

The Sibling Leadership Network: Recommendations for Research, Advocacy, and Supports Relating to Siblings of People with Developmental Disabilities

September 15, 2008

Tamar Heller, Ann Kaiser, Don Meyer, Tom Fish,
John Kramer, Derrick Dufresne



**The Rehabilitation Research and Training
Center on Aging with Developmental Disabilities**



VANDERBILT KENNEDY CENTER
FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES



Sibling Support Project

The Ohio State University **Nisonger Center**
A University Center for Excellence in Developmental Disabilities

Acknowledgments:

The Sibling Leadership Network meeting was sponsored by the Rehabilitation Research and Training Center on Aging with Developmental Disabilities at the University of Illinois at Chicago (UIC) and the Kennedy Center University Center for Excellence (UCE) at Vanderbilt University. Other conference organizers were The Institute on Disability and Human Development UCE at UIC, The Nisonger Center UCE at The Ohio State University and the Sibling Support Project of the United States. The Sibling Leadership Network steering group provided leadership and oversight. Funding was provided in part by the National Institute on Disability and Rehabilitation Research (grant # H133B031134) and The Arc of the United States. We would also like to acknowledge the Association of University Centers on Disabilities (AUCD) for its support.

Contact information:

For more information contact Katie Keiling, Rehabilitation Research and Training Center on Aging with Developmental Disabilities: Lifespan Health and Function, University of Illinois at Chicago, 1640 W. Roosevelt Road, MC 626, Chicago, IL, 60608

E-mail: kkeiling@uic.edu

Phone: (312) 996-1002

Websites: www.rrtcadd.org or sibleadership.blogspot.com or www.siblingsupport.org

Table of Contents

Introduction: The Sibling Leadership Network	4
Since the Conference	5
Chapter 1: Research Related to Siblings of Individuals with Disabilities	6
Purpose.....	6
Principles Guiding Research.....	6
Summary of Sibling Research to Date.....	7
Key Research Recommendations	9
References.....	11
Chapter 2: Expanding the Circle of Support: Brothers, Sisters and Caregiving for Individuals with Developmental Disabilities.....	12
Purpose.....	12
Principles Guiding Policy and Advocacy	12
Summary of Advocacy to Date.....	14
Key Policy Recommendations.....	15
Developmental Disabilities Assistance and Bill of Rights Act (DD Act)	15
Lifespan Respite Care Act (P.L. 109-442).....	16
Financial Security Accounts for Individuals w/disabilities (H.R. 2370/S.2743).....	17
The Community Choice Act (H.R. 1621 and S799).....	17
Family Medical Leave Expansion Act (H.R. 1369)	18
Conclusion	18
Chapter 3: Supporting Brothers and Sisters: A Low-Cost, High-Impact Means of Improving Life for People with Disabilities.....	19
Purpose.....	19
Principles Guiding Services and Supports.....	19
Summary of Services and Supports Issues.....	20
Siblings need information about	22
Siblings need opportunities to.....	22
Siblings need parents who	22
Siblings need service providers who.....	22
Key Services and Supports Recommendations.....	23
References.....	25

Introduction

The series of white papers reported here provide recommendations for research, advocacy, and supports relating to siblings of persons with developmental disabilities. They emanate from the first national meeting of the Sibling Leadership Network (SLN), whose goal is to provide opportunities for the siblings of more than six million Americans with developmental disabilities to increase their involvement in disability advocacy, policy-making and services concerning their siblings with disabilities. Its mission is “*to provide siblings of individuals with disabilities the information, support, and tools to advocate with their brothers and sisters and to promote the issues important to them and their entire families.*” The SLN promotes a broad network of siblings who share the experience of disability and people concerned with sibling issues by connecting them to social, emotional, governmental, and provisional supports across the lifespan enabling them to be effective advocates with their brother and sister, and to serve as change agents for themselves and their families.

