



THE SIBLINK | January 2016

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RECAP

Sibling Support & Advocacy with Carolyn Chen

Thank you to the siblings who attended our first JFGH Bruce K. Smith Sibling Network Educational Program on December 1, 2015. Carolyn Chen, Sibling Support Coordinator with the MD Developmental Disabilities Council, joined us for a meaningful discussion about sibling support and advocacy. Carolyn, a sibling herself, shared her personal story of relocating to support her adult sister and parents, and the emotional journey that followed. Her ability to openly share her story with a sense of humor was a model for the lively conversation that followed.

A long list of excellent topic ideas for future programs was generated, including how to communicate with parents about the future care of a JFGH sibling and how to guide JFGH parents on communicating with their typically developed children about future planning for a JFGH sibling. One of the attendees suggested one way to open such a conversation with parents was to express appreciation for the protection from burden parents provided over the years. We look forward to seeing you at the next educational program featuring Liz Mahar, Program Manager, Individual & Family Support at The Arc who will lead a discussion on "How to Have a Future Planning Conversation with Parents." (See "Coming Up" section below for details.)

MDSibs 2015 Conference: A Hugh Sibling Success

On October 17, more than 200 siblings of people with developmental disabilities, parents, family members and professionals gathered for Maryland's first-ever conference focused on sibling issues. The one-day conference - *MDSibs 2015* - was held at the Hilton Baltimore BWI Airport Hotel, and featured Maryland Delegate Eric Luedtke as Master of Ceremonies and over 35 speakers in sessions tailored for participants from ages 6 to 75 years old. As one of the participants stated, "We finally found our people".

MDSibs 2015 attendees traveled from 11 counties in Maryland with representation from DC, Virginia and five states around the nation to listen to keynote speaker Don Meyer of *The Sibling Support Project* and to hear the unique stories and experiences of Maryland siblings of people with developmental disabilities. The conference emphasized three themes: sharing inspiring stories, tips on increasing family communication and lessons learned throughout the process.



Maryland Delegate Eric Luedtke welcomes MDSibs attendees



Breakout session topics included: learning how to be an advocate through the Maryland services system, planning for the future and the national sibling movement.



Keynote Don Meyer (far left) facilitates a panel of siblings & family members (L), Dolly McMahon of Caroline County Schools runs a Sibshop (Center), "Calling All Men: Fathers & Brothers" small group session (R)

Participants were inspired to continue to share their story, stay connected and engage with fellow attendees to build a stronger, support network for siblings in Maryland. One hundred percent of participants reported they left the conference "...more supported and connected to siblings & others who care about sibling issues." To view the schedule and speakers that made MDSibs 2015 a success, visit www.mdsibs.com.

MDSibs 2015 was sponsored by the Maryland Developmental Disabilities Council with partners The Arc Maryland, By Their Side and supported by the Maryland Developmental Disabilities Administration, the Maryland State Department of Education, the Maryland Center for Developmental Disabilities and the Maryland Association of Community Services.

COMING UP

Join us at our next Bruce K. Smith Sibling Network program with **Liz Mahar**, Program Manager, Individual & Family Support, The Arc.

Topic

How to Have a Future Planning Conversation with Parents

Date

Wednesday, February 24, 2016

Time

7:00-8:30 PM

Location

Jewish Foundation for Group Homes
The Joy W. and Robert S. Cohen Building
1500 East Jefferson St.
Rockville, MD



Liz Mahar



RSVP

Please RSVP to Beth Shapiro, LCSW-W, Director of Social Work, at 240.283.6018 or BShapiro@jfg.org by February 19, 2016.

Note

We are in the process of purchasing an online video conferencing tool for our siblings who are unable to attend in person. We are hopeful that it will be in place for the February meeting.

About Liz Mahar

Liz is The Arc's Program Manager for Individual and Family Support. Previously, she spent five years as a consultant and Managing Supervisor for FleishmanHillard, managing stakeholder relations for government-funded public health campaigns on topics including binge drinking, drug abuse, and chronic diseases. She also brings social policy expertise from five years of working on Capitol Hill. Liz earned a Bachelor of Arts in psychology from the George Washington University in Washington, D.C. Liz is the sibling of a younger sister with Down syndrome.

Please Note: If Montgomery County Schools are closed part or all day due to bad weather, this program will be rescheduled. Please check the JFGH website for updates.

SIBLING SCRIBBLINGS

Man Plans and God Laughs?

By: David Fishback, brother of JFGH resident, Lewis

There is an old Yiddish saying that goes, "Der mentsh trakht un Got lakht": Man plans and God laughs.

My parents planned for a family. I was born in 1947. My brother Lewis was born 3-1/2 years later. But not as they had planned. An oxygen deficiency at birth left him mentally disabled.

Well, God may laugh at our plans, but that does not stop us from readjusting and making new plans to fit new realities. I was brought up to understand that someday I would shoulder the responsibility for Lewis' care. Because my mother Hilda, who passed away a year ago at the age of 95, was so dedicated and vibrant for so long, we had many years to accomplish that transition.

So our family planned, and God did not laugh.

