

American Academy of Pediatrics: The State of Transitions

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Purpose

National discourse surrounding the issue of transitioning youth to adult health care has been evolving over several years. While many provider groups, federal and state governments, community partners and parental efforts have been employed to approach this issue, transitions continues to challenge the United States (U.S.) health care system. It is an issue that equally encompasses clinical practice, legal statutes, managed care criteria, educational contexts, employment functionalities, as well as personal norms and attitudes. The enormity of this issue begs pediatric leaders to aggressively address its pervasive barriers, and acknowledge its significance in the provision of quality, compassionate, comprehensive healthcare for all.

In an act of acknowledgement, the American Academy of Pediatrics' (AAP) 2007 Annual Leadership Forum resolution process positioned "transitioning youth with special health care needs (YSHCN) to adult health care" in the top 10 of over 73 submitted. This identification prioritized transitions as a paramount issue for the AAP, and charged its Division of Children with Special Needs (DOCSN) and the National Center for Medical Home Initiatives (NCMHI) – funded by the federal Maternal and Child Health Bureau (MCHB) – to be the hub of central action. This placement, as well as its inclusion as one of MCHB's 6 outcome measures, situated transitions as a critical, integral component of the medical home.

Before announcing transition activities and/or programs, DOCSN/NCMHI leadership contracted with a consultant to assess current transitions literature, programs, and parallel initiatives. The intent of such an assessment was to provide the AAP with a comprehensive lens on past and current transition activities, needs of its members and other health care colleagues, existing barriers, as well as to reduce the possibility of duplication. While this contracted

assessment is not exhaustive, it is a formidable chronicle of literature, agendas, programs, and partners that the AAP should acknowledge, as it reaches a consensus regarding its future transitions efforts. This report outlines the assessment findings in the following order: 1) external efforts: federal framework, federal initiatives, national partner efforts, and community provider education programs; 2) AAP efforts: past and present; 3) needs assessments: external partners; 4) state-based transition research and clinics; and 5) peer-reviewed publication.

External Efforts - Federal Framework

The federal government has a longstanding presence within the transitions' initiatives. In 1999, the U.S. Supreme Court passed the *Olmstead Act* (Supreme Court of the United States, 1999). This federal decision operationalized the *Americans with Disability Act (ADA)* by charging state governments to integrate service systems in appropriate contexts for individuals with disabilities. While this order had a universal scope, it did not formally outline how each state was to integrate such services; it only stipulated such modification had to be "reasonable" in terms of states' efforts and/or budgets. Possible areas for modification included: health care, transportation, education, and social services (Department of Health and Human Services of the United States, 2002).

Building on the *Olmstead Act*, in February 2001, the *President's New Freedom Initiative* (NFI) was announced (Department of Health and Human Services of the United States, 2001). This federal effort outlined activities aimed at further enhancing individuals' with disabilities ability to live independently in communities nationwide. Scopes of these activities included: increasing access to assistive technologies, increasing educational opportunities, promoting home ownership, integrating individuals with disabilities into the workforce, increasing transportation options, and promoting full access to community living. In December 2001,

9 federal agencies responded to NFI, by outlining strategies to address barriers individuals with disabilities face within communities. This response was entitled, “Delivering on a Promise,” and contained 400 proposed strategies (Department of Health and Human Services of the United States, 2001).

In July 2005, the U.S. Surgeon General released a *Call to Action to Improve the Health and Wellness of People with Disabilities* (Department of Health and Human Services of the United States, 2005). This agenda focused on: increasing nationwide understanding of individuals’ with disabilities life trajectory; increasing health care professionals’ knowledge to screen, diagnose, and treat the whole person with dignity; increasing individuals with disabilities’ ability to self-manage and self-promote healthy lifestyles; and increasing accessibility of healthcare and social services for individuals with disabilities. This “call to action” was made on the 15th anniversary of the ADA.

In February 2008, President Bush put forth an executive order to improve the coordination and effectiveness of youth programs (White House, 2008). This order calls for the development and implementation of an interagency working group to assess, promote, and implement strategies focused on improving the health of America’s youth. Specific activities noted are: develop an interagency working group, engage private and nonprofit organizations to assist in coordinating needed services, create a new Web site for youth, assess strengths of other federal Web sites aimed at youth, promote youth training on the use of Web sites, promote community-based youth programs’ use of evaluations, promote community-based programs that utilize strong collaborations, volunteer activities, and demonstrate cost-saving alternatives for serving high-risk youth (White House, 2008). This order is the most recent of executive activities aimed at promoting the health of all youth in the U.S.

External Efforts - Federal Initiatives

The majority of federal YSHCN efforts reside within Department of Health and Human Services (DHHS), within the MCHB Division of Services for Children with Special Health Needs (DSCSHN). Within this federal division are a host of activities, many of which are grounded within the medical home initiative. The following offers a summary of the DSCSHN activities.

Review of Individual Transition Programs

In spring 2008, through an external consulting agreement, MCHB will receive a summative report on a variety of transition programs. These programs are clinic, governmental and resource-center based. It is the intent of MCHB's contracted report to glean useful strategies for successful transition, as well as possible models for best practice identification. *[Please note the consultant requested a report/ update from conference. As of June 2008, there has been no response to the request.]*

Contact: Elizabeth McGuire – MCHB

Health Ready to Work (HRTW)

Information: HRTW is a collaborative agreement with MCHB to formalize a national center for transition-specific technical assistance (TA). HRTW's Web site (www.hrtw.org) offers a warehouse of transition-based resources and tools, as well as connections to transition experts who provide TA opportunities. This group serves as MCHB's primary source of transition-based expertise and information (HRTW, 2008). Some key outcomes to note:

- In 2006, HRTW disseminated findings from a MCHB Title V agency survey; which highlighted the key transition issues 38 out of 50 state programs are facing. This survey confirmed that most states were in the formative stages of transition efforts. The lack of

adult providers to receive transitioning YSHCN was identified as a primary workforce barrier.

- In 2006, HRTW also surveyed pediatric practices and medical homes noting that referrals to adult practice mostly occurred due to personal relationship and location. Fifty-seven percent of responding providers utilized the AAP's *A Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs* (2002) as a transition reference (HRTW, 2008).

Contact: Patti Hackett – HRTW

Federal Interagency Collaborative Workgroup on Youth Transition

This workgroup consists of partnering federal agencies, such as the Department of Labor, Department of Education, Department of Transportation, Social Security Administration, Department of Justice, Centers for Disease Control and Prevention (CDC), Substance Abuse and Mental Health Service Administration, as well as other DHHS partners. Their quarterly meetings update all partners on the group's work plan, and existing activities. One of their paramount activity is their hosting a cross-agency Transition TA Center meeting in July 2008, aimed at increasing awareness of the federal programs able to provide TA, understanding resources they are utilizing, and highlighting communication strategies to optimize TA delivery among centers.

Agency Updates (as of December 2007):

- I. Department of Labor – Employment and Training Administration (DOL-ETA)
 - a. The new *YouthBuild* grants were announced.
 - b. There were 7 cities funded for better alternative education systems for youth offenders.

- c. Three-part grants will be released soon for youth offenders focusing on better apprenticeship programs, alternative schools for youth offenders, and programs based on best practices.
2. Department of Education – Office of Special Education and Rehabilitative Services (ED-OSERS)
 - a. There are 23 vocational rehabilitation (VR) agencies’ promising practices identified to assist in successful rehabilitation for YSHCN. Web site is:
<http://www.ed.gov/rschstat/eval/rehab/promising-practices/transition-age/index.html>
 - b. OSERS has funded an assessment of state VR agencies that is currently in the final draft stages.
3. Department of Labor – Office of Disability Employment Policy (DOL-ODEP)
 - a. There is an alliance between the Society of Human Resource Managers (SHRM) and ODEP. As a part of this alliance, ODEP is working with SHRM to help facilitate their mentoring activities to become more inclusive of all youth, including those with disabilities. Articles will be written by SHRM on mentoring youth with disabilities and will be posted to their website (www.shrm.org) shortly. ODEP also completed a Web cast with SHRM concerning:
 - i. Internships for college students with disabilities.
 - ii. Findings from ODEP’s work regarding career services offices and how closely they work with disability support offices at colleges and universities.

- b. ODEP has developed an alliance with CVS pharmacies. This alliance hopes to develop a strong youth component in CVS pharmacies' work force.
 - c. ODEP is working at updating their Disability History Fact Sheet on what groups are doing around the country to pass disability history legislation. This legislation mandates states either have a disability history week or month or a dedicated time period in which the school (K-12) present disability history topics to its students.
 - d. ODEP is part of the Federal Mentoring Council through the Corporation for National and Community Service. Through this partnership, ODEP is working towards an Executive Order recommending that youth-related RFPs include mentoring.
 - e. ODEP is working on training modules around the Knowledge, Skills, and Attributes (KSA) competencies (www.ncwd-youth.info/ksa/index.html). The drafts, which are being reviewed by professionals in the special education, juvenile justice, vocational rehabilitation, and workforce development arenas, will be completed in November 2008. The next phase of the KSA development will be field testing currently planned to take place in Arizona, California, Maryland, Oregon, Vermont and other locales.
4. Social Security Administration (SSA)
- a. Youth Transition Demonstrations
 - i. A main focus is the current development of the 36-month survey, aimed at self-determination.
 - ii. The 12-month survey is completed and SSA is waiting for final approval in order to begin collecting data.

Fueled by NFI, SSA developed 9 demonstration projects to elicit successful strategies for assisting youth with disabilities transitioning from post-secondary education to employment (Social Security Administration, 2004). Each site is developing a delivery system to enable successful transition. The youth selected to participate in the demonstration projects will be followed for 4 years in random-assignment evaluation to document if received demonstration intervention (such as increased service coordination or Medicaid Waivers) are successful. As noted previously, the 12-month surveys are completed, and project leaders are currently crafting the 36-month survey. SSA believes findings from these sites may alter specific Supplemental Security Income rules in order to incentives enrollees' efforts to work. The 9 demonstration projects exist in the following states: California, Colorado, Florida, Maryland, Mississippi, New York, Vermont, Washington, and West Virginia.

Contact – Elizabeth McGuire - MCHB

Substance Abuse and Mental Health Service Administration (SAMHSA)

Information: SAMSHA formulated the “Partnership for Youth Transition” within their Center for Mental Health Services Division of Service and Systems Improvement Child, Adolescent, and Family Branch. Along with OSEP, this program offered five 4-year cooperative agreements in 2004 (Substance Abuse and Mental Health Administration, 2004). These agreements were awarded to plan and implement youth transition programs for children and youth with significant emotional disturbances. The 5 awarded sites were: Partnership for Youth in Transition: Portfolio to Success (Augusta, ME), Persons Realizing Independence and Developing Empowerment (Willmar, MN), Comprehensive Youth Transition Program (Pittsburgh, PA), Project RECONNECT (Salt Lake City, UT), and Partnership for Youth Transition (Vancouver, WA).

Contact – Elizabeth McGuire - MCHB

DOL-ODEP's Summit "Blazing the Trail"

DOL-ODEP hosted a summit aimed at enhancing leadership development of youth with disabilities in August 2007. The summit was an invitation-only meeting, where more than 200 attendees representing federal, state and local government agencies, other policymakers, academicians, service practitioners, youth and leadership organizations, foundations, and youth and their family members met to discuss opportunities to enhance youth's skills and participation in leadership programs. A white paper outlining the summit's outcomes will be distributed in 2008 to the public.

Contact - Rachel Dorman – DOL-ODEP

External Efforts - National Partner Efforts

Research Consortium on Children with Chronic Conditions (RCCCC)

Information: The RCCCC is an established group of interdisciplinary professionals with an interest in CYSHCN. In April 2006, RCCCC decided to focus on the issue of transitions by initially drafting 8 papers to explore several elements related to this topic arena. The charge was to develop 3 papers that would focus on the global issues of transitions, while 4 would be aimed at addressing components outlined by NFI and the ADA. The final paper would synthesize all paper findings. The RCCCC had hoped to subsequently host an invitational workshop on transitions to present and discuss these papers in spring 2008; however the meeting was postponed. Based on the proposed workshop, further policy, program, and research recommendations had also hoped to be formulated.

Contact – Don Lollar, EdD – CDC or Bonnie Strickland, PhD – MCHB

National Committee on Quality Assurance (NCQA)

Information: In January 2008, NCQA announced a revised version of the Physician Practice Connections-Patient Centered Medical Home (PPC-PCMH) program (NCQA, 2008). The PPC-PCMH serves as an assessment tool for medical practices to assess their medical home functionality. This revised tool is based off of core standards collaboratively determined by the American Academy of Family Physicians (AAFP), AAP, American College of Physicians (ACP), and the American Osteopathic Association (AOA). PPC will be used nationwide in demonstration sites.

Stepping Up to the Plate (SUTTP) Alliance

Information: The American Board of Internal Medicine (ABIM) led the initiation of a collaborative consortium of specialty societies and other interested partners in health care in the effort of outlining principles and standards for managing transitions in care (Greiner, 2007). Involved partners include: AAFP, AAP, American College of Cardiology (ACC), ACP, American College of Surgeons (ACS), American Society of Clinical Oncologists (ASCO), Society of Thoracic Surgery (STS), Society of General Internal Medicine (SGIM), Society of Hospital Medicine (SHM), American Board of Family Medicine (ABFM), ABIM, American Board of Pediatrics (ABP), American Board of Surgery (ABS), Agency for Healthcare Research and Quality (AHRQ), NCQA, and Institute for Healthcare Improvement (IHI).

SUTTP has defined transitions in care as a process between physicians and institution-to-institution transfers. Moreover, it more narrowly defines transitions as being clinician-focused. In its initial conversations, SUTTP noted that changes in both medical culture and system infrastructure and standards would be needed in order to conduct successful transitions (Greiner,

2007). Additionally, “changes in physician payment would also be necessary to facilitate enhanced care transitions,” (Greiner, 2007, p. 1). While alterations in reimbursement would assist in covering physician-time spent on transition activities; discussion also illuminated that an eventual redistribution in funds from specialty care to primary care would also lessen financial difficulties currently felt by providers.

SUTTP suggests the following are principles for effective care transitions (draft 2007):

1. Accountability
2. Clear and direct communication of treatment plans and follow-up expectations
3. Timely feed-forward and feedback of information
4. The involvement and awareness of patient and family member, when appropriate, in all steps
5. Respecting the hub of coordination of care
6. Establishing national standards
7. Measurement

SUTTP suggests the following are standards for effective care transitions (draft 2007):

1. Coordinating clinicians
2. Community standards
3. Communication infrastructure
4. Timeliness
5. Transition responsibility
6. Standard communication formats
7. Transition record/care plans

SUTTP's intent is to have these principles and standards guide community and institutional discussions regarding transitions in care. Suggested future SUTTP efforts include: ACP hosted Transitions of Care conference; a SHM care transition toolkit; the ABIM's Foundation future summer forum to focus on care coordination; Centers for Medicare and Medicaid Services' Quality Improvement Organization's inclusion of care coordination (called patient pathways) as a ninth scope of work; and National Quality Forum to host a care coordination measurement workshop.