Beginning with a series of meetings in the Fall of 2006 to develop its mission, purpose, and values, the Sibling Leadership Network (SLN) convened for the first time on November 9 and 10th, 2007. Over 80 brothers and sisters of individuals with intellectual and developmental disabilities, researchers, policymakers, self-advocates, funders, and other committed professionals in the disabilities field attended the conference. The conference included ratification of the SLN mission, purpose, and values; presentations from experts, and the formation of working groups. During their two days together, SLN conference attendees heard presentations from a wide range of experts on the following topics: Sibling Issues Across the Lifespan, Future Planning Issues, Federal Agency Perspectives on Research, an International Roundtable on Research, and Leaders’ Perspective on Policy.

Three working groups formed to develop white papers that would develop recommendations for action: 1) Research, 2) Policy and Advocacy, and 3) Services and Supports. Their tasks at the conference were to establish principles and outline action steps. Over the next twelve months, these groups developed the white papers included in this report. Their ultimate goal was to create opportunities for siblings to partner with

INTRODUCTION

government and service providers to ensure the highest quality of life, now and in the future, for their entire families.

Since the Conference: Steering committee representatives have presented summaries of the information to other interested groups, created listserv methods of communication between members of the working groups, shared photographs online, debriefed the conference with members of SibNet, and provided follow up communication with important policy makers on Capitol Hill and at the state and local levels.



Chapter 1:

Research Related to Siblings of Individuals with Disabilities

A White Paper

Prepared in Collaboration with the Sibling Leadership Network

Tamar Heller and Ann Kaiser

For the Research Work Group

September 15, 2008

Purpose

The purpose of this White Paper is to provide a summary of key research findings on siblings of individuals with disabilities and an initial set of guidelines and recommendations to guide new research in this area. It emanates from the research work group at the Sibling Leadership Network Conference held in Washington D.C. on November 9 and 10, 2007. The research work group drew up principles that should guide research on siblings, identified gaps in the research, and proposed recommendations and action steps for moving a research agenda on siblings forward.

Principles Guiding Research

1. *Siblings with and without disabilities should be involved in all phases of research from conceptualization to dissemination.* It is important to get the perspectives of siblings both with and without disabilities. They are also the persons who can best identify strategies for getting the word out to families and policymakers.
2. *Research should be inclusive, representative of diversity, and culturally competent.* Most of the research focuses on convenience samples lacking minority families, as it is often difficult to find siblings. We need to find ways to reach these siblings.

3. *There is a place for both description and intervention research, using the range of state of the art research methods.* To date most of the research has been descriptive with very few intervention studies. Both types of research are needed to help identify the issues and to test models of providing support to siblings.
4. *Research on perspectives and outcomes for siblings with and without disabilities is of interest.* Siblings with and without disabilities may have a very different perspective on family relationships and supports needed. They may also have very different perspectives than parents, who are most often the family members targeted in research studies on families of people with developmental disabilities.
5. *Research should address lifespan issues and critical contexts for their families.* Siblings play varying roles and face varying issues at different life phases and at transition points. As parents age the roles and responsibilities of siblings in supporting their siblings with a disability likely increase.

Summary of Sibling Research to Date

Siblings provide the most long-lasting relationships for adults with developmental disabilities. Over 30 years of research on siblings has provided key information about the effects of being a brother or sister of an individual with a disability. The research results are mixed, with some noting more behavior problems and depression and others failing to find such differences or finding positive impacts (Rossiter & Sharpe, 2001; Stoneman, 2006). Generally siblings across the lifespan often regard their experiences as a sibling positively. Siblings report affection and positive regard for their brothers and sisters with disabilities, attribute high levels of empathy and altruism as deriving from their relationship with sibling, and on the whole, appear to be as well adjusted and successful as individual who have typically developing brothers and sisters.

Siblings who have brothers or sisters with mental health conditions, with autism, or with other severe behavior problems associated with their disability are more likely to report problems in the early relationship and to exhibit symptoms of depression or less positive adjustment in later life (Orsmond & Seltzer, 2007). While sibling relationships may be more asymmetrical due to the abilities of the brother or sister with disability in childhood

Chapter 1: Research Related to Siblings of Individuals with Disabilities

and later on, the resulting differences are somewhat predictable and seldom regarded by typical siblings as negative.

