

16th Annual Ohio SIBS Conference

November 11-12, 2016

Embassy Suites, Dublin

Day One: Friday, November 11, 2016

The 16th Annual conference started at 2:45 on Friday afternoon. This was the first year the conference has been created based around a theme. This year's theme was *Reaching for Well-Being*. There were approximately 90-100 registrants from all over the state of Ohio; as far north as Cuyahoga County (many from there) and Cincinnati was represented as well. I was told this is the largest gathering of siblings of people with disabilities in the United States.



The 12 Board Members of Ohio SIBS are all volunteer and are either siblings themselves or work in a DD related field. They are continuing to recruit new Board Members and are specifically looking for someone with a Marketing and Communications specialty. Current Board Members include Professors from the Nissonger Center at OSU, an Attorney, a CPA, etc. I was struck by how friendly and welcoming everyone was from the moment I walked in to register. They know so many of the return registrants by name and story. I was very impressed.

The group has recently developed a Strategic Plan and have updated their logo, website and overall path to improving the work they do, spreading the word about their organization and increasing their ability to reach more siblings.

This was the first year they provided "goodie bags" with donated items from various sources. Breakfast, lunch and dinner were provided over the course of the 2 days as well as a hospitality gathering and happy hour event for networking purposes among siblings. They also included door prize drawings and a 50/50 drawing to get everyone involved and infuse a bit of fun into the event.

Networking was stressed to everyone during the conference and the group as a whole seemed very motivated to talk and share. Everyone sees the value for siblings to connect and share their stories.

The theme of wellbeing was incorporated into every presentation throughout the conference. It began with a licensed social worker presenting on caregiver burnout and stressing the importance of caregivers “putting their oxygen mask on first”. You’re no help to others if you’re not taking care of yourself as well.

New Assistive Technology

One of my favorite presentations was given by John “Sid” Blair from Cuyahoga County who spent an hour sharing new technology. Everything is currently available to the public and works with iPhones and Android devices. He mentioned he has used many in his daily involvement with the DD community to improve quality of life. Items ranged from video door bells (used internally and externally) to virtual assistant devices to aid with reminders (i.e. meds, tooth brushing, etc).

***A copy of his handouts are included with this report.*

While I could not see a relevant application of this information to Bonni’s care I can see them being very helpful to those individuals who are higher functioning and more independent.

Importance of Preventative Dental Care

Shannon Skiba, DDS gave a great (and lighthearted) presentation on the importance of dental care for our siblings. She is the head Dentist at the Heinzerling Foundation and stressed to everyone that dental care specifically focused on the disabled was attainable through the Nissonger Center at OSU. The ability to get good (and patient/cooperative) dental professionals to work with this population can be a challenge, but should not outweigh the importance of getting that care.

Multiple speakers at the Conference were individuals with disabilities themselves. Marvin Moss shared his family story which included his mother’s accomplishments in starting the ARC of Ohio and ARC on the national level. He was noted as being the first person with a disability to legally become his brother’s guardian.

Day Two: Saturday, November 12

Day 2 started with breakfast for everyone attending the conference, whether you stayed at the hosting hotel or not. I spent breakfast chatting with Board Member, Michelle Long, who is a full time OT and volunteer Board Member. Again, just lovely people driving this organization.

The official program started the day with a 30 minute chair yoga group event to again teach siblings/caregivers how to take care of themselves. It was a great way to start the day.

Megan Rothermel shared her accomplishments as a young lady whose family did not allow her diagnosis of Downs Syndrome to limit her life. She shared her accomplishments which include graduating high school, attending college, learning ASL and Spanish. Her cousin, who has played the role of sibling in her life, also shared her experiences and attitudes about growing up with Megan.

Rachel Patterson spoke regarding her involvement in Policy creation in Washington DC and was very passionate and influential in getting “siblings” included in the FMLA law, which currently they are not. It could be argued we fall under “en loco parentis” (Latin for working in a parent-like fashion), however many HR departments do not recognize that because the actual word “siblings”, oddly enough, is not specifically included in the legislation. That process is changing, however, it is a slow process. She does currently have access to documents from the DOJ that have changed the language on one level of legislation, which they are happy to provide to anyone in need of them. They are not 100% confident it will change all HR department views on the matter, but some have waived their refusals based on these documents.

