



Health Care Transition

A Health Care Provider's Guide
to Helping Youth Transition
from Pediatric to Adult Health Care

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Accreditation

The Mountain Area Health Education Center (MAHEC) is accredited by the North Carolina Medical Society to sponsor continuing education for physicians.

Credit

For those physicians who wish to implement transition services into their practice, the Mountain Area Health Education Center designates a maximum of 20.0 AMA PRA *Category 1 Credit(s)*[™] for a Performance Improvement (PI) project. For details on how these credits may be earned, please see Appendix C, Process for Awarding CME Credit for Performance Improvement Activities.

Disclosure Statement

MAHEC adheres to the ACCME Standards regarding industry support to continuing medical education. The CHAT project was funded entirely by non-commercial support, and there are no relationships or conflicts of interest to report in connection with this project or the materials contained herein.

Introduction

Carolina Health and Transition (CHAT) is a systems-based project funded by a three-year grant awarded to the North Carolina Division of Public Health (NCDPH) from the Health Resource and Services Administration (HRSA). The purpose of CHAT is to ensure that youth with special health care needs (YSHCN) receive coordinated, comprehensive care within a medical home, as well as the needed services and supports to make transitions to adult life. Children and youth with significant special health care needs, their families and caregivers, and medical providers will develop an *understanding of and skills necessary* to successfully transition youth with special health care needs from pediatric to adult health care.

The goals of the CHAT program are:

- To increase the availability of and access to quality, coordinated, and comprehensive health care services within a medical home; and
- To facilitate the successful transition of YSHCN from pediatric to adult systems of health care.

The medical provider practicum is a component of comprehensive strategies developed to support these program goals. This resource, with clinical tools provided, is intended to help educate your staff and facilitate transition services in your practice.

The adoption of transition services will contribute toward:

- *Increasing the number of YSHCN* who have the skills necessary to successfully transition from pediatric to adult health care systems within a medical home;
- *Increasing the number of families* of YSHCN who are able to advocate for their child's successful transition, by recognizing differing transition issues and goals for each phase of development, and navigate insurance and service gaps in medical care; and
- *Increasing the number of medical providers* in pediatric and adult care practices who have knowledge and expertise in providing high quality, culturally competent, transition-related services.

Given the differences in the structure and management of health care provider organizations, there are likely to be many variations in staff knowledge, expertise, and administrative systems. Therefore, in addition to providing a “user friendly” format, the CHAT program is versatile enough so that it can be adapted to fit the needs of most public health clinics or health care organizations.

The information is not meant to be prescriptive. Rather it is an invitation for you to better understand the importance of transition care for YSHCN, and offers you tools to help meet the needs of these youth.

Section 1

Health Care Transition

Health care transition, according to the Society for Adolescent Medicine, is the **purposeful, planned movement of adolescents from pediatric to adult health care**¹. It is a “process” where the responsibility for managing health care shifts from the parent to the young adult. Health care transition is one aspect of the many transitions that occur in the movement from adolescence to adulthood. It is an active, multifaceted process that involves the medical, psychosocial, educational and vocational needs of youth. For those with special needs, transition can be especially challenging.

Youth with special health care needs (YSHCN) are **“those who experience significant health conditions that affect functioning on a daily basis, and require specialized accommodations or medical treatment”** (www.nichq.org, 2009). (www.nichq.org/CYSHN/index.html) They have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions that persist into adulthood. Approximately 30 percent of adolescents experience at least one or more of these conditions, such as ADD/ADHD, asthma, intellectual or developmental disability, cancer, autism, congenital heart disease, or sickle cell anemia to name a few.

Understanding the Issues

The need to focus on care of adolescents with chronic and disabling health conditions arose out of dramatically improved survival rates of children born since the 1970s. Today, most children with chronic disease and disability now survive into adulthood. It is estimated that more than 12 million children and youth in the United States (US)² have chronic conditions, with 500,000 to 750,000 reaching transition age each year^{3,4}. Almost half lack access to a physician familiar with their health condition.

The Surgeon General’s 1989 report, “Growing Up and Getting Medical Care: Youth with Special Health Care Needs,”⁵ first set forth a national agenda in training, research, and program development. The goal was to establish a seamless health care system that would allow young people with special needs to move successfully from pediatric to adult-centered services.

Even with increased awareness and understanding, two decades later we have made little progress. Successful efforts to date have been primarily directed towards youth and families. Despite leadership efforts by the American Academy of Pediatrics (AAP) and others, planning for transition and the purposeful transfer to adult providers has yet to become a standard of care for most pediatric practices. Only in the past few years has it even been acknowledged that adult care disciplines need to make a similar commitment to support transition care.

The Need for Health Care Transition Services

Attaining national and state goals will require a change in consciousness, systems of care, and practice.

In 2001, the U.S. Department of Health and Human Services Maternal and Child Health Bureau sponsored a national meeting of leaders from primary and subspecialty care, multi-disciplinary professionals, and parents of youth with disabilities. This effort resulted in “A Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs” adopted as policy by the American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians – American Society of

Internal Medicine⁷. The goal was to ensure that by the year 2010, all physicians who provide care to YSHCN will:

- Understand the rationale for transition from child-oriented to adult-oriented health care;
- Have the knowledge and skills to facilitate this process; and
- Know if, how, and when transfer of care is indicated.

There has been a resurgence in efforts to realize these goals. Attaining them will require a change in our consciousness, systems of care and practice-based change. It will take a commitment to collaboration among providers, improved insurance coverage, better reimbursement, and educational tools for youth, parents, and medical providers.

The North Carolina Experience

The 2005-06 national survey of Children with Special Health Care Needs (CSHCN) indicated that 60 percent of YSCHN in North Carolina did not receive the services they needed to make appropriate transitions to adult health care, work, and independence (Figure 1). This is comparable to the national average and reflects the need for youth to become better prepared for entry and self-management in the adult health care system. Results from the study also reported that 45 percent of YSHCN lack a provider familiar with their medical needs, while 30 percent in the 18-24 age range may lack health insurance coverage⁶.

Summary and Key Points

Points to remember in identifying and addressing the need for transitions services:

- Most children with chronic disease and disability now survive into adulthood.
- Almost half lack access to a physician familiar with their health condition.
- The goal of purposeful, planned and timely transition is to maximize lifelong functioning of all youth with chronic disease, disability or other special health care needs.
- Transition is a process, not an event.
- It is an individualized process; “no one size fits all.”

The following sections will prepare providers to respond to the need for a planned transition process for YSHCN in an actionable, culturally sensitive manner.

CME Note: Refer to ***Appendix A: Where Have All the Children Gone?*** for optional category 1 credit. This recorded presentation by Adrian Sandler, MD, FAAP, provides an overview of transition issues for clinicians. Dr. Sandler was a principle architect of the joint consensus statement referenced above (<http://pediatrics.aappublications.org/cgi/reprint/110/6/S1/1304.pdf>).

Section 2

Transition and the Medical Home

Expanding the Vision of the Medical Home

The term medical home has evolved and taken on added significance since its importance was first acknowledged by the American Academy of Pediatrics nearly four decades ago. It was defined at that time as a place where medical records are kept. Today it is more broadly defined as an approach to providing comprehensive primary care in a high quality and cost effective manner, in partnership with the family and patient to meet the medical and non-medical needs of infants, children and youth.

Pediatric and adult primary care providers often have an innate sense of the qualities of a medical home. Even sub-specialists often serve as medical homes for youth with complex and chronic conditions. There is agreement that medical home care exists along a continuum of care. Many providers have been using components of the medical home approach to regularly deliver care for years. The term medical home has been difficult to define and it has meant different things to different people. In addition, the epidemiology of chronic conditions in youth is characterized by a relatively large number of conditions affecting small subgroups. This makes it difficult to describe a “typical” subgroup for prescribing standards of care across a range of chronic conditions.

Fortunately, there have been recent efforts to better define the patient-centered medical home concept with the development of a 2007 statement by the AAFP, AAP, American College of Physicians, and American Osteopathic Society. *The Joint Principles of the Patient-Centered Medical Home* (www.medicalhomeinfo.org/Joint%20Statement.pdf) sets a high standard that requires commitments to policy, system, and practice level changes. “The patient-centered medical home is a health care setting that facilitates partnerships between individual patients, and their personal physicians, and when appropriate, the patient’s family. Care is facilitated by registries, information technology, health information exchange and other means to assure that patients get the indicated care when and where they need and want it in a culturally and linguistically appropriate manner.”⁷

The Patient Centered Primary Care Collaborative (PCPCC) has been key to promoting the patient-centered medical home and advocating for changes that are needed with legislators, businesses, purchasers, payors, health care providers, families, and others. The PCPCC website is a valuable clearinghouse of information, resources, and activities across the country related to medical home and can be found at www.pcpcc.net.

Convergence of Medical Home and Transition

The 2002 Consensus Statement on Transition called for the medical profession to take the steps necessary to realize the vision of a “family centered, continuous, comprehensive, coordinated, compassionate, and culturally competent health care system that is as developmentally appropriate as it is technically sophisticated”.⁸ The statement illustrates how the elements of the medical home approach support a successful transition process from pediatric to adult health care. The concept of medical home clearly converges with recommendations for transition care for youth with special needs. A medical home is even more important for those with a chronic condition. This is especially true for YSHCN as they move from what has been a nurturing, parent driven health care system of care to an adult oriented system of care that is more unfamiliar, and requires a new degree of independence and responsibility.

The National Committee for Quality Assurance (NCQA) has recently worked with the American College of Physicians (ACP), American Academy of Family Physicians (AAFP), American Academy of Pediatrics (AAP) and American Osteopathic Association (AOA) and others to create a set of standards to assess whether physician practices are functioning as medical homes. Building on the joint principles developed by the primary care specialty societies, the Physician Practice Connections – Patient Centered Medical Home (PPC®-PCMH™) standards emphasize the use of systematic, patient-centered, coordinated care management processes⁹. There are nine PPC® standards, including ten must-pass elements (which can result in one of three levels of recognition): access and communication; patient tracking and registry functions; care management; patient self management support; electronic prescribing; test tracking; referral tracking; performance reporting and improvement; and advanced electronic communication. Practices seeking PPC®-PCMH™ recognition complete a web-based data collection tool and provide documentation that validates responses. Several states are using the NCQA medical home standards to pilot medical home demonstration projects that are linked to enhanced reimbursement depending on the level of recognition that is met by the practice.

Prior to the release of the NCQA toolkit, the Center for Medical Home Improvement (CMHI) developed practice self-assessment survey tools to help with quality improvement in evaluating how well a practice is doing and where their score places them on the medical home continuum. The survey is directed toward primary care pediatricians, but it is also applicable for pediatric sub-specialists and adult providers. The “Short Version” survey is available at: www.medicalhomeimprovement.org/assets/pdf/MHI-ShortV_2006CMHI.pdf.

The Family Medical Home Index (also from CMHI) has been another valuable tool to evaluate the delivery of medical home care for several years. (See www.medicalhomeimprovement.org/assets/pdf/MHIK-tools.pdf. Scroll down to pp 18-21 for the Family Index.)

The National Institute for Family Centered Care recently developed several tools and resources for providers on how to partner with patients and families. These can be accessed at: www.pcpcc.net/files/Primary%20Care%20IFCC%20Resources.pdf.

Providers are encouraged to implement the NCQA standards of access, communication, registry and patient tracking functions, care management and patient self management support that are embedded within the medical home model to assure successful transition. The focus of care must move beyond acute illness management to comprehensive care of the youth in the context of their home and community. This requires close collaboration between primary care, subspecialty, public health, mental health, oral health, adult providers, and ancillary providers with community health and human services programs committed to serving the needs of YSHCN.

Health care providers can join or build a transition team composed of multiple agencies and individuals capable of:

- 1) assessing an individual's and family's knowledge, resources and abilities;
- 2) coordinating and communicating about information and resources; and
- 3) developing action steps to overcome barriers and facilitate transitioning in all aspects of the youth's life.

Well-defined and coordinated action steps must be developed to address the transition needs that exist within the context of the family and within the health care, educational, and vocational systems. For youth with special needs who anticipate a future physical transfer of care from a pediatric to an adult medical home, there are additional issues to consider. The adult health care provider should be a member of the transition team as the youth gets closer to the planning for the physical transfer.

The patient-centered medical home concept promotes good transition care and emphasizes the coordination of services. It is also consistent with the principles of chronic care management which also apply to transition care:

1. The use of defined plans and protocols;
2. Practice systems designed to meet the needs of individual patients (more time, broader array of services, and closer follow-up);
3. Systematic attention to meeting patient education needs and behaviors;
4. Ready access to necessary expertise; and
5. Effective information systems.

For more information on the chronic care model, please see the toolkit. Early results of the chronic care model are reported in the January/February 2009 issue of *Health Affairs*¹⁰.

Summary and Key Points

Professional organizations representing more than 330,000 physicians have agreed on patient-centered medical home principles and standards. There are tools and resources for practices to assess the quality of the care they deliver based on these Joint Principles of Patient Centered Medical Home. Those who qualify for certification by the National Committee for Quality Assurance (www.ncqa.org) as a recognized patient-centered medical home (PCMH) may receive additional reimbursement from some third party payors.

The patient-centered medical home approach promotes good transition care which requires:

- access and communication;
- patient tracking and registry functions;
- care management;
- patient self-management support;
- test tracking;
- referral tracking; and
- performance reporting and improvement.

Electronic prescribing and advanced electronic communication are not yet required at this time but are useful elements in the provision and success of care.

Collaboration is essential among primary and subspecialty providers, pediatric and adult health care providers, families and youth.

- It is helpful for the primary care provider to build ongoing relationships with specialists (and adult health care providers as needed in the case of pediatric providers).
- The primary care provider and sub-specialist share responsibility for effective exchange of information and communication.
- Changes to promote more effective transition care planning might include:
 - Delegation of some care coordination and transition care planning functions to non-physician staff;
 - Adaptations in the office processes to accommodate transition planning; and
 - Systematic attention to educational and behavioral needs of patients and their families related to transition knowledge and skills.

Appendix B provides guidance and recommendations for getting started with implementing transition services in the health care setting. Particularly useful for those practices currently providing family-centered medical home services, this guide provides ways to incorporate health care transition into your ongoing medical home activities.

Section 3

The Role of the Medical Provider

Transition will have different meanings and progress at different rates for each adolescent and family.

Health care providers play an important role not only in transition from pediatric to adult health care, but also in the related transitional issues of education, independent living, and employment. Whereas pediatric care has by nature been defined by dependency and parental control, adult-focused care requires growing self sufficiency and personal responsibility. Because of the complexity of their needs, YSHCN require support from professionals who are aware of and responsive to their medical, emotional and psychosocial needs.

Both pediatric and adult primary and sub-specialist health care providers should be cognizant of these challenges for the youth in transition and his or her family or caregiver. Transition will have different meanings and progress at different rates for each adolescent and family. It is important for health care providers to have a clear understanding of their roles and responsibilities in helping youth and families transition successfully.

The Role of Primary and Subspecialty Providers

The role of primary care and subspecialty providers will vary depending on their role in managing medical care and their relationship with the youth and family. Because transition is a dynamic process and dependent on multiple factors, transition planning works best with ongoing assessment of an individual youth's readiness and the assignment of roles and responsibilities associated with transition.

The multiple factors include the nature and severity of the health condition; the readiness of the youth, family and the health care provider; the youth's capacity for medical decision making and for management of her or his own daily needs; the family and psychosocial situation; whether there needs to be a physical transfer of the youth to another health care provider as part of the transition process; and the status of health insurance coverage.

