




NCC Collaborator

Expanding Genetic and NBS Services Through Multifaceted Partnerships

RCs Chart Course for Helping Youth Navigate from Pediatric to Adult Care

ties are building new models to train adult providers and to assist youth and their families as they navigate transition from pediatric to adult care.

In the early years of the 21st century, the American Academy of Pediatrics (AAP) recognized transition as a natural goal for sustaining wellness for all of our nation's youth and as a process that should be effortless and seamless. It is now one of AAP's top ten priorities, just as it has been one of six national MCHB key outcomes for children with special healthcare needs for several decades. A feature article by W. Carl Cooley, MD, Co-Director of the MCHB/HRSA-funded Got Transition—the National Health Care Transition Center (NHCTC) and chair of the NCC Medical Home Workgroup begins this newsletter. The article presents an overview of transition issues, discusses best practices and offers an algorithm depicting the key drivers of successful transitions.

You will also read about:

- **NEGC's** involvement with the Face4ward Project at Children's Hospital, Boston;
- **NYMAC's** model Sickle Cell Transition Intervention Program at Children's Hospital of The King's Daughters in Norfolk, VA;

- The transition initiatives for youth with sickle cell disease being undertaken by **SERC's** Transitioning and Hemoglobinopathies Workgroups;
- The resource development activities of **Region 4's** Transition Workgroup and the ways in which youth and their families in this region have become engaged in transition planning;
- The partnerships established between the **Heartland RC**, the **MS-GRCC**, the Denver Learning Collaborative of the NHCTC and local genetics clinics in both RCs; and
- How the Portable Health Record developed by the **WSGSC** is helping young adults with genetic conditions make both medical and non-medical life transitions.

We know you will enjoy reading about the various activities of the RCs related to improving transition to adult care and the ways in which they are contributing to and complementing national efforts to ensure smooth and effective transitions for all youth with heritable disorders, their families, and their healthcare providers.



Making the journey from pediatric to adult care often takes youth with heritable disorders and their families into uncharted waters. Early detection of genetic conditions through newborn screening and improved lifelong medical management have made productive adulthood an attainable destination for more affected youth than ever before. Yet, these youth often have difficulty finding adult healthcare providers who are comfortable taking care of individuals with inborn errors of metabolism, chromosomal problems and other birth defects. In this issue of the *NCC Collaborator* you will read about ways the HRSA Genetics Collaboratives (RCs) and other national enti-

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Opening the Door with Heritable Co

Submitted by W. Carl Cooley, MD, Co-Director, Got Medical Home Improvement; Chief Financial Officer

A fall off a cliff...a river without a bridge...a closed door. How many times have youth and families described the end of pediatric care and the prospects for continuing care in the adult healthcare world using these kinds of images? The statistics reinforce these images of apprehensions, gaps, and obstacles. More than half of youth with special healthcare needs in the United States fail to receive the support they need for a smooth transition from pediatric to adult healthcare. Most primary care pediatricians do not believe transition planning needs to begin before age 18, do not provide portable medical summaries, and do not make a direct connection for their patients with adult healthcare settings. Adult primary and specialty care providers express discomfort with childhood onset conditions, particularly those other than asthma, diabetes, or hypertension. They worry about the extra time that may be required and are more likely than pediatricians not to accept Medicaid payment. Adult providers say that they want care plans, portable medical summaries, and condition specific information sheets—all of which are rarely provided by pediatric healthcare settings. Meanwhile, young adults with chronic conditions experience more ER visits, hospitalizations, complications, and even deaths than they should, partly because of disruptions in the continuity of their care.

to a Healthy Future for Young Adults

Conditions

Transition—the National Health Care Transition Center; Medical Director, Center for
Crotched Mountain Foundation

No young adults are more vulnerable in this transition from pediatric to adult care than those with rare childhood onset conditions, including those identified at birth through newborn screening. Newborn screening sets the stage for life-changing, and often life-saving, care throughout childhood and adolescence. But, all that has been gained becomes subject to loss in early adulthood. Not only are adult primary care physicians apprehensive about assuming the care of these individuals, but also gaps in adult specialty care abound—from adult specialists in hematology with no hemoglobinopathy expertise to the near nonexistence of adult metabolic disease specialists.

