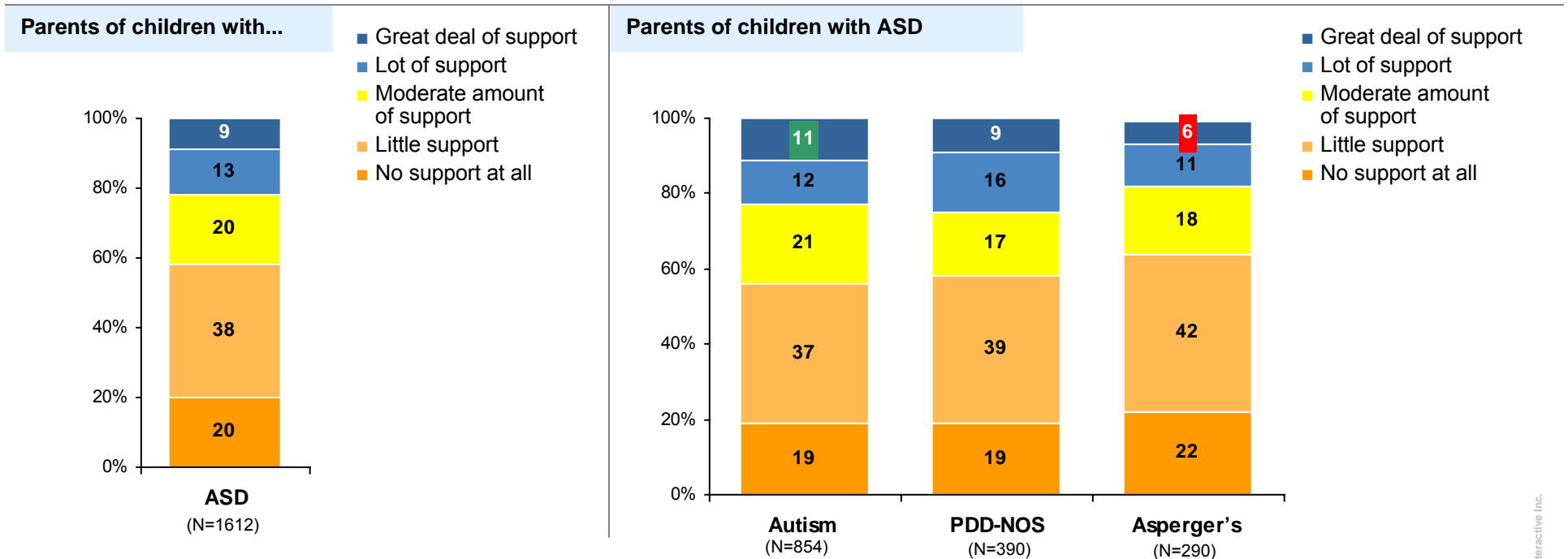
Q1420. On average, how long does it take the children in your household to get ready for school in the morning from the time they wake up (eat breakfast, brush their teeth, shower, etc.) To the time they walk out the door?

Q1425. On average, how long does it take the children in your household to get ready for bed at night?

They receive little support from their extended families

- Parents of children with Pervasive Developmental Disorder – Not Otherwise Specified tend to receive more support from their families than do parents of children with Asperger's.

Amount of Support from Extended Family and Friends



BASE: PARENTS WITH CHILD 30 AND UNDER WITH ASD AND LIVES WITH PARENTS, FAMILY OR INDEPENDENTLY
 Q1530 Overall, how much support do you receive from extended family or friends, related to caring for your child with special needs?
 By support, we mean emotional, physical or financial help you may be receiving.

But four in ten do receive some support from the government.

- Among those with different types of ASD, children with Autism are more likely than those with Pervasive Developmental Disorder – Not Otherwise Specified or Asperger’s to receive benefits.
- The most common types of government assistance received are special education and Medicaid.

Child Receives Government Benefits	Parents of children with...	Parents of children with ASD	
	ASD (OTHER THAN ASPERGER'S) (N=1352)	Autism (N=874)	PDD-NOS (N=398)
Yes	42%	47%	33%
No	58%	53%	67%
Type of Government Assistance Child Receives			
	(N=574)	(N=413)	(N=134)
Medicaid	50%	50%	49%
Medicaid waiver programs	30%	32%	25%
State Children's Health Insurance Program (SCHIP)	7%	7%	8%
Children with Special Health Care Needs, Provision of the Social Security Act	4%	3%	2%
Supplemental Security Income (SSI)	43%	43%	42%
Social Security Disability Income (SSDI)	11%	8%	12%
Early intervention	16%	16%	15%
Special education	53%	56%	45%
Other	12%	11%	16%

BASE: PARENTS WITH A CHILD WITH ASD, OTHER THAN ASPERGER'S
Q605. Does your child receive government benefits?

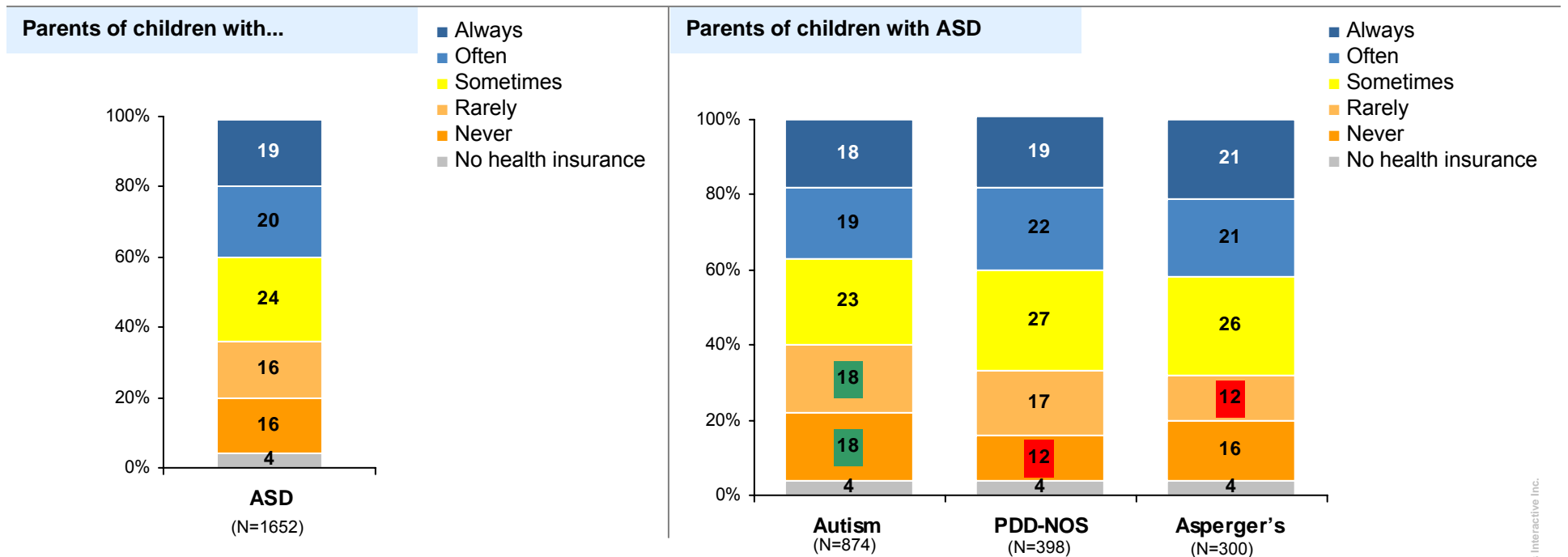
BASE: CHILD RECEIVES GOVERNMENT BENEFITS

Q610. Which of the following government benefits does your child receive? Please select all that apply.

... and health insurance.

- Regardless of the type of Autism Spectrum Disorder a child has, health insurance companies always or often pay for services only 39% of the time.

Frequency Health Insurance Company Pays for Services that Child with Special Needs Requires



BASE: PARENTS WITH A CHILD WITH ASD

Q620. How often does your health insurance company pay, at least in part, for the services that your child with special needs requires?

Families living with autism are significantly less likely to be divorced than families with children without special needs.

- Among those parents with children who have Autism Spectrum Disorder and who have been divorced, only one third say their divorce had anything to do with managing the special needs of their children.

