

ASD: Impact on the Family

Moms, Dads, Sibs, and Grandparents

Prepared for: CIGNA's Autism Awareness Series

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Interactive Autism Network

Kennedy Krieger Institute

Who am I?

- IAN's Community Scientific Liaison
- Graduate of USC's doctoral Sociology and Marriage & Family Therapy (MFT) program
- Mother of a teenager with Asperger syndrome – diagnosed at UCLA and Westside Regional Center at age 4.



What is IAN?

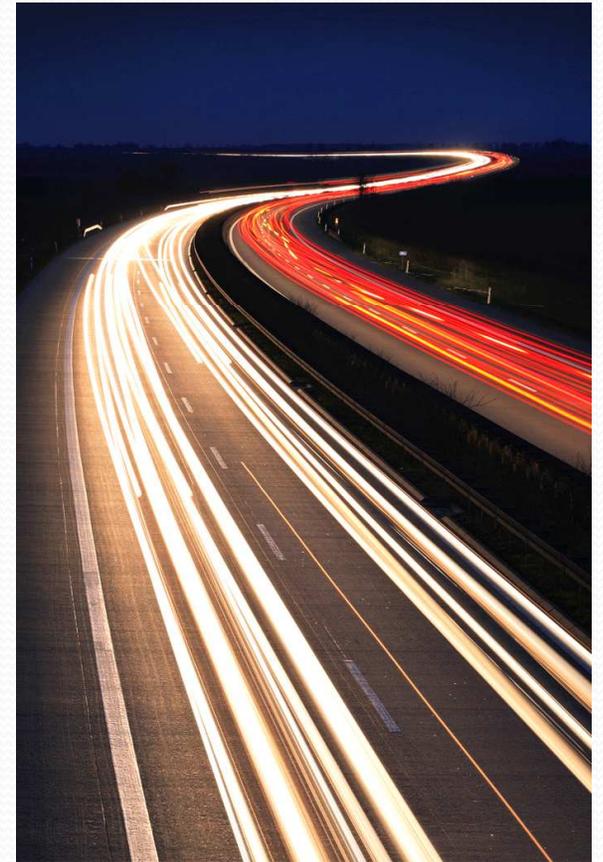
- IAN is the nation's largest online autism research project





IAN Project Goals

- To accelerate autism research
- To engage families as partners in the research process
- To share knowledge as it is gained



IANresearch

Interactive Autism Network • Linking Autism Researchers and Families

IAN User ID:

Password:



[>forgot my password or IAN ID:](#)



share research discover

We all have questions,
together we'll find answers.

What is IAN Research?

Every day thousands of people from across the country are coming together through IAN Research, an innovative online initiative connecting researchers with individuals and families affected by autism spectrum disorders (ASD). The information being shared by those living with an ASD is already helping researchers discover new insights about the disorder and is assisting community leaders advocating for improved services. This dynamic exchange is the nation's largest online autism research study and is making remarkable strides to improve the lives of individuals and families affected by ASDs. This collaborative effort strives to accelerate important breakthroughs about causes, diagnosis, and treatments which may lead to the discovery of a possible cure.

Why participate in IAN Research?

Each year, many important ASD studies are significantly delayed or not completed because researchers can not find enough qualified participants. As a result, valuable opportunities to learn about ASDs are lost. In the first year and

Join the Nation's Largest Online Autism Research Effort

By sharing your experiences and knowledge, you'll help researchers and advocates as they fight to improve the lives of those with ASD.

[Join Now](#)

How do I join?

- Click on the "Join Now" button and follow the instructions to create your IAN ID and password.

OR

- If you are already a member of IAN community and have an IAN ID and password, enter them



IAN is located at...

- The Kennedy Krieger Institute in Baltimore, Maryland
- The project is funded by Autism Speaks, the Simons Foundation, and the National Institute of Mental Health.
- ...and provided a lot of the information we'll discuss today.



ASDs: Impact on Families

- People on the spectrum have many wonderful, unique qualities, and their families love them.

BUT...

It ain't no easy road.



Family Stress Questions

- ...included as part of IAN Parental Depression History Questionnaire
- Parents left thousands of detailed comments

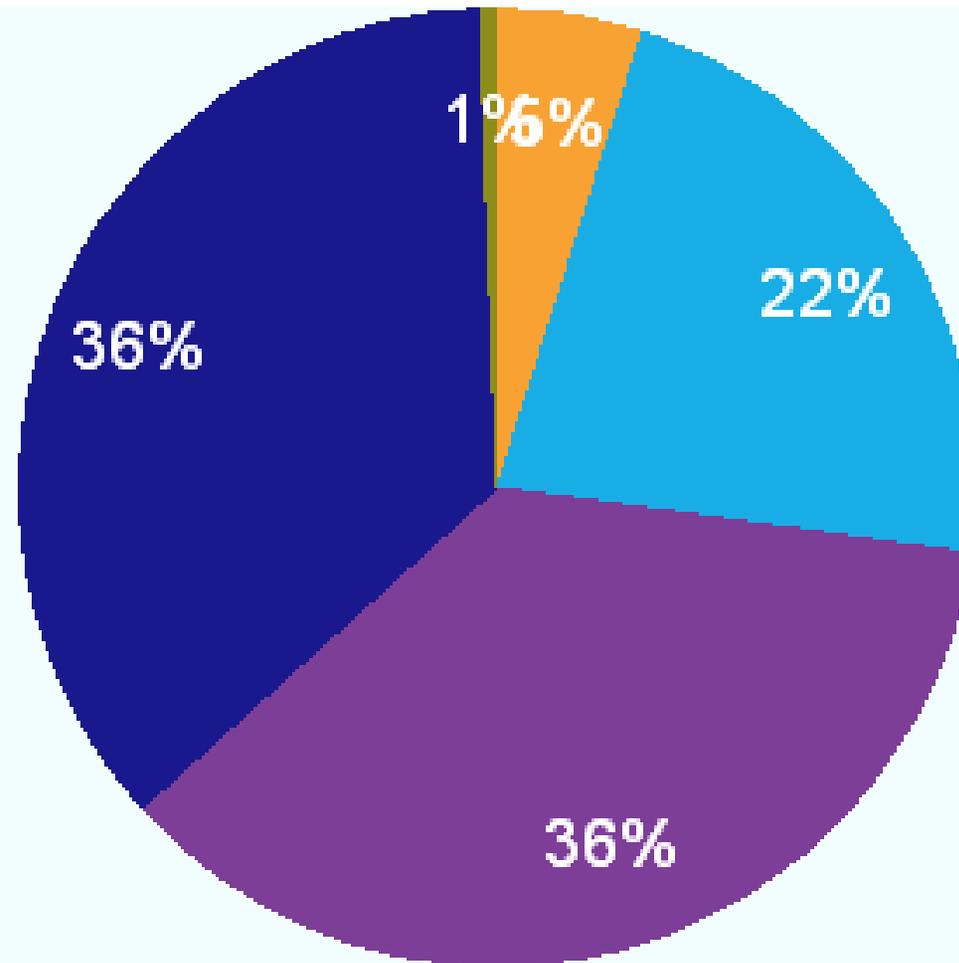
Direct Child-Related Factors

- Child's own issues can stress families big time.



Family Stress: Child Behavior

IAN data updated Apr 3 2009 N=4027



Not at all



A little



A moderate amount



A great deal



Not applicable



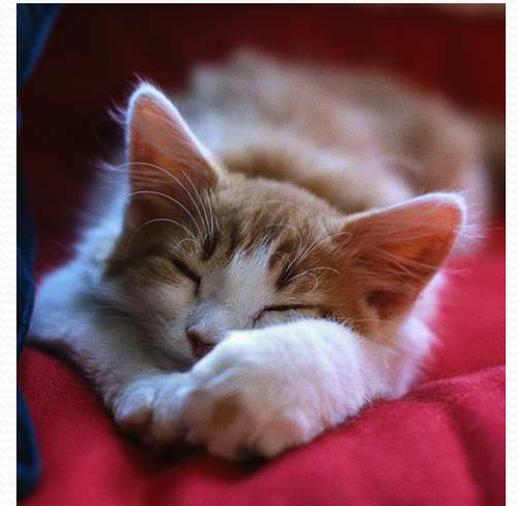
Child Behavior

- Meltdowns, aggression, and exhausting hyper-vigilance
- Stimming, unusual behaviors, self-injury
- Possible lack of connection to parent: no affection coming back the other way
- Hit to parent self-esteem and feelings of competency; increasing social isolation

Sleep Issues

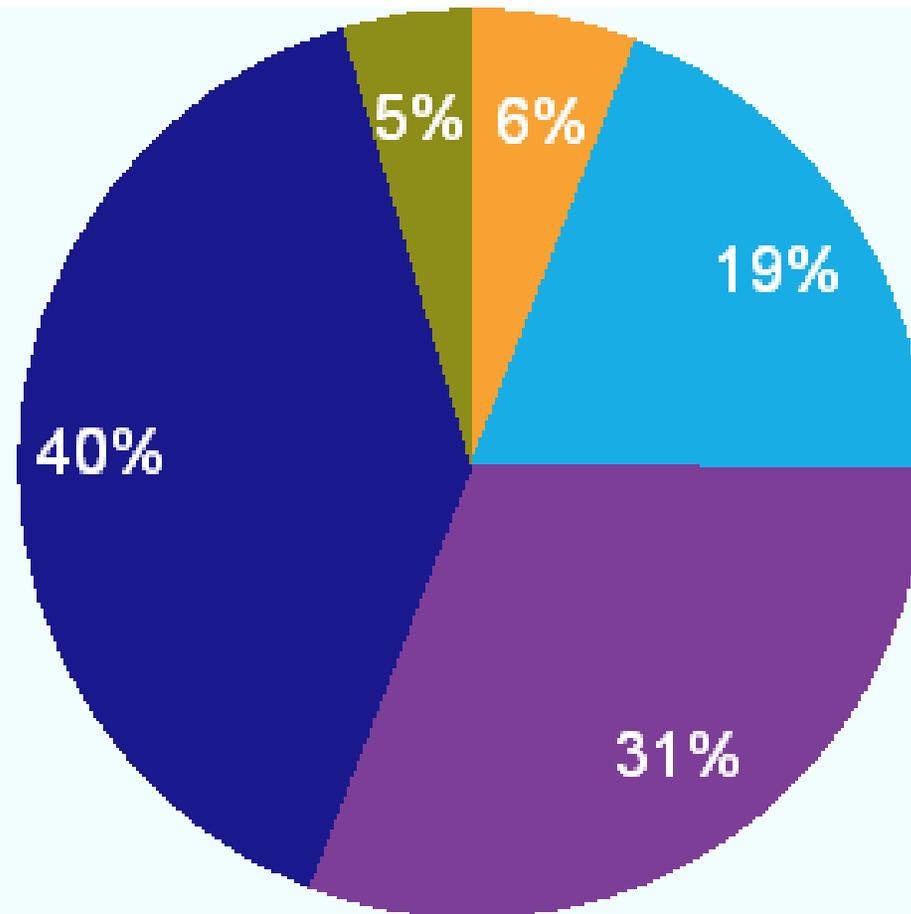
- Sleep issues – a problem for about 50% of the families
- Adds to stress, exhaustion, inability to cope

Sleep deprivation used as a form of torture...



