

# ***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

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# National Sibling Research Consortium

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## **National Sibling Research Consortium Goals**

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

## **National Sibling Research Consortium Activities**

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- 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

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- 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  
Consortium

# **Sibling Relationships Are Important**

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

# When One Sibling Has a Disability

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- 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**

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- 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

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- 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

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- 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**

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- 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

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- 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

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- 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

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- 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

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- 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**

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- 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

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- 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

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- 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*)

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- 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*)

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- 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**

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- 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**

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- 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

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- 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

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- 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

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- 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

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- 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

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- 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 ---**