Colleen Beard, a sibling of a brother with CP, shared the horrible stories of poor care her brother has received in ICFs since being moved over to the IO Waiver. While the stories were difficult to hear, her purpose was to educate siblings and make them aware of the pitfalls that can occur. One attendee, who is a member of the Franklin County Board, spoke up and shared about 50% of all individuals with DD currently in ICFs have no family involvement so these issues of neglect could be occurring on a much wider scale unbeknownst to many.

Immediately following lunch, Katherine Koenig, a sibling to a sister with DS, presented on the occurrence of dementia for individuals with DD, specifically Downs Syndrome. I was struck by the statistic that over 50% of all individuals with DS will develop Alzheimer's by the age of 50. The rate of Alzheimer's in the general population at the age of 50 is only 4% with the steady increase occurring between the ages of 80-90. The research shows the predictability and occurrence of Alzheimer's is linked to Chromosome 21, the same chromosome affected in Downs Syndrome, hence their "predisposition" to the disease.

She focused on early detection and how current tests for Alzheimer's are not conducive for use in the DS population since some questions asked would be difficult for folks with DS to answer even without indication of dementia (i.e. Who is the current President? What is today's date?)

She is currently heading a study at the Cleveland Clinic to study Alzheimer's and the DS community and is looking for 16 study participants. 2 visits to the Cleveland Clinic will be required along with additional testing (blood work and lumbar puncture). She did mention a \$300 stipend will be paid to each participant. Testing can involve folks from Indiana, Ohio and Pennsylvania.

***She provided a list of resources on this topic, which I've attached to this report.*

The final formal presentation of the Conference was given by Tabitha Woodruff, Esq, an attorney working with "vulnerable" populations involved in abuse and exploitation. She was recognized as the newest member to the Ohio SIBS Board as well. She shared things to look for when identifying events where folks with DD are being abused or exploited, especially human trafficking.

***The handouts she provided are attached to this report as well.*

Sibling Gatherings Project

One of the more exciting announcements for me was when Ohio SIBS shared they received a federal grant to begin a Sibling Gatherings Project across 6 regions within the state of Ohio. They welcomed anyone interested in being a group facilitator to share their contact information with the Board. The goal of these meetings would be to share information and facilitate networking more often than just once a year at the Conference. All group meetings, and information to be shared at them, will be supported by Ohio SIBS.

I did share my contact information with the Board for this and noted that while I may not have the spare time available to be a dedicated Facilitator of these events, I would like more information and would welcome to opportunity to assist with the meetings and definitely attend. They did not share their vision for frequency of gatherings, so this may be something left to the groups themselves. I will share more information as I receive it.

My Conference Take-Aways

Reflecting back over the Conference I was left with a few thoughts:

- While I was not able to talk with every attendee, nearly all the siblings I spoke with have siblings with autism or Downs Syndrome. Those seemed to be the prevalent level of disability represented.
- A majority of the siblings were involved from a distance or a minimal capacity currently. Most were at the Conference as a means of preparing to increase their roles with their siblings over time.
- Attendees included not only siblings, but a few folks included their brothers/sisters with DD and a few parents were in attendance as well. (A husband/wife attend annually and always bring her severely disabled sister along and have done so for at least the past 10 years. She was the most severely disabled sibling I learned of during the conference.)
- Many of the siblings' career paths were heavily influenced with their siblings' disability. This included OT, Speech therapists, policy attorneys, PhD researchers,
- Very few attendees were first-timers like myself. Nearly all had been to many of the previous Conferences in years past.
- The sibling movement is gaining ground and coming to the forefront of consciousness for a lot of the country. There is a sense it is gaining steam.
- The main concern of all siblings present was difficulty finding good quality DSPs. All were supportive of the need for an increase in wages for DSPs.
- A majority of attendees represented Franklin and Cuyahoga counties.
- A lot of the siblings shared their future role in their brother or sister's care (in the absence of parents) was an automatic assumption. The sibling would become an automatic parental replacement in the

same role, home, etc. Many came to the realization with their sibling that was not what either wanted and thereby created a new living arrangement that benefited both in a positive way.

My primary goal in attending this conference was to hopefully connect with another sibling whose brother or sister shared the same level of disability as mine. I was hoping I would find someone to “commiserate” with and share information, worries, etc. While I did not find that, what I did find was a large group of people who are faced with all the same concerns as me, regardless of their sibling’s level of disability. That might seem like common sense to some, but this conference reminded me of that fact and that, in turn, has provided me with a level of comfort that there are others out there maybe not like, but at least similar to me. In addition, I know I have a group of wonderful people now as resources who can help guide and support me.