Family Stress: Setback

IAN data updated Apr 3 2009 N=4027



Not at all



A little



A moderate amount



A great deal



Not applicable

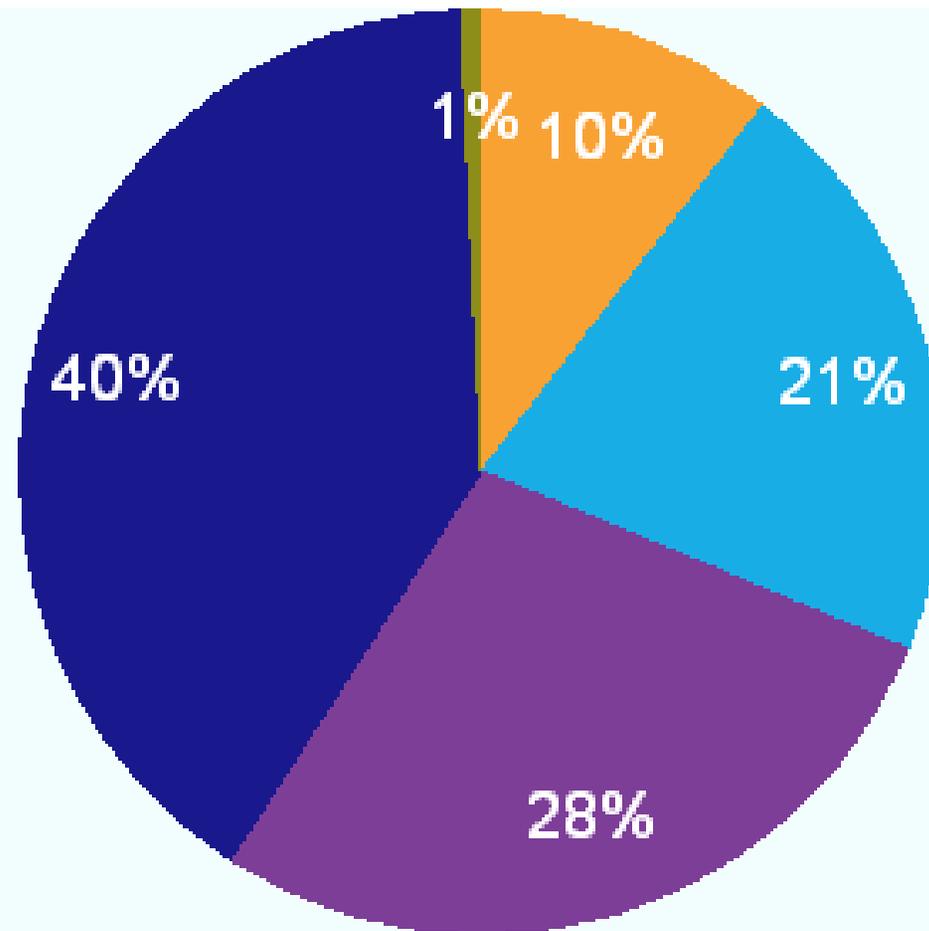
Setbacks

- Setbacks: from classic regression to onset of seizures to new stimming behavior to crisis a child hit in late elementary school/middle school
- Gut wrenching for parents investing so much hope in every tiny increment of progress



Family Stress: Getting Treatments

IAN data updated Apr 3 2009 N=4029



Not at all



A little



A moderate amount



A great deal



Not applicable

Getting Treatments

- “This is absolutely the MOST difficult part of having a child with ASD. I am so tired of fighting.”
- “We are told early intervention is vitally important but we have no support in getting or paying for the services. We are completely on our own to help our child.”



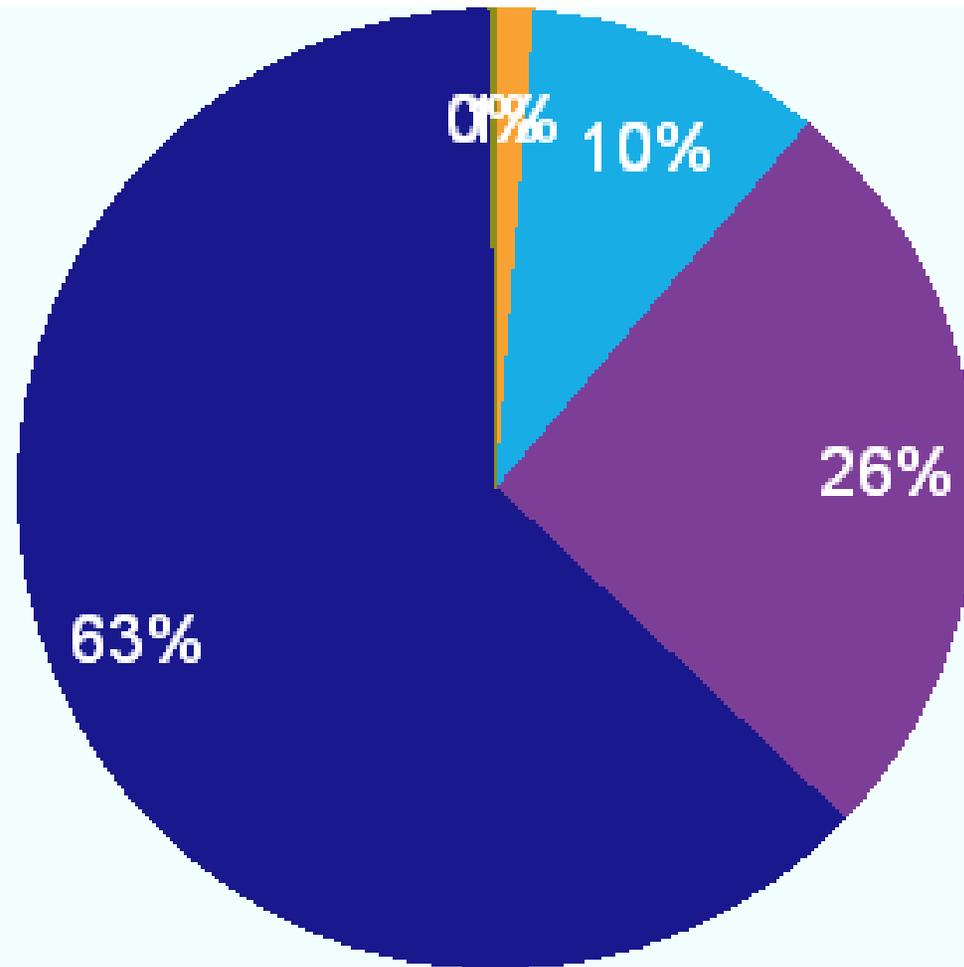
Treatment Disappointments

- 46% say treatment disappointments have a very negative impact
- Cycle of hope/disappointment as try new things at crisis point every time

See “*Evaluating Treatments*” article on IAN Community: www.iancommunity.org

Family Stress: Worry About the Future

IAN data updated Jun 9 2009 N=4405



Worry About the Future

- 89% of IAN parents reported a moderate or great deal of negative impact due to worry over their child's future.
- Affects parents of all kids on the spectrum, whatever the child's level of functioning.

“This is the question that enters my mind every single day. I have to put it away every day because if I let it, it can put me into depression. I use cognitive therapy to control my thoughts regarding her future. But really, it breaks my heart every moment of my life.”

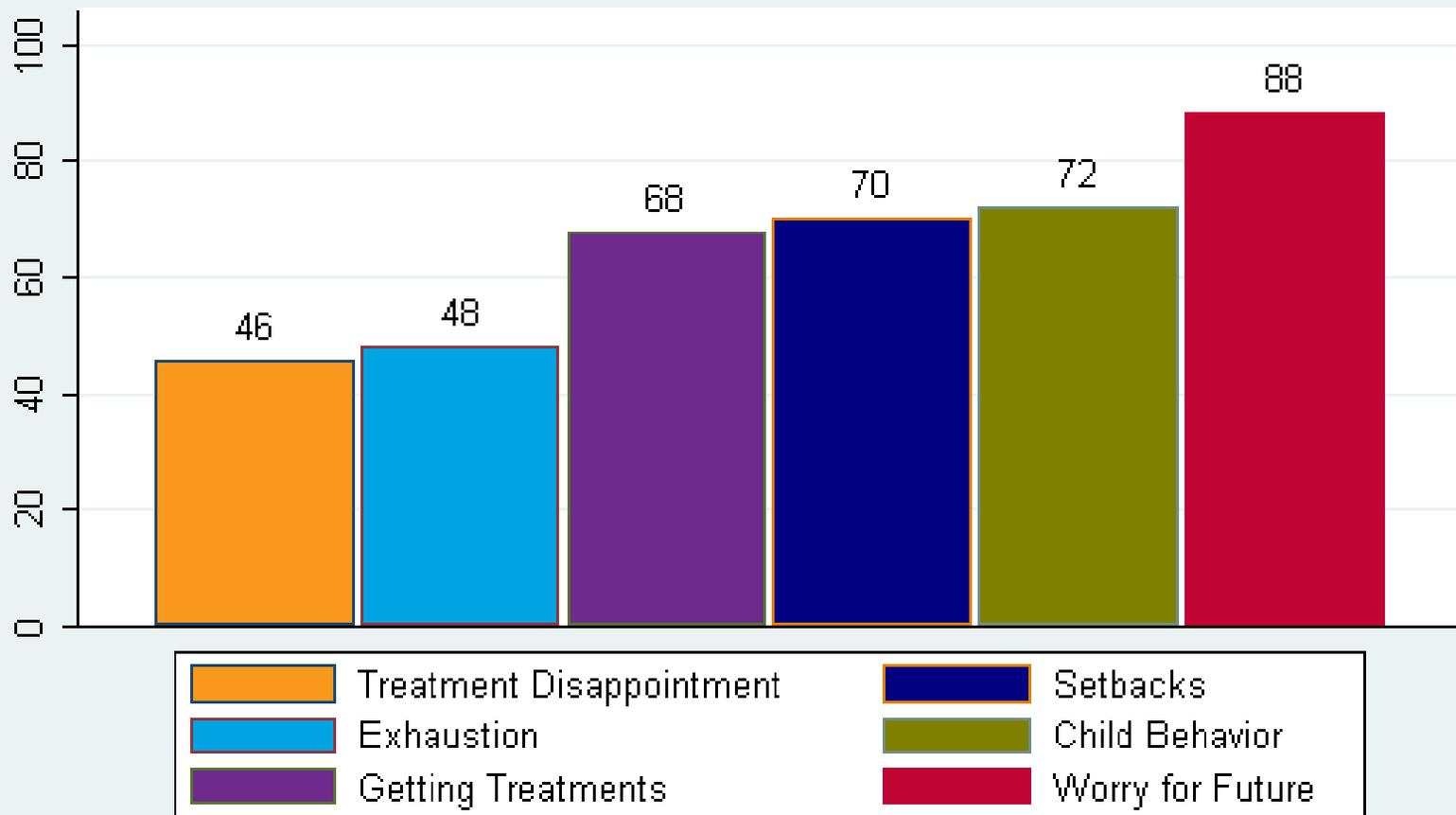


Child-Focused Stressors

Family Stress

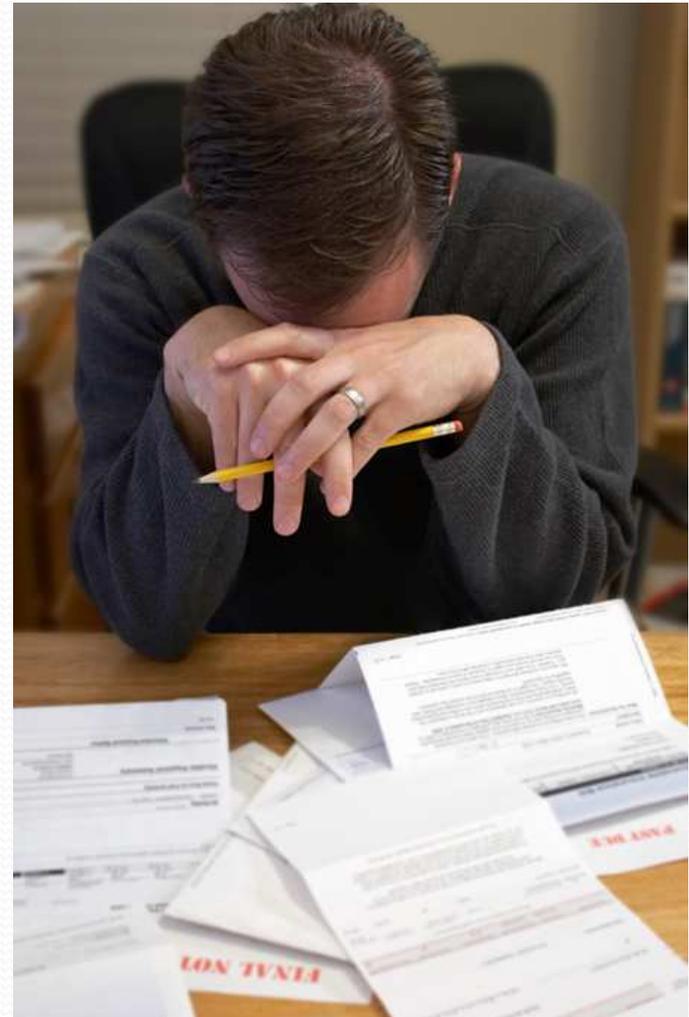
Percentage Reporting Moderate or Great Negative Impact

