“What about me? Supporting Siblings of Children with Disabilities”

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Overview of Presentation

• The significance of siblings
• Unique issues for siblings of children with disabilities
• Practical strategies for siblings

The Significance of Siblings

- Over 90% of Americans have a sibling.
- Most long-lasting relationship.
- Offers multiple psychological benefits including buffering.
Unique Issues for Siblings of Children with Disabilities

**WELL SIBLING MAY DEVELOP ADJUSTMNT DIFFICULTIES**

- Siblings may develop internalizing problems.
- Suppression of difficulties due to wanting to be well-behaved or protect overburdened parents.
- Some may develop externalizing issues when their internal resources are expensed.
- Academic issues may also surface due to limited time and money for academic help.
WELL SIBLING BECOMES OVERLY RESPONSIBLE CARETAKERS, MATURE, AND INDEPENDENT PREMATURELY

- Many experience Parentification having many responsibilities over the family.
- This may cause a rapid movement through normal developmental stages.
- May seem positive to parents but is a precursor to distress.

WELL SIBLINGS MAY FEEL NEGLECTED BY PARENTS

- Parents need to focus on child with needs and spend time on medical and therapy appointments.
WELL SIBLINGS FEEL IN THE DARK FROM PARENTS AND SERVICE PROVIDERS

• Siblings have similar concerns that parents have but little resources and information is available to them.

• Siblings have a lack of knowledge about what is happening, transmission, responsibility for the condition, how to discuss the problem with friends, and the future.

• With uncertainty siblings develop own ideas about the problem – much worst ones.
WELL SIBLINGS EXPERIENCE MIXED EMOTIONS

- Younger children see simple negative or positive feelings.
- Older children have more complex and integrated feelings.

Embarrassment about the behavior and appearance of sibling.

Guilt about “why not me?”, guilt over emotions, over moving on with life.
Fear about health of self and sibling and fear about future.

Resentment/Anger/Jealousy: May diminish with age but includes repressed feelings due to unequal treatment or resentment towards future.

WELL SIBLINGS ATTEMPT TO DISASSOCIATE FROM THE SIBLING WITH THE DISABILITY

Claim to be an only child.
Don’t invite over friends.

Want to avoid answering questions about sibling.

SITUATION PROVIDES OPPORTUNITIES FOR WELL SIBLING

Self Characteristics:

Self-control, cooperation, empathy, tolerance, altruism, maturity, responsibility, see some peers issues as trivial, new perspective on life.
Sibling dynamics:
Loyalty, protective, pride in strength of sibling, concern, use someone’s attitude about special needs as a test for screening friends and mates.

Other qualities:
Appreciation for diverse human qualities, appreciation of family strength, more certain about occupation and head towards helping professions.

The Sibling Daily Hassles and Uplifts Scale

Practical Strategies for Siblings
Engage the entire family and reconnect family members to each other

Overall Family Environment

Family Communication: Shared decision-making, negotiation, and problem-solving

Style of conflict/communication

Style of conflict

- Highest long term marital satisfaction:
  - Avoiders
  - Communicators
  - Fighters

The Family Problem Solving Communication Index
Provide early ongoing support

- Offer one-on-one time to talk about the ups and downs.
- Provide academic assistance.
- Don’t overlook achievements of sibling.

Deal with emotions:
- Information
- Validation
- Normalization
- Giving space
- Offering good answers for friends and bullies

Set reasonable expectations:
- Negotiate chores; what is normal chores?
- Balance needs of sibling and own needs
- Give space with extracurricular activities and hobbies
• Expand support network:
  – Friend support
  – Extended family for when parents are not available
  – Sibling/Family-centered services

Provide early and ongoing information and education to sibling

• Based on child age:
  – Younger children need information about the visible and medical aspects.
  – Older children need information about future of self and family.

Not just about willing to answer questions but setting an open atmosphere of talking
• Invite to be part of meetings and provide valuable input
• Siblings want to know what they can do to help

Create opportunities for older children to seek genetic counseling

• Fear of developing the disability
• Uncertainty leads to difficulty maintaining relationships
• Fear of passing genetics to children

Allow for beginning discussion of future planning
• More than 60% of families don’t have a plan and 70% don’t make financial arrangements
• Parents worry about burdening their well children and fear talking about mortality
• Well siblings worry about what will be expected of them and the emotional and financial burden

• Open communication, planning, and information about options for sibling regarding:
  – Activities and living situation
  – Social world
  – Employment
  – Available services
  – Legal issues

Connect siblings to other siblings

• For parents going at it alone is unthinkable - not so for siblings
• Support groups focusing on strengths, on their terms, non-judgmental, no forced topics about “the sibling”
• Do something active to counter the often non-active family life
Summary

- Offer information and validate emotions.
- Provide extended support.
- Focus on entire family.
- Plan for the future.