The quality of the sibling relationship and level of involvement of the typical sibling is related to childhood experiences and as well as to gender of each member of the sibling pair, the relative ages of the siblings, and continued geographic proximity. Many siblings indicate they will assume primary care for their brother or sister with disabilities at some point during the siblings' lifetime, although co-residence of siblings occurs for a minority of adult siblings (Greenberg, Seltzer, Orsmond, & Krauss, 1999). With the aging of the population siblings are likely to assume greater roles, including co-residence, as individuals with developmental disabilities outlive their parents (Freedman, Krauss, & Seltzer, 1997). Over 75% of adults with developmental disabilities in the U.S. live at home with families and over 25% of their family caregivers (716,212) are over the age of 60 years (Braddock, Hemp, & Rizzolo, 2008). Yet many families have not done planning or discussed future care with siblings (Heller & Kramer, 2006).

Relatively little is known about family, cultural, and psychological factors contributing to individual differences in sibling relationships and sibling outcomes. Understanding what allows siblings to cope and do well and what constrains sibling relationships and sibling well-being requires research. Almost all findings about sibling relationships are based on reports of the typical sibling or the parent. The views of the sibling with disabilities are notably absent. This is especially problematic in considering adult sibling relationships where there are few studies examining the relationship from the perspective of both siblings. There is a great need for a lifespan perspective on sibling relationships, capturing the perspectives of both siblings.

The relatively limited research on support provided to siblings during childhood suggests that information, meeting other siblings, and having opportunities to process concerns about family and sibling issues can have long-term positive benefits. There are relatively few studies of interventions at any point in the lifespan designed to enhance positive outcomes for the sibling with a disability, the typical sibling or the family as a whole. The need to describe and promote healthy, positive sibling relationships in adulthood is primary.

Key Research Recommendations

The research work group developed the following recommendations for future research on siblings of individuals with developmental disabilities:

1. Make findings from past research studies easily accessible to families, service providers and policy makers.
2. Include the voice of the sibling with disability in research
 - a. How do siblings with disabilities experience their relationships with their brothers and sisters across the lifespan?
 - b. How could these relationships be strengthened from the perspective of the sibling with disabilities?
3. Examine the contributions that individuals with disabilities make to the everyday lives, and longer term health and psychological well-being of typical sibling
 - a. From the perspective of the typical sibling
 - b. From the perspective of the sibling with disabilities
4. Focus on how sibling relationships, roles and experiences affect the sibling with a disability.
 - a. Specifically identify positive effects of the sibling relationship on everyday lives, and longer term health and psychological well- being outcomes for sibs with disabilities across the lifespan.
 - b. Determine how sibling involvement may affect community participation and inclusion, self-determination, employment of the sibling with disabilities.
5. Broaden the scope of sibling research during adulthood.
 - a. Study siblings across the adult lifespan to better understand the course of sibling relationships.
 - b. Focus on key transition points where siblings may play key roles in the lives of their brothers or sisters with disabilities.
 - i. Leaving school
 - ii. Living outside the home
 - iii. Aging or ill parents

Chapter 1: Research Related to Siblings of Individuals with Disabilities

- iv. Transitions in responsibility for siblings with disabilities
 - v. Adult life transitions for both siblings around health, living locations, and end of life.
 - c. Involve all siblings, not just those who self-identify as the most involved to better understand how siblings are affected and how they contribute to the lives of their brothers and sisters.
 - 6. Develop and study interventions that are designed to improve the lives of individuals with disabilities and their siblings.
 - a. Early intervention
 - i. To help parents address and improve sibling problem behavior at home that may affect the sibling
 - ii. To help parents in parenting both siblings
 - iii. To build communication and affective relationships between siblings
 - iv. To lay a foundation for self-determination by individuals with disabilities
 - v. To support typical siblings with information about their sibling, social support for themselves, and early involvement in futures planning.
 - b. Early transitions
 - c. Planning for the future
 - d. Later life transitions
 - 7. Study families as a basis for understanding sibling relationships over time.
 - a. Risk and protective factors related to sibling outcomes and relationships
 - b. Individual differences in family style, adjustment, view of disability
 - c. Cultural and social economic contexts
 - d. Parenting