IAN data updated Apr 3 2009 N=4031



Other Major Impacts

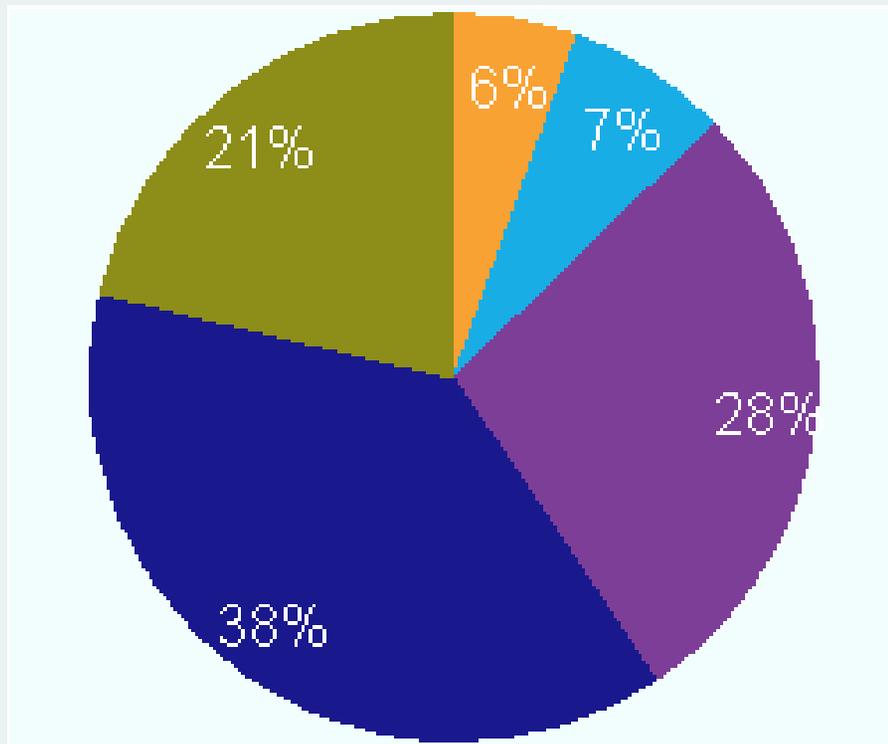
- A child's way of being, behavior, and needs has a direct impact on siblings, parents, etc.
- But there is a lot of “collateral damage,” as well.



Parent's Career or Education

Mother (n=3929)

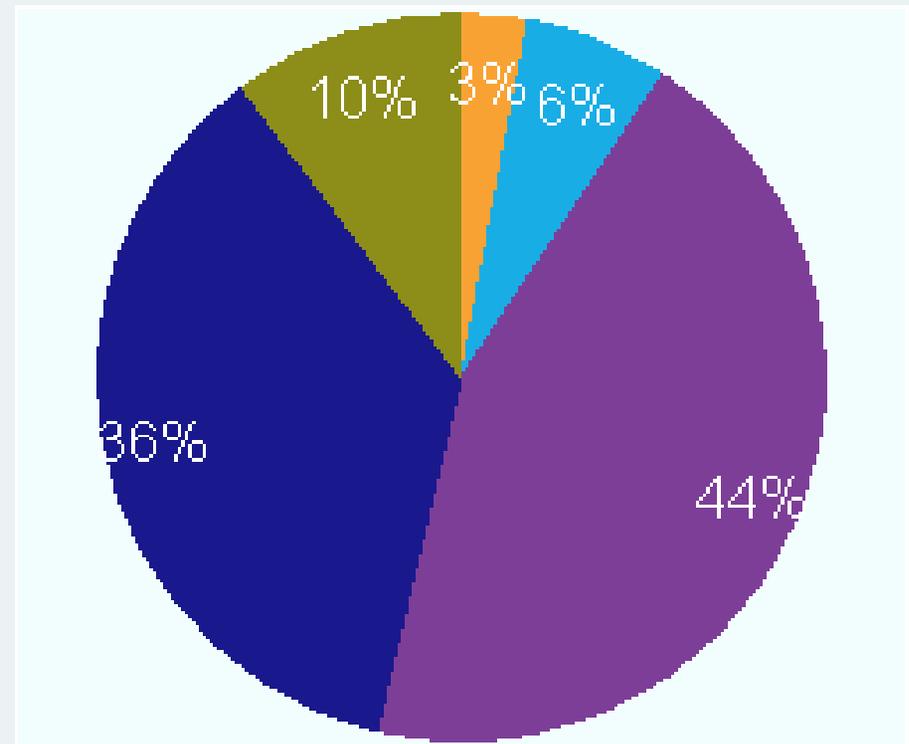
IAN data updated May 20 2009



Parent's Career or Education

Father (n=369)

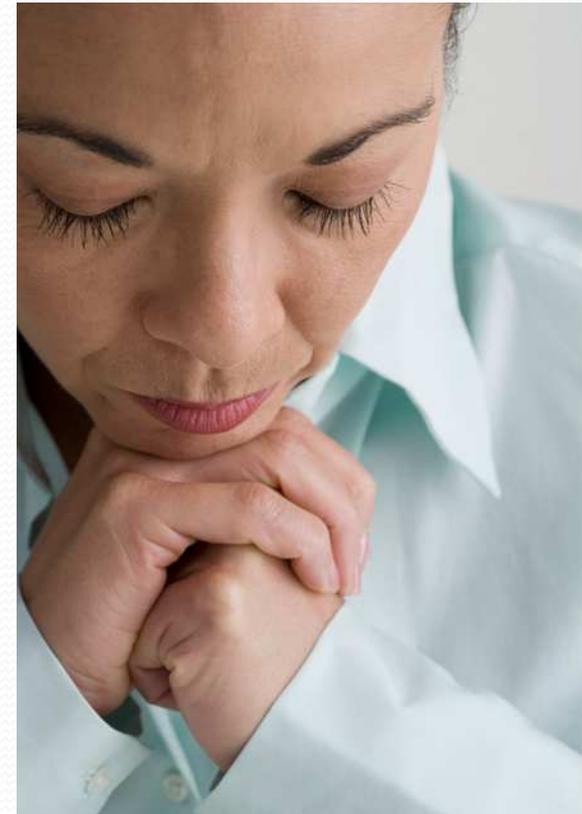
IAN data updated May 20 2009



Graphs by Gender

Parent's Career or Education

- Hit to income, identity, social network
- “I am on the verge of losing my job.... No one can understand what it's like.... It's like I work at a fire department. I never know when I will get a call, or when I'll have to leave.”



University of Rochester study reported:

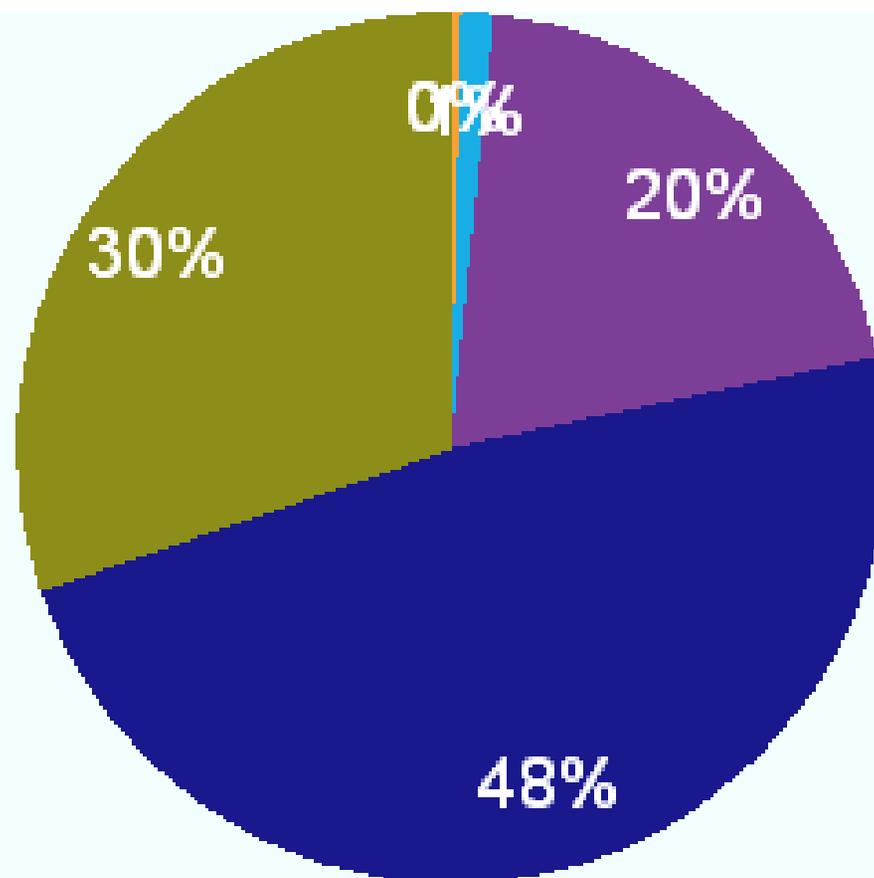
- 39% of parents of children with ASD said they had quit a job, not accepted a job, or greatly changed a job because of child care issues related to having a child with ASD – more than four times the 9% reported by families raising typically developing children.*

*Montes, G., & Halterman, J. S. (2008). Child care problems and employment among families with preschool-aged children with autism in the United States. *Pediatrics*, 122, e202-e208.

Child with ASD: Family Impact

Financial Situation

IAN data updated May 20 2009 N=4295



Financial Impact

- “We hemorrhaged money on our son between ages 3 and 6 and we never really recovered financially. We are still struggling with the effects, as far as debt.”



“A world of their own – a world of isolation”*

- Friendships/Social Network (59% negative impact)
- Extended Family (48% negative impact)

**from qualitative Canadian study on families with a child with ASD*

Isolation

- “If you have good friends they are good through the Autism diagnosis of your child; if they are not good friends, they are *gone*...they drop off the face of the earth.”
- “Those 'best friends' turn to shadows....”





Isolation

- “I quickly learned who my real friends were, so there was some very positive impact.... I no longer have the time, energy, or patience to put up with the old 'false' friends.”
- “Some relationships I thought were strong completely disintegrated; other family members I expected to have trouble with surprised me with their kindness and understanding.”
- Extended family members go on their own journey of acceptance or denial...



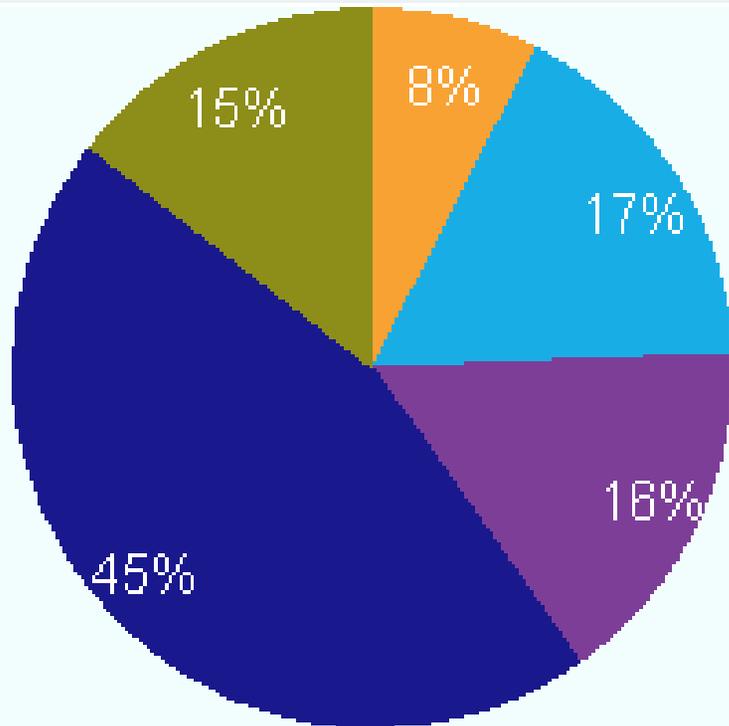
Critical looks of strangers...

