Adult Sibling Survey: Preliminary Findings

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Vanderbilt Kennedy Center

The Arc's 55th National Convention October 12th - 14th, 2006
Purpose: Describe the lifelong relationship of adult siblings to their brother or sister with disabilities.

https://kc.vanderbilt.edu/FamilyResearch
Recruitment - Promotion
How to get a questionnaire?

https://kc.vanderbilt.edu/FamilyResearch

Email: FamilyResearch@vanderbilt.edu

800.123.4567
Opening Web page

• Adult Sibling Survey Introduction
  – START Now
  – REGISTER
  – INVITE
  – QUIT
Respondent Age 18+

Brother/Sister

Parents
Demographics

- Gender
- Age
- Education
- Race
- Marital status
- Type of Disability
- State/Zip
- Health
- Living/work arrangement

Joint Activities & Involvement

- Relationship with Brother/Sister

Brother/Sister Support Needs

Transitions

Knowledge of Skills/Needs

Reflections
Question layouts

<table>
<thead>
<tr>
<th>Gender</th>
<th>Select 22</th>
</tr>
</thead>
<tbody>
<tr>
<td>What state do you live in?</td>
<td>Write In 22</td>
</tr>
<tr>
<td>What is your zip code?</td>
<td></td>
</tr>
<tr>
<td>Please select the one ethnicity category that best describes you.</td>
<td>Select 22</td>
</tr>
<tr>
<td>White non-Hispanic</td>
<td></td>
</tr>
<tr>
<td>African-American</td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td></td>
</tr>
<tr>
<td>Native American</td>
<td></td>
</tr>
<tr>
<td>Asian or Pacific Islander</td>
<td></td>
</tr>
<tr>
<td>Other:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Multiple Choice 157</td>
</tr>
<tr>
<td></td>
<td>Yes - Working on Associated Degree</td>
</tr>
<tr>
<td></td>
<td>Yes - Working on Bachelor's Degree</td>
</tr>
<tr>
<td></td>
<td>Yes - Working on post Bachelor's Degree but not graduate degree</td>
</tr>
<tr>
<td></td>
<td>Yes - Graduate Degree</td>
</tr>
<tr>
<td></td>
<td>Yes - Grad. Area</td>
</tr>
</tbody>
</table>
Question 40. Joint Activities …

How much time, per month, do you estimate that you spend with your brother/sister?

- Select
- 10+ hours
- 5 - 9 hours
- 3 - 4 hours
- 1 - 2 hours
- Less than 1 - 2 hours
Question 40. Joint Activities …

If the time that you generally spend together is not enough, to what extent is the following the reason?

- Lives too far away (not easy to visit)
- Brother/sister is hard to be with
- My own family commitments
- My work commitments
- Other: [ ]
**Question: 42. Relationship**

<table>
<thead>
<tr>
<th>Question</th>
<th>1 Not at all</th>
<th>2 Not much</th>
<th>3 Somewhat</th>
<th>4 Pretty much</th>
<th>5 Very much</th>
<th>6 Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>How much do you <strong>UNDERSTAND</strong> your brother/sister?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How much do you <strong>TRUST</strong> your brother/sister?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How <strong>FAIR</strong> do you feel you are toward your brother/sister?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How much do you <strong>RESPECT</strong> your brother/sister?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How much <strong>AFFECTION</strong> do you have toward your brother/sister?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Taking everything into consideration, how <strong>CLOSE</strong> do you feel in the</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>relationship between you and your brother/sister?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In general, to what extent do you think that your relationship with your</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>brother/sister with disabilities has been mostly <strong>POSITIVE</strong>?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Brother/Sister Gender

<table>
<thead>
<tr>
<th>Gender</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>60</td>
</tr>
<tr>
<td>Female</td>
<td>40</td>
</tr>
</tbody>
</table>
Age of Respondents