The providers' roles may vary. It is essential for the physicians involved (pediatric and adult, primary and sub-specialists) to maintain clear, consistent communication and collaboration.

As mentioned earlier, clear, consistent communication and close collaboration are essential. Multiple surveys have emphasized the importance of discussing the priorities, needs and specific roles of all participants as the transition process unfolds. The readiness of the health care providers to communicate and collaborate together with the family and other providers is critical to achieving a successful transition.

With the advent of changes in information systems and exchange technology, it is imperative that health care providers use appropriate and multiple ways to allow access to information about visits, referrals, and tests for optimal continuous and coordinated care. A focused telephone call is one way to support timely, effective and personal communication. The portable medical summary is another tool to use to promote communication and access to patient information.

The Role of Care Coordination

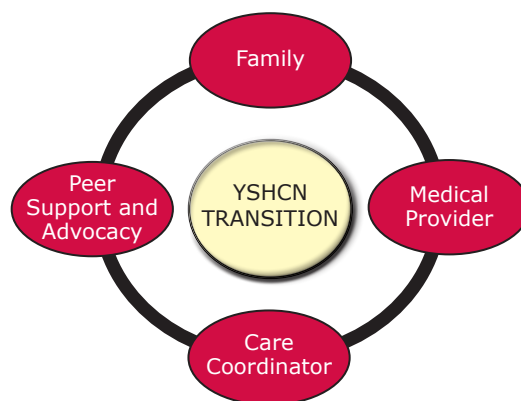
According to the Agency for Healthcare Research and Quality (AHRQ), care coordination is the “deliberate organization of patient care activities between two or more participants (including the patient) involved in the patient’s care to facilitate appropriate delivery of health care services.”¹¹

Care coordination can be implemented in varying ways based on the medical specialty, the amount of medical home responsibilities, the size of the practice, the patient and family-centered needs, and the available resources. Inherent in this concept is that youth and families will have seamless access to their health care providers in a way that is supported by the ongoing availability of a designated staff member who can facilitate a team approach to care.

Ideally, the youth in transition is supported by a team of stakeholders which includes the family, health care provider(s), care coordinator, community support agencies as needed, and the youth’s network of peers and advocates.

Practice-based care coordination can address transition care planning within the medical home and is designed to:

- Facilitate the provision of comprehensive health promotion, disease prevention, and chronic condition care;
- Ensure the development of ongoing, proactive transition and other care plans;



- Build effective communication strategies among family, the medical home, schools, specialists, allied health care providers, community professionals and agencies; and
- Help improve, monitor, and sustain quality outcomes and cost-effective care.

Potential benefits of practice-based care coordination that addresses transition care planning¹²:

Child/youth outcomes

- Enhanced self-management skills and self-esteem
- Increase in access to resources as they are needed
- Increased confidence in their physician and team of providers
- Decrease in ER visits, hospitalizations, & school absences

Care coordination can be customized to suit the size and type of medical practice and available resources to coordinate care of youth with special needs.

Family outcomes

- Improved satisfaction with team communication
- Decreased worry and frustration
- Increased sense of partnership with professionals

Staff satisfaction

- Improved communication and coordination of care
- Improved efficiency

- Elevated sense of responsibility and satisfaction in professional roles
- Minimized gaps and errors in care management

Improved systems outcomes

- Decreased fragmentation and duplication
- Better documentation and transmission of information
- Improved communication and coordination
- More cost-effective use of resources

Summary and Key Points

Transition proceeds at different rates for individuals and families depending on developmental readiness, medical complexity, adolescent and family characteristics, insurance coverage, and the readiness of the providers involved.

- Transition processes should be characterized by flexibility, continuity, and coordination.
- Fear and ambivalence often characterize health care transition and these feelings need to be addressed for all of the stakeholders involved in the process.
- Youth and families benefit from ongoing involvement and dialogue between referring and receiving providers. Pediatric and adult providers also have an opportunity for shared learning and improved professional satisfaction.
- Adolescents need the opportunity to take an active role and need ongoing encouragement.
- Families and providers should as much as possible remain positive, and help youth orient to the future.
- Though YSHCN with milder impairments may be more likely to transition earlier, they may have other challenges related to social isolation and mental health.

- Transition is more complex and challenging for those with more severe functional limitations, and may require more ongoing parental or guardian involvement.
- Youth should be able to describe the various roles and responsibilities of their providers.
- Youth should be able to describe the signs and symptoms requiring prompt medical attention and can do this using a wellness baseline tool.
- Youth should understand the relationship of their medical conditions to their individual sexuality and reproductive health issues and desires.
- Youth should be familiar with support organizations and resources in their community.

Additional information about the role of the physician can be found at www.hrtw.org/healthcare/doctors.html.

Section 4

Transition Planning Toolkit

Providing effective transition care for YSHCN depends on having an awareness of the need and a commitment to successful implementation. Success can be supported by systems, guides and tools that facilitate the process. There is as yet no evidence-based approach to transition planning. Many of these tools provide information to assist a health care provider with developing a transition plan specific to the individual health care needs of the adolescent with a view toward the youth's future goals.

This transition toolkit is offered knowing that, as with each adolescent's transition needs, “no one size fits all” to meet all of the varying needs and styles of primary and subspecialty providers in clinical practice. The tools are based on a comprehensive review of available resources and input from key informants that are most knowledgeable in the field of pediatric chronic care management in North Carolina and across the country.

The clinical tools selected for inclusion are organized around the six “critical first steps to ensure successful transitioning to adult-oriented care” identified by the joint AAP, AAFP, ACP-ASIM: Consensus Statement.¹³

The checklists and forms are included at the end of this manual.

- 1) Ensure that all young people with special health care needs have an identified health care professional who attends to the unique challenges of transition and assumes responsibility for current health care, care coordination, and future health planning.

Parents of infants and children find their way to medical care in a pediatric, family practice, or med-peds medical home. Patients and families receive consultation or subspecialty care through referral as needed and may use a shared management model of care. This shared management or co-management model is when the primary care and specialist define their roles and jointly manage the overall comprehensive care for the youth. This model often continues until the youth is 18 years of age, when youth begin to “age out” of pediatrics and/or face losing their medical coverage based on age limitations. At the appropriate time, it is a joint responsibility of the family, primary care, and sub-specialty provider to identify adult-care counterparts, and address whatever barriers there may be in completing the transition process.

Pediatric providers may need to advocate by calling an adult-care colleague to request a transfer of care.

The parent(s) or caregiver may have a primary care provider willing to accept the youth into their practice. This can provide a way for a parent to advocate for the growing child, and support a new sense of a shared medical home through a shared provider.

In other situations, pediatric-care providers may need to call an adult-care colleague to request a transfer of care, preferably a provider the pediatric care provider can have a comfortable working relationship with during the transition period. Primary responsibility for this function may be with either the general pediatrician or sub-specialist, based on shared decision-making with the youth and family. While there is no script or guide to accomplishing this step, it is incumbent upon us to find a way to make it happen, ideally without interruption. Meeting the care needs of emerging adults depends on it.

There are other examples of ways that the care management model is applied in practice. One is when the sub-specialist is the youth's medical home and only consults with the primary care provider for issues that the specialist needs assistance with (i.e., immunizations, school behavior or mental health issues). The other model is where the general pediatric provider provides all of the care and only periodically consults in a time limited manner with the specialist for assistance.

- 2) Identify the core knowledge and skills required to provide developmentally appropriate health care transition services (and make them part of training and certification requirements for primary care residents and physicians in practice).

Much of the essential knowledge has been summarized in the preceding sections, and builds on the preventive, health promotion, and disease-specific training that are the cornerstones of good medical care. The referring provider will have the benefit of an established physician-patient relationship, and therefore time to prepare for the transition-related needs in partnership with the youth, family, and/or caregivers. Transition is by nature a process that should evolve at the appropriate time and pace as determined by the parties involved.

For the referring pediatrician, there is an added step to transition that involves the physical transfer to an adult health care provider at a defined age limit. In order to ensure a smooth transfer at the appropriate age, the pediatric health care provider

should try to survey adult health care providers in the community to assess the availability and readiness of adult health care providers to take on new patients, particularly those with chronic and complex conditions.

Recommended Tools

- Practice readiness can be assessed by using the “Checklist for Transition: Core Knowledge & Skills for Pediatric Practices” developed by Healthy and Ready to Work, a national leadership organization in promoting healthy transitions. It provides a starting point to look at ways a referring provider can blend good transition care into standard practice.
- The “Provider Transition Checklist and Timeline” is a guide to the age ranges for which specific transition-related steps might be taken. These tools are included and can be accessed at www.hrtw.org/tools/pdfs/CP2SHC_Complans_transition_14-17.pdf and www.hrtw.org/tools/pdfs/CP3SHC_Complans_Transition_18-19-20.pdf
- The HRTW Transitions Changing Role for Youth and companion Changing Role for Families evaluate readiness by assessing health related knowledge and tasks that reflect their youth’s ability to manage their own care.
- The UNC T.R.A.N.S.I.T.I.O.N. Score™ for Adolescents and Young Adults is a health provider administered survey that takes no more than 10 minutes to complete. It is designed to help providers identify which area(s) of transition require education and to track each youth’s progress. It is an excellent tool to help assess transition readiness.

The transfer itself is by nature also an event, as the youth begins a new relationship with an adult practice and provider. This can be facilitated by the referring and accepting physicians having an initial phone conversation to introduce the youth to the adult provider. They may also want to consider shared care during the initial portion of the transfer process, such as alternating visits during the first six to twelve months. This can help reassure the youth and family while supporting optimal coordination and continuity.

The adult-care provider should remain aware of the significance of this change, and help the youth and family feel they truly have a new medical home. Depending on the complexity of care needs, it can be helpful to schedule regular extended visits

to thoroughly review the transferring medical information and allow the relationship to build at a pace that the youth feels is comfortable.

Below are some resources provided as guides to help pediatric health care providers with the transition process and transfer event.

The “Health Care Skills Checklist” and the “T.R.A.N.S.I.T.I.O.N. Score” are valuable tools to guide transition care for the receiving physician, and should be sent from the referring provider along with other appropriate medical information. These resources are equally valuable within a family or med-peds practice that will continue providing care for the youth. The same developmental issues and transfer to adult responsibilities need to occur.

- 3) Prepare and maintain an up-to-date medical summary that is portable and accessible.

The portable medical summary is one of the most valuable tools for everyone providing and receiving medical care. For the primary care provider, it is a useful at-a-glance reference for tracking the patient’s health status. For the sub-specialist, it serves as a reminder of the youth’s health issues outside his or her area of specialty. For the youth and family, it provides not only a reference but a level of assurance that, should the youth experience a medical need while away from home, a provider unfamiliar with the youth’s health issues can quickly assess the youth’s recent health history.

Each provider may have his or her own preference for which tool is most appropriate and how to prepare this, especially with the growing use of electronic medical records. Sample documents are included in the toolkit.

Recommended Tools

The “Transition Information Form” is a comprehensive medical summary designed for YSHCN that can be updated and modified as needed. The toolkit includes a blank form and completed sample. It is also important for youth and/or families to have a one-page portable medical summary to keep with them at all times.

Two options are included: a blank form from HRTW, and an Emergency Information Form jointly endorsed by the American College of Emergency Physicians and the American Academy of Pediatrics.

- 4) Create a written health care transition plan by age 14, together with the adolescent and family. At a minimum this should include what services need to be provided, who will provide them, and how they will be financed. This should be reviewed annually or whenever there is transfer of care.

This can be accomplished with thorough attention to the information addressed in the above forms, in conjunction with clear communication to define agreed-upon responsibilities and expectations with the youth and family.

Recommended Tools

The “Transition Action Care Plan” included in this section identifies responsibilities and time frame of areas to be addressed.

For those interested in building their own comprehensive care plan notebook, see “Build your Own Care Notebook” developed by Dr. Charles Onufer, director, Division of Specialized Care for Children at the University of Illinois at Chicago, available at www.medicalhomeinfo.org/tools/care_notebook.html.

- 5) Apply the same guidelines for primary and secondary preventive care for all adolescents and young adults, recognizing that youth with special health care needs may require more resources and services than do other young people to optimize their health.

Guidelines include the National Center for Education in Maternal and Child Health’s Bright Futures: Guidelines for Health Supervision of Infants, Children and Adolescents and the U.S. Public Health Services Guidelines to Clinical Preventive Services. There may be disease-specific guidelines for a particular condition for which references are available.

Recommended Tools

See <http://brightfutures.aap.org/index.html> and www.ahrq.gov/clinic/cps3dix.htm.

- 6) Ensure affordable, continuous health insurance coverage for all young people with special health care needs throughout adolescence and young adulthood. This should cover appropriate compensation for:
 - (1) health care transition planning, and
 - (2) care coordination for those who have complex chronic conditions.

This task is and will continue to be a major challenge. There are ways to optimize appropriate reimbursement for transition related care that will be addressed in the following section. Ensuring sufficient health care coverage for these youth will require political and systems-level change.

Recommended Tools

Additional information is available www.hrtw.org/healthcare/hlth_ins.html.

For a thorough review, one may reference “Access to Health Care: Health Insurance Considerations for Young Adults with Special Health Care Needs/Disabilities” by Patience White, MD from the 2002 Supplement to Pediatrics. The article is available online at <http://pediatrics.aappublications.org/cgi/reprint/110/6/S1/1328>.

Practice Improvement CME Activities

Refer to **Appendix C: Process for Awarding CME Credit for Practice Improvement (PI) Activities** for optional category 1 credit. For practices that wish to implement transition related activities, and utilize any of the tools listed above, review the criteria in Appendix C to determine which PI project would be most suitable for your needs.

Summary of CHAT Toolkit:

Checklist for Transition: Core Knowledge and Skills for Pediatric Practices (*practice self-assessment tool*)

Provider Transition Checklist and Timeline (youth to young adult guidelines)

Transitions – Changing Role for Youth (adapted from HRTW)

Transitions – Changing Role for Families (adapted from HRTW)

UNC-Chapel Hill T.R.A.N.S.I.T.I.O.N. Score™ for Adolescents and Young Adults

Transition Information Form (developed by the NY State Institute for Health Transition Training)

✓ Blank form

✓ Sample completed form

Sample portable health records

✓ HRTW form (blank)

✓ HRTW form (sample)

✓ Emergency Information Form for Children with Special Needs
(developed by AAP and ACEP)

Transition Action Care Plan

Section 5

Transition and Reimbursement Issues

The AAP, AAFP, and ACP Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs outlines the need for focused work on this issue. In this statement the need for seamless collaboration and communication among providers is emphasized. Challenges raised in this document include “advocating for improved health insurance coverage, and negotiating adequate compensation for services provided.” So, how does one provide coordinated, collaborative transition care in a system that is not yet designed to assure adequate reimbursement for these services? This document describes ways to use the currently reimbursed codes by most insurers to best accomplish this task.

Care planning may be done little by little in conjunction with the youth’s regular medical appointments, or the issue may require a dedicated appointment. If addressed as part of a routine medical visit, the provider can include history, physical exam components, and medical decision-making elements in the documentation, and use these to determine the level of evaluation and management (E/M) service. It is likely that addressing transitioning will require additional discussion and time. If the face-to-face counseling and/or care coordination part of the visit exceeds half of the total visit time, then time can be used to determine the level of visit (see chart below).

