

Summary of PA Consortium for Children and Youth with Special Health Care Needs Conference Breakout Sessions

Conference Summary

The Pennsylvania Consortium for Children and Youth with Special Health Care Needs Conference was held on June 22-23, 2009 at the Harrisburg Hilton. This was the inaugural meeting of a federally funded initiative, *State Implementation Grant for Integrated Community Systems for Children and Youth with Special Health Care Needs*, awarded to the Pennsylvania Department of Health to improve integration of systems and services for children and youth with special health care needs. Approximately 150 parents, youth, community group representatives, medical providers, and state agency representatives joined in discussing the issues facing children and youth with special health care needs (CYSHCN) in Pennsylvania. Conference attendees worked in topical and regional groups to identify strengths, areas of growth, and gaps in systems and service delivery for CYSHCN. This document is a summary of the groups' discussions and priorities.

Over the next two years, the grant will endeavor to implement the priorities identified at the conference and continue to ensure that the voices of families and youth are heard. Over the next two years, the grantees hope to engage and inspire Pennsylvania medical, education and human service providers and advocates to rethink and redesign the way services are delivered, coordinated and managed in order to more effectively meet family needs, while building on existing strengths of current systems. There are multiple venues through which this work will happen including Regional Parent/Youth/Professional Forums, the Transition Learning Collaborative, the Medical Home Program, and the PEAL Center's Parent Leadership Training.

Morning Breakout Sessions Summary

In the morning, conference participants chose one of three topical breakout sessions – Medical Home, Community Services, or Transitions in Care. Each group identified key issues, what currently works, and potential areas of improvement. The summaries of these discussions follow.

Medical Home Breakout Groups

A prime concern for members of the medical home breakout sessions was that many providers and families alike lacked full knowledge of available Medical Home services and providers. Educating both providers and consumers about exactly what a Medical Home was and who in the region was a Medical Home provider were both deemed important areas of focus. The additional work that an effective Medical Home practice took on also was an area of concern. Conference participants felt that reimbursement was inadequate for the work required. Thus, finding ways to convince payers to reward practices for their efforts was important. Additionally, increased reimbursement and expanding the numbers of Medical Home practices was seen as a way to ensure that excellent practices did not become overwhelmed with more CYSHCN than they could realistically handle.

Summary of PA Consortium for Children and Youth with Special Health Care Needs Conference Breakout Sessions

The Medical Home breakout groups also identified cultural competency and communication with parents as key issues. Cultural competency was seen as critical to reaching a range of populations and providing effective service. Participants acknowledged this was a complex task for providers because they needed to take the time to really know their patients including their beliefs, values, norms and traditions. The Medical Home groups suggested getting input from a cross-section of the community by using a Family Advisory Board or Parent Partners. The final key issue identified by the Medical Home groups was the disconnected nature of much information that families receive. The information that parents receive about their child's condition is complex, comes from multiple sources and hard to navigate. This disconnection was seen as a strong argument for the spread of Medical Homes. With more coordination, CYSHCN can get the care that they need in a more timely and family-centered fashion.

The Medical Home breakout groups identified several practices that provided excellent care and could be used as best practice models. An effective Medical Home was described as one that provided comprehensive, family-based, coordinated care. Specifically, parents feeling respected by staff, staff making appointments with specialists for families and staff providing help with prescriptions and medical equipment were all cited as making a difference for families. Some of the specific practices identified as models were: DuBois Regional Medical Center, Warren Pediatrics and Hope Pediatrics. Several insurance agencies were also cited as being helpful in the coordination of care – CHIP, Highmark Blue Cross and Blue Shield and the Caring Foundation were all identified as working to help families with any resource they needed. And, other organizations that support caregivers talking across traditional silos were identified as demonstrating best practices: Cincinnati Children's Hospital program, Diagnosis Specific Clinics (e.g. Cleft Palate), and School – Community Collaborative Transition Programs.

Conference participants identified several areas that needed to be improved as Pennsylvania spreads the Medical Home concept to more practices. Coming to a common definition of what a Medical Home is and spreading awareness of what Medical Homes are were the most basic recommendations of the workgroups. Conference participants were also concerned at the lack of equal access to Medical Homes across the state. In particular, assuring that all counties in Pennsylvania have Medical Homes, establishing Medical Homes in rural areas, and ensuring that the Medical Home practices were able to effectively serve a variety of ethnic and cultural populations were identified as important steps to insure equal access.

Many of the areas that participants identified as needing improvement related to coordination of care and communication among providers. Workshop members felt for care to be effective that providers should see the child as a whole person rather than as disparate needs. Their goal was to create a one-stop shop that brought together schools, pediatricians, specialists, community resources, home care, and eventually, a transition to adult care.

