

he following is text version (with slight modifications) of a presentation given by Cate Walsh Vockley, MS, CGC at the 2008 NNPDF Family Conference in Atlanta, GA

Siblings of Children Who Have Chronic Illness or Disability: Pointers for Parents

1. sib-ling (sb'lng) n. One of two or more individuals having one or both parents in common; a brother or sister. [Middle English, from Old English, from sibb, kinsman; see sib.]

All of your children are "siblings," whether they have the condition in question or not, and importantly, in some families, there are multiple sibs who have the same condition, which further modifies the dynamics of family relationships. Also, almost all of you (parents) are siblings, and some may have a brother or sister who has a chronic illness or disability. This talk will focus on children as siblings, but I will comment briefly on adult sibs as well.

2. First, what to call these siblings and children who have a chronic condition:

_____ vs. the other children

Have vs. have not???

Affected vs. unaffected (they may not have disease, but still "affected")

NPD vs. NPD-free

_____ vs. typically developing

Special Siblings

"Sibs" - they are all sibs

3. " the sibling relationship is often the longest lasting relationship in the family"

- depending on what you read, between 18 and 29% of children in the US have a moderate to severe chronic illness or disability – this leads to a lot of siblings of children who have a chronic condition!
- these siblings are at risk for emotional/behavioral, physical and financial consequences
- attention to these relationships is needed but often overlooked as the focus is turned to the affected child and parents by health care professionals.

4. These are the goals of this presentation:

Information
Increase Awareness
Promote Understanding
Accentuate the Positives
Identify Potential Problems
Optimize the Situation

5. These are NOT the goals:

Creating the Super-parent – we do our best
Making Parenting Easy

6. One more goal:

Focus on Moving from Sibling Rivalry to Sibling Revelry/Empathy

7. The focus is usually on the sibling/child who has a chronic illness/disability because he or she has the greatest number of needs. For these children and their caregivers, these needs might include:

8. General principles when considering sibling reactions:

- a. Sibling adjustment impacts on overall adjustment and self esteem of both/all children. If adjustment is significantly altered, it can affect the long term benefits of the sibling relationship.
- b. The sibling relationship is the first social network for children and is the testing ground for many future relationships – this testing is normal as a way to understand social norms and learn what is acceptable.
- c. Siblings fill many roles for each other: friend, companion, teacher, follower, protector, enemy, competitor confidant, role model – these are all impacted by the presence of a chronic condition. The sibling relationship can be seen as an “opportunity to learn the art of negotiation and reconciliation” (Fleitas, 2000)
- d. Sibling adjustment is different for each family. Critical factors in this adjustment, many of which are interwoven like a spider web, may include: personalities, finances/resources, severity, chronicity and type of illness, ages of the siblings and age differences, number of children who have the illness/disability, overall number of children, family structure, family lifestyle, family views of disability, childrearing practices, other stressors and previous coping mechanisms, support available (formal and informal, including access to extended family)
- e. Sibling conflict is normal, even in the face of a chronic condition – studies show it takes 30 minutes on average for sibs to resolve conflicts, whether or not the parents become involved. (Parents must always be aware of the need to protect from harm).
- f. Sibling adjustment changes over time and is dependent on developmental stage
- g. Being the sibling of an individual who has a chronic condition is not all bad: those interviewed say that the good and bad experiences balanced out, on average. Early published studies all appeared in the psychology literature therefore, because of ascertainment bias (only those with problems tend to get referred for psychological counseling), showed poor adjustment. McHale and Gamble concluded that “children with disabled siblings appear to have more positive and fewer negative behavioral interactions than those with nondisabled siblings

9. What do siblings feel/express about their siblings and the relationships they have?

- These feelings often mirror the parents’ feelings and attitudes
- They can be positive (showing resilience or recognition of opportunities) or negative (revealing stresses), and are often age-dependent. Much of the published data comes from the psychology literature, so focuses on resolving the negatives, so examples of positive comments are more difficult to access.

