Congratulations to Jocelyn Gorlin, PhD, APRN, CNP who successfully completed her dissertation on *Severe Childhood Autism: The Family Lived Experience*. Dr. Gorlin was a pre-doctoral fellow in the School of Nursing’s Center for Children with Special Health Care Needs, funded by the Maternal Child Health Bureau (MCHB) and the University of Minnesota Leadership Education in Neurodevelopment and Related Disabilities Fellowship also funded by MCHB.

Ann Garwick, Center Director
Overview of the Severe Childhood Autism: The Family Lived Experience
by Jocelyn Gorlin

There is limited literature on the experiences of families when a child has severe autism versus milder autism that includes the voices of various family members such as extended family. Most research has focused on milder forms of autism and only includes the viewpoint of one family member, usually the mother. My research examined the lived experience of families who have a child with severe autism. Van Manen’s phenomenological approach was used, involving unstructured interviews and Family Lifelines of 11 families (22 family members). Families identified who they considered to be family members that included mothers, fathers, grandmothers, other relatives and a friend. The family members often did not live under one roof, but often included extended family or friends who lived nearby and offered support. Six essential themes were identified. First, families found autism a mysterious and complex condition including: the stereotype that it is a mild
disability; stigma related to its invisible nature; the unpredictable nature of autism; and the fact that autism severity is difficult to assess. Second, families experienced the child’s severe autism-related behaviors that were often self-injurious, harmed others and damaged homes. Third, profound communication deficits resulted in isolation between the family and child. Fourth, families experienced unrelenting stress from their lack of sleep; caring for a child with developmental delays; coordinating health care services; health care costs; and concern for the child’s future. Fifth, extreme isolation from their child, friends, school, the public and, health providers ensued. Sixth was a strong dependence on families for compassionate support and formation of hybrid families including nuclear, extended families and friends. These study results can be utilized to educate nurses about the unique needs of families who have a child with severe autism and assist nurses in developing appropriate health care policy.