

# 2008 FOD & OAA METABOLIC FAMILY CONFERENCE

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

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# Sibling Workshop

Affected vs. unaffected

Have vs. have not

\_\_\_\_\_ vs. the “other” children

FOD/OAA vs. FOD/OAA- free

\_\_\_\_\_ vs. typically developing

Special Sibling

“Sibs”



# Sibling Workshop

- ❖ Between 18 and 29% of children in the US have a moderate to severe chronic illness or disability
- ❖ There are thus many siblings of these individuals
- ❖ These siblings are at risk for emotional/behavioral, physical and financial consequences
- ❖ Attention to these relationships is needed but had been overlooked, with focus on affected child and parents



# Sibling Workshop

“...the sibling relationship is often the longest lasting relationship in the family”

(ARCH Factsheet Number 23)



# Sibling Workshop Goals

- ❖ Information
- ❖ Increase Awareness
- ❖ Promote Understanding
- ❖ Accentuate the Positives
- ❖ Identify Potential Problems
- ❖ Optimize the Situation
- ❖ Sibling Rivalry ---> Sibling Revelry/Empathy



# Sibling Workshop

## ❖ The Sibling Who Has the Chronic Illness

### – Needs:

- ❖ Disease Management
- ❖ Emotional/behavioral health (decrease distress)
- ❖ Self-determination – let them express their needs, don't make assumptions
- ❖ Health Promotion
- ❖ Prevention of Illness



# Sibling Workshop

## ❖ The Sibling Who Has the Chronic Illness

### – Interventions:

- ❖ Clinicians
- ❖ Written Materials
- ❖ Computer Resources
- ❖ Workshops/Camps
  - social skills
- ❖ Peer Counseling



# Sibling Workshop

## General Principles: Sib Relationships

- ❖ Sibling adjustment impacts overall adjustment and self esteem of both/all children
- ❖ The sibling relationship is the first social network for children and is the testing ground for many future relationships
- ❖ 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 chronic illness
  - Having siblings presents “opportunities to learn the art of negotiation and reconciliation” (Fleitas, 2000)





# Sibling Workshop

## General Principles: Sib Relationships

- ❖ Critical factors influencing impact of chronic illness or disability on the family 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 or 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)
- ❖ Sibling conflict is normal, even in the face of chronic illness or disability - 30 minute rule



# Sibling Workshop

## General Principles: Sib Relationships

- ❖ Sibling adjustment changes over time and is dependent on developmental stage
- ❖ Being the sibling of an individual who has a chronic illness or disability has both ups and downs:

*“children with disabled siblings appear to have more positive and fewer negative behavioral interactions than do those with nondisabled siblings”*

*News Digest* *McHale and Gamble. NICHCY*



# Sibling Workshop

## Sibling Feelings

- ❖ Sibling feelings often mirror the parents' feelings and attitudes
- ❖ Feelings can be:
  - ❖ Positive (resilience or opportunities)
  - ❖ Negative (stresses)
  - ❖ Often age-dependent



# Sibling Workshop

## Sibling Feelings: 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



# Sibling Workshop

## Sibling Feelings: Opportunities

- ❖ Independence
- ❖ Increased self-confidence
- ❖ Altruism
- ❖ Increased empathy/sensitivity
- ❖ Increased patience
- ❖ Increased tolerance of differences
- ❖ Compassion
- ❖ Increased problem-solving skills
- ❖ Inventive problem- solving skills
- ❖ Greater leadership skills
- ❖ More responsible



# Sibling Workshop

## Sibling Feelings: 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
- ❖ Embarrassment – as young child, as teen
- ❖ “Out of the Loop” – not enough information

*“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)*



# Sibling Workshop

## Sibling Feelings: Stresses

- ❖ Resentment, especially about time spent by parents with affected sib
- ❖ Guilt: “did I cause these problems”/self-blame (imaginative thinking), survival guilt, about getting angry with 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?”*

*(Fleitas, 2000)*





# Sibling Workshop

## Sibling Feelings: Stresses

- ❖ Identification illness: sib wants the same thing because s/he'd get more time, more privileges (missing school, treats after MD visits); mimicking of condition to get attention, 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 nothing 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)*





# Sibling Workshop

## Sibling Feelings: Stresses

- ❖ Concern: about day-to-day care, about the future
- ❖ Anger: the “acting out” child
  - parents need to get to the root of the anger

*“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.”*

*(NICHCY News*

*Digest/ Binkard)*



# Sibling Workshop

## Sibling Feelings: Stresses

- ❖ 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)*



# Sibling Workshop

## Sibling Feelings: Stresses

- ❖ Overwhelmed, obligated
  - ❖ Care-giving responsibilities, especially for sisters
  - ❖ “I’m not her mom”; the “parent-ified child”
  - ❖ Pressure to achieve/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)*



# Sibling Workshop

## Sibling Feelings: Stresses

*“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 (conference*



resentation)