Opportunities:

- Love
- Insight on the human condition
- Increased maturity
- Increased coping skills
- Appreciation for health and families
- Loyalty, supportiveness, protectiveness

- Pride in their own and sib's accomplishments
- Independence
- Increased self-confidence
- Altruism
- Increased empathy/sensitivity
- Increased patience
- Increased tolerance of differences
- Compassion
- Increased problem-solving skills
- More inventive problem-solving skills
- Greater leadership skills
- Increased sense of responsibility

Stresses

- Sense of loss/regret: of normal sibling, normal family life and
- Activities, loss of spontaneity
- Isolation/loneliness/"invisibility" – can become a cycle of limited access to peers due to embarrassment about bringing friends home, then not getting invited out/no opportunity for reciprocating; the "withdrawn" child
- Embarrassment – as young child, as teen (what will dates think)
- "Out of the Loop" – not enough information provided; keeping family secrets

"It was eerie actually. The doctor looked through me as if I was a plant or something. He just talked to my mom. There I was, scared out of my wits...I felt angry and confused... and pretty lonely, too. She's my best friend." (Fleitas, 2000)

- Guilt: did I cause these problems/self-blame (imaginative thinking), survival guilt, guilt about getting angry at the sib

"Every time I thought about the stress I was experiencing, and complained to myself, I immediately felt guilty. How could I complain when Maddy was going through so much?"

- Resentment, especially about time spent by parents with affected sib
- Identification illness: I want the same thing because I'd get more time, more privileges (missing school, treats after MD visits);
- mimicking of condition to get attention, esp. with young siblings, or regression in behavior

"Dear Mom. Tonight Dad was telling me how hard it was when Trudy was in the hospital. He doesn't think it was hard for me at all. I missed you. I saw her get all these presents. I saw everyone visiting her and babying her, and there was no- thing I could do about it. Sometimes I feel so alone and left out and even unloved. I know I'm overreacting, and I know that some people have so much less than me, but its not my fault I don't have any medical problems. I wish I did!
Love, Jeffrey" (Fleitas,2000)

- Concern: about day-to-day care, about the future

- Anger: parents need to get to the root of the anger, don't assume you know what it is; the "acting out" child

"Non-handicapped kids can get pushed aside when their brothers or sisters have handicaps. Andrew seems to get help naturally – it's like attention to his needs is "built into the system." I'm the bad one, but he can do no wrong. He makes all the messes, but I get into trouble if I don't empty the dishwasher."
(from NICHCY News Digest/Binkard)

- Fear: "Will I catch the condition?" Fear of intimacy/loss, fear of one's own or the sib's early death, heightened sense of vulnerability

"..when mommy goes to the hospital, I'm scared that she will stay there forever. When I don't see her for a very long time, I'm just plain scared. That's all I can tell you, except that I got to come into the hospital to visit today. I don't want to leave my brother's room....ever.
(5 year old, Fleitas, 2000)

- Overwhelmed, sense of obligation - from care giving responsibilities, especially for sisters ("I'm not her mom"; the "parent-ified child"). Feeling pressured (real or imagined) to achieve to make up for sib; the "super-achieving child" "I find it difficult to live up to the expectations of being a super-kid...just for once I wish I wasn't the one that my parents say that they can always count on."
(Fleitas, 2000)

"My earliest memories are of being Colin's sister – I cannot remember being a child in my own rite. I was always expected to sit quietly and behave during his appointments – and as you can imagine – there were many! I felt that even from a young age there was a pressure on me to be more mature than other children my age. My preschool years were spent being dragged from appointment to appointment, or being left with people I did not know or like, while professionals tried to determine how Colin had been affected." (Mel Young, UK)

- Jealousy

"I think...I'd want them to understand that sometimes siblings are going to get jealous of the extra help and attention that a brother or sister who's handicapped receives. Parents shouldn't get mad about the jealousy or make the kids without a handicap feel too guilty about it if sometimes they resent the extra attention. Parents have to sit down and talk to the brothers and sisters who aren't handicapped about what the handicap really means. Kids don't automatically understand it by themselves."
(NICHCY News Digest/Binkard)

- Sadness/chronic sorrow/chronic grief – similar to what is being experienced by the parents
- Confusion, uncertainty
- Protectiveness

"..and with nobody having noticed what a huge impact having Colin as brother was having on me emotionally. I find it very difficult to articulate exactly how I do feel about him. Obviously I love him so much but it doesn't feel like an equal love. I often feel like I love him in a maternal way. Mixed in with this is also my sadness and feelings of loss like I'm grieving for the brother I should have had. This then brings guilt because I should accept him for who he is. As an adult I find this difficult to deal with but as a child I did not know how to begin to describe my feelings to anyone. So mostly my overriding feelings were that of anger and frustration." (Mel Young, UK)

- Different – especially for teens; "I don't want to feel different"
- Low self-esteem: I'm not good enough to be around my ill sibling, I'm not good enough to warrant my parents' attention, siblings may bury their own needs
- Difficulty coping – internalizing feelings

- Rivalry: Attention-seeking; Jealousy; Teasing- testing limits of social acceptability; Competitive

11. Sibling Needs

- Information – life-long need. This need is as great as, if not greater than, the need for information for the parents. Children identify with their siblings and along the entire path of the illness will constantly relate their experiences to those of their sibling. Especially in young children, they are very self-centered and may take the illness personally, may blame themselves or imagine worse than reality

For Roy, it meant that, in his words, "Now I know I am not stupid. There is a reason for the things I can't do." Roy had known that he had difficulties long before we were aware of it. Knowing has given him confidence and enabled him to make life choices that he might not have made had he not known."