Mean 36.7

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Age of Brothers/Sisters

Mean 34.2

Mean = 34.208
Std. Dev. = 14.46713
N = 1,143

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## Respondents by State

<table>
<thead>
<tr>
<th>State</th>
<th>Number</th>
<th>Percent</th>
<th>Rank</th>
<th>Census</th>
<th>Study</th>
</tr>
</thead>
<tbody>
<tr>
<td>CA</td>
<td>101</td>
<td>9%</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>FL</td>
<td>84</td>
<td>7%</td>
<td>4</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>NY</td>
<td>80</td>
<td>7%</td>
<td>3</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>IL</td>
<td>78</td>
<td>7%</td>
<td>5</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>OH</td>
<td>69</td>
<td>6%</td>
<td>7</td>
<td></td>
<td>5</td>
</tr>
<tr>
<td>TX</td>
<td>53</td>
<td>5%</td>
<td>2</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>VA</td>
<td>50</td>
<td>4%</td>
<td>12</td>
<td></td>
<td>7</td>
</tr>
<tr>
<td>PA</td>
<td>45</td>
<td>4%</td>
<td>6</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>MD</td>
<td>38</td>
<td>3%</td>
<td>19</td>
<td></td>
<td>9</td>
</tr>
<tr>
<td>TN</td>
<td>35</td>
<td>3%</td>
<td>16</td>
<td>10</td>
<td></td>
</tr>
</tbody>
</table>
## Race/Ethnicity

<table>
<thead>
<tr>
<th>Group</th>
<th>Number</th>
<th>%</th>
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<tbody>
<tr>
<td>White Non-Hispanic</td>
<td>1042</td>
<td>91</td>
</tr>
<tr>
<td>African-American</td>
<td>24</td>
<td>2</td>
</tr>
<tr>
<td>Hispanic</td>
<td>35</td>
<td>3</td>
</tr>
<tr>
<td>Native American</td>
<td>2</td>
<td>&lt; 1</td>
</tr>
<tr>
<td>Asian or Pacific Islander</td>
<td>11</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>28</td>
<td>2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>1143</td>
<td></td>
</tr>
</tbody>
</table>
## Respondent Marital Status

<table>
<thead>
<tr>
<th>Status</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never Married</td>
<td>470</td>
<td>40</td>
</tr>
<tr>
<td>Married</td>
<td>573</td>
<td>50</td>
</tr>
<tr>
<td>Separated</td>
<td>10</td>
<td>1</td>
</tr>
<tr>
<td>Divorced</td>
<td>82</td>
<td>7</td>
</tr>
<tr>
<td>Widowed</td>
<td>17</td>
<td>2</td>
</tr>
<tr>
<td>Total</td>
<td>1152</td>
<td>100</td>
</tr>
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</table>
### Condition of Brother/Sister

<table>
<thead>
<tr>
<th>Condition</th>
<th>Number</th>
<th>%</th>
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</thead>
<tbody>
<tr>
<td>MRDD</td>
<td>549</td>
<td>47</td>
</tr>
<tr>
<td>Down syndrome</td>
<td>284</td>
<td>24</td>
</tr>
<tr>
<td>Autism</td>
<td>146</td>
<td>15</td>
</tr>
<tr>
<td>CP</td>
<td>147</td>
<td>13</td>
</tr>
<tr>
<td>Emotional</td>
<td>87</td>
<td>8</td>
</tr>
<tr>
<td>Health</td>
<td>81</td>
<td>7</td>
</tr>
<tr>
<td>Sensory</td>
<td>63</td>
<td>5</td>
</tr>
<tr>
<td>Williams</td>
<td>13</td>
<td>1</td>
</tr>
<tr>
<td>Fragile X</td>
<td>9</td>
<td>1</td>
</tr>
<tr>
<td>Prader Willi</td>
<td>6</td>
<td>1</td>
</tr>
</tbody>
</table>
Open ended Questions

In your own words, tells us about

- Your relationship now
- Your relationship has changed in the last five years
- What you expect your relationship to like in 5 years’ time?
- What would make it easier to support your sibling?
I appreciate the time you have taken to explore this topic.

There are so few resources for siblings; I think this is a wonderful study and I hope it yields much needed information.

Thanks for looking into this area, I would be interested in viewing your results.
I think that having a sibling with disabilities has been an unconditionally rewarding aspect of my life. She has taught me how to value every day and not to take life for granted. Happiness is in the small things.

My sister has been a constant source of pride and enjoyment in my life, I can't imagine my life without her.
I do not have a close relationship with my sister, even though there is only a 15 month difference in our ages. She enjoys spending time with my children. I am not the sister she calls on a regular basis.