Number of times divorced	Parents of children with...		Parents of children with ASD		
	No Special Needs (N=866)	ASD (N=1573)	Autism (N=834)	PDD-NOS (N=377)	Asperger's (N=287)
Divorced (NET)	39%	30%	27%	32%	36%
Once	26%	23%	21%	25%	29%
Twice	10%	6%	5%	5%	6%
More than twice	2%	1%	1%	2%	1%
Believe managing the special needs of child contributed to divorce		(N=475)	(N=226)	(N=120)	(N=105)
Yes	-	34%	33%	37%	36%
No	-	24%	20%	25%	28%
Did not have child with special needs during previous marriage	-	41%	46%	37%	35%

BASE: MARRIED AT SOME POINT
 Q800. How many times have you been divorced?
 BASE: HAVE BEEN DIVORCED & HAS CHILD WITH ASD
 Q810. Do you believe managing the special needs of your child contributed to your divorce?

But divorce does create family strains with half of all divorced parents having sole custody of their children with autism.

- Three-quarters (75%) of divorced parents of children with some type of Autism Spectrum Disorder say their divorce has not affected the services that are available for their children.

Parents of children with...	Parents of children with ASD			
	ASD (N=277)	Autism (N=120)	PDD-NOS (N=74)	Asperger's (N=67)
Have sole or joint custody for child with special needs				
Sole custody	52%	54%	50%	50%
Joint custody	39%	40%	45%	34%
Neither of these	9%	7%	5%	15%
Child with special needs lives with them	(N=110)	(N=49)	(N=33)	(N=23)
Full-time	71%	73%	73%	60%
Part-time	24%	23%	21%	36%
Does not live with me	5%	4%	6%	4%
Divorce affected services for child with special needs	(N=277)	(N=120)	(N=74)	(N=67)
Yes	25%	24%	32%	17%
No	75%	76%	68%	83%

BASE: HAVE BEEN DIVORCED & HAS CHILD WITH ASD DURING PREVIOUS MARRIAGE

Q811. Do you have sole or joint custody for your child with special needs?
Q820. Has your divorce affected the services that are available for your child with special needs?

BASE: HAS JOINT CUSTODY OF CHILD WITH ASD
Q815. Does your child with special needs live with you?



Detailed Findings

Financial Planning

“We are drowning financially.”

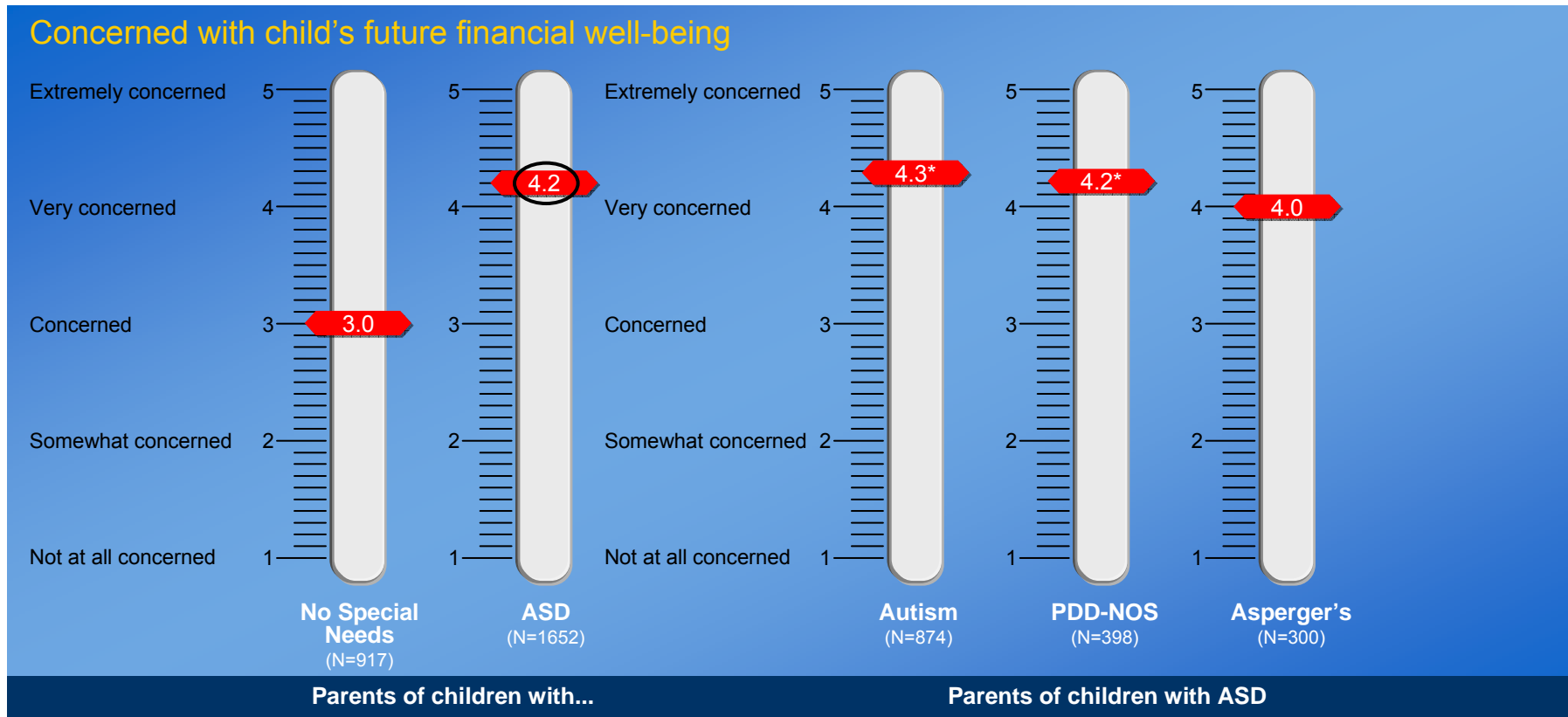
“We need a clear, concise timetable and roadmap of when, where and with whom we should be applying for assistance in order to make as many as supports available as soon as possible.”

*A sampling of verbatims shared by survey participants

Financial concerns are higher among parents living with ASD than typical parents.



- However, concern among parents of children with Autism (4.3) or Pervasive Developmental Disorder – Not Otherwise Specified (4.2) is higher than it is among parents of children with Asperger’s (4.0).



BASE: ALL PARENTS

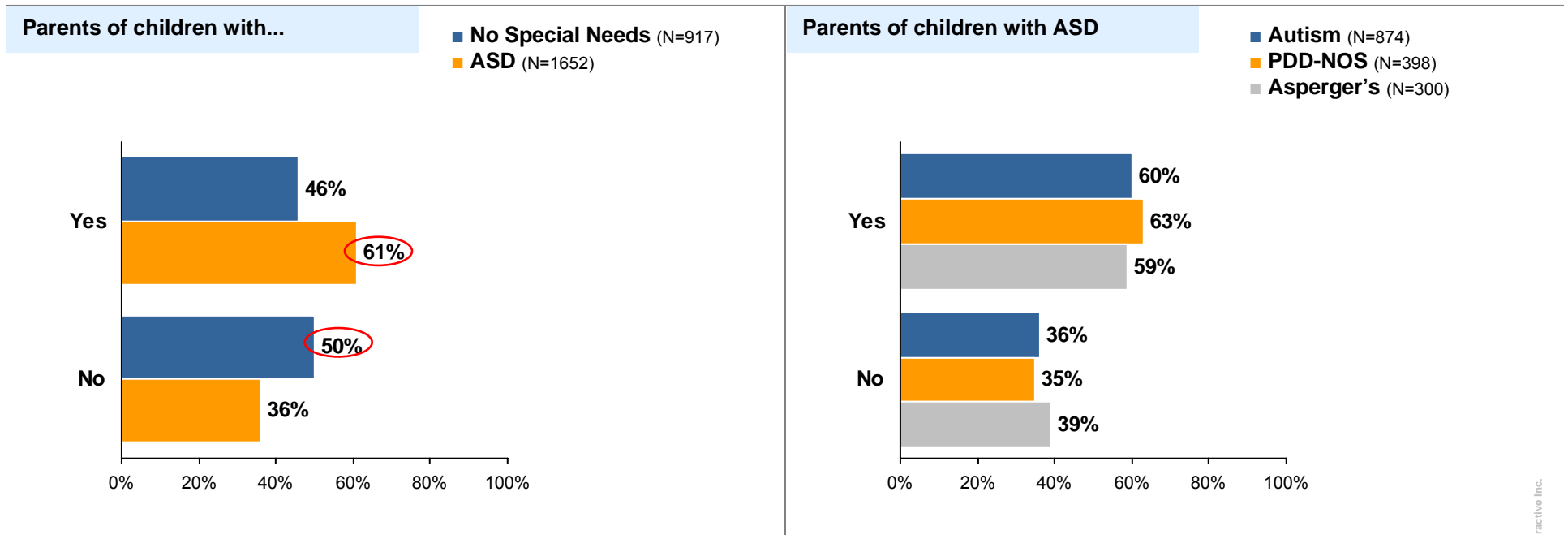
Q1500 How concerned are you for this child's future as an adult in regards to each of the following areas?
 *NOTE: The Autism group is significantly higher than the PDD-NOS and Asperger's group. And, the PDD-NOS group is significantly higher than the Asperger's group.