Summary of PA Consortium for Children and Youth with Special Health Care Needs Conference Breakout Sessions

The Medical Home breakout groups discussed the importance of creating regional support for Medical Home practices across Pennsylvania. They recommend continuing to engage new partners by personally inviting them and by focusing on the benefit to children and families that would come from more Medical Homes in Pennsylvania. They would like to see a minimum of one Medical Home practice per county and change in attitudes, behaviors, finances, and policies to help stakeholders see the benefits of Medical Homes. Participants recommended drawing on the following resources to create viable Medical Homes: transition councils, Medical Assistance, OVR, parent networks, providers, Elks Nurses, PA Youth Leadership Networks, schools, colleges, Andrews Center and the Office of Mental Health/Mental Retardation.

Community Services Breakout Groups

The Community Services breakout groups identified several key issues that most directly impacted the lives of CYSHCN. The first was that the uniformity of early intervention (0-5 years) services throughout Pennsylvania could serve as a sustainable model for the state. Participants advocated for more uniform screening across the commonwealth as a mechanism to ensure that all children who might qualify for Early Intervention services received them. In contrast to the Early Intervention program, conference attendees saw a lack of statewide coordination of services for older children and youth. Participants recommended that connections to resources should cross regional lines to ensure that families received the care that they need. They wanted agencies and providers to communicate with each other across regions to support families which requires additional knowledge of available services and more effective communication among community-based services. Wraparound services were also an area that participants felt could be improved both in terms of less provider turnover and higher levels of qualifications and education for the TSS staff. Attendees identified that a lack of opportunity to socialize and participate in everyday activities with their communities (sports, libraries, camps) was an area that should be addressed going forward in the grant. In general, participants felt that information, training and education for service providers, parents and medical caregivers all needed to be strengthened statewide in order to adequately serve CYSHCN.

The community services workgroups identified a series of elements that currently are working effectively. Medical Assistance and CHIP were both identified as key to helping CYSHCN attain the services that they need. As previously mentioned, the Early Intervention support for birth – 5 was also a resource that participants felt could be a model for older children and youth. Participants applauded Medical Homes and a range of dedicated local providers who want to help CYSHCN and their families and participants in bigger cities felt that there were a large number of services available. Specific resources that were cited as effective were the Elks Nurses, Vision for Equality, Ventilator Assisted Children's Home Program, Easter Seals, the PA Association of Nonprofit Organizations (PANO) and the Bureau of Charitable Organizations.

Despite the variety of resources available to families and CYSHCN, what was seen as critical is that various providers knew about these resources and could connect families to them as needed. Not only is the siloed nature of services a problem but geographically

Summary of PA Consortium for Children and Youth with Special Health Care Needs Conference Breakout Sessions

disparate services provide a challenge to coordination of care. Each county has a different set of services making it difficult to obtain care if families move or if needed services are not available in the county in which a family lives. The challenge of navigating the maze of specialists, primary care doctors, social supports, schools, and recreational opportunities, while making sure that families can pay for all of their needed services and attain transportation to the services was repeatedly identified as an impediment to gaining needed care and services.

Transition was labeled a nightmare by the community services workgroups. Families struggled to identify who was willing to care for their CYSHCN, transfer needed information, and find services for young adults.

Transition Breakout Groups

The transition breakout groups identified two major areas for potential improvement – medical care and dissemination of information. In the area of medical care, there was concern about the accessibility of health care (both physical and mental) for transitioning youth. Reimbursement issues for medically complex cases, a lack of transportation, and a shortage of trained providers compounded the lack of accessibility. Participants suggested incentive programs for providers to spend more time and resources on transitional care and that Pennsylvania should look to successful models in other programs for best practice suggestions. The concern around information included all levels of the state – local, regional, and statewide. Participants felt that there was poor dissemination of consistent information to parents, youth, and providers and that this lack of information meant that resources that might have been available went underutilized. Another concern of conference members was the uneven connection between various agencies and schools, which made planning for smooth transitions more challenging.

Conference attendees had a clear vision for successful transitions. The planning should be available starting early, available in all geographic areas of the state, and build upon the strengths and expectations of success at each stage of transition (early childhood, adolescence, early adulthood). For successful transition planning to occur, the consensus was that parents should be trained to better understand, access and advocate for transition services. Workgroup participants recommended transition councils with more parent and youth participation, divided by county or Intermediate Unit, with health and medical care integrated into all aspects of transition. Having parent advocates similar to CASA to serve as cultural brokers and peer mentors was also seen as a good model. On the state level, participants wanted to legislate a statewide system to implement transition services.

Summary of PA Consortium for Children and Youth with Special Health Care Needs Conference Breakout Sessions

PM sessions – Regional Breakouts

In the afternoon, participants broke up into regional groups. Each group identified the key priorities for their region that they plan to use the parent/youth/professional forums to develop and improve. The following are the main priorities for each of the six regions in Pennsylvania.

Northwest Region

The Northwest Region identified a range of issues critical to address to improve the care for CYSHCN. All three of the areas of focus of the grant – transition, Medical Home, and inclusive community activities were of interest to the conference participants from the Northwest. In addition, they were particularly focused on building youth participation in decision-making and self-advocacy skills for youth and families. In order to accomplish this advocacy, spreading knowledge of resources was identified as an important area of focus.

