Health Care Transition Leadership Team - Work Group Recommendations

Below is a comprehensive list of recommendations to improve Health Care Transition for Youth with Special Health Care Needs. These recommendations were developed by the statewide Health Care Transition Leadership Team from 2015-2016. Some recommendations, based on availability of resources and feasibility have been incorporated into the five year Health Care Transition State Action Plan for Children and Youth with Special Health Care Needs.

1. Partner to create a database listing of providers with information of their patient eligibility and criteria for services such as special areas of expertise, age of patient and insurance acceptance. The listing of providers should include information on physicians who accept patients until age 21 with expertise in disease specific conditions such as Spina Bifida. Share this database with Medical Assistance Organizations, parents and other providers statewide. Connect with local providers by referring patients to diagnosis specific agency, for ongoing care.

2. Build partnerships with physician education programs to build on provider education of children with special health care needs and Health Care Transition. Partner to develop curriculum programs offering Continuing Education Units (CEU)/Continuing Medical Education (CME) /Maintenance of Certification (MCE) Credits to encourage participation from professionals.

3. Conduct surveys of pediatric specialty providers and adult specialists providers to gather feedback on referrals and patient enrollments; possibly conduct survey through Maryland American Academy of Pediatrics.

4. Develop network of adult providers and specialists that are able to serve and meet the needs of people with childhood onset conditions.

5. Ensure availability of Health Care Transition tools. Create a small toolkit to be provided/available on various websites and in Primary Care offices, Managed Care Organizations, and other health care institutions.

6. Partner and collaborate with Maryland Division of Rehabilitation Services (DORS) to establish a "Buddy System/Peer Support" group to assist in transition navigation for peers that have transitioned successfully from pediatric to adult care.

7. Build a database of dental care providers. Conduct a statewide survey of dental provider capacity in Maryland. Build a network of dental providers based on survey response and analysis.

8. When focusing on addressing health disparities around health care transition education focus on the at-risk population such as youth in foster care, ensure specialists accept Medicaid insurance and work to ensure that health literacy is used in all educational and resource materials and that there is an ease of readability in the information distributed.

9. Change the name of the Office of Genetics and People with Special Health Care Needs to a name that adds more Pediatric Onset Conditions.

10. Office of Genetics and People with Special Health Care Needs to coordinate and partner with entities that serve "hard to reach youth" such as Department of Social Services and Foster Care around Health Care Transition.

11. Standardize school health services to ensure all students receive the same information and services on health care transition.

12. Advocate for the inclusion of school nurses in the Individualized Education Program (IEP) development for students in the transitioning age range 12-21 years of age.

13. Focus efforts on empowering and educating parents to request nurses in the IEP process.

14. Conduct survey and training of school nurses, school based health centers, other relevant school staff including the supervisors of school nurses on Health Care Transition.

15. Advocate for improved vision and hearing screen resources within Maryland State Department of Education. Partner with MSDE to promote these additional services into the schools.

16. Promote and advocate for health literacy as a component all health education program, in schools.

17. Review chronic health data in schools by county. Identify youth with chronic illnesses and the most prevalent conditions.

18. Add health questions to the Youth Risk Behavior Survey, such as “When was the last time you have seen a doctor?”

19. Look into piloting an Interagency Development Team for Youth. The goal would be to develop a team for “at risk” youth. Provide parents and youth with resourceful information. Utilize the models of the Early Learning Interagency Committee or the Care Management Entity with Maryland Choices.

20. Assess which community based organizations and supporting agencies are available to assist transitioning youth with special health care needs with various services; what are their models; what services are offered; and criteria for services; where possible provide a link and resource to families for support.

21. Provide advocacy for medical case manager for every child with a special health care need.

22. Incorporate the use of "technology" into health care empowerment and education for youth and parents. Develop a software application to share with YSHCN and their parents. In addition, develop a phone application (app) to provide reminders, resources, health care transition tips, etc.

23. Develop a “standardized letter” that agencies working with special needs youth can use to send to the physician caring for the youth. The letter will be used as a prompt to physicians to begin discussions and plans on transitioning to adult care.

24. Host and promote smaller open house events for parents of children with special health care needs. Smaller events will assist with parents being overwhelmed and can provide more one-one interaction and support for parents.

25. Promote more physical screenings for students that are required to transition from elementary to middle school and from middle school to high school. This will ensure routine preventive care, prompting more students to go to the doctor because it is required. This taps into youth that are not being seen. This will also assist with implementing Medical Home.

26. Advocate and develop a training on “Unified Cultural Proficiency and Cultural Competency" to be offered to school staff and office staff of supporting agencies. The training would provide more respect to various cultures and religions; and to provide education on how western medicine works. A possible model for this training would be the Parish Nursing Program.

27. Develop a more "Compatible and Synthesized" Electronic Healthcare Record System. A system that can be read by all health systems would be beneficial for sharing information.

28. Provide Insurance reimbursement for Electronic Health Records that are compatible.

29. Engage a core group of adult providers in a discussion about their awareness of transition and their willingness to accept young people with special healthcare needs as patients. This collaboration and discussion will include how providers can be educated and provide support in the process of caring for patients who are transitioning from pediatric to adult care.

30. Recruit providers from the several agencies including: Autism Speaks, Pathfinders or Autism and CHIMES.

31. Develop strategy for incorporating the Project Echo Tele Mentoring Model into the provider education component of the Maryland Health Care Transition project.