AVERAGE MINUTES (face-to-face or on unit)	NEW PATIENT OFFICE	ESTABLISHED PATIENT OFFICE	IN-PATIENT INITIAL	IN-PATIENT SUBSEQUENT
5		99211		
10	99201	99212		
15		99213		99231
20	99202			
25		99214		99232
30	99203		99221	
35				99233
40		99215		
45	99204			
50			99222	
60	99205			
70			99223	

Documentation should include the total length of time of the visit and a brief description of the issues addressed in counseling or care coordination. Because the activities required to successfully help youth with special health care needs transition care between providers largely involve counseling and care coordination, billing based on time is often the most appropriate way to receive reimbursement for this service.

When a pediatric provider refers a patient to an adult provider for the first time, the new provider can document and code for the initial visit using the E/M consultation codes, thus increasing the reimbursement for the initial visit and subsequent care if the consultation occurs as an inpatient. Overlapping care can allow for a smoother transition as well.

AVERAGE MINUTES (face-to-face or on unit)	OFFICE CONSULTATION	INPATIENT INITIAL CONSULTATION	INPATIENT FOLLOW-UP CONSULTATION
10			99261
15	99241		
20		99251	99262
30	99242		99263
35			
40	99243	99252	
55		99253	
60	99244		
80	99245	99254	

Another set of CPT codes that may be useful when billing for services related to transitioning care are the **prolonged services codes**. When the face-to-face time required to perform a visit is extended beyond what is typical, the provider can add these codes. This time need not be continuous. Add total number of minutes spent with the patient and/or family beyond what is expected for the level of visit (see charts above), and then use that additional minute value to choose the CPT codes to bill from the chart below. **These are added codes reported in addition to the E/M code for the level of visit.** You should document the reason for the prolonged services.

Billing based on time is often the most appropriate way to receive reimbursement for transition services.

OFFICE CARE		INPATIENT CARE	
Prolonged Service Minutes	Code	Prolonged Service Minutes	Code
< 30	Not reported separately	< 60	Not reported separately
30-74	99354	60	99356
75-104	99354 + 99355	61-90	99356 + 99357
105-134	99354 + 99355 x 2	91-120	99356 + 99357 x 2
135-164	99354 + 99355 x 3	121-150	99356 + 99357 x 3
165-194	99354 + 99355 x 4	151-180	99356 + 99357 x 4

Useful codes reimbursed by some insurers are the code series for **medical team conferences**. 99367 is used for a physician attending a medical interdisciplinary team conference without the patient and/or family present. If this type of conference is held with the patient and/or family, then the E/M codes can be used by the physician. 99366 is used for medical team conference participation by a non-physician qualified health care professional when the patient and/or family is present and 99368 is used when the patient and/or family is not present.

Other codes that hold promise for the future, but that are not yet reimbursed by most payors, include the prolonged codes for non face-to-face services (99358-9), care plan oversight services (99374-80), and the recently added telephone (99441-3) and on-line electronic (99444) medical evaluation codes. Advocacy efforts will continue to be important to assure providers can get reimbursement for providing care for the transitioning youth with special health care needs.

References regarding coding from programs around the country generally follow the above recommendations. A resource is www.medicalhomeinfo.org/tools/coding.html.

Section 6

Cultural and Linguistic Competence

Culture includes a wide range of experiences, beliefs, and practices that influence an individual's relationships and interactions with medical professionals and the health care system.

The **National Center for Cultural Competence** at Georgetown University Center for Child and Human Development provides six key reasons that cultural competence in health care is a priority:

- The perception of illness and disease and their causes varies by culture.
- Diverse belief systems exist related to health, healing and wellness.
- Culture influences help-seeking behaviors and attitudes toward providers.
- Individual preferences affect traditional and non-traditional approaches to health care.
- Patients must overcome personal experiences of biases within the health care system.
- Health care providers from culturally and linguistically diverse groups are underrepresented in the current health delivery system.

Cultural competence in the context of adolescents with special health care needs takes on an expanded definition. **Culture of disability** relates to the youth's particular disability (including cognitive function, motor skills, language and communication) and the disability community at large. The **culture of adolescence** relates to the developmental tasks of emerging adulthood. These are in addition to, and tend to overlay, the more traditional issues associated with the **culture of the family** related to values, beliefs, ethnicity, language and socioeconomic class.

For practitioners and their staffs, understanding these unique aspects of an individual patient's cultural composition can help achieve a mutually satisfying experience and health outcome.

Knowledge, Skills, & Abilities Essential to Culturally Effective Health Care¹⁴

The AAP believes the term “culturally effective pediatric care” is more inclusive than “cultural competence,” because it encompasses the values of competence but more importantly focuses on the positive outcomes of the physician-patient or physician-family

interaction. Culturally effective care can be defined as the delivery of care within the context of appropriate physician knowledge, understanding, and appreciation of all cultural distinctions leading to optimal health outcomes.

Knowledge

- Culture, history, traditions, values, and family systems of patients
- Impact of race/ethnicity on health status, behavior, attitudes, and values of patients
- Help-seeking behaviors of patients
- Roles of language, speech patterns, and communications styles of patient population
- Resources (e.g., agencies, persons, networks) that can be utilized on behalf of patients
- Recognition of the ways in which professional values may conflict with or accommodate the needs of patients

Skills

- Personal qualities that reflect genuineness, empathy, warmth, and capacity to respond to a range of possible situations
- Acceptance of racial/ethnic differences between and among people
- Understanding of personal values, stereotypes, and biases about one's own and others' race/ethnicity
- Techniques for learning and adapting to the personal and cultural patterns of patients and their impact on adherence to prescribed treatment regimens

Abilities

- Communicate accurate information on behalf of patients to their health plans.
- Discuss racial/ethnic differences and issues openly, and in response to culturally-based cues.
- Assess the meaning race/ethnicity has for individual patients.
- Interpret the implications of symptoms as they are expressed by individuals from different cultures.
- Work effectively with an interpreter to interview patients and provide health care.

- Evaluate new techniques, research, and knowledge to see if they are applicable in working with your patient population.
- Secure an appropriate level of adherence and/or cooperation with prescribed treatment regimens

Cultural and linguistic competence in the context of youth with special health care needs has even more significant meaning and importance. Competency in these areas can greatly improve the quality of the care that a youth with special health care needs receives from our health care system. Cultural and linguistic competency relates to appreciating the contributions and influence of the family home and traditions, ethnicity, language, socioeconomic class, the developmental tasks of adolescents, the youth's particular disability, and the disability community at large on the beliefs, attitudes, actions and values of each YSHCN.

Disability Tips¹⁵

- Make an effort to shake hands, even with those who may have restricted movement of the upper extremity.
- As the origin of the disability may be considered a personal issue, consider postponing inquiring about it until a therapeutic relationship is established.
- Before assisting an individual, ask permission and follow their guide or instruction.
- A wheelchair is an extension of the user's personal space. Treat it as such during the visit.
- As much as possible, speak at eye level and avoid seeming rushed or distracted.
- Be patient when an individual may take a longer time to answer a question or complete a task.
- Many with disabilities do not like or want excessive praise for accomplishing a normal task.
- Whenever possible, speak directly to the youth rather than to the accompanying adult or caregiver.
- If you do not understand what is being said, gently ask for clarification rather than pretending to understand or moving on to the next question.

- Speak calmly, slowly, in a normal volume, and directly in view for those who may have sight or hearing impairment.
- Be sensitive to your language (e.g., “non-ambulatory”, rather than “wheelchair bound”).
- Refer to the individual rather than the handicap. This is referred to as “people-first” (e.g., a person with a handicap, rather than a handicapped person).
- Do not consider the patient a victim or burden. Emphasize their positive qualities and roles as productive individuals with unique abilities.
- Don’t hesitate to ask them about their beliefs, cultural background, customs, or relationships as you would with any patient.

The Ten Tasks of Adolescents¹⁶

Social, cognitive and identity development of adolescents are areas that many health care providers are deliberately making some efforts to acknowledge and address, in order to assure better quality health care interactions with youth and families. Researchers and practitioners recognize that culture influences the youths’ ability to define themselves and their readiness to assume adult roles. The following tasks of adolescents can help us understand, be sensitive to, and advocate for the population of all youth, and especially youth with special needs.

1. Adjust to sexually maturing bodies and feelings.
2. Develop and apply abstract thinking skills.
3. Develop and apply a more complex level of perspective taking.
4. Develop and apply new coping skills in areas such as decision making, problem solving, and conflict resolution.
5. Identify meaningful moral standards, values, and belief systems.
6. Understand and express more complex emotional experiences.
7. Form friendships that are mutually close and supportive.
8. Establish key aspects of identity.
9. Meet the demands of increasingly mature roles and responsibilities.
10. Renegotiate relationships with adults in parenting roles.

Linguistic Competence

Linguistic competence is a component of cultural competence that emphasizes the cultural variations in verbal and nonverbal communication. According to the Maternal and Child Health Bureau, it represents the capacity of an organization and its staff to communicate effectively and to present information in a manner easily understood by diverse audiences, such as persons of limited English proficiency (LEP), those who are not literate or have low literacy skills, and individuals with disabilities.

Methods for providing culturally effective care include providing access to interpreter services, providing resources and materials in languages other than English, and addressing issues of health literacy. According to Healthy People 2010, health literacy is “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.” Addressing issues related to cultural and linguistic competence may include the use of:

- Bilingual/bicultural staff
- Assistive technology devices
- Sign language interpretation services
- Translation of confidentiality, patient rights statements and health materials
- Cultural brokers (have knowledge of a community/culture’s strengths and needs; act as liaisons to help bridge gaps in information dissemination)

Cultural Communication with Providers: What N.C. YSHCN are saying

In an effort to understand the communication preferences of YSHCN when working with their medical providers, we spoke with them directly. The CHAT youth initiative, led by Alliance of Disability Advocates-Centers for Independent Living, arranged focus groups of YSHCN across the state. The youth not only provided valuable input for the youth-based transition manual, they also responded to questions about how they wanted their doctors to communicate with them.

Top Ten List from North Carolina CHAT Youth Initiative¹⁷

- 1.** Focus on the problem at hand rather than focusing on personal questions.
- 2.** Compare and contrast alternative treatments and therapies for both emotional and medical issues.
- 3.** Explore and offer low- or no-cost alternatives.
- 4.** Offer options when possible.
- 5.** Give clear and concise answers to all questions.
- 6.** Provide a one-stop shop (*medical home approach*).
- 7.** Ask the youth, not the parent or companion.
- 8.** Ask, rather than tell, the youth.
- 9.** Be willing to be open to discussion.
- 10.** Don't underestimate patients across the disability community.

In closing...

Youth with special health care needs are one of many groups who deserve focused attention from a health care system that has struggled to find its voice in providing for our most vulnerable populations. We hope this effort will contribute in a meaningful way to help address the needs of at least one of these.

On behalf of youth, families, and care providers throughout North Carolina, thank you for your consideration of this practicum. We will have accomplished our goal if it increases both your willingness and ability to provide high quality care, not only for youth with special needs, but for all your patients as you strive to grow your medical home.

Our special thanks to the following individuals who gave of their time and energy in support of this medical practicum:

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CHAT Medical Provider Project Director

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Family Medicine
CHAT Medical Practicum Director

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- 15 Excerpted from Care of Patients with Disabilities: An Important and Often Ignored Aspect of Family Medicine Teaching, Sweetey Jain, MD, FAM Med 2006; 38(1):13-5.
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- 17 Carolina Health and Transition (CHAT) Project, Youth Project, compiled by Caroline Ambrose, Alliance for Disability Advocates – Center for Independent Living, Raleigh, NC

Appendix A

CME Presentation and Post-Test

"Where Have All The Children Gone?"

Health Care Transition for Youth with Special Health Care Needs



**“Where Have All The Children Gone?”
Health Care Transition for
Youth with Special Health Care Needs:
Making in Happen**

Adrian Sandler MD
Olson Huff Center - Mission Children’s Hospital
INTERNAL MEDICINE CONFERENCE
August 23, 2007 - Asheville NC

**500,000 US Children with
Special Health Care Needs
turn 18 every year**

Newacheck & Taylor (1994)

Who are CYSHCN?

“Children and youth with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”

CYSHCN

9.4 million (13%) <18 www.cshcndata.org
Includes children and youth in Title V and those on SSI

Title V CYSHCN: 963,634 (0-18*)

NC-CYSHCN : 59,422

SSI: 1,036,990 (0-17) **NC - 36,739**
386,360 (13-17) **NC - 13,875**

SOURCE: SSA, Children Receiving SSI, December 2005

SOURCE: Title V Block Grant FY 2006 Application

* Most State Title V CSHCN Programs end at age 18

Who are youth with special health care needs?

Condition	Incidence Per 1000	Survival rate to 21
• ADD/ADHD	50	normal
• Asthma	20	98%
• Mild mental retardation	20	normal
• Mod/severe Mental retardation	10	?
• Autism & other PDD	5	?
• Congenital Heart Disease (CHD)	5	50%
• All inborn errors of metabolism	3	?
• Hydrocephalus	3	(90% to 10 years)
• Cerebral palsy	2	near normal
• Hearing impairment	2	normal
• Down syndrome	1	normal
• Epilepsy	1	(90% to 10 years)
• Neural tube defects	0.7	80%

Developmental Tasks of Adolescence and Young Adulthood... Are CYSHCN prepared?

- Separate from parents
- Develop a healthy self-image
- Set & achieve education & vocational goals
- Financial independence
- Independent living
- Marriage – Partnership
- Participate in community life
- Be happy – intact mental health



John G. Reiss, PhD

Youth with Special Health Care Needs (YSHCN): A disadvantaged group

- 90% of YSHCN reach their 21st birthday
- 45% of YSHCN lack access to a physician familiar with their health condition
- 30% of all youth 18-24 years of age lack a payment source for health care
- 40% YSHCN use ER annually (vs 25% of 'typical' youth)
- YSHCN experience increased school interruptions

Inter-related Aspects of Transition

- **Health Care**
Health promotion and preventive care
Specialized care
Prevention of secondary disability
- **School to Work**
Education
Vocational readiness
Career choice
- **Dependency to Independence**
Housing
Adaptive living skills
Budgeting

Health Care Transition: A Definition

- The purposeful, planned and timely transition from child- and family-centered pediatric health care to patient-centered adult-oriented health care
- A process, not a single event
- Changing doctors and/or changing relationships
- Individualization: one size does not fit all
- Contributes to assuming adult roles and functions (along with social and educational transitions)

Transition from child-centered to adult health-care systems for adolescent with chronic conditions. A position paper of the Society for Adolescent Medicine. J Adolesc Health. 1993; 14:570-576

The Goal of Health Care Transition

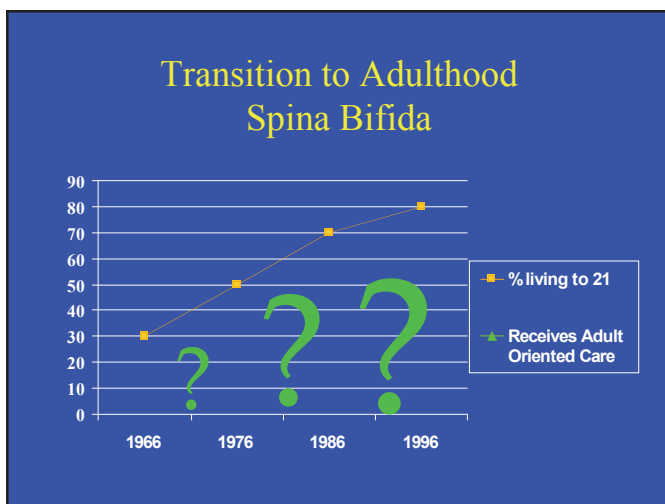
Maximize lifelong functioning and potential through the provision of high quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood.