I love her very much and feel incredibly loyal and protective toward her. On the other hand, I would like to feel closer to her. I get very resentful toward her sometimes and that gives me a huge amount of guilt.
Today: Four Findings

1) General Findings
2) Male vs. Female Siblings (of brother/sister with disabilities)
3) Siblings who Differ on Closeness
4) Siblings of Individuals with Different Conditions
1) General Findings

- **Old view:**
  - That siblings “suffer” from being a brother/sister to a person with disabilities (more depression, acting out, etc.)

- **Newer view:**
  - May be positive aspects to being a sibling

- **Our view**
  - Let’s look at the numbers…
Some General Findings

- A) Contacts with brother/sister
- B) Relationship Quality
- C) Positives from being sibling
- D) Health-depression
A) CONTACTS: Hrs/Month with Brother/Sister w/ Disabilities

<table>
<thead>
<tr>
<th>Hours per Month</th>
<th>Hrs/Month with Brother/Sister with Disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;1-2 hrs</td>
<td>20%</td>
</tr>
<tr>
<td>1 to 2</td>
<td>10%</td>
</tr>
<tr>
<td>3 to 4</td>
<td>15%</td>
</tr>
<tr>
<td>5 to 9</td>
<td>25%</td>
</tr>
<tr>
<td>10+</td>
<td>35%</td>
</tr>
</tbody>
</table>
B) RELATIONSHIP: Affection & Closeness

• 6 Relationship Quality questions
• Measured from
  – 1-Not at all to
  – 6-Extremely
  – From 60-75% feel “extremely” or “very much” affectionate and close to brother/sister with disabilities
Affection

1-Not at all         (Affection)          6-Extremely

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Closeness

1-Not at all (Closeness) 6-Extremely

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C) POSITIVES

As a result of having grown up with a brother/sister with disabilities, do you think that you have less, the same, or more of the following characteristics?

- 1 = less;
- 3 = same
- 5 = more
Empathy

Empathy

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D) Physical Health

in general your health is:

– 1=Poor;
– 2=Fair
– 3=Good;
– 4=Very Good
– 5=Excellent
D) Depressive Symptoms

5 questions: "during past week…"

- I felt depressed
- My sleep was restless
- I felt lonely
- I could not “get going”
- I had crying spells
D) Depressive Symptoms

**Scoring**

- From 1 (rarely or none of the time) to 4 (Most or all of the time)

- For all 5 questions, most responses are either “rarely or none of the time” (=1) or “some or little of the time” (=2)
Item: “I felt depressed”
Summary: General Findings

• Siblings are doing well
• Most:
  – Spend time with brother/sister with disabilities
  – Have close relationship & feel benefits
  – Have good health and low levels of depressive feelings
2) Male vs. Female Siblings

- In adulthood, siblings = a “female story”

- Females > males in
  - Involvement
  - Companionship
  - Positive affect
    - Orsmond & Seltzer, 2000
This Study

<table>
<thead>
<tr>
<th></th>
<th>Males</th>
<th>Females</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>N</strong></td>
<td>251</td>
<td>910</td>
</tr>
<tr>
<td><strong>%</strong></td>
<td>21.6%</td>
<td>78.4%</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td>34.9</td>
<td>37.2</td>
</tr>
<tr>
<td><strong>Education Level</strong></td>
<td>15.2</td>
<td>15.8</td>
</tr>
</tbody>
</table>
Some Findings

A) Contacts with brother/sister
B) Relationship Quality
C) Positives from being sibling
D) Life Choices (marriage, divorce, children)
A) CONTACTS: Hrs/Month with Brother/ Sister w/ Disabilities

<table>
<thead>
<tr>
<th>Hours per Month</th>
<th>Male Sib</th>
<th>Female Sib</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;= 2</td>
<td>40%</td>
<td>30%</td>
</tr>
<tr>
<td>3 to 4</td>
<td>10%</td>
<td>20%</td>
</tr>
<tr>
<td>5+</td>
<td>50%</td>
<td>60%</td>
</tr>
</tbody>
</table>