- Open communication and permission to ask any question – large or small

"I really appreciated not ever being kept in the dark and having my questions answered honestly. I would have become increasingly worried as in spite of all the tests to the contrary, I still had the fear that I had NPC." (Emma Ford, UK)

- Representation – "Nothing about us without us!"
 - see us as individuals with individual needs
 - recognize each child's unique qualities and contributions
- Parental understanding of the grief process/cycle: and knowing it's easy to get "stuck"

Kubler-Ross Grief Cycle

Shock – initial paralysis

Denial - avoidance

Anger – frustration spilling over

Bargaining – seeking in vain for a way out

Depression – realization of the inevitable

Testing – seeking realistic solutions

Acceptance – finding a way forward

- Participation – in clinic visits, family discussions, etc.
- Permission to have normal emotions and to openly express them; feelings are normal
- One-on-one time with parent(s) – utilize sitters and respite care. Little things can mean a lot, like asking what the child wants, not assuming the parent always knows
- All children in a family need to have very specific roles and levels of accountability
- Communication goes both ways: listening and informing
- Consistency – at home, at school (balance attending appointments with staying at school)
- Understanding/Patience – there may be a gap between a child's ability to understand/intellectualize and his/her behavior. Be careful that the sib doesn't receive more negative attention than positive attention "I think... I'd want them to understand that sometimes siblings are going to get jealous of the extra help and attention that a brother or sister who's handicapped receives. Parents shouldn't get mad about the jealousy or make the kids without a handicap feel too guilty about it if sometimes they resent the extra attention. Parents have to sit down and talk to the brothers and sisters who are non-handicapped about what the handicap really means. Kids don't automatically understand it by themselves."
Beth (from At Health)
- Limits on care-giving role

- m. Understanding that the developmental needs of the child who has a chronic illness and the child(ren) who does not may be in direct conflict. For example, treating the child with the illness as normal is good for that child, but may create distance between the unaffected sib and the illness, and thus inhibit normal development of an understanding of the illness and its consequences.
- n. Willingness to seek professional help if needed
- o. Future planning - children who have sibs with chronic illness become the “Uber-sandwich” generation – their aging parents live longer, their affected siblings live longer and they may have their own children to care for as well. They need to know that future planning has been done for the affected sibling if s/he is unable to care for him- or herself. Financial issues, guardianship, residence, etc. all need to be worked out in an equitable fashion.
- p. Genetic Counseling

12. What Sibs Want Us to Know

- a. We have a right to our own lives: “nothing about us without us”
- b. Acknowledge our concerns – accept them as normal and understand that they will change over time.
- c. Have reasonable expectations for ALL of you children
 - o this will minimize resentment
 - o assure us that there is no need to compensate
 - o convey clear expectations and unconditional support
 - o double standards which result in conflicts
 - o expect all that is possible from the CI/D child to foster independence
- d. Expect us to behave like typical kids
 - o teasing, name calling, arguing all promote normal social development...”now is the time to make mistakes”
- e. We deserve to have our own personal safety given as much importance as the safety of the family members who has special needs
 - o protect us from behaviors
 - o don’t ask us to do things beyond our skill level
- f. We have a right to receive age-appropriate information
- g. We like to know that we are not alone in this situation – provide opportunities to meet peers/connectedness
- h. We want to know that we and our siblings face a well-planned future and that we are involved in the process –give us the free choice to be involved and know what we want re. planning. Consider back up plans
- i. Include ALL of us in the planning; share responsibilities (sons and daughters, older and younger)
- j. We need open, honest communication
- k. We need one-on-one time with mom and dad
- l. One child’s needs should not overshadow another’s achievement, milestones, celebrations. (Use respite care)
- m. Your/parent’s interpretation of the sib’s disability has the greatest influence on our ability to adapt.
- n. Include siblings in the definition of family
- o. Actively reach out and invite sibling participation

- p. Learn more about how it feels to be a sib
- q. We benefit from connections with other who “get it” - promote sibling interactions, offer but don’t mandate because these could accentuate the “different” for some kids
- r. Respect our perspective. Include us on Foundation Boards and in policies
- s. Support services for sibs
- t. We don’t resent the person, but the disease!