And sometimes a community, through hard work and dedication, acts in what we like to see as the most Godly of ways. My mother joined with so many other wonderful parents to found the Jewish Foundation for Group Homes. And as a rehabilitation professional, Hilda served JFGH in many capacities. Lewis has been a resident of the Rubin Home since its founding in 1991. There, he has had as good a life as possible, with the stability provided by the excellent staff and his housemates (most of whom have also lived there since the beginning).



*Lewis & David Fishback
(2014)*

So JFGH planned, and God did not laugh.

Lewis is an enigma. He is without speech, so it is hard to know how much he understands. When our father died in 1993, and our mother died nearly 22 years later, he seemed to understand death, but I really don't know how much. Thankfully, those deaths did not put him into an emotional tailspin, which I had feared might happen. Perhaps the fact that he saw them in their physical declines enabled him to understand what was coming. It was a blessing that we were able to bring him for a family dinner at Landow House shortly before my mom's last illness. Lewis and my mom held hands through dinner. But I don't know how much he really understood. Again, he is an enigma.



Lewis, David & their mother, Hilda z"l (2008)

But we tried to plan, and, it seems, God did not laugh.

Lewis has a precise memory. When he is focused on something the way he believes it should be, he is relentless in making sure that it follows his plan. He is extremely protective of his housemates.

Lewis is into structure and routine. When I visit him at Rubin, or when he comes to our house, we always go for a walk after eating, weather permitting. At our house, after dinner, we sit together and watch television. It is a routine he seems to enjoy. It is hard to really interact with Lewis, but he seems comfortable in our routines.

So I do not have the kind of heart-warming interactions that many JFGH siblings have with their brothers or sisters. My wife Bobbi cheerfully makes wonderful meals when Lewis comes to our house, and is always supportive. As are my two adult sons and their spouses. Our two-year old granddaughter recently met Lewis. I have no doubt that as she grows older, she will also feel the love for and commitment to Lewis that the rest of us feel.

By providing a safe, secure home for Lewis, JFGH has made all of this possible.

We have all planned, and God has not laughed at us.

If you have a sibling story you'd like to share, please email BShapiro@jfgh.org.

SIB RESOURCES

[Sibling Advocacy: Perspectives About Advocacy From Siblings of Individuals With Intellectual and Developmental Disabilities \(IDD\)](#)

An article in Volume 3, Issue 3 of *Inclusion* by authors affiliated with University of Illinois at Urbana-Champaign, Illinois and University of Illinois at Chicago reports on four focus groups with siblings of individuals with IDD. Authors report that siblings defined and engaged in **case advocacy** (i.e., advocacy on behalf of their brothers and sisters with IDD) and **cause advocacy** (i.e., advocacy for larger systemic





changes). Regardless of the type of advocacy, all siblings felt they needed more information and peer support to effectively advocate. The [Abstract](#) is available at no cost, full text access available with subscription to *Inclusion*.

Disability Scoop: Study Highlights Health Risks For Those With Autism

"Researchers are warning that more attention needs to be paid to the overall health of adults with autism, with a new study finding them at greater risk for a host of maladies. Adults on the spectrum have higher rates of health conditions ranging from seizure disorders and depression to hypertension, high cholesterol, allergies and anxiety, according to findings published recently in the Journal of General Internal Medicine." [Continue reading the article on Disability Scoop.](#)



Call for Participants in Study of Sibling Caregivers

Posted on Monday, December 21, 2015 by the Sibling Leadership Network

Rick Glaesser, a social work doctoral student at the University of South Florida, is seeking study participants for research on the effects on siblings who become the primary caregiver to and co-reside with their sibling with a developmental disability after transitioning from the parental home. Participation includes 1-2 phone interviews about your experience of the transition itself and after the transition.

If you would like to participate, please email rclaesse@mail.usf.edu.

FROM THE DESK OF...

Beth K. Shapiro, LCSW-C, JFGH Director of Social Work

When I attended the MDSibs Conference this past October, I was impressed with everything about it. I came away with a deeper understanding of siblings and their relationship with their family members. I heard siblings of all ages express their joy in the comradery of the day. Regardless of their age, throughout the day they repeatedly expressed how good it felt to be around so many other sibs.

At the end of the day, everyone was invited to the main hall where two microphones were set up. Attendees were invited to share their impressions of the day. No one stepped up. You could have heard a pin drop! After several long minutes, the littlest among us, only six years old, walked up to a mic, stood on her tippy toes and expressed, in the littlest of voices, how great it was to "play with the beach balls and other kids like her." That opened the flood gates. Teens and adult siblings began to come up to the microphones one by one. Soon after, mothers and fathers began to get in line. Parents expressed their relief that their children could attend and that they too had learned the importance of communicating with each of their children.

I want to encourage you to download and read (or save for later) the [Planning Now: A Futures and Estate Planning Guide](#). This is a complete and free tool created by the MD Developmental Disabilities Council. It considers some basic questions, including how parents or other relatives, can help their family member with a disability.



Wishing you a healthy & happy New Year,
Beth



THE SIBLINK

A publication of the Bruce K. Smith Sibling Network



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