Agency for Healthcare Research and Quality (AHRQ) – Children's Health Advisory Group (CHAG)

Information: CHAG serves as AHRQ's primary source of guidance and expertise towards its child health activities (AHRQ, 2008). Its goals are to ensure child health issues are integrating into AHRQ's strategic plan, supporting child health research efforts, and promoting communication among AHRQ's working entities to ensure fluid collaboration on child health activities. Two paramount AHRQ's efforts in this arena were:

- Scal and Ireland's study indicating that YSHCN seldom receive adequate transition from pediatric to adult-oriented care (Scal & Ireland, 2005).
- Youngblade and Shenkman's validation of a screener to identify a special health care need in adolescents (Youngblade & Shenkman, 2003).

Current AHRQ activities geared at issues involving CYSHCN are:

- Assessing health care delivery for CSHCN (PI: G. Elaine Beane)
- Analyzing factors that influence quality of care delivery system for CYSHC (PI: Jean Mitchell)
- Improve quality of care for publicly insured children (PI: Peter G. Szilagyi)

- Determining quality of children's health care (PI: Christopher Forrest)

Contact- Denise Dougherty – AHRQ/CHAG chair

External Efforts - Community Provider Education Programs

Transitional Medicine

Stemming from *A Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs*, the need to educate future providers on successful strategies in transitioning care was illuminated (AAP, 2002). While no fellowship program focuses on transitions-specifically, there appears to be growing discussion of “transition medicine” in highlighting this scope of practice for current medical residents. Some literature suggests residents design his/her curricula to be more exposed to certain pediatric health conditions, such as: cerebral palsy, sickle cell disease, congenital heart disease, autism, and genetic syndromes during typical training. Clinical experience could then be scheduled in care coordination to garner a “transitions” frame of reference (Meeks, 2007). This motivation is based on surveys targeted at adult providers' comfort level with caring for YSHCN. Results indicate such providers experience a lower-level of comfort when caring for young adults with health conditions which were historically exclusive to pediatrics.

Baylor College of Medicine (BCM)

BCM initiated an elective to provide ambulatory outpatient experiences focusing on transitional care. These experiences are afforded within the BCM's Transition Medicine Clinic (TMC). These clinical opportunities present residents with the chance to work alongside physicians trained in both internal and pediatric medicine, as well as social workers engaging in coordination of care (Meeks, 2007).

The Family Medicine Education Consortium – Medical Homes for People with Intellectual and other Developmental Disabilities

The Family Medicine Education Consortium, Inc. (FMEC) is a not-for-profit corporation which supports the educational and scholarly needs of its members. The FMEC was founded by a Board of Family Medicine Chairs and Residency Directors from the northeast region of the U.S., and contains a working group focused on enhancing family medicine residents' knowledge and experiences when caring for individuals with intellectual and developmental disabilities (FMEC, 2008). This working-group consists of experts located in medical centers across the eastern part of the U.S. Their action steps are focused on curriculum development and training experiences.

Mountain Area Health Education Center (MAHEC) Mini-Fellowship in Developmental Disabilities

In 2006, MAHEC developed a 6-month continuing education mini-fellowship for adult providers interested in post-graduate education regarding care for adults with intellectual disability. This training experience is a mixture of didactic and on-line learning, and involves a clinical rotation. Providers from North Carolina and throughout the country have enrolled in this program.

Crossings: A Manual for Transition of Chronically Ill Youth to Adult Health Care

Through a HRSA grant, this transition curriculum was developed to assist pediatric health care providers throughout the transition process. The scope of the curriculum is broad, including strategies not only for the pediatric and the adult health care teams, but also for providers themselves (interpersonal reflection). Tools and resources are included in the informational packet.

Contact: Anne Keller, MD – PA Department of Health/St. Christopher’s Hospital for Children

AAP Efforts

The AAP has been involved in transitions activities for many years. Most of the AAP’s past efforts have stemmed from the DOCSN/NCMHI and/or the Council on Children with Disabilities (COCWD). The following briefly chronicles those activities:

September 2001: MCHB funded a national meeting, *Wingspread*, of health care professionals (including pediatricians; pediatric specialists including: adolescent medicine, neurology, neurodevelopmental disabilities, etc; adolescent health doctors; family practitioners; internal medicine doctors; social workers; nurses; etc), federal and state Title V policy makers, YSHCN and families. This meeting focused on developing strategies for improving transition to adulthood for YSHCN, and the role of the health care professional in planning for and implementing transition to adult health care, as an aspect of the broader transition to employment and other aspects of adult life.

December 2002: From the 2001 meeting, *A Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs* was published in *Pediatrics* and endorsed by the AAFP, ACP, and ABIM (AAP, 2002). Included in that supplement to *Pediatrics* were the following 4 articles: *Health Care Transition: Destinations Unknown*, *Transition for Youth with Chronic Conditions: Primary Care Physicians’ Approaches*, *Implementing Transitions for Youth with Complex Chronic Conditions Using the Medical Home Model*, and *Access to Health Care: Health Insurance Considerations for Young Adults with Special Health Care Needs/Disabilities*.

October 2003: The COCWD received the 2003 adopted AAP Annual Chapter Forum resolution, *Transition of Patients with Special Health Care Needs to Adult Health Care Providers*. It is AAP

protocol for resolutions to be referred to appropriate AAP Committees/Councils/Sections. After receipt, it is the expectation of the Board of Directors (BOD) that assigned resolutions be placed on the agenda of the group's next meeting for discussion and if appropriate, for actions to be identified for implementation of the resolution. At that time, COCWD decided to designate a Transitions Task Force. This group was essentially a subcommittee of the COCWD, not an official AAP Task Force. This group was tasked with responding to the resolution and considering other actions to assist with the implementation of the *Health Care Transitions Consensus Statement*, including: collaboration with the Institute of Child Health Policy; meeting with the AAFP, ACP, and ABIM regarding training issues; discussing this issue with the Section on Internal Medicine-Pediatrics; and writing an article for *AAP News* on successful primary care-based efforts to accomplish transitions of YSHCN. The task force consisted of Drs Edwards, Johnson, Levey, Kaplan, and Sandler.

December 2003: DOCSN/NCMHI received BOD approval on *Every Child Deserves a Medical Home -Transitions* component. This training component served as the fifth component in the medical home training curriculum funded by Shriners Hospitals for Children and MCHB. Its content, written in collaboration with HRTW, highlights core competencies for transitional care of YSHCN, as well as resources and tools.

Prior to 2004: COCWD introduced a resolution to the American Medical Association (AMA) House of Delegates entitled, *Transitional Care of Young Patients with Chronic Illness*. It called for the AMA to acknowledge the needs of YSHCN and providers regarding transitional care, to identify core knowledge and skills to enhance providers' capacity to transition care, to support the concept of a portable, accessible medical summary for a transitions healthcare plan by the

age of 14, to acknowledge the role of preventive medicine when caring for this patient population, and to advocate for accessible and continuous health insurance for these patients.

May 2004: COCWD staff attended the Council on Sections Management Committee (COSMAN) meeting where COSMAN discussed a proposal submitted by Dr Piatt, Chairperson of the Section on Neurological Surgery (SONS), calling for the creation of an AAP taskforce on transition to adulthood for children with chronic medical and surgical conditions.

July 2004: Several sessions at the Community Access to Child Health (CATCH)/Medical Home National Conference (sponsored by the AAP and the MCHB) discussed adolescent transitions.

October 2004: The COCWD EC reviewed the Transitions Task Force proposal and decided to focus on a small component of the larger issue: focusing their efforts on reaching out to adult physicians to discuss the issues surrounding transitioning YSHCN. Additionally, through COCWD EC's oversight of the AAP's Medical Home Surveillance and Screening Program (via a grant from CDC), it was thought that such a transition project could be incorporated into the next cooperative agreement.

June 2005: The AAP participated in a meeting held by MCHB with representatives from the AAFP to discuss increasing access to medical homes and improving transition services to adult health care providers.

June 2005: Per the previous recommendation, year 4 funding of the AAP-CDC (via DOCSN) cooperative agreement incorporated transition activities. To address the adult organizations, the following was written in to the agreement: "The COCWD believes that an important next step to achieving successful transition is promoting collaboration between pediatric and adult-oriented health care providers, both in education and in clinical practice. In order to further this agenda, COCWD plans to develop several presentations on adolescent transition for the adult-oriented

health care provider audience. Through the cooperative agreement manager, COCWD will submit proposals to present at prominent national meetings of these adult organizations. In addition, a COCWD representative will meet with the appropriate leadership of these organizations to lay the groundwork for future projects and collaboration.”

October 2005: The CDC-AAP cooperative agreement transition activities continued, with the aim to promote collaboration between pediatric and adult-oriented health care providers to achieve successful transition of youth with developmental disabilities into adulthood. In 2005, proposals were submitted to the Pediatric Academic Societies 2006 Annual Meeting, ACP 2007 Annual Meeting, and the Society for General Internal Medicine 2006 Annual Meeting, and the AAFP Scientific Assembly. Proposals were met with limited acceptance.

October 2007: At their bi-annual meeting, COCWD staff recapped the strategic planning session that the AAP EC, liaisons, and staff participated in during June 2007. Prior to the meeting, a four-question online survey was sent to the COCWD membership, asking them to submit topics and tangible outcomes associated with those topics that could realistically be achieved in the next few years. At the session, strategic themes emerged that were in line with those submitted by the membership.

COCWD staff reviewed those priority themes that included: (not in order of importance)

1. Transitions (statement/algorithm/dissemination plan)
2. Early identification/screening for developmental disorders
3. Resident education/awareness
4. COCWD member education
5. Medical home – care coordination (specifically)
6. Appropriate health care benefits for children with disabilities

Also at this meeting, COCWD staff noted that the healthcare transitions topic was submitted as a topic for an evidence report – a comprehensive review that is done by the AHRQ. It is anticipated that the final report will be completed in 2009.

December 2007: An internal AAP Transitions Survey was conducted in late 2007. It was distributed to all AAP Committee/Council/Section staff to elicit their membership entity's thoughts regarding provision of and barriers to transitional care. While its findings are not exclusive, its intent was to use them as a frame for future efforts in the realm of transitions. Please see **Attachment A** for survey summary.

January 2008: Through the support of Committee on Adolescence, an adolescent health periodic survey was distributed at the beginning of the year. The primary intent of the survey was to address provision of and barriers to adolescent health. Questions pertaining to transitioning YSHCN were added to the survey regarding services medical homes have in place to support transitional care, the duration of having such services in-place, and barriers to transitioning patients. Once results are collected, the AAP's Department of Research will analyze the data. An article summarizing the research process and findings will be published at later date.

January 2008: An AAP staff needs assessment was conducted to elicit further feedback on the upcoming AAP transition initiative's work plan. An overarching staff concern noted was the need to provide members with distinct AAP transition activity information; as well as their hopes that such activity would be transparent and collaborative. Additional comments included:

- Define what is meant by transition (i.e. to adult health care provider; from tertiary care to home)
- Include typically-developing child; not just focus on youth with special health care needs
- Include social issues

- Include mental health or behavioral issues (high risk populations)
- Include foster care
- Ensure it is aligned with any recommendations from *Bright Futures*
- Include adult membership organizations in drafting clinical guideline
- Integrate initiative within the framework of medical home
- Include parental representation throughout efforts
- Define transitions relationship with chronic condition management

June 2008: Medical Home Best Practices Meeting will have a transitions sub-focus in which it will host a panel presentation with several break-out sessions. Main areas of transitions focus will include: dispelling the myth that adult providers are not interested in transitions, reimbursement issues, care coordination, self-management skills, and resources. The intended outcome of this effort is further education about current transition practices and resources, as well as general awareness.

Needs Assessments – External Partners

In order to ascertain specific national partners' and experts' insights into AAP's future transition efforts, didactic interviews were conducted. These interviews were held via phone between the identified partner/expert and the AAP transitions consultant. Each conversation resulted in a fluid discussion on the current transitions landscape, while also illuminating targeted needs.

January 2008: A discussion with Dr Bruce Bagley (AAFP representative on the NCMHI Project Advisory Committee) was held to elicit the family physician (FP) perspective on future AAP transition efforts. A main theme generated from the discussion was the strong difference between FP's perspective of transitions (i.e. YSHCN do not physically leave a FP's practice) and a

pediatrician's heightened concern as patients "age-out of practice scope." He also indicated his preference to be involved in any future efforts in terms of a reviewer to the AAP Transitions Clinical Report and/or material development. Other general themes Dr Bagley supported the AAP might consider in their future transition efforts include:

- Address transitions within the context of the medical home
- When considering language in future AAP policies, clinical reports and materials, attempt to utilize more universal language, as pediatricians are not the only health care providers caring for CYSHCN (i.e. FPs and nurse practitioners)
- The term "principal care" is gaining favor within the FP community; its function is opposite of "specialty care."

February 2008: A conversation with MCHB leaders was held in order to ascertain MCHB's perspective on past, present and future AAP transition activities. MCHB leaders and the AAP consultant worked closely throughout this contract's scope in order to ensure awareness of both parties' intent and transition activities. Throughout the call MCHB leadership illuminated the following themes:

- Attempt to link future AAP transition activities with the National CSHCN survey for evaluation purposes.
- Explore all financial options/ models for providers engaging in transitional care (i.e. not just enhancing reimbursement).
- Collaborate with HRTW and adult-provider organizations (i.e. AAFP, ABIM).
- Consider incorporating the chronic care model into any future clinical report framework.
- Consider public health's role in future transition activities or policy recommendations.

March 2008: John Reiss, PhD, (Institute of Child Health Policy) has a long tradition of involvement within the transition initiative, at both the federal and clinical level. Due to his longitudinal perspective, the discussion addressed the current transitions' landscape, as well as past efforts. Several overarching themes Dr Reiss espoused the AAP should consider including:

- The promotion of youth-oriented care, separate from family-centered care model, with subsequent self-advocacy strategies.
- Development of (as well as promotion of) a matrix to assist providers in adapting practices to young adults (both in context, processes, and communication strategies).
- Consider revisions to recommended clinical interventions that address the developmental changes of adolescence.
- Similar to the framework AAP has developed to enhance participation of family liaisons on many Committees/Councils/Sections, consider parallel strategy with young adults (those who have made the "transition"; not adolescents).
- AAP should consider addressing the emotional barrier relevant to transitions from the providers' perspective. The emotional rapport that develops among pediatric providers and their patients is unique and tremendous. However, it may serve to hinder both entities when a transition is eminent and necessary. Acknowledging the "emotional bond" of pediatrics, and providing discussions and strategies for providers to handle its stressors may be much needed for truly successful transitions. Dr Reiss referenced the family medicine residency programs' use of *Baliant* methodology to teach and promote concepts of provider reflection.
- AAP should consider entering into a joint meeting with adult-membership organizations to discuss the cultural and attitudinal barriers that are illuminated by the transitions

process. Each medical specialty has its own norms and cultural distinctions; however, the issue of transitions forces all entities to step out of those norms. Furthermore, demonstration sites (funded by all entities; similar to CATCH grant methodology) focusing on addressing these cultural and attitudinal barriers may elicit further insight and/or useful strategies.

