

Healthy and Ready to Work Transition Models Project  
Summary of Effective Approaches

FINAL REPORT

August 13, 2008

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## ACKNOWLEDGEMENTS

Over six months, Healthy and Ready to Work Project Officer, Elizabeth McGuire, and JSI staff, Orla Kennedy and Frances Marshman, developed a series of questions, identified varied transition programs, and conducted interviews with leaders within each program.

Thank you to the transition leaders who took time out from their busy schedules to tell their programs' stories:

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## I. Introduction

The Maternal and Child Health Bureau (MCHB) Division of Services for Children with Special Healthcare Needs (DSCSHN) is charged with achieving a community-based service system for all children and youth with special health care needs and their families. As a generation of youth with special health needs has reached adulthood, the goal that “all youth with special health care needs receive the services necessary to transition to all aspects of adulthood, including adult health care, employment and independence” has taken on more importance.

As stated in the “Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs” from the American Academy of Pediatrics, the goal of transition in health care for young adults with special health care needs is to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood.<sup>1</sup> Providers, State Title V Programs and policymakers have increasingly been focused on developing and implementing innovative approaches to the organization, financing and delivery of transition services.

The purpose of this project was to gather and synthesize concrete details about the structure and components of a small sample of transition programs around the country. An interview guide was developed to address program components, including: *physical structure/facility, staffing, medical home, financing/insurance* and any *other component* unique to the program being interviewed. Potential transition programs to be interviewed were selected from recommendations generated by DSCSHN staff, experts in the field, and staff from the Healthy and Ready to Work National Center. Additional programs were obtained through an e-mail sent to a broad audience of Maternal and Child Health Bureau grantees and colleagues, outlining selection criteria and highlighting the six points from the Consensus Statement. Seven programs were selected to be interviewed.

This report is the summary of information gleaned from 90-minute interviews held with the seven programs and hour-long, follow-up calls with most of the seven. Materials that support or promote the programs were always requested; transition leaders sent them whenever possible. See *V. for Appendices/Supporting Materials*.

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<sup>1</sup> **A Consensus Statement on Health Care Transitions for Young Adults With Special Health Care Needs** American College of Physicians-American Society of Internal Medicine American Academy of Pediatrics, American Academy of Family Physicians and American College of Physicians-American Society of Internal Medicine *Pediatrics* 2002;110:1304-1306  
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## II. Transition Program Descriptions

The seven programs interviewed span the country and vary in their approach to addressing transition issues for children and youth with special health needs (CYSHN). Five of them have affiliations with local hospitals, while one is almost entirely focused on disseminating information to CYSHN, their families and providers and does not provide direct services. The seventh program has a transition component in relation to its medical home model and is fueled by quality improvement strategies overall. All of the programs relied on a thorough planning process, cohesive team, youth/family advisory group, and utilization of already-existing systems of billing and appointment-making to offer CYSHN comprehensive transition services. The following section summarizes each program's approach by generally following the categories of *physical structure/facility*, *staffing*, *medical home*, *financing/insurance* and *other* in the interview guide. It should be noted that these categories (italicized as are related words) and accompanying interview questions were not always applicable. Not all program leaders were able to answer all the interview guide questions, but certainly all share a commitment to providing high-quality, excellent transition services to CYSHN. Equally important and at the same time, the programs, presented in alphabetical order by state, reflect a diversity of approaches.

### Florida

In 2004, a group of pediatricians, other children's health services leaders and Title V program staff agreed that transition and mental health were two major children's health issues that must be addressed in the Jacksonville, Florida area. After conversing with children's health leaders in other states and reviewing policy statements of the American Academy of Pediatrics and its section on adolescent medicine, the ***JaxHATS (Jacksonville Health and Transition Services) clinic*** was launched. Although nearly a million people live in the Jacksonville area (including the counties of Duval, Nassau, Baker, Clay and St. Johns), it was agreed that there wouldn't be enough children and youth patients to sustain a disease-specific (i.e., Spina bifida) clinic. More importantly, the group wanted to establish a transition program that addressed multiple conditions. Today, the JaxHATS clinic follows a primary care model and provides a "medical home" for youth (14-25 years old) that have chronic medical or developmental problems. Clinic load is about 325 with patients seen three half days a week.

