NJ Tracking's Data Portal Helps NJ's Statewide Parent Advocacy Network (SPAN) Serve Families with Children with Disabilities

What was the problem/situation?

Advocating for New Jersey's 378,000 children with disabilities and their families is a huge undertaking. Diana Autin, Executive Co-Director of the Statewide Parent Advocacy Network (SPAN), Inc., is always looking for additional tools, data, partnerships, and funding to help SPAN enhance services for New Jersey families with children who have special needs. SPAN tackles many issues related to improving the lives of these New Jersey families by improving health care and educational services; linking families with needed services; advocating for improved public policies; evaluating where unmet needs exist; and obtaining funding to serve the needs of eligible families.

How was Tracking involved?

The New Jersey Environmental Public Health Tracking project (generally known as EPHT or Tracking) has partnered with the New Jersey Department of Health (NJDOH) Center for Health Statistics to make New Jersey's health and environmental data publically available through the NJ State Assessment Health Data (NJSHAD) system. NJ Tracking is working with partners to make NJSHAD the premier "one stop shopping" location for health data and statistics for a variety of New Jersey's residents: the general public; advocacy groups; local environmental and health officials; public health and medical professionals; and officials at local, county and state agencies. By design, NJSHAD serves the whole of NJDOH, and is structured to provide both queryable datasets and brief fact sheets which explain and frame what the data show.

What action was taken to resolve the problem?

Ms. Autin regularly uses NJSHAD in two distinct ways when she is preparing grant applications to increase SPAN's outreach and services:

- To analyze and quantify the difficulties families with children with disabilities are facing, and
- To identify which populations and locations have the greatest need for assistance.

As stated by Ms. Autin, "NJSHAD is a nice, one-stop site for the data and analyses I need when writing grants. I use it to obtain things like the percent of New Jersey kids living in poverty; infant and fetal death rates; and data on maternal health, smoking, nutrition, and obesity by community and demographic group. For example, I used NJSHAD data and information to apply for our current "Improving Pregnancy Outcomes" grant. We are receiving $300,000 per year for three years for Essex County, where we are now funding four full-time community health workers doing health promotion focused on women ages 18 to 35."

Ms. Autin also used NJSHAD for an earlier grant, "Innovative Evidence-based Programs for Latino Immigrant Families served by Federally Qualified Health Centers (FQHCs) in Three High-Immigrant High-Poverty Communities" which resulted in SPAN receiving $86,500 annually for three years to fund part-time family resource specialists at three FQHCs located in Hudson, Union, and Passaic Counties. "Our staff assisted parents in Spanish through a variety of activities, including workshops on the rights of children with special needs; training on how to work with school systems; advocacy for optimal health practices for children and parents; and we started parent-to-parent support groups. We reached ~750 Spanish-speaking families with more than 1,250 children. 100% of parents who attended project workshops indicated that SPAN had helped them increase their skills to collaborate with professionals, their ability to effectively navigate systems and advocate for their children, their ability to apply or access programs and services, their understanding of their rights and roles as parents, and the integration of their children with special needs in the larger community", said Ms. Autin. According to Ms. Autin, "Because of the state and local data we were able to access via NJSHAD, we were able to hone in on the communities that most needed our help, justify the funding for the project to the NJDOH's Maternal and Child Health Bureau, and help the targeted FQHCs understand why we were focusing on families in their community."

As NJ EPHT project coordinator, Barbara Goun, stated "It is so gratifying to know that CDC-funding for NJ EPHT is helping New Jersey children and teens with special needs and their families get the assistance they require and deserve. NJSHAD users are our best source of feedback on what is actually helpful, and what still needs to be added or improved. We will continue to work with our partners to provide data and resources to improve the health of New Jersey's residents. "

NJSHAD serves as a one-stop public data portal for NJDOH, providing public access to data and information provided by the entire New Jersey Department of Health, including the New Jersey Environmental Public Health Tracking (NJ EPHT) Program. NJSHAD provides static public health indicators which combine data and information, and dynamic custom query modules which allow users to filter and analyze public health datasets.

NEW JERSEY Environmental Public Health Tracking Program

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