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**The Sibling Daily Hassles and Uplifts Scale**

Instructions: Please answer these questions, by placing a circle around yes or no, relating to the way your life is impacted by your sibling with the disability…

### Uplifts Scale

<table>
<thead>
<tr>
<th>Community</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>I get to be part of different groups because of my brother or sister with a disability</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I know and understand a lot about disability</td>
<td></td>
<td></td>
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<tr>
<td>My brother or sister with a disability is happy</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>My family…</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>I get to share experiences and do things with my family</td>
<td></td>
<td></td>
</tr>
<tr>
<td>My mom/dad tell me that I am being a big help</td>
<td></td>
<td></td>
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<tr>
<td>My mom and dad tell me how happy they are of me</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>My friends…</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>They get along and play nicely with my brother or sister with a disability</td>
<td></td>
<td></td>
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<tr>
<td>I can trust they won’t make fun of me or tease me because of my brother or sister with a disability</td>
<td></td>
<td></td>
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<tr>
<td>They make me feel special because I know how to manage my brother or sister with a disability</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>My sibling with the disability…</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learns something new (e.g., a new word, good math or writing)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does cute things</td>
<td></td>
<td></td>
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<tr>
<td>Plays with me like other brother and sisters.</td>
<td></td>
<td></td>
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</tbody>
</table>

### Hassles Scale

<table>
<thead>
<tr>
<th>Community</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brother/sister draws attention to us</td>
<td></td>
<td></td>
</tr>
<tr>
<td>People stare or look at us</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I don’t feel ‘normal’</td>
<td></td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>My Family…</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>We can’t do things that other families can do</td>
<td></td>
<td></td>
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<tr>
<td>I have to do more jobs/chores around the home</td>
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<tr>
<td>I worry that my mom and dad don’t get enough rest</td>
<td></td>
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</tbody>
</table>

<table>
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<tr>
<th>My Friends…</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>I don’t invite them over because of the way my brother/sister with a disability will behave</td>
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<tr>
<td>I worry that they won’t want to come back and play if they come over and see my brother/sister</td>
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<tr>
<td>I get sad when they say mean things about people with disabilities</td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>My sibling with the disability…</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hurts, hits, pushes, scratches or kicks me or others</td>
<td></td>
<td></td>
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<tr>
<td>Touches or takes my things</td>
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<tr>
<td>Always gets his/her own way in order to stop a tantrum</td>
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</tbody>
</table>

Based on The Sibling Daily Hassles and Uplifts Scale (Giallo & Gavidia-Payne, 2006)
Family Problem Solving Communication Index

When our family struggles with problems or conflicts which upset us, I would describe my family in the following way:

1 = False, 2 = Mostly False, 3 = Mostly True, 4 = True

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>We yell and scream at each other.</td>
<td></td>
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<tr>
<td>2.</td>
<td>We are respectful of each others’ feelings.</td>
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<tr>
<td>3.</td>
<td>We talk things through till we reach a solution.</td>
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<tr>
<td>4.</td>
<td>We work hard to be sure family members were not hurt emotionally or physically.</td>
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<tr>
<td>5.</td>
<td>We walk away from conflicts without much satisfaction.</td>
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<tr>
<td>6.</td>
<td>We share with each other how much we care for one another.</td>
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<tr>
<td>7.</td>
<td>We make matters more difficult by fighting and bringing up old matters.</td>
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<tr>
<td>8.</td>
<td>We take the time to hear what each other has to say or feel.</td>
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<tr>
<td>9.</td>
<td>We work to be calm and talk things through.</td>
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<tr>
<td>10.</td>
<td>We get upset, but we try to end our conflicts on a positive note.</td>
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</tbody>
</table>

Scoring:

For Inflammatory communications add your scores on: 1, 5, and 7.

Your Score for inflammatory communications = ______

For Affirming communications add your scores on: 2, 3, 4, 6, 8, 9, and 10.

Your Score for Affirming communications = _____

Totals:

Inflammatory communications: High score is 12 (9-12 is high range)

Affirming communications: High score is 28 (21-28 is high range)