JSI interviewed David Wood, MD, MPH, a pediatrician involved in the planning process who emphasized the roles iterative decision making and innovative thinking played in leading JaxHATS to be the clinic it is today. Regarding *physical structure/facility*, the group was able to establish the clinic in an adult multi-specialty and resident continuity ambulatory care center that is part of the University of Florida with numerous patients receiving care there. The center already has appointment-making and billing systems with general (adult) internal medicine, outpatient and specialty care within five stories of each other. If a JaxHATS patient needs adult medical and surgical specialty care, a referral can easily be made from one clinic to another within this same building. *Staffing* is multi-disciplinary with Dr. Wood, Dr. Edwards, an adult internal medicine specialist, nurse care coordinators and a transition specialist providing primary medical care to address a young person's immediate

medical needs. Dr. Wood's position is that all pediatricians are in favor of transition services, but that adult providers are less knowledgeable, aware or interested in taking on the complex physical and emotional issues many of the JaxHATS patients have. In that way, it's best if pediatrics services are located in or near an adult system. Dr. Edwards, the internal medicine physician, has begun to build relationships with adult providers, raising awareness about youth with special needs, their eventual connection to adult services and need for referrals.

Whether referred through the use of a simple form or not, all 14- to 25-year-olds who come to the JaxHATS clinic go through an intake process that takes two visits. Youth fill out a general adolescent preventive services (GAPS) form (*see V. Appendices/Supporting Materials*) that asks 60 questions about health problems, medications, concerns and risk behaviors, sexuality, drinking, drugs, etc. At the second visit, the pediatrician, who has had a chance to review the patient's records, will go through the youth's answers to all 60 questions in order to develop a care plan similar to a primary care plan that addresses preventive and disease-specific concerns, medications, sexuality, diet, and exercise issues. During the first visit, youth also fill out a Transition Readiness Assessment Questionnaire, a 42-item tool that assesses a youth's independence in management of health issues, health care services and other transition issues (vocation, education, independent living). A licensed clinical social worker rounds out JaxHATS' approach to an enhanced *medical home* by asking youth about their vocational, educational and independent living goals and uses their answers to make referrals. JaxHATS has established relationships with public schools in the county and the community college in Jacksonville.

The JaxHATS clinic was able to hire dedicated staff by using *Title V funding* of approximately \$300,000 per year from December 2004 to present. The clinic, started as a pilot program, has conducted an ongoing evaluation of its impact, using measures of patient satisfaction, referral completion, emergency room use, and hospitalization rates pre- and post-enrollment, and, ultimately, the completion of successful transition. In-state funding continues, though is limited from year to year. Clinic services are paid for by Medicaid, Children's Medical Services and most other health insurance plans. Staff provides assistance to families to get them necessary health insurance coverage or other funding.

Overall, the clinic's philosophy, as outlined on its website (<https://jaxhats.ufl.edu/about.php>) is to support responsibilities being shifted from parents to young adults while at the same time preparing young adults to be active members of the health care team and promoting self-care skills and independence. The JaxHATS team is committed to helping youth gain the knowledge and skills they need to reach their long-term life goals.

## Indiana

The *Center for Youth and Adults with Conditions of Childhood (CYACC)* services are designed to facilitate care through a medical home with existing or new primary care providers. Overall, CYACC's mission is to serve primary care physicians throughout

Indiana and is sponsored by the Indiana University School of Medicine's Riley Hospital for Children. CYACC provides CYSHN (ranging from 11 to 22 years old) consultative and care coordination services throughout the state. It is not diagnosis or disease-specific.

In 2002, a group of general pediatric faculty received a Dyson Community Pediatric Training Initiative grant involving resident training in collaboration with community-based organizations (CBO), one of which was a state parent-to-parent network. (The Dyson Foundation, committed to innovative programs to enhance the health and well-being of children, has granted more than \$15 million to support new approaches to pediatric training in the community. See [www.aap.org/commpeds/CPTI](http://www.aap.org/commpeds/CPTI).) As part of Dyson sustainability efforts, three of the Dyson participants (two physicians and one CBO member) received an Indiana State Department of Health (ISDH) Maternal Child Health grant to conduct focus groups addressing the issue of transition and begin to pilot interventions.

In April 2007, with another ISDH grant, CYACC was funded to hire a team and began to provide consultation and care coordination for youth ages 11-22 with special health care needs. The team was hired through the ISDH grant, subcontracting for the services of a social worker and two nurses through the university primary care practice group, Indiana University Medical Group (IUMG), which has a particular emphasis on the underserved. CYACC also uses Title V funds to employ a part-time parent liaison through About Special Kids, a statewide parent-to-parent network that provides TA to parents of CYSHN, and a community advocate, who is employed by the Indianapolis Resource Center for Independent Living. The program manager was hired through the university.

