

# New survey finds grandparents play key role in lives of children with autism

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Today, the Interactive Autism Network (IAN), the nation's largest online autism research project, announces results of the Grandparents of Children with Autism Spectrum Disorders Survey, finding that nearly one-third of grandparents who participated were the first to raise concerns about their grandchild's development. Since its launch in 2007, the IAN Project has helped to accelerate the pace of autism research by gathering valuable information online from individuals on the autism spectrum and their parents. The launch of the October 2009 survey was the first time that the IAN Project has collected information from grandparents. The IAN Research Report: Grandparents of Children with ASD - Part 1, and the subsequent report that will be released later in the month, demonstrate the substantial impact having a grandchild on the spectrum has on grandparents' lives, as well as the contributions they make through early detection - which is crucial to early diagnosis and intervention - child care, and financial support.

"It became clear that [grandparents](#) - a population largely overlooked by policymakers and researchers - had valuable insights to share when they came to us asking how they could participate in the IAN Project," said Dr. Paul Law, Director of the IAN Project at the Kennedy Krieger Institute in Baltimore, Maryland. "These survey results show that experiences are remarkably diverse, but one thing is clear: grandparents often play a major part in their grandchild's life and experience their own stresses and triumphs in these families."

In just eight weeks, more than 2,600 grandparents completed the survey.

The findings highlighted below summarize the compelling results from the Research Report released today as well as Part 2 of the report, which will be released in mid-April:

### **Grandparents and their families**

Grandparents represented a wide age range, although most were between the ages of 55 and 74.

- **Family relationships:** Nearly 90% felt that the experience of facing their grandchild's situation together had brought them and their adult child -- the grandchild's parent - closer, although many worried for their adult child raising a child on the [autism](#) spectrum.
- **Support and coping:** Of those who were married or in a committed relationship, 92% said they felt their spouse or partner supported them "always" or "most of the time." The majority of grandparents reported that they had adjusted to their grandchild's diagnosis and were doing "very" or "fairly" well.
- **Genetics in autism:** Approximately 15% of grandparents had two or more grandchildren on the spectrum. Of those with more than one grandchild with ASD, two-thirds reported that their grandchildren were siblings, while the other third reported their grandchildren with ASD were cousins.

### **Grandparents as caregivers**

Many grandparents played a major role in raising concerns about their grandchild's development.

- Fully 30% said they were the first to raise concerns about their grandchild, while another 49% said they had supported others who began to raise concerns.
- Grandparents often play a major role in helping care for a grandchild with ASD: Nearly 11% reported living in the same household as their grandchild, with another 46% living within 24 miles.  
In addition, of those who were traditional grandparents (not their grandchild's custodial parent) 14% said they and their grandchild's family had moved closer to each other so they could help the grandchild's family "manage all that is involved with his or her ASD," while 7% said they had actually combined households for the same reason.
- 71% said they played some role in treatment decisions for their grandchild.
- More than 15% were providing transportation for their affected grandchild to or from appointments or school at least once per week.
- More than 31% said they provided some direct [child care](#) at least once per week.
- Participating grandparents kept themselves very well informed about ASDs; 99% said they "read or do research to better understand [Autism Spectrum Disorders](#)" because of their grandchild's diagnosis.
- Grandparents were very active in advocating for their grandchildren on the autism spectrum, with nearly 50% taking part in autism walks or fundraisers, 33% involved in political

advocacy, and 31% attending conferences or workshops on autism.

## **Financial impact**

A significant majority of grandparents reported contributing to their grandchild's general or special financial needs.

- More than 22% reported going without something they had hoped for in order to provide for their grandchild's financial needs. In fact, 18% had become primary babysitter so their adult child could work, 11% had raided retirement funds, and 8% had borrowed money.
- Nearly 60% had made sacrifices not provided in response choices, such as working more hours or taking on a second job, providing respite care, or leaving funds in a special needs trust.
- About 25% of grandparents reported spending up to \$99 per month to meet their grandchild's autism-related needs, while 30% paid even higher amounts. There were some grandparents spending more than \$500 per month.

"It is hoped that the results of this survey will help researchers, policymakers and advocates learn about the experiences and opinions of grandparents of children with an ASD, and advance efforts to advocate for improved services and resources," said Dr. Law.

**More information:** Read more about the survey results at [www.iancommunity.org/cs/ian\\_re...\\_arch\\_report\\_apr\\_2010](http://www.iancommunity.org/cs/ian_re..._arch_report_apr_2010)

Provided by Kennedy Krieger Institute

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