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Parents living with ASD are significantly more likely than typical parents to have incurred debt to meet their families' needs

- The type of autism does not appear to mitigate the perceptions of debt incurred by the family.

% of Parents Who Incurred Debt to Meet Family Needs



BASE: ALL PARENTS

Q1577. Have you had to incur debt to meet family needs?

Despite these strong financial concerns, one-half of parents living with ASD have NOT looked to a professional for financial advice, similar to the rate that typical parents have.

- There are no differences across the ASD diagnoses.

Person Looked to for Professional Financial Advice	Parents of children with...		Parents of children with ASD		
	No Special Needs (N=917)	ASD (N=1652)	Autism (N=874)	PDD-NOS (N=398)	Asperger's (N=300)
Financial planner	18%	18%	18%	20%	15%
Investment professional	17%	14%	13%	14%	15%
Accountant	9%	11%	10%	13%	8%
Bank officer	9%	5%	5%	4%	4%
Insurance professional	5%	8%	8%	10%	6%
Attorney	3%	16%	18%	15%	10%
Financial professionals trained in special needs planning	-	13%	14%	14%	10%
Other	14%	11%	10%	11%	14%
No one	55%	49%	48%	49%	52%

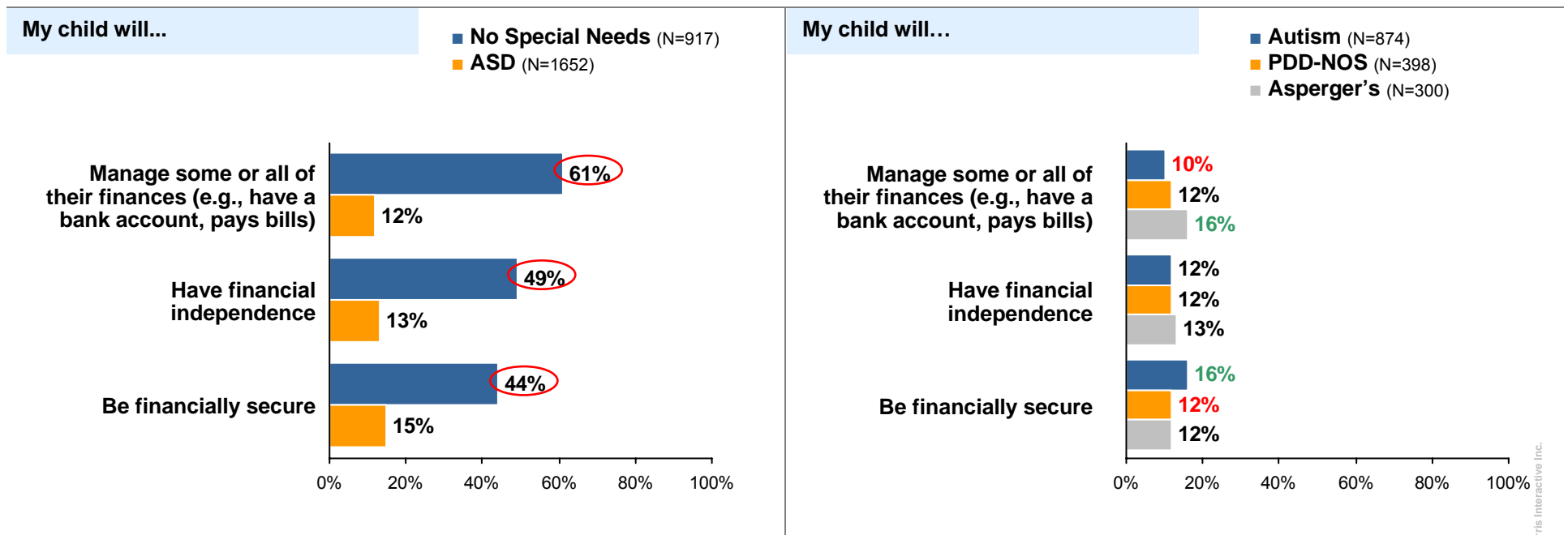
BASE: ALL PARENTS

Q1579. Who do you look to for professional financial advice? Please select all that apply.

Parents living with ASD are almost four times more likely than typical parents to feel their children will not have financial independence.

- Only 12% feel their children will be able to handle their day-to-day finances.

% of Parents Who Agree with Statements – Top 2 Box (Very strongly agree/Strongly agree)



BASE: ALL PARENTS

Q1510. Now, please think about the future, when you may not be around for your child. To what extent do you agree with each of the following statements regarding your child's future?

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Parents living with ASD have STRONGER financial concerns for their families than typical parents.

- Fear child will not have financial support after the parent dies
- Cost of caring for child drains the family's finances
- Cost of caring for child will drain family's future finances
- Cost of raising child financially impacts raising other siblings

Financial Issues Faced	Parents of children with...		Parents of children with ASD		
	No Special Needs (N=917)	ASD (N=1652)	Autism (N=874)	PDD-NOS (N=398)	Asperger's (N=300)
There's a challenge in creating a financial plan that supports my entire family's needs	27%	65%	67%	63%	58%
I fear my child will not have enough financial support after I die	18%	74%	77%	70%	69%
The cost of caring for my child will cause me to fall short of cash during retirement	13%	54%	56%	54%	46%
The cost of caring for my child drains my family's current financial resources	13%	52%	55%	47%	46%
The cost of caring for my child will drain my family's future financial resources	10%	50%	53%	47%	43%
Raising my child with special needs financially impacts raising typically developing siblings	-	47%	50%	43%	39%
None of the above	57%	8%	6%	10%	12%

BASE: ALL PARENTS

Q1575. Which of the following financial issues do you face? Please select all that apply.

Yet most have not taken the steps to financial security that they need to take for their children.

- Only 4 in 10 parents with children with Autism Spectrum Disorder have designated a guardian for their children or created a will. Only 2 in 10 have created a special needs trust.

Ways parents have prepared in the event they no longer can care for child	Parents of children with...		Parents of children with ASD		
	No Special Needs (N=917)	ASD (N=1652)	Autism (N=874)	PDD-NOS (N=398)	Asperger's (N=300)
Created a will	35%	38%	39%	38%	42%
Set up a savings account for the child	26%	33%	30%	37%	38%
Designated a guardian	19%	38%	40%	37%	34%
Identified living arrangements if the parent is no longer living	15%	24%	26%	23%	21%
Created an educational savings plan	15%	18%	17%	21%	22%
Identified a trustee for the child's finances	12%	28%	28%	30%	29%
Developed an estate plan	7%	14%	14%	13%	12%
Created a life care plan	4%	4%	5%	3%	2%
Identified living arrangements for when the child becomes an adult	3%	5%	6%	5%	3%
Written a letter of intent	3%	8%	9%	6%	9%
Created a special needs trust	1%	17%	21%	13%	11%
Will rely on siblings to care for the child with special needs	-	25%	28%	24%	19%
None of the above	40%	24%	24%	24%	24%
None of the above / ONLY Will rely on siblings	40%	30%	31%	28%	28%

BASE: ALL PARENTS

Q1580 In which of the following ways have you prepared for your child's future in the event you are no longer here to care for him/her? Please select all that apply.

When planning for their children's future care after their demise, most are working with family members.