We have been wringing our hands for years over these issues in spite of the long-standing national public health priority for seamless healthcare transitions. In 2002, the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians published *A Consensus Statement on Transitions for Young Adults with Special Health Care Needs*, recommending continuous, coordinated care including portable medical summaries and written transition care plans.¹ Over the past decade, healthcare transition leaders have developed tools for readiness assessment, transition planning, and communication among stakeholders, but these tools have not achieved widespread implementation. Pediatric and adult healthcare professionals are

mostly well-meaning individuals interested in high quality care with the best possible outcomes. However, they often lack the road map and methodologies for transforming the systems in which they work every day.

Fortunately, a number of recent developments may ignite a process for improving healthcare transition practices in primary and specialty care settings and demonstrate both the feasibility and the value of planned and proactive approaches to the cliff or river between adolescent and adult healthcare.

First, in 2011, pediatricians, family physicians, and internists have jointly published *Supporting the Transition from Adolescence to Adulthood in the Medical Home*, providing new, more precise standards for healthcare transition preparation, planning, and implementation.² While the 2002 consensus statement provided general guidance around transition, this new report offers a highly specific algorithm for the entire healthcare transition process in language designed for the logic of electronic health records. Authored by a group of professionals, youth, families, and policymakers, and reviewed by over 200 stakeholders prior to publication, the report addresses transition

for all youth, with an enriched pathway for youth with special healthcare needs. It provides a framework upon which those interested in specific chronic conditions could develop condition-specific overlays addressing the unique needs of a particular population. For example, the new transition algorithm provides a foundation for the development of transition planning tools for youth whose chronic conditions are identified at birth through newborn screening. In fact, the NCC has already begun incorporating principles derived from the algorithm into the development of new healthcare transition ACT sheets for a number of the newborn screening conditions.

Second, **Got Transition**—the new National Health Care Transition Center—was born in July 2010 through a cooperative agreement between the Maternal and Child Health Bureau (MCHB/HRSA) and the Center for Medical Home Improvement at Crotched Mountain in Concord, New Hampshire. Got Transition is applying collaborative learning and quality improvement methods to the implementation of healthcare transition best practices in real, community-based

Continued on page 11.



the new england **negc** genetics collaborative

Submitted by Tiffany Bowlby, MSW, LICSW, Children's Hospital Boston and Member, Transition and Medical Home Workgroups, NEGC

NEGC Leaders Participate in Face4ward Project

From July 12-15, members of the NEGC's transition initiatives were among the participants in a summer conference for youth with rare metabolic/genetic conditions. This youth-driven conference, developed through the Face4ward Project, focused on providing participants with the social support and practical skills necessary for a successful transition to adult healthcare. The conference goals were to:

1. Foster positive social support among these transition-age youth;
2. Raise participants' awareness about the issue of medical transition;
3. Provide resources and experiences aimed at helping the youth become informed and empowered healthcare consumers; and
4. Identify participants' goals/concerns and use those to promote improved adherence to treatment.

Currently, there are few programs to support young people with metabolic/genetic conditions as they navigate these transition years. Developing such programs is vital, as most young people must do a significant amount of out-of-clinic work in preparation for a smooth transition to adult medical care.