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B) RELATIONSHIPS

• NO differences between male and female siblings

• In both cases, predominantly close and warm relationships
C) POSITIVES

• “As a result of having grown up with a brother/sister with disabilities, do you think that you have less, the same, or more of the following characteristics?” (1-5 scale)

• Characteristics included:
  – Empathy, understanding of differences, open to opportunities to learn, compassion, aware of family dynamics
C) POSITIVES (F > M)

- Empathy
- Understanding Differences
- Open to learning

Male sib vs. Female sib
C) POSITIVES (F > M)

- Compassion
- Family Dynamics
- Responsible Person

Male sib  Female sib
D) Life Choices

- Marriage
- Divorce
- Having Children
- Comparisons to U.S. Census figures
## Life Choices--Married

<table>
<thead>
<tr>
<th></th>
<th>Males</th>
<th>Females</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average Age</td>
<td>35 years</td>
<td>37 years</td>
</tr>
<tr>
<td>Married</td>
<td>47.6%</td>
<td>51.2%</td>
</tr>
<tr>
<td>Never Married</td>
<td>45.1%</td>
<td>39.1%</td>
</tr>
<tr>
<td>Divorced</td>
<td>5.3%</td>
<td>7.2%</td>
</tr>
<tr>
<td>Widowed</td>
<td>1.5%</td>
<td>1.4%</td>
</tr>
<tr>
<td>Separated</td>
<td>0.8%</td>
<td>0.9%</td>
</tr>
</tbody>
</table>
Marriage--Males

• In US population, males generally marry later
  – At all age groups, males > females in % of “never married”
  – Male siblings “% never married” = to US population at every age period.
Marriage--Females

- Like U.S. population, more female siblings marrying at each successive age-period

- But slight delaying of marriage
  = higher % of “never married” at each age period
Female Never-Married %, by Age-groups

% "Never Married"

<table>
<thead>
<tr>
<th>Age-Group</th>
<th>US Census</th>
<th>Female Sib</th>
</tr>
</thead>
<tbody>
<tr>
<td>20-24</td>
<td>80%</td>
<td>80%</td>
</tr>
<tr>
<td>25-29</td>
<td>60%</td>
<td>60%</td>
</tr>
<tr>
<td>30-34</td>
<td>40%</td>
<td>40%</td>
</tr>
<tr>
<td>35-39</td>
<td>20%</td>
<td>20%</td>
</tr>
<tr>
<td>40-44</td>
<td>10%</td>
<td>10%</td>
</tr>
</tbody>
</table>
Divorce

• Male siblings: Similar to U.S. Census

• Female siblings: This time, fewer divorces at several age-groups
Divorce: Methodological Issues

• Unlike “never married”, divorce = “divorce at this time”
  – If divorced & remarried = “married”

• Our numbers are much smaller
  – Only 6.8% divorced overall (76 divorces)
  – Only 7.2% among female siblings (63)

• U.S. Census Age-categories differ
Female Divorced %, by Age-groups

Age-Group

- 20-24
- 25-29
- 30-34
- 35-44
- 45+

% Divorced

- 0%
- 2%
- 4%
- 6%
- 8%
- 10%
- 12%
- 14%
- 16%

US Census vs. Female Sib

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Having Children

• Again, males = U.S. Census

• Females
  - Higher % with children at each age-period
  - But lower compared to U.S. Census %’s at several periods
    • Even lower compared to U.S. Census % of women with children when only White, Non-Hispanic women considered
Female “% with 1 + children,” by Age-groups

<table>
<thead>
<tr>
<th>Age-Group</th>
<th>% With 1+ Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>20-24</td>
<td>30%</td>
</tr>
<tr>
<td>25-29</td>
<td>40%</td>
</tr>
<tr>
<td>30-34</td>
<td>60%</td>
</tr>
<tr>
<td>35-39</td>
<td>80%</td>
</tr>
<tr>
<td>40-44</td>
<td>100%</td>
</tr>
</tbody>
</table>

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Summary: Male vs. Female Siblings

- Male Siblings = same as U.S. averages
- Female Siblings
  - Delayed marriage and childbearing
  - Less likely to divorce at most ages

- A “cautiousness” on the part of female siblings in regard to life choices?
Summary: Male vs. Female Siblings

• Females > Males on
  – Amount of Contact
  – Degree to which they benefit from being sibling to person with disabilities