Person they have discussed child's future care with in the event they are no longer able to	Parents of children with...		Parents of children with ASD		
	No Special Needs (N=917)	ASD (N=1652)	Autism (N=874)	PDD-NOS (N=398)	Asperger's (N=300)
Family members	57%	73%	74%	72%	72%
Friends	21%	35%	35%	36%	35%
Lawyers	8%	18%	19%	20%	15%
Financial planners	6%	8%	7%	9%	6%
Clergy	2%	4%	3%	3%	7%
Accountants	1%	2%	1%	3%	2%
Therapists	1%	9%	8%	11%	11%
Trust officers	1%	3%	3%	3%	2%
Non-profit service providers	<1%	4%	4%	6%	2%
Medical practitioners	<1%	6%	5%	7%	6%
Teachers	<1%	8%	9%	8%	7%
Caseworkers	<1%	9%	9%	8%	7%
Financial pros trained in special needs planning	-	7%	9%	5%	5%
My child with the disability	-	8%	3%	7%	22%
Government organizations/workers	-	4%	4%	5%	4%
Someone else	5%	6%	6%	6%	8%
Have not discussed with anyone	36%	19%	18%	21%	19%

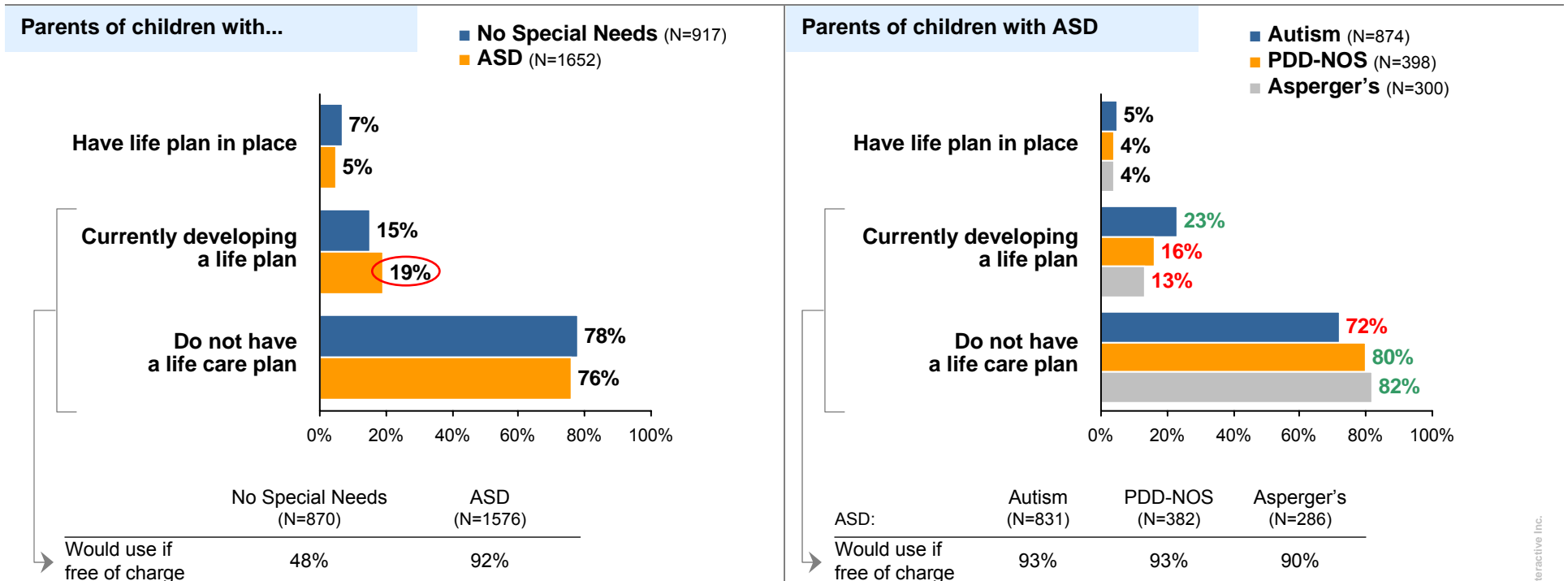
BASE: ALL PARENTS

Q1585. With whom have you discussed plans for your child's future in the event you are no longer here to care for him/her? Please select all that apply.

Most parents do not have a life care plan for their children. However, more parents living with an Autism diagnosis are in the process of developing a life care plan.

A life care plan incorporates basic needs and strategies for achieving the best quality of life in every area - food, clothing, shelter, health, finances, family life, entertainment, employment, retirement and so forth - now and for the long term. Primarily, it's for a person with a disability, but it may also incorporate elements to benefit the family, caregivers, future guardians, and others.

% of Parents Who Have a Life Plan in Place for their children



BASE: ALL PARENTS

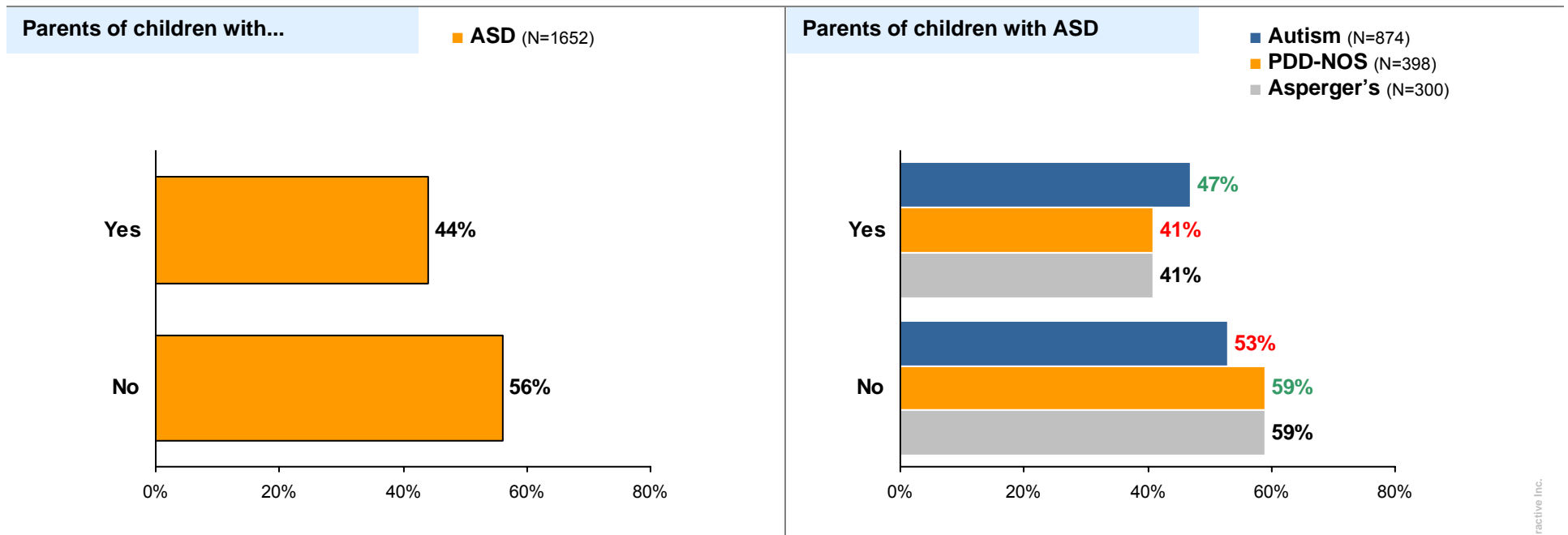
Q680. Do you have a life care plan/strategy in place for your child?

BASE: DOES NOT HAVE A LIFE CARE PLAN IN PLACE

Q685. If it were available free of charge, would you like to receive help developing a life care plan/strategy for your child?

Over half (56%) are unaware of Life Planners....

% of Parents Who Know of a Person Who Deals with Life Issues



BASE: PARENTS WITH A CHILD WITH ASD

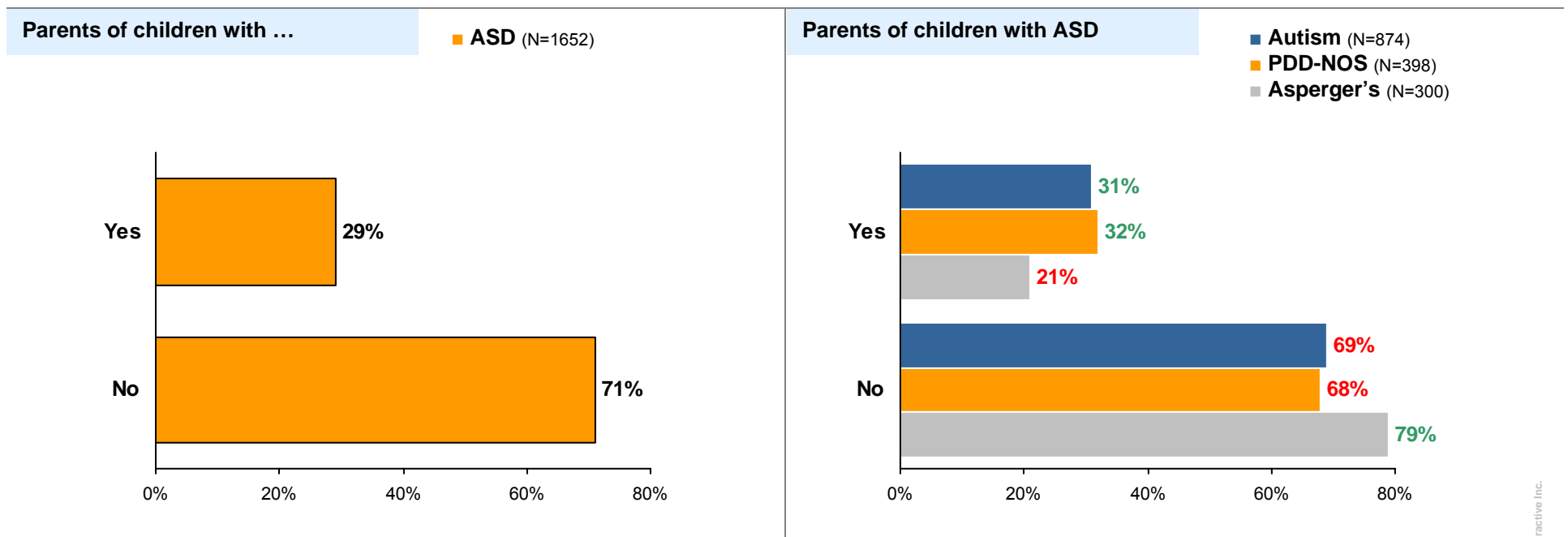
Q1590. Are you aware of people who specialize in helping you deal with life issues related to your special needs child?