To ensure that programs are available to teens/young adults with metabolic/genetic conditions, Children's Hospital Boston partnered with Next Step, an organization with expertise in de-



veloping supportive programming for young adults living with chronic and life-threatening illnesses. The staff from Next Step is highly skilled at engaging adolescents and young adults in fun and age-appropriate ways. Specifically, a model adapted from the *One Love: No Longer Voiceless* conference guided this conference. This innovative intervention was originally designed for older teens and young adults living with HIV. Since its inception, *One Love: No Longer Voiceless* has convened young people with HIV and engaged them in a range of creative and interactive techniques—including music, theater, poetry, and photography—to generate discussion about issues they face and to help them develop their personal stories and plans for success. Participating youth also attend life-skills and leadership development workshops. The youth develop the topics and framework for

“This is a conference for the kids who weren't supposed to live. Perhaps this accounted for so many Harry Potter fans among the participants. Harry wasn't supposed to live, either.”

the workshops, which are then led by experts from the community.

The impact of the Face4ward Project will be assessed pre- and post-conference using the Values Compass, which has four quadrants: Health, Social Relationships, School/Work and Independence.¹ In addition, participants completed a conference evaluation survey.

One young adult co-facilitator, Malory Cyr, described the event with good humor, “This is a conference for the kids who weren't supposed to live. Perhaps this accounted for so many Harry Potter fans among the participants. Harry wasn't supposed to live, either,” noted Mal with a sly smile.

Reference

¹Nelson EC, Mohr JJ, Batalden PB, Plume SK. Improving Healthcare, Part 1: The Clinical Value Compass. *Jt Com J Qual Improv* 22:243–258, 1996.

<http://www.negenetics.org>

Submitted By Mitzi K. Glass, LCSW, Sickle Cell Transition Coordinator, Children's Hospital of The King's Daughters, Norfolk, VA

Sickle Cell Transition Intervention Program at Children's Hospital of The King's Daughters

Most children with special health-care needs, even those with complex medical issues, are now, for the first time, living into adulthood. This fact demands that transition programs be developed to meet their needs. In their landmark paper reporting on the results of focus group research about transition in children with special healthcare needs, John Reiss and Robert Gibson defined transition as "... a multifaceted, active process that attends to the medical, psychosocial, and educational or vocational needs of adolescents as they move from the child-focused to the adult-focused healthcare system.¹" Healthy People 2010 went on to challenge healthcare providers to develop transition services that prepare all children with special healthcare needs to transition from pediatric to adult healthcare.

Children's Hospital of The King's Daughters (CHKD) has been on the frontline of addressing the transition needs of its young patients. In 2007, CHKD's Comprehensive Sickle Cell Program hired a Sickle Cell Transition Coordinator to implement a Transition

Intervention Program. The Transition Coordinator developed a transition pathway and now coordinates a multi-disciplinary approach to the transition process. In addition, she addresses the specific transition concerns of adolescent and young adult patients in the program, monitors their transition readiness, and educates them about sickle cell disease and transition. The transition process begins at age 15 when teens complete the Transition Teen Self Assessment and the Transition Coordinator Assessment. Both tools address medical, social, and educational/vocational domains. Currently, there are 154 patients in the program. Since 2007, approximately 13 patients per year have transitioned to adult providers. The Transition Coordinator routinely interacts with patients and families in the sickle cell clinic. In addition, she follows up with the young adults after clinic appointments, hospitalizations, and emergency room visits by telephone, and she accompanies patients to their first new adult doctor appointment.

Special programs such as the Sickle Cell Transition Retreat, begun in 2009, help to facilitate the transition process for CHKD sickle cell patients aged 17 to 21 years. Participant comments have included: "Transition is scary;" "sickle cell is not a priority;" "I will just take my Percocet at home until I die;" and "I need to get to know my adult provider before I leave CHKD." In 2010 and 2011, the retreat was expanded to include teens with other special healthcare needs, such as diabetes, renal disease and hemophilia, and their families.



CHKD is excited about the future of transition for children and families and will continue to be a model for other transition programs.

(Mitzi Glass can be contacted at 757-668-8599).