- Any future AAP transition effort must define the necessary components of a discharge summary/transition care plan, as well as the timeliness of its distribution, receipt, and response.
- AAP should consider addressing the “youth-friendliness” of in-patient, pediatric atmospheres. The concern of where to admit an adolescent or young adult (who has not been transitioned yet) stems from the knowledge that this patient’s development differs from other pediatric patients; however the pediatric scope of practice that is serving as his/her medical home as privileges at an in-patient setting. This setting typically is tailored to younger pediatric patients, and can emit a more isolated feeling for adolescents or young adult patients. The same is true when admitted to the “adult” hospital.

State-Based Transition Research

Rhode Island (RI): In 2006-2007, through the support of the RI Department of Health’s Office of Special Healthcare Needs (OSHCN), pediatric and adult providers across the state were surveyed, in an effort to identify service gaps, barriers, and current YSHCN transitional care practices. Adult health care responses stemmed from 170 internal medicine physicians (out of 399), and 119 family medicine physicians (out of 200). Highlights from such responses included:

- Family members typically initiate the transition into the adult system of care.

- Majority of respondents indicated a higher level of comfort when treating YSHCN with chronic conditions that are often seen in adult medicine (i.e. diabetes, obesity, hypertension) versus pediatric-specific conditions (i.e. spina bifida, cystic fibrosis, cerebral palsy).
- Most respondents reported that YSHCN should be transitioned by the age of 21.
- Respondents indicated they rarely receive a discharge summary/ transition care plan from “transitioning” provider; as well as rarely communicate “back” with the pediatric provider once YSHCN has transitioned.
- Majority of responses indicated that YSHCN’s health plans do not assist in transitions process.

The results from the pediatric providers’ survey will be published in an upcoming article in *Pediatrics*.

Massachusetts (MA): Through a partnership between the MA Medical Society (MMS) and the MA-AAP state chapter, a state-wide survey was conducted to identify physician attributes and training needs related to enhancing provider capacity to successfully transition YSHCN to the adult health care context. This effort utilized an electronic survey design, and was distributed to physicians across the state and in varying practices settings. Survey questions focused on physicians’ perceived barriers to transitions, comfort-level when caring for YSHCN, training needs, and willingness to manage this patient population.

The survey partners received a 23% response rate, with 88% indicating YSHCN were currently in respondents’ care. Majority of respondents reported being comfortable when caring for CYSHCN with physical disability (86%), cognitive disability (81%), mental retardation (74%), mental health disability (65%), technology dependence (61%), autism (57%). Barriers

reported as important by respondents were knowledge of community resources (89%), time (87%), training (86%), availability of community resources (85%), knowledgeable office staff (77%), and reimbursement (37%). Fifty-seven (35%) physicians requested further training. Twenty-five physicians were self-identified as resources for referring physicians, patients and families. These survey results will be available to the public in summer 2008 via the MMS Web site.

State-Based Transition Clinics

Information: Through state and/or academic institutions' efforts, transition-focused programs and/or clinics are sparingly seen throughout the U.S. These efforts clearly stipulate their intent to assist in "transitioning" YSHCN to "adult oriented services." Each of these programs target different age-groups, offer various services, and engage in differing models of care. A summary of several of the programs is included in **Attachments B and C**. Furthermore, as noted previously, MCHB contracted with a consultant in the winter/spring of 2007-08 to interview 5 transition programs. MCHB has granted the AAP privileged-internal access to this report. *[Please note the consultant requested a report/ update from conference. As of June 2008, there has been no response to the request.]*

Assessment: Upon review of the various transition clinics, the AAP may consider the varying strategies states/institutions are using to "transition YSHCN." Some do not address the medical aspect, but are more focused on educational/vocational service access. Those engaged in the "medical transition" are doing it as a medical home, or as a consultative service (either with or without defined communication with a medical home provider). These differing approaches illuminate 2 central themes: 1) the robust energy within the medical community to approach this patient need; 2) the AAP's paramount need to suggest standards of care within these practices

(i.e. what constitutes transitions; common methods to engaging in the process, etc.) Furthermore, such defined standards are first needed before pediatric leaders identify these early transition clinics as best practices, as the pediatric community has yet to know what precisely is “best” for transitions.

Peer-Reviewed Publications

Peer-reviewed literature regarding transitions has also begun to moderately appear in academic publications. Primary sources of such publications include *Pediatrics* and disease-specific journals. The discourse presented in these sources ranges from macro-system discussions on current barriers to successful transitions to commentary on disease-specific clinical transition programs, such as cystic fibrosis or sickle cell (Hait, Arnold, & Fishman, 2006; Wojciechowski, Hurtig, & Dorn, 2002; Van Deyk, Moons, Gewillig, & Budts, 2004; Zack, Jacobs, Keenan, Harney, Woods, Colin, & Emans, 2003; Boyle, Farukhi, & Nosky, 2001; Taylor, Edwards, & Ku, 2006). These publications, however, produce little evidence to support the notion of medical homes as the base for successful transitions versus specialty care. In order to cultivate a better understanding of the evidence-base for transitions, MCHB contracted in winter/spring 2007-08 with a consultant to conduct a thorough literature review. When completed, the outcomes of that review will be shared with the AAP, as well as the interim findings’ presentation to the AAP’s Transitions Advisory Meeting held in June 2008.

Discussion

The medical community’s interest in ensuring successful transitions from pediatric to the adult healthcare sphere is evident. Moreover, the federal government’s commitment to its practice within the U.S. healthcare system continues, as it is embedded within the *Healthy People 2010* agenda (Department of Health and Human Services, 2000). However, this zest is

mostly fueled by anecdotal and expert opinion, as the evidence-base to transitions' efficacy (within the context of the medical home) has yet to be determined.

The limited evidence-base to this pediatric practice is not surprising, nor should it provide pause for the medical community's pursuit of establishing transition best practices. The pediatric community may glean lessons from the geriatric body of research pertaining to aggressive, interdisciplinary "case management" of high-risk patients as they "transition" into another compartment of his/her chronic condition trajectory (Callahan, Boustani, Unverzagt, Austrom, Damush, & et al, 2006; Counsell, Callahan, Clark, Tu, & Battar, 2007). Such evidence indicates "high risk" geriatric patients receive a higher quality of care and have reduced utilization of acute care resources due to the interdisciplinary "case management" intervention, as they transition into the end-stages of disease processes.

Additionally, within the pediatric subspecialty of oncology, there is an increasing evidence-base and model programs focused on "transitioning" pediatric cancer survivors into adult healthcare provision due to this patient population's high rate of co-morbidities (due to chemotherapy and radiation exposure) (Oeffinger & Robison, 2007; Children's Oncology Group, 2008). The establishment of these pediatric cancer "survivorship" clinics engages patients to further develop self-management skills, knowledge about the long-term effects from their oncology treatment, and serve as an interim co-management conduit between pediatric medical home and receiving adult provider. Moreover, the "survivorship" clinic staff provides education to the adult clinician on pediatric long-term effects and the co-morbidities each patient has been screened for due to specific treatment plan his/she previously received. While not exclusively generalizable to the YSHCN, each of these research forums are producing clinical implications to be considered in the macro transitions initiative.

Proposed Next Steps for the AAP

With an acknowledgement of its partners' tremendous efforts towards furthering the transitions' initiative, as well as its own members call to prioritize this issue, the AAP has assumed a strategic lead in addressing the systematic and attitudinal barriers inhibiting successful transitional practice. In assuming such an agenda, the AAP remains aligned with its traditional position of valuing pediatric expert opinion in shaping practice recommendations. However, by using its own resources and partnerships, the proposed AAP transitions agenda is framed with the intent of cultivating a pediatric evidence-base to be shared with the larger medical community within the next 5 years. It is an aggressive and deliberate agenda aimed at approaching the barriers of transition clinical standards and definition, a continuous, comprehensive communication medium, provider training, and provider reimbursement.

Transition clinical standards

While the 2002 *A Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs* and the SUTTP guidelines effectively outline basic, shared principles regarding transitions, there remains a lack of clinical, operationalized standards. This chasm in clinical guidance may inhibit provider absorption of where transition fits within his/her practice scope, as well as clinic flow. Therefore, it is proposed that the AAP will form a multi-tiered interdisciplinary writing committee to develop a Transitions Clinical Report.

The clinical report narrative will stem from a tiered algorithm (i.e. typically developing youth vs. differing types of disability). The end result will allow providers to understand *how* a transition is embedded in pediatric practice scope. Additionally, by defining common clinical standards, adult subspecialties will have expectations as to the "receiving process" in transitions;

while using the algorithm to spring-board the development of common tenets within their specialties' culture.

After dissemination of the report, the AAP may consider a request for proposal (RFP) from practice sites across the country to implement the algorithm. Through this monitored evaluation period, the AAP will be able to assess the efficacy of its pediatric experts' opinions on transition process, as well as provide a testing ground for several transition tools and resources already developed by its partners. The outcomes of this evaluation will possibly lead to populating identification of transitions' best practices.

Future AAP transition initiatives may include:

- Defining the difference between transitions and chronic condition management
- Addressing mental health needs for transitioning YSHCN; consider inclusion in this initial algorithm as its tier or addressed separately
- Considering inclusion of adolescent-friendly atmospheres and equipment in pediatric settings (i.e. clinics, tertiary care settings); may want to be a subsequent effort spearheaded by Committee on Hospital Medicine
- Integrating the clinical transitions guidance into the next *Bright Futures* edition, especially if an algorithm tier is dedicated to typically developing youth

Lack of communication medium

The anticipation for electronic health record's (EHR) contribution to coordinating care continues in the pediatric and adult communities. In 2005, the AAP's commitment to that initiative was founded in its establishment of Partnership for Policy Implementation (PPI). This AAP program joins an existing group of pediatric medical informaticians that consult on policy statements and clinical reports in order to ensure the final content is written at a defined,

operational level which EHR developers can absorb into their products. Additionally, these AAP policies and reports provide the national forums aimed at developing pediatric communication and data EHR standards with needed vocabulary.

With the intention of ensuring the clinical transition competencies outlined by the proposed AAP guideline will be naturally absorbed into EHR development, a PPI representative will be part of the writing committee. Additionally, once the guideline is ready for distribution, the AAP will propose transitions to be a case study for the American Health Information Consortium's (AHIC) upcoming agenda. Each AHIC's case study is extremely involved and considered an intricate process of "flushing out" clinical competencies into the workflow and provider behavior navigated by EHRs. By achieving placement on AHIC's agenda, the AAP will be positing transitions as a healthcare issue for the entire system, not just Pediatrics.

Lack of provider training

To address the systematic barrier of providers' lack of clinical, psycho-social, and resource knowledge and skills necessary for leading a successful transition of care, the AAP will target the provider subset of medical residents in its transition efforts. A transitions residency education subcommittee may be formed to further delve into the resident educational system, identifying barriers and reviewing existing curriculums geared towards caring for youth. For example, there is a medical residency transition curriculum under development through the joint work of Med-Ped colleagues at the universities of Minnesota and Indiana. If this curriculum would be reviewed and approved by the AAP subcommittee, could be disseminated and evaluated across through natural channels. Lessons generated by the curriculum's implementation could be analyzed, distributed, and could frame future AAP provider transition education efforts.

The emotional nature that lends itself naturally into the practice of pediatrics serves as an attitudinal barrier to successful transitions. While the emotional rapport a pediatric provider creates among the patients and families he/she interacts is a positive trademark of the subspecialty, it also has been noted to potentially derail the providers' impetus for initiating and sustaining the transition process. Therefore, acknowledging the emotional component in pediatrics with residents may be fruitful in addressing this barrier.

Lack of reimbursement

Decision-making and coordination of care associated with the transition process is time and energy consuming. However, current provider payment for engaging in transition activities is inadequate, thus often serving as a deterrent rather than an incentive. This financial barrier, both from public and private payors, must be removed in order for long-term change in provider transitions-behavior to be possible.

Using similar methodology to AAP's efforts to increase reimbursement on developmental surveillance and screening and vaccinations, the clinical competencies embedded into the transitions clinical report will be highlighted through various initiatives mutually coordinated with other AAP's department and committees. Additionally, provider education material on proper coding for transition services and reimbursement strategies will be developed and distributed. Representation from Medicaid state leaders and experts throughout these efforts will also be sought.

While the aforementioned strategies are modest, ongoing efforts aimed at enhancing reimbursement will be outlined. However, in order for advocacy efforts to be truly effective, there must be a common understanding of what transitions clinically means for providers and its significance for quality of care (i.e. better resource utilization, decreased costs, increased patient

satisfaction). The first tenet in the AAP's agenda – development of a clinical guideline and evaluating its implementation – is proposed in order to fuel this greater clinical understanding and provide the necessary data to advocate for its role in the delivery of quality care.

Summary

The issue of transitioning youth to adult health care challenges our current care delivery system and process. Transition – is proposed in order to fuel this greater clinical understanding and provide the necessary data to advocate for its role in the delivery of quality care. Transition is a complex clinical journey for all involved, yet still an idealized achievement as it validates medicine's efficacy within patients' care plans. The complexity of transitions, along with the documented amount of interest and activity surrounding it, and the pediatric community's astuteness of its place within quality care, speaks to the critical need for the activities outlined in this report.

References

Agency for Healthcare Research and Quality. (2008). *Children's health advisory group*. Retrieved March 15, 2008, from <http://www.ahrq.gov/child/chagssn.htm>.

American Academy of Pediatrics. (2002). A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics*, *110*, 1304-1306.

Boyle, M., Farukhi, Z., & Nosky, M. (2001). Strategies for improving transition to adult cystic fibrosis care based on patient and parent views. *Pediatric Pulmonology*, *32*, 428-436.

U.S. Department of Health and Human Services. (2000). *Healthy People 2010: Understanding and improving health*. 2nd ed. Washington, DC: U.S. Government Printing Office.

Department of Health and Human Services of the United States. (2001). *President's New Freedom Initiative*. Retrieved March 15, 2008, from, <http://www.hhs.gov/newfreedom/init.html>

Department of Health and Human Services of the United States. (2001). *Delivering on the promise: Preliminary report of federal agencies' actions to eliminate barriers and promote community integration*. Retrieved March 15, 2008, from, <http://www.hhs.gov/newfreedom/presidentrpt.html>

Department of Health and Human Services of the United States. (2002). *HHS programs serves Americans with disabilities*. Retrieved March 15, 2008, from, <http://www.hhs.gov/news/press/2002pres/disable.html>.