AAP, AAFP, ACP-ASIM: Consensus statement on health care transition for young adults with special health care needs. Pediatrics 2002;110:1304-6

Health Care Transitions for YSHCN... “a journey without a clear destination”

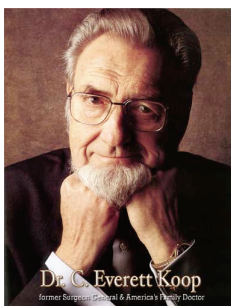
- Consensus Statement
- Where we’ve been...a historical perspective
- Barriers to health care transition
- Access to care and insurance considerations
- Risks and benefits of transition
- Primary care and subspecialty care strategies
- Action items...making it happen





HCT: Where we've been (1980s)

- 1984 Minnesota conference
- 1989 Conference "Growing Up and Getting Medical Care"
 - C. Everett Koop
 - Recommendations regarding provision of services, financing of care, training, research



HCT: where we've been (1990s)

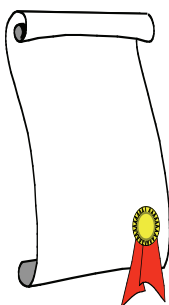
- 1999 ICHP conference "Transition Revolution"
- Development of transition components/resources
 - Identifying some training needs
 - Most efforts condition- or subspecialty-specific
- Limited health services research
 - Most young adults find their own way
 - Those with more severe conditions are at more risk
- Position papers and committee reports
 - Society for Adolescent Medicine, AAP, AMA
 - Cystic Fibrosis Foundation
 - Moving On (MCHB, 1992)

The Consensus Statement

- Frank Lloyd Wright's Wingspread, Racine WI, September, 2001
- MCHB, AAP, Johnson Foundation
- Robert W. Blum MD, Chairperson
- 38 individuals crafted a national policy statement
- Approved by AAP, AAFP, ACP-ASIM

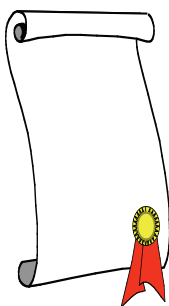


Consensus statement (AAP, AAFP, ACP-ASIM): Critical first steps



- All youth with SHCN have identified health care professional who attends to unique challenges of transition
- Identify core knowledge/skills, make them part of training/certification
- Prepare and maintain portable, accessible medical summary
- Create written HC transition plan by age 14; review and update annually

Consensus Statement: Critical first steps (continued)

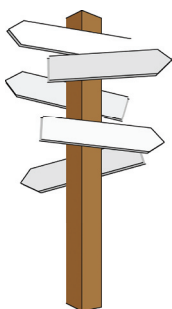


- Apply same guidelines for primary and preventive care for all adolescents and young adults (e.g., GAPS, Bright Futures, US PH Guidelines)
- Ensure affordable continuous health insurance coverage throughout adolescence and adulthood, to cover health care transition planning and care coordination

Where we should be going: Healthy People 2010 MCHB's 10-year agenda

- “All youth with SHCN will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work and independence.”
 - insure youth participate as decision-makers
 - insure all have medical homes responsive to needs
 - use Title V to facilitate development of transition systems
 - provide accessible, affordable health insurance

HCT: So where are we?



- Survey of States regarding MCHB Healthy and Ready To Work (HRTW) initiative
 - www.mchbhrtw.org
- Focus groups and qualitative studies with youth, families, providers
 - Institute for Child Health Policy
 - Reiss J, Gibson R. Pediatrics 2002, 110:1307-1314
- A local perspective

CSHCN National Survey National Performance on Transition

Only 6% of YSHCN Meet National Goal

Survey Questions:

- Teens receive guidance and support in the transition to adult health care
- Teens receive vocational and career training to prepare for adult job

See: <http://cshcnleaders.ichp.edu/triregionals2003/draft-agenda.htm>

Where are we?...a local perspective



- College students with ADHD see developmental pediatricians
- Young adults with CP lose insurance and access to care
- Youth with spina bifida are not getting out, working and “doin’ stuff”
- Disabled young women can’t find OBGYN care
- Lack of primary care prevention of secondary disabilities

Barriers to health care transition

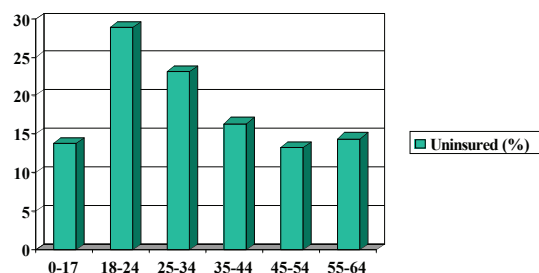
- Difficulty terminating pediatric care
- Adult-oriented care not readily available
 - training issues
 - lack of referral networks
 - lack of coordinated adult system of care
 - new relationships difficult, “cold,” unsuitable
 - lack of availability of ancillary supports/services
- Lack of funding
- Loss of insurance coverage

Youth with disabilities: insurance

- 52% of disabled employed (compared with 80% without disabilities)
- 67% of Americans without disabilities obtain health insurance from employer
- Parents’ or public insurance ends around 19-23 years of age
- Complex maze of state, federal and private insurance plans with changing eligibility
- All 18 year olds on SSI undergo redetermination: 30% lose SSI and often lose Medicaid

Percentage of population under 65 who are uninsured (by age)

Source: GAO. Analysis of March 2000 survey.
Washington DC: General Accounting Office, 2000



“We never can say goodbye...” The challenge of terminating pediatric care

- Pediatric providers’ distrust of adult providers
- No training in termination, saying “goodbye”
- Family-centered versus patient-centered care
- Getting parents to step back
- Lack of youth/family preparation for dealing with the adult medical system

Medical Issues in Adults

- | | |
|--------------------------|------------------------|
| • PAP smears | • Mitral regurgitation |
| • Mammograms | • Menorrhagia |
| • Colon cancer screening | • Smoking cessation |
| • Menopause | • Anorexia |
| • Pulmonary embolism | • Thyroid disorders |
| • Hypertension | • Deafness |
| • Type II Diabetes | • Obesity |
| • Osteoporosis | • Anemia |
| • Stress incontinence | • Sleep disturbance |
| • Glaucoma | • Decubitus ulcers |
| | • GERD |

Survey of Clients in Adult Training Centers (MR
Diagnosis) – Case Western Reserve; Shari Robins MD

Health benefits of transition

- Adult-oriented primary and preventive care
 - screen and treat adult health problems
 - sexuality, fertility, reproductive health, substance abuse
 - orientation to work and independent living
 - promotes responsibility, self-care, decision-making
- Adult-oriented specialty care
 - knowledge/experience of chronic conditions in adults
 - access to adult inpatient services and subspecialists
 - promotes adherence with therapeutic regimens

Health risks of transition

- Adult providers lack interest/experience with “pediatric” disease, e.g., Congenital heart disease
- Lack of continuity of care
- Lack of comprehensive care and supports
- Lack of individualization of care
- Expertise of youth/family not recognized
- Specialty services not readily accessible
- Loss of personal relationship > poor compliance
- Bouncing back to pediatric care in health care crisis

Psychosocial benefits of transition

- Promotes normal social and emotional development
- Promotes competence and independence
- Contributes towards independent living
- Supports long-term planning and life goals
- Broadens system of interpersonal support
- Gives parents great satisfaction to see their child become a young adult, reason to celebrate
- Gives family a sense of security “after we’ve gone”

Psychosocial risks of transition

- Transfer experienced as punishment/rejection
- Loss of formal and informal supports
- Loss of chronic illness peer group
- Facing realities of increasing morbidity/mortality
- Youth feel overwhelmed with new responsibilities for decisions, monitoring, self-care, self-advocacy
- Parents feel alienated from health care arena

Benefits of Transition to Pediatricians and Pediatric Facilities

- Practice within area of training and interest
- Consistent with organization's mission & focus
- Make room for new patients
- Transfer of time-consuming "problem patients"
- Reduce number of uninsured patients
- Satisfaction of promoting a desirable process

Benefits of Transition to Adult Physicians & Facilities

- Practice in a new area
- Responsive to a significant need
- Consistent with mission of Family Practice and Med-Peds/Internal Medicine
- Consistent with facility mission & focus
- Expanded patient base
- Clinical research opportunities

Clash of Cultures?



Culture of Pediatric Health Care



- Multidisciplinary
- Psychosocial support
- Developmental
- Family-focused
- Flexible
- Warm, optimistic
- Informal and relaxed
- Partnerships with parents

Culture of Adult Health Care



- Emerging multidisciplinary model
- Few psychosocial supports
- Business-like, formal
- Patient-centered
- Strong focus on disease process
- Insistence on compliance
- Procedure and lab-based
- Requires patient to be autonomous and to function independently

Models of Transition of Care

from Scal et al. J Adolesc Health 1999;24:259-264

- Survey of 126 programs:
 - Condition-specific, e.g., CF, spina bifida (62%)
 - Subspecialty service, e.g., pulmonology, cardiology, gastroenterology, rheumatology
 - Adolescent health services team
 - Community disability teams (UK and Europe)
 - Primary care models
 - few exist but great potential
 - comprehensive health promotion (GAPS)
 - disease and disability prevention
 - Transition primary care first, then subspecialty care?

Successful primary care models

(Scal, 2002)

- Survey of 36 nominated primary care providers
 - 10/13 included in analysis (8 peds, 1 FP, 1 med-ped)
 - Clinical need was point of awareness or entry
 - Self-care and reproductive health most imp issues
 - Key to process was individualized care, not protocol
 - “We’re alert for transition issues at each clinic visit”
 - Main barriers cited:
 - difficulty identifying adult PCPs and other training gaps
 - adolescent and family resistance
 - lack of institutional support
 - lack of time for care coordination activities

Promising Transition Practices in the Clinic

- Start HCT process at the time of diagnosis
 - Be explicit about eventual transfer of care
 - Celebrate every transition to independence
- Teach/reteach about health condition
- Promote independence and problem solving
 - Always involve child in medical encounter
 - Assign child medical self-care tasks
 - Involve child in medical decision making
 - Be future focused - plan and be flexible
- Instill positive health habits before age 12

Promising Transition Practices

- Focus on Participation: having a life/doin' stuff
 - What do you want to do when you grow up?
 - How can I help you get to do that?
- Anticipate changes: use adaptive planning/motivational interviewing
 - What challenges/goals in the next five years?
- Use life maps, see <http://chs.state.ky.us/commissionkids/transition.htm>
- Have youth create/keep a medical journal
- Negotiate and renegotiate the relationships among physician, family, and patient

Promising Transition Practices

- Negotiate specifics of desired ongoing pediatric involvement with patient, family, and adult providers, e.g., pediatrician...
 - Gets reports on medical care & health status
 - Is consulted by adult provider about medical advances & changes in treatment plan
 - Is available to youth and/or family as “friend of the family”

Promising Transition Practices

- Build relationships among providers
 - Bruce Kelly MD and Irene Jurczyk - Carolina Health and Transitions (CHAT) Project
- Transition primary care first and develop referral process from pediatric to adult primary care (Family Med/Med-Peds/Internal Med)
- Adapt the Medical Home model to adult health care
- Transfer patient when
 - Patient is medically and psychologically stable
 - External stressors are minimal

Systems Change to Promote HCT

- Develop health care transition policies and procedures
- Create framework of institutional support
- Develop transition plans by age 14
 - What services need to be provided?
 - Who will provide them?
 - How they will be financed?
 - Review/update annually and when there is a transfer of care
 - Link to school IEP or 504 plan
- Promote pediatric-adult provider meetings
- Build relationships and networks
- Develop curricula
- Monitor & measure transition practices
- Health services research urgently needed
 - study of “leavers” of child health insurance system
 - case studies exemplifying problems of youth with SCHN

Transition Tools for Youth and Families

- ‘Get Ready to Manage Your Health Care’
<http://www.fpg.unc.edu/~ncodh/Data/Articles/ManageHealthCare.html>
- Autonomy Checklist
http://www.spannj.org/Family2Family/adolescent_autonomy_checklist.htm
- Health Care Skills Autonomy Checklist
http://www.minnesotaschoolnurses.org/Health_Care_Skills.pdf



Transition Tools for Youth and Families

- Adolescent Health Transition Website
<http://www.depts.washington.edu/healthtr>
- Internet Resource for Special Children
<http://www.irsc.org>
- Healthy and Ready to Work <http://www.hrtw.org>
(great list of tools/checklists)
- Disability <http://www.disabilityinfo.org>

Transition Tools for Youth and Families

- Family Voices – <http://www.familyvoices.org>
- Assistive Technology – <http://www.abledata.org>
- *Life Maps* - 0-12 months; 13-35 months; 6-10 yrs; 11-13 yrs; 14-16 yrs; 17-21; short form –
<http://www.chs.ky.gov/commissionkids/transition.htm>

Transition Tools for Providers: Care Plans

- *Transition Summary*
<http://depts.washington.edu/transmet/The%20process/summary.htm>

Shriners Hospital – Two page summary designed to provide a succinct summary of care, current health status, including listing health care providers, current medications & therapies, equipment and supply needs, functional capabilities, and future
http://www.hrtw.org/tools/check_care.html

Medical Home Learning Collaborative & NICHQ
<http://www.medicalhomeimprovement.org/assets/pdf/Compre.pdf>

Transition Tools - Provider

❑ *Emergency Preparedness for CSHCN information -*
<http://www.aap.org/advocacy/emergprep.htm>

❑ *Emergency Form*
<http://www.aap.org/advocacy/blankform.pdf>

❑ *Child Health Note on Transition*
http://www.medicalhome.org/leadership/chn_topics_sa.cfm

Transition Tools - Provider

❑ *AHTP website*
<http://www.depts.washington.edu/healthtr>

- Transition Resource Notebook
- Transition Timelines
- Health History Summary
- Adolescent Autonomy Checklist
- Resources Section

Other Resources

Health Care Transition Web Site
<http://hctransitions.ichp.edu>

Pediatrics – Supplement to Dec 2002

Healthy and Ready to Work National Center
<http://www.hrtw.org/>



Case 1

- A 25 year old female with profound MR, CP, blind, scoliosis, who lives at home with her aging parents, is admitted to the pediatric ward with pneumonia and seizures
 - She has a primary care pediatrician and has been seen sporadically by peds ortho and neuro
 - What can and should be done to help transition care?

Case 2

- Your 19 year old patient with spina bifida, who has long been followed in a pediatric spina bifida clinic, is soon to start part-time at the community college. She has a history of attention problems/LD and anxiety.
 - What should be done to facilitate her HCT?

Case 3

- A 15 year old boy with severe Tourette, ADHD and OCD comes in to see his developmental pediatrician for ongoing subspecialty care.
 - He can't remember his PC pediatrician's name
 - Complex regimen of Luvox, clonidine, risperidone and atomoxetine
 - He tells you cigarettes are helping his tics
 - What can you do for his HCT?

Case 4

- A 7 year old boy with thoracic spina bifida comes in to his pediatrician with his mother because he has a small sore where he sits.
 - He is in diapers and his mother does clean intermittent catheterization 3 times a day
 - What can be done to sow the seeds for future health care transition and independence?

