Completing the Circle of Family-Centered Care:
Looking Beyond the Needs of the Patient and Caregiver

What About the Siblings?

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Workshop Objectives

• Provide awareness of the unique needs, challenges, and opportunities that siblings of children with special needs experience

• Gain an understanding of what Sibshops are and how they can benefit siblings

• Experience and learn strategies for working with siblings
Why Siblings?

- 13.9% of U.S. children have special health care needs, and 21.8% of households with children include at least one child with a special health care need (US Dept of Health & Human Services, 2008)
- More to serving families of children with special needs than just meeting with children’s parents/guardians
- Siblings are most likely to have the longest relationship with each other (usually outlasting parents and service providers)
- Siblings of children with special needs have special needs themselves
- Why NOT Siblings?!
Unique Experience of Siblings: **Sibling Challenges**

- Feeling as though life is “unfair”
- Isolation from peers, parents, family
- Resentment
- Feeling “left out”
- Unequal treatment
- Increased responsibilities and expectations
- Pressure to achieve
- Loneliness
- Guilt
- Embarrassment
- Shame
- Worry

Information adapted from “Sibshops” (Meyer & Vadasy, 2008)
Unique Experience of Siblings: Sibling Opportunities

- Self-concept
- Maturity level
- Gain perspective
- Insight
- Greater tolerance
- Empathy
- Work opportunities
- Loyalty
- Compassion
- Flexibility/Problem-solving skills
- Appreciation for siblings’ abilities

Information adapted from “Sibshops” (Meyer & Vadasz, 2008)
Unique Experience of Siblings: 
**Sibling Needs**

- Accurate, age-appropriate information regarding the special need
- Attention to their developmental and emotional needs
- Peer relationships
- Recognition of their accomplishments and uniqueness

(Carlson, 2004)
Creation of Sibshops

- Sibshops Model was created in 1982
  - Created by Don Meyer in Seattle
    - Founder of Sibling Support Project
    - Is a sibling himself
- Facilitated worldwide
  - Currently over 450 Sibshops in 8 countries

Sibshops groups in Ireland (left) and Argentina (right)
What are Sibshops?

• Opportunities to support sibs of children with special health concerns, mental health, and/or developmental needs
• Fun, recreational, and educational
• Peer support workshops
  – Not necessarily “therapy” but therapeutic, as they take a wellness perspective
  – Siblings relate with each other and begin to learn that they are not alone

Information adapted from “Sibshops” (Meyer & Vadasy, 2008)
1. Provide brothers and sisters of children with special needs an opportunity to meet other siblings in a relaxed, recreational setting.

2. Provide brothers and sisters with opportunities to discuss common joys and concerns with other siblings of children with special needs.

3. Provide brothers and sisters with an opportunity to learn how others handle situations commonly experienced by siblings of children with special needs.

4. Provide siblings with an opportunity to learn more about the implications of their brother’s and sister’s special needs.

5. Provide parents and other professionals with opportunities to learn more about the concerns/opportunities frequently experienced by siblings of children with special needs.

Information from “Sibshops” (Meyer & Vadas, 2008)
Sibshops Benefits

- Greater insight into siblings’ special needs
- Peer support
- Education
- Ability to relate to peers with similar challenges
- View the strengths of having a sibling with special needs
- Relationship-building
- FUN!

Information adapted from “Sibshops” (Meyer & Vadasy, 2008)
• University of Washington study (2005)
  + Over 90% of the respondents said Sibshops had a positive effect on the feelings they had for their siblings
  + Sibshops taught coping strategies to over two-thirds of respondents
  + Three-fourths of respondents reported that Sibshops affected their adult lives
  + 94% of respondents said they would recommend Sibshops to others
"My Sib..." is an expression of what it is like to be the sibling of a person with a disability. This very personal and direct video provides insight into the feelings, concerns and hopes of these brothers and sisters as they cope with the sometimes difficult reality of their siblings' disability.
Sibshops FAQ’s

• **Who Attends?**
  – Originally developed for 8- to 13-year-old children with siblings with developmental concerns
    • Adapted for wider range of youth
    • Increasingly, Sibshops are being offered for children of siblings with general health concerns as well as mental health concerns.

• **Who Sponsors?**
  – Early intervention centers, school districts, children’s hospitals, chapters of the Arc, Easter Seals programs, autism societies, Down syndrome groups, developmental disabilities councils, community centers, churches, parks and recreation programs, etc.