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... and 7 in 10 do not utilize a Life Planner.

- However, of those who do, parents of children with Autism or Pervasive Developmental Disorder – Not Otherwise Specified are more likely than parents of children with Asperger's to have someone help them deal with life issues.

% of Parents Who Utilize Services of a Person Who Deals with Life Issues



BASE: PARENTS WITH A CHILD WITH ASD?

Q1595. Do you utilize the services of anyone who specializes in helping you deal with life issues related to your child with special needs?

Interventions/treatments is the most popular area where parents get advice from specialists on life issues relating to their children's special needs.

- However, parents of children with Autism are more likely than parents of children with Pervasive Developmental Disorder – Not Otherwise Specified to get intervention or treatment advice.
- Parents of children with Asperger's more frequently seek advice from specialists for emotional issues and stress management than do parents of children with Autism or Pervasive Developmental Disorder – Not Otherwise Specified.

Areas of life that they get advice from a specialist in life issues relating to a special needs child	Parents of children with...	Parents of children with ASD		
	ASD (N=482)	Autism (N=273)	PDD-NOS (N=127)	Asperger's (N=64)
Interventions/Treatments	47%	50%	38%	51%
Health	41%	41%	40%	42%
Emotions	33%	27%	31%	59%
Family life	30%	28%	31%	36%
Stress management	26%	22%	26%	37%
Diet	25%	26%	25%	14%
Finances	22%	20%	24%	18%
Tax planning or estate planning	22%	22%	26%	18%
Spirituality	20%	19%	18%	27%
Employment	18%	16%	17%	23%
Life insurance	17%	20%	17%	13%
Entertainment	16%	17%	11%	14%
Shelter	8%	7%	9%	10%
Clothing	6%	6%	4%	-
Retirement	6%	7%	5%	3%
Sexuality	6%	6%	6%	10%
End-of-life issues	4%	3%	4%	3%
Other	11%	10%	13%	11%
Not sure	7%	7%	9%	2%

BASE: PARENTS WITH A CHILD WITH ASD AND UTILIZES SERVICES

Q600. In which of the following areas of your life do you receive advice from anyone who specializes in helping you deal with your life issues related to having a child with special needs? Please select all that apply.

More often than not, the life care strategies parents put together for their children include a financial aspect.

- While fewer than half of the parents of children without special needs have legally documented their life plans, more than 8 in 10 of those with children with Autism Spectrum Disorder have legally documented theirs.

Areas included in the life care plan/strategy for child	Parents of children with...		Parents of children with ASD		
	No Special Needs (N=47)	ASD (N=76)	Autism (N=43)	PDD-NOS (N=16)	Asperger's (N=14)
Financial aspects	59%	84%	86%	75%	88%
Residential needs	39%	66%	73%	50%	54%
Education	37%	62%	57%	56%	65%
Medical care	28%	63%	71%	56%	38%
Type of supervision	20%	54%	64%	44%	54%
Employment	19%	29%	27%	19%	31%
Social activities	16%	37%	45%	19%	38%
Other	17%	6%	-	19%	12%
Aspects of plan legally documented					
Yes	47%	84%	86%	81%	77%
No, they do not need to be	41%	9%	9%	6%	15%
No, but they should be	12%	8%	5%	13%	8%

BASE: HAS A LIFE CARE PLAN

Q690. What does your life care plan/strategy for your child include? Please select all that apply.

Q695. Are any aspects of your life care plan/strategy legally documented?

Life insurance policies are in place in half of households with children regardless of their special needs status.

- More parents of child with Autism Spectrum Disorder have a guardian, government benefits and a trustee.

Resources in place in event of parent's death	Parents of children with...		Parents of children with ASD		
	No Special Needs (N=917)	ASD (N=1652)	Autism (N=874)	PDD-NOS (N=398)	Asperger's (N=300)
Life insurance policy	55%	50%	49%	54%	51%
Will	37%	37%	36%	38%	42%
Guardian	20%	36%	37%	35%	34%
Inheritance or trust	18%	17%	15%	18%	22%
Government benefits	11%	18%	21%	16%	14%
Trustee for finances	9%	21%	21%	23%	22%
Legal assistance	4%	6%	7%	5%	7%
Residential and community support	3%	5%	5%	4%	3%
Special needs trust	-	15%	20%	12%	8%
Other investments	23%	16%	16%	17%	18%
None of these	23%	25%	25%	24%	26%

BASE: ALL PARENTS

Q697. In preparation for your child when you are no longer living, which of the following resources do you currently have in place? Please select all that apply.

Detailed Findings

Education

“What happens after high school? We have fallen into a black hole. Everything stopped and now we are on our own.”

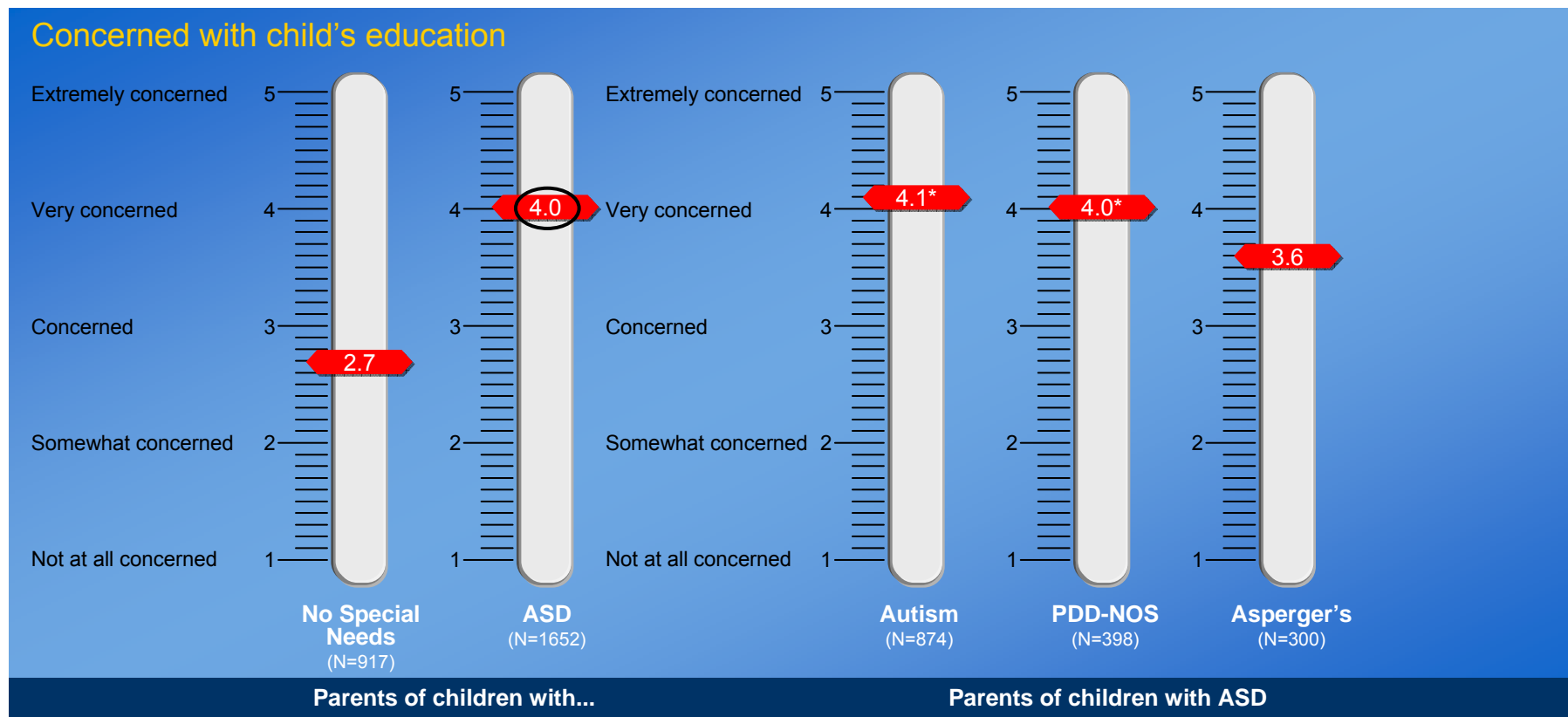
“What resources are available after our child ages out of the educational system? How will we best fill our child’s life after he is finished with school? Are there adult support services when he no longer qualifies for school-related educational services at age 21?”

