Grandparents of Children on the Autism Spectrum: Their Own Role, Their Own Challenges

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Who am I?

- Director of Towson U’s Post Baccalaureate Certificate in Autism Studies program.

- Former Community Scientific Liaison for the Interactive Autism Network (IAN) at Kennedy Krieger Institute in Baltimore
Definitions of “Family”

- When we hear the word “family,” there’s often an image that pops into our heads...

Photo by Eric Ward on Wikimedia Commons/CC BY 2.0 no changes
Definitions of “Family”

- In reality, families come in many shapes and sizes
  - Couple households
    - Not necessarily married
  - Single-parent households
    - Never married parents, divorced parents
  - Blended families, with step-siblings, half-siblings, and tangled relationships across the family tree.
  - Multi-generational families, sometimes living under one roof
  - Grandparent-headed families
When the IAN Project launched in 2006...

- Interactive Autism Network (IAN) was a national online autism research project – kind of an early SPARK.
  - For families of a child with ASD
  - Invited mothers and fathers to join and share their experience with their child on the spectrum via online surveys
  - Mission: To accelerate autism research across the board

- Started getting phone calls from... can you guess?
Photo “The Popiks” by Unknown on Wikimedia Commons/ CC BY-SA 3.0 – no changes
Grandparents unhappy...

- Yes, IAN had left grandparents out of the picture completely.

"I know my grandchild so well. Don't you want to know what I know?"
IAN had crafted magnificent software that could contain information about a single person and family groups.

But it had only envisioned two generations: parents and children.
Pilot Grandparents Survey

- Inspiration struck: Build a survey outside of IAN.
  - Built with input from grandparents and Bonnie Gillman of the Grandparents Autism Network (GAN)

- Pilot tested with 40 grandparents
Final Grandparents Survey

- The final web-based Grandparents of Children with Autism Spectrum Disorder Survey was launched on October 5, 2009.
  - Autism Speaks and AARP helped spread the word.
Final Grandparents Survey

- Some had feared older people wouldn’t respond to an internet survey. But...
  - The Pew Research Center (2021) reports that in 2009
    - 75% of Americans age 50-64 were using the internet (now 96%)
    - 40% of Americans over age 65 were using the internet (now 75%)
  - Grandparents were promised results would be shared with them if they provided their email address.
Final Grandparents Survey

- More than 2,600 grandparents responded
  - From all 50 states and the District of Columbia
  - From cities (17%), rural areas (23%), and suburbs (60%)
  - Grandparents’ age range: 40s – 80s
  - Grandchildren’s age range: 1 – 44 years
  - 15% had two or more grandchildren with ASD, 2/3 sibs and 1/3 cousins
  - 3% had an adult child with ASD; 8% more suspected they did
Final Grandparents Survey

- One caution: the “digital divide”
  - Gaps due to socioeconomic status, education, location
  - Including access to computers and broadband

- Likely explains why participants at the time were mostly white (95%) and suburban (60%)

![Photo](https://www.flickr.com/photos/san_jose_public_library/32865909220/ “Children Using the Computer” by San José Public Library -Willow Glen Branch / CC BY-SA 2.0 – no changes)
Final Grandparents Survey

Grandparents of Children with ASD
Grandparent Education
IAN data updated Mar 25 2010 N=2639

Bar chart showing the percentage of grandparents with different levels of education:
- No High School: 2%
- High School: 4%
- Some College: 15%
- Bachelor's: 18%
- Master's: 20%
- PHD/Prof Degree: 38%

Percentage scale ranges from 0 to 40.
Grandparents of Children with ASD
Work and Retirement Status
IAN data updated Mar 25 2010 N=2477

- Retired - Not Working: 40%
- Working Pre-Retirement: 37%
- Homemaker: 13%
- Unemployed or Taking Leave: 6%
- Working Post-Retirement: 4%
Final Grandparents Survey

- Both IAN and SPARK had a hard time recruiting fathers...
- Same with grandfathers!

Grandparents Survey
Grandmothers vs. Grandfathers

- Grandfathers: 83%
- Grandmothers: 17%
Final Grandparents Survey

- Interesting split between maternal and paternal grandparents...
  - Two-thirds of participating grandparents were *maternal* grandparents, i.e. their adult *daughter* had the child with ASD
  - Is it just that the more involved moms told their moms about the survey...?
    - Research suggests it is maternal grandmothers that provide more support (McCallion et al., 2004; Wright et al., 2012)
Different dynamics, different roles

- Some grandparents live far away and see a grandchild with ASD and their siblings only rarely.
- Some live down the street—or in the same household—and are deeply involved in the family’s every day concerns.
- Some have become, officially or unofficially, the primary caregivers of their grandchild with ASD.
- Some grandparents accept and understand the ASD diagnosis, and others reject it.
The Double Whammy

Grandparents of Children with ASD

How much do you worry about your adult child?
IAN data updated Mar 26 2010 N=2228

- Not at all: 3%
- A little: 12%
- A moderate amount: 28%
- A great deal: 57%
Worrying about adult children...

