



What your other children without Down syndrome are thinking:
Sibling Issues

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Importance of Sibling Relationships

- Most intense
- Longest lasting
- Shape who we are
- Teach sharing, social skills, competition, coping skills, problem- solving

Moderating Factors

- Family size
- Birth order
- Age difference
- Gender association

American Journal of Medical Genetics Part C (Seminars in Medical Genetics) 142C:180-186 (2006)

ARTICLE

What the Other Children Are Thinking:
Brothers and Sisters of Persons With Down Syndrome

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- More positive interactions (kindness, less conflict)**
matched for gender, age, birth order in Australia
- Less prone to behavioral problems**
matched for age and socioeconomic equivalents in Australia
- More caregiving, increased levels of empathy**
matched for age, gender, and birth order in Australia

RESEARCH ARTICLE

AMERICAN JOURNAL OF medical genetics PART A

Having a Brother or Sister With Down Syndrome: Perspectives From Siblings

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How to Cite this Article:
Skotko BG, Levine SP, Goldstein R. 2011. Having a brother or sister with Down syndrome: Perspectives from siblings. Am J Med Genet Part A 155:2348-2359.

Our Research

- Sent surveys to 4,924 families**
invited a theoretical 4,343 brothers and sisters
GA, MA, CO, NC, TX, and CA
- 822 responses from brothers and sisters (19%)**
593 from brothers and sisters >12 years old (18%)
229 from brothers and sisters 9 – 11 years old (24%)
- Majority full biological siblings with diversity among Hispanic origin and religion**

Our Research: Feelings

96% siblings, >12, like brother/sister with DS

87% siblings, 9-11, proud of brother/sister with DS

29% siblings, 9-11, feel sorry that brother/sister has DS

4% siblings, >12, wish they could trade sibling with DS

Real Questions

Medical Questions

How do they get the extra chromosome?

Can Down syndrome be deadly?

Is Down syndrome more common for boys?

Why are some people with DS short?

Are all kids with DS strong?

How can you tell someone has DS?

Why does his face look
kind of odd?

**Before you answer a question,
ask yourself if you need more
information.**

Do you need to ask another question first?

Education Questions

Does my sister have to go to a special school?

Why did he do pre-school twice?

What is the best way to educate people with DS?

Why is it called 'Down syndrome' ?

Can people with DS graduate from college?

Where will my brother with DS live when he gets older?

Our Research: Involvement

93% siblings, >12 yo, plan to be involved with their brother or sister with Down syndrome when they are adults

Social Questions

Can people with DS have normal jobs?
How come they talk different than us?
Does DS affect the way my brother's life is?
Will she be ugly?
Will they get into fights?

My brother knows that he has DS and that he is different. Does yours?

Our Research: Family Life

14% siblings, 9-11, think sib with DS do more chores

12% siblings, >12, feel parents give unequal attention

88% siblings, >12, feel comfortable asking parents about DS



... Favoritism is easier to take when there's a defensible reason for it."

"Still, even the most tolerant siblings will at some point begin to feel that, healthy or not, they deserve their full share of care. Talking about the situation openly is the best and most direct way to limit resentment."

"Research suggests that differential treatment may have no negative effects when children understand why."

Negative Feelings Questions

Does your brother throw big fits in public?
Why is my brother obsessed with TV movies?
How come he loves our new toys but not his?
I hate it when my sister copies me. What should I do?
Why does my sister make weird noises?

Sometimes my sister embarrasses me. What can I do about this?

Our Research: Social Life

61% siblings, 9-11, worry sibling getting made fun of
89% siblings, >12, think friends are comfortable with sib
7% siblings, >12, embarrassed by sibling with DS
5% siblings, >12, feel social life worse off

Difficult Moment Questions

Why do people stare at my sister in public?
How should I make my sister stop listening to baby music when she is 13?
Since I am his little sister, he feels bad that I read much faster than him. What should I do?
How do you deal with people who use the word, "retard"?
How should I explain DS to my friends?

What should I do when my brother talks about things I don't think are going to happen, like driving a car or becoming an actor?

Our Research: Life Lessons

41% Life is good/rewarding; learned important perspectives
29% Understanding of differences
27% Patience
15% How to love
9% Everyone has talents
7% People with DS more alike than different

Be open and honest,
explaining Down syndrome as
early as possible.

Allow brothers and sisters to
express negative feelings.

Recognize the difficult
moments that brothers and
sisters may be experiencing.

Limit caregiving
responsibilities.

Recognize the individuality
and uniqueness of each child
in the family.

Be fair.

Take advantage of supports
for siblings.

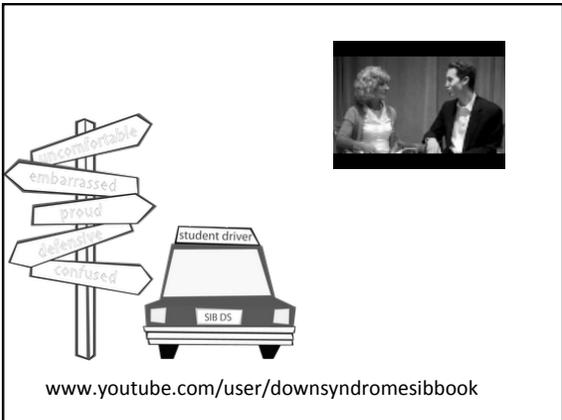
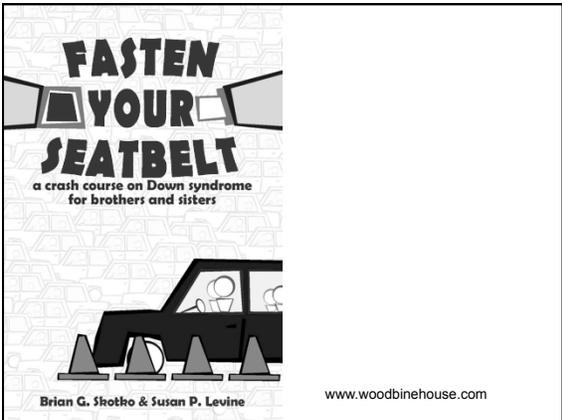
Parents should access
support for themselves.

Acknowledgements

NDSC and NDSS, brothers-and-sisters workshops
MDSC, DSALA, DSAA, MHDSA, TDSN, DSACT, DSSRI
Gary, Sharon, Allison, and Kristin Skotko, family
Gil Levine, Heather Reppert, research assistants
Allen Crocker, M.D., mentor, colleague, friend
Zoila Martinez, Spanish translation
Sion Kim Harris, Ph.D., statistical analysis
Alison Clapp, MLIS, literature search
All brothers and sisters who have shared their stories

Grant Sponsors

Tim White Foundation
Fred Lovejoy House-staff Research & Education Fund
Joel and Barbara Alpert Endowment for the Children of the City



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YouTube: www.youtube.com/brianskotko

Hospital: www.childrenshospital.org/downsyndrome



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“Mock My Pants, Not My Sister”



“Boston suffers from a kind of Style Down Syndrome, where a little extra ends up ruining everything.”

—John Thompson, *GQ Magazine*, July 15, 2011

<http://childrenshospitalblog.org/mock-my-pants-not-my-sister/>

How does one chromosome make kids so different?

If my sister is annoying, how should I deal with it?

How do they think?