- Becomes easier just to stay home.
- Grandparents as caregivers echoed the same feeling.
- Keenly felt the injustice of bystanders' critical looks when their grandchild "lost it" in public.

Couple Relationship

Mother (n=4270)

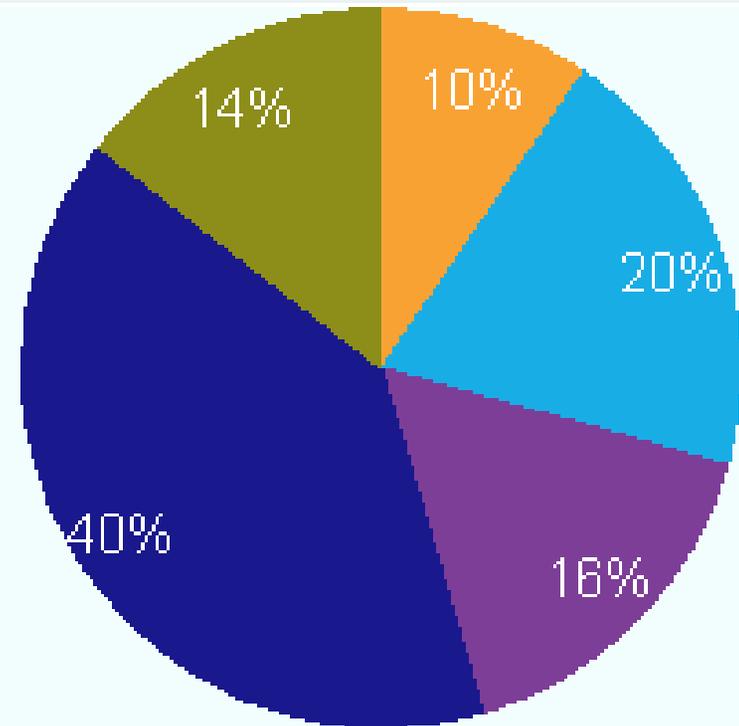
IAN data updated Sep 1 2009



Couple Relationship

Father (n=412)

IAN data updated Sep 1 2009



Graphs by Gender

Couple Relationship

- 80% divorce rate – FALSE
- A study looking at divorce rates for families of children with assorted disabilities found an average increase (over the rate for couples with non-disabled children) of only 5.97%.
- An Easter Seals' survey of families with a child on the autism spectrum, moreover, found parents of a child with an ASD to be *less likely* to have ever been divorced than the parents of a typically developing child.



KKI Divorce Study

- Not yet published, but...
- Used 2007 National Survey for Child Health on kids ages 3-17. Final sample: 77,911.
- The outcome variable of family structure was dichotomized as being either traditional (two parent household, either biological or adoptive) or non-traditional (a two parent household with step-parents, a single mother or father, other relatives, or other family types)



KKI Divorce Study

- “Found no consistent evidence of an association between a child having an ASD diagnosis and that child living in a traditional versus nontraditional family. Exploratory analyses suggest that having ADHD, Externalizing, and Internalizing disorders are more strongly related to the probability of not living in a traditional household than is ASD.”
- But remember: you don't always stay married because things are great. Without job, with \$ problems...can be trapped.

Key marital problems...

- Exhaustion and lack of time or desire for intimacy
- CONFLICT over burdens, path, division of labor
- One partner in denial
- Mental health issues; ASD or autistic-like traits in partner





Transformational Outcomes...

- “Before our son was born my wife and I were on the fast track to divorce: constantly arguing about money and nitpicky stuff. After he was diagnosed, all of our money went into treating him so there was no longer any money to fight about. Our marriage is stronger now because we spend our energy getting him better and being good parents for him and his sister. He has taught us a lot about what's important in life: to be happy just to be able to live a simple life and survive from one week to the next.”



Transformational Outcomes

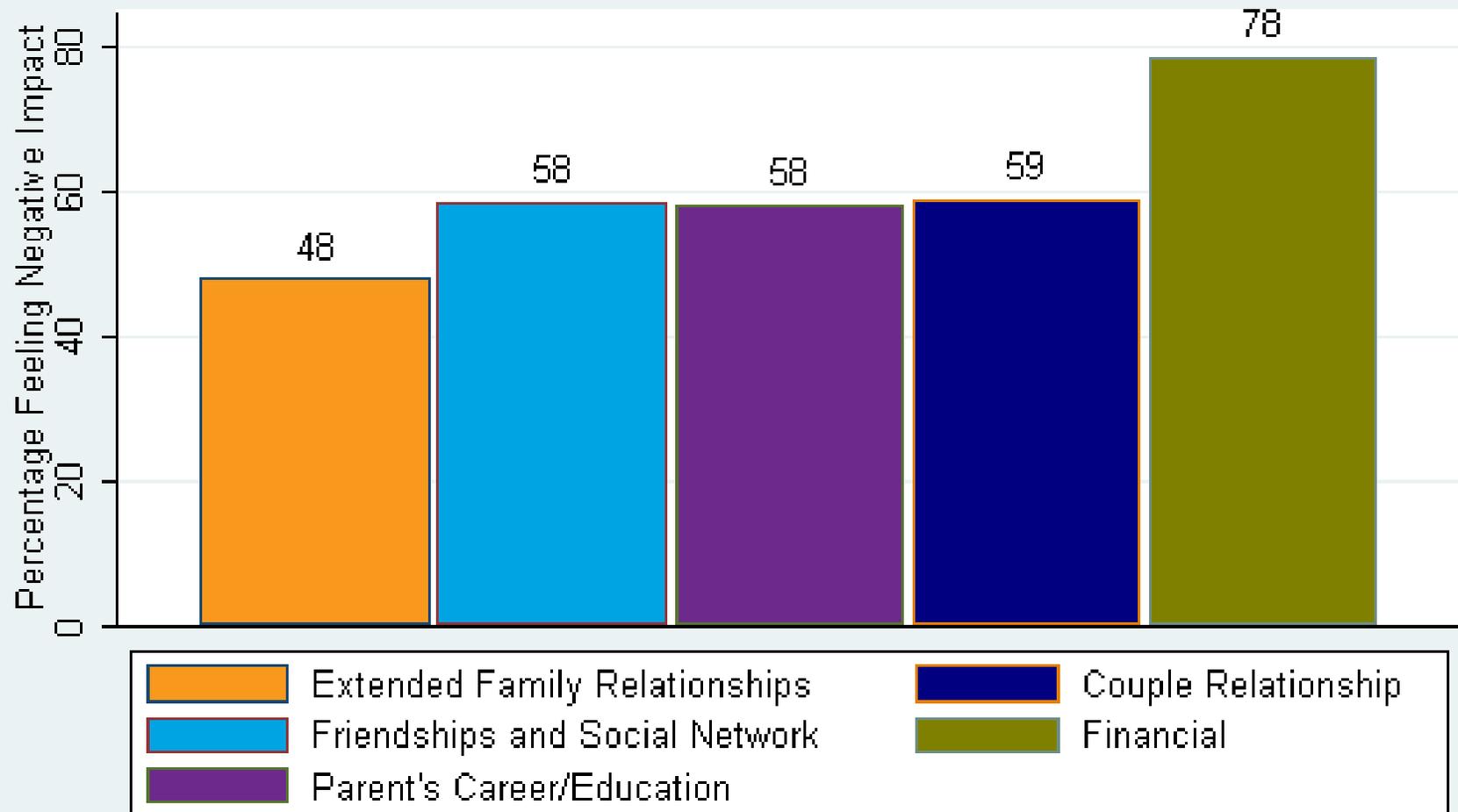
- “Most of the time we felt like no one else understood what we were going through. We felt like all we had to depend on was each other. It made us even closer because we made our marriage top priority. We knew it wouldn't do our son any good to lose the security of both parents. We decided not to let ASD be all our family was about.”

Parent-Focused Stressors

Negative Impact

Families with a Child with an ASD

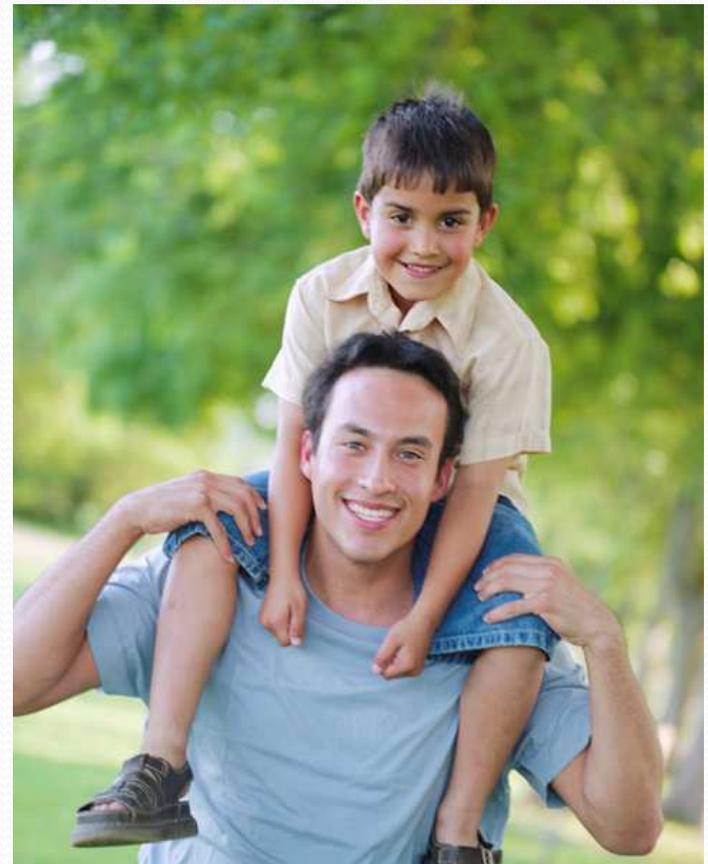
IAN data updated May 20 2009 N=4298



Resilience

Hastings and Taunt, who looked at a number of studies exploring parenting a child with a disability, noted very **positive perceptions** on the part of parents facing this life situation, including:

- Pleasure in providing care for their child
- Their child as a source of joy





Resilience

- A sense of accomplishment in having done their best for their child
- A sense that their marriage or family had been strengthened by what they had gone through together as a result of the child's diagnosis
- A new sense of purpose in life
- A sense of personal growth (because they had become more compassionate, less selfish, more tolerant)
- Increased spirituality
- A new perspective on what is important in life

What About Siblings?