Department of Health and Human Services of the United States. (2005). *U.S. Surgeon General issues first call to action on disabilities*. Retrieved March 15, 2008, <http://www.hhs.gov/news/press/2005pres/20050726.html>

Family Medicine Education Consortium, Inc. (2008). *Medical homes for people with intellectual and other developmental disabilities*. Retrieved March 15, 2008, from

http://www.fmec.net/projects/project.php?project_id=120

Hait, E., Arnold, J., & Fishman, L. (2006). Educate, communicate, anticipate: Practical recommendations for transitioning adolescents with irritable bowel disease to adult health care. *Inflammatory Bowel Disease, 12*, 70-73.

Healthy & Ready to Work. (2008). *HRTW: National resource center*. Retrieved March 15, 2008, from <http://www.hrtw.org/>.

Greiner, A. (2007). White space or black hole: What can we do to improve care transitions? *American Board of Internal Medicine Foundation, 6*, 1-4.

Meeks, J. (2007). Introduction to transition medicine. *American Board of Internal Medicine Foundation, 6*, 11-12.

National Committee for Quality Assurance. (2008). *NCQA program to evaluate patient-centered medical homes*. Retrieved March 15, 2008, from <http://www.ncqa.org/tabid/641/Default.aspx>.

Scal, P., & Ireland, M. (2005). Addressing transition to adult health care for adolescents with special health care needs. *Pediatrics, 115*, 1607-1612.

Social Security Administration. (2004). *Youth transition demonstration*. Retrieved March 15, 2008, from <http://www.socialsecurity.gov/disabilityresearch/youth.htm>.

Substance Abuse and Mental Health Service Administration (2004). *Youth transition in workplace*. Retrieved March 15, 2008, from http://www.samhsa.gov/grants/2004/nofa/sp04006_YIW.htm.

Supreme Court of the United States. (1999). *OLMSTEAD V. L. C.* Retrieved March 15, 2008, from <http://supct.law.cornell.edu/supct/html/98-536.ZS.html>.

Taylor, M., Edwards, J. & Ku, L. (2006). Lost in transitions: Challenges in the expanding

field of adult genetics. *American Journal of Medical Genetics*, 142C, 294-303.

The White House. (2008). *Executive order: Improving the coordination and effectiveness of youth programs*. Retrieved March 15, 2008, from

<http://www.whitehouse.gov/news/releases/2008/02/20080207-15.html>

Van Deyk, K., Moons, P., Gewillig, M., & Budts, W. (2004). Educational and behavioral issues in transitioning from pediatric cardiology to adult-centered health care. *Nursing clinics of North America*, 39, 755-768.

Wojciechowski, E., Hurtig, A., & Dorn, L. (2002). A natural history study of adolescents and young adults with sickle cell disease as they transfer to adult care: A need for case management services. *Journal of Pediatric Nursing*, 17, 18-27.

Youngblade, L., & Shenkman, E., (2003). Congruence between parents' and adolescents' reports of special health care needs in a Title XXI program. *Journal of Pediatric Psychology*, 28, 2393-401.

Zach, J., Jacobs, C., Keenan, P., Harney, K., Woods, E., Colin, A., & Emans, S. (2003). Perspectives on patients with cystic fibrosis on preventive counseling and transition to adult care. *Pediatric Pulmonology*, 36, 376-383.

ATTACHMENT A

Transition Survey: Results

The following provides a summary of the outcomes generated from the internal AAP Transitions Survey during December 2007. While its findings are not exclusive, they will be used to frame future efforts in the realm of transitions. Please review, and let us know your thoughts during the transitions' conference call on Friday, January 11, 2008.

Overall response rate: 112

**Responses were evenly generated among the following AAP bodies:

- | | |
|--|--|
| ▪ Administration and Practice Management | ▪ Injury Violence and Poison Prevention |
| ▪ Adolescent Health | ▪ Medical Home |
| ▪ Bioethics | ▪ Medicine -Pediatrics |
| ▪ Committee on Child Health Financing | ▪ Nephrology |
| ▪ Child Abuse and Neglect | ▪ Neurological Surgery |
| ▪ Children with Disabilities | ▪ Otolaryngology/Head & Neck Surgery |
| ▪ Clinical Pharmacology and Therapeutics | ▪ Parent |
| ▪ Critical Care | ▪ Pediatric AIDS |
| ▪ Community Pediatrics | ▪ Pediatric Emergency Medicine |
| ▪ Endocrinology | ▪ Pediatric Pulmonology |
| ▪ Epidemiology | ▪ Pediatric Palliative Care |
| ▪ Genetics | ▪ Pediatric Workforce |
| ▪ Hematology/Oncology | ▪ Rheumatology |
| ▪ Home Care | ▪ Surgery |
| ▪ Hospital Care | ▪ Uniformed Service |
| | ▪ Steering Committee on Quality Improvement and Management |

Regarding the issue of transitioning patients from your practice to an adult health care provider, the following issues/barriers were ranked accordingly:

Serious issue/barrier:

1. Lack of training (adult provider) on how to transition (54.1%)
2. Lack of available adult providers (51.8%)
3. Lack of communication between pediatricians & adult providers (49.1%)
4. Lack of payment for transitioning patients (38.3%)
5. Lack of resources on how to transition patients (36.4%)
6. Lack of training (pediatrician) on how to transition (30.9%)

Somewhat of an issue/barrier:

1. Lack of resources on how to transition patients (50.5%)
2. Lack of training (pediatrician) on how to transition (45.5%)
3. Lack of communication between pediatricians & adult providers (43.5%)
4. Lack of payment for transitioning patients (41.1%)
5. Lack of training (adult provider) on how to transition (34.9%)
6. Lack of available adult providers (32.7%)

ATTACHMENT A

Anecdotal comments regarding barriers:

- Planning needs to begin as early as age 8-10 and be an on-going process involving the patient, parent/caregiver, schools, and the doctors.
- No INTEREST among adult providers in these patients.
- Insurance barriers, independent living barriers, employment barriers, parent (and patient) reluctant to leave pediatrician.
- Major barrier is patients' lack of comfort with adult health care providers.
- We allow our patients to stay with us and do not force them to transition to adult endocrinologists unless they so desire. About 25% of my own practice is now young adults and this works extremely well. We know them. They know us.
- Extremely variable depending on the condition.
- Willingness of patients and families to transition.
- Need to teach how to let go and come up with standards - for subspecialty as well as general care patients.
- Many of the children that I need to transition have chronic health needs making it more difficult to find an adult practitioner who is willing to take them.
- Patient has no health insurance once they turn 18-21 and this also adds to transition problem.
- Lack of knowledge on the part of internists and family doctors who take care of adult survivors about the serious psychological and psychosomatic problems these patients have.
- 1. Lack of coverage for young adults with SHCN (not sure if this is what you meant by "lack of payment" above, but there are two separate issues: first is the lack of insurance coverage for the patient's regular medical care, and second is the lack of reimbursement for the medical office's handling of transition issues during the teen/young adult years as advocated by the Medical Home model 2. Lack of social/political recognition of the exponentially growing population of youth with special needs who will be transitioning into adulthood.
- Culture difference between pediatrics and medicine -- "all their patients have special needs" -- they generally don't see well people.
- Lack of coordinated, multidisciplinary medical resources in adult care setting.

Based on the issues identified in the above question, the following AAP efforts regarding transitions were ranked ordered 1 through 5:

Issue	Average Ranking
Identify adult providers	1.95
Develop transition tools	2.63
Identify best practices	2.82
Develop policy standards/guidelines	2.90
Address payment issues	2.91
Create an algorithmic "how-to" r/t transitions in practice	3.12
Provide training – residency	3.36
Provide training- CME	3.56
Develop communication tools (EHR)	3.59

ATTACHMENT A

Anecdotal comments regarding future AAP efforts:

- I wanted to include them all - they are all important.
- Teach internal medicine-trained people to be as nurturing and caring as pediatricians.
- Residency training should be partnered with internal med residency training programs.
- Consider working with Med/Peds programs both to interest more primary care providers to take these patients as well as to recruit them into our subspecialties. Support combined pediatric/adult fellowship models for Med/Peds MDs.
- Numbers 1 and 2 are inextricably related; having found a paucity of adult primary care providers willing to provide a "medical home" for young adults w/SHCN, the most common identified barrier from their perspective is not a lack of good intent, but rather one of an excess in time/lack of reimbursement; if #1 is addressed, I guarantee #2 will follow; from the pediatric end of transition, reimbursement for the transition process would allow dedicated office personnel who can perform the medical home coordinator/case manager role, which would also contribute to improved identification of adult community providers I did not check the "develop policy standards or clinical guidelines" button, as to me this provides the same end result of the "algorithm" button I believe that training in residency is extremely important, but this topic needs to be backed even farther into medical and nursing schools; waiting until physicians are in their residency is opportunity wasted.
- From my discussions with colleagues in the US, the payment issue for their transitioning patients is a major barrier to on-going care, as well as identification of appropriate adult colleagues. Any work that the AAP is going to do in this area must be in collaboration with adult medicine counterparts in order to be effective; you can publish all the guidelines or tools you want, but no one will use them if the personnel are not engaged to do the job!
- Training needs to be for adult providers as well as pediatric. A heavy emphasis on the psychological and social needs of the patient is critical (dating, achieving independence, future planning, conflicts re wanting independence and perhaps not being able to have it, adaptations to independent living, accessing community resources, living with a chronic illness/ being different, finding a job). Assisting the parent to allow independence of the child where appropriate is also critical.

Identifying interested experts:

100% of respondents indicated a contact person to consider for involvement in transition issues.

The following characterizes the respondents:

1. Academician (41.4%)
2. Subspecialty clinician (29.7%)
3. Primary care clinician (23.4%)
4. Other specialty (14.4%)
5. Surgeon (8.1%)
6. Researcher (6.3%)

Overall, additional comments offered by respondents:

- Important issue for children with special needs, gastrostomy tubes; CP; CHD.
- There are several pediatric endocrinologists who have done this, set up such clinics and have expertise already. Folks at UConn in Hartford (i.e. Karen Rubin) and folks at Riley Children's in Indianapolis (Don Orr and David Marrero) as well as Steve Green and colleagues in Dundee, Scotland.

ATTACHMENT A

- Living situation and estate planning and decision makers for health care.
- RI has developed several materials / transition toolkit for physicians, parents, and youth. I would be happy to share these materials.
- In our AAP chapter, Dr. Robert Burke has been very seriously involved in this issue. Here is his contact information: Robert Burke, MD 593 EDDY ST HASBRO LL PROVIDENCE, RI, 02903 Telephone: 401-444-4471 email: rburke3@lifespan.org
- As a rural pediatrician it is difficult to get anyone to take care of adults with severe cerebral palsy (need total care, non-verbal, weighing less than 50 pounds. There are no inpatient facilities around so the parents take care of these people. When they get sick (i.e. GI Bleeds) I can't get the children's hospitals to see them because of their age, and the internal medicine hospitals won't see because of their size.
- Parents and patients need more education on what transition to adult care should be like and how to make it work for the best of the patient.
- Several: 1. Since the 2002 consensus statement, and even prior to, there has been a proliferation of transition discussion; everyone in the pediatric world knows the importance of transition; I am ecstatic to see the amount of potential funding opportunities being created; however, everyone has been "talking the talk" and real transition "walking" is being started throughout the nation, but on an individual, uncoordinated basis; there are some excellent programs being developed which have the potential for being harnessed and consolidated; too many people are inventing their own wheels; the AAP is the perfect entity for this endeavor 2. There are also federal government programs being initiated involving transition; the AAP has to be the foremost voice representing pediatrics 3. We cannot create a "one-size-fits-all" model; I believe that it is imperative that from this point onward, any efforts towards transition must follow one of two paths/guidelines/algorithms (or whatever names we choose); there must be a separation based on the functionality of the patient, and therefore their (in)dependence from/upon their caregivers; those children who are less functional, and thereby more dependent, are the ones who currently are less likely to find adults primary and subspecialty care, although they are more likely to have better medical access/coverage; it just doesn't make sense!?
- Patients from our practice are given a letter to transfer with records. Their choice of provider depends on insurance. The adult provider does little beyond accept them.
- Without financial incentives, i.e., payment, this program will not function. While many pediatricians are willing to give their services for free, I do not believe that adult practitioners will take on these complicated, difficult patients without reasonable compensation.
- Transition is a very challenging issue and no one strategy can be wholly applied to each area of pediatrics. For example, cardiology. As of this year more adults are living with CHD than children with CHD. The side effects that are occurring in adults with CHD in many cases have never been seen before because these people have not lived into adulthood. Both pediatric and adult cardiologists are not comfortable seeing these adults. Many clinics are being established where both pediatric and adult cardiologists are seeing the patients together...to learn from one another. The issues go on and on....
- The failings of pediatricians account for only a very small fraction of the difficulties that patients and families face in transitioning to adult care settings. The hard problems lie outside the pediatric care setting. The AAP must view transition as an **ADVOCACY** challenge, not as an **EDUCATIONAL** challenge.

