



CASE STUDY: PHILADELPHIA DEPARTMENT OF PUBLIC HEALTH

Leveraging Strategic Partnerships & Innovation to Advance Inclusion of Children With Intellectual Disabilities

People with intellectual disabilities often face barriers to accessing public health promotion and protection activities, making them particularly vulnerable to preventable disease and injury. In turn, practicing inclusive health not only provides more equitable access to public health resources, but also leads to improved health outcomes and helps health departments meet and maintain a variety of public health accreditation standards. The Public Health Accreditation Board, with funding support and in partnership with Special Olympics International, presents this short case study for the purpose of exploring how the Philadelphia Department of Public Health leverages its role as a trusted community convener and cross-sector connector to advance health and inclusion for children and young people with intellectual disabilities. The Philadelphia Department of Public Health is among a handful of state and local health departments across the nation who are advancing inclusive health for people with intellectual disabilities.

THE PROBLEM

In many communities around the nation, families who care for children with intellectual disabilities face an unmet need. Even though there might be an abundance of available resources within the community to help those families, if no dedicated space exists – either virtual or physical – where families, advocates and other stakeholders can come together to share and explore those resources, there will be fewer opportunities for cross-sector partnership-building, resource-sharing and innovation.

BACKGROUND

Cross-sector partnership-building has long been central to public health success and progress and remains a key competency as practitioners increasingly turn upstream to tackle the social determinants of health. In fact, some of the greatest achievements in public health history — from tobacco control to immunization to fluoridation — have been rooted in the field's ability to engage both traditional and nontraditional partners in the pursuit of greater health for more people. In Philadelphia, public health workers are leveraging their roles as trusted community conveners and their skills at building cross-sector connections to advance health and inclusion for people with intellectual disabilities.

About 20 years ago, in response to changes to Pennsylvania's managed care programs, the Philadelphia Department of Public Health convened a group of stakeholders to ensure the changes wouldn't negatively impact families who care for children with special health needs. That original convening exposed an unmet need in the community — in particular, having a space where families and advocates could come together to better serve children with special needs — and so the group decided to stick together.

SOLUTION

Today, the Philadelphia Special Needs Consortium, which is convened by the Philadelphia Department of Public Health's Division of Maternal, Child and Family Health, meets on a regular basis to connect

stakeholders across sectors and provide education to families who have a child with special needs, including those with children up to age 21 and living with intellectual disabilities. Among the consortium's many participants are family members, health care providers, insurance providers, early intervention providers, legal advocates, policy planners, community-based social service providers, and representatives from state and local government agencies.

The consortium not only provides education and connection, it has also become a source of expertise and innovation. For example, health department staff can query the consortium's robust list serve for expert advice on a variety of health and policy issues, as well as reach diverse stakeholders with opportunities for grant-funded innovation.

"It's largely about building partnerships," said Nick Claxton, CQSW, Director of Title V Services/Children with Special Health Care Needs at the Philadelphia Department of Public Health. "At almost every meeting, you hear a new conversation or see new people connecting — it can be a really important opportunity for families."

The Philadelphia Special Needs Consortium meets about every two months to address issues related to children with special health needs, including those with a physical or intellectual disability. The meetings offer families and providers an opportunity to hear educational presentations, learn more about navigating support services, get updates on legal and policy issues affecting children with special needs, and meet face-to-face and network with fellow stakeholders. The consortium typically welcomes about 50 people at each meeting and now has a list serve of well over 500 people, which the Division of Maternal, Child and Family Health administers.

Claxton said the consortium's electronic community is particularly useful for quickly disseminating important information out to families and providers and for tapping into local expertise. For example, when a hospital social worker was looking for resources on housing to help a patient and her family, health department staff turned to the consortium list serve for expert input on housing needs among people with complex medical needs.

Beyond the consortium's work, the Division of Maternal, Child and Family Health also awards community activity mini-grants — most less than \$3,000 — for projects aimed at improving health and well-being among children with special needs. The grants, which have been awarded every year for about 20 years, support a wide range of projects, from helping families navigate early intervention systems to increasing physical activity among young people with intellectual disabilities. The goal of the grants, Claxton said, is to address issues not already funded by any other part of the system.

