Interview with Emily Rubin: An Innovator of Sibling Support Services
By Leigh Horte

Emily Rubin has a deep connection to siblings with a family crisis. As a child, Emily experienced ongoing medical crises involving her older sister with special health care needs. Now, she is the Director of Sibling Support at UMass Medical School’s Eunice Kennedy Shriver Center as well as an Assistant Professor in Psychiatry.

Emily gained recognition for a program she created to build resiliency and decrease trauma among siblings of children with mental health needs. The Sibling Support Program: A Family-Centered Mental Health Initiative supports families during a child or adolescent’s psychiatric treatment by mentoring caregivers and supporting siblings through the crisis. Currently, UMass partners with Cambridge Health Alliance and Franciscan Children’s to provide the program on their inpatient psychiatric units. The Sibling Support Program was featured by the local CBS station, WBZ-TV’s “Matters of the Mind” series, and features Emily herself! ...watch it here: http://boston.cbslocal.com/2015/12/08/matters-of-the-mind-bree-sison-sibling-support-program/.

Emily is also a founder and the President of the Massachusetts Sibling Support Network (MSSN). The mission of the MSSN is threefold: to create welcoming communities for siblings of people with disabilities, provide education on sibling-related issues, and to improve the range and availability of sibling services across the Commonwealth. The MSSN is a state chapter of the national Sibling Leadership Network. She lives with her family outside of Boston.

Emily, you are trailblazing sibling support on two paths: professionally at the Shriver Center and as the leader of the Massachusetts Sibling Support Network (MSSN). How did this all begin?

In 2008, I applied for the Barbara Wilensky Gopen Memorial Fellowship and that began this journey. I was working as a professional writer and was drawn to the fellowship because I wanted to write a curriculum about the impact of disability on siblings.

I am one of four siblings including a sister with critical health care needs, who was born in 1959. After a long illness and frequent hospitalization, she received open-heart surgery at Children’s Hospital in the early 1970’s. The extended medical crisis influenced the sibling dynamics among the four of us and affected each of us personally. It became normal to live with the crisis of her care.

What was unexpected about the Gopen Fellowship was its emphasis on leadership development. The fellowship propelled me into the disability world where I identified a gap in services for families of those with disabilities. Overall, it was an incredible learning experience and it resulted in the development of the Massachusetts Sibling Exploratory Committee, which was the forerunner of the MSSN. At the end of the fellowship year, I was asked to join the Eunice Kennedy Shriver Center of UMass Medical School where I continued to research sibling issues.

About the Author
Leigh Horte is a writer and communications specialist on the Board of Directors of the Massachusetts Sibling Support Network. She writes about sibling issues primarily for the 40+ adult demographic of the disability community.
Articles from Our Contributors

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In the “Matters of the Mind” video, Bree Sison calls the Sibling Support Program: A Family-Centered Mental Health Initiative your brainchild. Have you encountered any program or personal breakthroughs during its operation and expansion?

I was surprised by how many families wanted to participate in the program, and how the same themes -- representing internalized and externalized stigma around mental illness -- kept resurfacing. Patterns of shame, isolation, and guilt emerged over and over, and it was a reminder of how important it is for families of people with disabilities and special health care needs to be part of a supportive community.

I learned every member of the family is affected by the illness or disability. Parents can feel deeply discouraged when their child ends up on a locked psychiatric unit, especially given how society views mental illness. Many families find themselves in a whirlwind of feeling misunderstood and self-critical. It can be a very painful place for caregivers and for siblings.

*How are these families doing in the long term? Does the program conduct any follow up on sibling status post-crisis?*

We are rolling out a follow up survey to study the impact of the program on families and siblings in the longer term. Specifically, we want to see if we are reaching the broader goals of the program, which are increasing sibling resiliency, decreasing sibling trauma, strengthening families and building capacity among providers who practice family-centered mental health care.

Participating in a program like this one can have a domino effect; once caregivers and siblings are validated in their experiences, learn that they are not alone, and are introduced to specific coping and parenting skills, their awareness about the impact of disability on siblings can grow exponentially. Often for the first time, parents who have been preoccupied with the child with a disability will suddenly understand the impact on other family members. It can serve as a catalyst to talk more openly about what is happening at home. It can make the parents reevaluate their expectations of the typically-developing children, many of whom are given caregiving roles themselves at an early age.

*What is planned for 2018 and beyond for the program?*

The program is expanding to additional hospitals and looking to expand to agencies that provide outpatient services. We are at the planning stage of creating a treatment manual on how to replicate and implement the program.

