

**PA Consortium for CYSHCN
Background Brief
Home and Community Services**

This background brief presents an overview of the status of **community services** for children and youth with special health care needs in Pennsylvania.

The federal Maternal and Child Health Bureau identified six core outcomes as critical indicators of success in implementing community-based systems of services for all CYSHCN in accordance with Healthy People 2010 and the President's New Freedom Initiative. This background brief relates to Core Outcome #5:

Community-based services are organized so families can use them easily.

Background

The Maternal Child Health Bureau defines children with special health care needs as: *"those who have or are at increased risk for a chronic physical, development, behavioral, or emotional condition and **who also require** health and **related services** of a type or amount beyond that required by children generally."* (American Academy of Pediatrics, http://www.medicalhomeinfo.org/about/def_cshcn.html, *emphasis added*)

Thus, by definition, children with special health care needs require services in addition to health care services. These services can be provided at home, in early childhood settings, in schools, or in the community.

"In order for services to be of value to CSHCN and their families, the system has to be organized in such a way that needs can be identified, and services provided in accessible and appropriate contexts, and that there is a family-friendly mechanism to pay for them. Thus, effective organization of services is a key indicator of systems development." (Maternal and Child Health Bureau, <http://mchb.hrsa.gov/programs/specialneeds/measuresuccess.htm>)

Access to Services in Pennsylvania

National Survey of CSHCN in 2005-2006 (original survey 2001)

The National Survey of Children with Special Health Care Needs is a national telephone survey that collects data on the 6 MCHB Core Outcomes.

The question asked for Indicator 5 was:

Did respondents have any difficulties trying to use community-based services?

	Pennsylvania	National
Percentage of Children with Special Health Care Needs, 0 - 17 yrs old	13.0%	12.8%
Number of CYSHCN (0-17)	379,291	9,360,356
Community-based service systems are organized so families can use them easily	89.5 %	89.1%
Pennsylvania's ranking on this indicator	25th	Out of 51

(National Survey of Children with Special Health Care Needs, Pennsylvania Chart Book, <http://cshcndata.org/content/StatePrevalence.aspx?geo=Pennsylvania>)

As the MCHB points out there are three key elements for utilizing services:

- the child must be identified as needing services,
- the family must be able to find out how and where to get the service, and
- there must be a way for families to pay for the services.

**PA Consortium for CYSHCN
Background Brief
Home and Community Services**

Each of these requirements has serious pitfalls.

Identification. Recognizing the need for services often begins with the parent and the pediatrician. In addition, childcare settings and schools are instrumental in recognizing the need for services. Making meaning of the labels put on children can be confusing and emotionally difficult for parents. Some parents struggle with weighing having their child labeled and the negative consequences of that label versus the benefit of becoming eligible for publicly-funded services.

Finding Services. Finding out how to access services and where to go for those services is another major problem. There are a myriad of entities, both public and private not-for-profits, intended to assist parents with accessing services ranging from care coordinators in pediatric offices, to early intervention service coordinators, to school social workers, to county supports coordinators, to Elks Home Nurses, Medical Assistance Managed Care Organization Special Needs Units, and many more. The dilemma faced by parents is finding a trusted, consistent person who can help guide them through the maze. In spite of all of these “helpers” parents most often report that word of mouth by other parents is their best source of information (Ordinary Lives, Extraordinary Needs. Rosenau, 2005).

Paying for Services. The final key piece in accessing services is having a way to pay for the services. Parent advocacy has been a driving force in the development of community services systems. Notable are the two PA lawsuits that were the first of their kind in the nation: Pennhurst State School v. Halderman (1984) where parents organized to demand that children and adults with mental retardation had a right to receive needed services outside of state run institutions; and, PARC v. the Commonwealth of Pennsylvania (1971) where parents demanded that children with disabilities had a right to a free public education. These two landmark decisions created the foundation for our current public policy that children with disabilities and SHCN have a right to attend school and should receive supports at home and in the community. But in reality, access to services at home and in the community is limited by the ability to pay for these services. Parent advocacy has contributed to the organizational pattern of our current funding system.

Pennsylvania has taken the course of creating numerous diagnosis-specific funding streams that pay for services to individuals who qualify for services because they have a qualifying diagnosis. At present count, PA has created 13 distinct Medical Assistance waiver programs based on separate specific eligibility categories for each waiver program. The result has been that children with mental retardation, behavioral health needs and autism qualify for publicly funded services while a child with CP, spina bifida or epilepsy may not. Medical Assistance is one of the primary ways that services for CSHCN are publicly funded in PA. (See the White Paper on Insurance.) In addition, there are privately operated, disease-specific programs such as the Muscular Dystrophy Association and United Cerebral Palsy that offer varying services to children who have those specific conditions.

