Reciprocity and Social Capital in Sibling Relationships of People with Disabilities

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Sibling relationships

• Overall
• Dominant voices
• Disability is typically framed as individual tragedy, loss

• More importantly, who is the source of knowledge about sibling relationships?
  – Clear need to include people with disabilities
Inclusive research

• “...people with learning disabilities...are capable of...expressing views and preferences...” —Ramcharan & Grant, 2001

• framed the impact of the sibling with I/DD in a negative way

• Siblings with disabilities have an underrepresented voice in existing research.

• Siblinghood through the co-experience of disability
Introduction to Today

• Today in three Acts...
  – Act I: The study that got published
  – Act II: Strategies that were tried, but didn’t “make the cut” in the project/manuscript
  – Act III: Take homes
Act I: I/DD Article

Purpose/Research Question

• Perspectives of siblings with and without disabilities
• How do siblings support each other when parents are no longer around?
Recruitment/Sample

• Recruited through either sibling of the pair
  – Local self advocacy organization, sibling organization

• 8 sibling pairs
  – All were recruited through established relationships
    • Not random, but not needed for this study
  – All 8 were past “support transition” from parents to siblings
    • All but 1 pair had no living parents
    • 1 pair had aging mother with Alzheimer’s
<table>
<thead>
<tr>
<th>ND and D</th>
<th>Ethnicity</th>
<th>D</th>
<th>ND</th>
<th>Gender D/ND</th>
<th>Impairment</th>
<th>MI</th>
<th>ND Married</th>
<th>ND Children</th>
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</thead>
<tbody>
<tr>
<td>1. Matt and George</td>
<td>Caucasian</td>
<td>39</td>
<td>45</td>
<td>M/M</td>
<td>Down Syndrome</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td>2. Kim and Michelle</td>
<td>Caucasian</td>
<td>44</td>
<td>49</td>
<td>F/F</td>
<td>I/DD</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
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<td>3. Luisa and Miguel</td>
<td>Hispanic</td>
<td>53</td>
<td>50</td>
<td>M/F</td>
<td>I/DD</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td>4. Shirley and John</td>
<td>Caucasian</td>
<td>52</td>
<td>50</td>
<td>M/F</td>
<td>Asperger’s I/DD</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>5. Nicole and Micheal</td>
<td>Caucasian</td>
<td>43</td>
<td>55</td>
<td>M/F</td>
<td>Asperger’s I/DD</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td>6. Tammy and Jim</td>
<td>African American</td>
<td>53</td>
<td>59</td>
<td>M/F</td>
<td>Down Syndrome</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td>7. Stephanie and Miles</td>
<td>African American</td>
<td>25</td>
<td>32</td>
<td>M/F</td>
<td>Down Syndrome</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
<td>8. Gloria and Martin</td>
<td>Hispanic</td>
<td>43</td>
<td>35</td>
<td>M/F</td>
<td>Down Syndrome</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>
Procedure

• Individual and joint interviews
• Recorded, transcribed
• Field Notes
Procedure - Accessibility

• Content
  – questions were in plain language
  – rephrasings thought through ahead of time
  – assumptions
    • That being a sibling was not a “burden”
    • Wanted more open-ended questions
Procedure - Accessibility

• Process
  – 3 interviews allowed for more time overall
    • allowed opportunities to collect concrete examples to refer to for follow up
  – Friend or trusted ally
    • sibling was an ally
    • significant other was an ally in one case
Results

• siblings with and without disabilities experience reciprocity as a transitive exchange
• which occurs through the creation of social capital in their families and community
• nondisabled siblings mobilize their social capital to provide support to their sibling after parents pass away
Act II: didn’t make the cut

• Content and process strategies…
• Content strategy: Interview Guide with pictures
• Process strategy: Sending interview guide ahead of time
• Process strategy: Allowing extra response time during the interviews
Interview Guide

Questions for you…

Hello, my name is John. I am interested in what you think about being a brother or sister. I would like to ask you what you think about being a brother or sister.

Here are some questions to think about.

1. What do you like about being a brother or sister?

2. What’s your favorite story about your brother or sister?

3. What do you do with your brother/sister?
Act III: Thinking about accessibility in future work

• Lessons from sibling study
  – Multifaceted, but simple
  – Abandon the things that do not work

• Three types of accessible methods:
  – Cognitive access
  – Technological Access
  – Sensitivity to the power relationships…
Take home 1: Cognitive Access

• Content strategies
  – Using plain language
    • Connect with experts on plain language
    • Avoid jargon
    • Test materials with self-advocates!

• Process strategies
  – Be prepared to rephrase things, use individualized examples to help (rapport matters!
  – Sending questions ahead of time as an option
Take home 2:
Technological access

• Content strategies:
  – Technology logistics…
    • Cross platform access (Mac, Windows, iOS, Android)
    • Simplicity

• Process strategies:
  – Use of technology
    • Using natural supports for participation
    • Methodological benefits and drawbacks…
    • IRB issues? Couching this as ameliorating risk, increasing benefit…
Take home 3: Power relationships

• Process strategies:
  – Build rapport with people with I/DD
    • Longstanding relationships
    • Build in time to meet participants (feasible?)
  – Avoid assumptions
    • Knowledge base was almost exclusively from nondisabled siblings; is it valid to base questions off this?
  – Acknowledge your privilege as a researcher
    • Sensitivity to conversational dynamic...how are you perceived as a researcher?
    • Hire co-researchers with I/DD as professional research assistants/employees
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