Most CYSHN are referred to the services by subspecialists at the children's hospital, primary care physicians (especially those in the university practice), or families themselves. The most common reasons for referral are health care financing concerns, behavioral concerns and requests for assistance in future planning. Although all patients are eventually seen *in a clinic* at the Marion County Hospital's Wishard Health Services Primary Care Center, intake begins over the telephone when a family first calls. The CYACC program manager or clerk asks a brief set of questions to help focus the visit and informs the caller regarding available services. Consent forms are mailed to the family in an effort to obtain the most recent school evaluation and education plan, case manager notes and immunization records, for example, prior to the visit. The CYACC clinic assessment uses a comprehensive intake form modeled after a geriatric assessment form (*see draft in Appendix*). Each section is filled out by the appropriate person on the team, (physician, nurse, social worker, community advocate and parent liaison). The visit takes about two hours, including history and physical, future planning, goal setting, youth and parenting counseling, and may involve lab work and further consultations. Data are collected for the portable medical summary, including past medical history, school history, activities of daily living, and approaches to prevention, self care and sexuality.

Because most of the *staff* is either a parent or sibling of people with special health needs or adult consumers, the team approach emphasizes including families as partners in all

levels of care for a CYSHN while also encouraging the highest levels possible of independence and community inclusion. After the intake, an individual and family are rated by complexity of care coordination needs (1: excellent, individual/family serve as self advocates as a unit; 2: intermediate; 3: high-support need, i.e., difficulty completing a form without help), and the team meets to review the individual's health, education, employment, etc. data. Based on skills, family needs and availability, a team member is assigned to be the care coordinator.

The Individual Health Plan (IHP) is completed with a two-page portable medical summary, three-page interdisciplinary assessment, three-page complete history and physical, and a one-page goal sheet. The completed information is mailed to the patient, the primary care physician and the referring physician. The IHP is designed to help the individual youth understand her/his medical conditions and needs and also to facilitate care for the patient in the primary care medical home, with available contacts, referrals to community resources with contacts, etc. The plan addresses needs for preventive care that include, but are not limited to, routine and disease-related prevention, screening for sexually transmitted diseases, contraception needs, substance use, depression, nutrition and weight goals. CYACC believes that early intervention (prior to high school) enhances planning for and achievement of high independence and community inclusion. School performance, nutritional and exercise behavior changes are better met when established at a younger age.

CYACC also holds a contract with the Indiana Family and Social Services Administration, Bureau of Developmental Disabilities Services, to work with individuals with developmental disabilities who reside in group homes and need medical consultation specific to their developmental disabilities. In addition to clinical activities, the CYACC team is collecting data for two research projects; the first is collecting health and disability-related outcomes in youth at entry into the program and annually, and the second, monitoring of care coordination activity and outcomes for analysis. The educational initiatives within CYACC include the participation of pediatric and medicine-pediatric residents in clinic sessions during their community pediatric rotations and physician conference presentations, both at the medical school and at local hospitals.

CYACC's approach to successful transition revolves around partnering with the youth (or young adults) and families to provide transition training, supporting the primary care physician, and seeking new providers in the transfer from pediatric to adult health care, when necessary.

## **Minnesota**

Located in St. Paul, Minnesota, *Gillette Lifetime Specialty Healthcare* is a clinic that sees youth (16 years and older) and adults with childhood-onset special health needs. Gillette Children's Specialty Healthcare, a pediatric hospital and affiliated clinics, is the parent organization for Gillette Lifetime. The clinic began as a pilot project providing services to adults with cerebral palsy and then expanded to care for individuals with other conditions such as spina bifida, muscular dystrophy, adults with a history of polio, and

neurological conditions. The specialty clinics are co-located on the first floor of a new building with 23,000 square feet for 20 exam rooms, radiology, an assistive technology lab for custom seating, orthotics, and prosthetics, a rehabilitation therapy gym, and private treatment rooms. The discipline of the providers is determined by the patient population's need. For example, adolescents and adults with spina bifida see a neurosurgeon, urologist, and a physical medicine and rehabilitation (PM&R) physician working together (same time, same place), whereas patients with epilepsy see a neurologist with other disciplines by referral. Additionally, patients with Rett syndrome may see a Gillette adult general medicine physician if needing care coordination and status of medical condition, or this same patient may start with PM&R physician if functional or rehabilitation concerns are paramount.

