




Adult Sibling Survey: Preliminary Findings

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Purpose: Describe the lifelong relationship of adult siblings to their brother or sister with disabilities.

<https://kc.vanderbilt.edu/FamilyResearch>

Recruitment - Promotion



The
Arc



AUCD
ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES
RESEARCH, EDUCATION, SERVICE



SiblingSupportProject

Our brothers,
our sisters,
ourselves...



Vanderbilt Kennedy Center for Research on Human Development

[text only](#)



The
Arc

Issue #1, 2005



inSight

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

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



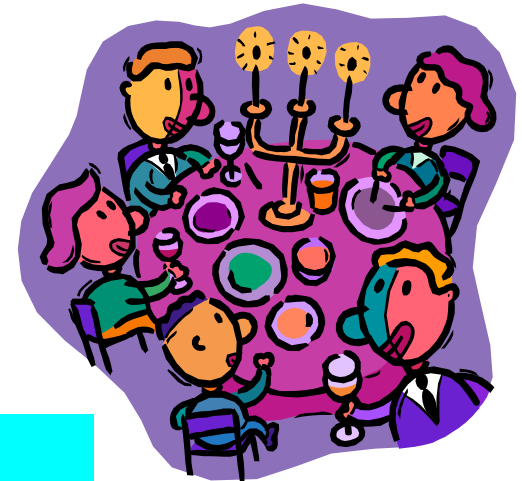
Respondent Age 18+

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

The image shows a survey form with several questions. Callouts identify different question types: 'Write In 22' for a text input, 'Select 22' for a dropdown menu, and 'Multiple Choice 157' for a list of radio button options.

Gender
<Select>

What state do you live in?
<Select>

What is your zip code?
[Text Input]

Please select the one ethnicity category that best describes you.
<Select>
White non-Hispanic
African-American
Hispanic
Native American
Asian or Pacific Islander
Other:

of school you completed? (12=High school, 16=College Gradu

nt?

☐ No
☐ Yes - Working on Associated Degree
☐ Yes - Working on Bachelor's Degree
☐ Yes - Working on post Bachelor's Degree but not graduate degree
☐ Yes - Graduate Degree
☐ Yes-Grad. Area: [Text Input]

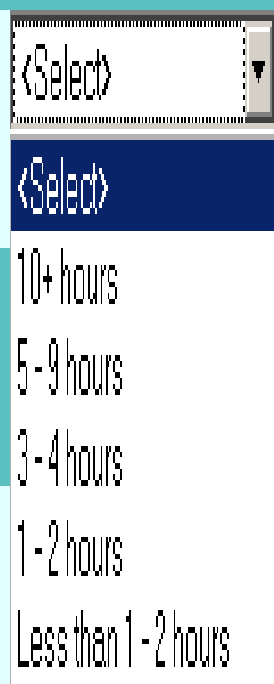
Write In 22

Select 22

Multiple Choice 157

Question 40. Joint Activities ...

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



A screenshot of a web form. A dropdown menu is open, showing the following options: <Select>, 10+ hours, 5-9 hours, 3-4 hours, 1-2 hours, and Less than 1-2 hours. The text 'The commitment is ...' is visible in the background.

- <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

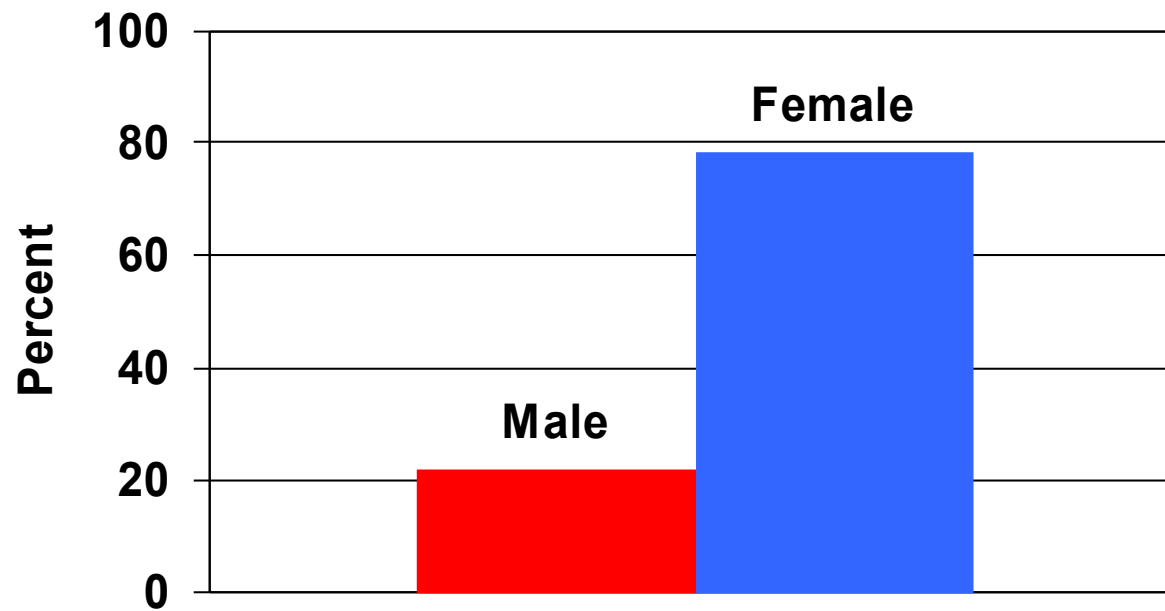
☐ My work commitments

☐ Other:

Question: 42. Relationship

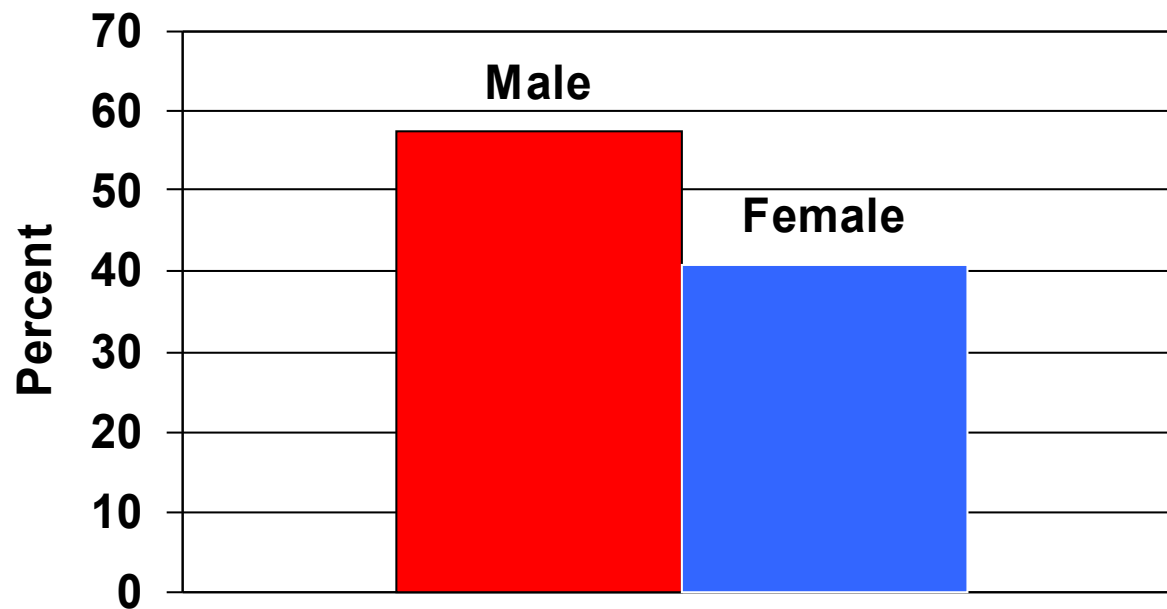
	1 Not at all	2 Not much	3 Somewhat	4 Pretty much	5 Very much	6 Extremely
How much do you UNDERSTAND your brother/sister?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How much do you TRUST your brother/sister?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How FAIR do you feel you are toward your brother/sister?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How much do you RESPECT your brother/sister?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How much AFFECTION do you have toward your brother/sister?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Taking everything into consideration, how CLOSE do you feel in the relationship between you and your brother/sister?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
In general, to what extent do you think that your relationship with your brother/sister with disabilities has been mostly POSITIVE?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Respondent Gender

