

Background:

Early diagnosis and intervention is essential for children with Autism Spectrum Disorder (ASD). Although previous research suggests that grandparents often play a role in helping families cope with having a child with ASD, little is known about the role that grandparents may play in recognizing the condition itself. It also remains unclear what informational resources grandparents use to learn about ASD.

Objectives:

The goal of the study was to gather information from the first person grandparent perspective, and examine the extent to which grandparents played a role in the recognition of a grandchild's ASD, and to ascertain factors associated with such recognition. A secondary goal was to identify what resources grandparents turned to for ASD information. Such knowledge may help foster early diagnosis and guide professionals in the development of educational materials.

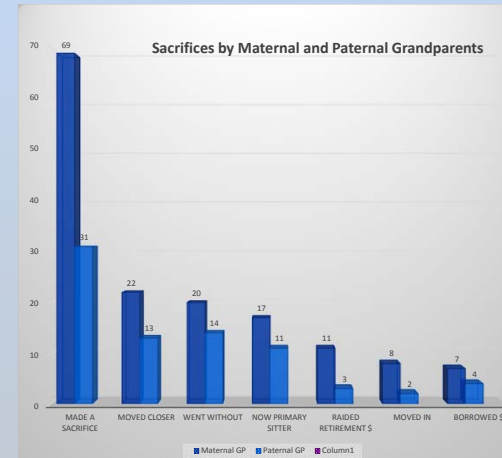
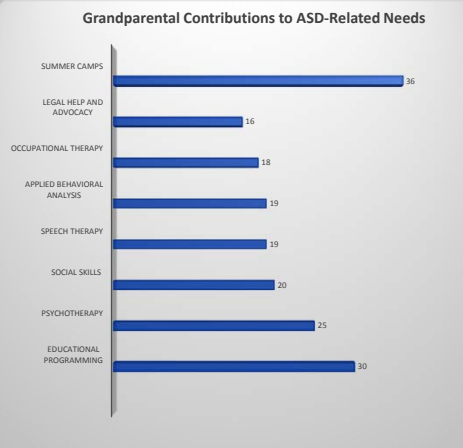
Methods:

Participants were asked to anonymously complete an online survey designed to take approximately 30 minutes. The survey was deployed by Survey Monkey. Participants were recruited via the Kennedy Krieger Institute's Interactive Autism Network's (IAN) Research e-newsletters and the IAN Community website, along with the assistance of the Autism Speaks Foundation, the Grandparent Autism Network, and The American Association of Retired Persons (AARP).

Criteria for inclusion required participants to live in the U.S. and its territories, and to have at least one grandchild with an ASD. The grandchild had to be the biological, adoptive, or stepchild of the respondent's biological or adopted son, stepson, daughter, or stepdaughter.

Results:

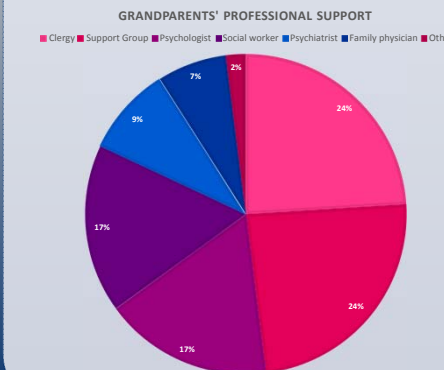
A total of 1881 non-custodial grandparents completed the on-line survey, including 1534 grandmothers (81.6%) and 347 grandfathers (18.4%), who also identified as maternal (63.4%) and paternal (35.6%) grandparents. In terms of grandparental status, more than half of the respondents were maternal grandmothers (52.3%) followed by paternal grandmothers (29.2%), maternal grandfathers (11.9%), and paternal grandfathers (6.5%). The majority were White (96%), middle-aged (55%), married (80%), and working (51%), with at least some college education (80%), from a suburban setting (61%).



A logistical regression analysis ($X^2=207.76$, $p<.001$) revealed that middle-aged, working grandmothers who lived within 25 miles of their grandchild were significantly more likely to play a role in ASD identification. Explained variance for the model was in the acceptable range (Nagelkerke $R^2= .18$)

Predictor	Odds Ratio	95% CI
GP Age	2.25*	1.82-2.73
GP Work status	2.47*	2.00-3.05
GP Lineage	*	
Distance from grandchild	1.42*	1.15-1.75

* $p<.001$.

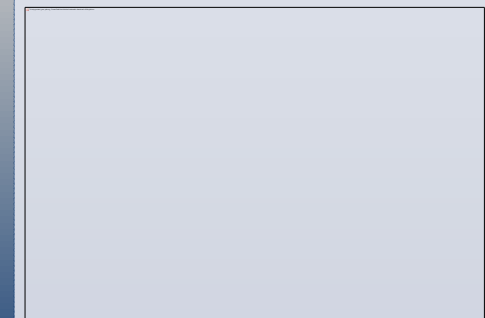


More than 75% of grandparents indicated that they had played a role in identifying their grandchild's ASD, with 27.5% "independently raised concerns about [their grandchild's] development" and 48.2% "supporting others who raised concerns."

The younger the age that grandparents reported that they first worried about their grandchild's development ($x=2.08$ years; $sd=1.95$), the younger the age that their grandchild first received an ASD diagnosis ($x=3.10$ years, $sd=2.12$), $r=.43$, $p<.001$.

Conclusions:

The majority of grandparents played a role in identifying their grandchild's ASD. More than one quarter were the first to raise concerns about a grandchild's development. Encouraging professionals to include grandparents in the diagnostic process, particularly middle-aged grandmothers who live within 25 miles of their grandchild, may offer benefits for the early detection of ASD. Professionals and organizations can also be encouraged to target educational materials specifically for grandparents.



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