

Transition Revolution

You can make it happen in health care

**An MCHB Invitational Meeting
Hilton-Savannah DeSoto
Savannah, Georgia
March 20-22, 1999**

Meeting Summary

In 1989, then Surgeon General C. Everett Koop convened "Growing Up and Getting Medical Care: Youth with Special Health Care Needs." This conference essentially kicked off a decade of discussion on the burgeoning topic of transitioning youth with special needs from pediatric to adult health care.

Ten years later, in March, 1999, a group of 50 health policy administrators, analysts and leaders, as well as physicians, nurses, teachers, family representatives, advocates, and adolescents with disabilities gathered in historic Savannah, Georgia, to again discuss this difficult topic. This time they met under the banner, "Transition Revolution: You Can Make it Happen in Health Care." Participants at the conference addressed how far the health care industry has come since 1989 in facilitating transitioning youth from pediatric to adult health care. They also addressed work that still needs to be done in this challenging national environment in which managed care is

the emerging paradigm. These were just some of the issues that were addressed during the two-day meeting.

The March '99 conference raised many other issues and questions. How will services be coordinated and financed? How can a continuum of quality care be maintained as children move from one set of health care providers to another? How can the issues of transition in mental health services be addressed? How do Medicaid, managed care, and the medical home facilitate transition? Who or what should drive the transition process forward? And finally, is transition the right term to use when describing the change of an individual into a new system of services?

Policy Implications and Recommendations

The Transition Revolution conference provided a forum for physicians, families and youths with disabilities to share with

one another their personal and professional experiences (including constraints, barriers and solutions) in transitioning youth from pediatric to adult health care. Stakeholders and participants heard the broad range of issues others face throughout the transition process. It was also a chance for participants to educate one another.

The conference generated dynamic discussions from which a set of concrete initiatives and recommendations emerged. The participants self-selected into four groups to engage in detailed discussion on one of the following fundamental areas in transition:

- Access: From Pediatric to Adult Health Care
- Partnerships for Successful Outcomes: Family, Youth & Professional
- Coordination: Sustaining Quality Health Care
- Financing: Bridging the Funding Streams of Health Care

Each group was asked to present a list of changes it would like to see made or particular ideas it would like to see implemented at the state and/or federal level that would

positively impact transition. Partnerships and working collaborations were created at the conference that will help to move forward a transition agenda of action. The following are

identified themes and recommendations for action at the state and federal levels.

Agency Specific Recommendations

Group	General Discussion Suggestions & Recommendations	HRSA/MCHB	Other Federal Agencies	PTFEAD	HRTW Interagency Workgroup	Other
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<p style="text-align: center;">Access: From Pediatric to Adult Health Care</p>	<ul style="list-style-type: none"> Assure that service providers adopt the principles and practices outlined in the federal mandate of OBRA '89. This legislation states, 'Title V CSHCN Programs were given a responsibility to facilitate the provision of family-centered, community-based coordinated care, including care-coordination for children with special health care needs, including SSI child beneficiaries.' Additional MCHB guidance also requires cultural competency as a service system component and as a component of family centered care. Therefore, a key part of these assurance efforts ought to be the use of existing definitions of cultural competency and tools to measure service-based cultural competence, adapting them when necessary. How this form of competence is linked to the practice of family-centered, community-based service and coordinated/collaborative care, must also be addressed. Understanding and addressing cultural competence, which is mandated through State Title V Block Grant Performance Measures, and MCHB/DSCSHCN discretionary grant guidances is difficult but achievable if it is uniformly and periodically supported and assessed (using well validated methods). Everyone must understand that assurance efforts leading to the adoption the intended practices of OBRA '89 is a continual, long-term process. Ensure that each individual has a primary care physician who provides a coordinated, affordable, and streamlined comprehensive care program. This program should embrace the "family-centered, community-based and culturally competent" principles that are a part of Title V CSHCN program and policy initiatives. Remove barriers to blending funding streams, especially funding streams that come from both federal and state sources in order to provide better teaching, research and training. Expand group home and respite care services to alleviate the burden on family members who want to care for individuals at home but who are employed or are themselves aging adults. Funding should be available to support group homes and respite care. Every person with a chronic illness or disability should have access to a home where they can live independently but with assistance if they need it. 	<ul style="list-style-type: none"> Create a Title V equivalent for adults. Rather than create a separate federal agency that handles this, expand the scope of Title V to encompass responsibility for promoting family-centered, community-based, coordinated care for all. 	<p>HCFA</p> <ul style="list-style-type: none"> Create a uniform benefit package for all individuals with chronic illnesses and disabilities across states. A specific "needs" assessment or test should be developed to determine eligibility for this benefits package. This would help ensure that people with chronic illnesses and disabilities not lose essential health and support services or have to pay for such services out-of-pocket because of the high costs of caring for their conditions. 		<ul style="list-style-type: none"> Develop a unified knowledge base about individuals with chronic illnesses and disabilities that would include a life-span perspective. 	<p style="text-align: right;">p. 4 of 4</p>
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Partnerships for Successful Outcomes: Family, Youth & Professional	<ul style="list-style-type: none"> Develop comprehensive research agenda, develop quality assurance measures, and implement practice guidelines based on those measures. Promulgate research findings about people with disabilities in general. Identify and describe the family practice literature that is relevant to the topic of the care of children, adolescents and young adults with chronic conditions. Establish ongoing dialogue between pediatricians and family medicine regarding the transition process. Dialogue should take place at the professional (practice) and the training (residency) levels. 	<ul style="list-style-type: none"> Cross-train professionals across disciplines and sectors such as social service sectors and medical sectors. 	<p><u>SSA</u></p> <ul style="list-style-type: none"> Develop appropriate quality measures and practice guidelines for transition. Start by examining Social Security's definition of "disability." Implement state-level, outcome-based research on what is actually working for people with disabilities and professionals. <p><u>HCFA</u></p> <ul style="list-style-type: none"> Implement consumer-directed personal assistance so that services and activities for an individual could be more spread out. <p><u>Dept. of ED/OSERS</u></p> <ul style="list-style-type: none"> Develop more Independent Living Centers (ILCs). ILCs promote self-advocacy and encourage society to develop relationships with people with disabilities. 			