# Sibling Workshop

## Sibling Feelings: Stresses

### ❖ 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 sister who aren’t handicapped, about what the handicap really means. Kids don’t automatically understand it by themselves.”*

*(NICHCY News Digest/ Binkard)*





# Sibling Workshop

## Sibling Feelings: Stresses

- ❖ Sadness/chronic sorrow/chronic grief – like parents
- ❖ Protectiveness
- ❖ Confusion, uncertainty

*“..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 (conference presentation)*



# Sibling Workshop

## Sibling Feelings: Stresses

- ❖ Different – “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 deserve my parents’ attention
  - ❖ May bury their own needs
- ❖ Difficulty coping – internalizing feelings



# Sibling Workshop

## Sibling Needs

- ❖ Information – life-long need
  - ❖ Children identify with their siblings
  - ❖ May take the illness personally
  - ❖ May blame themselves
  - ❖ May imagine worse than reality





# Sibling Workshop

## Sibling Needs

*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.”*

*communication)*

*Susan (personal*



# Sibling Workshop

## Sibling Needs

- ❖ Representation – “Nothing about us without us!”
- ❖ 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.”*

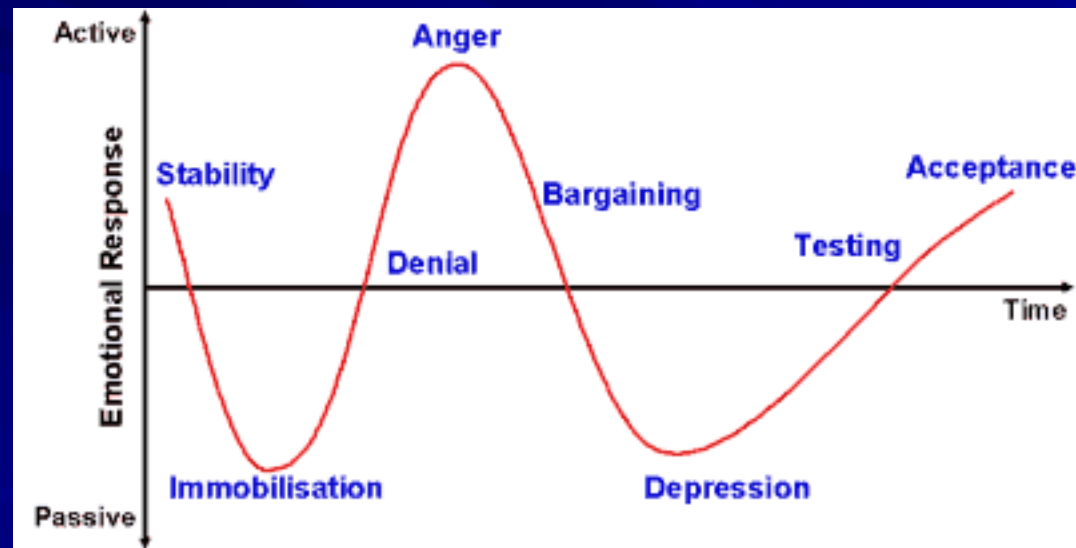
*Emma (Niemann-Pick News Sheet, UK)*



# Sibling Workshop

## Sibling Needs

- ❖ Parental understanding of the grief process/cycle



# Sibling Workshop

## Sibling Needs

- ❖ Participation
- ❖ Permission to have and openly express normal emotions
- ❖ One-on-one time with parent(s)
- ❖ All children in a family need to have very specific roles and levels of accountability
- ❖ Communication goes both ways: listening and informing
- ❖ Consistency



# Sibling Workshop

## Sibling Needs

### ❖ Understanding/Patience

*"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 (At Health)*



# Sibling Workshop

## Sibling Needs

- ❖ Limits on care-giving role
- ❖ Understanding that the developmental needs of the child who has a chronic illness and the child who does not may be in direct conflict
- ❖ Willingness to seek professional help if needed
- ❖ Genetic Counseling



# Sibling Workshop

## What Siblings Want Us to Know

(The Sibling Project)

- ❖ We have a right to our own lives: “nothing about us without us”
- ❖ Acknowledge our concerns – accept them as normal and understand that they will change over time.
- ❖ Have reasonable expectations for ALL of you children
  - ❖ This will minimize resentment
  - ❖ Assure us that there is no need to compensate
  - ❖ Convey clear expectations and unconditional support
  - ❖ Double standards with results in conflicts
  - ❖ Expect all that is possible from the CI/D child to foster independence
- ❖ Expect us to behave like typical kids
  - ❖ Teasing, name calling, arguing all promote normal social development
  - ❖ “Now is the time to make mistakes”





# Sibling Workshop

## What Siblings Want Us to Know

- ❖ We deserve to have our own personal safety given as much importance as the safety of the family members who has special needs
  - ❖ Don't ask us to do things beyond our skill level
  - ❖ Protect us from behaviors
- ❖ We have a right to receive developmental- or age-appropriate information