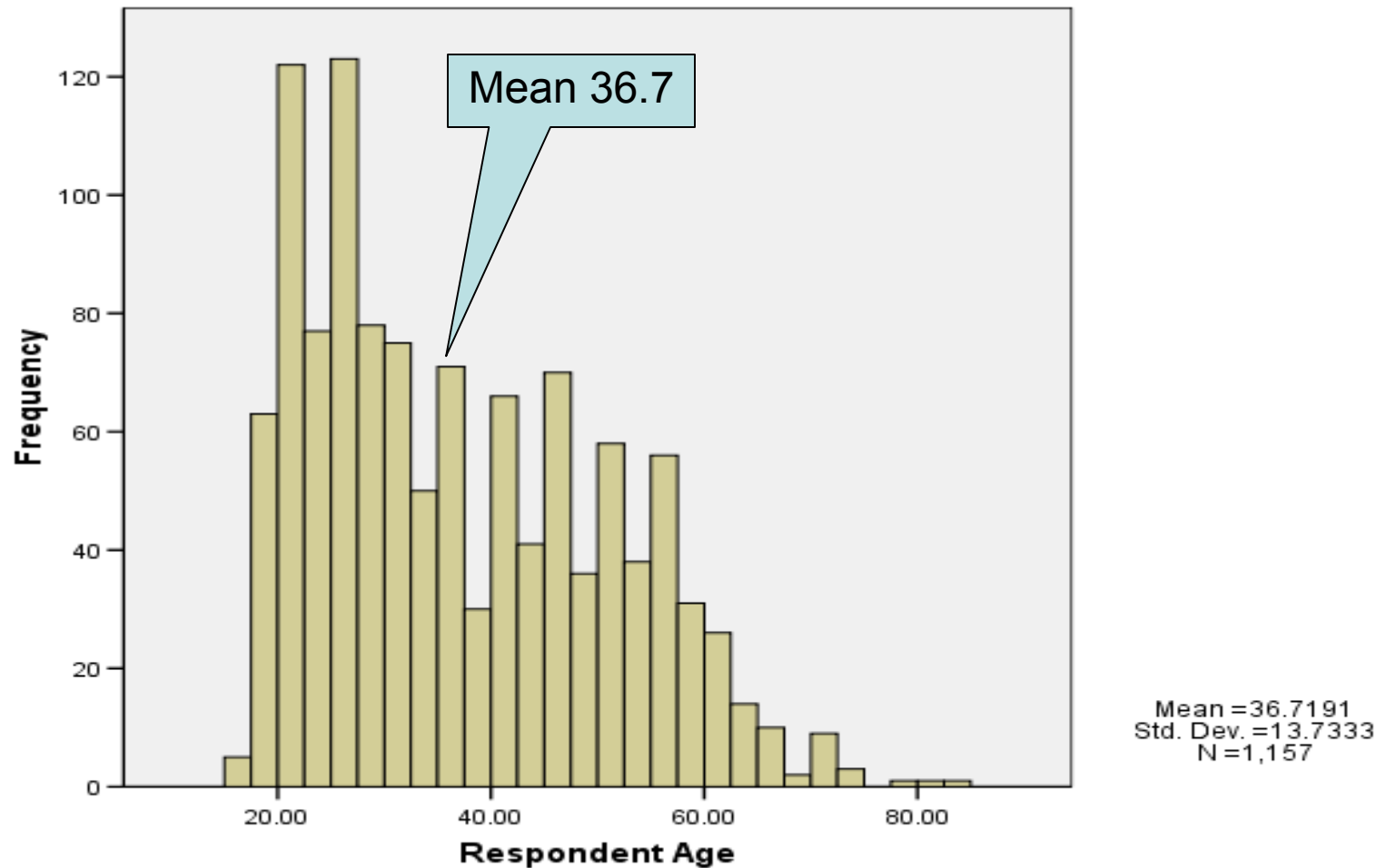




Brother/Sister Gender

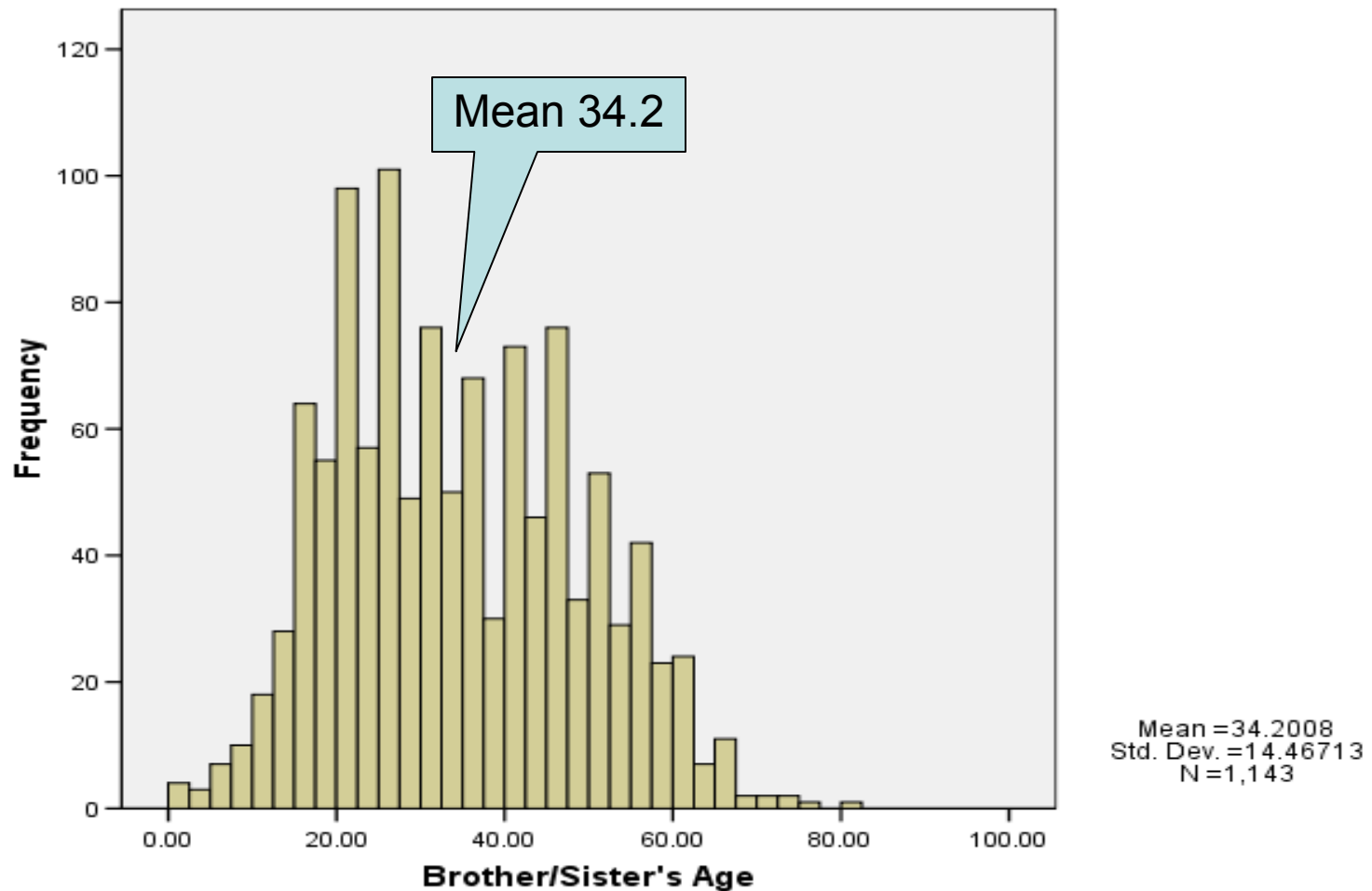


Age of Respondents



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


Age of Brothers/Sisters



Respondents by State

State	Number	Percent	Rank	
			Census	Study
CA	101	9%	1	1
FL	84	7%	4	2
NY	80	7%	3	3
IL	78	7%	5	4
OH	69	6%	7	5
TX	53	5%	2	6
VA	50	4%	12	7
PA	45	4%	6	8
MD	38	3%	19	9
TN	35	3%	16	10

Race/Ethnicity




Group	Number	%
White Non-Hispanic	1042	91
African-American	24	2
Hispanic	35	3
Native American	2	< 1
Asian or Pacific Islander	11	1
Other	28	2
Total	1143	

Respondent Marital Status



Status	Number	%
Never Married	470	40
Married	573	50
Separated	10	1
Divorced	82	7
Widowed	17	2
Total	1152	100

Condition of Brother/Sister



Condition	Number	%
MRDD	549	47
Down syndrome	284	24
Autism	146	15
CP	147	13
Emotional	87	8
Health	81	7
Sensory	63	5
Williams	13	1
Fragile X	9	1
Prader Willi	6	1

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?

Comments: Questionnaire



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.

Comments: Positive Relationships



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.

Comments: Challenging Relationships



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



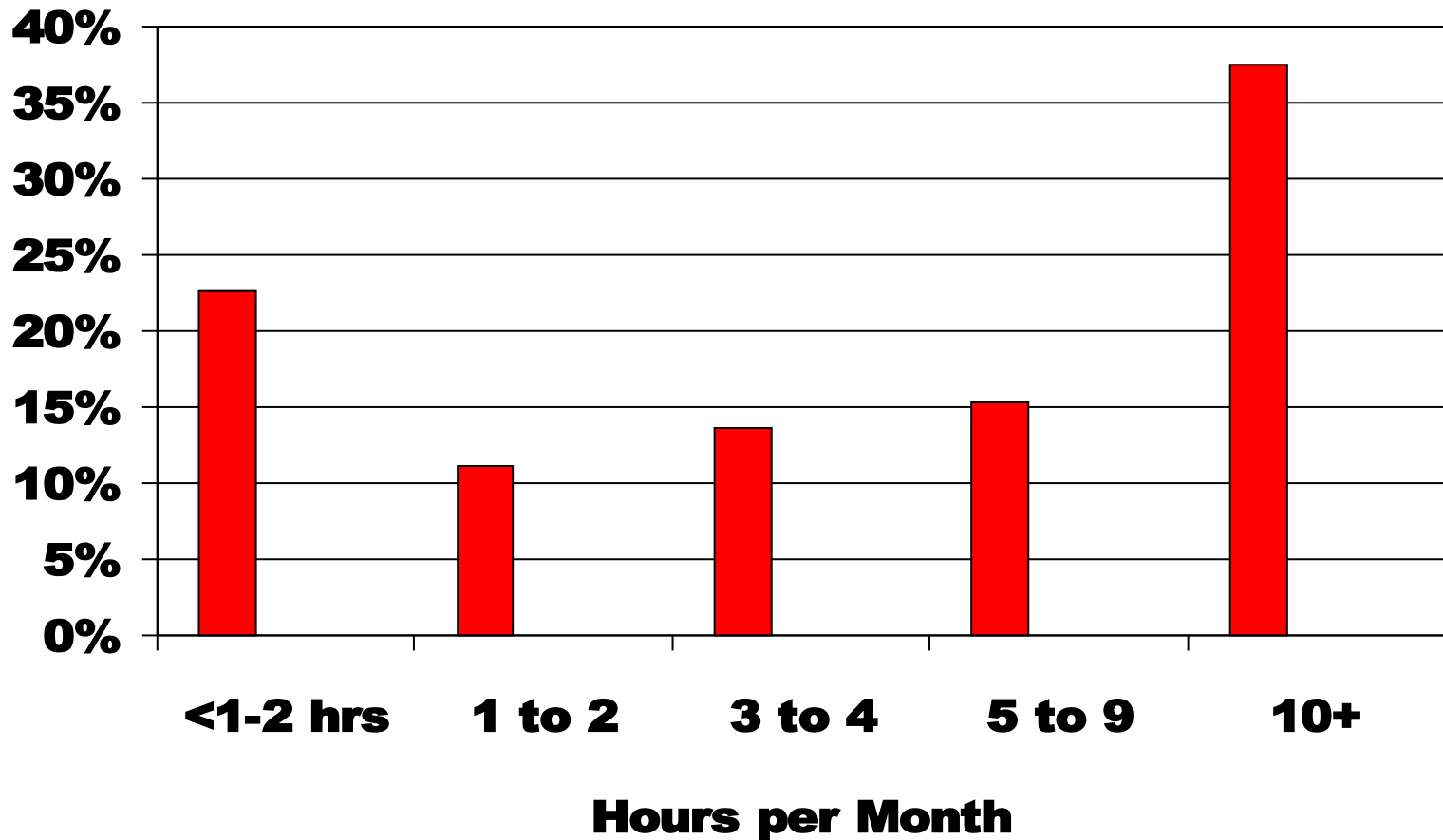
- Old view:
 - That siblings “suffer” from being a brother/sister to a persons with disabilities (more depression, acting out, etc.)
- Newer view:
 - May be positive aspects to being a sibling
- Our view
 - Let’s look at the numbers...

Some General Findings



- A) Contacts with brother/sister
- B) Relationship Quality
- C) Positives from being sibling
- D) Health-depression

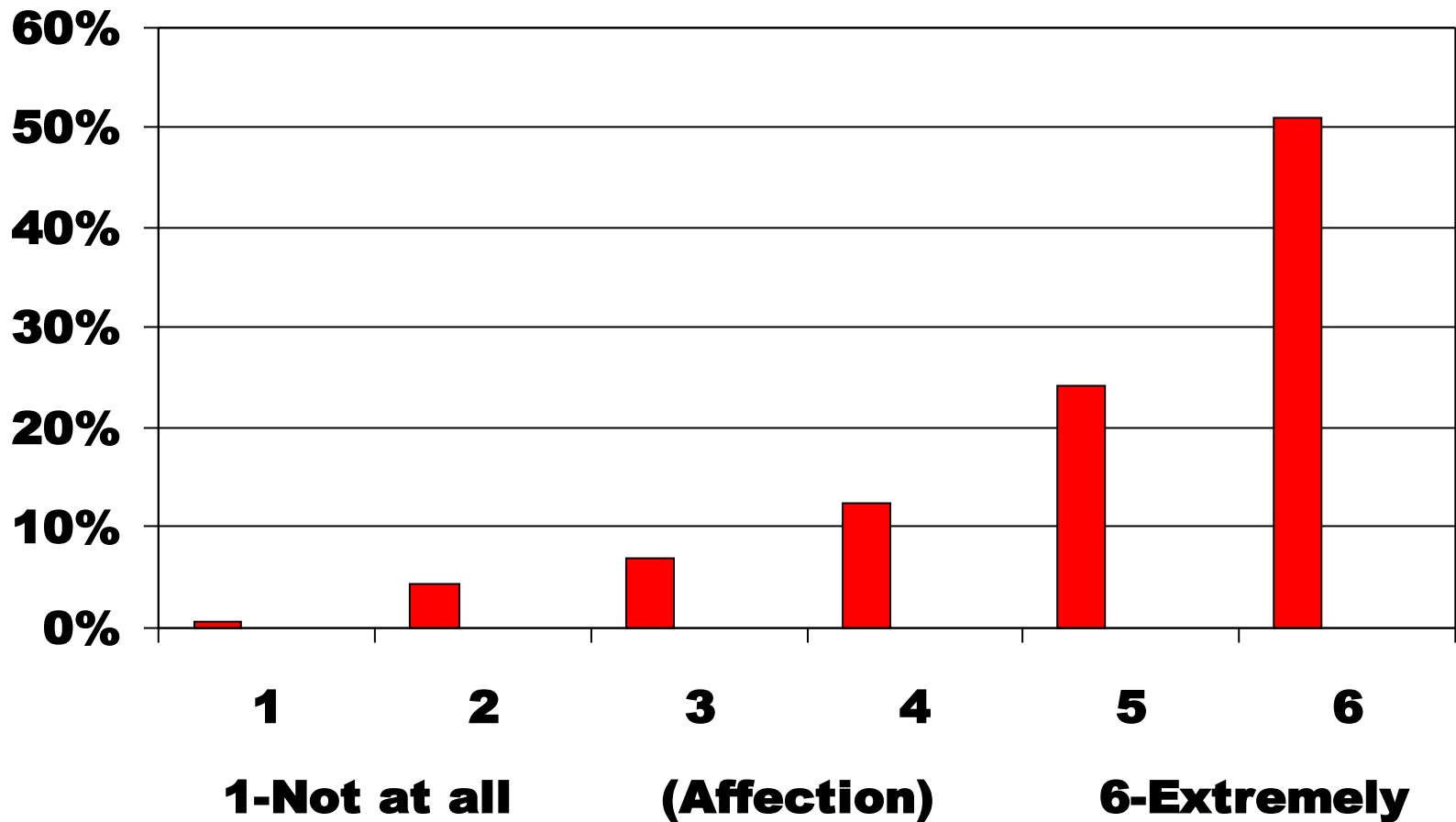
A)CONTACTS: Hrs/Month with Brother/ Sister w/ Disabilities