Where Have All the Children Gone?
Reaching Consensus in Health Care Transition for Youth with Special Health Care Needs

Adrian Sandler, MD
Director, Olson Huff Development Center
Mission Children's Hospital
Asheville, NC

Post Test

1. ☐ True ☐ False 90% of YSHCN reach their 21st birthday.
2. ☐ True ☐ False 45% of YSHCN lack access to a physician familiar with their health condition.
3. ☐ True ☐ False 40% of YSHCN use ER annually (vs. 25% of “typical” youth).
4. ☐ True ☐ False YSHCN do not experience increased school interruptions.
5. ☐ True ☐ False 500,000 children in the U.S. with special health care needs turn 18 each year.
6. ☐ True ☐ False Transition of YSHCN involves changing doctors and relationships.
7. ☐ True ☐ False Transition of YSHCN contributes to the youth assuming adult roles and responsibilities.
8. ☐ True ☐ False Transition of YSHCN is purposeful, planned and timely.
9. ☐ True ☐ False Transition of YSCHN is an event.
10. ☐ True ☐ False Pediatricians often find it difficult to terminate care for YSHCN.
11. ☐ True ☐ False Adult providers are readily available and prepared for care of YSHCN.
12. ☐ True ☐ False Lack of funding can be a barrier to health care transition.
13. ☐ True ☐ False Loss of insurance can sometimes impede transition to adult care.
14. ☐ True ☐ False Most adult providers are familiar with caring for young adults with congenital disease.
15. ☐ True ☐ False Specialty services for YSHCN are readily available within the adult care setting.
16. ☐ True ☐ False YSHCN will often bounce back to pediatric provider in a health care crisis.
17. ☐ True ☐ False Focused transition promotes normal social and emotional development.
18. ☐ True ☐ False Self-care and reproductive health have been cited as important issues for YSHCN transitioning to adult care.
19. ☐ True ☐ False Following a fixed protocol is more important to successful transition than individualized planning.
20. ☐ True ☐ False Pediatricians should be explicit about the eventual transfer of care for children and YSHCN.
21. ☐ True ☐ False Children and youth should not be involved in the medical encounter or medical decisions.
22. ☐ True ☐ False Positive health habits should be instilled in youth before the age of 12.
23. ☐ True ☐ False The Consensus Statement recommends maintaining a portable, accessible medical summary.
24. ☐ True ☐ False The Consensus Statement recommends creating a written healthcare transition plan by age 14, to be reviewed and updated annually.
25. ☐ True ☐ False 60% of YSHCN meet the national goal for receiving provider guidance and support in the transition to adult health care.

Accreditation

The Mountain Area Health Education Center (MAHEC) is accredited by the North Carolina Medical Society to sponsor continuing education for physicians.

Credit

The Mountain Area Health Education Center designates this enduring material educational activity for a maximum of 1.0 AMA PRA *Category 1 Credit(s)*™. Physicians should only claim credit commensurate with the extent of their participation in the activity.

Disclosure Statement

MAHEC adheres to the ACCME Standards regarding industry support to continuing medical education. This activity was developed with the support of the NC Department of Public Health, Office on Disability and Health. No commercial support was received, and the activity is free of industry influence. As noted in the speaker introduction, Dr. Adrian Sandler has no industry relationships or conflicts of interest to disclose.

Award of Credit

Physicians are eligible for 1.0 AMA Physicians Recognition Award Category 1 Credit™ upon completion and submission of the following post-activity test and activity evaluation form. Non-physicians are eligible for a Certificate of Participation in this CME activity, following the same guidelines for completion and submission of the required forms. Test scores must be 70 or higher for award of certificates. You may mail or fax the completed forms to:

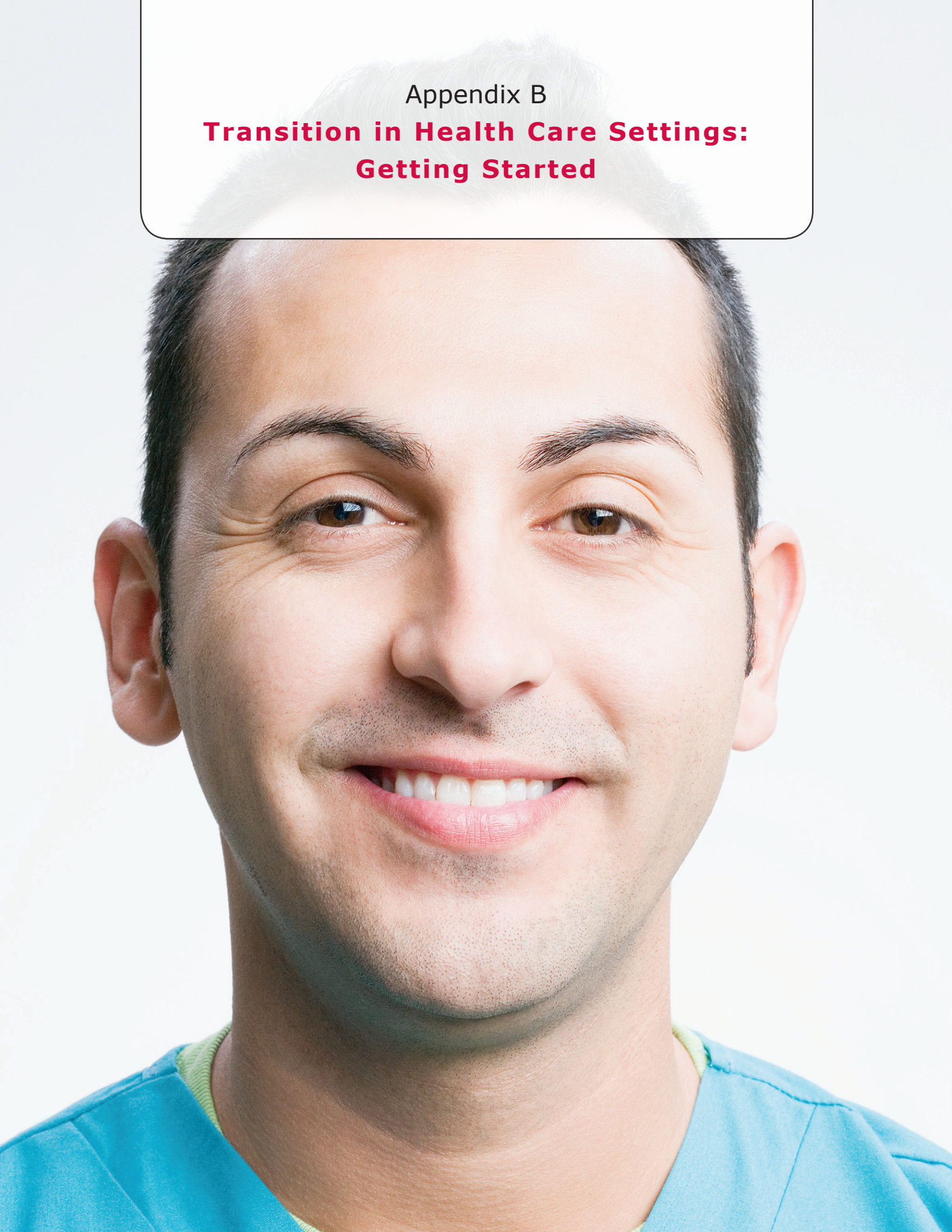
Dina Gillespie, Sr. Administrative Assistant
Mountain Area Health Education Center
501 Biltmore Avenue
Asheville, NC 28801
Fax: 828-257-4713

If you have questions regarding the transmittal of these documents, please contact by email dina.gillespie@mahec.net. Please contact the project director, Irene Jurczyk, with questions or comments regarding the content of this activity, phone 828-257-4790 or email irene.jurczyk@mahec.net. Thank you for your participation.

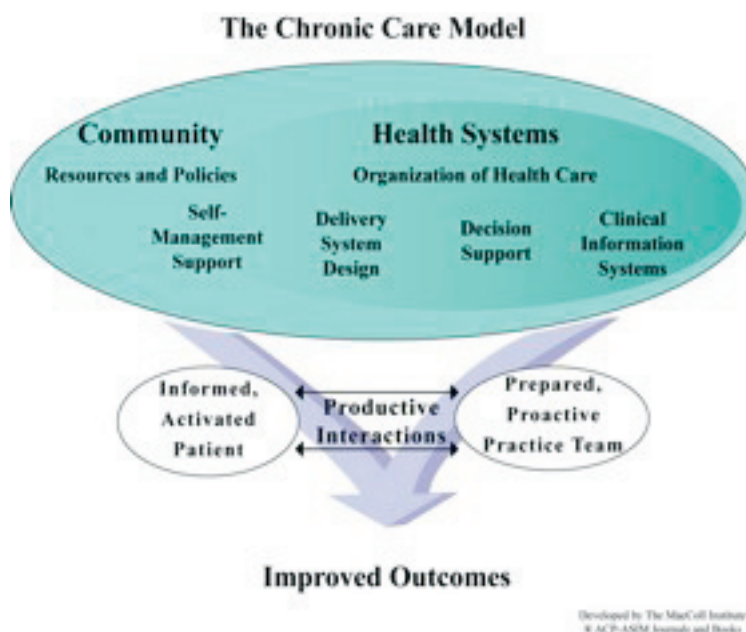
NAME: _____ CREDENTIAL: _____
PRACTICE/MEDICAL SPECIALTY: _____
COUNTY: _____ LAST 4 DIGITS SS# _____
ADDRESS: _____
CITY: _____ STATE: _____ ZIP: _____
PHONE: _____ FAX: _____ EMAIL: _____

Appendix B

**Transition in Health Care Settings:
Getting Started**



Transition in Health Care Settings: Getting Started



Frequently Asked Questions

So how do we take the chronic care model and apply it to implementing health care transition in the clinical setting?

How can we successfully implement transition services and demonstrate positive and effective outcomes?

How can we apply practice improvement principles and implement health care transition tools that are both cost-effective and time-efficient?

The ability to successfully guide the transition process in the health care setting is not as daunting as it may appear. Various approaches to implementing health care transition can range from adopting a policy about transition and informing patients about the policy, to engaging in active dialogue with youth and their families about the process of transition and follow-through with the adult specialist and provider. Whatever procedures are determined to be the best approach, some key things can assist you in beginning to implement transition:

7 Steps to “Get Started with Transition”

- Identify a transition champion.
- Create a transition policy.
- Determine timing and level of services that will be provided.
- Develop the Transition Plan and establish goals.
- Communicate with the transition team.
- Collaborate/coordinate transfer with adult health care providers.
- Select tools and resources to support health care transition process.

Step 1 Identify a Transition Program Champion within Your Practice

The primary responsibility of the **program champion** is to become an authority on the program and to serve as the primary coordinator in the planning and integration of transition policies and practices. This person will champion the principles of transition and serve as an advocate for adopting these strategies within the practice. Leadership is an extremely important function of the program champion, because successful adoption of the program depends on having someone who can effectively communicate the goals of the program and who is empowered to take action.

Once the management has agreed to implement health care transition in the clinic setting, the next step is to determine the amount of resources available and recommended levels of involvement from other members of the clinic staff. Program leaders should work with management to determine which aspects of the program can be feasibly implemented, while taking into consideration existing supports and services.

Step 2 Create a Transition Policy

SAMPLE DRAFT Policy re: Upper Limit of Age for CHP care

“In keeping with the recommendations of the American Academy of Pediatrics, the physicians of Chapel Hill Pediatrics, P.A. will provide care for children and adolescents through the age of 21. After that time, regular medical care, including checkups, should

be established and continued with a physician for adults. Chapel Hill Pediatrics is happy to provide care until the transfer to an adult physician has been accomplished, and will try to assist in locating a new medical home for each patient.”

Step 3 Determine Timing and Levels of Services

Developmental Timeline

Transition typically refers to the process of preparation for shifting care from the pediatric primary care physician to the adult specialty care physician. The process of preparing the YSHCN can start as early as 12, although the actual age of the planning process may vary based on readiness and availability. The ultimate outcome of the transition process is the transfer of care from the pediatrician to the adult care provider.

**Transition must
start early.**

*Health and Ready
to Work National
Resource Center*

The transfer itself is by nature also an “event” as the youth begins a new relationship with an adult practice and provider. This can be facilitated by the referring and accepting physicians having an initial phone conversation to introduce the youth to the adult provider. They may also want to consider shared care during the initial portion of the transfer process, such as alternating visits during the first six to twelve months. This can help reassure the youth and family while supporting optimal coordination and continuity.

The adult provider should remain aware of the significance of this change, and help the youth and family feel they truly have a new medical home. Depending on the complexity of care needs, it can be helpful to schedule regular extended visits to thoroughly review the transferring medical information and allow the relationship to build at a pace that the youth feels in comfortable.

Levels of Services

- 1) **Anticipatory Transition Services** – for youth between the ages of 12 and 15 years. This is a continuous, dynamic, developmentally-based process with services aimed at educating youth about their chronic conditions and promoting gradual independence, informed decision making and successful navigation of resources and

support systems. Transition education and planning can be part of each regular health care visit or provided through chronic condition management visits. Preparation for transfer to adult provider(s) will be anticipated.

- 2) **Intensive Transition Services** – for youth ages of 17-21 and older. This process requires a focused assessment, medical history and record review, with development of a comprehensive plan to provide education around any gaps in knowledge and skills about a specific chronic condition and other topics, such as health insurance, in preparation for the transfer to the adult provider. This process may extend over 6-18 months.

Step 4 Transition Planning: Establishing Goals

Often forgotten, one of the most important goals of developing a health care transition plan for YSHCN is youth participation. Without the ability to engage the youth and have them actively participate in decision making processes about their future, the support systems we put in place will have limited effectiveness. For health care transition, the best results are achieved when medical professionals work in partnership with the youth and families and empower them to make the best choices for their future.

Phases of transition planning:

1. Preparation
2. Readiness
3. Assessment
4. Integration/Transfer

Understanding the barriers and benefits of the successful health care transition process can give us insight into how to prepare youth to progress through the process.

Step 5 The Transition Team: An Integrated System of Support

Beyond the Core: Expanding the Transition Team

While the core transition team is generally defined by the youth, family and the health care provider, others can also play a key role in supporting the transition process. For example, other individuals/organizations who may be involved in the care management of the youth with special health care needs include:

- Specialty providers (e.g., tertiary medical center staff)
- School nurses (including school-based health centers)
- Community-based health workers
- Hospital personnel
- Physical therapists
- Behavioral health specialists
- Nutritionist

The members of the care management and transition team will depend upon the nature and complexity of the disabilities. Clearly, there will be some variability in the level of participation for members of the extended team. However, recognizing the value that each of these brings to the effort can be of enormous benefit to smooth and seamless transition planning and transfer of care.

Step 6 Transfer of Care: Coordination between Primary Care and Specialty Care Providers

As previously noted, it is essential for the physicians involved to maintain clear, consistent communication and coordination with each other. This takes on added significance in a medical arena that involves a breadth of physician care unlike any other in the practice of medicine. The transition of youth involves pediatric and adult primary care, often pediatric and adult sub-specialists, inpatient and hospital-based physician care, as well as an array of ancillary providers. With the advent of changes in information systems and exchange, it is imperative that each provider share their knowledge and documentation with all who need it. A focused telephone call remains a valuable tool in supporting timely, effective and personal communication.

Given the multiple issues involved in the transition and transfer process, pediatric and primary care providers may require additional support systems to adequately accomplish these goals. One method of coordinating the services and supports that are needed is to work with care coordinators. Within this role, care coordinators can be instrumental in planning and implementing transition related services within the health care organization.