• **Who Facilitates?**
  – Service providers who are familiar with the special needs represented in the group
  – Adult siblings
  – Parents
Sibshops FAQs continued…

• When?
  – Often held on Saturdays for 3-4 hours

• Where?
  – Nationwide and beyond!

• How often?
  – Varies (Annually, monthly, weekly)
  – Open or closed enrollment

• Size of Group?
  – Ideally between 12 and 20 kids, but successful with as few as 5

• How to start a Sibshop?
  – Contact Sibling Support Project
  – No fee but must register and adhere to Standards of Practice
  – Attend facilitator training held by Don Meyer/Sibling Support Project
Sibshops Activities

• Introductory/Trickle-In
• Discussion/Peer Support
• Recreational
• Snack!!
• Closing
Minnesota Sibshops

• 12 registered Sibshops around the state
  – Full list/description of registered Sibshops can be found at Sibling Support Project’s website: www.siblingsupport.org

  • Groups offering workshops for sibs ranging in age from 5-13

  • Groups on different days including weekdays and weekends
PrairieCare Sibshops!

- Geared specifically toward youth with siblings affected by mental health issues (but open to all)
- Facilitated by social workers, therapists, nurses, recreational/occupational therapists, psychiatric technicians
- Ages ~7-12
- Last Saturday of the month (9:30-12:00)
- Fee for family
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<thead>
<tr>
<th>Time</th>
<th>Activity</th>
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<tr>
<td>9:30-9:40</td>
<td>Registration</td>
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<tr>
<td>9:40-10:00</td>
<td>Get to Know You Activity</td>
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<tr>
<td>10:00-10:30</td>
<td>Discussion/Peer Support Activity</td>
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<tr>
<td>10:30-10:55</td>
<td>Gym / Physical Activities</td>
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<tr>
<td>10:55-11:10</td>
<td>Snack</td>
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<td>11:10-11:30</td>
<td>Arts &amp; Craft Activity</td>
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<tr>
<td>11:30-11:50</td>
<td>Discussion/Peer Support Activity</td>
</tr>
<tr>
<td>11:50-12:00</td>
<td>Closure</td>
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Parents’ & Families’ Hopes for Siblings

• “To be his own person... that he doesn’t have to copy his brother’s behaviors”
  • “Just to talk about his brother and his feelings”
• “To see that others have siblings with special needs and to feel better about herself”
  – “Learn how to cope with being a sibling of a brother with Autism and find others who are”
    • “That fairness and equal is not the same... she feels as though her brother with FAS gets special privileges”
• “To learn more about their brother’s illness”
  » “Learn how to cope with sister’s behaviors, how to stay safe, and how to not verbally engage with put-downs”
• “For him to be able to express himself when scared or upset... he’s very sensitive and cries a lot”
  – “To learn more about stress management and coping by sharing”
If you could have just one day when your sibling didn’t have a disability, what would you choose to do on that day?

• “We would go to the Mall of America together and go to a lot of stores, and he wouldn’t have a hard time leaving every store.”

What do you want people to know about your sib?

• “He has autism and he knows a lot of movie lines…and he loves cats.”

Do you like hanging out with your sib? What do you do?

• “We like playing Minecraft and watching YouTube videos together.”

Has your sib ever embarrassed you?

• “One time when I had a friend over, we had to lock ourselves in the bathroom because he was mad and throwing things…sometimes at school, too.”
Is there something about your sib that just makes you smile?

• “Yeah, when he is good at something.”

Does your sib ever frustrate you? How?

• “Yes! When he has a temper tantrum when he doesn’t get to do something, and he’s really loud…but I do that too.”

Do you think your sib knows he/she is differently-abled?

• “I don’t think so, but sometimes he might. At home, we say he has autism, but I don’t think he knows what that means.”
Let’s Get Interactive!!

Human Bingo

Feelings on a Rope

Time Capsule

Strengths & Weaknesses
Resources for Sibs

- **Sibling Support Network**
  - To find a Sibshop near you: [http://www.siblingsupport.org/sibshops/find-a-sibshop](http://www.siblingsupport.org/sibshops/find-a-sibshop)
  - SibKids Yahoo Group
  - SibTeen Facebook Group
  - SibNet Yahoo Group & Facebook Group for Adult Siblings
  - SibParent Yahoo Group for Parents
Questions?

Contact Sara Owens-Keenan, LICSW at 952.826.8386 or sowens@prairie-care.com and/or http://www.prairie-care.com/resources/forfamilies/sibshops/

Contact Sibling Support Project at http://www.siblingsupport.org/
THANK YOU FOR YOUR TIME AND ATTENTION!!!
References


