

SIBLINGS OF PEOPLE WITH DISABILITIES: AN UNTAPPED CONSTITUENCY FOR POLICY ADVOCACY

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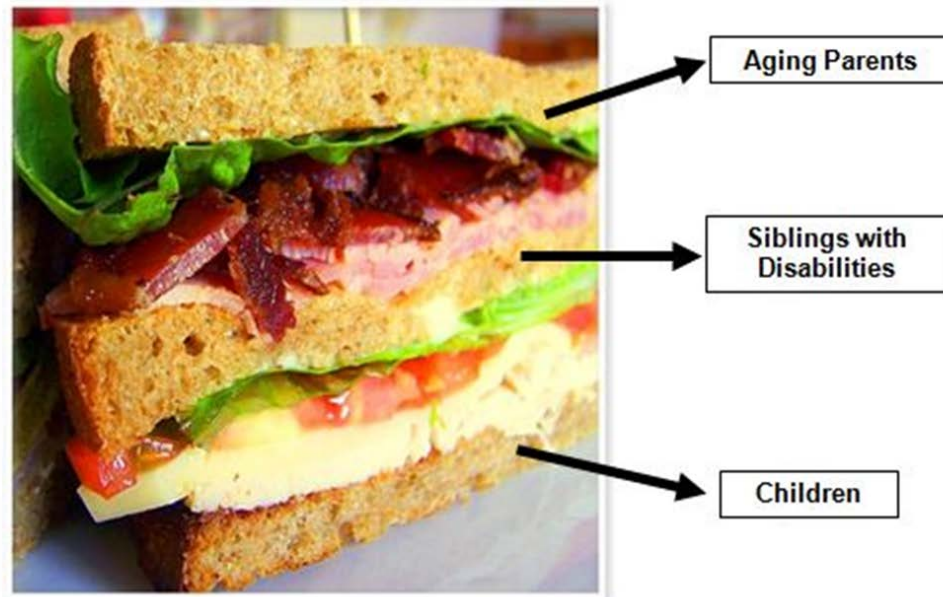
OVERVIEW

- Intro and Background
- Sibling Policy Forums
- Focus group findings



WHY FOCUS ON SIBLINGS?

- Family support policy often overlooks sibs
- Siblings are the next generation of supporters



- Siblings have the longest relationship
- Siblings are an untapped constituency

SIBLING VOICE AT THE POLICY TABLE



www.siblingsleadership.org

Join an SLN Committee:

- ❖ Policy & Advocacy
- ❖ Research
- ❖ Support & Information
- ❖ Communications
- ❖ Chapter Development

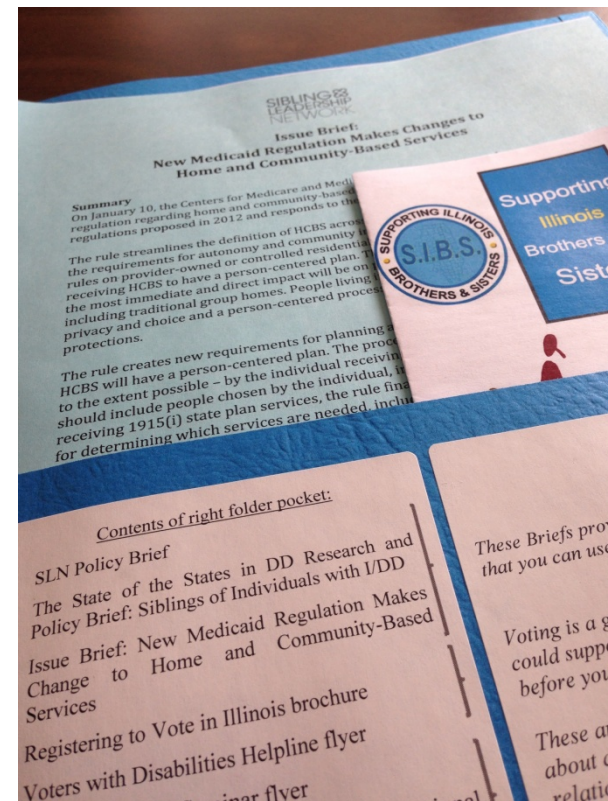
SIBLING POLICY FORUMS

- Held across Illinois in March 2014
- Half day training on state and federal policies
- Created videos for policy makers



ADVOCACY TOOLKIT

- Research & Policy Briefs
- SLN's Sibling Policy Brief
- Sample letters to policy makers
- Letter writing tips
- How to tell your story effectively
- Talking points about siblings



POLICY VIDEOS BY SIBLINGS

- Siblings used the “hook, line, and sinker” process to share their stories



- Employment First Policy: Sibling Perspectives
- Policy Video by Siblings on Future Planning

LEVELS OF ADVOCACY



FOCUS GROUPS



- 4 focus groups ($n=21$)
- Research questions:
 1. How do siblings define advocacy?
 2. How do siblings advocate?
 3. Why do siblings advocate?
 4. What do siblings need in order to more effectively advocate?

