Multiple Levels of Support!

“It is amazing to me that I can just pick up the phone and be connected to so many other parents who truly understand what my life is like” says Sarah Odell, Parent to Parent of PA participant and volunteer Peer Supporter.

Sarah is the mother to three children, one with special needs and two with developmental delays-Kayla, Trey, and Sadie. All three of the children have a diagnosis of Speech Impairment/Delay and Trey also has a diagnosis of Autism Spectrum Disorder and PICA. Sarah initially discovered Parent to Parent of Pennsylvania when she encountered a Parent to Parent exhibit table at the 2012 National Autism Conference in State College, Pennsylvania. She was initially interested in the idea of being connected with other parents in similar circumstances, but did not know just how far the Parent to Parent of Pennsylvania network spanned. “I got more than I bargained for” says Sarah. “I just wanted to talk to another parent of a child with autism, just talk. I never imagined that I would receive support and resources that I hadn’t even imagined existed.”

“My family and friends are very supportive of his [Trey’s] diagnosis, but sometimes, it seems like they don’t get it. It is hard for them to understand all of the trials and hardships involved with raising a child with special needs. The ability to talk with another mom, who experiences the same things I do on a day to day basis, is even more helpful sometimes than talking with my well-meaning husband. These matches totally get it. I don’t have to explain all the trials. They live it, so they get it.” Parent to Parent of Pennsylvania is such a unique support for families who have a family member with special needs; all of the participants, from the volunteer Peer Supporters to the Regional Coordinators and the Program Director all have a family member with a disability or special need. When a family member contacts the program looking for support, they receive an exceptional level of understanding from the very first call they make to the program until the very last follow-up call they receive and beyond.

It is Parent to Parent of Pennsylvania’s mission to link families of children and adults with disabilities or special needs for the purpose of support and information. In keeping with that mission, the program houses a community of families that both seek and give support as their children grow and their needs change. Family members are linked with one another not just based on a similar diagnosis, but similar life circumstances and/or very specific needs. For instance, Sarah Odell was matched to volunteer Peer Supporter Kim Buckley because she requested to be linked with another parent whose child had a diagnosis of Autism Spectrum Disorder and had experience with feeding issues. Sarah described her match to Kim as “amazing and unbelievable” because she and Kim not only connected, but “hit it off.”

However, as Sarah continued on her voyage of raising children with special needs, more concerns surfaced. “Initially, I was given a match based on my son’s diagnosis of Autism Spectrum Disorder and feeding issues, but when I felt I needed some support regarding his IEP and services, I called my local Regional Coordinator for Parent to Parent of Pennsylvania once again.” Sarah was then matched to Robin
Maines, a parent extremely knowledgeable regarding IEP’s and advocacy issues who runs a support
group called G.A.P.S (Group for Advocacy and Parent Support), geared towards that purpose. Later,
Sarah was matched to Mary Davenport, a local mother to two young children with a diagnosis of Autism
Spectrum Disorder who knows of many valuable resources and support services in the area.

“Mary was able to help me with names of organizations who could possibly help with the cost of
the Autistic Service dog we are researching for Trey, as well as give me information on a safe indoor play
area which is perfect for children who elope and are typically unsafe in regular play areas. Mary also was
able to give me ideas and information on how to get organized and work through a schedule, which many
autistic children strive” said Sarah after she connected with Mary.

Overall, Sarah Odell was given a total of 7 parent matches through the program from issues
relating to a diagnosis of Autism Spectrum Disorder, feeding concerns and Individualized Educational
Plans (IEP’s), to raising multiple children with special needs and service/therapy dogs. Her story is a great
illustration of the level of support Parent to Parent of Pennsylvania can provide. As Sarah described,

“The fact that I can get Trey’s diapers paid for through the
insurance company was so helpful! We were paying about $100 a
month on diapers, with no hope of potty training in the future.
Parent to Parent gave me the information I needed to have his
diapers supplied by matching me to parents that have been
successful with it already. Nicole, the North Central Regional
Coordinator has been such a great help too. She follows up on
each match to make sure they are helpful. She is more than happy
to work with me and make sure I am benefiting from the program.
In fact, I saw Nicole at a public event on a Saturday and
mentioned in friendly conversation that we were researching
Autism Support Dogs, the following Monday she called me with
matches she had researched.”

Additionally, Sarah was so pleased with the support she received from Parent to Parent of
Pennsylvania that she became a volunteer Peer Supporter herself. As a result of the program, Sarah has a
vast net of information, resources and others to talk to that truly understand. Sarah describes Parent to
Parent of Pennsylvania as her first mate, assisting her in keeping her family’s ship in its best working
order, and her lifeboat, keeping her emotionally afloat as she ventures down the uncharted course of being
the parent of children with special needs.