ATTACHMENT B

Site	Title	Description	Contact	Additional information
JaxHATS	Transitions Readiness Tool	The Transition Readiness Tool is available in two versions. One version is a client version that should be used by youth who are expected to acquire the skills needed to independently manage their own condition and health care needs, to set educational and career goals and to live independently. The second version is a caregiver version for caregivers or parents and should be used when the youth, due to developmental disabilities or cognitive deficits, will not be able to learn the skills needed to independently manage their condition, health needs etc.	David Wood, MD, MPH, FAAP	
Oregon Health and Science University	Planning for Success	This tool serves as a comprehensive transition planning self-assessment tool for YSHCN. It is a computerized format, based off of the International Classification Functioning (ICF) methodology (classifies disability and health per WHO perspective.) While this classification populates question sets, developers "filled in the holes" by adding questions pertaining to oral health, nutrition, health literacy, and civic participation. The questions are divided into two parts: medical and social. It is conveyed in a 5th-grade language, and framed in strength-based language.	Randell Phelps, MD, PhD	Currently, submitting NIH proposal for future pilot testing
The UNC Successful Transition to Adulthood with Rx-treatment Program	The Medical Passport Program	A personalized credit-card sized identification card; created by transition coordinator. Information includes: diagnosis, patient's picture, allergies, medication allergies, insurance, and emergency contact information. Each card is assigned a unique ID in the clinic for tracking purposes. In-person or in-clinic follow-up occurs every three-months to ensure card accessibility and/or need for updates.	Paul Sagerman, MD, FAAP	
The UNC Successful Transition to Adulthood with Rx-treatment Program	The Self Administered Transition Readiness Survey	This survey takes 10 minutes to complete, and was developed per outcomes from focus group, chart abstractions, focused and cognitive interviews, and anecdotal conversations. Areas included in the survey are: knowledge of disease diagnosis, medication/treatment, health insurance, ability to make medical appointments, ability to use health resources, and disease self-management.	Paul Sagerman, MD, FAAP	
The UNC Successful Transition to Adulthood with Rx-treatment Program	The Health Provider Administered T.R.A.N.S.I.T.I.O.N. Score	Developed for patients 12-22 years in order to ascertain process of transition from parent-directed care to self-management among adolescent/ young adult patients. It outlines 10 global self-management skills the patients needs to demonstrate before a successful transition. Those skills are: Type of illness, Rx=medication, Adherence, Nutrition, Self-management, Issues of Reproduction, Trade, Insurance, Ongoing Support, and New Health Providers.	Paul Sagerman, MD, FAAP	

ATTACHMENT B

Waisman Center	Youth Fact Sheets	Youth Fact Sheets are a series of six fact sheets developed and edited by youth with special health care needs. Topics include planning for technical or 4-year college, how to get supports in the workplace, how to be involved in the Individual Education Planning process and others. The series is free.	Beth Sweeden	
Waisman Center	Transitions to Adult Health Care: A Training Guide in Two Parts	This training guide is intended to serve as a framework for anyone interested in helping young people with special health care needs and their parents prepare for the transition to adult health care. The Maternal and Child Health Bureau of the U.S. Department of Health and Human Services defines a child with special health care needs.	Beth Sweeden	
Waisman Center	Stories of Transitions to Adult World	The road to adulthood is rarely smooth, even for young people who have had the best possible preparation. When a young person has a significant disability, that journey can be even more challenging. Work experiences can be harder to come by and require more support. A young person may have to learn how to manage medications and talk to doctors along with learning how to cook and balance a checkbook. Inadequate transportation and long county waiting lists further complicate the ability to live and work in the community.	Beth Sweeden	
Waisman Center	Caleb's Story	An 11-minute video developed in partnership with Wisconsin Council on Developmental Disabilities and Wisconsin Coalition for Advocacy, highlighting the work and home experiences of a young man with very involved health, cognitive and physical disabilities. It includes footage of him at work in the community, shopping and traveling in the community, and at the home he purchased. Discussion questions included.	Beth Sweeden	
Waisman Center	Youth as Partners	Youth as Partners is a training curriculum that helps adult organizations more meaningfully include youth with disabilities as full team members and active participants in community organizations, decision-making councils and policy-making boards. Included are modules on the disability culture, the youth culture, and creating active partnerships with youth.	Beth Sweeden	

ATTACHMENT C

Program Name:	Primary Contact Name:	Which of the following most appropriately describes the setting in which the program exists?	What is the primary source of funding for the program?	Phase indicate all of the disciplines involved in the program's implementation and maintenance.	Of all the disciplines you indicated in question #4, which is the primary discipline necessary for the program's operationalized success?
Children's Hospital of WI Spina Bifida Program	Karen Raney, CNS	Response Other (please specify) Ambulatory Care Spine Bifida Program	Response Provider reimbursement - Also a lot of Medicaid private	Physician Physician Advanced practice nurse Advanced practice nurse RN Physician assistant Social Worker Case Manager Patient Youth Educator Legal expert Insurance expert Other (please specify) Medical Secretary Advanced practice nurse	Physician Advanced practice nurse Advanced practice nurse RN Physician assistant Social Worker Case Manager Patient Youth Educator Legal expert Insurance expert Other (please specify) Medical Secretary Advanced practice nurse
CVACC	Donna Gore Olsen	Referral-based, consultative service	State grant	Physician Advanced practice nurse RN Physician assistant Social Worker Case Manager Patient Youth Educator Legal expert Insurance expert Other (please specify) Disability Advocate Physician	Physician Advanced practice nurse Advanced practice nurse RN Physician assistant Social Worker Case Manager Patient Youth Educator Legal expert Insurance expert Other (please specify) Disability Advocate Physician
Health Services for Children with Special Needs, Inc.	Cyd Campbell, MD, Medical Director	MCO Healthcare for Children w/Special Needs	Provider reimbursement - Medicaid	Physician Advanced practice nurse RN Physician assistant Social Worker Case Manager Patient Youth Educator Legal expert Insurance expert Other (please specify) Disability Advocate Physician	Physician Advanced practice nurse Advanced practice nurse RN Physician assistant Social Worker Case Manager Patient Youth Educator Legal expert Insurance expert Other (please specify) Disability Advocate Physician
Special Kids Support Center	Barbara Draheim AFREN	Tertiary Hospital	Combination	Physician Advanced practice nurse RN Physician assistant Social Worker Case Manager Patient Youth Educator Legal expert Insurance expert Other (please specify) Disability Advocate Physician	Physician Advanced practice nurse Advanced practice nurse RN Physician assistant Social Worker Case Manager Patient Youth Educator Legal expert Insurance expert Other (please specify) Disability Advocate Physician
TAY One Stop Program	Andrie Bosselaux	Transition Age Youth One Stop Center	State grant	Physician Advanced practice nurse RN Physician assistant Social Worker Case Manager Patient Youth Educator Legal expert Insurance expert Other (please specify) Disability Advocate Physician	Physician Advanced practice nurse Advanced practice nurse RN Physician assistant Social Worker Case Manager Patient Youth Educator Legal expert Insurance expert Other (please specify) Disability Advocate Physician
The Children's Hospital/University of Colorado	Joyce Olmsted, MD	Academic institution	Provider reimbursement - Medicaid	Physician Advanced practice nurse RN Physician assistant Social Worker Case Manager Patient Youth Educator Legal expert Insurance expert Other (please specify) Disability Advocate Physician	Physician Advanced practice nurse Advanced practice nurse RN Physician assistant Social Worker Case Manager Patient Youth Educator Legal expert Insurance expert Other (please specify) Disability Advocate Physician
Children's Medical Services Branch	Isoken Aderin-Freeman	State-based program	Federal grant	Physician Advanced practice nurse RN Physician assistant Social Worker Case Manager Patient Youth Educator Legal expert Insurance expert Other (please specify) Disability Advocate Physician	Physician Advanced practice nurse Advanced practice nurse RN Physician assistant Social Worker Case Manager Patient Youth Educator Legal expert Insurance expert Other (please specify) Disability Advocate Physician
University of Minnesota Adult Metabolism Clinic	Kristl Bartler	Academic institution	Provider reimbursement - private	Physician Advanced practice nurse RN Physician assistant Social Worker Case Manager Patient Youth Educator Legal expert Insurance expert Other (please specify) Disability Advocate Physician	Physician Advanced practice nurse Advanced practice nurse RN Physician assistant Social Worker Case Manager Patient Youth Educator Legal expert Insurance expert Other (please specify) Disability Advocate Physician
Shriners Hospitals for children, Leavenworth	Cindy Terry	Hospital/clinic	Funded through Shriners	Physician Advanced practice nurse RN Physician assistant Social Worker Case Manager Patient Youth Educator Legal expert Insurance expert Other (please specify) Disability Advocate Physician	Physician Advanced practice nurse Advanced practice nurse RN Physician assistant Social Worker Case Manager Patient Youth Educator Legal expert Insurance expert Other (please specify) Disability Advocate Physician
Developing a Children's Hospital at Wisconsin-wide Transition Process	Nicole Kyrle	Tertiary Center & Academic Institution	Hospitalist support	Physician Advanced practice nurse RN Physician assistant Social Worker Case Manager Patient Youth Educator Legal expert Insurance expert Other (please specify) Disability Advocate Physician	Physician Advanced practice nurse Advanced practice nurse RN Physician assistant Social Worker Case Manager Patient Youth Educator Legal expert Insurance expert Other (please specify) Disability Advocate Physician
University of Wisconsin Pediatric Pulmonary Center	Mary Mallouk	Academic institution	Federal grant	Physician Advanced practice nurse RN Physician assistant Social Worker Case Manager Patient Youth Educator Legal expert Insurance expert Other (please specify) Disability Advocate Physician	Physician Advanced practice nurse Advanced practice nurse RN Physician assistant Social Worker Case Manager Patient Youth Educator Legal expert Insurance expert Other (please specify) Disability Advocate Physician

read buy-in and collaboration of all team members

ATTACHMENT C

Please provide primary contact information for the program.	Which of the following most appropriately describes the setting in which the program exists?	What is the primary source of funding for the program?	Please indicate all of the disciplines involved in the program's implementation and maintenance.	Of all the disciplines you indicated in question #4, which is the primary discipline necessary for the program's operationalized success?
Genetic Lifetime Specialty Healthcare	Outpatient specialty clinic for adolescents and adults with childhood onset conditions	We accept all payers & payers are Medicaid and Medicare	Physician RN Advanced practice nurse Social Worker Parent Youth	Occupational Therapy, Physical Therapy, Speech Language Pathology, Custom seating, orthotics, prosthetics, Psychiatric Physician, Therapists, audiologists, Nutritionists Physician
Baylor Children's Hospital	Pediatric primary care provider's office	Initially, this is funded via institutional support	Physician RN Advanced practice nurse Social Worker Case Manager Parent	This is a group effort, led by one a pediatrician
Comprehensive Care	Academic institution	Provider reimbursement Medicaid	Physician RN Advanced practice nurse Social Worker Youth	Physician
Petersleuth Camp Care	Academic institution	Provider reimbursement Medicaid	Physician RN Advanced practice nurse Social Worker Legal expert	Susan Walker
Illinois Center for Rehab and Education	State-based program	State funding (non-grant related)	Physician RN Advanced practice nurse Social Worker Case Manager Youth	Therapists For the medical expert APN, but we are revamping the assessment tool used for all disciplines created by the OT
JaxHATS (Jacksonville Health and Transition Services)	Hospital-based outpatient clinic	State funding (non-grant related)	Physician RN Advanced practice nurse Social Worker Parent Youth	Physician
JaxHATS, Jacksonville Health And Transition Services Program	Academic institution	State funding (non-grant related)	Physician RN Advanced practice nurse Social Worker Parent Youth	Physician
Tulane University School of Medicine	Academic institution	State grant	Physician RN Advanced practice nurse Social Worker Case Manager Parent	Physician Community advocate Insurance expert
Project DOCC - Delivery of Chronic Care	Academic institution	Grants and small one time fee from each medical center	Physician RN Advanced practice nurse Social Worker Case Manager Parent	A program manager, who may be a social worker, nurse, PA, etc. Director of residency training & parents

ATTACHMENT C

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WISHES	Academic institution	Institutional support	Physician	Physician
Bureau for Children with Medical Handicaps	State-based program	Federal grant	Physician	Parent
Care connection for children	Contracted by state to local health system	Federal grant	Physician	Case Manager Transition coordinators
Sickle Cell Transition Intervention Program	Pediatric Regional Hospital	State grant	Physician	Transition coordinator
matigan army medical center	Adult ARNP embedded in developmental pediatrics clinic	TRICARE/federal	Physician	Advanced practice nurse
Adolescent Healthcare Transition	State-based program	Federal grant	Physician	Advanced practice nurse Youth
Boys Town Transitions Clinic	Pediatric primary care provider's office	Federal grant	Physician	RN
New Jersey Department of Health and Senior Services, Special Child Health and Early Intervention Services	State-based program	Federal grant	Physician	Case Manager Youth Transition involves all disciplines and emphasis expanded in child/youth's care

ATTACHMENT C

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Health Care Transitions	Dominic Callaghan	Referral-based consultative service	Provider reimbursement private	Physician	Parent
Community Case Management	Julie Meyers, MD	Academic institution	State funding (non-grant related)	RN	Case Manager
Metrolink Health Center Comprehensive Care	Grey Nertz	Academic institution	Provider reimbursement Medicaid	Physician	Physician
MCHB HRW Initiative Transition Team pilot Hospital for Children	Elizabeth McGuire Louis Bartoshewsky	Academic institution	Federal program	Physician	PT, OT
Los Angeles County Children's Medical Services	Dr. Stephen Wolf	State-based program	Federal grant	Physician	Physician
WVS Institute for Health Transition Training	Wenke P. Dasa MD, MPH	Academic institution	State grant	Physician	Physician
Adolescent Transition Program	Eric Lavey, R.D.	Referral-based consultative service	Provider reimbursement Medicaid	Physician	Physician
Training Up for Transitions, Phoenix Children's Hospital	Tressia Shaw	Pediatric primary care provider's office	Private grant	Physician	Social Worker
Prescribed Pediatric Center	Elizabeth Guppert M.D. FAAP	School-based program	Provider reimbursement Medicaid	Physician	Physician
Cystic Fibrosis Center	Mark L. Miller	Academic institution	institutional support	Physician	Physician
USF/CYU Adolescent Program	Kris Millrose	Academic institution	Provider reimbursement Medicaid	Physician	Physician
Medical Home/Transition CS/CO	Harper Randall	State-based program	State funding (non-grant related)	Physician	Case Manager
Adolescent and Young Adult with Congenital Heart Disease	Thomas S. Kitzner, MD, PhD	Academic institution	Joint venture between adult and pediatric cardiology	Physician	Physician

ATTACHMENT C

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Brenner Children's Hospital	Academic institution	State funding (non-grant related)	Physician	Case Manager
Storwade Parent Advocacy Network	Tertiary-center multispecialty clinic	Combination of federal, state, and foundation funds	Physician	Family Advocate
Transition Clinic	Referral-based consultative service	Provider reimbursement	Physician	Parent
Easter Seals New York DTC	Community health center	Private grants	Physician	Insurance expert
University of Michigan Medical Center - Inpatient/Outpatient Federal Hemophilia Treatment Centers/Region IX	Academic institution	Provider reimbursement Medicaid	Physician	Parent
Oklahoma Transition Council/Institute	State-based program	Federal grant	Physician	Physician
UAB/ Children's Hospital Cystic Fibrosis Center - Transition Program	Academic institution	All above except State grant	Physician	Regional Network Manager/ Data Manager/ Physical therapist/ registered nurses
Children's Medical Services	State-based program	Multiple collaborative funding streams	Physician	Higher education/ education department & health science center/ pediatrics/ state agencies/ Vocational Rehabilitation/ Education/ Mental Health & Substance Abuse/ Health
CEC: Medical Transition Project	State-based program	Provider - private and Medicaid	Physician	Physician
UNC Transition	Academic institution	Federal grant	Physician	Primary staff are medical social workers
	Adult primary care provider's office	Hugh Evans Legacy Award	Physician	RN
	Pediatric Subspecialty Program	Foundation Agency	Physician	Transition Coordinator