*Interesting... Are there any plans to make this program a national initiative?*

Yes, I am working toward meeting criteria for the program to be included in the National Registry of Evidence-Based Programs and Practices. NREPP is a national database of interventions overseen by SAMHSA (Substance Abuse and Mental Health Services Administration).

*You have another major effort leading the Massachusetts Sibling Support Network (MSSN). What drives you to dedicate yourself so fully to sibling outreach?*

Through this work, I have encountered amazing people! This includes siblings, of course. I have been struck by how overlooked siblings are as a group. When there is a disability in a family, we do not often think about how that disability shapes the lives of siblings.

Yet research has shown that many siblings, particularly sisters, grow up to become primary caregivers and advocates for their brothers and sisters; given this reality, I have felt compelled to help siblings as much as I can. The more support and understanding siblings receive early in life, the greater the chance they will develop into emotionally healthy adults capable of future caregiving.

*The MSSN was the only state chapter of the Sibling Leadership Network in New England for many years. Connecticut just formed a state chapter in 2017. Will the MSSN extend to regional coverage until the other New England states develop chapters?*

We do the best we can to stretch our resources to help our neighboring states. We often get calls or email from people outside of Massachusetts, especially New Hampshire and occasionally Rhode Island. We have traveled to Connecticut to do presentations. I sometimes end up doing long-distance mentoring with adult siblings or parents of young siblings and I encourage them to start chapters in their state.

Our main target area is Massachusetts and it is a big territory to cover. Our primary role is to increase visibility to siblings in Massachusetts, although we are supportive of anyone with sibling concerns in the disability community.
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What is the most vital sibling support issue for the MSSN in 2018?

The MSSN has grown in recognition over the past seven years, and demand for our services has increased, but the level of operating manpower within the organization has remained the same. Since its inception in 2011, the MSSN Board of Directors has functioned with an active, volunteer board of directors. The board has been responsible for all aspects of organizational governance and program development, including service delivery, marketing and community outreach, even though most board members also have full-time jobs. It is now time to make the leap in infrastructure from a volunteer board to hiring paid staff who can help us to expand services, serve a broader community, and help generate funding to fulfill our growing mission.

Taking this important step to grow the organization is an eventuality for young non-profits as they expand into larger entities. My hope is to ultimately assume a staff role as Executive Director of the MSSN. In the meantime, I will continue to do all that I can in my volunteer capacity as MSSN President.

TASH Connections is an international publication. Who at the national or international level has influenced or inspired you?

That is easier to answer at the state level. In particular, the four agencies that sponsor the Gopen fellowship have been very influential: the Massachusetts Developmental Disabilities Council, the Institute for Community Inclusion, the Disability Law Center, and the Eunice Kennedy Shriver Center. On a national level, and not necessarily with regard to siblings, one person who has inspired me is Michelle Obama. I admire her intellect, her value system, and her commitment to equality among all people.

You mentioned the influence of your childhood sibling experience. How is your sister now?

She is doing very well. Her heart is repaired and she is healthy. She has a resilient personality.

Thanks Emily! You have done impressive work on behalf of siblings. Anything else you would like to share?

Thanks, Leigh! I am excited about the year ahead for the Mass Sibling Support Network and for my sibling work at UMass Medical School. I feel lucky to have found work that I love.

Sibling Resources

- Eunice Kennedy Shriver Center at UMass Medical School: https://shriver.umassmed.edu/sites/shriver.umassmed.edu/files/documents/UMass-Sibling-Support-Program.pdf
- Massachusetts Sibling Support Network: http://masiblingsupport.org
- Sibling Leadership Network: http://siblingleadership.org
- “Sibling Support Program: A Family-Centered Mental Health Initiative”—Emily Rubin, guest blog on February 10, 2016 for Franciscan Children’s: http://franciscanchildrens.org/blog/sibling-support-program-a-family-centered-mental-health-initiative
- Sibling Support Project: www.siblingsupport.org

Siblings are a fascinating group of individuals to learn about, study, and support. I have always been interested in people’s stories, and the intersections in their lives that bring them to unexpected places. Siblings tend to be unusual people, having grown up with brothers and sisters who are trying to overcome enormous obstacles — sometimes physical, sometimes intellectual, and sometimes psychological. Interesting dynamics develop as the result of these intense relationships.

I have heard many adult siblings say that the most influential person in their life is their brother or sister with a disability; it can influence the type of life partner they gravitate toward, the type of work they choose to do, and where they decide to live. I am glad that through vehicles like the MSSN, the Sibling Leadership Network, and the Sibling Support Project, more and more siblings are getting the support and attention that they deserve.