“We try to help my daughter and son-in-law cope, and to make their lives bearable by giving them as much support and money as we can.”
Pride in adult children...

- “My daughter-in-law has become a very strong advocate and caregiver for her sons. I am so proud of and awed by both my son and daughter-in-law for their strong commitment to their children.”

- One grandmother expressed joy at “seeing how my son has become an incredibly responsible and nurturing father.”
Pride in adult children...

- Nearly 90% felt that the experience of facing their grandchild's situation together had brought them and their adult child closer.

- Caveat: Happier, more connected grandparents probably more likely to take the survey...
Conflicts with adult children

- All grandparents face this challenge: when to give an opinion.
  - Even more pronounced for grandparents of children with ASD

- “My son and his partner are dealing with my grandson’s autism quite capably. As a result, my husband and I are challenged to remain on the sidelines and only give an opinion if asked.”
Conflicts with adult children

• Just as mothers and fathers may disagree about a diagnosis or treatment, grandparents and adult children can, too.

  • Conflicts over whether an evaluation was needed
  • Conflicts over a diagnosis given
  • Conflicts over a treatment: Essential? Harmful?
Grandparents’ Contributions: Diagnosis

- Grandparents, with their experience, often played a vital role in early recognition of their grandchild’s ASD

- But many hesitated to say anything...
Grandparents’ Contributions: Diagnosis

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: 49%
- I supported others who noticed a problem: 30%
- Concerns were raised, but I didn't believe: 12%
- Not made aware until after diagnosis: 9%
Grandparents’ Contributions: Diagnosis

“I was the first to put a name to his condition. I knew earlier, but it was extremely difficult to tell your child that you believe her child has autism.”

“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.”
Grandparents’ Contributions: Diagnosis

- Saying something was challenging, and could lead to a clash.

  - "Back when I suspected it, my son got bitter with me, and still is.”

  - "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."
Support and Coping

- Many grandparents felt supported “always” or “most of the time”
  - By a spouse (92% of married grandparents)
  - By friends and relatives (70%)

- May explain why most were coping well.
Grandparents’ Coping

- 50% Fairly well
- 36% Very well
- 12% Not that well
- 2% Not well at all

Grandparents of Children with ASD
How well are you coping?
IAN data updated Mar 25 2010 N=2541
Contributions

- The help grandparents could offer was somewhat dependent on how far away they lived from their grandchild’s family.

<table>
<thead>
<tr>
<th>How far do you live from your grandchild w/ ASD?</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Live in same house</td>
<td>9%</td>
</tr>
<tr>
<td>Live in same neighborhood</td>
<td>20%</td>
</tr>
<tr>
<td>5-24.99 miles</td>
<td>28%</td>
</tr>
<tr>
<td>25 – 99.99 miles</td>
<td>12%</td>
</tr>
<tr>
<td>100-499.99 miles</td>
<td>15%</td>
</tr>
<tr>
<td>500 miles+</td>
<td>17%</td>
</tr>
</tbody>
</table>
Contributions

- 7% had combined households with their grandchild’s family so they could help them manage all that is involved with ASD
- 14% had moved closer (but not into the same home).
**Contributions**

- Noncustodial grandparents who were close provided a great deal of caregiving and transportation for their grandchild with ASD.

<table>
<thead>
<tr>
<th></th>
<th>Live 24 miles or less from grandchild</th>
<th>Live 25 miles or more from grandchild</th>
<th>Overall</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiving (n=2146) at least once per week</td>
<td>56%</td>
<td>6%</td>
<td>34%</td>
</tr>
<tr>
<td>Transportation (n=2153) at least once per week</td>
<td>29%</td>
<td>4%</td>
<td>18%</td>
</tr>
</tbody>
</table>
Contributions

- Sacrifices included financial ones as some grandparents helped pay for clothing, food, housing, health insurance, special camps or summer programs, therapy or counseling, legal and advocacy costs, and other expenses related to a child’s ASD.

- “As I am in my senior years, sometimes finding the strength and/or energy to just keep up with our grandson is hard... It's difficult to take him out to public places, which keeps my husband and me home, too, as our daughter (mother of the child) is divorced from the father, and she needs to work. They live with us, full-time.”
"We are paying for services that aren't covered by health insurance," explained one grandfather. "We have spent our retirement and would do it again to benefit our granddaughter. We have her with us 3 to 4 days a week. This was a shock to our family; her parents were in their early 20s and they weren't prepared for a child with special needs."
Grandparents’ Sacrifices

Grandparents' Sacrifices On Behalf of Grandchildren with ASD
IAN Grandparent Survey
IAN data updated Apr 21 2010 N=2018

- Went Without: 21%
- Raided Retirement: 17%
- Main Babysitter: 11%
- Cont'd Working: 8%
- Borrowed Money: 7%
- Returned to Work: 3%

Percentage
Contributions

- Like parents, many were trying to juggle work, saving, spending, and care giving.