*A sampling of verbatims shared by survey participants

Education ranks as their 6th highest concern.



- Thinking about the future of their children's education, parents of children with Asperger's are the least likely to be concerned for their children (3.6), possibly due to mainstreaming in school.



BASE: ALL PARENTS

Q1500 How concerned are you for this child's future as an adult in regards to each of the following areas?

*NOTE: The Autism group and the PDD-NOS group are each significantly higher than the Asperger's group.

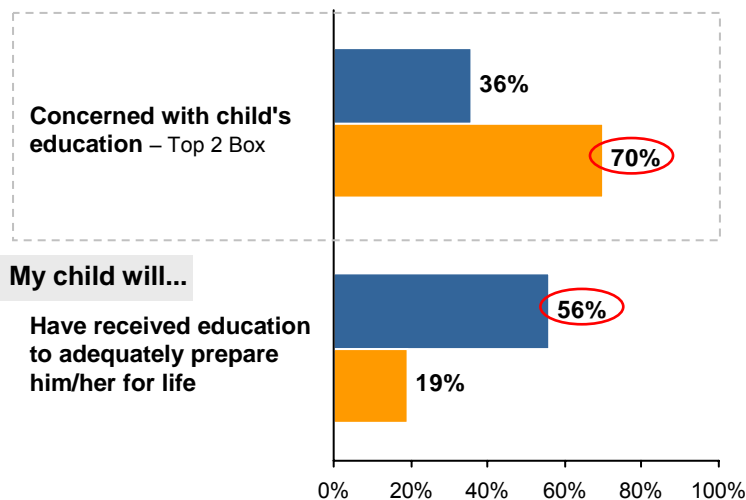
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Those who have children with ASD are much more concerned that their children's education will adequately prepare them for life.

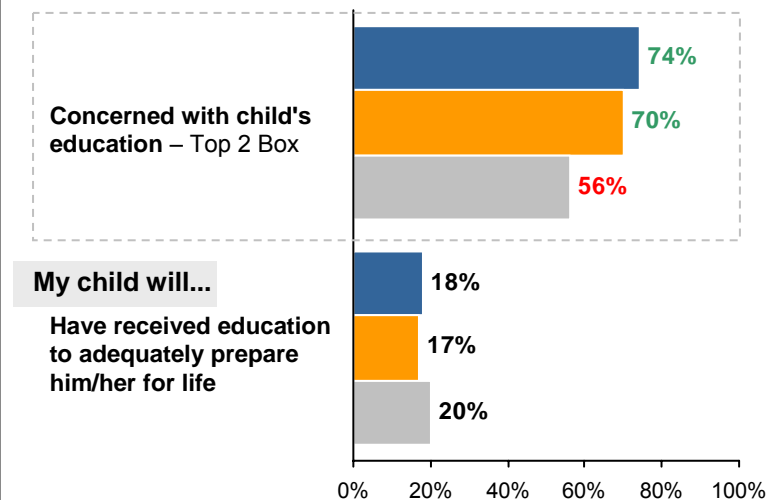
- Those that have Asperger's are less concerned with their children's education than other types of Autism Spectrum Disorders.

% of Parents Who Agree with Statements – Top 2 Box
(Very strongly agree/ Strongly agree)

Parents of children with...
 ■ No Special Needs (N=917)
 ■ ASD (N=1652)



Parents of children with ASD
 ■ Autism (N=874)
 ■ PDD-NOS (N=398)
 ■ Asperger's (N=300)



BASE: ALL PARENTS
 Q1500 How concerned are you for this child's future as an adult in regards to each of the following areas?
 Q1510. Now, please think about the future, when you may not be around for your child.
 To what extent do you agree with each of the following statements regarding your child's future?

Yet, parents have fairly low expectations for their children's education.

- Not even half (46%) of parents with children with some type of Autism Spectrum Disorder expect their children to receive education beyond a high school diploma.
- However, among children with Asperger's, 70% are thought of as college-bound by their parents.

Highest level of education child is expected to complete	Parents of children with...		Parents of children with ASD		
	No Special Needs (N=917)	ASD (N=1652)	Autism (N=874)	PDD-NOS (N=398)	Asperger's (N=300)
Less than elem. school (< 5th grade)	3%	3%	5%	2%	<1%
Elementary school (5th grade)	<1%	1%	2%	1%	-
Middle school (8th grade)	2%	1%	1%	1%	<1%
Some high school (9th-11th grade)	2%	4%	5%	4%	3%
H.S. degree or equivalent (e.g., GED)	13%	27%	30%	27%	21%
Certificate of completion (Non-H.S. diploma)	1%	17%	22%	17%	3%
Some college, but no degree	7%	8%	5%	9%	12%
Associate degree	9%	7%	4%	7%	15%
College degree	44%	26%	21%	28%	38%
At least some graduate school	19%	5%	4%	4%	8%

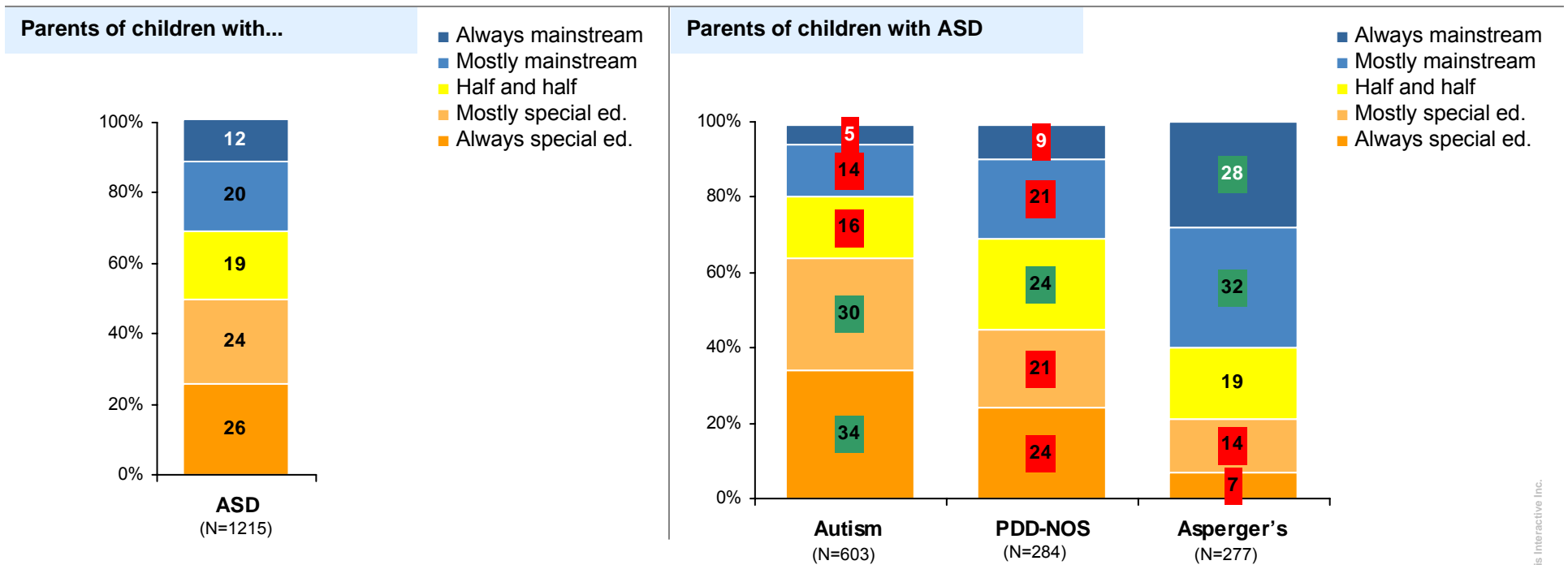
BASE: ALL PARENTS

Q1565. What is the highest level of education you think your child will complete?