- First of all... siblings of children with ASD may not always be “normal” themselves. Share genetics, etc.
- Latest estimated sibling recurrence rate: 19% overall.*
- Higher for male sibs (26%) and for sibs in families who already had more than 1 child with an ASD (32%).
- 20% are diagnosed with language disorders – in gen'l population, it's only 7-9%.**



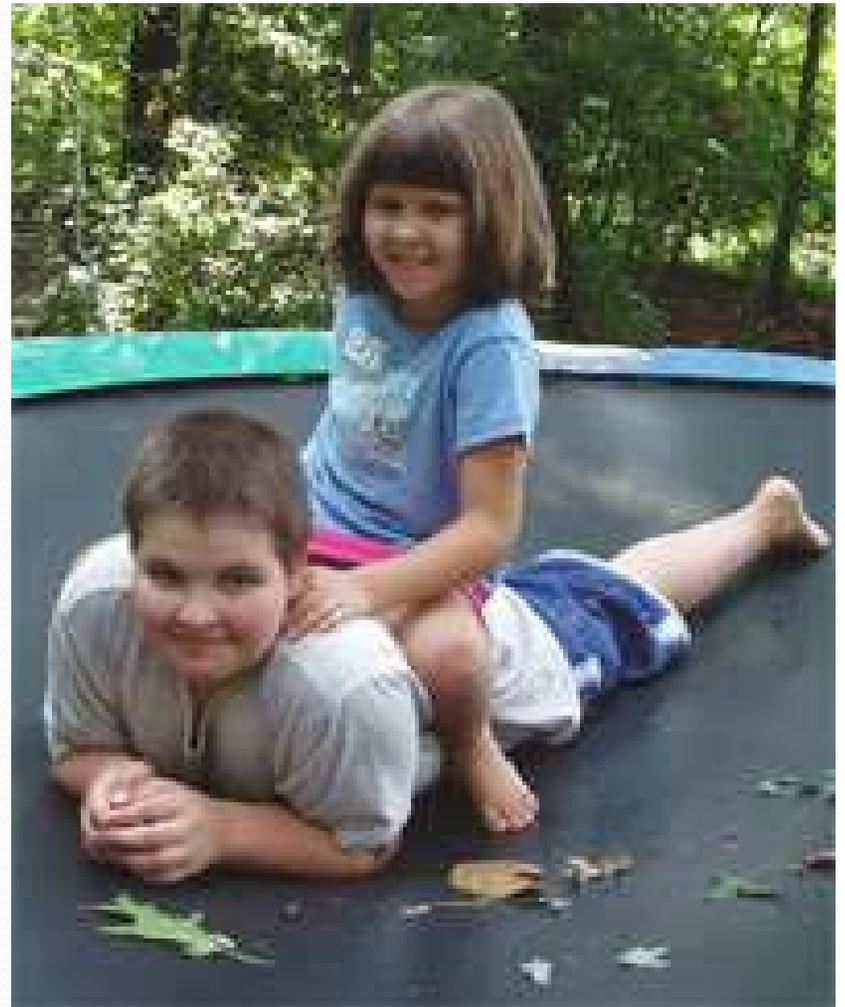
*Ozonoff, S. et al. (2011). Recurrence risk for autism spectrum disorders: A Baby Siblings Research Consortium study. *Pediatrics*, published online 8/15/11.

** Constantino, J.N. et al. (2010). Sibling recurrence and the genetic epidemiology of autism. *American Journal of Psychiatry*, 167(11), 1349-1456.

Siblings!

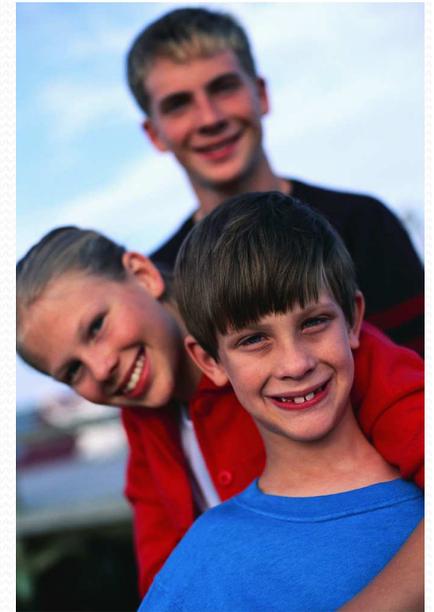
- May serve as models and playmates for ASD child.
- May “get” the ASD child.
- May defend the ASD child.

- But have their own burdens.
What are they?



It's hard being a sib because...

- So much attention goes to the affected child
- The affected child may not play in the way the other child expects/hopes.
- The affected child may be nonresponsive or aggressive.
- The affected child may do things that embarrass the sib in public or in front of peers.
- The sib may worry that autism is “catching.”
- The sib may worry about distressed parents.
- The sib may worry about having to be responsible for the affected child in adulthood.





Sibshops for Kids and Teens

- Support network for siblings of children with special needs or disabilities.



Introducing SibTeen!

For quite a while, we have been wanting to create a place on the

internet **just for teenage brothers and sisters**. We're happy to announce that SibTeen is available as a Yahoo group and a Facebook group. Learn more about SibTeen **here!**

Grandparents!

- Grandparents often play a key role.
- Experiences differ widely, with some slow to accept, others first to recognize ASD.
- If they are close enough, geographically/emotionally, to care for the child with ASD, many of their concerns and experiences come to echo those of parents.



IAN Grandparents Survey

- More than 2,600 grandparents of children with ASD participated.
- Word spread by:
 - Autism Speaks
 - AARP
 - Grandparent Autism Network

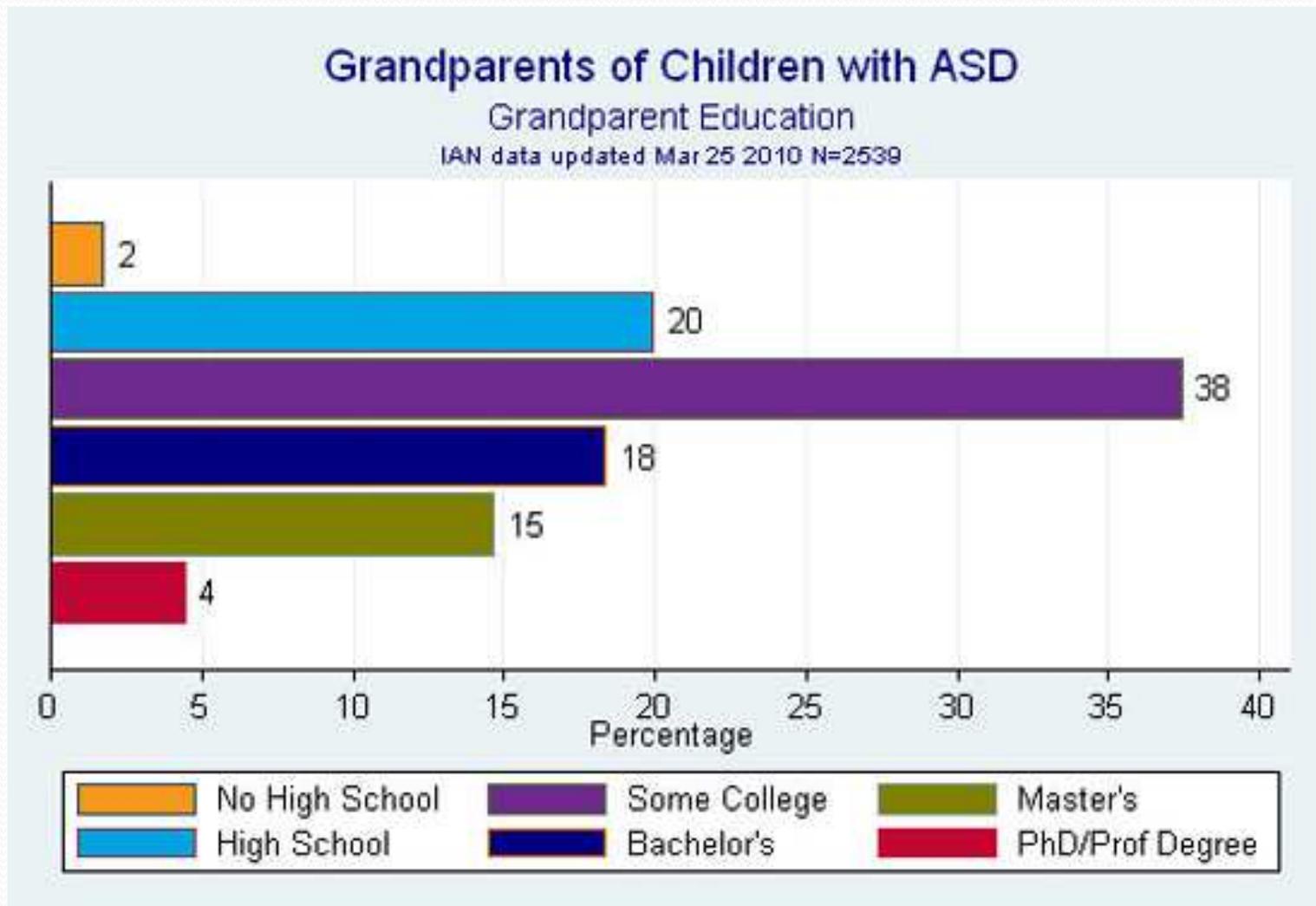


Grandparent Respondents

- Racially, not very diverse (95% white) – digital divide?
- From all 50 states and District of Columbia
- 17% from cities; 23% rural; 60% suburban
- Age: from 40-somethings to 80-somethings
- 83% – grandmothers; 17% - grandfathers
- 2/3 – maternal grandparent



Diverse educational backgrounds

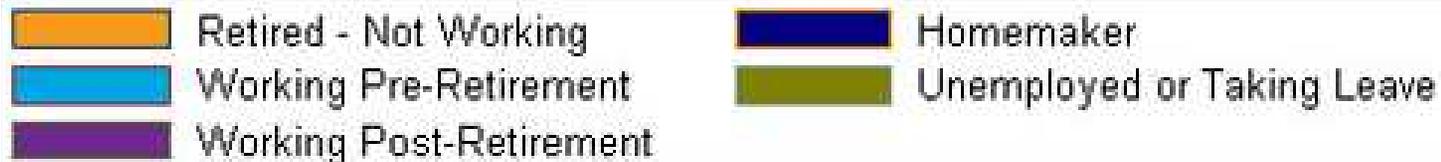
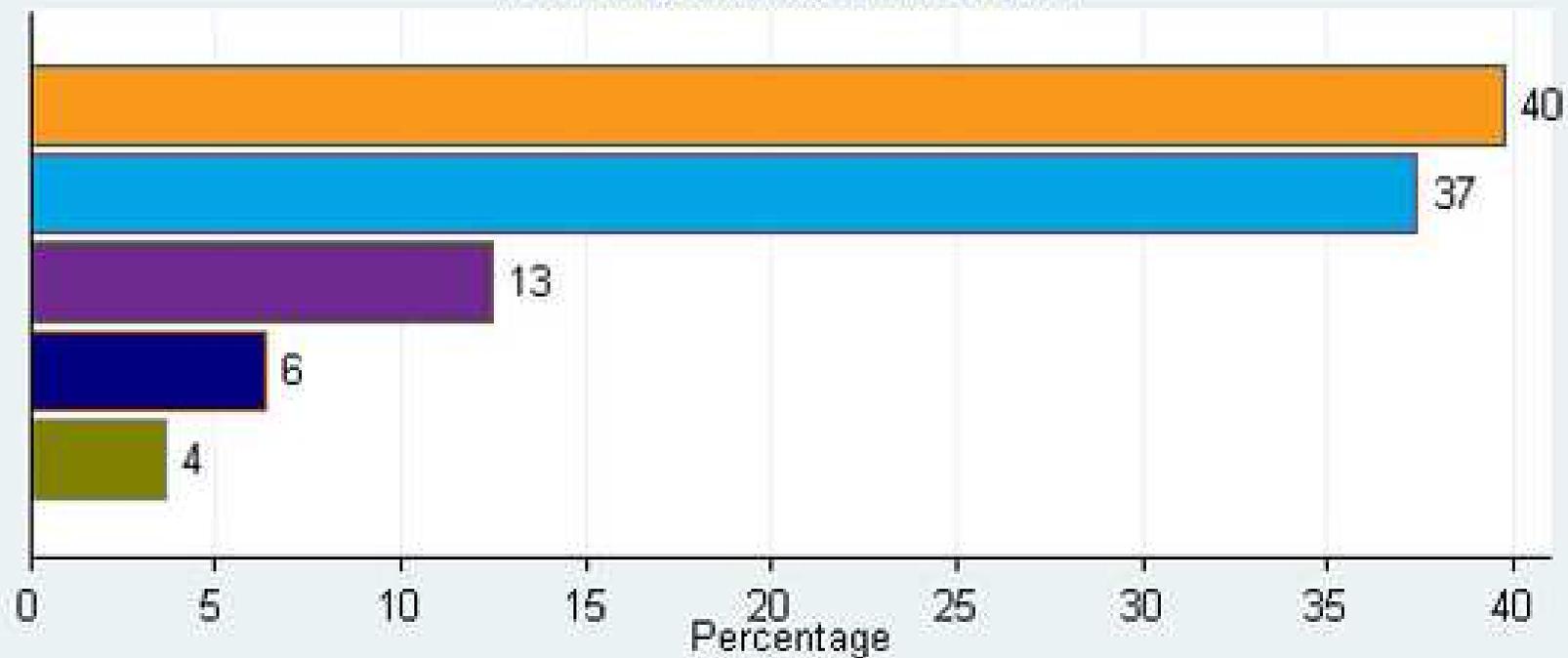


