Parenting a child with special healthcare needs often has poor outcomes within families, negatively affecting inter-family relationships, sibling needs, and finances. Further, it puts parents at higher risk of stigma, divorce, anxiety, depression, and poor physical outcomes including sleep problems, pain, and even earlier death. However, these outcomes are not the end of the story. They do not adequately present the story of families and ill children, nor do they provide translational evidence that informs practice and offers support to families during especially vulnerable times. For years interdisciplinary research about children and youth with special healthcare needs (CYSHCN) has concentrated on the “identified patient,” for the most part ignoring or treating as ancillary the importance of caring for the same patient’s family. Children are cared for in the context of family. In this sense, caring for their families, is caring for ill children. We have made incredible technological and treatment advances that prolong the lives of ill children for decades beyond the expectations of even twenty years ago. At the center of these advances is the ill child who is living longer often with higher support needs, and surrounding that child – even before they reach the expert skills of the social worker, nurse, or physician – is the child’s family. The family is the primary support for ill children. Researchers are given the incredible opportunity to be the collective scaffolding that reinforces and strengthens the family that is supporting the ill child.

My research focuses on creating directly translatable interventions and knowledge to support the scaffolding, that supports the family, that supports the child. It has captured data that reveal the attitudes, needs, and behaviors of children and youth with special healthcare needs (CYSHCN), their parents, and the healthcare professionals that care for them. Using quantitative and qualitative methods, systematic literature reviews, and community-based participatory techniques my research has generated curriculum, healthcare care delivery strategies, medical decision-making knowledge, and psychological and social modalities that support CYSHCN and their families as well as the professionals that support them. Because of their vulnerability and proximity to CYSHCN, families have an ethical claim to good community-based mental and medical care. Further, my research is guided by the understanding that social workers and other healthcare and community professionals should feel compelled to deliver care that is rooted in research, is evidence-based, and is client- and family-centered.

My research focus has been directly translatable to create changes in medical and family care for CYSHCN. After working as a parent-volunteer within a pediatric palliative care service, in 2011, I co-wrote a Texas DSHS Medical Home grant that allowed me to write and conduct a 200-family survey of families of children with medical complexity. In 2012, with a physician colleague, I translated these findings and other research into a proposal to Seton Healthcare, initially funded at over two million dollars, to create the Children’s Comprehensive Care Clinic. After co-writing the research protocol for the randomized controlled trial attached to this funded clinic, I began my PhD program at The University of Texas at Austin. As a co-investigator, along with Dr. Barbara Jones and others, I co-wrote and co-led the research that looked at the
medical care for 300 children with complex medical needs. As that study ended, I had progressed from parent-volunteer to being hired by Seton/Ascension Healthcare as a program manager, to my final position as Research Scientist I. As part of my ongoing association with this study, I am currently analyzing over 60 associated qualitative interviews of parents in both English and Spanish in hopes of describing parent experience, and have been involved in ongoing analysis and interpretation of PedsQL (family impact/quality of life), CAHPS (patient satisfaction), and cost and utilization data. As of the first week in August the initial manuscript for this study has been submitted for publication and is currently under review.

Finding ways to translate evidence about supporting CYSHCN and their families has led me to translate evidence into curriculum. I am currently in my third year researching, creating, implementing, evaluating, and changing curriculum that seeks to operationalize national standards for transition of CYSHCN from pediatric to adult care. Although transition standards from the American Academy of Pediatrics and the American Medical Association have been consistently clear for decades, cases of successful transition of CYSHCN from pediatric to adult settings are the minority. After securing funding from Texas Department of State Health Services in 2015, over the course of three years, I conducted research, analyzed data, designed, taught, and evaluated outcomes for the only national, university-level curriculum devoted to YSHCN transition. The resulting curriculum is based on my initial research that surveyed healthcare professionals and graduate students, including physicians, nurses, and social workers and conducted focus groups of healthcare professionals, parents, and youth with special healthcare needs. Findings have informed the implementation and problem-solving focus of the curriculum.

This summer, I proposed an amendment to the DSHS grant to expand and extend the project so that I could offer information and problem-solving opportunities to already-practicing healthcare professionals involved in transitioning YSHCN. Additionally, the amendment allows me to design, implement, and evaluate YSHCN transition modules aimed at educating physicians in medical school, residency, and internship. The proposed amendment was approved, adding 20 months to the project and giving me an opportunity to further translate evidence to education and practice.

My recently-completed research on a small subset of CYSHCN focused on parent decision-making for infants with end stage renal disease (ESRD). I used two types of phenomenological designs: 1) to capture parents' essential experience of medical decision-making with specific attention given to the areas of decisional conflict, decisional uncertainty, and communication and information-needs, and 2) to further interpret experiences of care giving and decision making, focusing on the maternal performance of unrecognized and unrewarded emotional and instrumental labor that included tasks such as decision making, care coordination, and considering the contextual needs of the affected family. I will further use these data to develop an evidence-based decision-making tool for parents who make decisions for children with ESRD. I am currently preparing these articles based on this research for journal submission.
In addition to these research efforts, I have contributed to a book chapter based in systematic review of research and consensus about communication in pediatric palliative care. Additionally, the ethical claim of families to care from physicians, and evidenced-based care practices for families of children with disability or complex illness have led to the publication of “Supporting Parent Caregivers of Children with Life-limiting Illness,” *Children* (2018), and “The Duty of the Physician to Care for the Family in Pediatric Palliative Care: Context, Communication, and Caring,” *Pediatrics* (2014). I consistently contribute to and promote other research collaborations through the Institute for Collaborative Health Research and Practice at the University of Texas at Austin Steve Hicks School of Social Work, led by Dr. Barbara Jones.

My own experience of parenting my daughter, Caelan, who lived almost nineteen years with Aicardi Syndrome has given me the unique opportunity to conduct research as an insider. While honoring my own experience as one experience, being an insider has allowed me to speak the language of parents, healthcare professionals, and youth. It has also given me a greater understanding of more subtle aspects of parent experience such as grief and guilt. My unique circumstance has also given me vast and intimate exposure to the experience of hundreds of families of CYSHCN allowing me greater access to emotions, meanings, and gaps in care associated with CYSHCN and their parent caregivers.

I aim to secure an academic position in which I can continue to pursue my research agenda, teach and mentor students, and engage in participatory and community-based mixed methods research. My future research agenda includes securing further funding for research that focuses on the lifespan needs of YSHCN and their families, asking questions in ways that promote translational research that results in better education and clinical interventions for practicing social workers. I want to be in an academic setting that sees the support of CYSHCN family as a primary aim in medical and family support settings, as I continue to write and promote research that acknowledges that children and youth with special healthcare needs live within the context of families, and that caring for the family is caring for the child.