



Sibling Connections Newsletter

Fall 2005

A Call For Sibling Leaders!

Are you a sibling of a person with a disability? Are you interested in uniting with other siblings across the state to affect change for people with disabilities?

The Rehabilitation Research and Training Center on Aging with Developmental Disabilities is currently drawing up plans to organize the first ever group of only siblings interested in policy issues in the state of Illinois.

The working title for this group is the "Sibling Leadership and Advocacy Group."

Resources

Check out the recent issue of *Mental Retardation*—

In this issue, researchers explore recent trends in sibling research and offer suggestions on different ways to learn more about siblings.

Researchers highlight the need for new methods, measurement, and most of all cultural issues that need to be addressed in future work.



Very Special Thanks:

We extend our thanks to the Center for Enriched Living for hosting the Sibling Connections and the College of Applied Health Sciences at UIC for its generous financial support.

Additional thanks to our sponsors for promoting this event and all our speakers and breakout session leaders for their generous contributions and expertise. Special thankst to Derrick Dufresne and Anne Guthrie for their hard work!

-The Sibling Connections Staff

Sibling Connections Sequel a Success

Riverwoods, IL— Brothers and sisters of people with disabilities descended on the Center for Enriched Living for the 2nd annual Sibling Connections Conference on October 22, 2005. The Rehabilitation Research and Training Center on Aging with Developmental Disabilities organized the event and welcomed over 50 attendees, including mostly siblings from Chicago and the surrounding suburbs.

Siblings are important because often they assume a variety of key roles in the lives of people with disabilities, yet still go relatively under the radar of most people who specialize in the disability field. Agencies, professionals, and, most of all, and people with disabilities often see the rise in importance of siblings as parents age. However, siblings sometimes do not have the years' experience of navigating service systems that parents do because they are not frequently considered by providers and professionals.



The roles of siblings vary widely. Their siblings with disabilities, for instance, may live in group homes, with other family members, or with their own families.

This year's conference attendees were from a wide variety of backgrounds: some were younger siblings who were looking for more information on benefits and planning for the future, others were full guardians of their brother or sister with a disability, while still others were mostly concerned with how to deal with the challenges of navigating agencies and dealing with direct care staff. Together they had a chance to network, get information, and hear some of the latest research trends on siblings and families of people with disabilities.

Sibling Connections is unique to Illinois because it is a conference designed to reach out to brothers and sisters by providing them with valuable information. Finding a variety of different topics that are relevant to siblings is crucial given the variety and diversity of sibling experiences.

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Vision for a Sibling Constituency?

Brothers and sisters, we are important. We are important because we will be a central person in our brother or sister's life. Agencies, professionals, and, most of all, our siblings with disabilities will all most likely be dealing with us as our parents age. Therefore, long term care policy in our state of IL needs to be of primary concern to us. So what do we do? How do we organize ourselves to represent the long-term issues important to families? What needs to happen after Sibling Connections?

How do you envision siblings increasing their presence? Siblings at Sibling Connections indicated that we need more media exposure— we need more of our stories represented. Another avenue is to create a Sibling Leadership Network that would work in tandem with other existing agencies. What do you think? Please email comments to John at jkrame3@uic.edu.

Suggestions are welcome!

Contact Us!

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Sibling Connections also serves as part of the ongoing research at the University of Illinois at Chicago on families and disability. The RRTCADD currently is providing training to siblings who are planning care for their adult relative with a disability. The training will involve siblings with disabilities, parents, and other members of the family.

Brothers and sisters also had many ideas about where to go next after Sibling Connections. Some indicated that siblings need more media exposure, while others were voicing a need for a stronger sibling voice in advocating policy. Another avenue that is currently being explored by the RRTCADD is to create a Sibling Leadership Network that would work in tandem with other existing agencies. Please email comments to John at jkrame3@uic.edu or contact by phone at 312-996-7988.

Filmmaker Tells a Uniquely Sibling Story

Chicago, IL— Award-winning film director Susan Hamovitch came to the University of Illinois in October to screen her film "Without Apology." In her film, she reconnects with her brother Alan who had been institutionalized since the 1950's. This film portrays the long-lasting

implications of institutionalization not only on people with disabilities, but also parents and, in this case, siblings. In her film, for instance, Susan brings Alan to a restaurant for the first time even though her brother is well into his 50's. Hamovitch's film is important not because it touts either a community-based living or a range of services approach, but rather portrays the realities that families have faced in providing care for people with disabilities.

"Without Apology" is currently available via the web from one-eyed care productions at www.withoutapology.com



Events

The Institute on Disability and Human Development currently maintains a website with upcoming events that might interest siblings and family members of people with disabilities.

For more information, please go to, <http://www.uic.edu/orgs/idhd/events.htm>