Grandparent Work Status

Grandparents of Children with ASD

Work and Retirement Status

IAN data updated Mar 25 2010 N=2477

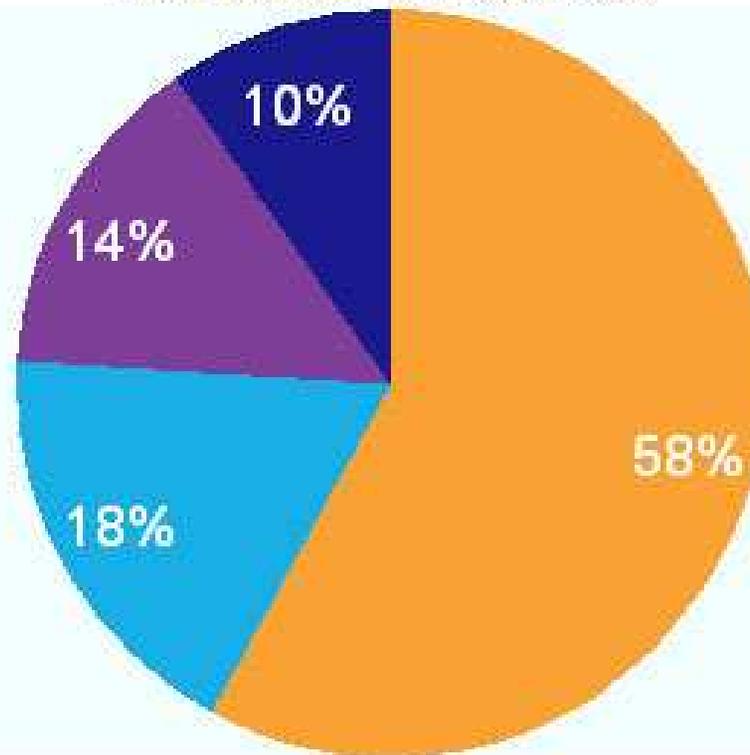


Grandchild's Diagnosis

Grandchildren with ASD: Diagnosis

IAN Grandparent Survey

IAN data updated Apr 21 2010 N=2066

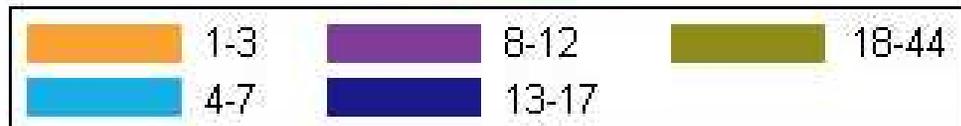
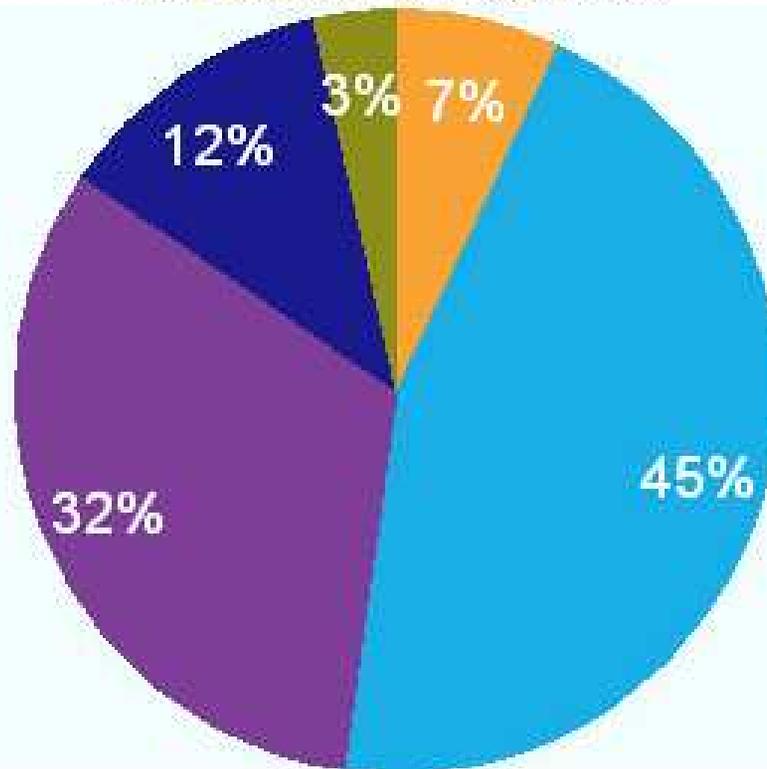


Grandchild's Age

Grandchildren with ASD: Age

IAN Grandparent Survey

IAN data updated Apr 21 2010 N=2286

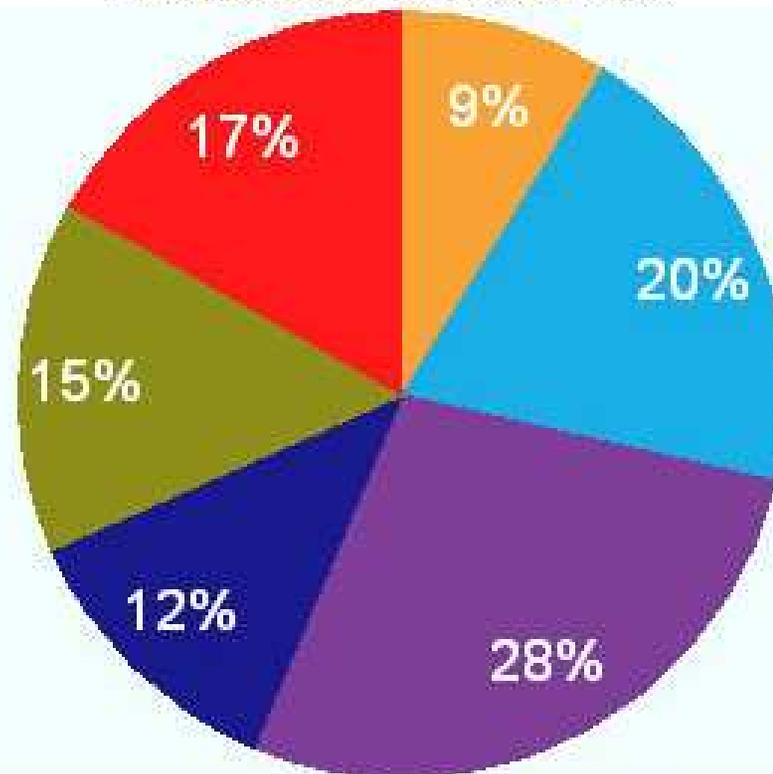


Distance to Grandchild

How Far Do You Live from Your Grandchild with ASD?

IAN Grandparent Survey

IAN data updated Apr 21 2010 N=2191



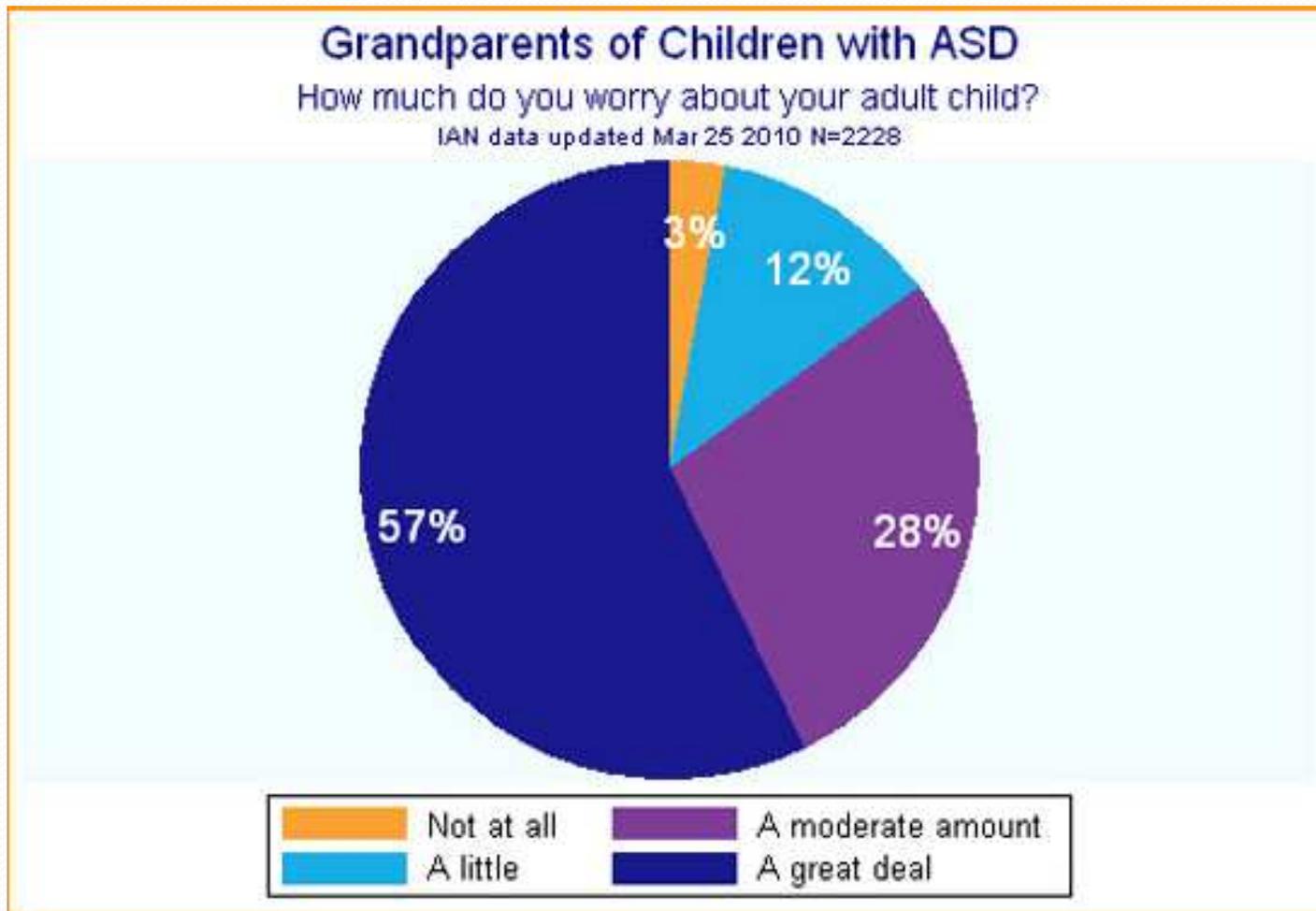
Family History and ASD

TABLE 11

Grandchildren with ASD	Children with ASD	Self -- ASD?
Only 1 (85%)	None (89%)	No (97%)
2 or more -- siblings (10%)	Suspected ASD (8%)	Suspected ASD (2%)
2 or more -- cousins (5%)	Diagnosed ASD (3%)	Diagnosed ASD (1%)

Suffer “Double Whammy”

- Worry about both grandchildren (affected and unaffected) and their own child (the parent).



One Challenge: Give Advice?