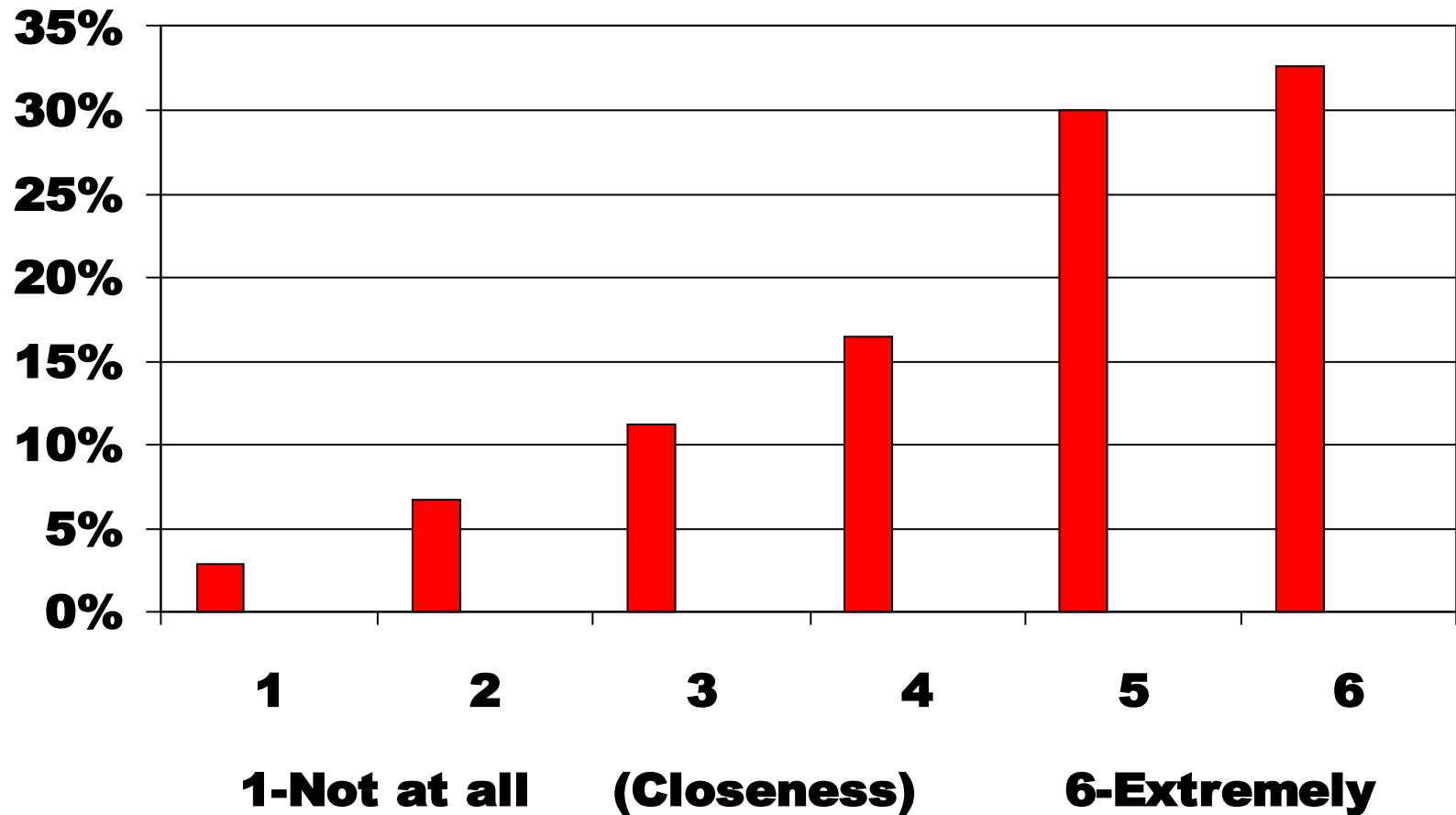
B) RELATIONSHIP: Affection & Closeness

- 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



Closeness



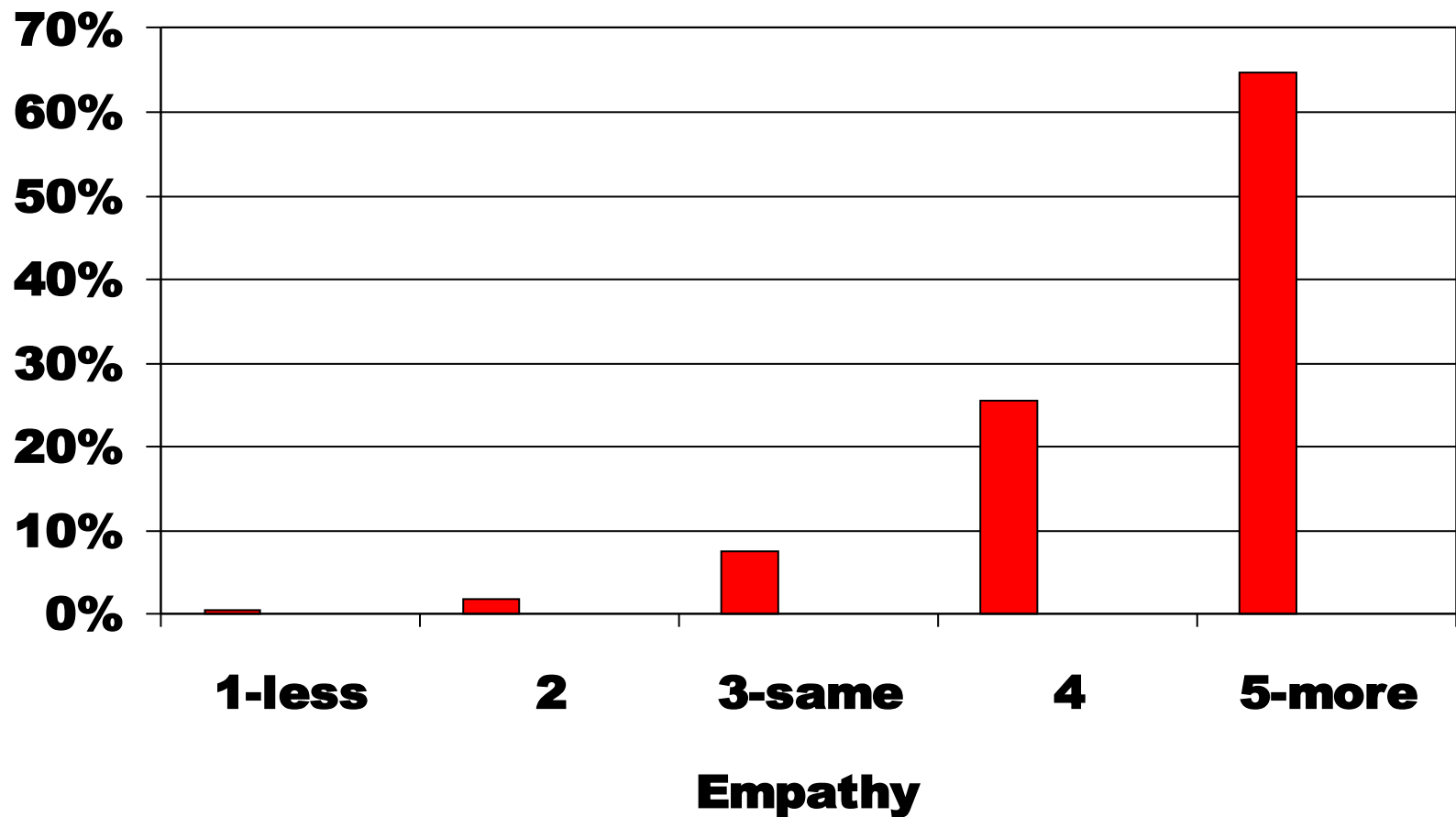
C) POSITIVES



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



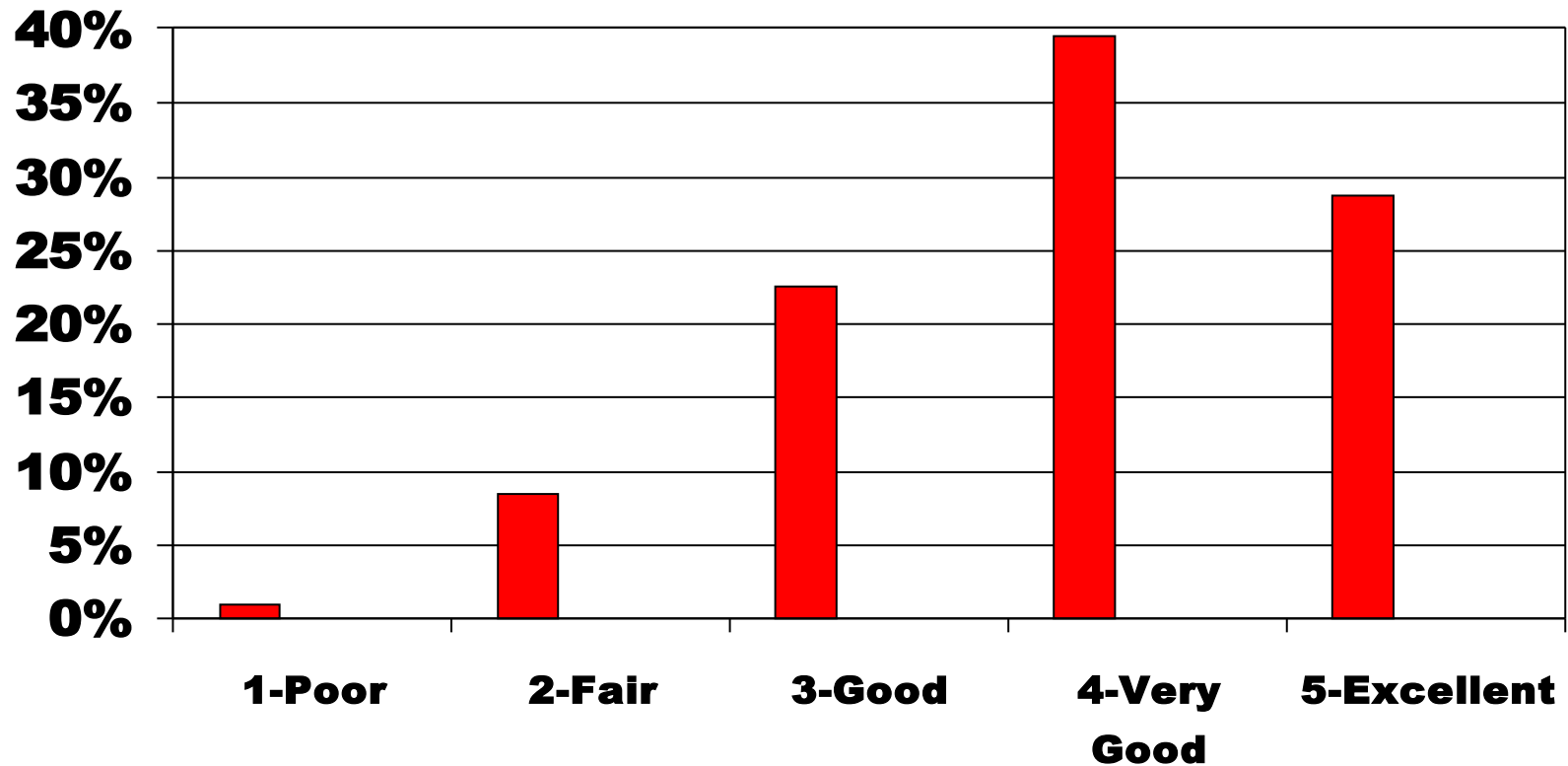
D) Physical Health



in general your health is:

