Supporting Siblings of Individuals with Disabilities: From the Local Level to the National Level

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Introductions: Ashley Coulter
Introductions: Meghan Burke

• Oldest of five siblings: Ryan, 15, has Down syndrome

• Doctoral student in Special Education at Vanderbilt

• Research interests: Families of individuals with disabilities and disability policy
Overview of this Presentation

- 1. Why include siblings in The Arc’s activities?
- 2. Who are siblings? From the research, what do we know about siblings?
  - Childhood
  - Adolescents
  - Young adults (18-30)
  - Adults (post 30)
- 3. Using this research, what exists to support siblings?
  - Young - SibSaturdays/SibShops
  - Adolescents - Teen Fusion
  - Adults
- 4. What supports do siblings need?
- 5. What can The Arc do for siblings?
The purpose of this presentation...

- We are intertwining research, our VKC activities, and what additional supports siblings need.

- We are hoping this conversation will springboard further dialogue and action regarding The Arc and siblings.

- This presentation will discuss siblings across the lifespan but we will primarily focus on adult siblings.
Why include siblings in The Arc?

- The sibling relationship is the longest lasting familial tie (Cicirelli, 1982)

- Yet, little research has been done regarding adult siblings of persons with disabilities (Seltzer, et. al., 2005; Stoneman, 2005).
Siblings of Individuals with Disabilities

- There are over 700,000 individuals with intellectual disabilities (ID) in the US
  - The population of persons with ID aged 60 years and older is expected to reach 1.5 million by 2030 (National Center for Family Support, 2000).

- Approximately 60% of these individuals live in their parent’s homes

- Who will take care of these individuals in the future?
  - Siblings of individuals with disabilities
Siblings of Individuals with Disabilities-Ctd.

- Prior to the 1970s, siblings of individuals with disabilities were thought to be prone to depression or other psychological problems.

- Now, these siblings seem to be doing reasonably well in life, with any negative effects of being a sibling to an adult with disabilities fairly minor (see Seltzer, Greenberg, Orsmond, & Lounds, 2005 for a review)
Siblings of Individuals with Disabilities-Ctd.

- As children and as adults, most siblings have been reported to be doing well (Stoneman, 2005; Hodapp & Urbano, 2008)

- Most siblings report positive and satisfying relationships, and report that the sibling has a positive influence on life (Johnson & Sandall, 2005)
Who are siblings? From the research, what do we know about siblings?
Younger Siblings - Research

- If there is a difference, it is small at best (Rossiter & Sharpe, 2001) and not likely to be harmful (Taunt & Hastings, 2002)

- Compared to siblings of individuals without disabilities:
  - No difference in self-concept (Dyson, 1996; Bischoff & Tingstrom, 1991; Burton & Parks, 1994; Fisman et al., 2000)
  - Mixed results on whether they have more internalizing and/or externalizing behaviors
    - Some say no (Cuskelley, Chant, & Hayes, 1998; Gold, 1993)
    - Some say yes (Hastings, 2003; Coleby, 1995; Nixon & Cummings, 1999)
Adolescent Siblings-Research

- Very little research exists regarding adolescent siblings of persons with disabilities.

- Recently, studies of teens and young adult siblings of individuals with ASD have been reported to have relatively higher levels of depression and anxiety than other young adult siblings (Orsmond & Selzer, 2007).

- Slight but not significant negative effect on adolescent siblings of individuals with disabilities (Rossiter & Sharpe, 2001).
Adult Siblings-Research

- **Siblings are healthy** (Hodapp, Urbano & Burke, in press; Kaiser, Morse, & Burke, 2008)

- **Most siblings have close and positive relationships into adulthood**
  (Hodapp, Urbano & Burke, in press; Orsmond & Seltzer, 2000)
Most siblings have close, positive relationships