Overall, two-thirds of children with Autism Spectrum Disorder do not attend mainstream classes.

- However, among children with different types of Autism Spectrum Disorder, those with Asperger's (60%) are more likely to end up in mainstream classes.
- Half as many children with Pervasive Developmental Disorder – Not Otherwise Specified mostly or always attend mainstream classes, while children with Autism or other types of Autism Spectrum Disorder only end up mostly in mainstream classes about one-fifth of the time.

% Attends Mainstream or Special Education Classes



BASE: ALL PARENTS WHOSE CHILD IS 6+ YEARS OLD AND HAS ASD
 Q1562. Has your child attended mainstream classes or special education classes?

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According to parents, their children are functioning at an educational level lower than other children their age.

- Among children with Autism age 7 to 12, almost 4 in 10 are functioning at a preschool kindergarten level. Meanwhile, only about 2 in 10 with PDD-NOS and few (4%) children with Asperger's are functioning at the preschool or kindergarten level.
- Children with Asperger's are more likely to be functioning at their appropriate age level for middle school or high school than are children their same age with Autism or Pervasive Developmental Disorder – Not Otherwise Specified.

Child's Functioning Educational Level	Parents of child(ren) with...			
	ASD 7-12 (N=592); 13-18 (N=331); 19-24 (N=112); 25-30 (N=44)	Autism 7-12 (N=287); 13-18 (N=156); 19-24 (N=57); 25-30 (N=21)	PDD-NOS 7-12 (N=146); 13-18 (N=76); 19-24 (N=22); 25-30 (N=9)	Asperger's 7-12 (N=132); 13-18 (N=87); 19-24 (N=29); 25-30 (N=11)
At preschool/ kindergarten level	7-12: 26% 13-18: 14% 19-24: 21% 25-30: 12%	7-12: 39% 13-18: 22% 19-24: 30% 25-30: 19%	7-12: 23% 13-18: 12% 19-24: 27% 25-30: 11%	7-12: 4% 13-18: 0% 19-24: 0% 25-30: 0%
At an elementary school level	7-12: 64% 13-18: 41% 19-24: 32% 25-30: 28%	7-12: 58% 13-18: 51% 19-24: 42% 25-30: 39%	7-12: 73% 13-18: 47% 19-24: 45% 25-30: 22%	7-12: 68% 13-18: 16% 19-24: 6% 25-30: 19%
At a middle school level	7-12: 9% 13-18: 27% 19-24: 13% 25-30: 28%	7-12: 3% 13-18: 17% 19-24: 14% 25-30: 29%	7-12: 5% 13-18: 28% 19-24: 14% 25-30: 22%	7-12: 26% 13-18: 46% 19-24: 7% 25-30: 38%
At a high school level	7-12: 1% 13-18: 16% 19-24: 17% 25-30: 16%	7-12: 0% 13-18: 8% 19-24: 5% 25-30: 13%	7-12: 0% 13-18: 13% 19-24: 9% 25-30: 11%	7-12: 2% 13-18: 34% 19-24: 44% 25-30: 19%
Beyond a high school level	7-12: 0% 13-18: 2% 19-24: 17% 25-30: 16%	7-12: 0% 13-18: 1% 19-24: 9% 25-30: 0%	7-12: 0% 13-18: 0% 19-24: 5% 25-30: 33%	7-12: 0% 13-18: 4% 19-24: 44% 25-30: 24%

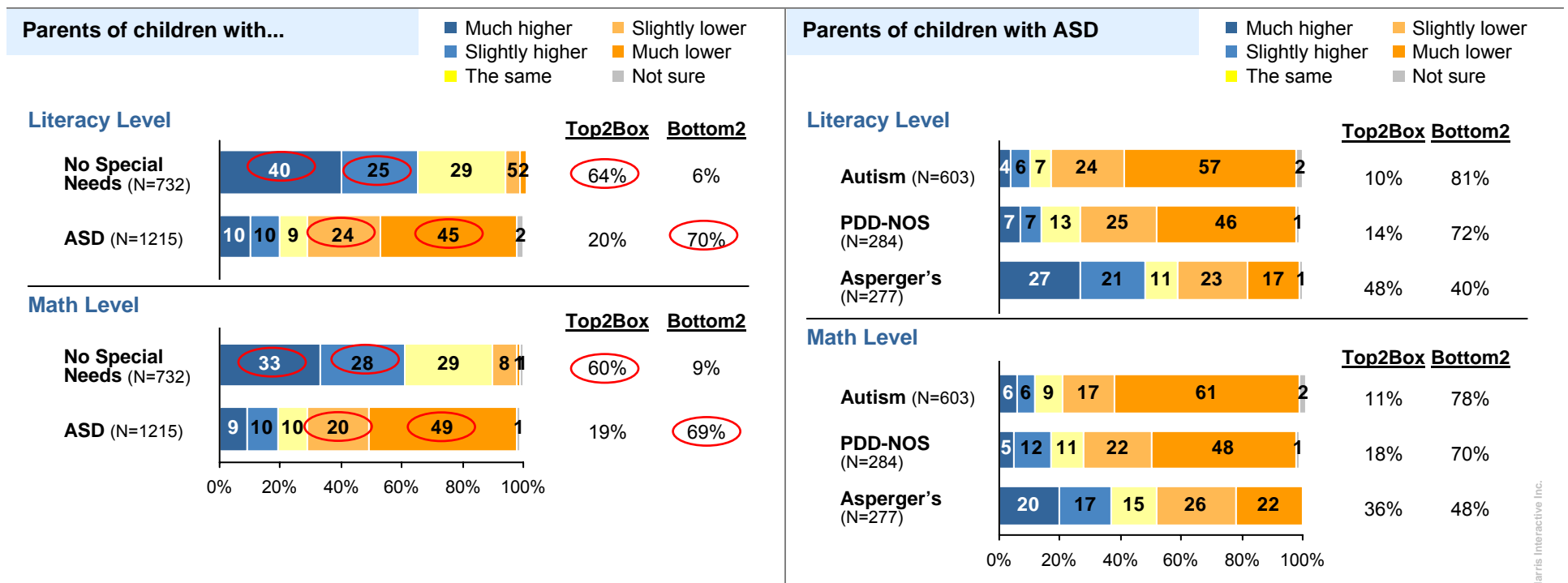
BASE: ALL PARENTS WHOSE CHILD IS 6+ YEARS OLD AND ASD

Q1547. Regardless of the highest level of education your child has received, at what educational level does your child function?

2 out of 3 parents living with ASD say that their children have slightly lower or much lower literacy and math skills than other children their age.

- However, according to their parents, children with Asperger's are more likely than children with other types of ASD to not only function at an age-appropriate level, but to also have slightly higher or much higher literacy and math skills than other children their age.