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¹Reiss J and Gibson R. (2002). Healthcare Transition: Destinations Unknown. *Pediatrics*. 110 (S), 1307-14. http://pediatrics.aappublications.org/content/110/Supplement_3/1307.full.html (Accessed August 4, 2011)

<http://www.wadsworth.org/newborn/nymac>



SOUTHEAST NBS & GENETICS COLLABORATIVE

Submitted by James R. Eckman, MD, Professor of Hematology and Oncology, Winship Cancer Institute, Emory University School of Medicine and Robert W. Gibson, PhD, MSOTR/L, Associate Professor, Department of Occupational Therapy, College of Allied Health Sciences, Georgia Health Sciences University

Addressing Transition to the Adult Medical Home for Youth with Sickle Cell Disease



Dramatic improvements in quality of life and longevity for individuals living with sickle cell disease represent one of the greatest successes of newborn screening and public health genetics programs. In the 1970s, the average life expectancy for someone diagnosed with this disease was about 16 years, and few children were expected to live past the age of 20. Today, our expectation is that 90 to 95 percent of children with sickle cell disease will live to adulthood and that many will reach old age. This change has necessitated preparing youth with sickle cell disease for high quality, productive lives as adults, and preventing complications of the disease over the life course. Helping youth with sickle cell disease make the transition from pediatric to adult medical homes has become a major priority of the SERC's Transitioning and Hemoglobinopathies Workgroups.

A number of models for transitioning youth living with sickle cell disease were highlighted at the June 23 annual meeting of SERC's Hemoglobinopathies Workgroup, and at the SERC and SERGG Annual Meetings

a month later. For example, the program led by Drs. Alcuin Johnson and Ify Osunkwo at Children's Hospital of Atlanta includes formal transition activities beginning at age 13 years. Semi-annual Teen Scene entertaining education events introduce the youth to adult providers, and transition clinics—held twice a month for 13 to 21 year olds—address transition concerns, insurance, independence, communication skills training, and peer support. Events for 16 to 21 year olds are held at the adult health setting to introduce the facilities to the youth and present topics related to financial planning, access to care, career/education, and vocational rehabilitation resources. Gender-specific lunches enrich the program experience and include the participation of older adults with sickle cell. The transition activities culminate in graduation during a formal lunch ceremony that includes certificates and gifts for the graduates. Other models for transition in each of our states are shared at our annual meetings. Future efforts of the Transitioning and Hemoglobinopathies Workgroups will focus on evaluating these different approaches to transition and sharing findings in future publications.

One of the major challenges facing those who seek to improve transitions is the difficulty in identifying appropriate adult medical homes for youth with sickle cell disease. Our second transition priority in SERC is to evaluate adult medical home models for these patients using family and general internal medicine providers. SERC is exploring a variety of existing models and approaches in Alabama, Florida, Georgia, Louisiana, North Carolina, and Tennessee that have been developed with federal, state and private funding. One specific activity supported by SERC will expand the HRSA-funded Baby STEP® program developed by Dr. Thomas Howard and Kristen Osborn to educate primary providers caring for children detected with sickle cell disease by newborn screening.

Plans include developing new educational modules for early transition, to be led by pediatric providers, and modules for late transition led by adult providers. These modules standardize the information that the providers share with parents and families, and they are expected to become valuable educational support tools for transition in all sickle cell programs in the region and perhaps the nation.

<http://www.southeastgenetics.org>



Region 4 Genetics Collaborative

Submitted by David Entwistle, PsyD, Transition Workgroup Co-Lead, Region 4

Engaging Youth in Transition Planning

Our lives are marked by many transitions: from the womb to the outside world; from home to school; from grade to grade; from school to work; and ultimately, from life to death. For individuals with genetic conditions and their families, there are additional transitions to be made as well as additional challenges. The Region 4 Transition Workgroup is addressing this issue by developing resources that can help youth and families affected by genetic disorders gain the information and skills they need to adapt to some of the transitions they may face.

The Transition Workgroup began by identifying the many types of transitions with which children and youth with special healthcare needs, and their families, must deal. It soon became obvious that these transitions are quite varied. Some families may need to focus on providing long-term custodial care for their growing children, while others may need to focus on physical, educational, or occupational accommodations. Other youth and their families may not face educational and intellectual difficulties, but instead deal with declining physical health. In each case, youth and their families need access to information and resources so that they can deal with these transitions as effectively as possible.