- 1=Poor;
- 2=Fair
- 3=Good;
- 4=Very Good
- 5=Excellent

Physical Health



Physical Health

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

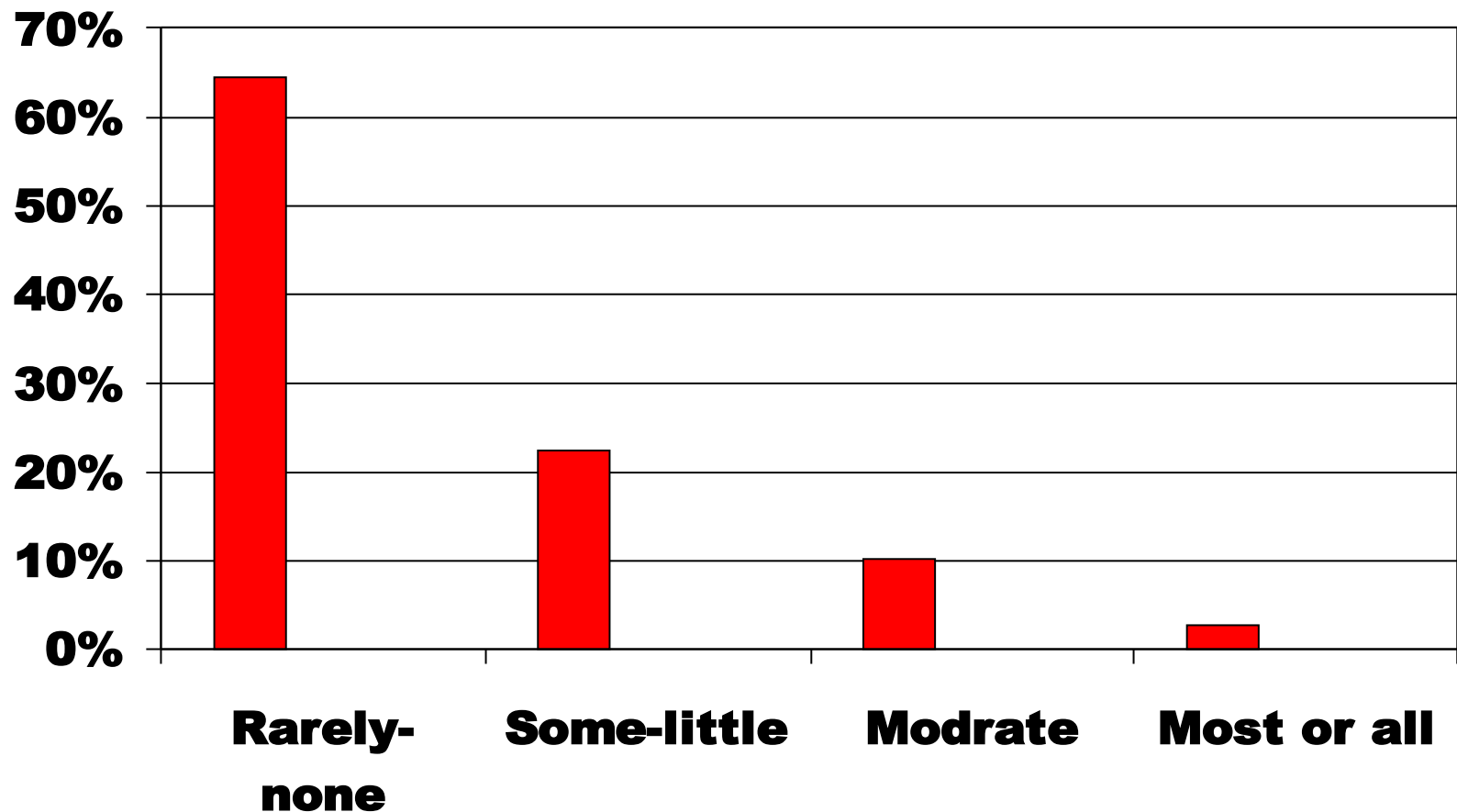
D) Depressive Symptoms



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



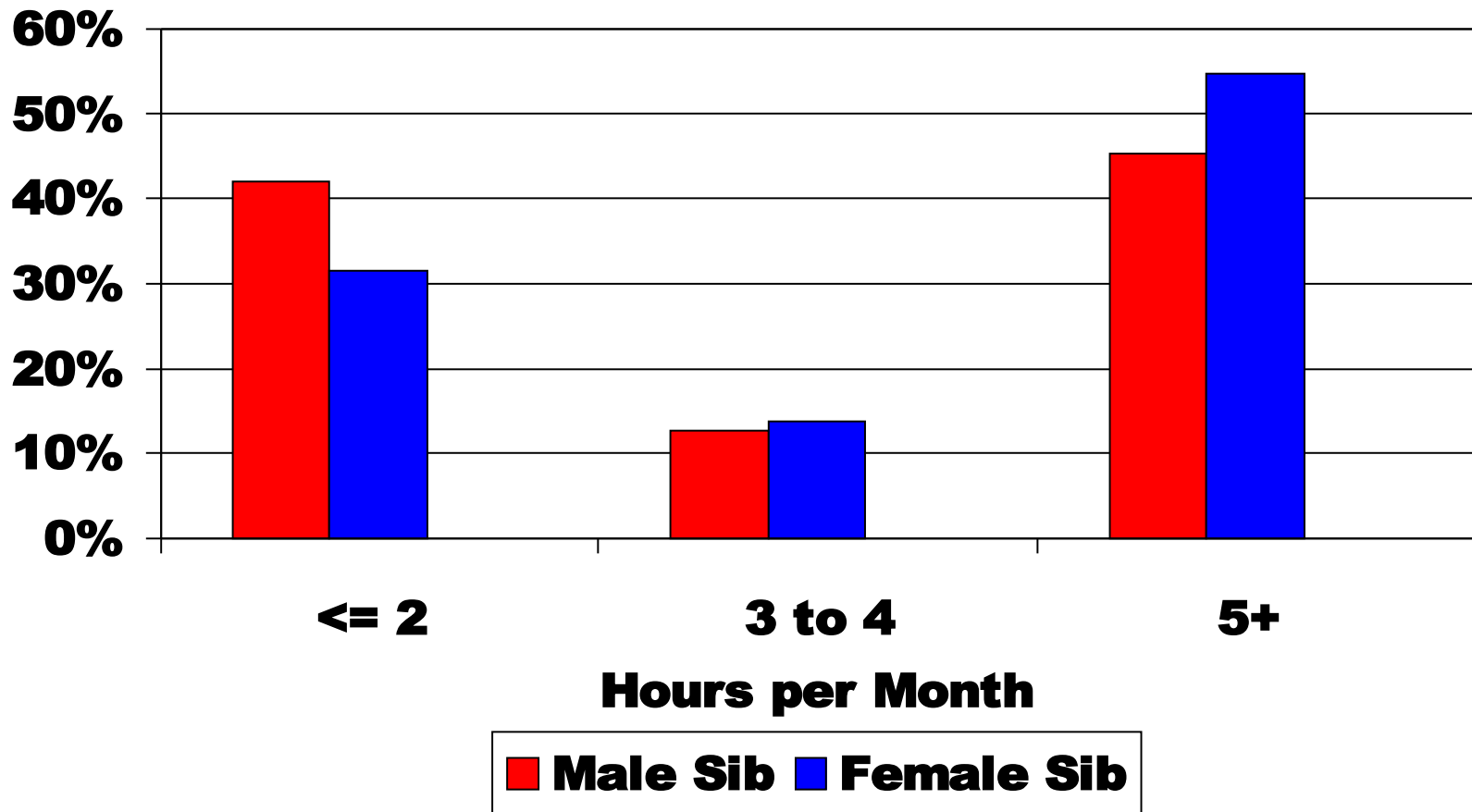
	Males	Females
N	251	910
%	21.6%	78.4%
Age	34.9	37.2
Education Level	15.2	15.8

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



B) RELATIONSHIPS



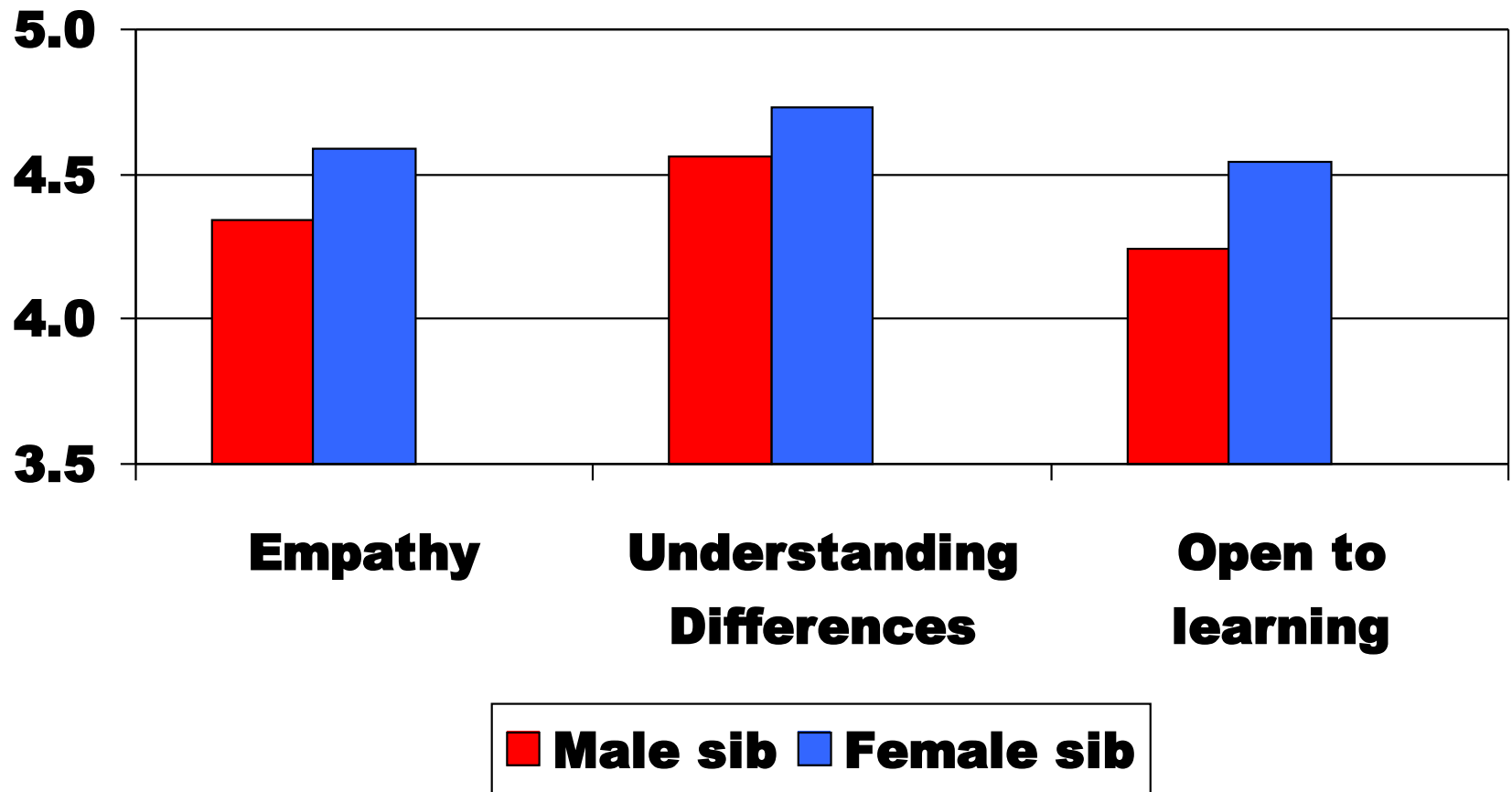
- NO differences between male and female siblings
- In both cases, predominantly close and warm relationships