References

- Braddock, D., Hemp, R., & Rizzolo, M. (2008). *The state of the states in developmental disabilities*. Boulder, CO: Coleman Institute for Cognitive Disabilities, University of Colorado.
- Freedman, R., Krauss, M., & Seltzer, M. (1997). Aging parents' residential plans for adults with mental retardation. *Mental Retardation*, 35(2), 114-123.
- Greenberg, J., Seltzer, M., Orsmond, G., & Krauss, M. (1999). Siblings of adults with Mental illness or mental retardation: Current involvement and expectation of future caregiving. *Psychiatric Services*, 50(9), 1214-1219.
- Heller, T. & Kramer, J. (2006). Involvement of adult siblings of people with developmental disabilities in future planning. *Disability Research Brief*, 2. Chicago: Institute on Disability and Human Development, University of Illinois at Chicago.
- Orsmond, G. I. & Seltzer, M.M. (2007). Siblings of individuals with autism spectrum disorders across the life course. *Mental Retardation and Developmental Disabilities Research Reviews*, 13, 313-320.
- Rossiter, L., & Sharpe, D. (2001). The siblings of individuals with mental retardation: A quantitative integration of the literature. *Journal of Child and Family Studies*, 10, 65-84.
- Stoneman, Z. (2005). Siblings of children with disabilities: Research themes. *Mental Retardation*, 43(5), 339-350.

Chapter 2:

**Expanding the Circle of Support
through Policy and Advocacy:
Brothers, Sisters and Caregiving for
Individuals with Developmental Disabilities**

A White Paper

Prepared in Collaboration with the Sibling Leadership Network

Cathy Allen, John Kramer, Emily Marino, Shea Obremski, Anna Zendell

For the Policy and Advocacy Work Group

September 15, 2008

Purpose

The purpose of this White Paper is to provide a summary of principles and recommendations to guide the advocacy efforts for and by the siblings of individuals with developmental disabilities. In a time of increasing fiscal constraint on federal, state, and local government, policymakers are looking to other avenues to buttress the support of people with disabilities. The brothers and sisters of people with disabilities are a key constituency of interested and essential allies and resources for agencies and policymakers in the movement toward full inclusion and participation of all individuals with disabilities. This White Paper emanates from the Policy and Advocacy Work Group at the Sibling Leadership Network Conference held in Washington D.C. on November 9 and 10, 2007. The Policy and Advocacy Work Group developed principles that should guide advocacy initiatives and proposed recommendations and action steps for including siblings in future policymaking.

Principles Guiding Policy and Advocacy

1. *The term “family” should include siblings.* Federal law generally allows states to define “family” as they interpret various statutory provisions. But where a state

Chapter 2: Expanding the Circle of Support through Policy and Advocacy

defines family as “parents and guardians,” or fails to define family at all, brothers and sisters are left without an opportunity to participate in planning and care.

2. *Siblings have a unique and under-represented voice in advocacy for and with their brothers and sisters with disabilities.* The sibling relationship is considered the longest-lasting relationships of the human experience, providing the greatest opportunity for reciprocal support and care. Adequate representation of brothers and sister in the lives of people with disabilities can lead to more balance in regards to independent living, personal freedom and self-sufficiency.
3. *Policymakers and agencies must incorporate siblings into the collective discussion of the rights and supports of citizens with disabilities.* Including siblings will enhance the quality of life of individuals with disabilities and ensure quality services, support and long-term care for people with disabilities
4. *Siblings should be included in policy development, programmatic planning, services and supports.* While many state and local regulations require family representation on policymaking boards and committees, parents have consistently been the identified family representatives. With the aging of American society, it is prudent to start investing in the next generation - siblings. Many siblings are already providing support with little or no input in shaping public policy, services or supports.
5. *Family support policy must enhance the quality of life of all family members.* The focus of federally funded family support is the child with the disability and their parents. The current policy omits brothers and sisters who can also benefit from an enhanced quality of life. We believe it is time to strengthen family support policy by explicitly including brothers and sisters of people with disabilities in federal family support program guidelines.
6. *There are millions of siblings who are an untapped resource who can, with the proper support and encouragement, make a positive impact in the lives of their brothers and sisters and others with disabilities.* When given the opportunity to meet other brothers and sisters of individuals with disabilities, people often note their sense of comfort and relief to know they are not alone. With support and information, an increasing number of brothers and sisters are capable and willing to play significant roles in the lives of people with disabilities.

