

# Perspectives of siblings of children with different disabilities/chronic conditions

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# Sibling relationship

- Longest, most significant, dynamic, and influential relationship brothers/sisters have
  - Spend considerable time together
  - Life spans overlap



# Sibling relationship when child has disability

- Positive
  - Interactions: kinder, more empathetic
  - Mature, assume adult responsibilities at early age
  - Greater admiration, less competition/quarreling
- Negative
  - Extra responsibilities (caretaking, significant companions, helping socialize to others)
  - Needs of child take priority: interferes with family activities
  - Characteristics
    - Diminished self-concept
    - Less pro-social behavior
    - Anxiety/depressive symptoms
    - Academic difficulties



# Purpose

- To investigate perceptions siblings of children with intellectual/physical disabilities/chronic conditions have about their experiences and then compare perceptions across disabilities/conditions.



# Participants

- 23 siblings of children with Down syndrome (11 brothers; *M* age = 16 years);
- 20 sibling of children with autism (11 brothers; *M* age = 12.3 years)
- 13 siblings of children with diabetes (7 brothers; *M* =10.7 years)



# Method

- One on one interviews
  - Siblings of children with autism
  - Siblings of children with Down syndrome
- Focus groups
  - Siblings of children with diabetes



# Open ended questions

- What it was like growing up with (name of CWD)?
- What was difficult/hard about the experience?
- What was easy/rewarding about the experience?



# Analysis

- Interviews/focus group comments transcribed verbatim
- Appropriate qualitative methods
  - Categories refined by collapsing across or creating sub-categories
  - Exemplars identified through selective coding
  - Looked for similarities/differences





# Children with Down syndrome



# Siblings of children with Down syndrome

## – Positive

- Learned to be responsible
- Became patient, tolerant, compassionate

## – Challenges

- Frustrating, worrisome
- Assumed more family responsibilities
- Hard on parents



# Positive effects

- “He’s taught me acceptance and responsibility so I’ve...learned a lot really...and it’s been amazing. It’s the biggest blessing I’ve ever had.” (16 year old sister)
- “I think...I actually, I love it... she’s just...so happy all the time and...really fun to be around.” (14 year old sister)



# Positive effects

- “I am a lot more patient with people and a lot more humble. I keep thinking about what kind of person I’d be. I’d probably be one of the biggest jerks if I didn’t have [child’s name]. It’s made me very considerate of other people.”  
(18 year old brother)



# Challenges: behaviors

- “She doesn’t listen very well and she’s very stubborn and she gets mad easily.” (17 year old brother)
- “When I have to do homework sometimes he can really be nagging on me the entire time I’m doing the homework because he wants me to go and do something else.” (16 year old brother)



# Challenges: behaviors

- “It’s trying, it’s really frustrating...because you just want him to be able to do things as quick and understand things as easy as a normal child.” (16 year old sister)
- “It causes me to sometimes get really angry at him...even though he can’t control it...it is still...a pain.” (16 year old brother)



# Challenges: responsibilities

- “I’m really careful around her. I’ll make sure she’s always alright...” (14-year-old sister)
- “We just have to always be aware of what’s going on. He has to have multiple medicines every morning and night....if you don’t get it to him then he can get really sick.” (18-year-old brother)



# Ambiguous

- “It’s so much fun. She can be kind of crazy at times, and it can be kind of hard watching other sisters that are around our same age and see how functional that the little sisters and how much...they do with each other. It’s kind of hard when I see [child’s name] and I know we’re never going to have those kinds of things, but I feel like ....it’s great. It’s really hard sometimes and...sometimes I really wish she was normal.” (18 year old sister)





# Effect on parents

- “My mom spends every day watching out for him, working with him, trying to find people to work with him that will help him improve his understanding and his mental and physical needs and she’s always working.” (18 year old brother)
- “I think it causes a lot of stress, and they’re very patient with her and they take care of her the best they can. I think in some ways it’s put a stress on their marriage but at the same time it really reinforces it, ‘cause there’s no way that they could do it alone. But I think they’ve learned to work together a lot...more.” (19 year old brother)



# Effect on family

- “ We can’t go out as much...we all get frustrated and it’s hard to deal with...Sometimes...we come back and everyone’s frustrated and you have to deal with her (CWDS)...You have to have new patience and everyone is worn out.” (13 year old sister).
- “I think it’s actually been a big family builder ‘cause it gives us a cause for us all to...bond together better and get to know each other better.” (17 year old brother)



# Siblings of children with autism

- Ambiguous
- Challenges
  - Received less attention from parents
  - Assumed extra family responsibility
  - Child's bothersome behaviors (screaming, hitting, crying, tantrums, destructive behaviors, and repetitive behaviors)
  - Poor communication



# Ambiguity

- “It has been a rocky road . . . Sometimes it’s really hard, sometimes it’s nice and easy.”
- “It has ups and downs certainly, but mostly it’s been pretty good.”



# Less Attention

- “He always comes first... [we] make sure he’s always taken care of first before we are taken care of.”
- “She’s . . . the center of attention, so everything is pretty much mostly about her.”



# Responsibility

- ◎ “You constantly have to know where he is because he can’t be left alone.”