CASE AND CAUSE ADVOCACY



	Case Advocacy	Cause Advocacy
Definition	Individual advocacy focused on one individual	Class advocacy focused on creating change for a group of people
Method	Special education services for child	Filing lawsuits to create systemic change
Rationale	To qualify for services	To change how the service system delivers services

DEFINING ADVOCACY

Case Advocacy	Quotation	Cause Advocacy	Example
Providing Support to brothers/sisters with IDD	“I think advocacy is supporting my family member”	Educating Others	“Creating an opportunity for the general public to know about a subject”
Giving a Voice	“Relaying things that my brother cannot necessarily relay himself to people”	Creating systemic Change	See example



METHODS OF ADVOCACY

Case Advocacy	Example	Cause Advocacy	Example
Including brother/sister	“I’ve always tried to include my brother in as many activities as possible”	Collective Advocacy	“started a non-profit that we all started. For my brother and for all people with disabilities”
Securing Services	“We definitely advocated on his behalf that he needed to continue in some sort of programming post high school”	Creating Systemic Change	“Helping to mobilize families and groups to call, e-mail, and show up for rallies and getting touch with legislators”
----	----	Educating Others	Spread the Word to End the R-Word



ADVOCACY OVER TIME

- Advocacy changes over time for siblings
- Often starts as case/individual advocacy and moves to cause/collective advocacy



“I feel like my advocacy role is changing. I used to be...well I still am a sibling. Now that my mom is gone, it is more in a parental role...I feel like I am trying to move into a different role in advocacy.”

REASONS FOR ADVOCACY



Case Advocacy	Example	Cause Advocacy	Example
Love and Obligation	"I couldn't imagine not. He is my brother, so, isn't it obvious? It is what you do"	Pay it forward	"It is giving back to the people that did help us...paying it forward what they have done for us"
Part of their Identity	"You wake up to it every morning. That is part of who I am"	Educate the Public	I think we have the ability to change the way people think. And I think that is one of the greatest gifts we have.
To receive services	"It is out of necessity that I advocate"	----	----



SUMMARY OF FINDINGS

- Siblings advocate via both case and cause advocacy
- Siblings advocate for a variety of reasons
- Siblings want information/knowledge as well as peer support

Knowledge and Information

“What do we do when my brother turns 21? What are we doing?”

Peer Support

“I would love to meet other people that are in my boat. If I could have a little support group, that would be great. I am sure they are out there. I just haven’t had time to find them.”



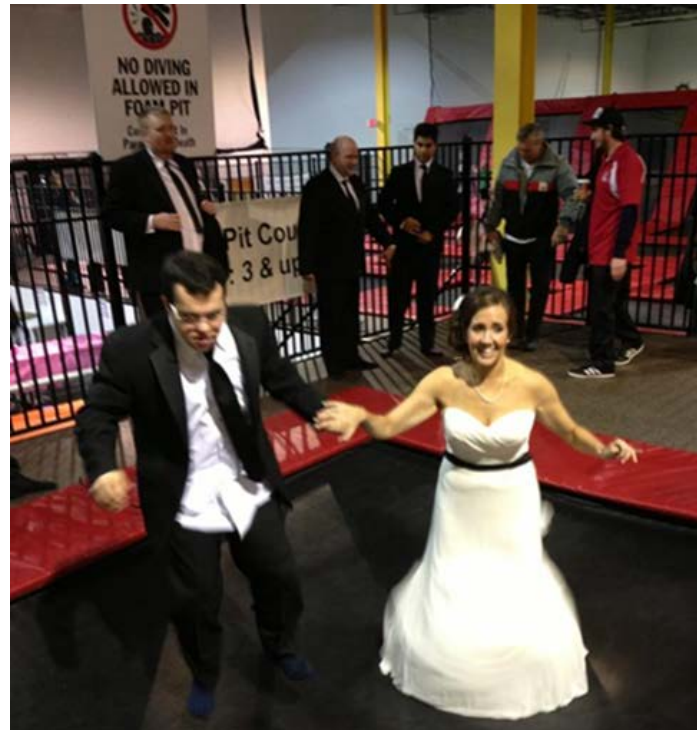
IMPLICATIONS

- More research on how advocacy roles change over time
- Service providers should target siblings and give information about navigating the service system
- Providers may need to connect with the Sibling Leadership Network as a resource
- Policymakers should recognize siblings as an untapped advocacy constituency

CONCLUSION

Recap:

- Siblings matter
- Engaging siblings is important—give them tools, information and connections
- Siblings advocate at various levels in different ways enacting both case and cause advocacy
- Siblings need for more information and peer support



SIBLING 
LEADERSHIP
NETWORK

Save the Date!



**2015 National Sibling
Leadership Network
Conference**

**May 30 & 31, 2015
Louisville, KY**



www.siblingleadership.org



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