Gillette Lifetime Specialty Healthcare is an evolving model that has adapted through the years to best accommodate and serve youth with special health needs. During the interview that JSI conducted with Gillette, Ronna Linroth, Manager of Adult Outpatient Services at Gillette Lifetime Specialty Healthcare Clinic, described the various "phases" through which the clinic has evolved. In the first phase, the clinic's approach was to create an adult model of care. The second phase involved creating the "bridge" between pediatric and adult care. This bridge between pediatric and adult care consists of four "pathways to transfer care," or, in other words, ways in which an individual comes to receive services at Gillette. These four pathways (approaches) continue today.

The first pathway to care is that an individual can call and schedule an appointment at the Lifetime Clinic directly. The second pathway is through the adult nurse practitioner at the clinic, who can help match personalities with physician providers based on patient need. The third pathway is to invite pediatricians with large adult populations to the Lifetime Clinic to provide services within an adult model of care. This has been an effective process, fostering continuity of care in an age-appropriate milieu. The fourth pathway to care is for "recalcitrant" patients, meaning those adults who are reluctant to change health care providers can be seen by a pediatrician and an adult provider at the same time. This meeting demonstrates connectedness of services to the patient, while at the same time the pediatrician makes it known that she/he can not continue to be the provider, but recommends the adult provider also attending the appointment.

Along with these four different pathways to reaching patients, Gillette is currently confronting the future of transition, referred to as phase three. Ms. Linroth emphasized the importance of "transition" to adult care, versus a "transfer" of care. Phase three is equipping patients, caregivers, pediatric, and adult care providers through a more formalized, intentional and planned transition program of skills building. Also involved in phase three are providers helping youth of various capabilities get better at advocating for their own health care needs.

The Lifetime Specialty Healthcare Clinic is considered hospital-based, but it is actually in its own building one mile from the hospital. The *facility* is fully accessible with extra-wide hallways, multiple surfaces, power and ceiling lifts designed with adults and their disabilities in mind. *Staff* on site includes a team of physicians, nurse practitioners,

nurses, social workers, assistive technology specialists and therapists. A patient care team appointment precedes a physician appointment to facilitate open access to information about allied health services and a screening of health needs. Although not all physician specialists are on site every day, referrals are made easily. In addition, if a service is not offered within the Gillette system, an individual can get a referral for that service elsewhere. The clinic is open Monday through Friday, 8 a.m.-5:30 p.m. In 2007, there were 5,746 physician-related visits in the clinic.

Over time, Gillette has attempted to articulate what transition means and to produce materials for individuals to refer to. Gillette's website ([www.gillettechildrens.org](http://www.gillettechildrens.org)) has resources such as *Never Too Early to Talk about Adulthood* and *Making the Transition* that can be downloaded. At the same time, patients who come to the clinic are given individualized *Make Your Move* binders, written at a sixth-grade reading level, that have sections addressing "your health," "your independence," "your relationship & sexuality," and "your future." Gillette is currently developing a material entitled, *As the Journey Continues*, a transition guide for parents and caregivers, and distributes a quarterly newsletter to patients and families called *Family Focus*.

The clinic does address school and work considerations with its patients. Lifetime offers appointments with a psychologist for diagnostic testing in order to support requests for accommodations in post-secondary education. Occupational therapists conduct an independent living evaluation. Evaluation can include assessing how an individual can access and use a computer. Collaboration with vocational rehabilitation for work (or preparing to work) is a developing component of the program. Additionally, the clinic has attempted to match individual patient needs for recreation and skills building with summer camps and programs in the St. Paul area. *Education around the concept of transition* is paramount. According to Ms. Linroth, there is a lack of understanding around the concept of transition and what it entails. She believes that people generally understand it to mean "transferring care," that is the same care and same set of services just delivered in a different place. Instead, the Lifetime Specialty Clinic focuses on skills building as a process and on partnerships with individuals and different providers, specialists and agencies within the community that can help them achieve during the transition period. "These are patients with complex issues that are operating in two health care subcultures, one pediatric and one adult," she explains.

Gillette accepts all payers and will help find ways to *finance all services* rendered. As with many hospitals, charity care is available for needed services when other means have been exhausted or are unavailable. Employees within Gillette Children's Specialty Healthcare contribute to a fund to help purchase assistive technology such as computers and recreational adapted devices. The clinic does not receive any Title V funding.

## **Nebraska**

The Transition Consultation Project at Munroe-Meyer Institute in Omaha, is funded through a contract with the Nebraska Department of Health and Human Services (DHHS), with monies from the Centers for Medicare and Medicaid Services (CMS), to

improve the medical transition process for young adults with special health care needs who are preparing to move from pediatric to adult-based health care. The Transition Consultation Project's target population is CYSHN between the ages of 15-19 but does accept youth up to age 21 if they are still struggling with transition issues.