Realizing it was impossible to focus on all the transitional issues youth with genetic conditions and their families may face, the workgroup decided to



concentrate its efforts on providing resources to help families negotiate transitions as a developmental process. Adapting the work of John Reiss, PhD, Associate Professor of Counseling Psychology at the University of Florida, the Transition Workgroup is designing a webpage that will link users to transition resources on the Internet. These will be organized for several audiences: developing children, older adolescents, and parents. Links will be provided to video and other resources dealing with transition from pediatric to adult care, educational issues, occupational issues, and other topics. The workgroup has been reviewing the resources and evaluating them for accuracy of information, ease of accessibility, and appropriateness for the target audiences. Throughout the process, the workgroup has been highlighting the

importance of viewing transition as a developmental process in which children and youth work with parents, guardians, and medical professionals to gradually assume more responsibility for their own medical care and life choices—based on their level of ability and maturity.

The workgroup is obtaining input from adolescents and family members who might use the materials in order to ensure that their needs and desires are central to the crafting of the webpage and that the final format is accessible and appealing.

<http://region4genetics.org>



Heartland Genetics and Newborn Screening Collaborative

Submitted by: Liza Creel, MPH, MSGRCC Project Manager; Lori Williamson, MS, LCGC Heartland Program Manager; Laura P. and Joyce Hooker, MSGRCC Director of Regional Outreach

Healthcare Transition and the Interdisciplinary Int



The Mountain States and Heartland Genetics and Newborn Screening Regional Collaboratives (RCs) have joined forces to address healthcare transition for children with heritable disorders. Encouraged by HRSA's challenge that the RCs develop projects focused around the special transition needs of these children and built on existing, successful work, both RCs began exploring resources and options within their regions.

Since 2008, the Mountain States Genetics Regional Collaborative Center (MSGRCC) has supported a transition project, led by Dr. Laura Pickler at Children's Hospital Colorado in Aurora, Colorado. The project aims to improve transition-related planning to help youth move successfully from a pediatric-oriented system of care to an adult-oriented system of care by implementing medical home standards within a specialty clinic that serves youth with genetic disorders and inherited errors of metabolism (IEM). By providing a clinical setting that strives to be part of a young adult's medical home team, Dr. Pickler's hypothesis is that transition outcomes will improve for this patient population. To this end, Drs. Pickler and Yvonne Kellar-Guenther have docu-

mented a transition model that has been standardized. Future efforts will involve testing the model and measuring outcomes for youth with IEM.

In the first two years of her project, Dr. Pickler explored the transition needs of patients attending the metabolic disease/genetics clinic. She and her team investigated the differences in transition experiences between youth with genetic disorders and their typical siblings. She also collected data on adult provider preferences when accepting a transitioning patient with a special healthcare need. With the combined support of the National Health Care Transition Center (NHCTC) and MSGRCC, Dr. Pickler is now leading the Denver Health Care Transition Learning Collaborative (LC).

Simultaneously, the Heartland RC hired a consultant to explore transition issues, form an *ad hoc* workgroup, and if appropriate, develop a project focused on transition. That investigation led to Dr. Pickler, and subsequent discussions about each region's needs ultimately resulted in Dr. Pickler inviting the Heartland RC to participate in the Denver Health Care Transition Learning Collaborative.