C) POSITIVES

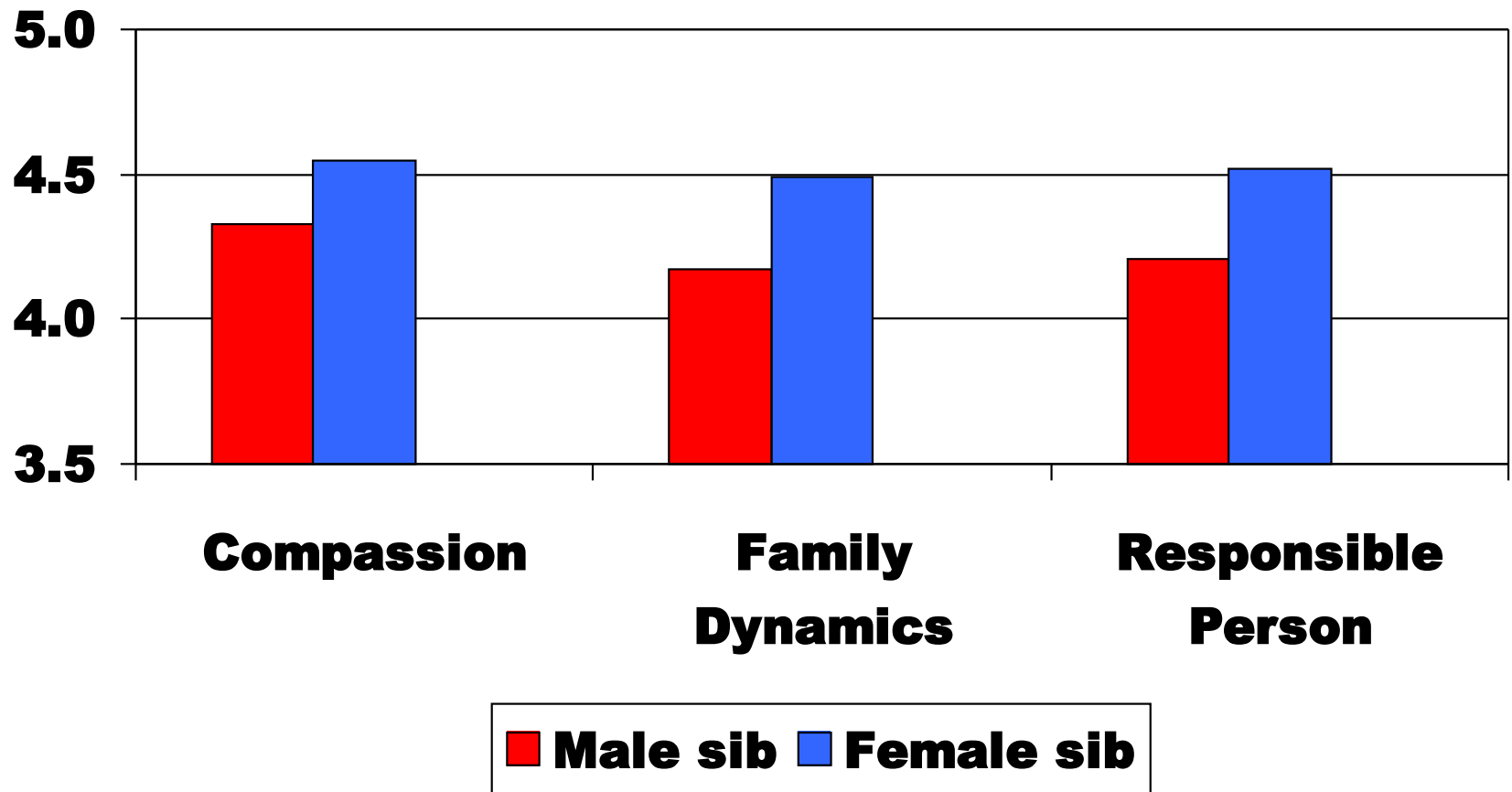


- “As a result of having grown up with a brother/sister with disabilities, do you think that you have less, the same, or more of the following characteristics?” (1-5 scale)
- Characteristics included:
 - Empathy, understanding of differences, open to opportunities to learn, compassion, aware of family dynamics

C) POSITIVES (F > M)



C) POSITIVES (F > M)




D) Life Choices



- Marriage
- Divorce
- Having Children

- Comparisons to U.S. Census figures

Life Choices--Married




	Males	Females
Average Age	35 years	37 years
Married	47.6%	51.2%
Never Married	45.1%	39.1%
Divorced	5.3%	7.2%
Widowed	1.5%	1.4%
Separated	0.8%	0.9%

Marriage--Males



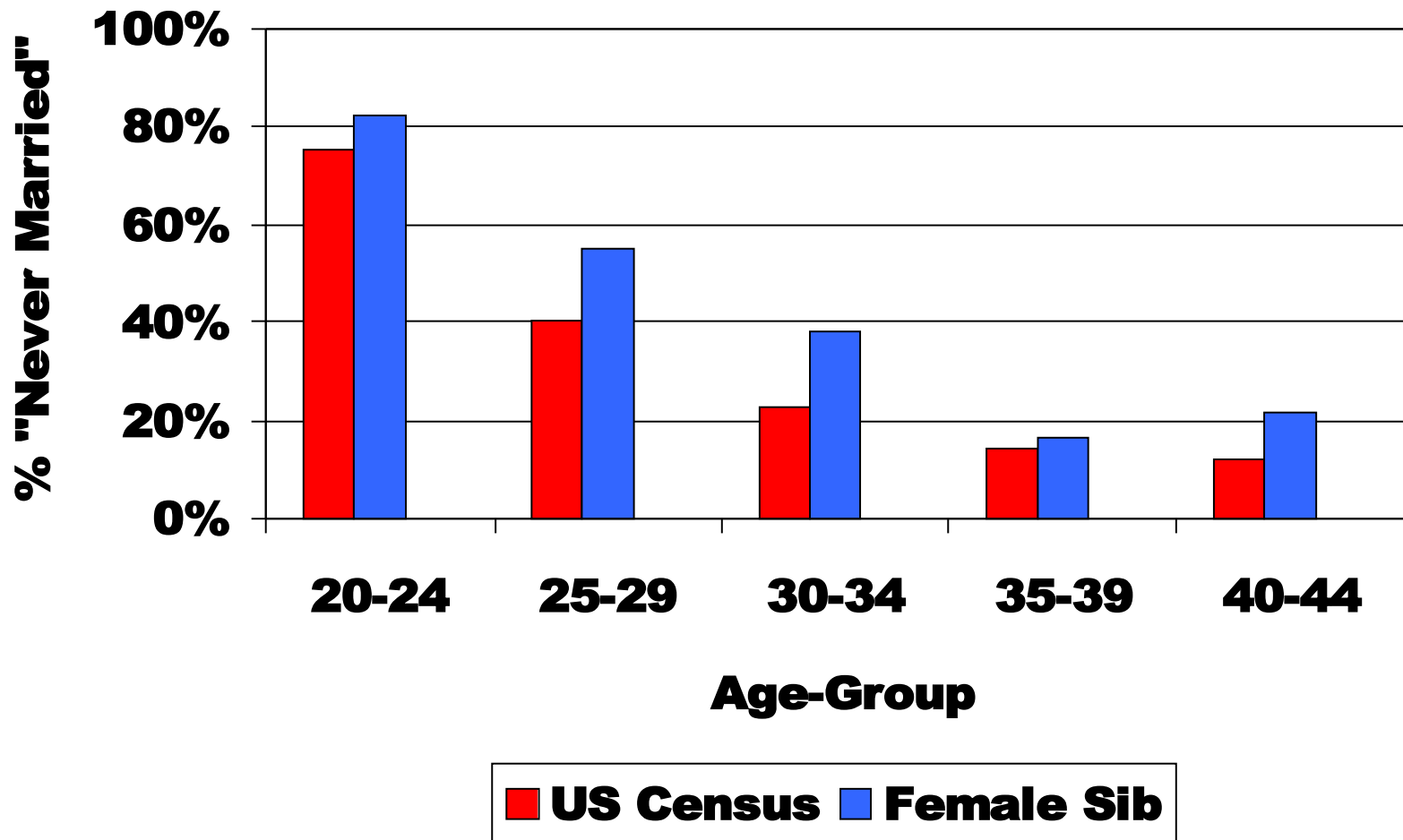
- In US population, males generally marry later
 - At all age groups, males > females in % of “never married”
 - Male siblings “% never married” = to US population at every age period.

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



Divorce



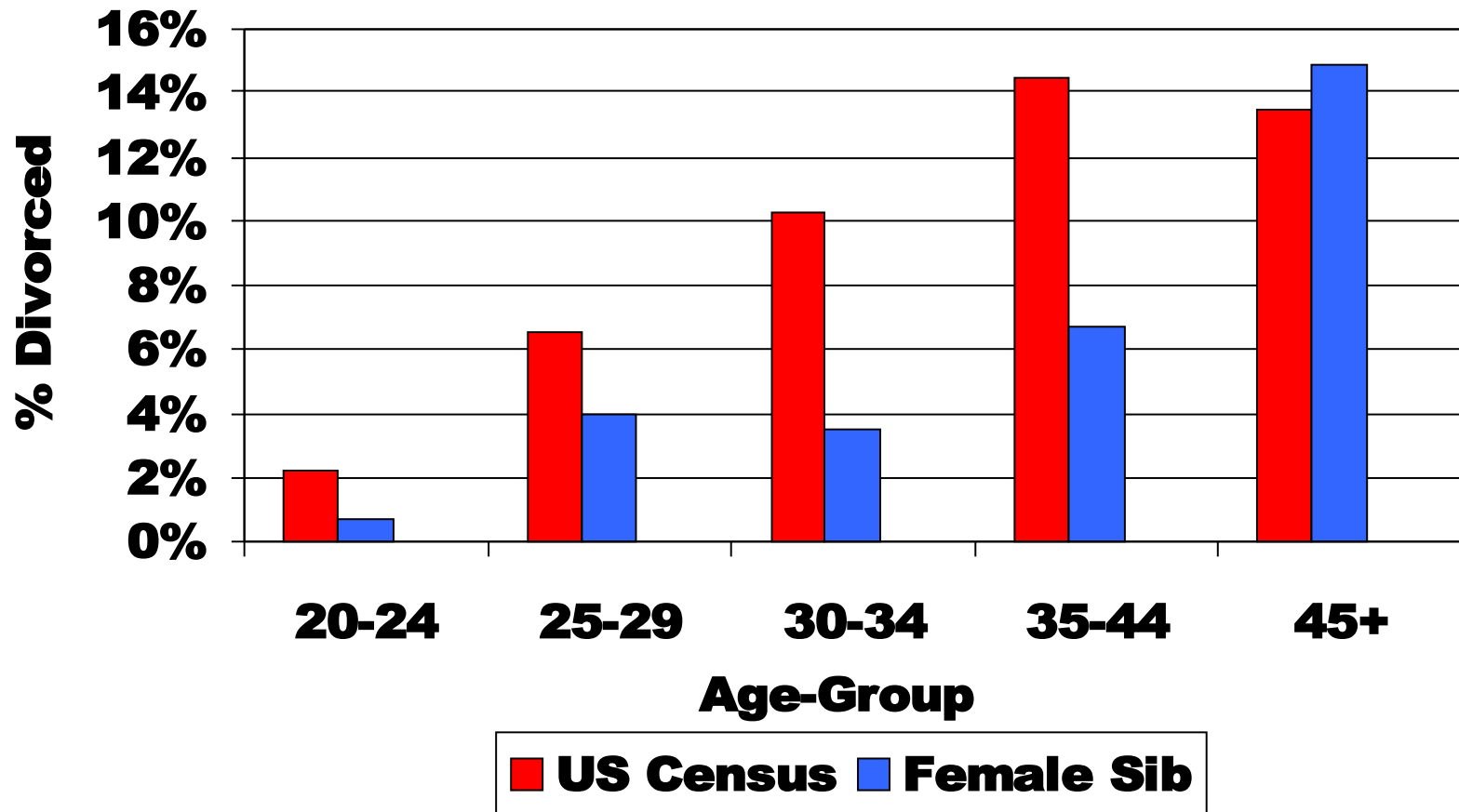
- Male siblings: Similar to U.S. Census
- Female siblings: This time, fewer divorces at several age-groups