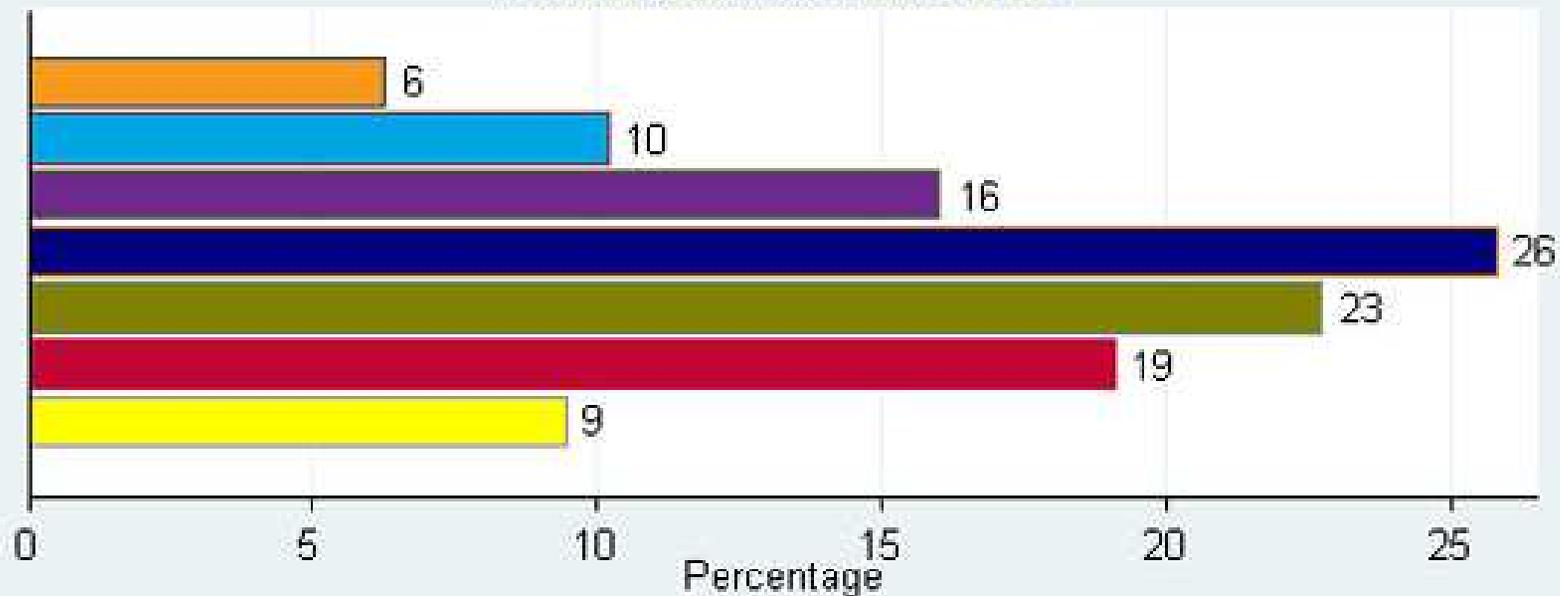
- Typical problem for grandparents even harder for grandparents of kids with ASD – Should they offer an opinion?
- Differences of opinion, and limited power to act, can make it very hard for the grandparent, such as when:
 - A grandparent felt a child should be evaluated, but a parent refused.
 - A grandparent thought a certain treatment was necessary, but the parent wouldn't act to access it.
 - A grandparent feared a treatment was potentially harmful, but was helpless to stop it.

We asked about “Denial” ...

Grandparents of Children with ASD

Their View: Who Has Ever Been in Denial?

IAN data updated Mar 25 2010 N=2338

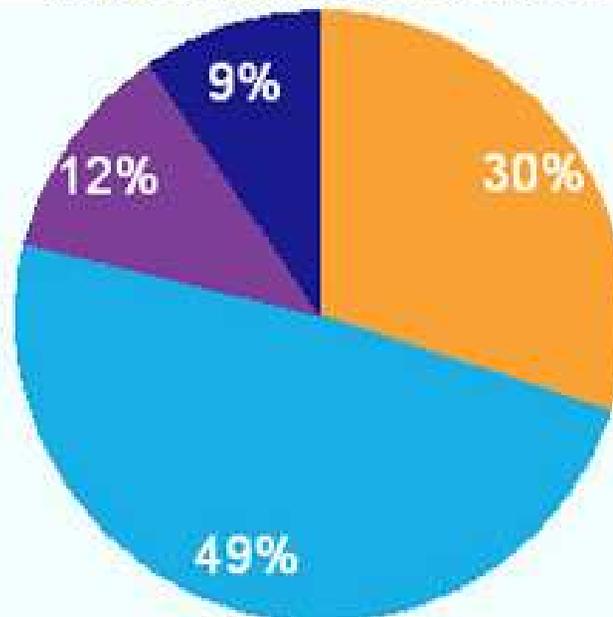


Identifying ASD

Grandparents of Children with ASD

Did you play a role in identifying your grandchild's ASD?

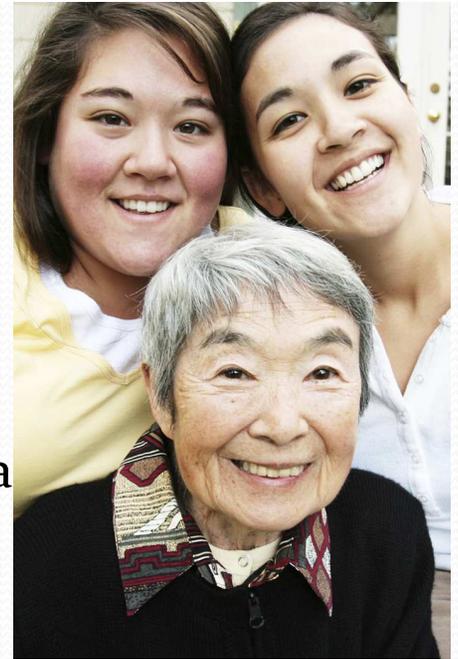
IAN data updated Mar 25 2010 N=2238



-  I was first to notice a problem.
-  I supported others who noticed a problem.
-  Concerns were raised, but I didn't believe.
-  Not made aware until after diagnosis.

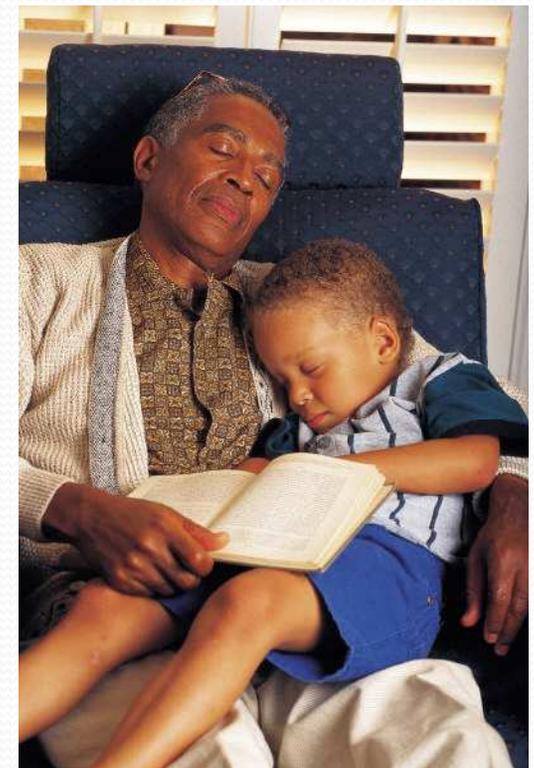
Difficult issue: “I think it’s ASD”

- “I noticed signs when he was 2, but didn't know how to voice my concerns without hurting his parents. So we prayed for someone they would believe to notice. He entered pre-school two half days a week in September, and they noticed by October.”
- “Back when I suspected it, my son got bitter with me, and still is. He copes some days. It's very hard for him...”
- "From before the diagnosis, I knew what it was, but had a very hard time communicating that something was wrong to my daughter who didn't understand the subtlety of the symptoms and thought I was seeing ghosts."



Loving, Supporting, Worrying: Having a Grandchild with ASD

- “My grandson with autism loves me more than any individual has ever loved me in my life, except possibly my wife and mother. One on one, he is the most loving person I have ever known.”
– a grandfather



Caregiving and Transportation

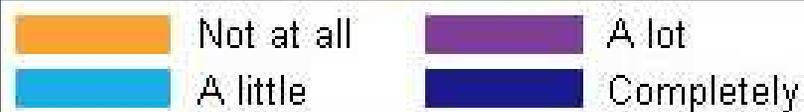
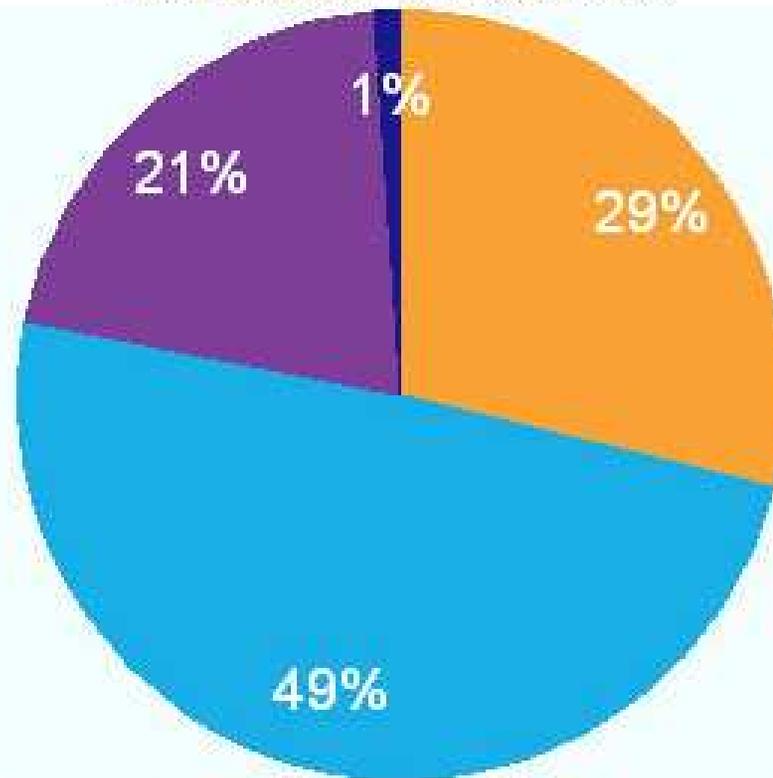
Care Giving and Transportation by Distance			
Non-Custodial Grandparents			
	Live <u>24 miles or less</u> from grandchild	Live <u>25 miles or more</u> from grandchild	Overall
CARE GIVING (n=2146) <i>at least once per week</i>	56%	6%	34%
TRANSPORTATION (n=2153) <i>at least once per week</i>	29%	4%	18%

Treatment Decisions

How Involved Are You In Treatment Decisions?