The *staff* available to youth on a consultation basis includes a developmental pediatrician, an internal medicine-pediatrics physician (experience in both), a clinical nurse specialist, psychiatrist, social worker and consumer/family coordinator. The team strongly believes in the concept of *medical home* and actively promotes it through the materials it develops and distributes to youth/families as well as physicians. Youth/families are assigned to services coordinators through the Home and Community-Based Aged and Disabled Medicaid Waiver (ADMW) and the medically handicapped children's programs; the Nebraska project also provides education and training to these professionals.

A main component of the project was to design and implement a transition clinic on a demonstration basis with the plan to amend the ADMW to include this service formally and to then provide it on an ongoing basis. Nebraska was one of only two states selected to pilot the development of this new waiver service that could ultimately serve as a national model. Having offered transition consultation services since 2005, the Munroe-Meyer Institute has expanded the number of youth to be seen in the clinic. Having operated on a no-cost extension basis, Nebraska Department of Health and Human Services has now decided that this service (i.e., the Transition Consultation) will be continued on an ongoing basis under Title V and not under the ADMW, according to Shirley Dean, the Consumer/Family Coordinator at the Transition Consultation.

Every youth covered through the ADMW and DHHS's medically handicapped children's programs in Nebraska has an assigned services coordinator whose job is to advocate for the youth and family, get services and support youth to stay at home rather than move into a long-term care facility. The Transition Consultation offers workshops and monthly teleconferences to services coordinators around the state. Teleconference topics often come from the coordinators themselves requesting an update or in-depth session on a particular medical condition or transition issue. These sessions are also the primary way that the project disseminates information about its services, though the content of the monthly conference is always developed by an expert from within the Munroe-Meyer Institute or other collaborating agency.

The clinic has also served as a site for family practice physicians to observe and participate in transition care. A notebook, *Physicians Training Curriculum and Resources on Transition from Pediatric to Adult-Based Health Care for Youth with Special Health Care Needs* (also available on CD), was provided as part of the orientation, education and discussion with the faculty who train residents and medical students at the University of Nebraska Medical Center. Eight physicians participated from July 2006 to September 2007; two others met with the clinic physician separately.

Clinic is held only once a month for half a day. During the first two years, the entire team saw only one youth per clinic; at the beginning of the third year this increased to seeing

two youth in that four-hour time period. Over the past two and one half years, the project has seen a total of 28 youth. The interdisciplinary team completes the assessment of the youth during the first visit. A summary report and initial transition plan are then provided to the youth and family. During the second clinic visit, the youth, family, and team review any additional assessment information and finalize the initial transition plan to support the youth/family in transition to adult-based health care. After this extensive health care assessment, which includes discussion of medical diagnoses, medications, mobility, employment and educational needs, the youth receives a “resources” book that has been assembled specially for her/him. The book includes transition planning details and pertinent services information. If a youth or family member has questions, they are welcome to call the clinic. Visits are spaced out six to 12 months apart, though staff at the Transition Consultation will provide information to youth, families and services coordinators between visits, as well as after the second visit.

Finally, the project does have access to video conferencing equipment across the state, and, therefore, can see youth that otherwise would have had to drive eight or more hours to Omaha. According to Ms. Dean, every hospital, and some health departments, in Nebraska has the capacity for “telehealth hook-up.”

## **Ohio**

The Cincinnati Children’s Hospital Medical Center transition clinic is in its sixth year and started off with Leadership Education in Neurodevelopmental Disabilities (LEND) money. In 2002, transition clinic planners felt there was a need, as children were “aging out” of the hospital and families were “feeling abandoned,” according to Katherine Thoman-Godshalk, a nurse practitioner with the clinic. Thomas Webb, a physician certified in both pediatrics and internal medicine who was heading up the hospital’s spina bifida clinic used the grant money to hire a full-time public health nurse, a half-time social worker, a “school guru” and a fellow/resident (being in a teaching hospital environment) to determine the range of services the clinic would need. The nurse developed a pre-screening questionnaire that she and the social worker began to use with families who were referred to them from within the hospital system. They found that some families already had a plan and did not need comprehensive transition services.

Over time, the transition clinic has developed a relationship with the residents in general pediatrics at the University of Cincinnati’s College of Medicine, out of the University Hospital physicians office, so there is a direct tie to University Hospital. The referral system in Cincinnati proper and within the tri-state area of Ohio, Kentucky and Indiana (Cincinnati is right in the middle) is growing. Additionally, families who come to the transition clinic from outside Cincinnati tell transition clinic staff about their physicians in more rural areas. The nurse and social worker follow up with these providers, introducing the clinic and its services, answering questions, and discussing referral arrangements.