For example, recent grantees include Philadelphia's Center for Autism, which received funding to provide training on autism spectrum disorder to a range of key audiences, including mental health providers, private businesses, schools, day cares, first responders, security guards, and emergency room and hospital staff. Another recent grantee was the Philadelphia Autism Project, a citywide initiative that received funding to support its Birth to Five Navigator Summit, a gathering of families and systems that care for and serve children with autism. The former Blossom Philadelphia, a local nonprofit that provided services to adults and children with physical and intellectual disabilities, received a mini-grant to upgrade the inclusive curriculum in its child care center. The center, which served children from ages 3 months to just before kindergarten, embraced the philosophy that "children with special needs can learn best and develop to their fullest potential when educated with peers who are typically developing."

"From the perspective of the children who come to us who have an intellectual disability, it's good for them to develop relationships with and learn from children without disabilities — it can help give them a model for language and social and emotional skills," said Melissa Swain, who had served as Director of Children Services at Blossom Philadelphia. "On the reverse side, it teaches kids about diversity among children and helps them become more understanding of the fact that people learn differently."

At Blossom’s child care program, children with autism, cerebral palsy and Down syndrome learned alongside their typically developing peers, with the classroom usually a 50/50 ratio, Swain said. With the local mini-grant, Swain and colleagues sought out a state-approved quality curriculum to adapt to its inclusive philosophy, with a goal of implementing the curriculum and sharing their experiences and lessons learned with fellow agencies that serve children and people with intellectual disabilities. For example, Swain said one goal of the newly tailored curriculum is to better integrate the needs of individualized education programs into the overall curriculum as well as schedule more structure into the day, which organizers hope will make it easier for providers to meet requirements associated with serving children with special needs.

“We want a more concrete foundation in being able to support what’s happening in the classroom,” Swain said. “We wanted to create a curriculum that understands different cognitive abilities and can adapt and scale down to help children who need additional support be successful.”

Claxton said the Philadelphia Department of Public Health plans to continue its work on behalf of families and children with intellectual disabilities, noting that with relatively little funding support over the years, the grantees have been able to create a number of long-lasting and self-sustaining efforts.

“We’re always pleasantly surprised at how sustainable the outcomes (of the grants) are,” he said.

CHALLENGES

As is the case with designing and implementing any community health program, there are challenges to overcome, such as:

- **Many communities lack a dedicated space** where families and advocates can come together to share resources and better serve children with intellectual disabilities.
- **Curriculums need to be tailored** to better integrate the needs of individualized education programs into the overall curriculum as well as to schedule more structure into the day.
- **Awarding grants requires careful thought.** Funds should ideally go to projects not already funded by any other part of the system.
- **Barriers must be confronted**, such as landscape features that impede physical access to the convening space, or signs that are not easy to spot or comprehend.
- **Understanding the cultural competencies** needed to better engage and serve families of children with intellectual disabilities involves a learning curve for many stakeholders.

LESSONS LEARNED

Best practices for leveraging strategic partnerships and innovation to advance inclusion of children with intellectual disabilities include:

- **Support innovative inclusion efforts.** Numerous long-lasting and self-sustaining successes have resulted from connecting subject matter experts, linking stakeholders and resources, or providing funding support.
- **Be welcoming.** Create a space – physical, virtual or both -- where families can come together to access information, education, resources and support.
- **Engage trusted partners.** Engaging in cross-sector partnerships, especially with local partners who are already positioned in the community as trusted providers for people with intellectual disabilities, is a key best practice for building cross-sector connections to advance health and inclusion for people with intellectual disabilities.

- **Think “mainstream.”** Children with intellectual disabilities can learn best and develop to their fullest potential when educated alongside peers without disabilities. On the reverse side, children who do not have intellectual disabilities become more understanding of the fact that people learn differently.

ADDITIONAL RESOURCES

Philadelphia Special Needs Consortium

Philadelphia Department of Public Health

<https://www.phila.gov/services/mental-physical-health/get-health-care-and-support/family-and-childrens-health-care/get-support-for-a-child-with-special-health-care-needs/>

QUESTIONS?

If you are interested in learning more about this program or how you can apply some lessons learned to your own organization, please contact Nick Claxton, CQSW, Director of Title V Services/Children with Special Health Care Needs at the Philadelphia Department of Public Health at 215-685-5232 or Nick.Claxton@phila.gov.