The PA COMPASS, a one-stop, online common application for many public services, is available 24 hours a day/7 days a week and it automatically screens a family’s information to determine what services they may qualify for. It shows promise of potentially becoming a single clearinghouse for state-funded services for CSHCN.

**PA Consortium for CYSHCN
Background Brief
Home and Community Services**

Organization of Services. Another confounding element in accessing services is that in Pennsylvania many of the publicly funded service systems are organized through a county-based system created by the MH/MR Act of 1967. The result of our county-based system is that availability of services varies widely from one county to another, and the process to apply for services varies depending on whether the county administers programs directly or contracts with other agencies to administer service coordination.

Disparities in access to services.

Population density. Forty-eight of PA 67 counties are defined as rural by the 2000 US Census. In rural counties there are very limited numbers of service providers. In densely populated areas such as Philadelphia even though there may be numerous service providers, the capacity of service providers often falls far short of the need for service. Capacity is an issue in both rural and urban community.

Transportation. This continues to be a barrier to receiving services, especially in the rural areas of Pennsylvania because Medical Assistance transportation will not transport across county lines even though the only provider for some services may be in another county. Additionally, medical access transportation only permits transporting the child who is the patient and a parent. For parents with other young children and no child care the restrictions on medical assistance transportation forces them to choose between leaving their other children at home unattended or missing the appointment.

Digital divide. It is still difficult to find information about many programs, to determine qualifications for eligibility, and to navigate the application processes. Families without computers and Internet access are at a distinct disadvantage, as more information is made available on the Internet. Families with the computers report they do extensive research and find supports for their child with special health care needs on-line. However, both groups continue to need additional help to find services.

Respite Care. Respite is a critical service that has huge gaps in eligibility, and inadequate capacity to staff of the approved nursing shifts for children.

Language and Racial disparities. Minority populations can have difficulty getting services because of language or cultural differences. Needing to find bi-lingual staff, and finding staff that are willing to go into neighborhoods with high levels of violence compounds staffing home care cases.

Child Care. There is a serious shortage of childcare for young children with special health care needs and also a scarcity of after-school programs that will include children with disabilities. In addition of the financial burden for families to provide in-home care, it also means that children with SHCN are isolated from their peers and denied opportunities for social interaction.

Child Welfare, Foster and Residential Placement. Children in the child welfare system and foster care are eligible for more services, respite care, and other forms of support than children living with their birth families. The physical and financial demands of caring for a child with special health care needs can contribute to instability in family life and can result in a child with special health care needs being placed in foster care. It is ironic that foster families can get more support than birth parents when the stress and demands of the child's care often is a large

**PA Consortium for CYSHCN
Background Brief
Home and Community Services**

contributing factor that brings the family to the attention of CYF. Even with the increased supports available to foster parents, the demands of the medically complex child can result in removal from foster care and placement in a residential facility. The result is that CYF is far more likely to place a child with disabilities in residential care than a child without a disability.

Faith Communities. Although it is not an uniquely Pennsylvanian issue, the participation in faith communities is often restricted by inaccessibility to the building, print too small to read, inaccessible bathrooms, or a hostile atmosphere. Very few older churches, meetinghouses, mosques and synagogues have been modified to support full participation by those with mobility impairment, which gives families the “not welcome” signal. For many families, this is a loss of spiritual and community support that could greatly benefit CSHCN.

Questions for Discussion

1. Are those supports that parents identify as important services for CYSHCN and their families services that systems offer and fund?
2. Is there awareness of available services and how to access them?
3. Is there sufficient capacity of specific services so that CYSHCN who need them are able to get those services?
4. Where do people go for support/education/resources on this issue?
5. How can we make information of available services more accessible?
6. Does insurance, both public and private, cover the needed services?
7. How can we make the services equally available to urban and rural and families who have language and cultural differences?
8. How can we move to take a “functional” vs. a diagnosis-based approach to determining eligibility for services?
9. What is the appropriate level at which to solve these problems - local, state, federal? Are these issues within the private or public domain?
10. How can we provide inclusive childcare and after-school programs?
11. How can we give families the support that foster families receive?

Prepared by the Pennsylvania Consortium for Children & Youth with Special Health Care Needs
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