Another approach is for the pediatric and adult provider to co-manage care during the transition process. An example of co-management would be to alternate well visits between the pediatric and adult provider.

The following steps are provided as recommendations for strategies that can support positive outcomes for the transition process.

Recommended Steps for the Pediatric Provider

- Encourage parents to discuss with their own adult health care provider the possibility of receiving their youth into their practice.
- Identify adult care providers in your local area/state/region who have the skills and interest in becoming a partner, and are accepting patients in their practice.
- Identify youth who are of transition age and start preparing them early for the transfer event.
- Develop a transfer plan for working with the adult care provider.

Recommended Steps for the Adult Provider

- After receiving a call from the referring pediatric provider, ask office staff to alert you when transfer information is received.
- Let the scheduler know the new patient will require an extended first visit.
- Have practice coder review prolonged service codes included in Chapter 5 of this manual.
- Review materials the referring provider sends.
- Call referring pediatrician with any questions pre- and post-initial patient/family visit.

Appendix C

Process for Awarding CME Credit for Practice Improvement Activities



Appendix C

PROCESS FOR AWARDING CME CREDIT FOR PRACTICE IMPROVEMENT ACTIVITIES

OVERVIEW:

The Mountain Area Health Education Department of CME (MAHEC/CME) can award AMA PRA category 1 CME (Cat. 1) credit for practice improvement (PI) activities (PI-CME). In so doing we must ensure compliance with all standards for such activities as prescribed by the AMA and the ACCME (the accrediting body for providers of CME). MAHEC is accredited by the North Carolina Medical Society to sponsor continuing medical education. We have established an oversight mechanism that ensures:

- Compliance with all standards for AMA PRA category 1 activities
- Content integrity of the selected performance measures
- Clear instructions to the learner that define the educational process of the PI activity (documentation, timelines, etc.) and establish the mechanism for the learner to apply for such credit
- Validates the depth of physician involvement by a review of submitted PI activity documentation
- Provides adequate background information and resources to guide physicians in PI activities including the evidence-base for selecting the measures to be impacted by the PI activity

Physicians may apply for activities that address “any facet (structure, process, or outcome) of the practice of medicine with direct implications for patient care. The measures selected guide the physician in choosing a practice improvement and evaluating its efficacy must be EVIDENCE-BASED and well designed.” (American Medical Association)

The following is an excerpt from “Standards for Designating Performance Improvement Activities for AMA PRA Category 1 Credit” (American Medical Association):

Providers must ensure that participating physicians integrate all three stages described below to develop a complete, structured performance improvement activity:

Stage A: Learning from current practice performance assessment

Assess current practice using identified performance measures, either through chart reviews or some other appropriate mechanism. Participating physicians should be actively involved in data collection and analysis.

Examples of Stage A practice improvement projects relevant to transitioning youth with special health needs from pediatric to adult providers:

- **Review of transition medical curriculum and completion of self-assessment tools** (i.e. Cultural Competence Indicators and Medical Home readiness in your practice).
- **Review of sample patient charts to determine measures** (e.g. % or numbers of patients who are adolescents with special needs, estimation of types of special needs and health challenges projected from sample).
- **Review current policy manual and other practice guidelines** to measure the level of sensitivity and/or awareness of patients with special health care needs served by the practice.

Stage B: Learning from the application of performance improvement to patient care

Implement an intervention based on the performance measures selected in Stage A, using suitable tracking tools (e.g., flow sheets). Participating physicians should receive guidance on appropriate parameters for applying an intervention and assessing performance change, specific to the performance measure and the physician's patient base (e.g., how many patients with a given condition, seen for how long, will produce a valid assessment?).

Examples of Stage B activities include:

- **Pilot of medical curriculum**, with youth and family curricula completed, and transition of at least one patient with special needs from pediatric to adult care.

For the pediatrician, the activities will include:

- introducing the topic of transition
- utilizing the medical provider toolkit materials
- providing the youth and family members with their respective curricula
- asking youth and family to complete their workbooks to assess transition readiness
- assisting parents in identifying an appropriate adult provider
- consulting with the adult provider to assure smooth transition

For the adult provider, the activities will include:

- consulting with the pediatric provider, youth and family
- reviewing the health record and establishing line of communication for follow-up, if needed, with pediatric consult
- reviewing youth/family workbooks, getting acquainted
- accepting the new patient into the practice with a view toward family- and patient-centered (medical home) service delivery

- **Based on sample survey of charts in Stage A, conduct staff training on readying children and youth with special needs for transition to adult care.** Begin process of noting in charts those with special needs who will need orientation and toolkit/ training materials for youth and family. Documentation of training and staff evaluation of training required; documentation of process, including who is responsible for what activities, number of charts noted, training materials for youth and family distributed, etc., also required.
- **Implementation of cultural competence training for practice providers and support staff**
Documentation of training timeline, resources used (film, journal articles, online education modules, etc.) and staff evaluation of training required. Patient/family evaluation of provider's cultural competence strongly recommended.
- **Implementation of key elements of the Medical Home Model** into the practice - You must identify clearly what elements of the medical home you will implement, the timeline for implementation, who will be responsible for which tasks, and how you will measure program effectiveness (e.g. referrals, establish relationships with key community partners, develop a policy and procedures manual that incorporates formal transition process into the practice).

Stage C: Learning from the evaluation of the performance improvement effort

Reevaluate and reflect on performance in practice (Stage B,) by comparing to the assessment done in Stage A. Summarize any practice, process and/or outcome changes that resulted from conducting the PI activity.

Assigning Credit:

Physicians may be awarded incremental AMA PRA category 1 credit for completing each successive stage of a performance improvement activity.

Incremental credit for PI activities should be awarded as follows:

- Five (5) AMA PRA category 1 credits can be awarded for the completion of each of the three Stages (A, B and C). Completion of the full PI cycle is not required.
- Provider may design PI activities so that physicians can enter at any of the three Stages. Providers that do so must design a mechanism by which physicians who enter after Stage A can document their review of work completed for previous stage(s). Credit will only be awarded for those stages in which the physician was an active participant.
- Physicians completing, in sequence, all three Stages (A-C) of a structured PI activity may receive an additional five (5) Category 1 credits, for a maximum of twenty (20) AMA PRA category 1 credits. This credit allocation acknowledges the best learning associated with completing a well conceived PI activity.
- You will receive a confirmation of receipt and affirmation that the specified PI activities qualify for category 1 Credit. Credit for Stage B and Stage C will be awarded upon completion and approval of both stages. (Allow approximately 3 weeks).

MECHANISM:

At the time a physician wishes to initiate a potential practice improvement activity he/she should contact the MAHEC Department of Continuing Medical Education Program Office. The contact may be made by telephone to Irene Jurczyk, Assoc. CME Director (828-257-4490) or by email to Irene.Jurczyk@mahec.net. A visit to your practice to meet with you may be required in order to ensure your activity is eligible for category 1 credit. At that time the activity will be discussed in concept so that requirements for Category 1 credit can be adhered to and work to date documented. For instance, what is the evidence base to validate the measures you will use and how will you obtain these measures. Also at that time anticipated resources arranged by the MAHEC CME Program Office (if any) can be clarified. Potential resources include:

- PI activity design and consultation, including assistance with accessing MAHEC Health Sciences Library services (www.mahec.net);
- Assessment of completion of each stage for participating physician and filing of documentation of completion
- Awarding of credit at completion of each stage of the activity
- Entry and maintenance of CME Cat. 1 credit records into AHEC CASCE system and EEDs system.

The fee to be paid for any PI activity will be determined based on the number of hours of credit awarded, the number of physicians participating and the resources required. At a minimum, MAHEC will assess a \$15 per credit hour for the 15 credit hours of activity for Stages A, B and C. An additional five hours of credit is given at no charge for completion of all three stages.

If extensive administrative, consulting or research support is required to implement or complete the project, these costs will be factored separately and paid in addition to the minimum activity fee. (The MAHEC CME program office will provide individual physicians and group practices estimated fees for a particular PI activity in advance of initiating the project.)

After review and approval of data obtained in *Stages A and B*, a certificate for 5 hours of Category 1 CME credit is issued. Brief verbal or written progress reports will be requested approximately halfway through Stage B and again when Stage B is complete. Following review and approval of *Stage C*, a certificate for 5 hours of Category CME credit will be issued, or 10 hours if all three stage were completed in sequence.

At NO TIME should data identifiable to a specific patient be cited as a part of this credit application. Staff from the MAHEC CME Program Office are available to advise regarding practice-based learning and completion of the documentation.

- The application must be legibly written or typed.
- THE APPLICATION MUST BE COMPLETED BY THE PHYSICIAN.
- Payment of fees as agreed upon at the initial contact should be enclosed at each stage of the application process.

STAGE A – CURRENT PRACTICE PERFORMANCE ASSESSMENT

Name: _____

Last four digits of SSN: _____

Address: _____

APPLICATION FOR PRACTICE IMPROVEMENT CREDIT:

Assess your current practice using identified performance measures, either through chart reviews or some other appropriate mechanism. Participating physicians should be actively involved in data collection and analysis. (Attach additional pages and documentation as needed.)

1. Describe your current patient management process/procedures.

2. Describe your current outcomes, i.e. performance measures.

Please return to:
Mountain Area Health Education Center
Department of CME Program Office
501 Biltmore Avenue
Asheville, NC 28801

You will receive a confirmation of receipt and affirmation that the specified PI activities qualify for category 1 Credit. Credit will be awarded upon approval. (Allow approximately 3 weeks). A visit to your practice to meet with you may be required in order to ensure this activity is eligible for category 1 credit.

STAGE B – THE APPLICATION OF PERFORMANCE IMPROVEMENT TO PATIENT CARE

Name: _____

Last four digits of SSN: _____

Address: _____

APPLICATION FOR PRACTICE IMPROVEMENT CREDIT:

Brief verbal or written progress reports will be requested approximately halfway through Stage B and again when Stage B is complete.

- 1) After review of data from the practice, I will embark upon activities (processes or practices) aimed at improving: (Utilize additional pages if necessary to describe why each area for improvement is indicated)

- 2) Please describe the specific practice or process to be undertaken (or modified) aimed at achieving the improvement(s) described above and include an estimated time line for completion—(Utilize additional pages if necessary)

- 3) Describe the desired outcome of this activity.

- 4) If you have them now, please enclose copies of policies, procedures, clinical tools, chart forms, and so forth that would support this application for credit.

- 5) Do you anticipate you will need help with this practice improvement activity? If so, please describe?

- 6) Please describe your role in this activity. (In order to qualify for category 1 credit your role must be direct and substantial).

Please return to:
Mountain Area Health Education Center
Department of CME Program Office
501 Biltmore Avenue
Asheville, NC 28801

APPLICATION FOR CATEGORY 1 CME CREDIT FOR PRACTICE IMPROVEMENT ACTIVITIES:

- 1) After reviewing the data from *Stage B*, I determined that the following outcomes resulted after the PI activities:
(describe outcomes below)

- 2) The following activities seemed to be effective in contributing to the desired outcome:

- 3) Please describe briefly the obstacles encountered in implementing these activities:

- 4) Were there any unexpected beneficial outcomes for your patients, your practice, or you personally? If so, please describe:

Please return to:
Mountain Area Health Education Center
Department of CME Program Office
501 Biltmore Avenue
Asheville, NC 28801

Appendix D

Medical Provider Toolkit



Medical Provider Toolkit

Contents

1. Core Knowledge and Skills for Pediatric Practices
2. Provider Transition Checklist and Timelines
3. Changing Role for Youth
4. Changing Role for Families
5. UNC STARx self-assessment tool
6. T.R.A.N.S.I.T.I.O.N. Scale provider-administered
7. Transition Information Form (completed sample)
8. HRTW Health Record Form
9. Emergency Information for Children with Special Needs
10. Transition Action Care Plan



www.hrtw.org

CHECKLIST FOR TRANSITION: CORE KNOWLEDGE & SKILLS FOR PEDIATRIC PRACTICES

POLICY STATEMENT - A Consensus Statement on Health Care Transitions for Young Adults With Special Health Care Needs (PEDIATRICS Vol. 110 No. 6 December 2002, pp. 1304-1306)
<http://aappolicy.aappublications.org/cgi/content/full/pediatrics;110/6/S1/1304>

This checklist addresses one of the critical first steps to ensuring successful transitioning to adult-oriented health care: the need for core knowledge and skills required to provide developmentally appropriate health care transition services to young people with special health care needs.

The HRTW National Resource Center believes these skills apply to all youth with and without a diagnosis.

Core Knowledge & Skills Checklist for Practices

POLICY	YES	NO
1. Dedicated staff position coordinates transition activities		
2. Office forms are developed to support transition processes		
3. CPT coding is used to maximize reimbursement for transition services		
4. Legal health care decision making is discussed prior to youth turning 18		
5. Prior to age 18, youth sign assent forms for treatments, whenever possible		
6. Transition policy states age youth should no longer see a pediatrician is posted.		
MEDICAL HOME		
1. Practice provides care coordination for youth with complex conditions		
2. Practice creates an individualized health transition plan before age 14		
3. Practice refers youth to specific family or internal medicine physicians		
4. Practice provides support and confers with adult providers post transfer		
5. Practice actively recruits adult primary care /specialty providers for referral		
FAMILY/YOUTH INVOLVEMENT		
1. Practice discusses transition after diagnosis, and planning with families/youth begins before age 10		
2. Practice provides educational packet or handouts on transition		
3. Youth participate in shared care management and self care (call for appt/ Rx refills)		
4. Practice assists families/youth to develop an emergency plan (health crisis and weather or other environmental disasters)		
5. Practice assists youth/family in creating a portable medical summary		
6. Practice assists with planning for school and/or work accommodations		
7. Practice assists with medical documentation for program eligibility (SSI, VR, College)		
8. Practice refers family/youth to resources that support skill-building: mentoring, camps, recreation, activities of daily living, volunteer/ paid work experiences		
HEALTH CARE INSURANCE		
1. Practice is knowledgeable about state mandated and other insurance benefits for youth after age 18		
2. Practice provides medical documentation when needed to maintain benefits		
SCREENING		
1. Exams include routine screening for risk taking and prevention of secondary disabilities		
2. Practice teaches youth lifelong preventive care, how to identify health baseline and report problems early; youth know wellness routines, diet/exercise, etc.		

The HRTW National Resource Center is headquartered at the Maine State Title V CSHN Program and is funded through a cooperative agreement (U39MC06899-01-00) from the Integrated Services Branch, Division of Services for Children with Special Health Needs (DSCSHN) in the Federal Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA), Department of Health and Human Services (DHHS). Activities are coordinated through the Center for Self-Determination, Health and Policy at the Maine Support Network. The Center enjoys working partnerships with the Shriners Hospitals for Children and the KY Commission for CSHCN.

The opinions expressed herein do not necessarily reflect the policy or position nor imply official endorsement of the funding agency or working partnership

Name: _____

Provider Transition Checklist and Timeline

Checklist Instructions: The timeline provided here can be modified as developmentally appropriate for your adolescent patient. Use your clinical judgment as to which items apply to your patient. Refer to content-specific sections of this booklet for further information about these points.