North Central Region

Conference participants from North Central Pennsylvania identified the transition to adult care, access to Medical Home providers, and the siloed nature of care and services for CYSHCN as the key issues for their region. They described a system that was a “forest”, said that you needed to know someone to get services, and saw a lack of coordination between complimentary services. This lack of coordination was exacerbated by the fact that many families do not have access to computers and social services at hospitals lack needed information to give to families. Workgroup participants suggested patient-centered yellow pages or resource guides with address and phone numbers or a care coordinator who could provide contacts to services and resources.

A key element for the North Central conference participants was ensuring that all of the right people were included in the regional forums so that the communication and coordination could start to be built into the system. They generated a substantial list of the stakeholders who should be included in the conversations: IUs, Legal system, Teachers / Educators, School nurses, Funders, DME providers, Private sector insurance, Home based service providers (SLP, OT, PT), State legislators, Physicians, Foster Care, Children and families, Youth, County based MHMR, County leaders and health commissioners, Participants at conference, Elks Nurses, Department of Health, state health centers, FHNCs, Department of Education, School Health Nurses, PEAL, Family Resource Network, P2P, PEN, Health Care Quality Unit (HCQU), County resource providers, Families in remote areas.

Northeast Region

The conference participants from the Northeast discussed goals in each of the three grant areas of focus. For the Medical Home initiative, participants from the Northeast identified support for providers as critical so that they can provide the desired

Summary of PA Consortium for Children and Youth with Special Health Care Needs Conference Breakout Sessions

coordination of care. Communicating between providers, especially at transitional points (discharge, initial diagnosis, to adult systems) was also a key area of focus for participants from the Northeast. In the area of community services, there were many areas that workgroup members thought needed to be bolstered. Like the North Central workgroup, participants in the Northeast region singled out the silos and communication between providers as an area of concern. They saw care as something that should be viewed holistically – with recreational services, early intervention, wraparound, and transportation all identified as areas that impacted care. Finally, as with most other regions, transition was identified as an area in which there needed to be much greater coordination so that there could be a seamless transition between the pediatric world and adult care.

Southwest Region

The Southwest participants discussed key issues in each of the three goal areas – community services, medical home and transition. In the area of community services, the group identified disparities in services across the region and across age groups. Services need to be streamlined and consistently available without waiting lists. In terms of the medical home goal area, participants expressed concern that the term “medical home” was not fully understood by families or medical providers. Practices need training and families need to understand what they can expect from a medical home. As with other regions, transition was identified as an area needing a great deal of information dissemination and coordination. When discussing what to focus on first, the group emphasized education and information dissemination as core needs. The group generated a long list of others that need to be at the table for this effort. Some of the groups identified were: Insurers, school districts, MH/MR, OVR, ODP, youth/young adults, employers, community leaders.

South Central Region

The South Central participants identified key regional issues: lack of coordination, lack of youth participation, lacking capacity (or maybe just unknown), access to mental health services, transition from pediatric providers to adult providers, no parity within the region, lack of specialists (especially dental), no universal practice of barrier free design to allow equal access, and the need for increased advocacy and policy making. They identified resources in their region now and outlined resources still needed. Like the North Central participants, the conference attendees from South Central Pennsylvania identified a wide range of stakeholders who they thought needed to be included in the conversations about how to integrate and coordinate care: Elks Nurses, Home visiting, Insurers, Family Centers, Youth / young adult, OCD, Employers, School Districts, School Nurses, Schools, PATTAN, MH /MR, ODP, OVR, ARC, UCP, Other providers, Social Security, MA, Medical Providers – specialists, pediatrics, rehabilitation services, neonatology, Behavioral Health, Community – churches and the Urban League, College supports, Apprenticeship programs, Voc-tech, C & Y, Parents and families, Early Intervention.

Summary of PA Consortium for Children and Youth with Special Health Care Needs Conference Breakout Sessions

Southeast Region

The Southeast Region identified several areas that were needed to successfully integrate services for CYSHCN. These included doing needs assessments with participatory research tools and then building sustainable, county-specific resources. For health care providers, the workshop participants wanted to develop more skilled pediatric providers who would accept complex cases and more adult providers in general.

Ultimately, conference participants from the Southeast saw success as being when there were enough adult providers and enough coordinated care to provide a smooth transition for youth into the adult world with increased independent living and employment leading to an improved quality of life for families. Members of the workgroup envisioned CYSHCN as involved in their care and parents not as just caregivers but as consultants who were educated to serve as coaches for their children as they gained independence. Success would also be reflected in an increased visibility and awareness of people with disabilities.

Like other regions, the Southeast identified a wide range of stakeholders that needed to be at the table in order to fully integrate care for CYSHCN. These included many of the groups already identified in this summary as well as specific departments that serve transitional needs such as the Office of Vocational Rehabilitation, Centers for Independent Living, the Office of Developmental Programs and potential employers. As in the other regions, the Southeast stressed the need to have the most diverse group of participants in attendance at the Regional Forums to ensure that all needs were met. They advocated looking to best practices, creating networks for training and development, and drawing on the voices of people at the Institute on Disabilities and the PA Youth Leadership Network.