

Family Mentorship Program Offers Insight | CPD

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Travis, Tracy and Peyton Smith of South Jordan, Utah

Tracy and Travis Smith of South Jordan, Utah, are the parents of a daughter, Peyton, age 7. Peyton has Nager Syndrome, a rare craniofacial syndrome, as well as a heart condition, asthma, upper extremity deformities and a severe bilateral hearing loss. She is considered medically fragile and has a tracheostomy and a feeding tube.

“When my daughter was younger and I couldn’t see a light at the end of the tunnel, I remember telling myself that there had to be good things that would come out of our difficult experiences,” Tracy said. “At the time, I had never heard of URLEND, but when I heard about the program, I remember thinking, this was why--to make it better for the families that come after us by helping to train the people they will be interacting with in the future.”

Smith chairs the Family and Consumer Involvement Committee of the Utah Regional Leadership Education in Neurodevelopmental Disabilities (URLEND) program, an interdisciplinary training program that is housed jointly at Utah State University’s Center for Persons with Disabilities

and the University of Utah Medical School. Last year, she was a family trainee, and this year, she serves as a family faculty member.

The Family and Consumer Involvement Committee was recently charged with formalizing and enhancing the Family Mentorship Program (FMP), something that has always been a part of URLEND.

“The overall purpose of the FMP is for trainees to gain insight and appreciation of the perspectives of families who have children with special health care needs,” said Gina Pola-Money, URLEND core family faculty member and director of Utah Family Voices. “Specifically, the FMP is designed to enhance the trainee’s knowledge and skills in implementing an interdisciplinary, family-centered, and culturally competent approach to support families who have a child with special health care needs. Because these outcomes cannot be learned in the classroom or from a textbook, the family is the most important part of the FMP’s success!”

According to Judith Holt, URLEND co-director, the Maternal & Child Health Bureau, which funds URLEND, places high value on family partnerships.

Building partnerships

“This is the 14th year for URLEND and the Family Mentorship Program,” Holt said. “During that time we have consistently worked at strengthening those partnerships, helping trainees better understand how to serve families. We’ve asked them to visit families in a non-professional role to better understand the life of the family.”

Trainees visit their mentor families four times a year and journal their insights, debriefing with their site coordinators to help them process what they’ve learned, Holt said.

“For some trainees, it’s a daunting experience,” she said. “They’re not sure how to relate to families if not in their professional role. Many are students, and they’ve been trained, ‘this is how you interact with families.’ This gives them more opportunities to self-reflect, and reflect with their coordinators on what they’ve learned. It makes it a stronger learning experience.”

In addition to observing how a child or youth with special health care needs is included as a member of the family and community, trainees also get the benefit of putting a face to the issues and data that are taught in didactic seminars.

“They learn about what is important to those who are impacted in their everyday life by the systems, agencies, providers and other professionals that serve them,” Pola-Money said. “This also helps them realize that we all need to make sure we have ‘family’ in ‘family-centered care’ and ‘public’ in ‘public health.’ This is a great way to start developing the family and professional partnerships which should be the guiding best practice in any discipline.”

Dallin Burgon is a URLEND trainee from Salt Lake City who is enrolled in the University of Utah’s Master of Business Administration/Master of Healthcare Administration program. He was assigned a family at the beginning of the school year and so far has visited with them in their home, at an IEP meeting, and at a doctor visit.

“The family I have followed has been able to give me insight into what happens in the lives of families with children who have disabilities,” Burgon said. “In a very real way, the family has let me into their lives to see what their joys and challenges are.”

Burgon’s mentor family explained that they would do anything for their children, and encouraged them to dream big when it came to career aspirations.

Turning point

“This was a real turning point for me,” Burgon said. “It made me wonder if, from my very narrow and uneducated point of view, I had ever really expected much from people with disabilities. I expected that they were capable of living life and having fulfilling jobs, but never thought that their dreams and aspirations could also be something that seemed out of their reach. By allowing them to dream, just like any other kid, we can help them obtain a higher standard of life and push them to be the best they can be. As a future administrator, I hope to be able to take this knowledge and remember it when I am dealing with people who have disabilities.”

JoLynn Webster is a research associate at Minot (N.D.) State University’s North Dakota Center for Persons with Disabilities and is also a member of the Family and Consumer Involvement Committee. She is responsible for recruiting mentor families to participate in the program as well as reviewing the family mentorship assignments of the URLEND trainees at the North Dakota site.

“Trainees are indicating that they are developing new respect and admiration for families who have a child with disabilities or special health care needs,” Webster said. “To hear trainees report that they are gaining insight and

understanding about families that they could not get in just a clinical setting or textbook or lecture is very rewarding.”

But trainees are not the only ones who benefit from the program, Pola-Money said. Families benefit as well.



URLEND trainees during a recent meeting.

“Families are able to provide both their experiences and expertise to the future professional leaders that will make an impact on our system of services for children and youth with special health care needs,” Pola-Money said. “This will provide the opportunity for families in the future to have a workforce that is better prepared to provide family-centered and culturally sensitive care to our children and youth as well as providing leadership to be our partners in advocacy and positive system change.”

Smith said the best part of her family’s experience with a trainee is that their experience is considered valuable enough that others want to learn about it.

“There is immense validation for any family that participates because suddenly the tables are turned – often for the first time – and they are recognized as an expert in the experience of raising a child with special health care needs,” Smith said. “In the school setting or the clinical setting, families often feel like they are an inferior participant in the process. The Family Mentorship Project can really build confidence for a family in recognizing the importance of their voice.”

It’s also important for trainees to learn that families are more than just a label, billing code or number on a waiting list somewhere, Pola-Money said.

“The disability or special need is only a part of what their life is made up of,” she said. “These families do have a lot on their plates but they are also members of their communities, they are participating in recreational activities, civic engagement, religion or spiritual services. They are living life to the fullest to the best of their ability and resources and want to be included in every aspect of community.”

Since the trainees involved in the FMP are future health care providers, there are other things they should know, Smith said.

"I believe most families are very capable of being partners in the health care journey with their child and their provider," she said. "Too often, families are treated as second-class citizens because they weren't trained formally in the medical field. So when we have an experience with a provider where we are viewed as a true partner, it is an amazing experience. We have had both experiences, and I can say we are much more engaged and 'compliant' with provider requests when we are treated as an equal.

"In addition, I think providers don't have a true understanding of everything that is on our plates and have unrealistic expectations of what can be accomplished at home without additional supports to the family," she continued. "This is not an issue of not wanting to be engaged or compliant but an issue of resources-- most often, time, but sometimes financially as well. But most providers when adding something to our list aren't finding out what the barriers might be or helping to overcome them once identified."

Smith said the trainees with whom she has interacted say the relationships they build with the mentor families is the most valuable part of the program.

"Although 'book learning' is great, actually spending time with a family and walking in their shoes--even if it is only for a little while--gives them a more complete picture of a family than they will ever experience in their clinical or school setting," she said. "Many say they are amazed by how much time and energy and resources the family must devote to supporting their child, they are surprised by how happy and positive the families are despite how complicated their lives are, and they are impressed by the capacity families have to learn new skills to support their child."

Burgon agreed.

"The experience really made me do a shift in thought," he said. "I see children with disabilities as opportunities now instead of people I should feel sorry for. This really was a great experience for me."