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

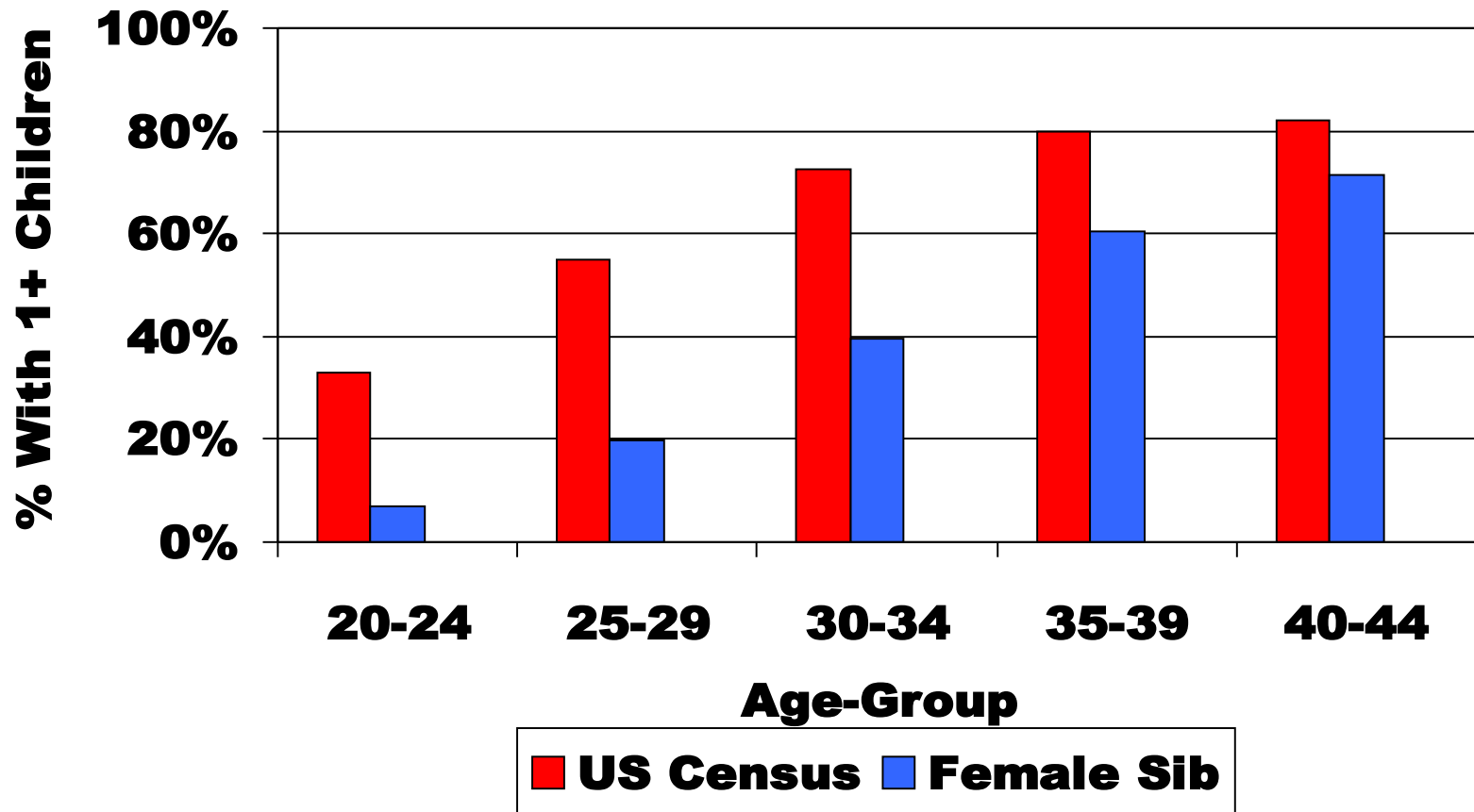


Having Children



- 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



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



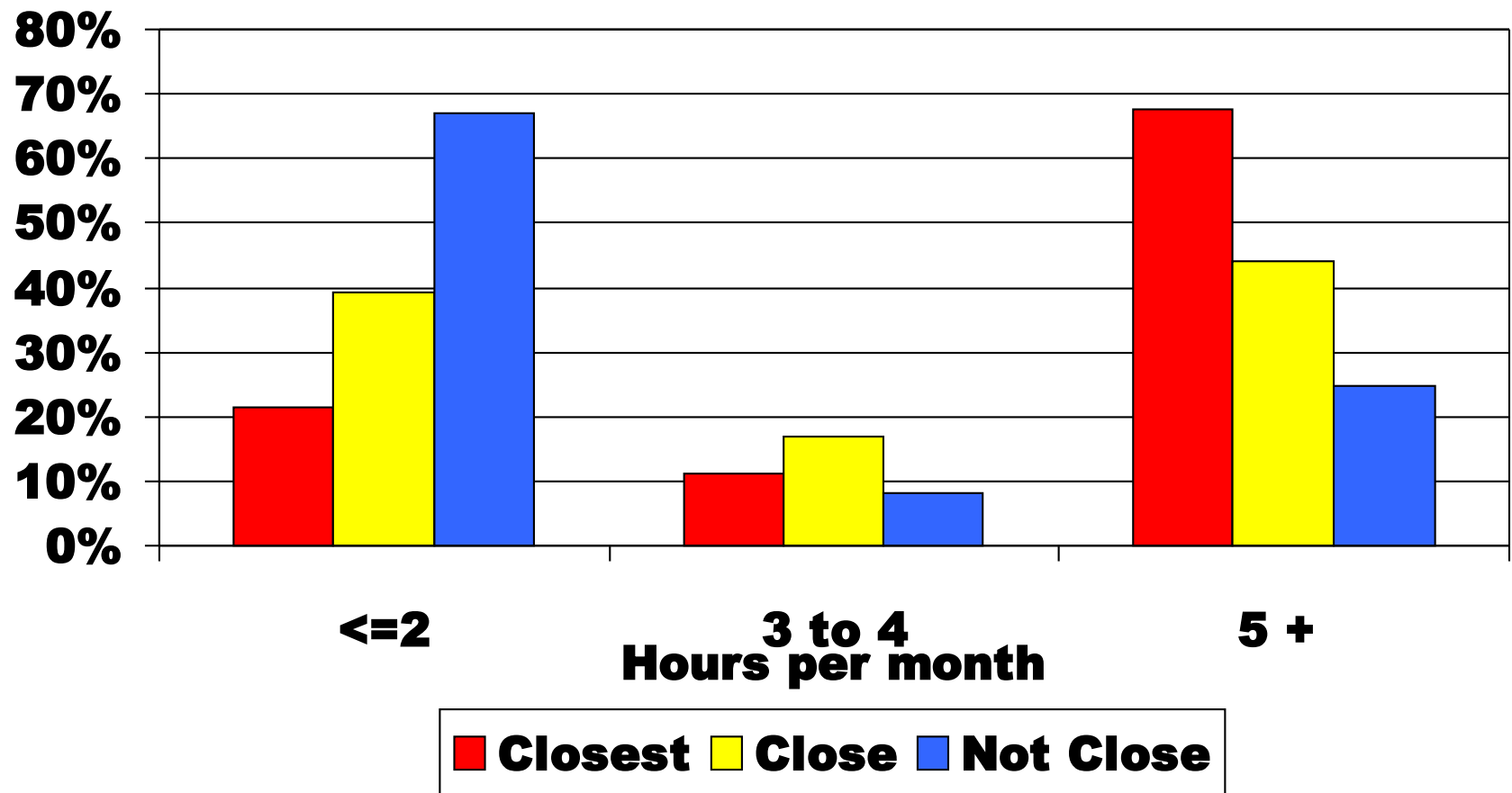
- Majority of adult studies examine closest, “most involved” sibling
- Skewed picture of sibling relations in adulthood?
- This study has large enough numbers to examine this issue

Sibling Closeness

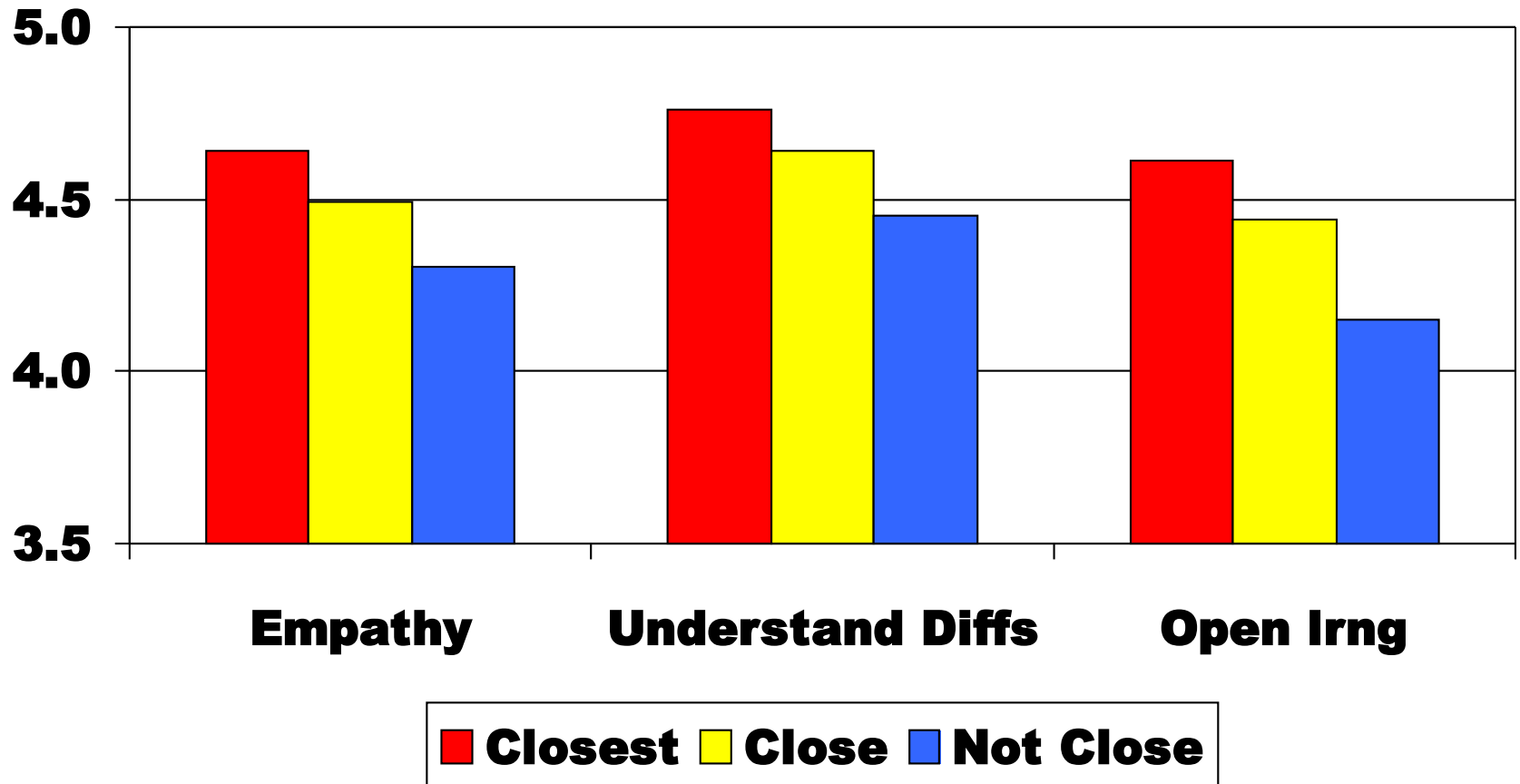


	N	%
I am only child	268	25%
I am closest to my brother/sister with disabilities	402	37%
I am close, but not closest	319	30%
I am not very close	87	8%