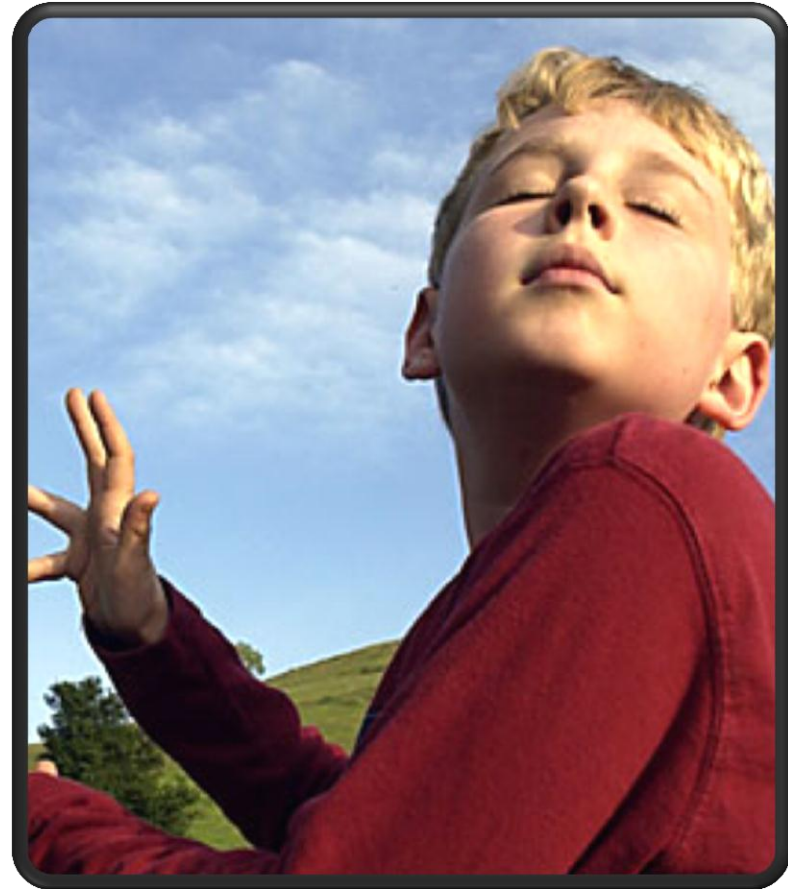
# Bothersome Behaviors

- ◎ “He cries a lot and doesn’t understand much....He hits me when he cries.”
- ◎ “When she’s really frustrated and mad, it’s hard to talk to her or anything without her screaming.”



# Communication issues

- ◎ “I didn’t really understand when I was little what was wrong with him, like, why he couldn’t talk to me. And it was hard that he wouldn’t answer back to me.”





# Positive Aspects

- Child characteristics
- Became better people



# Child characteristics

“He’s very smart, even though he can’t communicate a lot of stuff, and he really likes to be loved on by his family, so that’s fun and it just makes it easy to play with him.”

“[He]’s so nice to be around and loves everyone, and is just fun to be with. He’s really funny and makes us laugh.”



# Child characteristics

- “She always comes to you, and she seems to feel your pain... and she sort of just cheers you up, and I don’t think I’d ever be able to live without it.”
- “He is a very smart boy, I can tell you that. He has brought a lot of joy into our family . . . Overall it’s been a great experience.”



# Lessons learned

- “I think everything that happened, it teaches me something, and I can use it in my life, so I’m glad [about] the things that happened.”



# Age differences

- Younger children: behaviors
  - “Hard, because she destroys everything.” (9 year old brother)
  - “Sometimes pretty annoying, because he always runs around screaming.” (11 year old sister)
- Older children: experience and what they learned
  - “I’m glad I had the experience because it’s taught me so much ... [about] unconditional love and not judging.” (17 year old sibling)



# Siblings of children with diabetes

- No mention of challenges/positive aspects of living with a child who had diabetes
- Did not have a clear understanding of diabetes and its treatment
- Siblings knew parents were affected
  - Parental stresses related to diagnosis
  - Changes made within family because of diagnosis



# Challenges/positive aspects

- “... you just kind of get used to it after a while. You just hardly notice it. I don't even know that she has diabetes...promise you, you will not notice it.”



# Poor understanding

- Not aware of what terms meant: ‘glucose’, ‘highs/lows’, ‘pumps’, etc.
- Long term consequences
  - “...so like he eats something get he’ll... he’ll die. Well he won’t die he’ll just have to battle for it. And he won’t have anything to help it. I know there’s something to help it. And I know what it’s called...I know what it’s called but I forgot.”





# Effect on parents

- “My mom and my dad have to pay a lot of money for all the supplies and stuff.” (8 year old brother)
- “My mom gets frustrated with my sister when she doesn’t do something.” (9 year old brother)
- “...it freaked them out at first.” (12 year old sister)



# Conclusion

- Understand sibling perspectives
  - Intellectual disability
    - Child's behaviors
    - Increased responsibilities
  - Physical disability
    - Need information about condition
- All sibling groups aware of effect on parents



# The Forgotten



- Be aware of siblings' experiences
- Give siblings time and attention
- Answer questions
- Help siblings cope
- Educate parents about sibling perceptions