ATTACHMENT C

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The Transitions Program	Lori A. Anderson, M.Ed.	Podiatric Specialty Hospital - Burns	Institutional support	Physician	RN	Social Worker	Educator	Educator
Children's Medical Services Tampa Bay Region Transition Planning and Assessment Team	Julie Force, RN	State-based program	State funding (non-grant related)	Physician	RN	Social Worker	Parent Youth	RN
Children's Rehabilitation Services Tegen Transition Clinic	Kathryn Chodkiewicz, LGSW	State-based program	State funding (non-grant related)	Physician		Social Worker	Parent Youth	Physician
Transition program	Tressia Shaw MD	Academic institution	Provider reimbursement	Physician	RN	Social Worker	Educator	Physician
Special Adolescent Clinic	Lawrence B. Friedman, MD	Academic institution	Combination of several federal and institutional resources	Physician		Social Worker	Youth	Social Worker
All Dept of Rehabilitation Services	Children's Rehabilitation Service	State-based program	State funding (non-grant related)	Physician	RN	Social Worker	Parent	Physician
Pennsylvania Ventilator Assisted Children's Home Program	John J. Downes, MD, FAAP	State-based program	State grant	Physician	RN	Social Worker	Case Manager	Program requires MD, CRNP Administration, RN's and MSW's
UPMC Adult Spina Bifida Clinic	Brad Dicianno, MD	Adult specialty provider's clinic	State grant	Physician	RN	Social Worker	Parent Youth	Physician
Flagstaff Med Ctr's Children's Rehab Site	Joanne Parks	State-based program	State funding (non-grant related)		RN	Social Worker	Case Manager	Orthotic, Nutritionist, Psychologist, Wound care nurse
Special Kids Support Center	Barbara Drakeley APRN	Tertiary Care Free Standing Children's Hospital	Combination State Grants and Institutional support	Physician	RN	Social Worker	Parent Youth	Advanced practice nurse
Center for Disabilities and Development/University of Iowa	Jack Hilyard	Academic institution	Federal grant	Physician	RN	Social Worker	Educator	Youth

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Shriners Hospital Transition	Pediatric Orthopaedic Hospital	Institutional support	Physician Physician assistant Advanced practice nurse Social Worker Youth Parent	Social Worker PT, OT, Child Life Specialist, Orthotic Tech, Hospital Administrators, Physiatrists Parent
HCP Program for Children with Special Health Care Needs	State-based program	Federal grant	Physician	Parent
Children's Medical Services	State-based program	Federal grant	Physician	RN RN is the care coordinator in our program
Adolescent Health Transition Project	Academic institution	State funding (non-grant related)	Physician	Parent
Locus Pediatric Care Group	Academic institution	Institutional support	Physician	Physician Undergraduate Research Asst
Shriners Hospital for Children, Transitions Program	Pediatric Orthopaedic Specialty Hospital	Institutional support	RN Social Worker Case Manager Youth Parent	Case Manager Case Manager
Baylor Transition Clinic	Academic institution	Institutional support	Physician	Physician Social Worker

ATTACHMENT C

Response	Please indicate the greatest barrier your program has experienced to date.	Describe the assessment tool the program uses. Please include information about the fields included (i.e. health, social, education), when it is administered, how often a patient is assessed with this tool, and if more than one assessment tool is used by the program.	Describe the program's means of evaluation.
Other (please specify)	None	Open Ended Response	Open Ended Response
Communication among systems of care (i.e. school, health, legal, etc.)	Time to have the transition visit and do the Clinical Summary for the receiving physicians in the adult hospital	1. Age determines who is transitioned. 2. We use an assessment tool developed by our City Committee for the state wide collaborative to transition children with special needs to adult care. I have modified it to suit the spine bifida population.	The transition to adult care is a pilot project that has a research component to it for those who volunteer to participate. They get transitioned to adult care regardless of their participation in the study. The study uses a variety of standardized measurement tools to assess the satisfaction with the services and providers in the adult facility.
Communication among systems of care (i.e. school, health, legal, etc.)	None	CACC has developed a tool for an Individual Health Assessment Plan (IHAP) that helps the interdisciplinary team involve the youth, young adult and family in looking at all aspects of transition including health, independent living, education, employment, social/leisure.	Dr. Nancy Swigonski, MD, MPH has helped the team develop a tool to collect data based upon the work done by Rich Anshel, MD. Staff use PDAs to collect data.
Communication among systems of care (i.e. school, health, legal, etc.)	None	Transition planning is governed by the organization's policy on Transition to Adult Level Care and Services, which specifies what areas are to be addressed, and its documentation in the Care Coordination Plan. In addition, a Transition Coordination Events Guide for Care Managers is available for use to determine what care coordination interventions are necessary, at what age, for each life domain.	There is no formal/means of evaluation.
Provider resistance to receive transitioning patients	None	We sent at about age 13 years, interviewing family about the idea that they will need to seek adult health care some day. We use a check list to make sure we cover all parameters, health care providers, vocation, education, housing, insurance, etc.	This office stays involved with family/patient until they are satisfied with adult situation.
None	None	Yes more than one assessment tool used however once engaged youth consistently across program.	Both treatment team peer review and client feedback.
Lack of adult medical physicians knowledgeable in caring for CSHC	None	Not sure.	Not sure as it is a new clinic.
Lack of physical space	None	Assessment tools will be finalized in the Spring of 2008	Starting in Fiscal Year 2007/2008 our program implemented a new Performance Measure with our local California Children's Services in the area of transition. It is "Children, 14 years and older will have documentation of transition planning into adult services on an annual basis." This is our first step in gathering information on what our local programs are doing in the area of transition.
Communication among systems of care (i.e. school, health, legal, etc.)	None difficult if young person does not have insurance	1. Internal resource and tracking tool bases: medical specialists, primary care provider, medical financial, SSI, employment, DVR, schools, housing, guardianship and legal aide. 2. Assessment is done on first clinic visit and approximately once a year or as needed.	1. Internal verbal feedback 2. Client satisfaction survey
Accessing initial funding	None	Youth's assessment tool that reviews: health issues, physician provides such primary health care and specialty care, health care funding, educational/academic planning, needs for equipment/supplies/medication, living arrangements, transportation, legal issues, guardianship, wills and trusts, recreation/recreational activities.	As the process of developing for all services begins an exit visit evaluation and follow-up six-12 months later.
Provider resistance to receive transitioning patients	None	Although provider surveys have been utilized and a business plan has been created, the program is still working to achieve proper funding and hire staff to spearhead the program. Grants have been applied for as well.	N/A-see response above.
None	None	Developmental checklists were created and customized to specific diagnosis care guidelines. These checklists are administered 5 times between the Ages of 8 and 18 yrs of age.	Pre and post surveys for youth. Program has not been implemented long enough to have reportable results, only anecdotal at this time.

ATTACHMENT C

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<p>Provider resistance to let go of their adolescent and other patients to adult provider/services and patient/family uncertainty of the unknown adult model. There needs to be a permission and encouragement to move on to adult care.</p>	<p>Youth self-assess using a brief self-identifying checklist. More specific assessment may be used depending on the expressed need.</p>	<p>From an operational point of view we track the number of patients that transition from Gillette's pediatric providers to adult providers, their age at transition, what provider disciplines the patients are transitioned from. Most telling is if the patients choose to stay in adult care or return to pediatric providers.</p>
<p>Sustaining funding</p>	<p>one to one referral, close work with DMR and the schools</p>	<p>Being developed</p>
<p>Receiving adequate reimbursement</p>	<p>We do not have a formal tool.</p>	<p>None now</p>
<p>Receiving adequate reimbursement</p>		
<p>Communication among systems of care (i.e. school, health, legal, etc.)</p>	<p>We have a STEPS program in which everyone evaluates the child's abilities and they move from level to level. For medical they first deny the health care providers and eventually make appointments</p>	<p>Re-assessment often 6-12 months</p>
<p>Sustaining funding</p>	<p>We have developed a Transition Readiness Tool, which is administered to all patients in the program at the time of intake and 1 year follow-up</p>	<p>Various deliverables such as number of emergency department and hospital admissions are tracked. Patient scores on the Transition Readiness instrument are also used to demonstrate program effectiveness. We have conducted tests of the instruments validity and reliability as well.</p>
<p>Communication among systems of care (i.e. school, health, legal, etc.)</p>	<p>We have developed a tool and call KTRAC 3.0-Transition Assessment Questionnaire. We administer it to patients and their support networks every 6 months. It measures the following domains: Managing your own health, interacting with the health care system, and other activities related to transition. I would be happy to send you a copy of this instrument.</p>	<p>We conduct patient/family satisfaction surveys quarterly. We assess impact of this program on use of the ED and hospitalizations. We monitor the status of youth exiting the program- either by successfully transitioning or other outcomes.</p>
<p>Accessing initial funding</p>	<p>Multiple instruments used to assess patient and family... developed internally... make comprehensive assessment and annual outcome survey</p>	<p>Two main methods of evaluation are the annual patient survey and care coordination activity log</p>
<p>Provider resistance to broach transition issues</p>	<p>Residents of our evaluations</p>	<p>One page evaluations</p>

ATTACHMENT C

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Provider resistance to receive transitioning patients	No specific assessment tool. Med-Peds residents assist patients in filling out their own health history.	Patients are referred to selected Med-Peds resident for assistance in transition. Residents also meet with community and hospital groups to provide transition education.
Communication among systems of care (i.e. school, health, legal, etc.)	We have quarterly meetings of 3 Regional Youth advisory councils and use many of the Healthy and Ready to Work Materials.	Feed back from the Council Members
Patient/ family resistance	Lack of resources after age 21.	We are WORK here. Family satisfaction survey
Provider resistance to broach transition issues	I am still attempting to create a tool. There are many tools for transition. I have not found one tool is specific to stroke that can be used for my purposes.	I have only been in the position since 3/07. I am tracking all patient contacts and related activities so that we can develop a useful evaluative tool.
Provider resistance to receive transitioning patients	Needs assessment for transition performed with 69 families, and also with focus groups abstract available above results.	Patient/parent satisfaction outcomes measures such as: administration rates of population, referral for adult issues, well organized care, etc.
	Portable medical summary, physician checklist, youth / parent self-determination checklist	Increases in awareness, successful transition of youth, risk to needs.
Lack of full-time dedicated staff as care coordinator/ health educator	Ansel-Carey Life Skills Assessment and new questionnaire developed to assess youth's knowledge of personal health, how to access health services and maintain healthy lifestyle. Questionnaire is administered pre and post-intervention.	Use of questionnaire as described above and long term follow-up interviews with youth 2, 5 and 16 years post discharge.
Sustaining funding	A collaborative effort with the Statewide Stroke Network (NS-PTT) yielded supplemental funding used to develop a demonstration project on transition to adulthood for CSKN. A template for a county based protocol of transition materials was developed in the pilot county, and used as a framework for other counties statewide. However, the additional funding provided through the demonstration project that partially supported a parent of a CSKN to assist with targeted transition could not be sustained.	Program monitoring is conducted by State staff. Site visit to local management unit including review of individualized service plan. A family satisfaction survey requesting feedback on case management service and referrals is administered by State staff.

ATTACHMENT C

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Communication among systems of care (i.e. school, health, legal, etc.)	We have developed a comprehensive assessment that is a very detailed review of systems that looks at medical necessity for nursing interventions. The tool is administered in the member's home yearly.	pending
Receiving adequate reimbursement	In planning	We are currently undergoing our first localized program evaluation
Communication among systems of care (i.e. school, health, legal, etc.)	2 Tools: Adolescent Transition Review (ATR) Adolescent Transition Care Plan (ATCP) Each focus on 5 main areas: 1. Medical Home 2. Medical Subspecialist(s) 3. DME/Medical Supplies 4. Funding (sources for Independent Living) 5. Recreational/Social/Vocational	Feedback survey from client/care givers
Provider resistance to broach transition issues	10-item Transition self checklist developed by our program. For study purposes we are also adopting the Assessment of Chronic Illness Care instrument and will use the transition questions on the medical home index. We also are assessing satisfaction	As outlined above
Recruiting patients	No single tool.	None
Sustaining funding	An initial assessment includes evaluating both medical and non-medical needs of transition - i.e. living situation, education, need for guardianship, transportation, as well as - pt knowledge about their condition, ability to care for self etc. This is done at first visit, repeated as needed and then at time of transition to an adult provider.	Number of patients transition Pre and post evaluation of medical needs, knowledge
Provider resistance to receive transitioning patients	IEP and IFSP Family Burden Index used also	The early intervention system and Public Education district do IEP and IFSP? The Family Burden Index is done by a social worker or RN
Communication between providers	Questionnaire used to determine knowledge and management of disease. Ability to function independently without parent support.	Questionnaire and team and family input
Provider resistance to receive transitioning patients	The CHS Transition Planning and Assessment team addresses the medical, social, vocational and daily life issues during the transition period.	Transition staffing summaries are used along with recommendations in order to evaluate medical/psychosocial/vocational and funding needs of the patient.
Accessing initial funding		None current program consists of case managing transition youth from our CSHCA clinics
Recruiting patients	A self (patient) administered health questionnaire that includes a self-management checklist (filled out by APN) examine patients' knowledge re: health, health seeking behaviors, and health risk behaviours; plan to use QOL measures: either TAAQOL, Pods-QI or SF 12.	As we started we used patient/parent focus group and made changes based on their input; we plan to do not only program evaluation, but implement a pre-test post-test control design. Once we get a critical mass, we plan to do both

ATTACHMENT C

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Just standing up barriers being identified	Will be using "It's Time to Transition" workbook by Dr. Laura Pickler, will also be using patient plan of care being self-developed, currently North Carolina is developing "curriculum" which hopefully will be piloted at our institution	Plans for evaluation initially based on patient/parent response/survey, identifying a control group of young adults who have self-transitioned over the past 15-10 years. We obtained comparative information; will extend evaluations into realm of adult primary care providers to assess their opinion of program's utility; this is a second phase plan
Communication among systems of care (i.e. school, health, legal, etc.)	Our Family to Family IRC uses the Adolescent Autonomy Checklist which has a section on Health Care skills as well as at home skills, emergency skills, community skills, self care skills, etc.	We conduct follow-up interviews with a sampling of participants 6 months after their participation to determine outcomes using a standardized tool that we modified from the tool used by the US Department of Education-funded Parent Training & Information Centers (SPAN is also a PTI)
Accessing initial funding	Self-managed database to look at participation in self care and community activities	Change in participation levels
Receiving adequate reimbursement		
Sustaining funding	Customized survey	Individual survey
Receiving adequate reimbursement	Each of the 13 Hemophilia Treatment Centers uses their own assessment tools covering similar fields: assessing physical, social, emotional domains. We also participate in the CDC surveillance of bleeding disorder complications--we're part of the U.S. network of 130+ federally supported Centers. This is the world's largest such prospective database for hemophilia and other inherited bleeding disorders.	1. The CDC surveillance system, 2. voluntary Hemophilia Data Set, 3. Performance measures developed in conjunction with HRSA, 4. Site visits, 5. Accomplishment of regional goals/objectives in line with HRSA/CDC grant goals/objectives
Provider resistance to broach transition issues		Higher education is developing an evaluation process currently
Communication between providers	We use a transition checklist to assess readiness for transition and it is given annually.	Above mentioned tool as well as ongoing text building between adult and pediatric teams
Sustaining funding	Our Family, medical/psycho-social, educational centers transition planning tool is utilized with client's aged 18-21. A general family medical/psycho-social, educational service plan is used with all clients. Prior to clinic visit, clients' needs are assessed.	Following feedback feedback & outreach clinics, clients are surveyed on satisfaction with services provided. Interim client evaluation surveys are performed
Communication among systems of care (i.e. school, health, legal, etc.)	Beginning phase, identifying resources, using model from Florida	In progress
Sustaining funding	1. The UNC T-RAX M.S.T.T. L.O.N. Score (19) (Administered by a "Health Provider") 2. The Transition-Readiness Survey (Self-administered by the adolescent) 3. The Medical Questionnaire 4. The Liberty Program	Longitudinal measurements on patient's transition process based on our tool. Our tools adapted the website check lists to a system that facilitates the transition process.