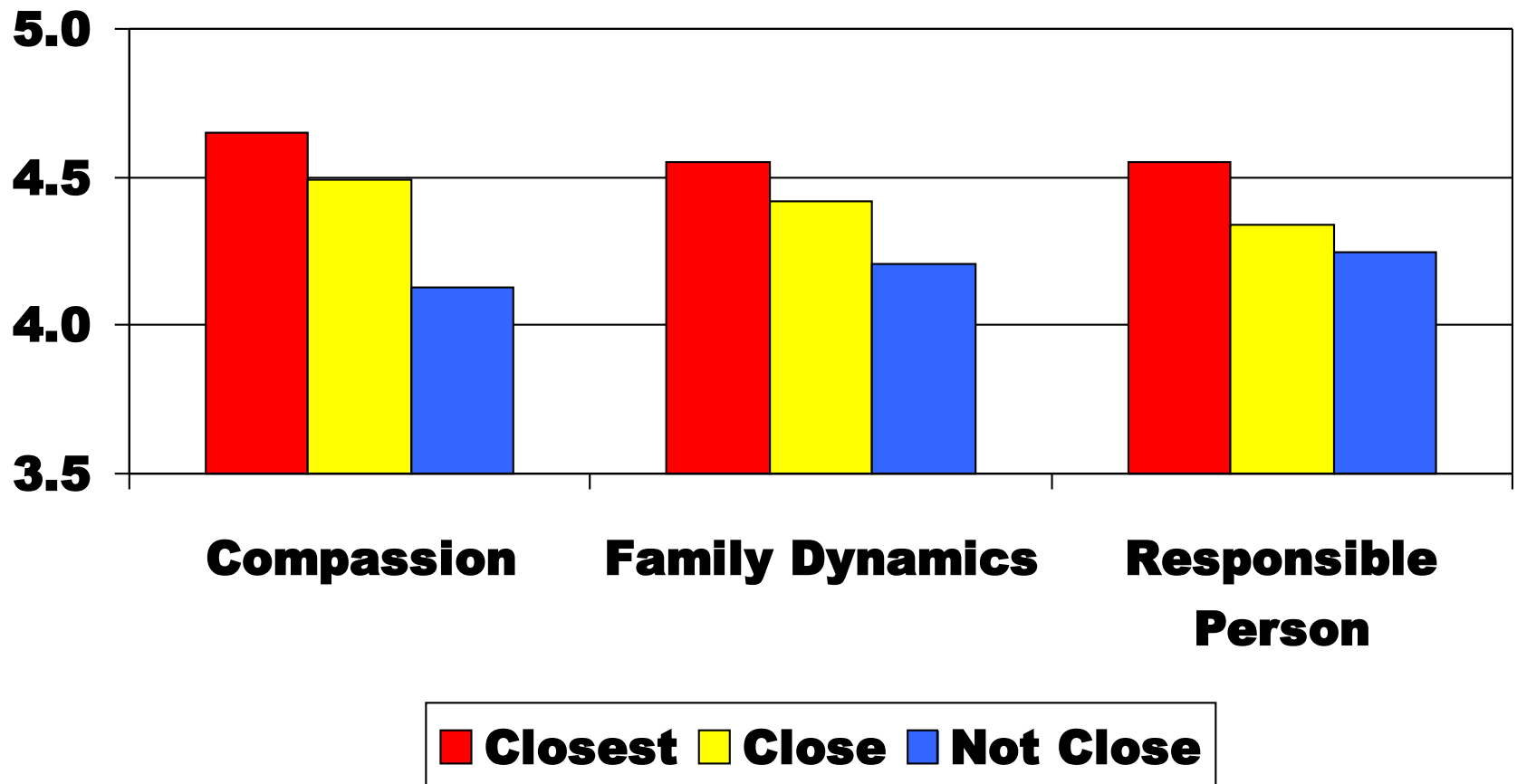
Hours per Month by Sibling Closeness



Positives



Positives



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



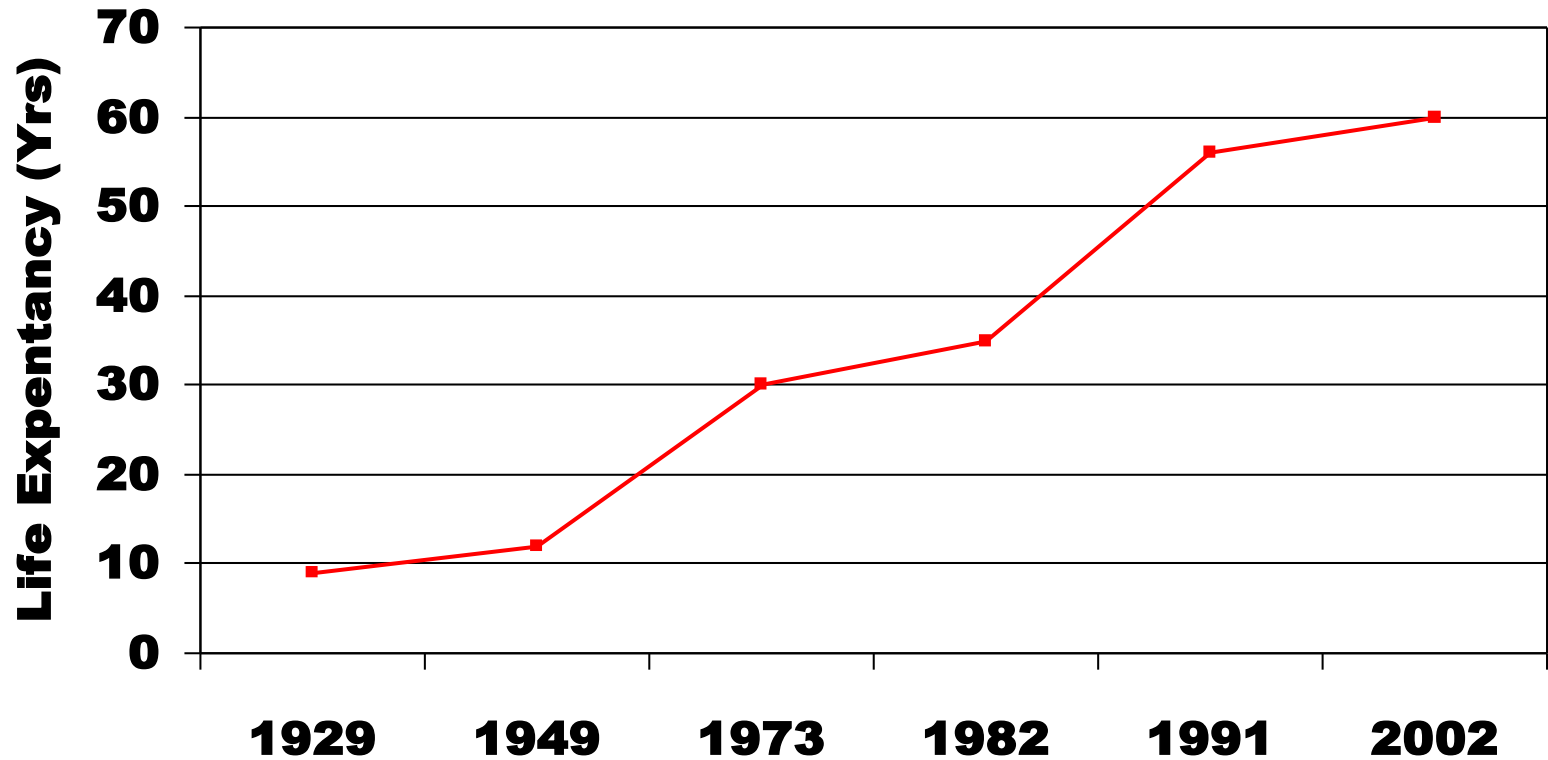
- Long interest in
 - A hypothesized “Down syndrome advantage”
 - Families of persons with autism
- New interest in changing life-spans (particularly in Down syndrome)

Down Syndrome Advantage



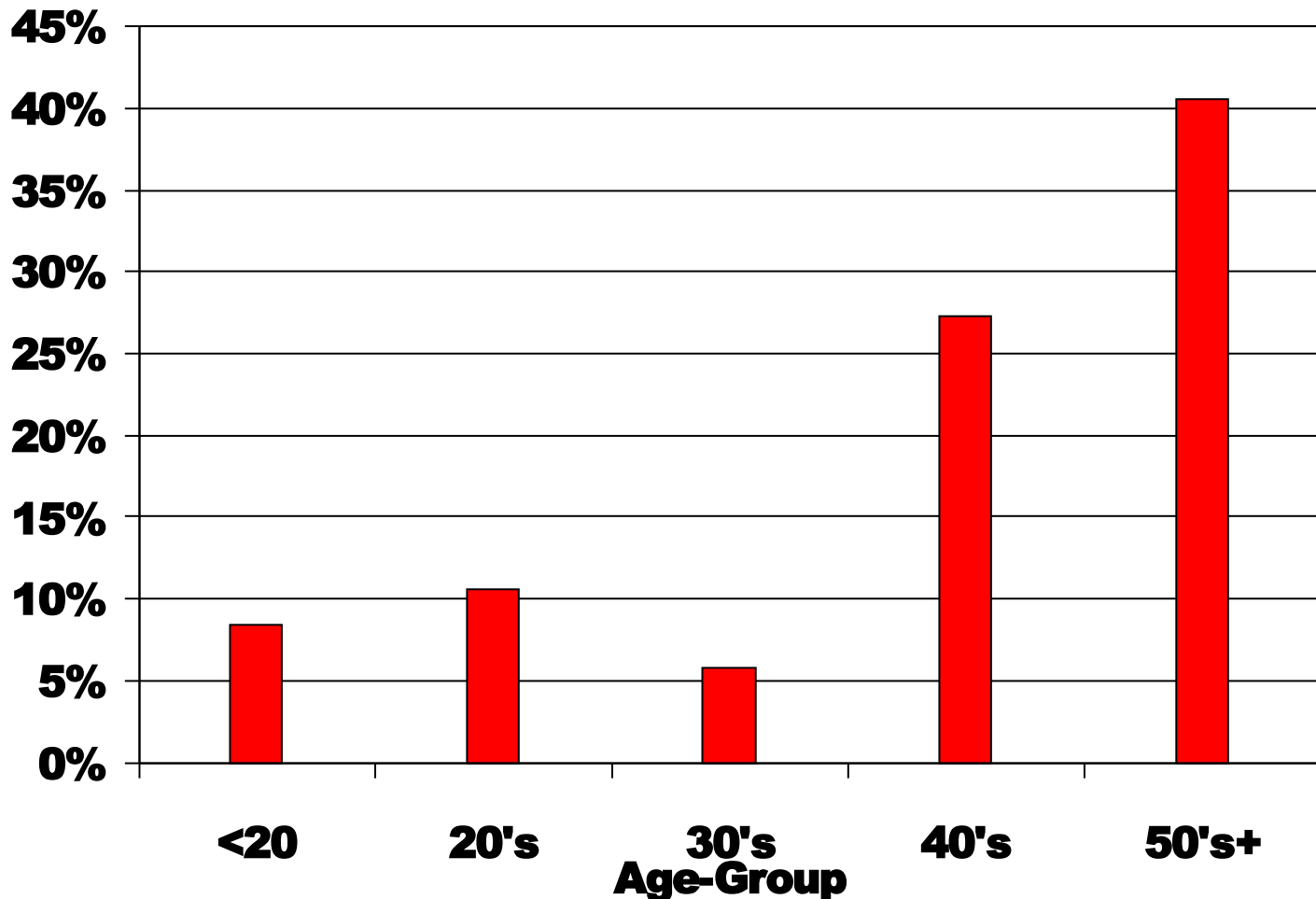
- Families of persons with DS (vs. with other disabilities) seem to cope better
- Siblings of adults with DS > with autism
 - Amount of in-person contact
 - More positive affect (both towards & from brother/sister with disabilities)
 - Lesser amounts of pessimism
 - Orsmond & Seltzer, 2006