Child's Literacy and Math Level Compared to Other People His/Her Age

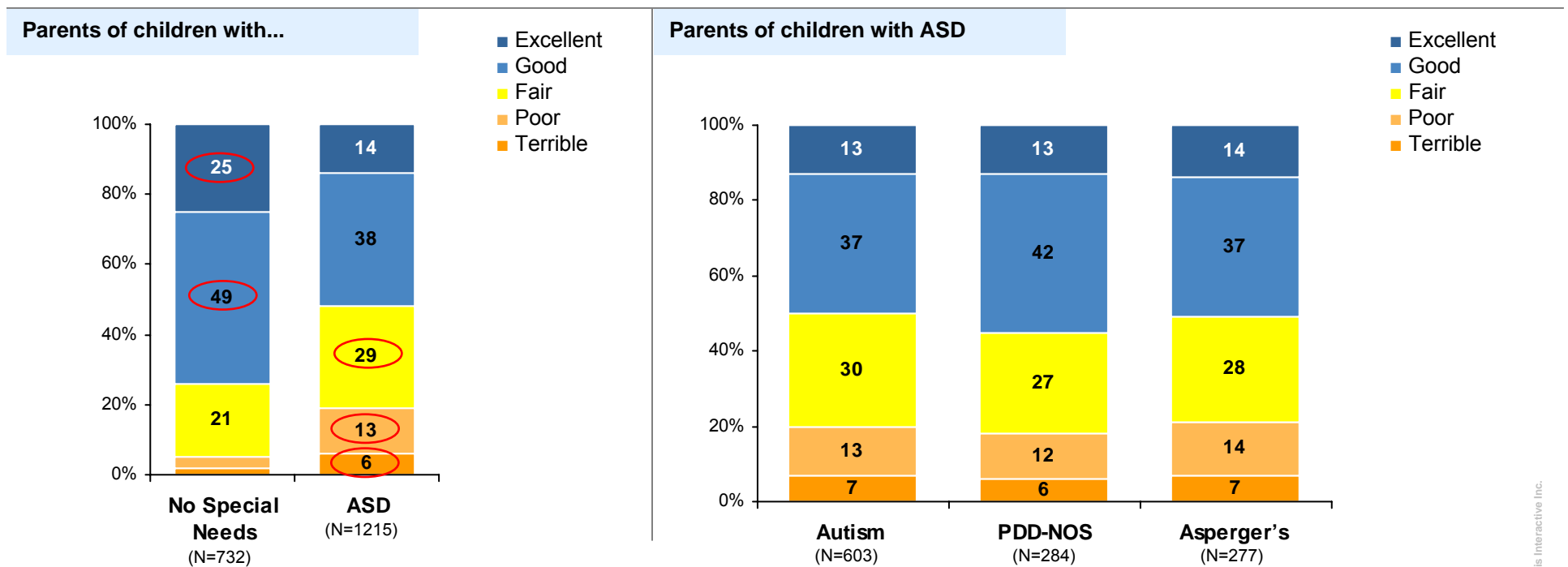


BASE: ALL PARENTS WHOSE CHILD IS 6+ YEARS OLD

Q1550. In your opinion, what is your child's literacy and math level compared to other people his/her age?

Parents of children with Autism Spectrum Disorder are more likely to give a lower rating to the quality of education their children have received...

% of Parents Who Rate the Quality of Education their children Has Received



BASE: ALL PARENTS WHOSE CHILD IS 6+ YEARS OLD
 Q1560. Overall, how would you rate the quality of the education your child has received?

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... and parents perceive that their children are completing their grade levels (perhaps being passed through) even though they are not functioning at these grade levels.

Highest Level of Education Child Has Completed	Parents of children with...							
	No Special Needs				ASD			
	7-12 (N=129)	13-18 (N=167)	19-24 (N=171)	25-30 (N=242)	7-12 (N=592)	13-18 (N=331)	19-24 (N=112)	25-30 (N=44)
Not yet completed first grade	3%	-	-	-	9%	1%	1%	-
Some elementary school	80%	1%	-	<1%	79%	6%	6%	-
Some middle school	15%	30%	-	3%	12%	41%	1%	2%
Some high school	-	46%	11%	4%	-	43%	19%	9%
Has high school degree or equiv.	2%	17%	28%	26%	-	6%	24%	34%
Some college, but no degree	-	5%	31%	23%	-	<1%	18%	14%
Associate degree	-	-	11%	10%	-	-	2%	2%
College degree	-	<1%	17%	24%	-	-	1%	-
At least some graduate school	1%	-	2%	7%	-	-	-	6%
Certificate of completion	-	-	<1%	3%	-	3%	28%	33%

BASE: ALL PARENTS WHOSE CHILD IS 6+ YEARS OLD (Q1605/1-3 AND CHILD'S AGE IS 6+)
Q1555. What is the highest level of education your child has completed?

Among children between the ages of 19 and 24, those with Asperger's are more likely than others their age with Autism Spectrum Disorder to have completed some college.

Highest Level of Education Child Has Completed	Parents of children with ASD											
	Autism				PDD-NOS				Asperger's			
	7-12 (N=287)	13-18 (N=157)	19-24 (N=57)	25-30 (N=21)	7-12 (N=146)	13-18 (N=76)	19-24 (N=22)	25-30 (N=9)	7-12 (N=132)	13-18 (N=87)	19-24 (N=29)	25-30 (N=11)
Not yet completed first grade	14%	2%	2%	-	8%	-	-	-	2%	-	-	-
Some elementary school	78%	6%	5%	-	84%	9%	18%	-	74%	1%	-	-
Some middle school	8%	40%	2%	-	8%	42%	-	11%	23%	43%	-	-
Some high school	-	43%	26%	8%	-	43%	14%	11%	-	44%	7%	9%
Has H.S. degree or equiv.	-	4%	15%	34%	-	4%	18%	22%	-	11%	23%	38%
Some college, but no degree	-	1%	2%	5%	-	-	9%	33%	-	-	60%	19%
Associate degree	-	-	-	-	-	-	-	-	-	-	7%	-
College degree	-	-	-	-	-	-	-	-	-	-	3%	-
At least some grad. school	-	-	-	-	-	-	-	-	-	-	-	24%
Certificate of completion	-	4%	37%	53%	-	1%	41%	22%	-	1%	-	9%

BASE: ALL PARENTS WHOSE CHILD IS 6+ YEARS OLD (Q1605/1-3 AND CHILD'S AGE IS 6+)
Q1555. What is the highest level of education your child has completed?



Detailed Findings

Information Resources

Networking with other families who have children with special needs, as well as, specialty websites, are the most useful sources of information.

Usefulness of Information Sources – Top 2 Box (Extremely useful/Very useful)	Parents of children with...	Parents of children with ASD		
	ASD (N=1652)	Autism (N=874)	PDD-NOS (N=398)	Asperger's (N=300)
PROFESSIONAL (NET)				
Local autism support centers	26%	26%	26%	26%
Pediatricians	15%	14%	18%	12%
Developmental Pediatricians	22%	22%	29%	14%
INFO SOURCES (NET)				
Search engines (e.g., Google, Yahoo, etc.)	40%	41%	39%	39%
Specialty websites (e.g., Easter Seals, Autism Society of America, etc.)	49%	47%	51%	48%
Online news (e.g., CNN, MSNBC, FOX, etc.)	11%	11%	11%	9%
Television news	8%	7%	7%	7%
Magazines	13%	12%	14%	15%
Newspapers	6%	6%	5%	4%
PERSONAL (NET)				
Support groups	29%	32%	28%	25%
Friends or family	24%	24%	26%	22%
Religious organizations	7%	6%	8%	7%
Other families who have children with special needs	53%	54%	53%	47%

BASE: PARENTS WITH A CHILD WITH ASD

Q660. How useful do you find the following sources of information for supporting your child with special needs?

Parents living with ASD are most interested in receiving information in print format.

Format they find most helpful in receiving info about life topics	Parents of children with...	Parents of children with ASD		
	ASD (N=1652)	Autism (N=874)	PDD-NOS (N=398)	Asperger's (N=300)
Face-to-face	45%	46%	42%	46%
Print	67%	69%	67%	64%
Electronic	63%	65%	63%	63%
DVD	35%	35%	33%	37%
Seminars/workshops	55%	55%	54%	58%
Other	4%	4%	3%	6%
Would not like to receive info	2%	1%	2%	3%

BASE: PARENTS WITH A CHILD WITH ASD

Q670. In what format would you find it most helpful to receive information about life topics? Please select all that apply.

Parents living with ASD would like to receive life skills training for their children, emotional and stress training for their families and financial training for themselves.

- Among parents of children with Asperger's, many expressed that information resources for high-functioning children with Autism Spectrum Disorder just does not exist.

Information they need but can not find regarding raising a child with special needs	Parents of children with...	Parents of children with ASD		
	ASD (N=1652)	Autism (N=874)	PDD-NOS (N=398)	Asperger's (N=300)
Medical Issues	14%	13%	14%	13%
Financial Coverage	18%	19%	17%	18%
Programs/Training (Net)	20%	17%	19%	32%
Emotional Support	6%	6%	5%	6%
General (Net)	32%	32%	31%	32%
None/Nothing	3%	3%	3%	4%
Don't know	1%	1%	1%	1%
Decline to answer/No answer	34%	35%	37%	28%

What they say they need...



"Everyone seems to think that since my daughter is high-functional, that I don't need the help."

"I cannot find help for an adult (18 yrs old) PDD-NOS for things like Life Skills or job skills training. There's help for people with severe disabilities, but not for people with High Functioning Autism."

"How to navigate through the educational and government systems, receive services with a high-functioning autistic child, and be able to maintain our standard of living without draining every financial resource we have."

"Parent support group or specialized psychologist in San Francisco that/who deals specifically with the emotional toll raising a child with autism brings on parents."

"Long term outcome info for financial planning."

"If a child is high-functioning how can you get them the help they need if they do not qualify for benefits?"



BASE: PARENTS WITH A CHILD WITH ASD

Q675. What information do you need, but cannot find regarding raising a child with special needs?



Visit www.actforautism.org to learn more about the study, find local services, volunteer and contribute to support Easter Seals autism services.

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