

Health care providers recognize that patients are often impacted not only by physical symptoms but also emotional ones. And, their families are affected, too. But, sometimes, providing the needed range of support stretches the capacity of practices or clinics. **Peer support** can be a resource that will help patients – and enhance the care provided as well as strengthen family engagement. An integrated program in Yakima, Washington provides specialty medical services for children with special health care needs as well as peer support to their families.

Children's Village

Partnerships to Foster Family Engagement

Since opening in 1997, Children's Village has served thousands of children with special health care needs, integrating specialty care programs and other services in one location. A collaboration between Yakima Valley Farm Workers Clinic, Virginia Mason Memorial hospital and The Memorial Foundation, the Village provides a variety of services including medical, dental, pediatric therapy (OT,PT, Speech), and behavioral services to children from birth through 18. The Village serves over 6,100 children annually in a 15-county area (a rural, geographically isolated, and culturally diverse region), where 77% of clients live at or below 200% of the Federal Poverty Level. 60% of its clients are Hispanic.

A key partner at Children's Village is Parent to Parent (P2P), a comprehensive peer support program for families. P2P staff offer English and Spanish language support groups for parents and siblings, family events, social/recreation programs for children, a disability awareness program, care coordination and more. In 2018, P2P served over 1,600 individuals participating in nearly 230 events. P2P also facilitated 29 parent mentor matches. Overall patient and family satisfaction scores have continued an upward trend and 97.8% was the most recent overall satisfaction rating.

Building Family Confidence and Engagement

P2P is not just located at the Children's Village; it is a valued component of its services. When a child receives a new diagnosis, clinical staff often introduce parents to P2P. For many parents, that is the beginning of a long-term relationship that builds skills, confidence and knowledge in managing their children's health conditions.

An 8-week program called Holland supports and educates parents as they process new and difficult information about their children's health and/or development. Holland brings parents together to share the emotional side of raising children with special needs, learn about the importance of self-care, build resiliency, and gain awareness of community resources. In evaluations of the program, 100% of parents "agreed" or "strongly agreed" that they gained the tools needed to parent their child with special needs.

Working as community health workers, P2P staff help parents navigate the health care system and connect them with community resources. With a 60% Hispanic population, bilingual/bi-cultural staff members become trusted allies in meeting family needs and mitigating the isolation parents sometimes experience in the community.

Educating Staff

Another important role of P2P is to expand the knowledge of health care professionals about working with children with special health care needs and their families. Professionals can then work better with families in ways that encourage mutual respect and partnership. P2P leads monthly staff meetings at the Village that bring together interdisciplinary teams and, when needed, facilitate meetings with the clinical team and parents/children. P2P also participates in new staff orientation at Children's Village. Through storytelling, P2P raises awareness of the strengths and needs of families and how staff can respect the family role and partner effectively in care. In 2019, 98.7% of families responded yes to the question: provider involved you in healthcare decisions. P2P staff and parent volunteers also speak to community organizations. As a trusted community resource, P2P shares information broadly through newsletters and listservs – reaching out to over 1300 providers, parents and community organizations regularly.

“Parent to Parent is an essential component of the care we provide at Children’s Village. Parent to Parent staff are always willing to meet with families, sometimes on an urgent basis, to help them navigate systems and support them after a new diagnosis. We could not do the work we do so effectively if we didn’t have Parent to Parent as our partner.”

Diane Liebe, MD, Developmental and Behavioral Pediatrics
Children’s Village Medical Director

Engaging Parents as Improvement Partners/Leaders

Children’s Village has a deep commitment to involving and supporting parents as quality improvement partners. A facility-wide Family Voices group meets quarterly to identify and resolve gaps in care from the patient/family perspective. Because Children’s Village is expanding its space, plans have been brought to this advisory group for input and guidance. Parents have also served as members of a team focused on improving the phone system. One outcome of this effort was improved customer service.

P2P has organized a Yakima County Parent to Parent Advisory Board. Comprised of parents and community agencies working in partnership with staff, the purpose of the Board is to ensure that P2P activities are directed by parents of children with special health care needs and deliver quality support consistent with the program’s mission.

Additionally, graduates of P2P’s Holland program become speakers on panels and participate in community-wide presentations about children with special health care needs – thereby, influencing the perceptions, attitudes, and actions of others in the community in positive ways.

Lessons Learned

Over the years, Children’s Village has learned that it truly ‘takes a Village’ to support a family raising a child with special health care needs – specialty services to meet the medical and therapeutic needs of the child and peer support to meet the family’s unique emotional, social, and recreational needs. Research shows that families who are well supported socially and emotionally are more engaged members of their children’s care teams.

“I couldn’t fathom where I’d be today without the Parent to Parent program. I’m making connections and getting support to put me in a ‘place’ where dealing with the daily challenges of parenting a child with special needs is manageable. I’m better equipped to parent my child, free from judgment and society’s lack of acceptance or norms. Because of Parent to Parent, I have a safe place, and I know that, for many other families, this has become, very literally, a ‘life saver.’”

-Danielle - Parent