ATTACHMENT C

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Locating physical space	Form scans/disengagement services offered in adult healthcare are viewed as cosmetic and not covered by insurance	Currently working on a formal means of program evaluation.
Provider resources to receive transitioning patients	Funding/resources for children with special health care needs	The assessment information is reviewed by the Transition Team during a staffing that includes the client. Referrals are made based on client needs that are discussed at the staffing. After a staffing is complete, a "staffing summary" form is compiled and outlines everything that was discussed at the staffing. In case the client could not attend, as well as any referrals needed and who is responsible for following up on those referrals made during the client's transition staffing.
Recruiting patients	Pre-Functional Assessment done prior to the actual clinic. It requires two days of testing with the student.	Multi-Discipline Team approach. All members make recommendations.
Receiving adequate reimbursement	Not known	Not known
Sustaining funding	MD, ARNP, peer advocate, and social worker all assist to assess readiness, provide program information, encourage initiation, and support adherence. A form captures dates of transitioning events and milestones over the usual 2-year process.	Social Worker's telephone and personal contacts monitor whether appointments are kept with the adult providers.
Sustaining funding	CRS uses multiple assessment tools, each specific to the professional discipline. Social workers perform psychosocial assessments upon enrollment, follow up with mini-assessments at clinic visits, home visits, and school visits. Nutritionists use their own assessment tool, as do nurses, PTs, OTs, STs.	UNKNOWN
Communication among systems of care (i.e. school, health, legal, etc.)	Complex enrollment form to enter ongoing admission & quarterly phone interviews of parents, annual and as needed home visits by SN & KSW from program.	Admission forms from referring hospital at discharge to have copies of ventilator dependent child, credentials for appropriate discharge and admission to home care, formatted quarterly phone interviews with parents, monthly clinical conference by all staff with focus on patient's transitioning to adult care & patient/families facing extraordinary problems.
Locating patients who are in the community but have no access to services	State contract with four CRS sites mandates beginning transition at age 14, documenting personal discussion re transition and continuing transition with a transition paperwork to future plan at age 21	ADHS at the state audits the four sites to include ours to verify documentation of transition is in the medical record.
Sustaining funding	Starting at 15 years of age, family/child introduced to concept of transition to adult providers. Using a checklist, we establish a transition care plan with the family. Education about physical condition, vocational needs, housing needs, insurance need for PCP and 2 subspecialists addressed, guardianship 2. Advanced directives, living will, anything else family/child brings up.	Family patient satisfaction survey
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Accessing adequate funding	Health, Legal, Independent Living, Psychosocial, Employment, Education, Transportation, Community Resources. At the age of 13 patients are evaluated. The patient is evaluated every six months during their follow-up appointment and if needed the evaluation will be done more often.	Data collected in the clinical appointment or a hospital admission a transfer evaluation order has been placed in our system for patients 13 and up to be evaluated that day.
Receiving adequate reimbursement	We are using evaluation through Medical Home Standards recently developed by our State Medical Home Initiative Evaluation Task Force.	Medical Home outcomes, specific criteria developed as part of our pending MCHP Mt grant.
Have no additional funding and limited staff	Use a modified version of manual developed in Massachusetts (Institute for Community Inclusion/LAB Children's Hospital/Boston). The sections are health, education, employment, legal rights, independent living and community living and recreation. We begin the process by at least age 16 but may start earlier depending upon client. We have a client assessment tool and family assessment tool which are the same form but used independently by the client and family. After the initial assessment, there is at least twice a year updating.	Interviews of client, family, physician, etc face-to-face and by phone.
Provider reluctant to receive transitioning patients	Informational services only, not a clinic.	
Communication between providers	We do not have such a tool yet.	Our program is still formative.
Knowledge and wide spread use of tools, etc among all health care providers	Patient screening tool self-identifying needs—done yearly from age 15 on for complex patients with certain diagnoses—addresses health, insurance, education, work, adaptive driving/equipment, social health, adult providers, etc. tool for identifying types of information given out; computer e-chart documenting transition assessments; final exit assessment done prior to the patient exiting the system at 24 covering the following sections: adult health care providers, ability to manage health, ability to use public transportation, understanding medication and how to access in the future; sex rehab; college information/financial aid; how to get a copy of their medical records after etc., insurance etc.	Currently in a pilot study assessing the information given out to our transitioning youth with 4 other Shiloh hospitals. Phase II in development for an additional survey document 6 months after exiting our system to see how our patients are doing.
Sustaining funding	In the process of developing	In the process of developing

ATTACHMENT C

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<p>The tool is called "BRIEF CLINICAL SUMMARY". The tools include the following: Power of Attorney, Primary Care Provider, Specialty Providers, Code Status, Chronic Diagnoses, Past Surgical History, Arise Problems / Plans, Patient / Family Goals; Emergency Plan; Allergies; Current Medications; Pharmacy with phone & fax; Current Functional Status in 12 areas; Meds; Assistive Technology Supports; Current enteral / parenteral nutrition; Baseline Physical Exam; Recent Lab / Imaging Findings; Future Recommended lab / imaging; Phone list of appropriate community services currently serving the patient (DMR, Transportation Co., DME Supplier, etc.)</p> <p>In addition to the JMAP tool, there is a health care financing options sheet as well as a multitude of forms to assist the physician and staff in meeting the needs of the individual and family.</p>	<p>Population Specific: Spina Bifida Patients. Age: These 13 years of age and older. Approach: A transition visit with the APN is scheduled. During that time the following is accomplished: Purposes / Review process; Research Opportunity; Healthcare Updates (Spina Bifida Data Base); Brief Clinical Summary; Questions & Tests results to add; clinic; SBA Laxax Ltd; SBA Health Guide for Adults Living with Spina Bifida; Medical Information Release Form; Insurance Coverage); Systems at the adult hospital - making appointments; Tour of the adult facility (which is next to Children's Hosp); Appointment table (always the 1st / 3rd Thursday of the month)</p> <p>The program serves patients from ages 11 to adult cross disabilities and serious chronic health conditions. The program is consultative with employees of community based organizations (i.e. state wide parent to parent independent living center) as part of the interdisciplinary team. Team also includes two team members with disabilities and three parents of children, youth and adults with disabilities. Dr. Mary Ciccarelli, MD is the Medical Director and is joined by three other physicians who also see patients (Dr. Kerstin Sobus, Dr. Kate Weber, and Dr. Jason Woodward).</p>
<p>Transition Coordination Events Guide for Care Managers, 30-Day Disenrollment Notification Letter, (Transition) Care Coordination Plan</p>	<p>HRCSM Inc. is a DC Medicaid MCO that specializes in coordinating medical and mental health treatment for children w/special needs. These children range in age from 0-22, have been diagnosed with a medical or mental diagnosis that qualifies them for SSI, receive DC Medicaid and are DC residents. Upon entry into the healthplan, every member (100% of the population) is assigned to a Care Navigator and team (disease management focused) based upon diagnosis, acuity of condition and level of care coordination intensity needed.</p>
<p>Program is very individualized based on patient/family needs, strengths and weaknesses. It's a process not a tool. We use check lists to keep us on track.</p>	<p>Our patients deal with multiple problems/abilities. We see any and all State agencies available to assist. We walk them through the process.</p>
<p>Not sure.</p>	<p>Our Tawny program outcomes are consistent with the California Mental Health Service Act. We have met our 3 year goals in less than one year. Please feel free to contact me for more info.</p>
<p>Our program has developed a variety of tools for local staff and families to use during transition planning. However, the tools are still in our program's review process. Once the tools are approved we would be happy to share with you. Technical time frame for release is the Spring of 2008.</p>	<p>This is an adult spina bifida clinic that was just started in December 2007. Patients over 18 are being transitioned to the University of Colorado from The Children's Hospital. Patients are also referred from the community. Physicians specialists involved are: Pediatric Rehab; Adult Rehab; Urology / Neurosurgery. Social work, genetic and a continuum of specialists.</p> <p>California has a very culturally diverse CHCCT population - each with their own unique needs. Our state also has a very large foster care population which often requires transition planning.</p>
<p>Informal tools (see #7) adopted for center specific use.</p>	<p>The program serves a target population of individuals with genetic metabolic disease 18yo thru adult who need ongoing specialist medical care. Conditions are very rare with high incidence of developmental disability and need for resource referral and coordination of services.</p>
<p>Shinetsu Hospitals have developed numerous tools which can be found on the the IRTW web site.</p>	<p>Orthopedic and orthodontic related problem.</p>
<p>Short provider survey assessing need for a transition program and business plan highlighting need at our institution.</p>	<p>The program would encompass all CSHCCTs with the Children's Hospital of Wisconsin health system. We would like to bring together the great, yet siloed efforts across the institution.</p>
<p>Patient education booklets were developed based on the checklists described in #7 above. Yes, they can be shared with National Center for Medical Home Initiative.</p>	<p>Patient education materials described in #9 were developed for cystic fibrosis, diabetes, neuromuscular conditions, and pulmonary disorders.</p>

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<p>We developed an online survey asking for barriers and facilitators to caring for young adults with mental health care needs. It was presented at the figure of evidence conference. It was subsequently revised with the assistance of the MS Chapter of the ADP Committee on Disabilities and administered with the support of the mass Medical Society on line. The results have just been compiled and a manuscript will be put to gether in short order.</p>	<p>Silvestre Children's Specialty Healthcare Hospital and clinics for children with disabilities is the largest company to offer Lifetime Specialty Healthcare. The adult services were developed starting in 2001 with a pilot program for adults with cerebral palsy, expanded in 2003 to adults with spinal blebs and muscular dystrophy/neurology needs, and incrementally expanded further as service providers were recruited.</p>
<p>We did a survey of families regarding guardianship issues.</p>	<p>We have built a center for medical home. We have parent training. Here, we have nursing students from the community help parents complete care coordination manuals to help parents and build nursing capacity within our community.</p>
<p>STEPS assessment tool created by our OT. It is in the process of revision.</p>	<p>The Division of Comprehensive Care at InterHealth Medical Center has been a medical home for children with special health care needs for more than fifty years. We have always provided inpatient services to our patients as well. As more and more patients reached adulthood, we faced challenges in placement when they required admission to the hospital. Several of our providers have dual training in Internal Medicine and Pediatrics, all are familiar with the care of adults with Special Health Care Needs. Beginning in 2005, we worked with many departments within the hospital to create an inpatient unit. Four beds were assigned for our patients. Although physically located on an adult medical floor, the patients are admitted to the "Camp Care" service under one of our attendings and covered by the Pediatric and Internal-Medicine residents assigned to Camp Care. Chief Life Specialists, Pediatric pharmacists, and the Camp Care social worker are involved with each patient. Admission assessments are done by an adult nephrologist. When specialists are consulted, the team can choose between a pediatric or adult consultant. The nurses on the unit underwent special training and education between a pediatric or adult consultant.</p>
<p>We are eager for other transition programs to use the Transition Readiness Tool we developed.</p>	<p>This is a state run residential facility for children and adolescents with disabilities. The primary focus for those who have technically graduated for high-school is transition. The program teaches them money management, cooking, life-skills, etc. as well as health and wellness and how to proceed with taking care of themselves after they leave here.</p>
<p>Happy to share Individual Health Assessment and Plan, Self-management reflection instrument, Parent assessment questionnaire. We have a number of other instruments in pilot phase...</p>	<p>The Jacksonville Health and Transition Services (JvHATS) pilot program was initially created in 2005 to establish a "medical home" for all youths and young adults with chronic medical or developmental problems in Northeast Florida (Duval, Baker, Clay, Nassau and St. Johns counties), so they can obtain coordinated and comprehensive primary care and gain access to adult specialty medical or surgical care. The JvHATS program works with clients to help them develop the skills to be as independent as possible in the management of their health and health care, to learn to successfully navigate the adult health care system, to remove health-related barriers for achieving their educational, vocational and independent living goals. The pilot program is based at the University of Florida Shands-Jacksonville campus and has collaborative arrangements with other providers such as Children's Medical Services.</p>
<p>Project DOCC Curriculum</p>	<p>As I described above we have the TRAQ 3.0. I am happy to share it but it is still under development so I would like to engage other transition programs to help us further develop the tool.</p>

ATTACHMENT C

<p>Describe any tools the program has developed. In your description, please indicate if those tools could be shared with the National Center for Medical Home Initiatives.</p> <p>A Teen Health Brochure to help teens record their health history. A health information card for Sickle Cell patients.</p> <p>None</p> <p>Transition Tool Kit: Emergency preparedness tool kit</p> <p>I have developed tools that I use to document patient contacts and activities. I use them for outpatient and inpatient activities.</p> <p>The RI Department of Health, Office of Special Healthcare Needs Program in Adolescent Healthcare Transition assists youth patients, physicians, schools and other providers in the transition and transfer of youth with special healthcare needs from pediatric to adult healthcare. Several statewide efforts aim to improve transition outcomes for youth with disabilities and chronic health conditions in RI. The Department of Health has joined the RI Chapter of the AdP. Besides to Independence and Healthy and Ready to Work to implement RI's three-pronged approach to addressing the long including a comprehensive statewide needs assessment, family / youth leaders and education, and healthcare provider training. Comprehensive Needs Assessment. The Office has surveyed pediatricians, family physicians and nurses to gain their perspective on the transition process and to determine their willingness to accept transitioning youth with disabilities and chronic health conditions. Results from these surveys can be found at: www.health.gov/spacelines/ Family / Youth Outreach and Education. RI currently provides many materials to families and youth about the transition process from</p>	<p>Please provide additional narrative regarding uniqueness of the program's patient population, as well as any other information you would like us to know.</p> <p>This is a resident driven initiative, joining forces with existing programs through the social work and therapy programs.</p> <p>Our Councils are made up of young adults from the age of 15 to 18 to the age of 25. They have varied abilities and come from multiple cultures.</p> <p>We focus on children and youth with physically disabling /chronic conditions</p> <p>It is unique that we have adult providers at Eastern Va Medical school to refer our sickle cell patients. It is also unique that I can offer therapy to patients to enhance their quality of life and overall transition.</p> <p>Abstract available about this program, adult children of military families who are dependent on parents for care can obtain indefinite continuation of health care under the Tricare system at age 21. Abstract available, this could be a model for all military or a national health care system.</p>
<p>N/A</p>	<p>patient population are youth in out-of-home care (similar to treatment foster care)</p>
<p>County specific transition packets and a Roadmap to Transition CD was developed for care by youth.</p>	<p>Please note, I'd started to respond to the survey earlier today & had erroneously hit the "next" button. I've disregarded the earlier response from NCDHHS. Thank you, Fatima Lucetti</p>