HEALTH CARE	Ages 11-13	Ages 14-16	Ages 17-19	Ages 20-22
Meet privately with the adolescent for part of the office visit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Encourage the adolescent to assume increasing responsibility for his/her health care management				
<ul style="list-style-type: none"> Assure the adolescent understand his/her health condition and medications Send copies of reports, letters and tests to the adolescent and family 	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/>
Provide anticipatory guidance				
<ul style="list-style-type: none"> Nutrition and fitness Sexuality and relationships Substance abuse and smoking 	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Assess the adolescent's and the family's readiness for transfer to an adult health care provider				
<ul style="list-style-type: none"> Initiate discussion about transfer to an adult health care provider Identify possible adult care providers Encourage patient to meet and interview adult providers Initiate communication with the adult provider that the family has selected 		<input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Implement the transfer to an adult primary care provider				
<ul style="list-style-type: none"> Transfer medical records Discuss nuances of care with the adult provider Follow-up after the transfer 			<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Assess the adolescent's ability to make independent decisions regarding health care, finances and other adult concerns for determining whether there is a need for guardianship/conservatorship				
<ul style="list-style-type: none"> Initiate referral for assessment of competence if needed Provide medical documentation Follow-up on the process with the family 			<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

Children's Special Health Care Services Transition Timeline for Youth and Families

Age 14-16

According to developmental ability youth can begin to:

- Develop knowledge of their special health care needs
- Take responsibility in making appointments and getting prescriptions refilled
- Explore appropriate work and volunteer opportunities
- Talk to medical providers about age appropriate information such as, physical, emotional, and sexual development

According to their child's needs, parents can begin to:

- Make arrangements for the steps above if child is unable to be independent
- Keep a health record for youth. Include all medical paperwork
- Explore options of transition planning through the local school district
- Explore the eventual need to transfer your child's care to adult providers

Transition to Adult Services

Age 16-18

According to developmental ability youth can begin to:

- Take responsibility in making appointments and getting prescriptions refilled
- Contact Michigan Rehabilitative Services (MRS) to explore vocational assistance if needed
- Attend all meetings where future plans are discussed (school IEPs or doctor's office)
- Research adult health care providers for transfer of medical care
- Explore employment opportunities
- Explore living arrangements

According to their child's needs, parents can begin to:

- Make arrangements for the steps above if child is unable to be independent
- Explore options for health care coverage
- Check eligibility for SSI from the Social Security Administration
- Research adult health care providers for transfer of medical care
- Explore the option of legal guardianship or the many alternatives to guardianship if child's special needs interfere with the ability to make financial and medical decisions

Transition to Adult Services

Age 18-20

According to developmental ability young adult can begin to:

- Complete a CSHCS financial assessment. At age 18 only young adult's income is reviewed
- Take responsibility for signing all CSHCS materials
- Finalize health care coverage as an adult
- Transfer medical care from pediatric providers to adult providers
- Check eligibility for SSI from the Social Security Administration
- Contact Michigan Rehabilitative Services (MRS) to explore vocational assistance if needed
- Contact the disability student services office if attending college and accommodations are needed
- Explore employment opportunities

According to their child's needs, parents can begin to:

- Make arrangements for the steps above, if young adult is unable to be independent
- Complete and submit a release of information signed by young adult if parent/caregiver would like to participate in their care
- Provide documentation of legal guardianship to all providers if needed

Transition to Adult Services

Age 20-21

According to developmental ability young adult can begin to:

- Explore living arrangements. If assistance is needed contact the nearest Center for Independent Living
- Learn about and continue to investigate adult services there may be need for
- Investigate possibility of enrolling in a Medicaid Health Plan at 21 if currently enrolled in Medicaid
- Transfer all medical care from pediatric providers to adult providers
- Explore employment opportunities

According to their child's needs, parents can begin to:

- Make arrangements for the steps above, if young adult is unable to be independent
- Complete and submit a release of information signed by young adult if parent/caregiver would like to participate in their care
- Explore private duty nursing options if young adult is receiving in-home nursing. Young adult must qualify for and enroll in an adult Medicaid waiver program to continue nursing services as of age 21

Transition to Adult Services



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Transitions - Changing Role for Youth

Health & Wellness 101 The Basics	Yes, I do this	I want to do this	I need to learn how	Someone else will have to do this - Who?
1. I understand my health care needs, and disability and can explain my needs to others.				
2. I can explain to others how our family's customs and beliefs might affect health care decisions and medical treatments.				
3. I carry my health insurance card everyday				
4. I know my health and wellness baseline (pulse, respiration rate, elimination habits)				
5. I track my own appointments and prescription refills expiration dates				
5. I call for my own doctor appointments				
7. Before a doctor's appointment I prepare written questions to ask.				
8. I know I have an option see my doctor by myself.				
9. I call in my own prescriptions				
10. I carry my important health information with me everyday (i.e.: medical summary, including medical diagnosis, list of medications, allergy info., doctor's numbers, drug store number, etc.)				
11. I have a part in filing my medical records and receipts at home				
12. I pay my co-pays for medical visits				
13. I co-sign the "permission for medical treatment" form (with or without signature stamp, or can direct others to do so)				
14. I know my symptoms that need quick medical attention.				
15. I know what to do in case I have they have a medical emergency				
16. I help monitor my medical equipment so it's in good working condition (daily and routine maintenance)				
17. My family and I have a plan so I can keep my healthcare insurance after I turn 18.				



www.hrtw.org

Transitions - Changing Role for Families

Health & Wellness 101 The Basics	Yes, my child/ youth can do this	I want my child/ youth to do this	I need to learn how to teach my child/ youth	Someone else will have to do this for my child/youth Who?
1. My child/youth understands his/her health care needs, and disability and can explain needs to others.				
2. My child/youth can explain to others how our family's customs and beliefs might affect health care decisions and medical treatments.				
3. My child/youth carries his/her health insurance card with him/her				
4. My child/youth knows his/her health and wellness baseline (pulse, respiration rate, elimination habits)				
5. My child/youth tracks appointments and prescription refills expiration dates				
6. My child/youth call to make his/her own doctor appointments				
7. Before a doctor's appointment my child/youth prepares written questions to ask.				
8. My child/youth is prepared to see the Doctor by him/her self.				
9. My child/youth orders his/her own prescriptions				
10. My child/youth carries his/her important health information everyday (i.e.: medical summary, including medical diagnosis, list of medications, allergy info., doctor's / drug store numbers, etc.)				
11. My child/youth helps file medical records and receipts at home				
12. My child/youth pays co-pays for his/her medical visits				
13. My child/youth co-signs the "permission for medical treatment form" (with or without signature stamp, or can direct others to do so)				
14. My child/youth knows his/her symptoms that need quick medical attention.				
15. My child/youth knows what to do if they have a medical emergency				
16. My child/youth knows how to monitor medical equipment so it's in good working condition (daily and routine maintenance)				
17. My child/youth and I have discussed a plan so they will continue to have insurance after they turn 18.				

STARx Questionnaire



THE UNIVERSITY
of **NORTH CAROLINA**
at **CHAPEL HILL**

SMOOTH TRANSITION TO ADULTHOOD RX

Section 1 Directions:

- **How often have you done the following things?**
- **Please check the one that shows how often you did each thing in the past 3 months**

	Never	Almost Never	Sometimes	Almost Always	Always
1. How often did you make an effort to understand what your doctor told you?					
2. How often did you take your medicines on your own?					
3. How often did you ask your doctor or nurse questions about your illness, medicines or medical care?					
4. How often did you make your own appointments?					
5. How often did you need someone to remind you to take your medicines?					
6. How often did you use things like pillboxes, schedules, or alarm clocks to help you take your medicines when you were supposed to?					
7. How often did you use the internet, books or other guides to find out more about your illness?					
8. How often did you forget to take your medicines?					
9. How often did you work with your doctor to take care of new health problems that came up?					

Section 2 Directions:

- **Some patients know a lot about their health and some patients don't.**
- **How much do you know?**
- **Please check the answer that describes you most.**

	Not Much	A Little	Some	A Lot	
--	-------------	----------	------	-------	--

10. How much do you know about your illness?

11. How much do you know about taking care of your illness?

12. How much do you know about what will happen if you don't take your medicines?

Section 3 Directions:

- **Some patients may find it hard to do certain things.**
- **How easy or hard is it for you to do the following things?**
- **Please check the answer that best describes how you feel**

	Very Hard	Somewhat Hard	Somewhat Easy	Ver y Eas y	
--	--------------	------------------	------------------	----------------------	--

13. How easy or hard is it to talk to your doctor?

14. How easy or hard is it to make a plan with your doctor to care for your health?

15. How easy or hard is it to see your doctor by yourself?

16. How easy or hard is it to take your medicines like you are supposed to?

17. How easy or hard is it to take care of yourself?

18. How easy or hard do you think it will be to move from pediatric to adult care?

Patient Name				Date	
Medical Record #		Transition ID		Institution	

UNC TR_xANSITION Scale™ for Adolescents and Young Adults:

Instructions: Read the question to the patient, and circle the choice on the right that best describes the patient's response. Sum the scores for each section in the "Subtotal" row. Not all questions may be applicable to each patient. Divide the subtotal by the number of applicable questions in each section to obtain the "Proportion".

Type of chronic health condition		Yes	Somewhat	No
1	Can you tell me the name of your health condition?	1.0	0.5	0.0
2	Can you describe symptoms of your health condition?	1.0	0.5	0.0
3	Can you tell me how this condition may affect your health in the future?	1.0	0.5	0.0
Sum the scores for this section		Subtotal T		_____ out of 3
Divide the subtotal by the number of applicable questions		Proportion T		

R _x : Medications		>90% Correct	51-90 % correct	<50% correct
4	Can you tell me the names of the medicines, vitamins, and/or supplements you are supposed to be taking?	1.0	0.5	0.0
[If possible, write meds in advance and circle them as the patient names them]				

5	Can you tell me when you are supposed to take [name each medication, vitamin, and supplement patient should be taking]?	1.0	0.5	0.0
6	Can you tell me why you are taking [name each medication, vitamin, and supplement patient should be taking]?	1.0	0.5	0.0
7	Can you tell me what could happen to you if you stopped taking [name each medication, vitamin, and supplement patient should be taking]?	1.0	0.5	0.0
Sum the scores for this section		Subtotal R _x		_____ out of 4
Divide the subtotal by the number of applicable questions		Proportion R _x		

Created under the direction of Dr. Maria Ferris with assistance from Kristi Bickford, Dr. Carol Ford, Caroline Jennette, Dr. Susan Hogan, Donna Harward, Nicole Fenton, Bradley Layton, Lynn McCoy, James O'Neill, Robert Imperial, the UNC adolescent patients, the interdisciplinary transition team & Teresa Edwards from the Odum Institute.

Funding: The UNC Kidney Center, Center for Education Research and Therapeutics, and K.B. Reynolds Charitable Trust. Version 12_18_09

Adherence

		Yes	Sometimes	No
8	In a typical week, do you usually miss a full day of medicine, either because you forgot to take it or didn't want to take it?	0.0	0.5	1.0
9	Do you usually have trouble remembering to take your medicines every day?	0.0	0.5	1.0
10	Do you usually come to your doctor appointments when they are scheduled?	1.0	0.5	0.0
Sum the scores for this section		Subtotal A	_____ out of 3	
Divide the subtotal by the number of applicable questions		Proportion A		

Nutrition

		Yes	Somewhat	No	
11	Do you know how to read nutrition labels on food or drinks to see if they are healthy choices?	1.0	0.5	0.0	
12	Do you know if there is any special diet you are supposed to follow because of your health condition?	1.0	0.5	0.0	
13	[if the patient is on a special diet] Can you name specific examples of the foods or drinks that you should not have?	1.0	0.5	0.0	N/A
Sum the scores for this section		Subtotal N	_____ out of (2 or 3)		
Divide the subtotal by the number of applicable questions		Proportion N			

Self-management skills

		Yes	Sometimes	No
14	Do you usually remember to take your medicines on your own?	1.0	0.5	0.0
15	Does someone usually have to remind you to take your medicines?	0.0	0.5	1.0
16	Do you usually call in your prescription refills yourself?	1.0	0.5	0.0

Created under the direction of Dr. Maria Ferris with assistance from Kristi Bickford, Dr. Carol Ford, Caroline Jennette, Dr. Susan Hogan, Donna Harward, Nicole Fenton, Bradley Layton, Lynn McCoy, James O'Neill, Robert Imperial, the UNC adolescent patients, the interdisciplinary transition team & Teresa Edwards from the Odum Institute.

Funding: The UNC Kidney Center, Center for Education Research and Therapeutics, and K.B. Reynolds Charitable Trust. Version 12_18_09

17	Do you usually pick-up refills from the pharmacy yourself?	1.0	0.5	0.0	
18	Do you yourself usually call or email your doctor when you have a question or need to speak with him/her?	1.0	0.5	0.0	
19	Do you usually make your own doctor appointments?	1.0	0.5	0.0	
20	<i>[if the patient has medical procedures to perform]</i> Do you usually perform your medical procedures yourself (catheterization, insulin shots, etc?)	1.0	0.5	0.0	N/A
Sum the scores for this section		Subtotal S	__ out of (6 or 7)		
Divide the subtotal by the number of applicable questions		Proportion S			

Note: Some patients may be too young for the following questions to be appropriate. Score these patients as 0's, as these are important skills not yet obtained.

Issues of reproduction		Knows full answer	Knows answer	Doesn't know answer	
21	Would your health condition likely affect your ability to: <i>[if female]</i> become pregnant? <i>[if male]</i> get someone pregnant?	1.0	0.5	0.0	
22	<i>[Females only]</i> Do you know if your health condition would get worse if you got pregnant?	1.0	0.5	0.0	N/A
23	<i>[Females only]</i> Would any of your medicines be harmful to an unborn baby if you become pregnant?	1.0	0.5	0.0	N/A
24	Can you tell me ways sexually active people protect themselves from unwanted pregnancy or sexually transmitted diseases?	1.0	0.5	0.0	
Sum the scores for this section		Subtotal I Male Female	____ out of 2 ____ out of 4		
Divide the subtotal by the number of applicable questions		Proportion I			

Trade / School

		Yes	Has some idea	No
25	Can you tell me about your future plans in regards to school and/or a job?	1.0	0.5	0.0
26	Can you tell me how your current health insurance status will change after you graduate from high school?	1.0	0.5	0.0
Sum the scores for this section		Subtotal T	_____ out of 2	
Divide the subtotal by the number of applicable questions		Proportion T		

Insurance

		Yes	Somewhat	No	
27	Can you tell me why it is important to have health insurance?	1.0	0.5	0.0	
28	Can you tell me the name of your current health insurance provider?	1.0	0.5	0.0	
29	[If he/she is currently insured] Can you tell me at what age your current health insurance coverage will end?	1.0	0.5	0.0	N/A
30	Can you tell me how you can get health insurance for yourself when you are an adult?	1.0	0.5	0.0	
Sum the scores for this section		Subtotal I	_____ out of (3 or 4)		
Divide the subtotal by the number of applicable questions		Proportion I			

Ongoing support

		Yes	Has some idea	No
31	When you are an adult, who will manage your health condition, for example help you remember to take your medicines, call in prescription refills, pick up meds from pharmacy, and make doctor appointments?	1.0	0.5	0.0
Sum the scores for this section		Subtotal 0	_____ out of 1	

New health care providers

		Yes	Has some idea	No
32	Can you tell me how you would find a new doctor if you needed one?	1.0	0.5	0.0
33	Can you tell me how you could transfer your medical records from one doctor to another?	1.0	0.5	0.0
Sum the scores for this section		Subtotal N	_____ out of 2	
Divide the subtotal by the number of applicable questions		Proportion N		