Summary of Advocacy to Date

Services and policies concerning individuals with developmental disabilities have evolved over the past five decades. Today people with disabilities who were once relegated to isolated institutions, deprived in many cases of basic human rights, are provided with the supports and resources to live independent, productive and fulfilling lives in their communities. The social revolution that enabled this transition was led by concerned professionals, courageous legislators, loving family members and determined self-advocates.

The concerns of brothers and sisters of people with disabilities, and their desire to become a positive component of the future planning solution, represent a new era in the collective story of the civil rights of people with disabilities in the United States. The Sibling Leadership Network is dedicated to working with legislators and service providers in order to carry on the legacy of the professionals, family members and self-advocates who revolutionized the field to ensure that our brothers and sisters with disabilities continue to have opportunities to lead lives of independence, dignity, love and joy.

Prior to the Sibling Leadership Network Conference held in Washington D.C., a group of brothers and sisters from Ohio visited their United States Senator, Sherrod Brown. Under the leadership of Dr. Tom Fish of the Nisonger Center at The Ohio State University, the group educated their senator on the SLN's goal of developing a national policy agenda, and of Ohio's tradition of leadership in sibling advocacy. A member of the Senate Health, Education, Labor and Pensions (HELP) committee, Senator Brown is positioned to champion the cause of people with disabilities and their families.

The group also paid a courtesy call to U.S. Senator Edward M. Kennedy from Massachusetts, the youngest brother of Rosemary Kennedy, a woman with developmental disabilities. Senator Kennedy, who chairs the Senate HELP Committee, and his staff greeted the SLN representatives warmly and listened empathetically to their discussion of the unique situation of siblings. With encouragement and support, they discussed the upcoming reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act (DD Act), which establishes and funds the Councils on Developmental

Chapter 2: Expanding the Circle of Support through Policy and Advocacy

Disabilities, University Centers for Excellence in Developmental Disabilities, and Protection and Advocacy Systems in all U.S. states and territories.

Key Policy Recommendations

Cutting-edge policy development and implementation provide critical mechanisms to move forward in promoting opportunities for the full inclusion and participation of persons with developmental disabilities in society, while concurrently supporting the unique needs and roles of siblings within their families. The Sibling Leadership Network is committed to partnering with policy-makers in order to provide a sibling perspective in formulating policies that will benefit people with disabilities and the families who provide support and care. The primary focus of initial SLN advocacy efforts is the Developmental Disabilities Act.

Developmental Disabilities Assistance and Bill of Rights Act (DD Act)

The DD Act is scheduled for reauthorization this year. This Act ensures that individuals with developmental disabilities and their families participate in the design of and have access to culturally competent services, supports and opportunities that promote the full inclusion and participation of citizens with disabilities. The SLN has identified this Act as a primary focus for implementing change because of its importance in the lives of individuals with disabilities and their families. The SLN finds that the DD Act is largely written in such a way that family members are referred to equally, without favoritism to parents. The expression “individuals with developmental disabilities and their families” is used fairly consistently throughout the act. In order to ensure that siblings and other caregivers are legally included in the process of planning for services and supports, the SLN proposes the following modifications of the language in the Act itself.

1. The Sibling Leadership Network recommends redefining “family” as follows: “the term ‘family’ means, mother, father, brother, sister, spouse, child, and anyone else that an individual with a disability considers family.”