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<p>funding</p>	<p>Children and youth with special health care needs.</p>
<p>Our main tool is the comprehensive assessment, which is currently not available to be shared.</p>	<p>Our patient population is medically fragile children under the age of 22 in Massachusetts who require home continuous nursing services in order to live safely at home.</p>
<p>Brochures for parent, physician, young adult patient</p>	<p>700 or so young adults with various chronic conditions or developmental disabilities who turn 21 each year and can no longer receive services at the children's hospital</p>
<p>1. Policy & Procedure of Transitioning 2. 2 Tools as mentioned above (ATO & ATCP) 3. "Simplify Care" announcements for clients. Can be shared</p>	<p>CHRON Care Management Program - Los Angeles County CGS (California Children's services)</p>
<p>The New York State Institute for Health Transition Training has developed a health care transition curriculum for youth with developmental disabilities ages 14-25 years, family caregivers, and healthcare providers (www.HealthyTransition.org). The curriculum presented in a variety of ADA accessible formats, including video and audio and interactive web-based forms. The website also offers automated Spanish language translation. The curriculum can be used for self-study or by groups with a moderator guide. It is designed to promote (a) self-determination, (b) information sharing, (c) system navigation, and (d) self-care/prevention of secondary conditions. The curriculum is organized into 10 skill-building units: 1) Schedule a medical appointment, 2) Get health insurance, 3) Decide about health guardianship, 4) Speak up at doctor's office, 5) Learn about Developmental Disability, 6) Manage medications, 7) Keep a health summary, 8) Look into service coordination, 9) Set health goals, 10) Find out about community resources. Interactive tools for developing transition skills will also be presented. These include a checklist to determine health transition readiness, a goal letter to be shared with the family, and a checklist to determine health transition readiness, a goal letter to be shared with the family, and a checklist to determine health transition readiness, a goal letter to be shared with the family.</p>	<p>Although a variety of transition curricula have been developed to facilitate the transition from pediatric care to adult healthcare, few are specific to developmental disabilities, most have a pediatric focus, and all use a traditional didactic format. The curriculum and tools developed by the New York State Institute for Health Transition Training are specific to youth with developmental disabilities and based on ongoing multi-year research with this population. The materials can be used on both the giving and the receiving end of the transition process. Our format offers video vignettes and interactive tools that engage youth and foster explicit collaboration with family caregivers and health care providers. Our dissemination strategy for the curriculum includes academic detailing at primary care family medicine sites affiliated with the Area Health Education System and Patient to Patient of New York State. We are also collaborating with the NY State Office of Mental Retardation and Developmental Disabilities and the NYS Department of Health on this project. Research partners include the Burton Blatt Institute and the Center for Digital Access at the School of Information Studies.</p>
<p>KIS-58, Kennedy Independence Scale-58 (in final version).</p>	<p>We would accept any youth with a developmental disability of that is cared for at KCI already.</p>
<p>We have an intake assessment - under modification currently and a intake and discharge checklist.</p>	<p>Very high acuity patients - over half of them with significant disabilities requiring guardianship. In addition working with the internal medicine residency to start a curriculum regarding adults with "pediatric" conditions. Set to start soon.</p>
<p>None</p>	<p>We were the first medical day treatment program in Ohio when we opened in 1993. We now have children who are ready to transfer to an adult facility but we have not been able to make that happen. Schools are not motivated to recognise the need to bring late teens together with others up to 21 years of age.</p>
<p>Medical and psychosocial assessment tools are used and can be shared with the National Center for Medical Home Initiatives.</p>	<p>All patients have CF and are transitioning from pediatric care to adult care in the same institution.</p>
<p>Transition module at www.medhomeportal.org brochures Young adult video presentation at national meeting and posted to youtube</p>	<p>USF Pediatrics and Children's Medical Services are committed to providing a smooth transition for chronically ill and disabled youth.</p>
<p>A health assessment intake form, a adolescent health self management checklist and a binder for patients to use to organize information about their health. As we are in early stages, they haven't been used extensively and need to be evaluated, but willing to share ideas and show samples</p>	<p>In transition from direct services to education and training. Building block at state not funded</p> <p>Because we have an established adult CHD program on same campus, the transition from pediatric to adults should be relatively smooth for patients followed here at UCLA. Educational programs for families, initially and patients are part of program, as we started, our consultative services for non-cardiac medical issues was established so we have a complete program. The only piece missing is psychosocial support.</p>

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<p>We are currently "reshaping" a plan of care based on pieces of plans used by several other sites, currently not finalized, but hope to share them in near future.</p>	<p>Our program is case management based not on a case manager. We serve children's hospital outpatient clinic which serves multiple sub-specialties; our target population are those teens with mild to moderate intellectual disability, which means some dependence from other adults caregivers. We are addressing transition on two fronts: primary care and sub-specialty care, both from pediatric to adult providers; cooperative is to determine the utility of a focused, dedicated case management system in facilitating transition; future plans are to investigate case management in transitioning from pediatric to adult inpatient services.</p>
<p>We have developed an interactive search engine CD of Youth Transition Resources; one page fact sheets, Transition Resources for Health Practitioners (hard copy and online, hot links online), and several workshops, which we would be happy to share with the National Center for Medical Home Initiatives.</p>	<p>We work with families and youth representing the full diversity of NJ, including a significant number of African American and Latino families & youth, immigrant families and youth, and families who do not speak English.</p>
<p>We are currently evaluating the database we have created, and would share it, it documents ADLs, fitness, reading and math levels, and social ability for youth with spina bifida.</p>	<p>Patients with spina bifida require special attention in transition, due to complex interplay between physical and cognitive impairments, and family overprotectiveness, as well as community barriers. The organizational and relational skills appear to be particularly affected.</p>
<p>Q/D based resource manual. Would be willing to share.</p>	<p>We use a diagnostic and treatment center providing interdisciplinary, strength-based clinical services including primary care, psychiatry, psychology, social work, speech therapy, occupational therapy, physical therapy, educational services, and case coordination. The primary population served are adolescents with both a developmental disability and mental illness. We are individuals across the lifespan for all of our services except primary medical care which serves only adults and transition age youth.</p>
<p>1. The CDC surveillance "UCC" system. Yes, contact the CDC, Sally Owens, for more information. 2. Our nationwide network of 130 regionalized Hemophilia Treatment Centers is a model of comprehensive team-based care for people with chronic inherited rare disorders. CDC studies document 60% reductions in mortality and blood related hospitalizations among males with hemophilia who get at least one visit annually from a Hemophilia Treatment Center.</p>	<p>Hemophilia -- rare, catastrophic, inherited. Expensive: annual cost of medicine alone is \$100K - \$300K/year; if patient has inhibitors (19% of patients). We care for 70% of the US' hemophilia population. Plus other under-recognized but prevalent disorders (eg Von Willebrand Disease -- affecting 1% of the population) Prior to 1985, patients at risk for HIV and Hepatitis C (1992) due to contamination of blood supply. With proper, timely diagnosis/treatment, patients can live productive, longer, healthier lives. Strong regional network for assessment and response, program planning, implementation, clinical education and evaluation.</p>
<p>Above mentioned checklist</p>	
<p>Transition planning & service plan tools. Developed a Transition Toolkit for teens with special health care needs, film depicting multi-agency collaboration for successful transition along with accompanying film discussion guide.</p>	<p>The Children's Medical Services Program is the State's Title V Children and Youth with Special Health Care Needs Program. We provide outreach services to typically underserved communities including Native American Communities, immigrant population. CMS provides opportunity for access to health care for pediatric specialty conditions by coordinating with each clinic, statewide.</p>
<p>questionnaires for practitioners, assessment of health care independence of patient,</p>	<p>this is a need program working within a large academic center to identify resources and client needs. The center is part of a large system center, child evaluation center, HIV center, PAS center, and sickle cell, asthma and neuromuscular center.</p>
<p>As above, and we can share all of them</p>	<p>We are a program that is based primarily in a pediatric nephrology practice, but have expanded our program to other sub-specialties (G-I, Cardiology)</p>

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<p>Transition assessment form was developed by the Interdisciplinary Transition Committee. This tool can be shared with ACHHE.</p>	<p>Difficulty finding qualified reconstructive surgeons for this population in adult healthcare</p>
<p>Tools developed include the Transition Planning and Assessment Team Briefing Assessment form as well as the Staffing Summary form. We have also developed invitation letters that are mailed to the client inviting them to the starting as well as a fax form that is faxed to the client's primary care provider asking for their input in the client's transition process. These forms could be shared with the National Center for Medical Home Initiatives.</p>	<p>Our population is unique in that we provide transition services to children with special health care needs. This population also has the burden of maintaining funding as they are mostly covered by Medicaid during their youth and find difficulty in maintaining their Medicaid status once they turn 18. The other obstacle encountered is the lack of primary care providers willing to accept these children because of their complex medical needs.</p>
<p>None</p>	<p>Students must be between the ages of 14 - 20 and be eligible for services through Children's Rehabilitation Services.</p>
<p>there is a check sheet the primary physician uses</p>	<p>This is staffed by a physician double boarded in medicine and pediatrics who is doing a phenomenal job</p>
<p>Algorithm, documentation forms, and general monitoring informational questions have been developed. They would be shared.</p>	<p>This program specifically addresses the needs of HIV-infected children and adolescents, who mature into young adulthood and then require continued health care by adult providers</p>
<p>Unknown</p>	<p>CSS serves children with special health care needs, including those who have developmental disabilities and chronic diseases such as cystic fibrosis, hemophilia, juvenile rheumatoid arthritis, to name a few of the diagnoses. We serve children from birth to age 21. We also focus on transition issues related to education, adult health systems, and independence.</p>
<p>Nursing educational workshop program for allergy and respiratory care in the home (5 year's experience with hundreds of patients)</p>	<p>WACHV is a state Dept. of health grant/contract funded program administered through the Children's Hospital of Philadelphia's Dept. of Anesthesiology and Critical Care Medicine since 1979. The program serves infants, children, adolescents and adults up to age 21 yrs. who are venous dependent and cared for at home. Since inception it has served over 800 patients and families statewide. Services include: medical and nursing care oversight and coordination; coordination of social, developmental and educational services; funding of respite nursing care; family counseling; advocacy for patient and family with healthcare providers, insurers, and community resources; epidemiologic surveys of chronic respiratory failure causes, outcomes, and costs; and educational program participation in home care and transition issues for physicians, nurses, and respiratory therapists social workers and others at the local and national level.</p>
<p>Manual spreadsheets used to track children reaching age 14, stickers put on records, calls made if it has not come in for an appt by 14 3/4 to meet requirement for initial transition. Tools not really helpful outside of our program.</p>	<p>We are one of only 5 adult spina bifida clinics in the U.S.</p>
<p>Didn't really "develop" tools. Used existing care plan templates with a check list.</p>	<p>Info on the CSS program can be found at http://www.nachv.com/pp_fnc/dept_services/childrens_rehabilitation_services.htm</p>
<p></p>	<p>Challenging population of medically complex children with various diagnoses. Many young adults with Medicaid insurance, cognitive impairment and multisystem involvement.</p>

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<p>We have created for our teens that will address education, independent living skills, employment and psychosocial. In addition we have an annual resource fair where we invite different community and governmental institutions to provide families with information. We also have a summer employment mentorship program.</p>	<p>Most of the patients at Shriners have chronic orthopedic conditions that will have to be managed throughout their lives. Shriners patients are initially seen at 18 years and followed till the age of 30 for their orthopedic conditions. The transition program success is attributed to the report we are able to maintain with our families.</p>
<p>It's Time To Transition Workbook is being used for medical transition.</p>	<p>We have so much in process. We want to establish a Youth Advisory Council and incorporate young adults onto local NH advisories.</p>
<p>There are handouts for each area listed above for the client and handouts for the family for each area listed above. Also have a transition planning checklist and a portable health summary form. The manual also has resources, recommended readings, etc.</p>	<p>Children's Medical Services (CMS) serves clients from birth to 21 years of age with chronic medical conditions (limited list) and income 236% FPL or below.</p>
<p>website: http://dettec.washington.edu/health/; transition notebook; transition checklists; and more - please see website. Yes, I think you already share some of the MHP tools on the National Center for Medical Home Initiatives website.</p>	<p>not a clinical service.</p>
<p>We perceived that the biggest barrier for transitioning CYSHCN to adult care was a lack of knowledge, on the part of the pediatric medical community, about resources in the adult care community. We used a questionnaire to survey PM and Int/Peds physicians in our area to devise a resource list for our transitioning patients. We would be happy to share the questionnaire, though it has some regional specificity. We are early in the pilot now of putting together the list.</p>	<p>Ours is a children's hospital based clinic, with a stable number of CYSHCN who have difficulty leaving the care they are used to. This was a simple effort, done to help our patients and those throughout the institution facing the same problem.</p>
<p>Our transition nurse specialist has developed a web program which has multiple resources for several of the states for which we service. This program uses Freedom and is continuously updated by our specialist and is readily and easily accessible to all my nurses, social workers, aides, care coordinators for instant access to identify resources that our patients may need or want. It is also available in our patient/family transition library on the computer for them to access. We also have a fully stocked transition resource board for our patients in our clinic. The web based program was developed by our nurse specialist using Freedom (free software) and is unique to the states our patients come from. She has shared this with other Shriners Hospitals who have and are creating their unique resource database for their populations. It can be used by any program but would need to be custom fit for individual purposes.</p>	<p>Many of our patients are special needs with complex orthopedic conditions. Many of our children stay in our system until the age of 21 and look to us for much in the way of health care (although we don't do primary care) but to help them navigate through the health care system as it can be daunting for those with special needs. This is particularly true for our special needs children as they transition to adulthood. Our transition nurse specialist also holds a transition camp yearly with lots of information, specialty speakers such as those from Voc Rehab, adaptive driving, secondary education, scholarship availability, SSI, disability, etc. We also have resource boards with materials in our clinics at our patient's ready disposal. Our nurse specialist has been asked to speak at many conferences around the country as well as outside the country illustrating our program.</p>
<p>Practice guidelines for adults with childhood diseases</p>	<p>We offer a medical home for adolescence young adults with childhood illnesses or disabilities who are transitioning over from a major children's hospital.</p>