Raw total score	Sum all section subtotals here (max 33)	
T.R_xA.N.S.I.T.I.O.N Score™	Sum all section proportions, or divide the raw total score by the total number of eligible questions (max 10)	

<http://unckidneycenter.org/hcprofessionals/transition.html>

Carolina Health and Transition (CHAT) TRANSITION INFORMATION FORM

	Date Form Completed _____ By Whom _____	Revised _____ Revised _____	Initials: _____ Initials: _____
Name: Jane Doe	Date of Birth: 1/25/87		
Home Address: 123 Maple Lane Anytown, USA 12345	Home Phone: 123-456-7890		
	Work Phone: 234-567-8901		
Health Care Guardian: <u>X</u> (N/A)	Health Care Guardian Phone:		
Signature/consent:	Emergency Contact Names and Relationship Jane Doe		
Communication barriers: Non verbal learning disability: Provide written Instructions	Phone Number(s): 234-567-8902		

Current insurance provider	Anticipated adult insurance provider
Primary: BCBC Account Number: XZ-2345-6789-20 Case manager: none	Primary: BCBS student rider Account Number: XZ-2345-6789-20 Case manager:
Secondary: Medicaid Account number: AB-123-456789- Case manager:	Secondary: Account Number: Case Manager:
ICD-9 codes: 741.03 (Spina Bifida with shunted hydrocephalus) 344.61 (neurogenic bladder)	

Current pediatric healthcare providers	Anticipated adult healthcare providers
Primary Care:	
Current Provider: Hometown Doc Address: Phone/fax:	Adult Provider: College Town MD Address: Phone/fax:
Specialty: Neurosurgery	
Current Provider: Hometown Doc Address: Phone/fax:	Adult Provider: College Town MD Address: Phone/fax:
Specialty: Urology	
Current Provider: Hometown Doc Address: Phone/fax:	Adult Provider: College Town MD Address: Phone/fax:
Specialty: Orthopedics	
Current Provider: Hometown Doc Address: Phone/fax:	Adult Provider: College Town MD Address: Phone/fax:
Specialty: Mental Health	
Current Provider: Social Worker: Spina Bifida Center Address: Phone/fax:	Adult Provider: College Town Counselor Address: Phone/fax:
Specialty:	
Current Provider: Address: Phone/fax:	Adult Provider: Address: Phone/fax:
Emergency Department:	
Current: Hometown ED	Anticipated: College Town/State Hospital
Tertiary Care Hospital:	
Current: Home Town Medical Center 123-456-6789	Anticipated: College Town/State Hospital 987-654-3210

adapted with permission from New York Institute Health Transition Training Developmental Disabilities Planning Council

Current ancillary service providers		Anticipated ancillary service providers	
Pharmacy:			
Current: Hometown Pharmacy Address: Phone/fax:		Anticipated: College Town Pharmacy Address: Phone/fax:	
Durable Medical Equipment Vendor:			
Current: Hometown Vendor Company Address: Phone/fax:		Anticipated: College Town Vendor Company Address: Phone/fax:	
Medical Service Coordinator:			
Current: Address: Phone/fax:		Adult: Address: Phone/fax:	
Home Health Agency:			
Current: Address: Phone/fax:		Adult: Address: Phone/fax:	

Diagnosis/Past Procedures	Physical Exam
<p>Problem List:</p> <ol style="list-style-type: none"> 1. Lumbar myelomeningocele s/p closure at birth. S/P detethering 1/1999 and 2/2004 2. Ventriculo-atrial shunted hydrocephalus, s/p V-P shunt placement at birth with revision x2 in first year of life. VP was changed to VA shunt when there was shunt malfunction after ACE/Mitrofanoff 3. Chiari malformation, has problems swallowing pills and has mild dysarthria, otherwise asymptomatic. Is known to have C6-T4 syrinx, stable~ Does have weakness in hand intrinsic on left, but otherwise no symptoms 4. Neurogenic bladder: S/p augmentation cystoplasty and Mitrofanoff in 2/2002. Catheterizes via umbilical stoma q. 4 hours. Normal renal function. 5. Neurogenic bowel s/p Chaitt tube placement in 2/2004. Flushes with 800 cc's tap water nightly. Occasionally uses immodium. 6. Motor impairment: L2 paraplegia-primarily uses wheelchair for mobility. Has left dislocated hip. 7. Scoliosis s/p Harrington rod placement in 2000. 8. Osteoporosis s/p pathologic fracture left femur in 1996. DEXA scan in 2004, on fosomax 700 mg weekly. 9. Insensate in saddle distribution and below knees bilaterally. Coccygeal decubitus x 2, with hospitalization for osteomyelitis in 2/1999. 10. Depression, in remission. No longer on medications. <p>Synopsis: Dusty is a 17 year old with mild lumbar level paraplegia who had Chaitt ACE/Mitrofanoff procedures when he was 14. The Mitrofanoff stoma has been problematic and if he is not able to cath easily he needs to be seen promptly. He has short term memory problems.</p>	<p>Baseline physical findings: Venous stasis resolves when legs elevated (not lymphedema) See neuro exam below for pertinent positives</p> <p>Baseline vital signs: Normal</p> <p>Baseline neurologic status: Mild dysarthria (Chiari-related) Tongue deviates slightly to left Left exotropia End point horizontal nystagmus with leftward gaze L2 level paraplegia</p>

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Medication List Bicitra 10 MEq BID 16 French catheters Water soluble lubricant Prostheses/Appliances/Implantable Devices: Quicki manual wheelchair with ROHO cushion	Significant baseline ancillary findings (lab, x-ray, ECG) CT Head (2004, when asymptomatic): Mild Ventriculomegaly of lateral ventricles. Thickened calvarium
---	---

Management Data	
Allergies: Medications/Food to be avoided Latex	And why: Latex sensitive (hives)
Procedures to be avoided MRI studies Prolonged immobilization without pressure relief surface	And why: Harrington rods Insensate L2: Prone to pressure sores

Immunizations (mm/yy)			
Dates			

Common Presenting Problems/Findings with Specific Suggested Managements		
Problem 1. Unable to catheterize 2. Odiferous urine, no fever	Suggested Workup Cystogram No urine culture is needed. Please follow guidelines for management of asymptomatic bacterium	Treatment considerations This is potentially a surgical emergency. Call urologist immediately for inability to catheterize. At high risk for bladder rupture Increase fluid intake. Re-evaluate in 24 hours if symptoms persist or if symptoms worsens or if febrile

Condition-specific health maintenance recommendations:
Augmentation cystoplasty: 1) Beginning 10 years after surgery, annual cystoscopy 2) Urinary alkalization to prevent osteoporosis, 3) Annual B12 level. SBAAGuidelines for Health Maintenance in Adulthood: http://www.sbaa.org/site/PageServer?pagename=about_livingadults

Additional comments:
Jane has impairment of short term memory and non-verbal learning disability. Please provide written healthcare instructions. Thorough skin examination is recommended. He has recently has several decubitus ulcers.

Physician/providers signature:	Print Name:	Date:

adapted with permission from New York Institute Health Transition Training Developmental Disabilities Planning Council



TRANSITION INFORMATION FORM

North Carolina Health and Transition (CHAT)
Original Form Developed by New York State Institute for Health Transition Training
Developmental Disabilities Planning Council

Adapted from the Emergency Information Form for Children with Special Needs
American College of Emergency Physicians – American Academy of Pediatrics

Date Form Completed _____	Revised ____/____/____ Initials _____
By Whom: _____	Revised ____/____/____ Initials _____

Patient Information	
Name:	Date of Birth:
Home Address:	Home Phone:
Health Care Guardian: (N/A) __	Work Phone:
Signature/consent:	Health Care Guardian Phone:
Communication barriers: Non verbal learning disability: Provide written Instructions	Emergency Contact Names and Relationship
	Phone Number(s):

Current insurance provider	Anticipated adult insurance provider
Primary: Account Number: Case manager:	Primary: Account Number: Case manager:
Secondary: Account number: - Case manager:	Secondary: Account Number: Case Manager:
ICD-9 codes:	

Current pediatric healthcare providers	Anticipated adult healthcare providers
Primary Care:	
Current Provider: Address: Phone/fax:	Adult Provider: Address: Phone/fax:
Specialty:	
Current Provider: Address: Phone/fax:	Adult Provider: Address: Phone/fax:
Specialty:	
Current Provider: Address: Phone/fax:	Adult Provider: Address: Phone/fax:
Specialty:	
Current Provider: Address: Phone/fax:	Adult Provider: Address: Phone/fax:
Specialty:	
Current Provider: Address: Phone/fax:	Adult Provider: Address: Phone/fax:
Specialty:	
Current Provider: Address: Phone/fax:	Adult Provider: Address: Phone/fax:
Specialty:	
Current Provider: Address: Phone/fax:	Adult Provider: Address: Phone/fax:
Specialty:	
Emergency Department: Current:	Anticipated:
Tertiary Care Hospital:	
Current:	Anticipated:



TRANSITION INFORMATION FORM
 North Carolina Health and Transition (CHAT)
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 Developmental Disabilities Planning Council

Current ancillary service providers	Anticipated ancillary service providers
Pharmacy:	
Current: Address: Phone/fax:	Anticipated: Address: Phone/fax:
Durable Medical Equipment Vendor:	
Current: Address: Phone/fax:	Anticipated: Address: Phone/fax:
Medical Service Coordinator:	
Current: Address: Phone/fax:	Adult: Address: Phone/fax:
Home Health Agency:	
Current: Address: Phone/fax:	Adult: Address: Phone/fax:

Diagnosis/Past Procedures	Physical Exam
Problem List: 1. 2. 3. 4. 5. (Add space for additional lines or categories as needed.) Synopsis:	Baseline physical findings: Baseline vital signs: Baseline neurologic status:



TRANSITION INFORMATION FORM
 North Carolina Health and Transition (CHAT)
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 Developmental Disabilities Planning Council

Medication/Past Procedures	Physical Exam
Medication List 1. 2. 3. 4. Prostheses/Appliances/Implantable Devices:	Significant baseline ancillary findings (lab, x-ray, ECG) CT Head (2004, when asymptomatic):

Management Data	
Allergies: Medications/Food to be avoided	And why:
Procedures to be avoided	And why:

Immunizations (mm/yy)			
Dates			

Common Presenting Problems/Findings with Specific Suggested Managements		
Problem	Suggested Workup	Treatment considerations
1.	1.	1.
2.	2.	2.

Condition-specific health maintenance recommendations:

Additional comments:

_____ Physician/providers signature	_____ Print Name	_____ Date
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LEGAL NAME

Address, City, State, Zip
Phone, cell, email

INSURANCE	Company Name	Certificate # ADD	BC Plan ADD / BS Plan ADD	Rx BIN ADD
		Group # ADD	ADD PH / 800-XXX-XXXX	

Legal Health POA *	ADD Name	Relationship	Cell ADD	Work ADD	Work ADD
	ADD Name	Relationship	Cell ADD	Work ADD	Work ADD
	ADD Name	Relationship	Cell ADD	Work ADD	Work ADD

DOB xx-xx-19xx

HEIGHT/WEIGHT: x'x", xxx lbs

ADVANCE DIRECTIVES: YES NO

DNR: YES NO

SS# xxx-xx-xxxx

BLOOD TYPE: X positive/negative

ORGAN DONOR: YES NO

- ADD comment about pain threshold
- ADD comment regarding patient preference
- ADD comment regarding patient preference.

ALLERGY: ADD

HEALTH ISSUES			
ADD Body system	ICD-9 XXX	ADD Name of Health Issue	age on onset
ADD Body system	ICD-9 XXX	ADD Name of Health Issue	age on onset

MEDICATIONS					
Rx	What for?	Name of Drug Dosage x ? how many times a day, ADD RX #			
OTC		List any over the counter Drug -indicate daily or PRN			
MEDICAL HISTORY					
Add Body System	ICD9 - XXX	Diagnosis?	age on onset	age next episode	age next episode
	ICD9 - XXX	Diagnosis?	age on onset	age next episode	age on onset
	ICD9 - XXX	Diagnosis?	age on onset	age next episode	age on onset
	SURGERIES				
	ICD9 - XXX	What treatment? Note if benign or cancer	age on onset	age next episode	age on onset
	ICD9 - XXX	What treatment? Note if benign or cancer	age on onset		
Add Body System	ICD9 - XXX	Diagnosis?	age on onset	age next episode	
OTHER		Diagnosis?	age on onset	age next episode	
			age on onset	age next episode	

MEDICAL TESTS			
Blood	Month/Year	Fasting	Cholesterol XXX, HDL XX, LDL XX, Trig XXX, CRP XX, glucose XX
	Month/Year	Negative	- Name of Company, Address
	Month/Year	Normal	- Name of Company, Address

IMMUNIZATIONS					
Tentanus	YR	TB	YR	Pneumococcal vaccine	YR

FAMILY HISTORY		
Father	Alive/Deceased Age?	Health Issues, Cause of Death
Mother	Alive/Deceased Age?	Health Issues, Cause of Death
Child	Alive/Deceased Age?	Health Issues, Cause of Death

PHYSICIANS			
FAMILY PRACTICE	Name	Phone	Address
	Name	Phone	Address

OTHER			
Dental	Name	Phone	Address
Rx -Pharmacy	Name	Phone	Address

Emergency Information Form for Children With Special Needs



American College of
Emergency Physicians®

American Academy
of Pediatrics



Date form
completed
By Whom

Revised
Revised

Initials
Initials

Name:		Birth date:	Nickname:
Home Address:		Home/Work Phone:	
Parent/Guardian:	Emergency Contact Names & Relationship:		
Signature/Consent*:			
Primary Language:		Phone Number(s):	
Physicians:			
Primary care physician:		Emergency Phone:	
		Fax:	
Current Specialty physician: Specialty:		Emergency Phone:	
		Fax:	
Current Specialty physician: Specialty:		Emergency Phone:	
		Fax:	
Anticipated Primary ED:		Pharmacy:	
Anticipated Tertiary Care Center:			

Diagnoses/Past Procedures/Physical Exam:	
1 .	Baseline physical findings:
2.	
3.	Baseline vital signs:
4.	
Synopsis:	
	Baseline neurological status:

Diagnoses/Past Procedures/Physical Exam continued:

Medications:

Significant baseline ancillary findings (lab, x-ray, ECG):

1.

2.

3.

4.

5.

6.

Prostheses/Appliances/Advanced Technology Devices:

Management Data:

Allergies: Medications/Foods to be avoided

and why:

1.

2.

3.

Procedures to be avoided

and why:

1.

2.

3.

Immunizations**Dates**

DPT

OPV

MMR

HIB

Dates

Hep B

Varicella

TB status

Other

Antibiotic prophylaxis:

Indication:

Medication and dose:

Common Presenting Problems/Findings With Specific Suggested Managements

Problem

Suggested Diagnostic Studies

Treatment Considerations

Comments on child, family, or other specific medical issues:

Physician/Provider Signature:

Print Name:

TRANSITION ACTION CARE PLAN

Child's/Youth's Name: _____ D.O.B. _____ Patient # _____ Parents/Guardians: _____

Primary Diagnosis: _____ Secondary Diagnosis: _____ Phone # _____

Main Concerns	Related Current Information	Current Plans/Interventions	Person(s) Responsible	Date - Initials	Review Date
Topics to Review Health promotion Health Condition Management Health Insurance Functional Independence	High School Goals/Plans Post secondary plans Work Plans Independent Living Issues Community Inclusion				