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Coordination: Sustaining Quality Health Care	<ul style="list-style-type: none"> Implement the idea of “youth-centered” care. Incorporate youth into the planning process, especially when developing state plans on transition. Encourage more agencies and organizations, such as the American Academy of Pediatrics, American Academy of Family Practitioners, Parent Training Centers, and Family Voices to develop broader state plans that focus more on transition issues. Overall, states need a blueprint from which to develop their state plans -- a blueprint that includes mental health programs and issues. Encourage tertiary health care facilities to interface better with young people with chronic illnesses and disabilities so they are enabled and ready for work. Increase public awareness about the seriousness of transition issues. Who are the youths in transition? What are their successes and their barriers? 	<ul style="list-style-type: none"> Provide guidance to state Title V Programs to promote their participation in developing the health component of the Individual Education Plan (IEP). 	<p><u>HCFA</u></p> <ul style="list-style-type: none"> Support a redesigning of the Medicaid system to make it more of a general support model. <p><u>Dept. of ED/OSERS</u></p> <ul style="list-style-type: none"> Enhance the health component of the Individual Education Plan (IEP). 	<ul style="list-style-type: none"> Create a stronger, consumer- and youth-driven interagency collaboration around transition issues, including performance evaluation. Support a redesigning of the Medicaid system to make it more of a general support model. 	<ul style="list-style-type: none"> Create a stronger, consumer- and youth-driven interagency collaboration around transition issues, including performance evaluation. 	

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Financing: Bridging the Funding Streams of Health Care	<ul style="list-style-type: none"> Educate policy makers about systems in place that do not work for certain segments of the disabled population. Educate employers, families and youths about transition issues and their roles and responsibilities. Implement a state-level needs assessment. Define the population of adolescents and youth with SHCN in terms of from where, whom and what systems they are receiving services. Answer the question, "What is an 'effective' transition?" States need to know how many youth with disabilities are employed as well as barriers to their employment. Encourage states to fully implement the Medicaid option for extended coverage. Coverage for personal-care assistants should be available within Medicaid and should also be available through private coverage. Address the incentives to leave SSI and Medicaid. 	<ul style="list-style-type: none"> Develop a broad database that addresses transition issues. Develop a Title V Block Grant performance measure on transition and include the issue of transition in the Title V needs assessment. Introduce a type of Title V for adults that is not focused on an entitlement for health care coverage. 		<ul style="list-style-type: none"> Mandate linkages in federal laws for different systems so that the issue of transition becomes a focal point around which to work. 		