Chapter 2: Expanding the Circle of Support through Policy and Advocacy

2. The Sibling Leadership Network recommends the inclusion of all types of family members as representatives on state Councils on Developmental Disabilities. We specifically request one seat be occupied by a sibling representative.
3. The Sibling Leadership Network recommends several changes in the Council on Developmental Disabilities State Plans. First, the language should include brothers and sisters. Second, incentives should be provided for University Centers for Excellence in Developmental Disabilities to specifically include siblings in the demonstration grant development process and/or submissions. Third, State Protection and Advocacy Systems include siblings in its Board of Directors or Advisory Panel. Last, the outcome indicators must measure the involvement of siblings when evaluating the participation of families.
4. The Sibling Leadership Network recommends specific efforts to reach out to, inform, and involve brothers and sisters in training opportunities and programmatic activities.
5. The Sibling Leadership Network recommends enhancing outreach, information, and involvement of siblings of people with developmental disabilities in the creation and development of projects of national significance.

The SLN also strongly supports the following legislation and proposed amendments, in alliance with groups of self-advocates and other disability organizations across the country.

Lifespan Respite Care Act (P.L. 109-442)

The Lifespan Respite Care Act provides competitive grants to states to develop coordinated systems of quality, community-based respite services for family caregivers of children and adults with special needs regardless of age and disability. The Sibling Leadership Network supports the Consortium for Citizens with Disabilities (CCD) Long-Term Services and Support Task Force in urging full funding (\$53.3 million) for the Lifespan Respite Care program in the FY09 Labor, HHS, and Education funding bill. In addition, the SLN proposes the inclusion of siblings in family trainings about respite care; access to information about available services and supports; respite worker and volunteer

Chapter 2: Expanding the Circle of Support through Policy and Advocacy

training and recruitment; and the development of specialized training to support siblings as new caregivers in times of transition.

Financial Security Accounts for Individuals with Disabilities (H.R. 2370/S.2743)

Financial Security Accounts for Individuals with Disabilities (FSAID) H.R. is new federal legislation introduced in both the House (H.R. 2370) and the Senate (S.2743). The legislation proposes providing individuals with disabilities and their families a means to save money and build assets on behalf of people with disabilities without jeopardizing their entitlement to crucial federal, state, and local programs that enable them to pursue their goals and dreams. Specifically, the FSAID allows people with disabilities, any family member or guardian to establish a Financial Security Account, a savings account specifically for persons with disabilities, which would accrue interest tax-free. Funds from this account could be used for various expenses not covered by traditional government benefit programs, such as medical care, education, vocational training, assistive technology, housing, relocation, and transportation. All FSAIDs would be federal accounts. If this legislation is passed, the regulations overseeing FSAIDs will be consistent in every state. These accounts are not treated as income or assets when determining eligibility for benefits to any federal entitlement program.

The Community Choice Act (H.R. 1621 and S799)

The Community Choice Act allows individuals and families long-term care options in services and supports by reforming Title XIX of the Social Security Act to end institutional bias in Medicaid funding. The SLN proposes that the legislatively mandated Development and Implementation Councils should include siblings as Council representatives in the language of the Act. The definition of “family” as determined by the Secretary should include siblings. Under the definitions concerning flexibility in transition to community-based home settings, funding assistance should be included for transitions from a home setting to another home setting (e.g. a sibling’s home), to avoid institutional placement in the event of a crisis, such as parent death or incapacity. Finally, the SLN proposes mandated evaluations of the provision of community based attendant services and supports include both agency-based services and family-based supports.

Chapter 2: Expanding the Circle of Support through Policy and Advocacy

Family based evaluation should include opportunities for the joint support of parents, siblings and other family members.

Family Medical Leave Expansion Act (H.R. 1369)

The Family Medical Leave Expansion Act (FMLEA) supports family members through local and state projects that support wage replacement for family members responding to caregiver needs. The SLN proposes inclusion of siblings caring for a brother or sister with a disability in the FMLEA provisions. This included group should receive the wage replacement benefits in the same way as parents and other defined beneficiaries, as well as the entitlement to “school” involvement leave. Siblings should have increased access to training that enables them to provide necessary care for a brother or sister with a disability, without jeopardy to employment. To this end, sibling language should be added to the benefit of “meaningful involvement in training.” Provisions for the inclusion of non-parental family caregivers should be added in policy evaluation initiatives proposed in the FMLEA to develop an evidence base of this benefit.