# Sibling Workshop

## What Siblings Want Us to Know

- ❖ We like to know that we are not alone in this situation
  - ❖ Provide opportunities to meet peers
  - ❖ Promote connectedness
- ❖ We want to know that we and our siblings face a well-planned future and that we are involved in the process
  - ❖ Free choice to be involved
  - ❖ Consider and implement back up plans
- ❖ Include ALL of us in the planning; share responsibilities
  - ❖ Sons and daughters
  - ❖ Older and younger



# Sibling Workshop

## What Siblings Want Us to Know

- ❖ We need open, honest communication



# Sibling Workshop

## What Siblings Want Us to Know

- ❖ We need one-on-one time with mom and dad
- ❖ One child's needs should not overshadow another's achievement, milestones, celebrations.
  - ❖ Use respite care
- ❖ Your (parents') interpretation of the sib's disability has the greatest influence on our ability to adapt.
- ❖ Include siblings in the definition of family



# Sibling Workshop

## What Siblings Want Us to Know

- ❖ Actively reach out and invite sibling participation
- ❖ Learn more about how it feels to be a sib
- ❖ We benefit from connections with other who “get it”
  - ❖ Promote sibling interactions
  - ❖ Offer, don’t mandate because these could emphasize the “different” for some kids



# Sibling Workshop

## What Siblings Want Us to Know

- ❖ Respect our perspective
  - ❖ Include us on Boards
  - ❖ Include us in policy development and policies
- ❖ Support services for sibs
- ❖ We don't resent the person, but the disease!



# Sibling Workshop

## Multiple Affected Siblings

- ❖ Limited information
- ❖ Issues related to Newborn Screening
- ❖ Research needed

*“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 (personal communication)*



# Sibling Workshop

## Parental Roles

- ❖ Communication goes both ways: listening and informing
- ❖ Provide age-appropriate information about illness
- ❖ Role-play answers to difficult questions children may face from peers, teachers, others
- ❖ Model positive problem-solving behavior for the children
- ❖ Encourage journaling or other forms of expressing feelings





# Sibling Workshop

## Parental Roles

- ❖ 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 (conference presentation)*





# Sibling Workshop

## Parental Roles

- ❖ Develop sound financial plans for the child with chronic illness if s/he will not be able support him- or herself
  - ❖ Metlife's MetDESK – Division of Estate Planning for Special Kids



# Sibling Workshop

## Professional Roles

- ❖ Redefine “Family” to include all children
  - ❖ IFSP - Individualized Family Service Plan
- ❖ Invite sibs to participate
  - ❖ “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
- ❖ Provide age-appropriate information about illness
- ❖ Create preventive rather than interventional programs



# Sibling Workshop

## Interventions to Help Siblings

- ❖ Programs are designed to be preventive and/or to step in during difficult times
- ❖ Sibling Center (UCSF)
  - ❖ Developmental/preventive model focusing on education and psychosocial issues
  - ❖ Group program
  - ❖ Four sessions:
    - ❖ Session 1. Evaluation and treatment plan development
    - ❖ Session 2. Focus on communication, emotions and coping skills
    - ❖ Session 3. Continuation of session 2
    - ❖ Session 4. Recap with sib alone and then with parent



# Sibling Workshop

## Interventions to Help Siblings

### ❖ SibLink (Brown University)

- ❖ Family-based, initially targeting 8-13 year olds, modified to serve 4-7 year olds
- ❖ 6 sessions for siblings targeting knowledge, communication within the family, identifying and managing emotions, problem solving, connectedness (peer interactions), identification of strengths and needs
- ❖ Sessions for parents targeting communication, normal pediatric development and implications for adaptability, within family functioning, and knowledge
- ❖ Joint group to enhance understanding

### ❖ Outcomes

- ❖ Increased knowledge
- ❖ Increased self-competence
- ❖ Improved social functioning
- ❖ Improved connectedness



# Sibling Workshop

## Interventions to Help Siblings

- ❖ ISEE (Community-based Intervention for Sibs and Parents of Children with Chronic Illness or Disability) (Kansas, Missouri)
  - ❖ Camp setting for siblings focusing on education, social support, self-esteem, sib mood, behavioral adjustment and attitudes toward illness
  - ❖ Parents are involved in pre-camp information session only.
  - ❖ 2 follow up sessions, 4 and 9 months after camp
- ❖ SIBS: Support, Information, Balance, Sensitivity
  - ❖ Clinical intervention as outlined in "When Jack Fell Down...Jill Came Tumbling After: Siblings in the Web of Illness an Disability" by Joan Fleitas, EdD, RN
  - ❖ Based on clinical needs of siblings
  - ❖ Primarily a one-on-one therapeutic and educational approach facilitated by the nursing staff



# Sibling Workshop

## Closing Perspective

*“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, one of Reba’s favorite things to do! 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)*