Increasing Life Expectancy in Down Syndrome



Bittles & Glasson, 2004


DS % with “Significant Health Problems”, by Age-Group



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

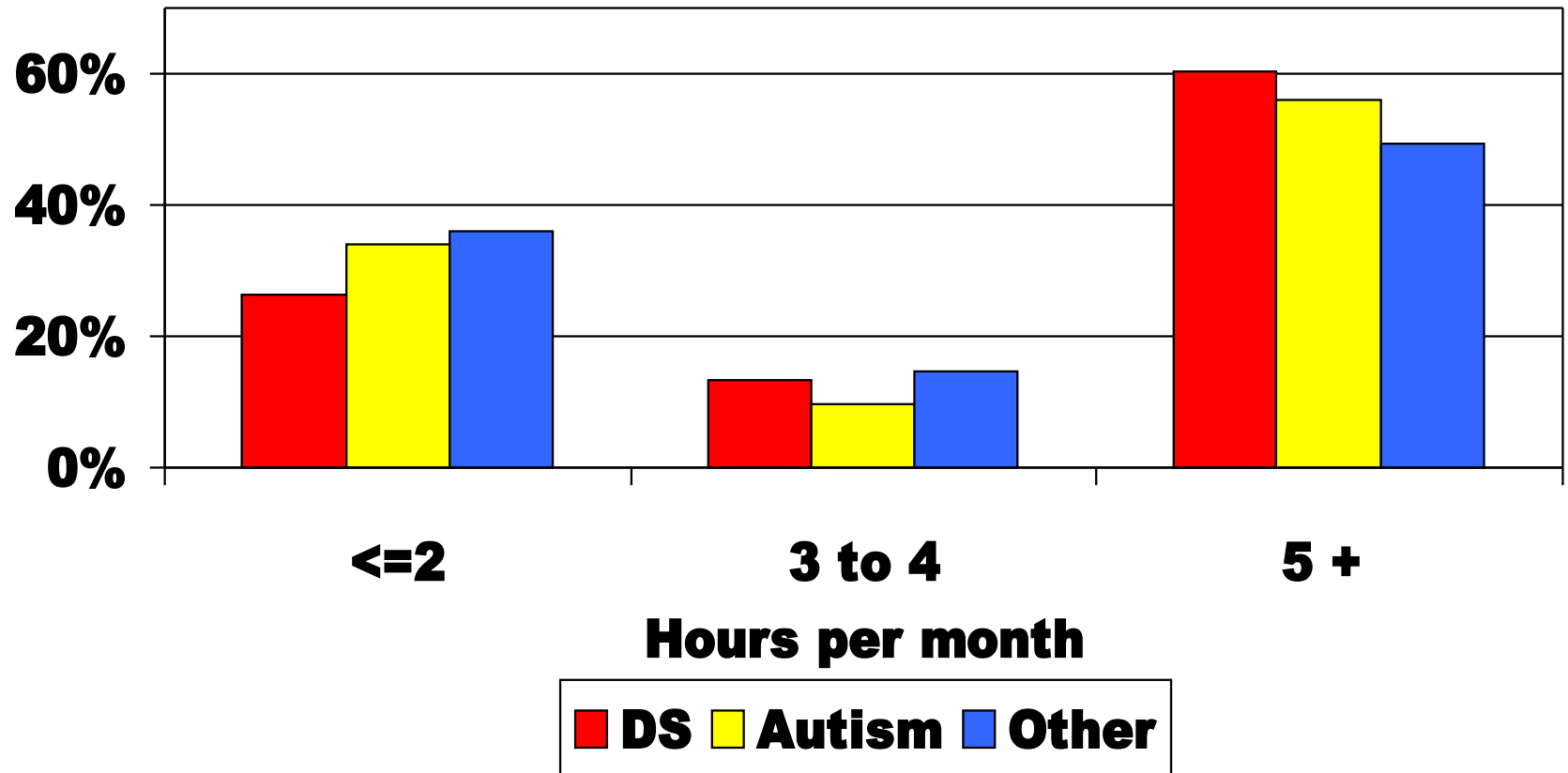
Results I:

Down Syndrome Advantage

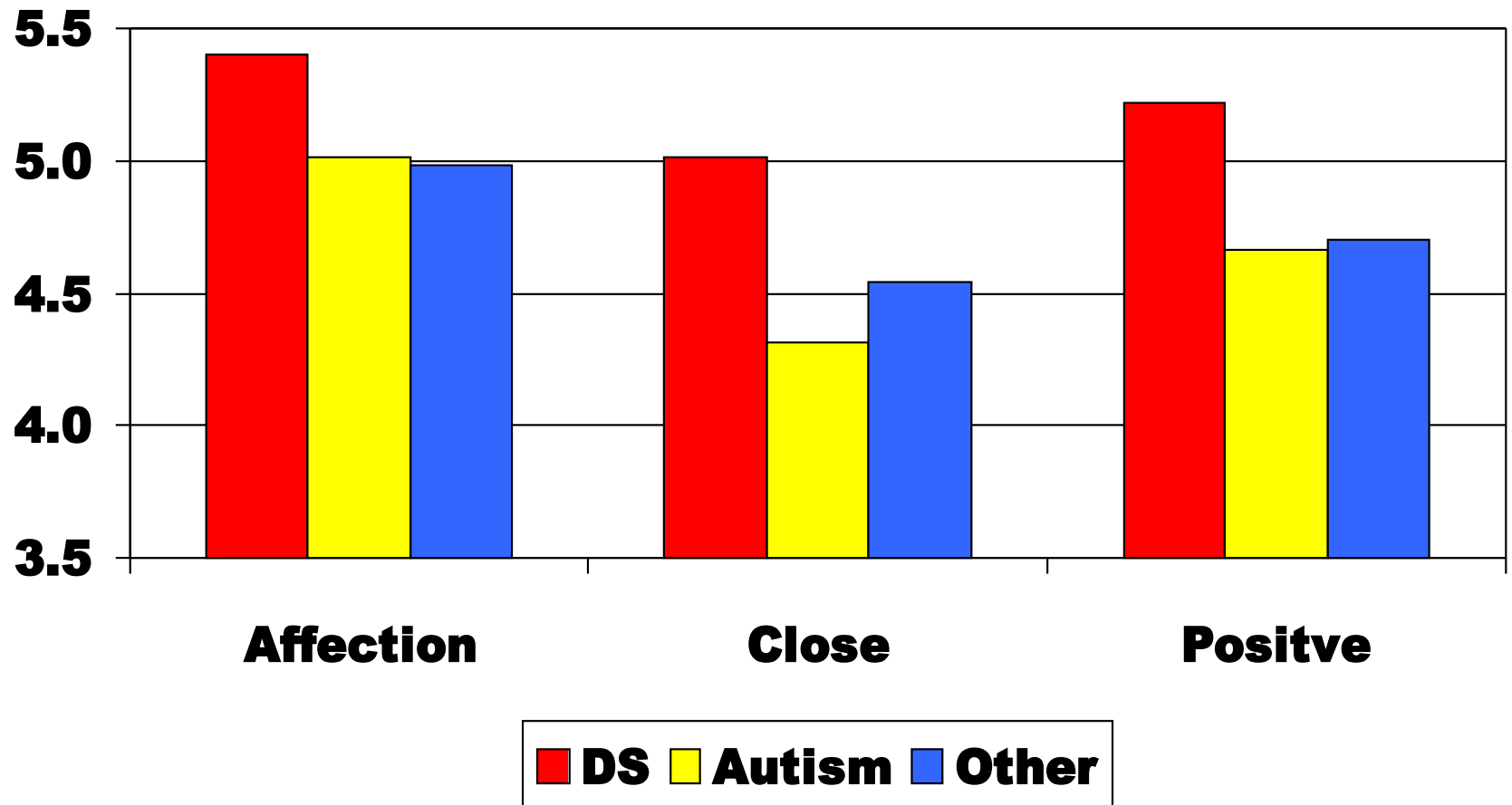


- A-Contacts
- B-Relationship between siblings
- C-The sibling's overall rating of their own health and depression

Hours per Month with Brother/ Sister with Disabilities



Relationship Questions, DS-Autism-Other



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



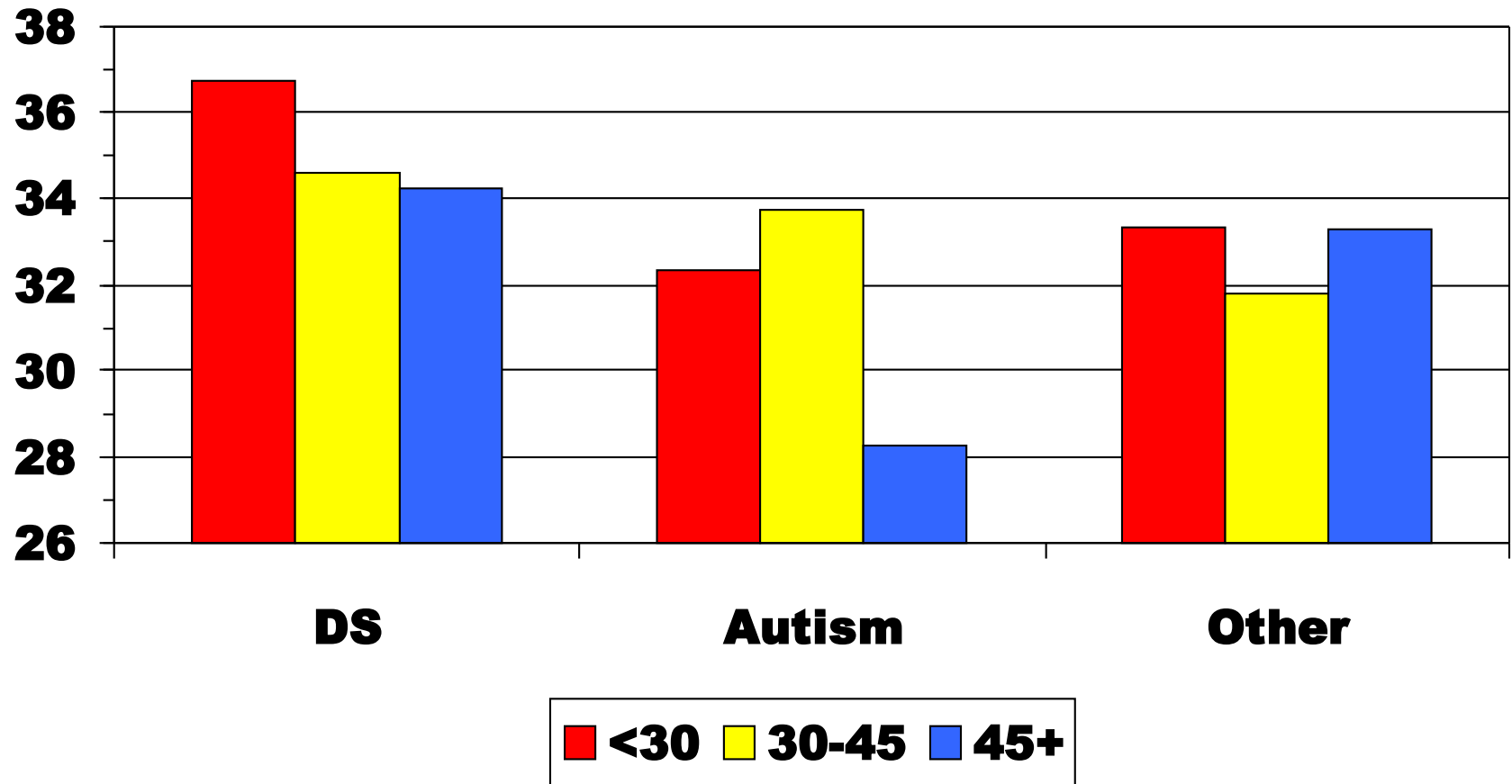
- Decline in all 3 groups (DS, autism, other) with age of brother/sister with disabilities

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



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

Thanks to...



- The Arc, US
- National Sibling Consortium
 - Elisabeth Dykens Laraine Glidden
 - Carolyn Graff Ann Kaiser
 - Gael Orsmond Marsha Seltzer



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