The Denver LC is one of three LCs participating in the Got Transition project of the MCHB/HRSA-funded National Health Care Transition Center (see article on page 2). MSGRCC



ickler, MD, MPH, Assistant Professor, University of Colorado School of Medicine and MSGRCC; Celia Kaye, MD, PhD, MSGRCC Project Director

er-RC Learning Collaborative

and Heartland are supporting the participation of four genetics clinics in the LC, in addition to the three Denver primary care clinic sites funded directly through the NHCTC. The two genetics clinical sites supported by the MSGRCC are the Special Care Clinic at Children's Hospital Colorado and Potomac Street Health Center, a federally qualified health center. The Heartland RC is funding the participation of the University of Oklahoma Medical Genetics Clinic and the Genetics Clinic located at Kansas University School of Medicine-Subspecialty Clinic. These clinics will receive feedback from youth (ages 14 to 23 years) and parents regarding the transition process. The youth being seen in the two Heartland clinics have a variety of non-metabolic genetic and chromosomal conditions because the Heartland team wants to test the applicability of the transition principles and practices to any transitioning youth in the Medical Genetics Clinic.

The purpose of the **Got Transition** project is to implement and evaluate a practical package of tools and systems for seamless transitions from pediatric to adult care. In addition to contributing data, these four additional pilot sites ensure that children with genetic disorders are represented in the national study and that similarities and

differences between their transition needs and those of the larger population of children are identified. Results of this project will also provide information on the role of the genetics professionals in healthcare transitions for youth with genetic conditions.

The Heartland and Mountain States RCs are also collaborating on a survey of pediatric genetics providers regarding their knowledge, attitudes, and practice behaviors related to healthcare transition. Baseline data are lacking in the regions, and the literature reveals no studies about the knowledge, attitudes, and practice behaviors of medical geneticists, genetic counselors, and genetic nurses regarding transition. Release of the survey is expected for Fall 2011, with completion of data collection and analysis planned for Spring 2012.

An overarching goal of both transition projects being undertaken by the MSGRCC and Heartland is to reassure families that their children will be receiving the same quality of care in adulthood as they did as children. Families and consumer advocates are involved in these projects, and incorporating the family perspective is seen as key to the projects' ultimate suc-

"My biggest fear of transition is getting a doctor who does not understand her. She is so well taken care of right now; nothing has been missed. What is going to happen to her health if she transitions to an adult doctor who doesn't know anything?"

family member noted, "My biggest fear of transition is getting a doctor who does not understand her. She is so well taken care of right now; nothing has been missed. What is going to happen to her health if she transitions to an adult doctor who doesn't know anything?"

Both regions will consider the experiences of their pilot sites in the NHCTC project and results of the provider survey in determining next steps for promotion of healthcare transition in the regions. Transition is an important issue, and both the Heartland RC and MSGRCC want to proceed in ways that meet regional needs, incorporate best practices, and are cost-effective.

<http://www.msgrcc.org/>
<http://www.heartlandcollaborative.org/>





Submitted by Jacquie Stock, MPH, Evaluator, Work Group Leader and Family Advocate; Susan Atkins, Polly Bleavins, Barb Chambers, Julie Finholm, Kristine Green, Angela Lindig, Kauí Rezendes, and Alfred Torres, Jr., Family Advocates, WSGSC

Young Adults with Genetic Conditions Talk about Using a Portable Health Record

Individuals living with genetic or metabolic conditions know how difficult and time consuming it can be to share information about their condition and health status with a new care provider. Providers also know how much time it takes to understand the history and current health status of a person with a complex chronic condition. To address these challenges and make sure that this vital information is communicated in a timely fashion, family advocates and primary care providers in the Western States Genetic Services Collaborative created, and are now evaluating, a portable health record form designed specifically for people with genetic or metabolic conditions. The portable health record, designed especially to be used in times of transition or emergencies and described in the March 2011 issue of the *NCC Collaborator*, is intended to be kept up to date through a partnership between

"This form gives me a place to keep a record of myself for me. Some of the parts of the form I wasn't clear on, but I might have been more knowledgeable with my doctor helping me."

an individual and his/her primary care doctor.

Three young adults with genetic conditions were among those who completed the portable health record and participated in an interview evaluating the form. Each young adult has a different complex genetic condition that affects multiple body systems. At the same time, each is moving into the responsibilities of adulthood along with their peers—graduating college, looking for a job, learning to manage their own healthcare.