13. The similarly affected sibling (2 children who have the same condition): there is very little written about this, especially in the degenerative diseases, but as expanded newborn screening becomes widely implemented, I think this is an area opening up to investigation. For some families, the first child is diagnosed because of a significant episode. Subsequent children who have the condition may feel they are well at the expense of their sib. They may worry that they will have a similar episode. One mother whose son died from NPC is most eloquent as she speaks about her second affected child:

“Roy had memory problems first then physical difficulties. He has never had any behavioral problems. Roy was 14 and was quite well when we first talked to him about NPC and able to understand the explanation we gave. He saw the devastating effect that NPC was having on his younger brother. Our pediatrician had explained to Roy that this disease was so rare that no one could predict how it would be for him. He explained that both Roy and Murray had their own particular disease and that they would each deal with it in their own particular way. Roy's response was that Murray had his own disease but it would be different for himself. He understood that research was going on to find out the causes of NPC and to look for a treatment.”

(Susan, UK)

14. Parental Roles

- a. Communication goes both ways: listening and informing
- b. Provide age-appropriate information about illness
- c. Role-play answers to difficult questions children may face from peers, teachers, etc.
- d. Model positive problem-solving behavior for the children
- e. Encourage journaling or other forms of expressing feelings
- f. Advocate for children with teachers and other adults

“...I realized that my teachers would often let me hand in work late without saying anything about it. They probably thought they were being helpful to me because they know I have a bit of a difficult time at home, but leaving my problems unchecked did me more harm than good.”

(Mel Young, UK)

- g. Develop sound financial plans for the child with chronic illness if s/he will not be able support him- or herself. – this is a whole topic for a talk by itself. Some information can be found through Metlife’s MetDESK – Division of Estate Planning for Special Kids
- h. One approach:
 1. Take 2 steps back and evaluate the impact of the disability or illness. How does it organize family interactions?
 2. Evaluate the level of stress. Increased stress leads to disorganization and rigidity
 3. Identify a counselor with expertise
 4. Work on resolutions and do your homework!
 5. Praise success

6. Create stability – recreate “normal”

15. How Professionals Can Help

- a. Redefine “Family” to include all children, e.g. IFSP – Individualized Family Service Plan
- b. Invite sibs to participate – often parents hear “it might be best if you leave the other children at home;” sometimes it’s necessary, but be open to including sibs or creating programs for them
- c. Provide age-appropriate information about illness
- d. Create preventive rather than interventional programs

16. Interventions: preventive and/or in Times of Trouble

- a. SibLink (Brown University)
 1. Family-based, initially targeting 8-13 year olds, modified to serve 4-7 year olds
 2. 6 sessions for siblings targeting knowledge, communication within the family, identifying and managing emotions, problem solving, connectedness (peer interactions), identification of strengths and needs
 3. Sessions for parents targeting communication, normal pediatric development and implications for adaptability, within family functioning, and knowledge
 4. Joint group to enhance understanding
 5. Outcomes: increased knowledge, self-competence, social functioning and connectedness
- b. Sibling Center (UCSF)
 1. Developmental/preventive model focusing on education and psychosocial issues
 2. Group program
 3. 4 sessions:
 - Evaluation and treatment plan development
 - Focus on communication, emotions and coping skills
 - Same
 - Recap with sib alone and then with parent
- c. ISEE (Community-based Intervention for Sibs and Parents of Children with Chronic Illness or Disability) (Kansas, Missouri)
 1. Camp setting for siblings focusing on education, social support, self-esteem, sib mood, behavioral adjustment and attitudes toward illness
 2. Parents are involved in information session only.
 3. 2 follow up session 4 and 9 months after camp
- d. SIBS: Support, Information, Balance, Sensitivity

Closing Quote:

“Living and loving Rebecca has taught me so many things. I’ve learned how to be patient, understanding, and caring. How to love fully. I’ve learned to take the time for little things in life, like looking at the trees and watching the leaves blow. To my amazement, I love the life I have because of her...I would never trade it in for anything else! I learned that when in life we are faced with challenges, we should deal with them the best way we can, we should take time out for ourselves, and we should never give up!”
(Fleitas, 2000)