The transition clinic team anticipated that it would have to work hard to establish relationships with adult specialists but did not think they would have to work so hard to

establish a network of primary care providers outside the Cincinnati metropolitan area. Sometimes a family will call the team after being referred and say they don't like the physician. Physicians aren't always accepting new patients or are apprehensive about a CYSHN referral with multiple conditions and medications to maintain. The team understands that many physicians aren't familiar with or haven't been trained to provide such complex care. They aren't resistant to seeing youth referred from the transition clinic but are reluctant to write prescriptions that are typically written by psychiatrists. (The transition clinic has many youth on medications, mostly antipsychotic.) Many primary care physicians won't write these prescriptions and refer the youth to a psychiatrist, which in the rural areas surrounding Cincinnati can be tricky, given the low number of practicing psychiatrists and the distances youth/family must drive to see them. Consequently, the team is always looking for new physicians, either internists or family practice, to provide primary care and to be willing to write prescriptions. Educating primary care physicians has been crucial, and the team has made some headway.

The transition clinic is open every Wednesday from noon until 5:00 p.m. Current patient load is around 500. The scheduling system operates around new patients being seen once a month until the transition plan is established, every three-month visits for those in the middle of making a transition (may still come to the clinic for medical care while looking for an adult provider but are making progress on work/career decisions), and every six-12 month visits, mostly to confirm medications are fine and because an adult primary care physician doesn't assume responsibility for this prescribing medications. A youth/family will receive a copy of the transition plan, including the typed-up dictation of the physical/medical exam and any other useful resources (book on guardianship, community college catalogue, summer camp/job opportunities). The clinic keeps Medicaid, SSI and other paperwork relevant to all the different counties surrounding Cincinnati, and staff will help youth/families fill it out properly for submission. Because the clinic is part of a greater hospital system, assistance in getting all visits paid for is readily available. The team knows all codes that can be put into the hospital system, ensuring payment.

Due to increased demand, the transition clinic will be moving to a bigger space in 2009. Ms. Thoman-Godshalk commented, "We could use improvement in transitioning youth out of the clinic. We try hard to 'graduate' them but are also a security blanket for parents who sometimes are unable to find other medical providers to take care of their kids." The clinic's primary goal is to transition youth, not to provide a *medical home*. "We are the jumping-off point into adult medicine."

## **Pennsylvania**

In 2001, the Education Practices in Community Integrated Care (EPIC IC) program was funded as a Maternal and Child Health Bureau medical home grant that emphasizes quality improvement (QI). The program is also funded by the Pennsylvania Department of Health and is housed in the Pennsylvania chapter of the American Academy of Pediatrics. Since the program's inception, EPIC IC has worked with 62 pediatric practices in 33 counties in Pennsylvania and defines *medical home as an approach to primary care, not a physical structure*. The grant revolves around CYSHN, focusing on

patient- and family-centered care. The QI process is led by Renee Turchi, MD, MPH, as part of a team with Molly Gatto and Deborah Walker, who emphasizes that all pediatric practices are unique. Within a QI context, they are leading the practices they work with to identify areas to improve upon and then employ relevant methodologies in their practice settings to make increments of change. Pediatric practices work with EPIC IC for different reasons. Some choose to better understand how medical home works in order to demystify the concept with their patients, while others are seeking strategies to engage parents more effectively or to gain better access to community resources. Not all of the practices working with EPIC IC receive *funding*, which ranges from \$3-10,000 to offset costs from transition efforts, hiring care coordinators, conducting evaluations, etc. To date, over 30 practices have received funding for care coordination activities.

Transition has only been a part of what the medical home grant efforts have worked on. EPIC IC has begun to partner with the pediatric chapter of Academy of Family Physicians (AFP), along with the Pennsylvania chapter of the AAP. In 2005, EPIC IC conducted a survey to understand what, if any, formal programs and/or policies the 24 pediatric practices that completed the survey had in relation to transition. Less than a quarter had programs or policies with more than three-quarters asking for help addressing transition. The barriers included pediatricians not knowing which family physicians to transition children to, an overall reluctance to let children “go” to adult providers as well as feeling lost navigating the adult arenas of insurance, employment, vocational education, etc.