- “My daughter works full time and then works every Saturday and Sunday all day and one night in a store to pay for all the extra expenses. I try to contribute financially to take off some of the pressure they experience every day trying to pay bills, and keep things going. I work also, and have some flexibility so I can help them out when kids are sick and out of school, but I pay the price because I should be making more money and putting it away for retirement.”
Grandparents as primary caregivers

- About 6% of grandparents said a family situation had become so untenable they had taken on the role of parent.
  - Only 1% were official foster or adopted parents
  - The other 5% were primary caregiver in fact
Grandparents as primary caregivers

- “The child’s parents have their own mental health issues and really don’t parent this child in the way he deserves.”

- “I have too little control over the parents and their failure to deal with my grandchild by obtaining the help he needs and modifying their lifestyle to accommodate him (i.e. control household noise, try to communicate with him).”
Grandparents as primary caregivers

- Grandparents who had taken on the parent role, as adoptive or foster parents or guardians, faced the full brunt of the financial burdens associated with ASD.

- “We have spent over $300,000 over the last 4 years with ABA therapies and other expenses trying to get the best treatments for our grandson, now 6 years old. My husband has to go back to work now after we have exhausted our savings and retirement. What are we to do when we run out of money? Our friends do not understand the challenges we face every day.”
Grandparents’ Experiences

- Faraway grandparents sometimes experienced guilt that they couldn’t do more.

- The more grandparents were involved in raising their grandchild with ASD, the more their experiences paralleled those of parents.
  - Accepting and understanding the diagnosis
  - Worrying about finding and paying for effective treatments
  - Isolation or loneliness
  - Critical looks from others who don’t understand a child’s behavior
Challenges

- Though many were coping, there were many challenges. Some reached out to clergy, therapists, support groups for assistance.

- One grandmother said it was very hard “...watching my gentle grandson suffer from the effects of autism. He cannot sleep through the night. He struggles to verbally communicate. My daughter is suffering from depression. Doctors are ignorant about what can be done for the children. Insurance doesn't cover therapies, e.g., speech, PT, OT. There is so much financial strain on families.”
Challenges

“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...”
Challenges

- Communication was one key issue.
  - “Communicating with my grandchild remains my greatest challenge. I love him with all my heart! He is a sweet, good-natured six-year old boy. We often sing to communicate. However, I would love to actually have a conversation with him.”
Challenges

- Caring for a child who might be physically aggressive, resistant to sleep, or prone to wander beyond safe spaces could be tough.

- “My grandson is nine and is severely challenged by his autism. We are the main providers of respite for him, and as he’s gotten older the care has become more difficult... The biggest issues concerning the care are: 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. Perhaps the biggest challenge is the continual need to keep him safe... He has no sense of danger at all, and requires constant watching.”
Challenges

- Many regretted that what should have been fun and easy activities with a grandchild could be overshadowed with anxiety over a potential scene.

  “Everything becomes a 'project' instead of a fun outing. Simple things are often just too much to tackle...not worth the effort and drama.”
Challenges

- As is often the case with an “invisible” disability, one burden grandparents had was educating others so they would understand.

- Some became fierce 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
Joys

- Many grandparents found their grandchild with ASD to be loving and caring, and felt intensely connected to him or her. They celebrated their uniqueness and their successes.

  “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.”
Joys

• “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.”

• “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.”
Takeaways

- Grandparents often play a major role in identifying ASD, researching treatments for ASD, care giving, transportation, and all around support while worrying about their adult child, the grandchild on the spectrum, and the unaffected grandchildren.
Takeaways

- Clinicians, researchers, therapists, and educators should keep in mind that a grandparent:
  - May be an influential figure in the family
  - May have critical insights about their grandchild with ASD
    - Including their history, behaviors, strengths
  - May be involved in advocacy with school, clinical settings, and more broadly
  - May need support themselves
Still so little known...

- According to a recent review (Novak-Pavlik et al., 2021)
  - In the last decade, only 15 articles were published on grandparents of children with physical, intellectual, or neurodevelopmental disabilities
  - Only six were focused on ASD
  
  *Two of those were based on IAN’s data*
Still so little known...

- One group hoping to re-create and update the Grandparents of Children with ASD Survey:
  - The Autism Grandparents Club in association with Virginia Commonwealth University
  - Ran 2021 National Autism Grandparents Survey 9/9 – 10/31
  - Can’t wait to see what they discover!
Questions?
References