How can a portable health record help? All three young adults believed that use of a portable health record would help them feel more confident and that they would be better cared for when seeing a new provider or being admitted to the hospital. One said, *"It [portable health record] gives me something to take with me anywhere I go, traveling, moving—when filling the record out I saw it would be useful going on a trip out of state and I needed to seek medical help. In college I went to Japan so this would have been helpful, everything is consolidated into one document, which is good. [It] makes me feel confident that everything someone would need to know is in one place."*

The evaluation participants mentioned that it was important to fill out the portable health record in partnership with their primary care doctor. One participant said that, although s/he had learned a lot of medical jargon, s/he still did not know all the terminology or areas of information that a new provider may need. This is where the primary care

doctor can help. For example, *"This form gives me a place to keep a record of myself for me. Some of the parts of the form I wasn't clear on, but I might have been more knowledgeable with my doctor helping me."*

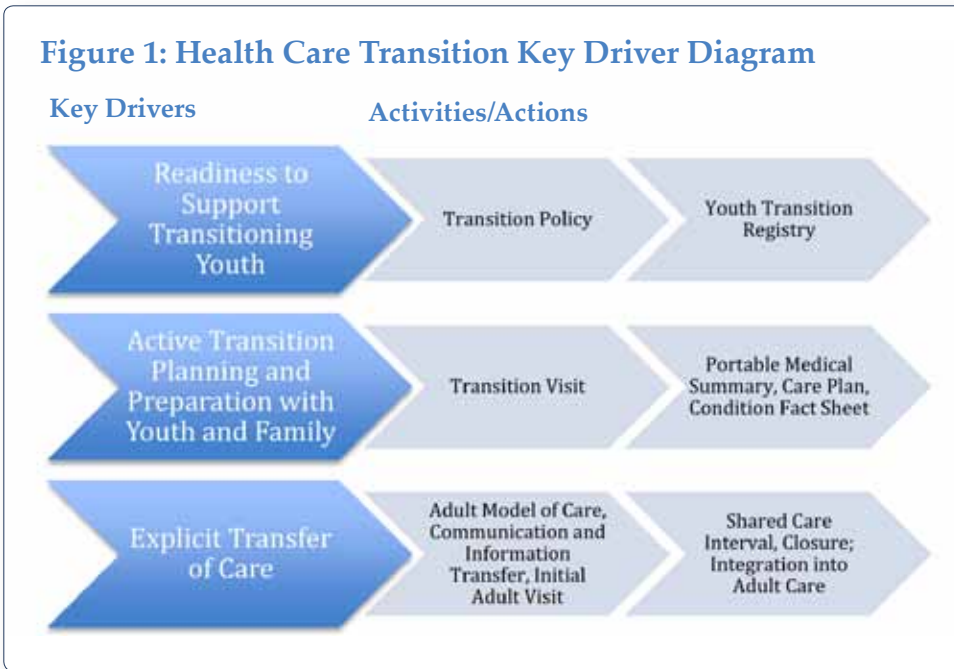
Participants also indicated that, if they were too sick to answer questions (for example, they were being admitted to a hospital), the form would help their parents or other family members provide answers. Having a trusted individual knowledgeable about their current health status was important to the young adults.

The portable health record can be on paper, uploaded to a health record application, or maintained on a flash drive or CD. Participants felt most providers are still using paper medical records but believed the time is not too far off when doctors, clinics and hospitals will use the Internet and electronic health records not only to manage their own patient documents, but also to receive up-to-date information from patients themselves.

Participants indicated that completing the form was a time consuming process that could be a deterrent to many people. Yet, they felt the benefits to them and their families outweighed the time required to fill out the form. The young people we talked with are looking forward to the day when all providers and patients will be "online together."