Conclusion

Services and policies concerning individuals with developmental disabilities have evolved over the past five decades. We have moved together as a society that relegated people with disabilities to isolated institutions, deprived in many cases of basic human rights, to one in which, today people with disabilities are provided with the supports and resources to live independent, productive and fulfilling lives in their communities. The social revolution that enabled this transition was led by concerned professionals, courageous legislators and, most of all, by determined and loving parents. The Sibling Leadership Network is dedicated to working with legislators and service providers in order to carry on the legacy of our parents to ensure that our brothers and sisters with disabilities continue to have opportunities to lead lives of independence, dignity, love and joy.

Chapter 3:

Supporting Brothers and Sisters: An Effective Means of Improving Life for People with Disabilities

A White Paper

Prepared in Collaboration with the Sibling Leadership Network

Don Meyer and Tom Fish

For the Services and Supports Work Group

September 15, 2008

Purpose

The purpose of the White Paper is to develop recommendations for needed services and supports for siblings of brothers and sisters with developmental disabilities. This paper is a product of the services and supports work group at the Sibling Leadership Network Conference held in Washington D.C. on November 9 and 10, 2007. The Services and Supports Work Group articulated principles guiding their work, delineated needs for and benefits of various services and supports, and made recommendations for low cost and high impact programs and services.

Principles Guiding Services and Supports

- Supporting siblings with and without disabilities benefits the entire family and society as a whole.
- Siblings of individuals with disabilities need information, opportunities to share, training, and opportunities for guidance.
- Siblings have a unique perspective due to our life experience that should be valued and recognized.
- Siblings should be respected in their choice to be lovingly involved at whatever level and in whatever way they choose.

Summary of Service and Support Issues

In the United States over 4.5 million people have developmental disabilities¹. Most of these people have typically developing brothers and sisters. These brothers and sisters are too important to ignore, if for only this reason:

Siblings will be in the lives of family members with disabilities longer than anyone. Brothers and sisters will typically be there after parents are gone and special education services are a distant memory. There is a relationship that can easily exceed 65 years. When provided with support and information, these brothers and sisters can help their siblings with disabilities live dignified lives from childhood to their senior years.

Siblings of people with disabilities share most of the concerns that their parents experience, including isolation, a need for information, guilt, concerns about the future, and caregiving demands. Brothers and sisters also face issues that are uniquely theirs, including resentment, peer concerns, embarrassment, and pressure to achieve. Yet, compared to what is available for parents, services and supports for siblings are almost non-existent.

Today's siblings assume a larger role in the lives of people with disabilities than in previous generations. This is due to at least three converging social phenomena:

- First, because of advanced medical technologies, people with disabilities now routinely outlive their parents.
- Second, current social policies encourage people with disabilities to live and work in the community. While these are desirable policies, it means that adult siblings assume the *in loco parentis* roles previously played by the state.
- Third, these changes occur at a time when many states—facing diminishing dollars for social services—find housing and employment options for people

¹ <http://www.acf.hhs.gov/programs/add/Factsheet.html>

Chapter 3: Supporting Brothers and Sisters

with disabilities scarce. Currently, more than 70% of adults with intellectual disabilities remain at home after high school.

Consequently, siblings of the baby boom and post-baby boom generations are called upon to be more involved in the lives of their brothers and sisters with disabilities. More than anyone, they will be the most important source of information regarding their vulnerable brothers and sisters. “The types of support that these relatives--primarily adult siblings--will need once they assume caregiving responsibility may well be different than those of aging parents, and will be a growing concern for the service delivery system (Seltzer,& Krauss, 1995).”

Services and supports specifically for brothers and sisters have a long-lasting impact on families and the lives of people with disabilities. Seventy-five per cent of adult siblings who attended a peer support and education program for siblings as children reported that the program affected their *adult* lives and the *adult* relationships they have with their siblings with intellectual disabilities. These programs “serve as protective factors for siblings of individuals with disabilities, a population who is frequently considered at-risk” and the “positive results last into adulthood.” The study concluded, “The positive effects are not only apparent, but enduring (Johnson & Sandall, 2005).”