EPICIC provides training and resources to involved pediatric practices to help their CYSHN patients make the transition to adulthood. Technical assistance, monthly teleconferences and sharing of information on job/vocational training, education and insurance from the National Healthy and Ready to Work Program are available. Another solid approach to understanding transition has been through the establishment of conferences devoted to transition issues. Held in April 2008, the third annual conference addressed insurance, estate planning, state residential facilities and resources at the county and state levels. In addition, each practice worked together in their practice team developing QI change cycles around transition, including developing a transition policy for the office (to be posted), transition care plans and working on “action items” for their transition efforts.

Dr. Turchi and the EPIC IC team attempt to link family and pediatric practices geographically to provide access to care. They do this by superimposing maps of locations of pediatric practices and adult providers and then link them by geographic proximity. Of the practices that are part of the medical home project and have attended the transition conferences these past two years, Dr. Turchi and staff have broken down their practice data and developed registries for all CYSHN, not just those in transition. A registry lists information such as date of birth, insurance, medical equipment needs, etc.; also, each child is assigned a severity score. Dr. Turchi and staff identified all the youth 14 years and older in each practice’s registry, and then divided patients by the age groups of 14-15-year olds needing to start transition, 16-17 year olds, and 18 and older in the practice. The number of 18-and-older year olds still in pediatric practices was high and

has alerted Dr. Turchi that practices not only need transition policies but also need direction on how (and even at what age) to start transition for youth. In addition, pediatric practices that attend the transition conference usually bring a team, consisting of the pediatrician, a nurse (sometimes the care coordinator), always the office manager or front desk person, sometimes a social worker and a parent/youth representative. Together, they examine the Access database reports Dr. Turchi and staff generate for discussion at the conference. Whenever possible, family practices that are also in attendance at the conference and are in geographic proximity to any attending pediatric practices work together to streamline communication and set up what could be a transition arrangement.

Pennsylvania was recently the recipient of a MCHB State Implementation Grant with transition as one of the three main goals. The EPIC IC team will continue to work on these efforts with medical home practices, and, while integrating other work, educational and community services.

### **Wisconsin**

*The University (of Wisconsin in Madison) Center for Excellence and Developmental Disabilities at the Waisman Center* is one of five Title V-funded CYSHCN Regional Centers that provides information and technical assistance to individuals, families and community agencies on youth transition from birth through age 21. JSI spoke with Beth Swedeen, who spends a quarter of her time devoted to Regional Center activities and emphasized the Center's five major components related to youth transition: personalized planning with youth, community development by building both formal and informal support, interagency cooperation, continuous quality improvement and youth leadership. The Center grew out of a MCHB-funded Healthy and Ready to Work Demonstration project and does not provide services directly but through a regional system of information and referral that answers questions from youth, their families and providers about benefits counseling, health insurance, employment and other transition issues.

With funding from the MCHB Title V Block Grant, Ms. Swedeen has worked with Daniel Bier, Associate Director of the Waisman Center, and three other part-time staff focused on transition in developing a statewide transition listserv, curricula, fact sheets, audiovisuals and other related materials. The Center also has up-to-date information for parents on support groups, parent liaisons (organized by county) who are connected to the Center, and opportunities for training, conferences and workshops. Finally, the Center compiles information on local resources and programs available to CYSHN and their families as well as relevant local public health department activities.

Ms. Swedeen explained that the Title V funding has allowed the Waisman Center to collaborate and coordinate transition efforts with other partners in the state and embed "lessons learned" from earlier transition efforts into new projects. Currently, a small project provides stipends to people the Center calls "community connectors." These individuals work with three to five youth over a year's time attempting to connect them to resources and opportunities based on each youth's interests and goals. Seven

connectors are now working with about 30 youth statewide. The same strategy is being used with a federal special education research grant the Center received to try to improve youth employment for students with developmental and emotional/behavioral disabilities.

Over the past six months, the Center has formed a Community of Practice on Health and Transition Workgroup that developed from a merging of the Center's efforts across 30 or more agencies in the state doing transition and adopting a federal Office of Special Education model for creating workgroups and sharing work across agencies related to transition. Within this statewide group are five workgroups devoted to the topics of 1) employment; 2) post-secondary education; 3) youth leadership; 4) health/transition; and 5) family engagement. The health/transition group is working to disseminate different materials that its members are developing. The state's Department of Public Instruction is developing a care plan for youth transitioning from the hospital back to school; another group is disseminating the health training. One state pediatric pulmonary center is developing models for transitioning youth from pediatric to adult care and aims to create a "toolkit" for other health care institutions that want to develop a transition program from pediatric to adult care revolving around specific health conditions (cystic fibrosis, diabetes, sickle cell, etc). The workgroup, though new, is trying to coordinate the development of all training materials and curricula, so that they are not duplicative in nature and are disseminated widely as a single tool currently called the *Wisconsin Transition Health Care Checklist*.