<table>
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<tr>
<th>Contact</th>
<th>Daily</th>
<th>Several times/week</th>
<th>Weekly/biweekly</th>
<th>Monthly</th>
<th>&gt; Monthly</th>
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<td>Is time enough?</td>
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<td>Some what too much</td>
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<td>7%</td>
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<td>How much affection?</td>
<td>Extremely/ Very much</td>
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<td>77%</td>
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<td>Pretty much/somewhat</td>
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<td>Not much</td>
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<td>4%</td>
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<td>How close?</td>
<td>Extremely/Very much</td>
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<td>67%</td>
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<td></td>
<td>Pretty much/ somewhat</td>
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<td>22%</td>
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<td></td>
<td>Not much/not at all</td>
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<td>12%</td>
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<td>How positive?</td>
<td>Extremely/ very much</td>
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<td>60%</td>
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<td></td>
<td>Pretty much/somewhat</td>
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<td></td>
<td>Not much/not at all</td>
<td></td>
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<td>8%</td>
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# Sibling Closeness Has Many Forms

<table>
<thead>
<tr>
<th>Theme</th>
<th>Examples</th>
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<tbody>
<tr>
<td>Very close</td>
<td>“We are VERY close. I see her or talk to her every day…She is a very important part of my life.”</td>
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<tr>
<td></td>
<td>“It is a very close and caring relationship built on years of trust and understanding.”</td>
</tr>
<tr>
<td>Close, Typical Sibling is like a mother</td>
<td>“I have a close relationship with my sister. When my parents aren’t there, I treat her more like she I my child making sure everything she needs is taken care of”</td>
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<td>“Often, I take over the mommy role.”</td>
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<tr>
<td>Close, Typical Sibling provides instrumental/affective support</td>
<td>“We have a very close relationship. I have taken care of him a lot since he was born. I currently spend most of my week watching him and help home school and tutor him”</td>
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<tr>
<td>Close, but changes would help us be closer</td>
<td>“Good. But I would like to live closer so we could see each other more.”</td>
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<td>“It is better. She is now correctly being treated for her behavior problems, which we tried for years to get.”</td>
</tr>
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Kaiser, Morse, & Burke, 2008
## Adult Siblings - Research

<table>
<thead>
<tr>
<th>Choices</th>
<th>Percent of sample reporting sib was considered (N=77)</th>
<th>Mean rating of importance of sib in choices (0-5)</th>
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<tbody>
<tr>
<td>College or training location</td>
<td>64%</td>
<td>2.34</td>
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<tr>
<td>College Major</td>
<td>17%</td>
<td>3.0</td>
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<tr>
<td>Dating</td>
<td>41%</td>
<td>3.94</td>
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<tr>
<td>Marriage</td>
<td>32%</td>
<td>3.96</td>
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<tr>
<td>Move away from home</td>
<td>58%</td>
<td>2.67</td>
</tr>
<tr>
<td>Friends</td>
<td>35%</td>
<td>3.62</td>
</tr>
</tbody>
</table>

Kaiser, Morse, & Burke, 2008
Adult Siblings-Research

- Female siblings are likely to marry and have children later than females without a brother/sister with a disability.

- Female siblings are also less likely to divorce than a female without a brother/sister with a disability.

- Males marry, divorce, and have children at the same rate regardless of whether or not they have a brother/sister with a disability.

Hodapp, Urbano, & Burke, in press
Hodapp, Urbano, & Burke, in press
Adult Siblings-Research

- Siblings are likely to be future caregivers (Pruchno, 1996; Griffiths, 1994)
- Future caregivers were more likely to be sisters (Griffiths, 1994)
- Difficult for sibs to get involved in service coordination (Lukens, 2002; Carter, 2002)
Most siblings expect to have primary or shared responsibility for their brother or sisters (72%)

Relatively few are current legal guardians (17%)

Although only 18% said they were unclear about their future role, most reported specific plans had not been made

Kaiser, Morse, & Burke, 2008
Adult Siblings-Research

Kaiser, Morse, & Burke, 2008
What About The Future?

