Children with Special Health Care Needs During COVID-19: Findings from the Family Strengths Research Study

Children with Special Health Care Needs: Children with Special Health Care Needs (CSCHN) and their families may experience unique challenges during the COVID-19 pandemic. CSCHN are defined as having a health problem or multiple health problems that cause them to be limited in their ability to do things that other children of the same age can typically do. These children may be more likely to get sick and lose access to the care and support services that help them day-to-day.

How are Families with Children with SHCNs Doing in Western PA?
Almost one in eight respondents to the Family Strengths Survey report having a child with special health care needs.

- 67% experienced reduced access to early intervention services
- 55% experienced reduced access to outpatient/home based therapies, such as occupational therapy (OT) and physical therapy (PT)
- 77% experienced reduced access to school based therapies
- 38% stated they do not have a plan for their child if they or another caregiver becomes ill

Families described the challenges associated with caring for a child during the COVID-19 pandemic: “Parent is a health care worker... We are concerned about bringing home (COVID-19). One child should have had major and much needed surgery ... which has now been postponed. This is stressful as it leaves him susceptible to further infections.”

“My son has special needs. As we can help him the best that we can at home...it breaks my heart he's missing important OT, PT and Speech Therapies that he received at school... it’s been hard meeting each and every need for him as everything in his routine/world just abruptly stopped and he does not know why.

Programs That Can Help:
The PEAL Center offers safe, confidential support for parents of children (0-26 years of age) with SHCN needs in PA. Families can call 866-950-1040 or email info@pealcenter.org.

The Education Law Center has created a helpful resource sheet to help parents of children with SHCN navigate the closure of schools.

The Pennsylvania Health Law Project can help families navigate health insurance options to ensure all young people are covered.

Disability Rights PA has compiled a list of COVID-19 resources and advocacy opportunities to help families informed across Pennsylvania.

The PA Elks Home Service Program can provide in-home nursing care and advocacy services for families of children with developmental disabilities.

About this Study: The Family Strengths Study is a weekly survey of parents or expecting parents in Western PA. The study is a collaboration between UPMC Children’s Hospital of Pittsburgh (CHP), University of Pittsburgh (Pitt), United Way, and the Allegheny County Health Department and Department of Human Services. This survey is part of the Pittsburgh Study and made possible through support from the CHP Foundation, Pitt Department of Pediatrics, The Grable Foundation, and The Shear Family Foundation. For more information, visit https://www.pediatrics.pitt.edu/family-strengths-survey