<http://www.westernstatesgenetics.org/>

Figure 1: Health Care Transition Key Driver Diagram



pediatric and adult healthcare settings. Based on the new clinical report and on the creative efforts of other transition projects, Got Transition has articulated the key drivers (see figure 1) and developed the Six Core Elements of Healthcare Transition to guide office and clinic practice change. Initially piloting their work through local learning collaboratives in Washington DC, Denver, and Boston, Got Transition will consolidate and make available the tools and processes tested in these sites by mid-fall 2011 and expand pilot projects to additional sites during 2012 and 2013.

In addition to its primary focus on practice-level change, Got Transition has an active strategy for communication and information exchange among youth, families, professionals, and state policy makers. This Healthcare Transition Information Exchange includes quarterly webinars, social networking

connections, and a new Healthcare Transition Healthcast “talk show” hosted by Got Transition’s youth and family leaders. Got Transition has also partnered with the National Alliance to Advance Adolescent Health to systematically track and report state-level healthcare transition data, as well as to identify innovative projects based on National Survey data, the review of state maternal and child health block grant applications and reports, and targeted conference calls. Get transitioned at www.gottransition.org or on Facebook by searching Got Transition!

Finally, and perhaps most important, efforts to improve healthcare transition supports have gained momentum in multiple arenas. National conversations are occurring among interested health systems researchers, and a healthcare transition special interest group (SIG) was formed by the Pediatric Academic Societies at their

May 2011 meeting in Denver. Many of the HRSA Genetics Collaboratives are joining monthly healthcare transition conference calls to share transition-related activities and information. The American College of Physicians is considering including healthcare transition guidance and tools, based on the new clinical report, as a new module in their forthcoming on-line Build Your Medical Home toolkit for general internal medicine physicians. Along with medical home implementation, HRSA/MCHB has made healthcare transition a priority for nearly all of its initiatives, and the American Academy of Pediatrics has adopted a multi-year healthcare transition agenda founded upon the new clinical report as a basis from which to address further issues for research, medical education, reimbursement and financing policies, and ongoing improvements in pediatric practice.

www.gottransition.org

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¹American Academy of Pediatrics; American Academy of Family Physicians; American College of Physicians-American Society of Internal Medicine. (2002). A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics* 110(6 (Part 2)):1304 - 1306.

²Cooley W, Sagerman, P, and Transition Authoring Group. (2011). Clinical report—supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics* 128(1):182 - 200.

Both documents can be downloaded here: <http://www.gottransition.org/about-us-research>

The logo features a stylized green and blue cross-like symbol on the left, followed by the text "NCC Calendar" in a large, elegant, blue serif font.

NCC MEETINGS

WSGSC Annual Regional Summit	Sep 12-14	Seattle, WA
Region 4 RC Meeting	Sep 13-15	Lansing, MI
NEGC Annual Meeting	Nov 15-16	Portsmouth, NH
NCC/RC/GSB PD/PM Face-to-Face Meeting	Nov 17-18	Bethesda, MD

NATIONAL CONFERENCES

Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) Meeting	Sep 22-23	Washington, DC
National Coalition for Health Professional Education in Genetics (NCHPEG) Annual Meeting: Strategies for Evidence-Based Genetics Education	Sep 26-27	Bethesda, MD
American Society of Human Genetics (ASHG) Annual Meeting in conjunction with the International Congress on Human Genetics	Oct 11-15	Montreal, Canada
Association for Public Health Laboratories (APHL/CDC) Newborn Screening and Genetic Testing Symposium	Nov 7-10	San Diego, CA

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September 2011 Edition Volume 5, Number 3

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The NCC Collaborator is the official newsletter of the National Coordinating Center for the Regional Genetic and Newborn Screening Service Collaboratives (NCC). The newsletter is published quarterly and is available in a portable document file (PDF) via email and at www.nccreg.org. Copyright © 2011 American College of Medical Genetics. The National Coordinating Center is funded by cooperative agreement No. U22MC03957 between the American College of Medical Genetics and the Genetic Services Branch/Maternal and Child Health Bureau/Health Resources and Services Administration.

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