- Hopeful and positive
  - Positive relationship continuing (38%)
  - Growing closer when time, proximity allow (60%)
- Normative changes alter but not disrupt sibling relationship
  - Marriage, college, children, retirement, increasing independence for sibling
  - Moving away from family home or town
- Concerns for the future
  - Sibling health and health care needs
  - Access to services (residential, job, leisure, care)
  - Transitions when parents cannot provide care
    - How to manage while working, family care
    - Options for living, work, day time occupation or care

Kaiser, Morse, & Burke, 2008
Concerns for the future

- “I’m just scared about what I’m going to do the day that my parents aren’t here and I might have a husband and kids of my own and how I am supposed to take care of my sibling.”
- “I think one of the scariest things about being a sibling of someone with a severe disability is the knowledge that someday you will probably end up being their caretaker.”
- “It is my concern that should my mother become unable to care for my sibling, I would be left in the dark on how to handle his needs.”
- “I do not know what my parents’ plans are or what they have saved for his support in later years.”

Kaiser, Morse, & Burke, 2008
Adult Siblings-Research

Top 10 Reported Needs of Siblings in Tennessee

1. Information and Referral (25.6%)
2. Day Services (25.8%)
3. Dental Care (21.5%)
4. Job placement/support (20%)
5. Post-Secondary Education (19.9%)
6. Behavior Intervention (19.2%)
7. Residential Placement (15.3%)
8. OT, PT, or Speech (15%)
9. Case Management (14.8%)
10. Respite Care (14.7%)  

Kaiser, Morse, & Burke, 2008
Adult Siblings-Research

- Is there anything else you would like to tell us?
  - My sibling with a disability made me a better person (26.3%)
  - Guardianship is a concern for the future (15.8%)
  - Siblings needs support too (12.3%)
  - This survey has been valuable to me (10.5%)
  - There need to be more services available for my sibling (5.7%)
  - My sibling will affect my marriage or choice of spouse (5.3%)

Kaiser, Morse, & Burke, 2008
Using this research, what exists to support siblings?
Younger Siblings-Available Services

- SibShops in five areas around the state
- SibSaturdays expanding around Nashville (Facilitator Trainings)
- VKC Tipsheet
- Enjoyed activities, recommend to others, more comfortable talking about feelings, more knowledge (Meyer, Vadasy, Gooding & Coulter (1995))
- Enjoyed activities, meeting others and experiences, learned coping (Flynn, McCarthy, O’Conner & Tierney, 2005)
Younger Siblings-Available Services

- What are SibSaturdays?
  - Led by an adult sibling
  - Two Groups: 5-7 year-olds and 8-12 year-olds
  - Sibling Activities

- Expanding the SibSaturday Model
  - Parent Conferences
  - Graduation for 12 year-olds
    - Teen Group (to be discussed more later)
    - Junior Facilitators
Adolescent Siblings-Available Services

- No formal, national programs for adolescent siblings of persons with disabilities

- VKC Tipsheet

- New “Teen Fusion” Group at the Vanderbilt Kennedy Center
  - Separate outings chosen by the teenagers
  - Discussion of relevant and age-appropriate issues
Adult Siblings-Available Services

- Vanderbilt Kennedy Center Tipsheets
  - Gives you information about younger siblings
  - Gives you further resources
  - Resource and tips for you and your families
Adult Siblings-Services

- Futures Planning at the Vanderbilt Kennedy Center
  - Developed by the University of Illinois-Chicago
  - Family-based futures planning for an individual with a disability
  - Led by a social worker
  - Several sessions long
  - Held once in 2007 and will be again in 2009
Adult Siblings-Services

- SibNet and Adult Sibling Network (National groups for adult siblings of individuals with disabilities)
Adult Siblings-Services

- TABS Conference 2009
Adult Siblings-Services

- Tennessee Adult Brothers and Sisters Group
  - Developed in 2008
  - State-wide group for adult siblings
  - Has its first annual two-day conference in April of 2009
What do siblings need?

- Our personal experience, research, and services tell us:
  - Information about navigating the service system
  - Training about conservatorship, special needs trusts, and adult supports and services
  - Networking opportunities to meet other siblings
  - Networking opportunities to forge change and improvement in adult services system
  - Involvement in decision-making regarding sibling with a disability
What can The Arc do for siblings?