Meeting Participants' Personal Commitments

	<p align="center">Physicians Pediatricians, Internists Family Practitioners, & Geneticists</p>	<p align="center">Youth with Disabilities Adults with Disabilities Family Leaders Advocates</p>	<p align="center">Nurses, School Nurses, Therapists, Social Workers, Nutritionists</p>	<p align="center">Vocational Educators, General Educators, Employment Specialist, Employers</p>	<p align="center">Other Academia , Federal Employees HRTW Projects, Researchers Private Funding Agency</p>
<p align="center">General Follow-Up Action Commitments & Future Objectives</p>	<ul style="list-style-type: none"> • Encourage MCHB to fund the development of policy papers on successful transition from the pediatric to adult health care system written from the medical, family, and youth perspectives. • Encourage MCHB to update their initiatives to include youth and transition in health care issues. 	<ul style="list-style-type: none"> • Encourage expanding dialogue in MCHB-supported electronic mailing lists to include youth transition issues. • Promote the creation of a federal initiative for youth-centered care. • Encourage expanding dialogue in MCHB-supported electronic mailing lists to include youth transition issues. 	<ul style="list-style-type: none"> • Develop health care goals and objectives for yearly review on IEP (Individual Healthcare Plan). 		<ul style="list-style-type: none"> • Develop a website devoted to linking resource materials and highlighting exemplary models of transition from pediatric to adult health care. • Convene a federal workgroup to provide annual targeted technical assistance in incorporating successful strategies for assuring a continuity of quality health care. • Develop a website devoted to linking resource materials and highlighting exemplary models of transition from pediatric to adult health care.

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State / National/ Federal Level	<ul style="list-style-type: none"> • Ensure at the state level that each individual has a primary care physician who provides coordinated, streamlined, and affordable comprehensive care. • Persuade Health Commissioner to provide leadership to Medical Society & Hospital Association to conduct statewide MD survey on transition. 	<ul style="list-style-type: none"> • Increase awareness of which state level agencies/programs are addressing transition. • Bring transition issues to the Governor's Office. 	<ul style="list-style-type: none"> • Work with Student Support Project (interdisciplinary task force for school nurses, psychologists, social workers, guidance counselors) to identify/promote awareness of issues. 	<ul style="list-style-type: none"> • Expand the number of youths with SHCN served through interagency transition teams. • Bring transition issues to the Governor's Office. 	<ul style="list-style-type: none"> • Ensure that state demonstration projects examining health barriers to employment for people with disabilities are focused not only on adults but also on adolescents who want to work.

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Interagency Collaboration	<ul style="list-style-type: none"> • Have the American Academy of Family Practitioners' (AAFP) Committee on Public Health research transition issues. • Raise level of transition (from pediatric to adult health care) activity at Association of Maternal and Child Health Programs. • Increase American Academy of Pediatrics' (AAP) Medical Home Project Transition Training content. Design an AAP insert on transition. 		<ul style="list-style-type: none"> • Add adult issues to strategic plan of the Department of Public Health. • Develop a lifespan care coordination model with Department of Human Services. 	<ul style="list-style-type: none"> • Convene a Work Improvement Panel to advise the Governor and the Directors of Human Services, Education, Workforce Development, Economic Development & Public Health on the employment of youths with disabilities participating in government programs. • Disseminate STFM national meeting information on disabilities. 	

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Research & Data Gathering	<ul style="list-style-type: none"> Research and identify health-related issues with concern to young adults transitioning into the workplace, adult health care and school. 	<ul style="list-style-type: none"> Obtain data and literature on basic clinical problems on individuals with special needs. Develop a database of resources that people can use for referrals for support services [in recreation, employment, health (behavioral, medical), and education]. 	<ul style="list-style-type: none"> Research and identify health-related issues with concern to young adults transitioning into the workplace, adult health care and school. 	<ul style="list-style-type: none"> Plan to strategize with ILCs and others in the disability industry to compile information relevant to youth and health care. Make information known to Institute for Child Health Policy and the Maternal and Child Health Bureau for external dissemination. 	<ul style="list-style-type: none"> Obtain evidence-based data on models, utilization, demographics, epidemiology, and characteristics of patients. Develop local databases for personal care attendants, respite care, etc. Databases should be printed and kept online. A pilot project in Massachusetts is being done for pediatricians.

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Professional Development & Training	<ul style="list-style-type: none"> Bring the issues of education and job opportunities (or lack thereof) into the discussion of transition in medical training. These are key factors that influence access to health care after the transition between pediatric and adult settings. Integrate transition issues into interdisciplinary health professional classes (short term). Expand "disabilities" teaching to undergrad medical students by offering a weekly session in our Physical Diagnosis Clinic. Integrate training of residents in pediatric and family practice at Community Hospitals in terms of chronic illnesses across the life span. 		<ul style="list-style-type: none"> Continue to work on the integration of "health related" transition with "education" and "work" issues through policy (advocacy) and training efforts. Complete a booklet for MDs, Nurse Practitioners, and School Nurses in the areas of health, education, employment and recreation. Include resources. 		<ul style="list-style-type: none"> Bring the issues of education and job opportunities (or lack thereof) into the discussion of transition in medical training. These are key factors that influence access to health care after the transition between pediatric and adult settings. Make alterations to medical training to foster respect between providers. Mentor students and residents in areas of disability and chronic conditions.