• But Females = Males on:
  – Relationship closeness, warmth
Summary: Male vs. Female Siblings

Demographics: Compared to U.S. Census, female siblings seem to be:

- Delaying marriage
- Delaying having children
- Experiencing fewer divorces
3) Siblings Who Differ on Closeness

- Majority of adult studies examine closest, “most involved” sibling
- Skewed picture of sibling relations in adulthood?
- This study has large enough numbers to examine this issue
## Sibling Closeness

<table>
<thead>
<tr>
<th>Sibling Closeness</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am only child</td>
<td>268</td>
<td>25%</td>
</tr>
<tr>
<td>I am closest to my brother/sister with disabilities</td>
<td>402</td>
<td>37%</td>
</tr>
<tr>
<td>I am close, but not closest</td>
<td>319</td>
<td>30%</td>
</tr>
<tr>
<td>I am not very close</td>
<td>87</td>
<td>8%</td>
</tr>
</tbody>
</table>
Hours per Month by Sibling Closeness

- 0% to 10% of siblings
- 20% to 30% of siblings
- 40% to 50% of siblings
- 60% to 70% of siblings
- 80% of siblings

- 0 to 2 hours per month
- 3 to 4 hours per month
- 5 + hours per month

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Summary: Sibling Closeness

- Relates to amount of time spent with brother/sister with disabilities
- Siblings who feel themselves closer benefit more
- “Not close” siblings seem to benefit least
4) Different Conditions

• Long interest in
  – A hypothesized “Down syndrome advantage”
  – Families of persons with autism

• New interest in changing life-spans
  (particularly in Down syndrome)
Down Syndrome Advantage

• Families of persons with DS (vs. with other disabilities) seem to cope better

• Siblings of adults with DS > with autism
  – Amount of in-person contact
  – More positive affect (both towards & from brother/sister with disabilities)
  – Lesser amounts of pessimism
    – Orsmond & Seltzer, 2006
Increasing Life Expectancy in Down Syndrome

Bittles & Glasson, 2004
DS % with “Significant Health Problems”, by Age-Group

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Results I: Down Syndrome Advantage

- A-Contacts
- B-Relationship between siblings
- C-The sibling’s overall rating of their own health and depression
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Hours per Month with Brother/Sister with Disabilities

- Hours per month:
  - <=2
  - 3 to 4
  - 5 +

- Categories:
  - DS
  - Autism
  - Other

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Relationship Questions, DS-Autism-Other

The Arc's 55th National Convention October 12th - 14th, 2006
Age-Related Changes

- Recall facts about aging in Down syndrome:
  - Lengthening life-span
  - Health problems, particularly in 40’s and 50’s

- Compared 3 groups:
  - Up to 30
  - 30-45
  - Above 45
Contacts

• Decline in all 3 groups (DS, autism, other) with age of brother/sister with disabilities
B) Relationship

• Seems to work differently in three groups

  – DS: gradual decline from <30 to later
  – Autism: marked decline from 45 on
  – Other: Stable over time
Relationship Scores: 3 Groups X Age

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Summary: Different Conditions

• Seems to be a “Down syndrome advantage” for
  – Contacts (# of hrs/month)
  – Relationship

• Age-Changes
  – Seem to differ by group
Overall: Adult Siblings

1) General Findings
   – Siblings doing well overall
   – Most have fair amount of contact with brother/sister with disabilities
   – Most in close, affectionate relationships
   – Most benefiting from relationship
   – Most in good health, with little depression
Overall: Gender

2) Females > Males on
   – Contact
   – Benefiting from relationship
   – Females also seem to be
     • Delaying marriage & children
     • Showing lower levels of divorce
Overall: Closeness

3) Closer sibling relationships =
   – Greater amounts of contact
   – Greater amounts of benefit from relationship
Overall: Different Conditions

4) Compared to autism and Other groups, Down syndrome advantage in
   - Greater Amounts of Contact
   - Closer Relationships

5) Age changes differs by Group
   - DS—slight relationship decrease from <30 to after
   - Autism—major decrease after 45
   - Other—more stable overall
Overall Summary

- Sibling survey provides generally positive picture
- Early study in this area
- Today’s talk = early stage in understanding sibling relationship
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