



Parent to Parent of New York State NEW YORK FAMILY-TO-FAMILY HEALTH INFORMATION CENTER (F2F) 2016 DATA REPORT

Parent to Parent of NYS, which began in 1994, is a statewide not for profit organization established to support and connect families of individuals with special needs. The 13 offices, located throughout NYS, are staffed by Regional Coordinators, who are parents or close relatives of individuals with special needs. The F2F offers families: information on health topics, connections with Health Care Resource Parents, referrals to community resources, and trainings on health care financial issues, collaborating with professionals and other health care topics.

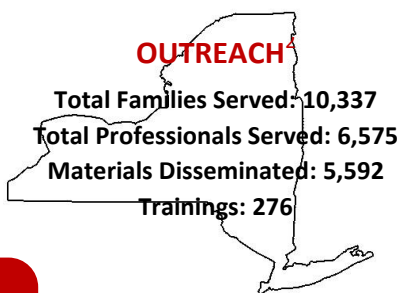
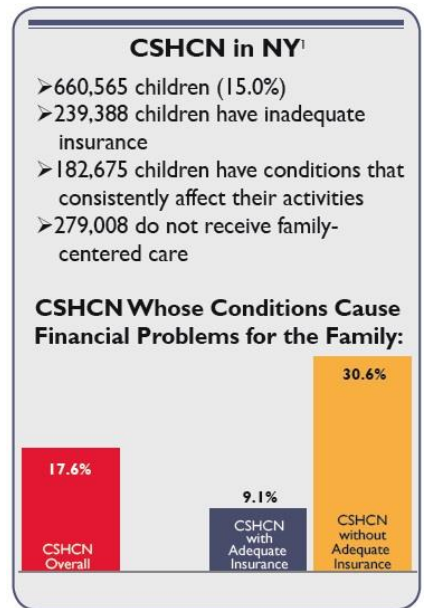
2016 IMPACT on a FAMILY

NY F2F received a call from a mother whose teenage daughter was diagnosed with Poland Syndrome leaving her with one breast significantly smaller than the other and causing significant anxiety and depression. However, the patient was initially diagnosed by a local certified genetic counselor (not an MD) and referred to a plastic surgeon. Therefore, when the plastic surgeon requested insurance approval to perform corrective surgery on the breast tissue, it was denied as cosmetic. NY F2F worked with the family to understand why the surgery request was denied, to find an MD geneticist for diagnosis, and worked collaboratively with the plastic surgeons to prove medical necessity to obtain insurance approval for the surgeries.

2016 HIGHLIGHTS

Public Health Crisis Impact Hurricane Sandy left massive damage in our downstate regions, including the extended loss of power. As part of the F2F work, P2P NYS maintains a listserv for Medically Fragile Families. After the storm, they reached out to check in with families they knew to have children requiring ventilator use at home through interactions on the listserv. They identified two families who were at risk, despite being connected with state agency services and despite having completed the usual preparation strategies (i.e. have a generator, register with the power company and local community emergency response team, etc.) In one case, the family had a generator but was running low of gas (gas delivery was also a huge problem after the storm) and another whose generator was experiencing maintenance problems. The F2F was in contact with both the Department of Health and the Office for People with Developmental Disabilities (OPWDD) on their behalf, and after several phone calls were able to get these families the services they needed through OPWDD.

System Impact Project Director Lin Perry has been very involved in the New York Mid-Atlantic Consortium (NYMAC) over the last two years serving as a parent/professional/advocate for genetic services and research at both Advisory Councils and Summits. Lin serves on the Healthcare Access and Finance work group, which has been working to improve insurance coverage for medical foods. Lin is also on the NYMAC Steering Committee where she provided feedback on the proposed "Genetics Help Desk" which will assist both patients and professionals.



CONTACT

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¹National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 04/03/2014 from www.childhealthdata.org.
²FY2016 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2015 through May 31, 2016.
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