

Vanderbilt Kennedy Center for Research on Human Development

Adult Sibling Survey: Report to Respondents

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A Word of Thanks

Before beginning, we would like to thank each of you for participating. We realize that each of you took time out of busy schedules to answer our many questions. We appreciate your time, effort, and candor, particularly the many of you who also wrote at length about your experiences.

We also would like to thank the many groups and organizations that promoted our survey. Special thanks go to The Arc U.S., especially Mike Coburn and Sue Swenson; the network of the Association for University Centers on Disabilities (AUCD); and Don Meyer's SibNet network. We would not have had such large numbers of participants without the help of each of these organizations.

The Study Itself

From March through late Fall 2006, we received over 1,300 surveys from across the United States (all 50 states and DC). The distribution of responses by state roughly matches the U.S. population as a whole, with large states such as California and Florida high in participants, small states lower. As might be expected by a web-based study, participants are predominantly White (almost 90%) and well-educated (the average "highest level of education" = almost 16 years, or college graduates). The average age of sibling respondents is almost 37 years, with ages ranging from 18 to 85.

Your responses are amazingly rich in details about your relationship with your brother/sister with disabilities. In many respects, we have barely scratched the surface in understanding what you have told us. We will continue to analyze these surveys but already have several interesting findings to share with you. These findings relate to four separate areas.

1) General Well-Being of Siblings

Overall, siblings of adults with disabilities are doing well. Siblings report that, as a group, they spend a fair amount of time with, feel very affectionate and close to, and have benefited greatly from their brother/sister with disabilities. Most of you report that your physical health is either very good or excellent, and only small percentages report being depressed or blue. Specifically:

- Over half of all siblings report being in contact with their brother/sister with disabilities 5 or more hours per month. Only 1 in 5 report spending 2 hours or less in contact with their brother/sister with disabilities each month.
- Almost 75% report that they feel "very" or "extremely" affectionate toward their brother/sister with disabilities.
- Most siblings (over 80%) report becoming more empathic, understanding of differences, and in other ways benefiting from having a brother/sister with disabilities.
- Almost all of you report good health and low levels of feeling depressed or blue.

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2) Gender of Sibling of Brother/Sister with Disabilities

- As in prior studies, when we speak of “siblings,” we are mostly speaking of female siblings. Almost 3/4 of you are the sisters of brothers/sisters with disabilities.
- Compared to the male siblings, female siblings differed in some ways, but not in others.
 - Relationship Quality (closeness, warmth, affection, degree to which relationship with brother/sister is positive) is the same, but sisters had more contact and longer contact than brothers.
 - Benefits. On all of the questions that cover the degree to which the sibling has benefited from having a brother/sister with disabilities, sisters rated themselves higher (on average) than brothers.
- For some of the demographics, we noted that sisters of brothers/sisters with disabilities seemed to be delaying marriage and to be less likely to have children; these females also seem less likely to be divorced. In contrast, males of brothers/sisters with disabilities were very similar to males in the general U.S. population. Our sense right now is that the pattern of differences between brothers and sisters may reflect a degree of “cautiousness” on the part of sisters of person with disabilities, both compared to their brothers and to overall census norms. We will be looking further into this finding.

3) Type of Disabilities: Down Syndrome, Autism, and Other Disabilities

- Like many studies of families of children with disabilities, we, too, are finding a “Down syndrome advantage.” On several measures, siblings of brothers/sisters with Down syndrome seem to be doing better than are siblings of brothers/sisters with either Autism or with “Other Disabilities.”
- This Down syndrome advantage occurs in:
 - Contacts. In both the number of contacts and in the number of hours spent in joint activities per month, siblings of adults with Down syndrome have more contact than do the other two groups.
 - Relationship Quality. For all 7 of the relationship questions, the siblings of brothers/sisters with Down syndrome have average scores above siblings of adults with Autism and of adults with Other Disabilities. These relate to items like the degree (on a 6-point scale) one understands, trusts, respects, feels affection toward, and feels close to your brother/sister with disabilities, and the degree to which the sibling considers the sibling relationship to have been mostly positive.
- In addition to this Down syndrome advantage, there are some changes depending on the age of the adult with disabilities. For example, contacts (both number and hrs/month) seem to lessen—in all three groups—as the individual with disabilities is older. In some groups (particularly Down syndrome and Autism), there is also a decline in Relationship quality in the older years (brother/sister with disabilities 45 years of age and older); we did not find this decline in relationship quality in the “Other Disabilities” group.

4) Closer vs. Less Close Siblings

Although most siblings report close, involved relationships with their brother/sister with disabilities, a few hundred respondents (about 20-25%) reported that they were not close to their brother/sister with disabilities. In addition to spending less time together, less close relationships were characterized by lower levels of benefits from the relationship. Thus, siblings who considered themselves “less close” also reported that, as a result of being a sibling to a brother/sister with disabilities, they had not become more empathetic, or more understanding of differences, or a better person.

Again, we thank you for your help and hope that this report gives a beginning sense of what we are finding. We very much appreciate the support of The Arc of the U.S. and look forward to continuing to partner in this important area.

