

Roles, Responsibilities and Needs of Adult Siblings

Vanderbilt Kennedy Center
National Sibling Research
Consortium
The Arc of the United States

Sibling Relationship Last a Lifetime



National Sibling Research Consortium

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National Sibling Research Consortium Goals

- Promote and conduct research
- Translate research to policy and practice
- Translate research for families and sibling consumers

National Sibling Research Consortium Activities

- Semi annual meetings
- Networking for sibling researchers nationally
- Special Issue on Sibling Research and Policy (*Mental Retardation*, Vol. 43, 5, 2005)
- National research forum (*Vanderbilt*, December, 2006)
- Policy Meeting jointly with the Arc (*Washington, DC*, February, 2007)
- National web based survey of adult siblings

Agenda for Today

- Summarize key issues and research findings related to siblings
- Introduce national study of adult siblings
- Describe purpose, methods
- Describe results of the study
- Discuss findings
- Raise questions and issues for future research

***Risk and Resilience in Siblings
of Individuals with
Developmental Disabilities: What
Does Previous Research Tell Us?***

Ann P. Kaiser
National Sibling Research
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Sibling Relationships Are Important

- Longest lasting family tie
- Sharing family heritage, genetically, experientially
- Ideal sibling relationship: egalitarian, reciprocal and mutual

When One Sibling Has a Disability

- Many aspects of the sibling relationship may be affected
 - Shorter life span
 - Less genetic and experiential similarity
 - Less egalitarianism and reciprocal exchange due to differences in abilities
- Idealized models of sibling relationship may not apply

Demographics Suggest More Adult Siblings Will Be Responsible for Their Brothers and Sisters with Developmental Disabilities

- Persons with disabilities are living longer
 - 526,000 persons with DD over 60
 - 1.5 million by 2030
- Currently about 60% of adults with DD are cared for by their parents
- Adult sibs are often assumed to be future caregivers and responsible for sibling

Sibling Research: History

- Landmark study of college age siblings—Grossman, 1972
- Studies have examined sibling feelings, psychological, social and academic functioning
- Most studies focused on potential negative effects of being a sibling
- More research with younger than older siblings, relatively little research on adults

Sibling Research: Findings

- There is no convincing or pervasive evidence that being a sibling of person with developmental disabilities is bad
 - Have unique experiences
 - Coping well
 - Are indistinguishable in many ways for siblings of typical individuals

Stoneman, 2005

Siblings in Childhood: Resilience

- No differences in self concept or perceived competence
- No difference in behavior problems
- Not disadvantaged in peer relationships
- Children in well functioning families are doing quite well

Childhood: Sibling Relationship Quality

- Warm, close, similar to typical children
- Spend relatively large amounts of time with brothers and sisters
- Play and activities depend on ability level of siblings with DD
- Less sibling conflict

Childhood: Sibling Relationship Quality

- Roles and relationship have more asymmetry
 - More childcare
 - Moderate levels of responsibility are associated with positive learning by typical siblings (perspective taking, responsibility)
 - Age cross-over as younger sibling surpasses older sibling with DD

When are Siblings At Risk in Childhood

- Family is at risk due to poverty, mental health of parents, drug or alcohol abuse
- Care giving is excessive
- Children have a negative perception of their parents' differential parenting
- Sibling DD has acute behavior problems that directly affect sibling

Childhood Risk and Resilience Summary

- Most children are well adjusted and showing no negative effects
- Many children report that being a sibling has benefited them in multiple ways
- Healthy families help siblings thrive
- Gender of both sibs, ages, birth order, age span, expected roles and relationships affect many aspects of sibling relationships

Research on Siblings as Adults

- Nature of the relationship between the typical sibling and their brother or sister with DD
- The health and well being of the typical adult sibling
- Life transitions

Adult Siblings

- High level of involvement across life course
 - 41% had weekly visits
 - 30% had weekly phone calls
 - 58% lived within 30 minutes of sibling
 - Most involved siblings were female

Seltzer (2005); Wisconsin Longitudinal Data Set

Adult Siblings

- Many expected to live with their brother or sister (19%) but almost half (48%) did not have a specific plan
 - Sisters more likely to expect to cohabitate
 - Siblings who shared more time were more likely to expect to cohabitate
- Follow up data indicated only 10% actually did cohabitate, but sibling ties remained strong across transitions

Comparison of adult siblings of individuals with MR and adult siblings of individuals with MH (*Seltzer, et al 1997*)

- MR siblings were closer, had more contact
- MR sibling reported more pervasive effects of being a sibling: jobs, partners
- 87% of MR siblings —mostly positive experience; 53% of MH siblings ---mostly negative experience
- MR siblings provided more emotional support
- MR siblings more likely to assume future care

Comparison of adult siblings of individuals with MR and adult siblings of individuals with MH *(Seltzer, et al 1997)*

- Emotional closeness in adolescence in both groups predicted current and future care giving
- Variability within groups
- Important to understand the specific characteristics associated with poor sibling adjustment and less supportive close relationships

Siblings of Individuals with ASD

- Adolescent and young adult siblings at increased risk for anxiety and depression
- Genetic and environmental experiences contribute
- Gender, family context, culture and supports moderate risk

(Orsmond, 2006)

Summary: Limitations in Empirical Knowledge Base

- Individual differences in sibling well being
- Individual differences sibling relationship
- Only most involved sibling has been studied
- How siblings adapt, cope and flourish

Summary: Limitations in Empirical Knowledge Base

- Lifespan issues
 - Adolescence, early adulthood,
 - Middle adulthood
 - End of life issue
 - Changing contexts of services, culture, health
- Interventions to support siblings
 - Childhood interactions
 - Supports to siblings across the lifespan
 - Critical transitions and decision making

Summary: Limitations in Empirical Knowledge Base

- Experiences of the person with developmental disabilities in the sibling relationship
 - How do relationships benefit siblings with DD?
 - How can relationships be strengthened to the benefit of the person with DD?
- Influence of culture, community and resources on all aspects of siblings well being and experience

Limitations in Empirical Knowledge Base

- Methodological challenges
- Prevailing deficit model
- Lack of theory of positive adaptation and sibling relationships across lifespan
- Little funding for systematic inquiry about siblings, especially in adulthood

Future Research

- Guided by theory, models and perspectives that embed positive, lifespan approaches
- Measurement beyond parent report, psychopathology
- Focus on resilience as well as risk
- Population specific studies of individual differences
- Attention to context of family, community, culture
- Interventions to support siblings
- Perspectives of individuals with DD

Research, Policy and Practice

- Family support policies and practices address only parents, rarely siblings
- Demographic changes indicate siblings will become care givers, decision makers
 - Adult supports for individuals with DD remain challenging
- Models for support for siblings across the lifespan are important

Sibling Relationships Last A Life Time ---