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<p align="center">Professional Development & Training (Con't.)</p>	<ul style="list-style-type: none"> • Submit for funding a grant proposal to develop a curriculum for physicians, young adults, family members, and other health care professionals that relates to the transition from pediatric to adult health care systems. • Suggest to local universities that curricula include psychosocial issues related to disability and youth. • Develop a curriculum plan for a website to provide transition training for practicing physicians. • Develop certificate programs for special interest and expertise in various areas. • Educate interdisciplinary faculty and LEAH trainees on the themes, directions and issues of the Transition Revolution. 		<ul style="list-style-type: none"> • Include "transition" issues into School Nurse Training Program (currently sponsored in Florida by the Chiles Center, DOE, and DH). 		

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Create or Enhance Local Projects and Developments	<ul style="list-style-type: none"> • Create a center at Children's Hospitals that provide comprehensive voc-ed and other transition education to patients/people with disabilities. • Develop pilot programs wherein physicians are working together in the same cases (Peds, Family Practitioners, Internal Medicine) to facilitate collaboration. • Implement University Medical Center needs assessment with family/young adult input. 	<ul style="list-style-type: none"> • Examine how subspecialties in pediatric hospitals are assisting their patient populations to transition to the adult setting, thereby creating an awareness of a commitment to addressing this issue. • Use the Independent Living Centers more for transition issues. Also refer parents to ILCs for training their young adults on advocacy skills and employment issues. 	<ul style="list-style-type: none"> • Request position statement from National Association of School Nurses (NASN) for acknowledgement by all affiliate state organizations. • Duplicate this meeting at the local level with county stakeholders. Involve all agencies and programs. • Develop a community-based project in service-learning to help health professions students learn about these issues first-hand (long term). 	<ul style="list-style-type: none"> • Create a center at Children's Hospital in Cincinnati that brings together Project SEARCH and rehab services to provide comprehensive voc-ed and other transition education to patients/people with disabilities. 	<ul style="list-style-type: none"> • Implement local Children's Hospital needs assessment with family/young adult input regarding transition readiness needs for health care and employment.

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<p align="center">Information and Empowerment Outreach</p>		<ul style="list-style-type: none"> Increase opportunities for youths with disabilities to be involved in planning and implementing health promotion/education activities regarding transition and health care. 	<ul style="list-style-type: none"> Design and develop educational and informational multi-media materials articulating transition health-related issues. 	<ul style="list-style-type: none"> Develop fact sheets with tips for successful transition in health care for teens and families and put in on the WWW. Conduct workshops for families and young adults on record-keeping. Discuss how to do it, forms that simplify it, and how it can empower youth in transition to assume responsibility for their own health care. 	<ul style="list-style-type: none"> Produce "Healthy and Ready to Work: The Health Connection" video; a work incentives video for SSA; and develop and post transition materials to the <i>Go to Work</i> and <i>Transition Revolution</i> web-sites. Develop communication tools to disseminate to the field outcomes data on increasing access to/retention of health care. Identify, catalogue, review, and make information available about training and program-development activities related to transition from pediatric to adult health care systems that are being carried out in Pediatric Residency Programs; Family Practice Residency Programs; Med/Peds Residency Programs; Internal Medicine Residency Programs; University Affiliated Programs (supported by MCHB and/or Administration on Developmental Disabilities); AAP, American Academy Family Practitioners, state Title V CSHCN Programs; and other health care and managed care organizations.

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Funding			<ul style="list-style-type: none"> Encourage professional organizations to provide grant incentives to develop/pursue avenues of transition which may be used by health care providers. 		<ul style="list-style-type: none"> Convene a workgroup to discuss and identify strategies to remove barriers from blending funding streams.
Journal/Publication Materials	<ul style="list-style-type: none"> Write a joint association paper for publication in <i>American Family Physicians</i>. Communicate among professionals about youth with disabilities in the <i>Journal of Family Practice</i> to promote "youth-centered care." 				
Innovative Ideas	<ul style="list-style-type: none"> Encourage retired doctors to give their time to help see expensive (in time) patients. 		<ul style="list-style-type: none"> Enlist professional state organizations to develop/implement goals in targeting special needs individuals to assist in developing avenues for appropriate health services. 		



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