Providing siblings with services and supports is a low-cost, high impact means of improving the lives of people with disabilities because supported, informed siblings are more likely to remain lovingly involved in their lives as adults—and when their parents no longer can. But others benefit from these efforts as well:

- Typically-developing siblings are reassured when they have the skills and know-how to advocate for their brothers and sisters;
- Parents enter their senior years knowing that their children with disabilities will be cared for when they no longer can;
- Service providers serving adults with disabilities benefit from having siblings as active partners--and siblings are an especially important source of information about their brothers and sisters; and

Chapter 3: Supporting Brothers and Sisters

- Taxpayers benefit because adult siblings who are involved in the lives of their siblings with special needs will reduce the need for costly social services.

Because they make life-long contributions to the lives of their brothers and sisters who have disabilities, siblings of all ages benefit from simple, but critical considerations.

Siblings need information about:

- Their sibling's disability and its implications
- Treatments and services for their brothers and sisters
- Plans their parents have for their sibling's future
- The genetic implications of their sibling's disability
- How to effectively advocate for their brother or sister
- Services for adults with disabilities

Siblings need opportunities to:

- Meet their peers
- Discuss common joys and concerns with other siblings
- Learn how other siblings address problematic situations frequently faced by brothers and sisters
- Discuss their current and future roles in the life of their sibling who has a disability.

Siblings need parents who:

- Understand siblings' life-long and ever-changing concerns
- Learn proven strategies to minimize siblings' concerns and maximize their opportunities
- Provide their typically developing children with information and opportunities to meet their peers

Chapter 3: Supporting Brothers and Sisters

- Plan for the future of their child with an intellectual disability, and involve their typically-developing children in this planning
- Value the right to self determination for each of their children

Siblings need service providers who:

- Understand siblings' life-long and ever-changing concerns
- Proactively provide brothers and sisters with information
- Create programs specifically for siblings
- Make systemic changes to include brothers and sisters in their working definition of "family."

Key Services and Supports Recommendations

To help their brothers and sisters who have disabilities lead dignified lives, siblings will benefit from funding effective programs, services, and considerations, including:

1. ***A national clearinghouse for sibling-related resources***, which would make the following available online:
 - A national directory of Sibshops and adult sibling programs;
 - Information regarding local and national sibling-related events;
 - A source for a wide range of sibling-related materials: recommendations for parents, service providers, and siblings of all ages; fact sheets about disabilities and services for siblings of all ages; sibling-related books, curricula, etc.;
 - A single comprehensive source for listservs and social networking websites for young, teen, and adult sibs as well as listservs for those running programs for siblings and for parents concerned about their typically-developing children; and
 - A hotline for siblings, parents, and family members who do not have access to the Internet or wish to discuss concerns about their families.

Chapter 3: Supporting Brothers and Sisters

2. **Training** for agency staff who wish to create programs for brothers and sisters of all ages and **technical assistance** to agencies who wish to make changes to include brothers and sisters in their working definition of “family.”
3. **Presentations at national, state, and local conferences for parents and service providers** on how to proactively address sibling concerns.
4. **Creating and promoting innovative curricula** to meet the support and information needs of preschool, school-age, teen, and adult siblings.
5. **An annual national conference for adult siblings**, featuring workshops on topics identified by clearinghouse surveys and adult sibling listservs.

In the United States, there are millions of brothers and sisters of people with disabilities. We will likely become caregivers for our siblings when our parents die. Anyone who is interested in the welfare of persons with disabilities ought to be interested in us. --Kitty Porterfield, sister, Alexandria, Virginia



References

Seltzer, M.M., & Krauss, M.W. (1995). Older families with adult children who have disabilities: What are their service needs? *Intraactions*, Waisman Center, University of Wisconsin, February <http://www.waisman.wisc.edu/ia0295.html>

Johnson, A. B., & Sandall, S. (2005). *Sibshops: A Follow-Up of Participants of a Sibling Support Program*. University of Washington, Seattle