IAN Grandparent Survey

IAN data updated Apr 21 2010 N=2183



Financial Support: General Needs

Non-Custodial Grandparents	Pay <u>all</u> , <u>a great deal</u> , or <u>a moderate amount</u> of this expense
<i>GENERAL ITEMS</i>	
Clothing	28%
Childcare	26%
Food	20%
Other Health (co-pays, etc.)	17%
Housing	16%
Health Insurance	4%

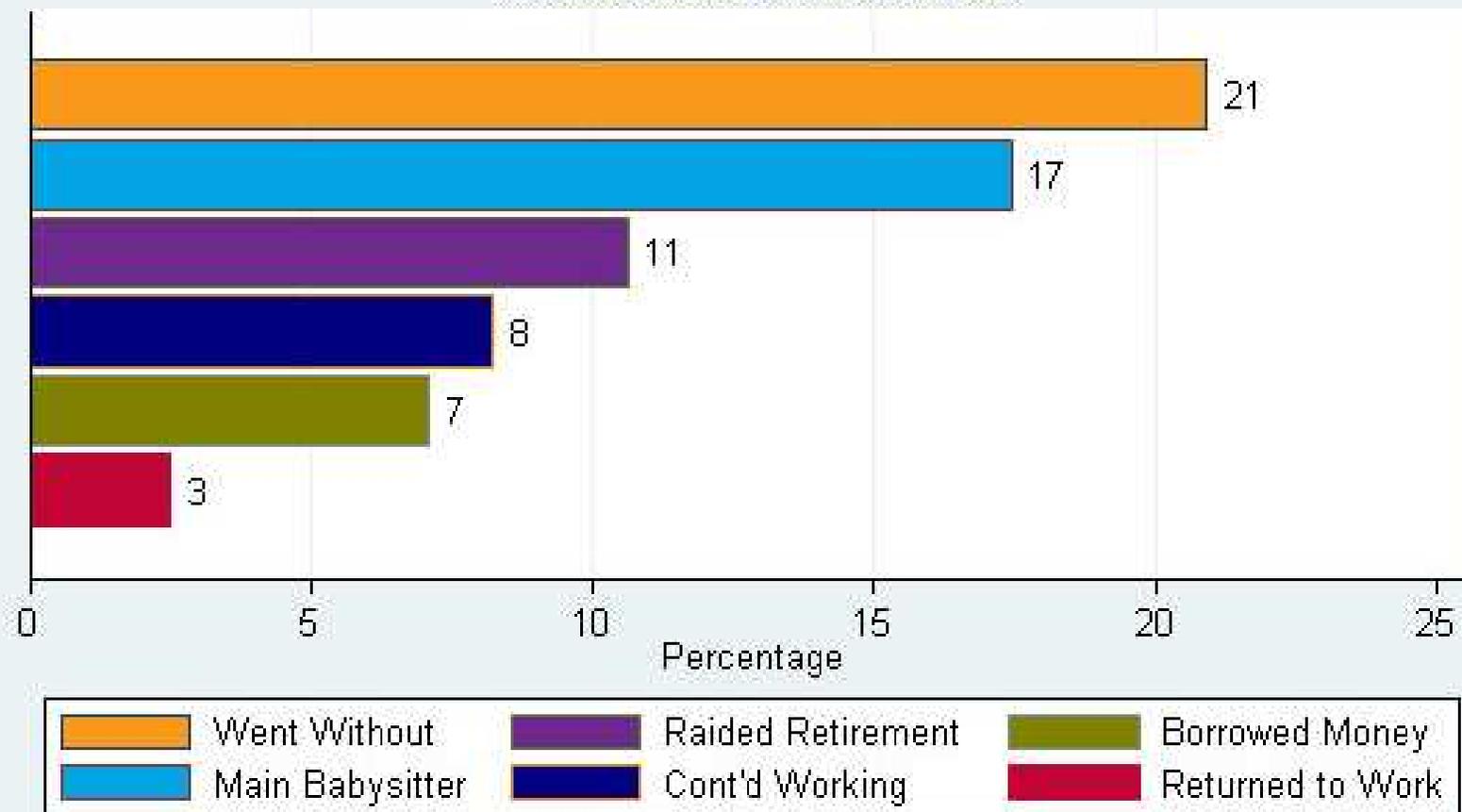
Financial Support: Special Needs

Non-Custodial Grandparents	Pay <u>all</u> , <u>a great deal</u> , or <u>a moderate amount</u> of this expense
<i>SPECIAL NEEDS (if applicable to family)</i>	
Special Camps or Summer Programs	20%
Educational Program	16%
Other Therapy or Counseling	15%
Legal or Advocacy Costs	14%
Applied Behavior Analysis (ABA)	13%
Speech Therapy	12%
Social Skills Training	12%
Occupational Therapy	10%

Sacrifices

Grandparents' Sacrifices On Behalf of Grandchildren with ASD

IAN Grandparent Survey
IAN data updated Apr 21 2010 N=2018



The Challenges



- **Sadness**

“One challenge is keeping my sadness to myself so I don't further upset my children, and not giving advice or information when I know my children are stressed enough. I have problems relating to my autistic grandson - I feel sad and frightened by his autism and I am afraid he will go out of control and I won't know what to do. There is also lots of guilt since I live 2 hours away...”

- “It is overwhelming, all the obstacles my daughter and granddaughter must endure. I feel lost and inadequate on how to face it head on. So many dreams of her future have been washed away with this.”

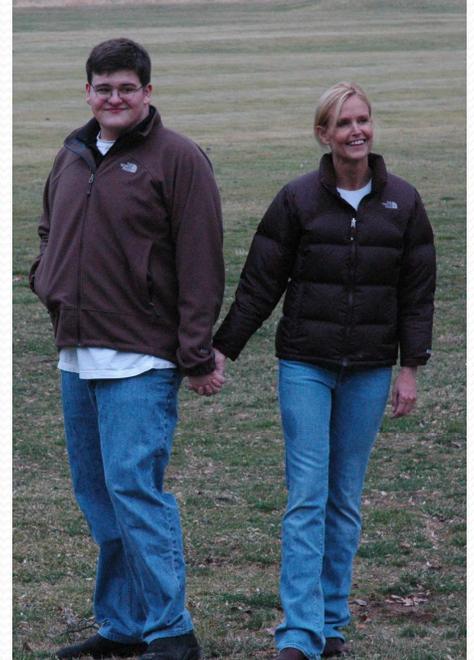
The Challenges

- **Physical**

“Babysitting an autistic child is extremely difficult. My grandson is big for his age - he's 6 years old and not potty trained. He is not always cooperative, but does not know he hurts me when he head butts (not often - but I think he cracked my tooth once).”

- “My grandson is 9... We are the main providers of respite for him, and as he's gotten older the care has become more difficult. He's not potty trained, he's non-verbal, and very physical. When he's upset, he'll have meltdowns where he'll bite, scratch, and pinch. He has no sense of danger at all, and requires constant watching.”

- “My grandson is 23 years old and 6 feet tall. When he is upset, I cannot handle him.”



The Challenges

- **Critical Looks of Strangers**

“I realize it's uncomfortable to witness a temper flair up or meltdown, but if people were informed that this behavior is not a brat having a temper tantrum but a child struggling to cope with outside stimulus, it would be helpful to the caregiver to have that silent support instead of judgmental looks.”

- “It’s hard dealing with people who have the smug belief that if other parents were like them, these kids would be perfect. Ignorance!”

The Joys

- Intense Connections

“My grandson is the sweetest, kindest soul I know. He feels safe with me because I try to embrace the wonderful qualities he has. I love him so much and wish I could get him the help he needs. He is 11 years old and in Jr. High and he is picked on for his differences. I don't know what to do except tell him that he is awesome, and that I am always here for him.”

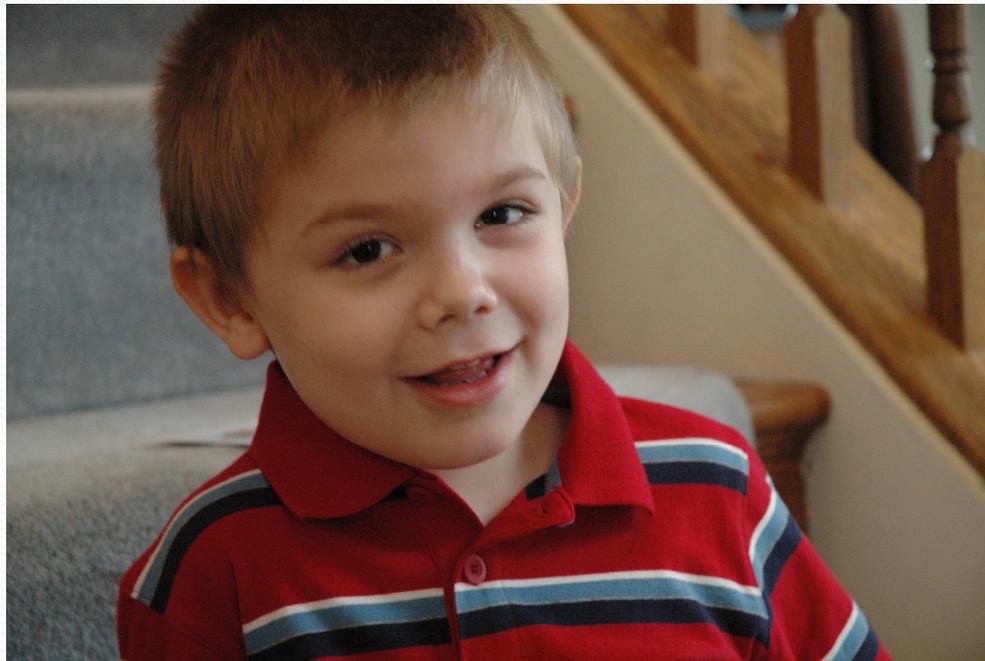
- “The relationship that I have with my grandson is one of my greatest joys. We have a special relationship... My heart nearly burst when he began saying my grandparent name, Baba. If I go for a visit, and he comes running and screaming 'Baba' with a smile as big as Texas, I feel so elated. I can't imagine my life without him. I love all my grandchildren, but he holds a special place in my heart.”



The Joys

- **Witnessing Gains**

“My greatest joys have been the success of this little guy growing from a non verbal and non ambulatory 18 month old who was totally uninterested in another human being to a 4 year old who talks constantly, sings, laughs and expresses love. He runs and jumps and actively seeks approval with hugs and kisses.”



The Joys

- The “Beauty” and the “Innocence”

“I know that when I receive a hug or a kiss, it's because he truly wants to give it to me, it's not obligatory.”

- “My grandson just lights up and gives me a big hug when he sees me, even though he knows it means that Mom is going out and his routine is upset. The other grandson (who is neurotypical and younger) may say ‘what did you bring me?’, but the ASD grandson says ‘tickle me, Grandma!’”

- “My grandson is the most precious, beautiful little boy I have ever met. He teaches me so much about living in the here and now. He challenges me to be more patient and to see the world in a different way. My joy is to just spend time with him.”



Grandparent-Advocates

- Nearly 50% had participated in autism walks or fundraisers.
- 33% had been involved in autism-focused political advocacy.
- 31% had attended educational conferences or workshops on autism.

Grandparents founded one of the biggest advocacy organizations now funding huge amounts of research:

Autism Speaks

"Autism has made me stand up and fight for a cause. I will fight till the day I die for all the help my granddaughter needs... I go to seminars and research biomedical interventions, I research educational strategies. I pushed her parents to get her out of public school and found an attorney to get her into a special school. I have taught my daughter and son-in-law to fight...to be the 'squeaky wheel.'"

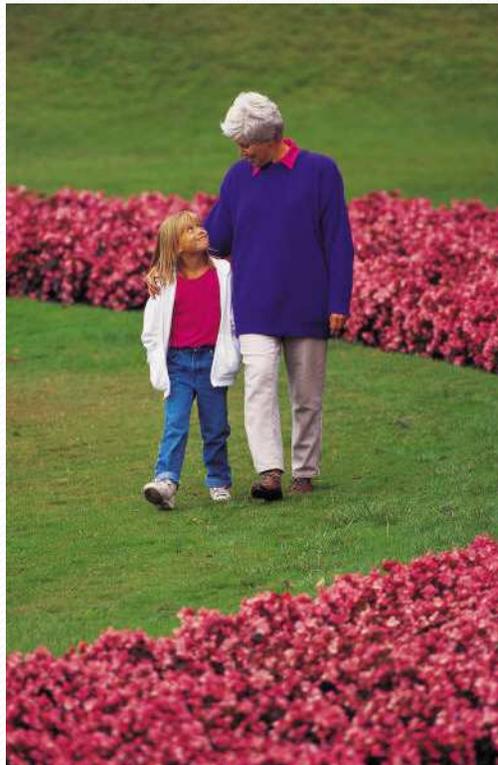
Supporting Grandparents

- We need to better recognize:
 - The source of emotional/financial support grandparents are for some families of children with ASD
 - That they can be key “early identifiers” of ASD
 - The burdens and stresses they face, and fact they may need support



Grandparents are key!

- Anyone investigating ASD and its impact on families leaves the grandparent generation out at their peril.



Family Tool Kits from Autism Speaks

family services

Family Support Tool Kits



Family members and friends of individuals with autism are presented with many joys and many challenges throughout their lives. Learning that a family member or friend is affected by autism is a powerful moment. People respond with a wide array of emotions: shock, grief, fear, denial, anger, acceptance, and many more. Many begin to feel their lives will never be the same. Parents can feel overwhelmed, siblings can feel isolated, grandparents can feel

helpless, and friends can feel apprehensive.

In an effort to ease the fears of and provide encouragement to all people with individuals with autism in their lives, Autism Speaks has created 4 support tool kits, each designed specifically for the following groups:

Parents

Siblings

Grandparents

Friends

Questions?