Finally, the Center held a Medical Home Summit for 140 participants in November 2007 and continues to partner with agencies to have its curricula, particularly the safety awareness and health self-care materials, used directly with youth. The Center has offered the health training to youth free of charge across the state; staff is currently pursuing how to train more people to work directly with youth, as the demand has been great. In the past, Center staff has worked with cooperative state educational regions to offer the SAFE curriculum to teachers, so they can implement it with students.

Included in the Center's link to publications (<http://www.waisman.wisc.edu/hrtw/Publications.html>) are Youth Fact Sheets that have been popular with physicians who attended the Medical Home Summit as well as with teachers who attend transition conferences and health fairs.

### III. Findings/Promising Strategies

The “Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs” reiterates the Healthy People 2010 goal that all youth with special health care needs must receive the services needed to make transitions to the crucial aspects of adult life: health care, work and independent living. The challenge is that all people, including those with special health needs, receive health care that is both medically and developmentally appropriate.<sup>2</sup> Also, as outlined in the “Consensus Statement,” successful transition to adult care requires adherence to six critical first steps outlined by the American Academy of Pediatrics:

1. Ensure that all CYSHN have a health care professional who recognizes the unique challenges that come with transition and assumes responsibility for health care, care coordination and any future health care planning. This is done in partnership with other providers, the youth and family and intended to be “uninterrupted, comprehensive, and accessible care within their community.”
2. Identify the core knowledge and skills required to provide “developmentally appropriate health care transition services.” Incorporate them into training and certification requirements for primary care residents and physicians in practice.
3. Have a medical summary that is current, portable and accessible. This information is critical for successful transition, allowing for common knowledge and collaboration among health care professionals.
4. With the young person and family, create a written health care transition plan by age 14. The plan should include what services must be provided, who will provide them, and how they will be paid for. It’s important that the plan be reviewed and updated once a year and whenever there is a transfer of care.
5. While recognizing that CYSHN may need more services and resources to maintain good health, apply the same guidelines for primary and preventive care for all adolescents and young adults. Guidelines such as the American Medical Association’s *Guidelines for Adolescent Preventive Services (GAPS)*, the National Center for Education in Maternal and Child Health’s *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents*, and the US Public Health Services’s *Guidelines to Clinical Preventive Services*. (See *Helpful Links in V. Appendices/Supporting Materials*.)
6. Ensure affordable, continuous health insurance coverage for all CYSHN throughout adolescence and adulthood. This insurance should cover health care

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<sup>2</sup> **A Consensus Statement on Health Care Transitions for Young Adults With Special Health Care Needs** American College of Physicians-American Society of Internal Medicine American Academy of Pediatrics, American Academy of Family Physicians and American College of Physicians-American Society of Internal Medicine *Pediatrics* 2002;110:1304-1306  
HRTW Transition Models Project  
Summary of Effective Approaches

transition planning and care coordination for those with complex medical conditions.

During the interviews, all transition leaders emphasized how committed they are to ensuring comprehensive care for CYSHN and were articulate about the challenges they face. There were recurrent themes in the interviews; core components and critical success factors were referred to at the same time barriers and challenges were identified.

### **Core Components**

As previously mentioned, AAP's Consensus Statement outlines critical steps to a successful transition program. There was overlap between these critical steps and the core components elaborated on below.

A thoughtful *planning process* allows for all approaches, issues and concerns, individuals and agencies to be discussed and scrutinized at the beginning of designing a transition program, not after the fact. The physicians who were behind the establishment of JaxHATS Clinic in Jacksonville began their discussions determining what the most pressing children's health issues were. As pediatrician David Wood explained it, "We brainstormed and held multiple group votes before arriving at transition and mental health being the top ones." Having decided that they didn't want to establish a disease-specific clinic, the planners shifted to figuring out financing the clinic and were able to do it with Children's Medical Services (Title V) money on a pilot project basis. (Note: Some financing does continue.) Similarly, Nebraska launched its clinic on a demonstration basis, hoping that what was learned could be used to inform and solidify payment of the clinic through the Medicaid waiver in the state (outcome still pending). In its pilot phase, Gillette Lifetime Specialty Clinic analyzed the capacity of all providers in the Minneapolis-St. Paul metropolitan area and conducted site visits to determine who was (or wasn't) being served. Gillette's intent was to fill the gaps and not duplicate services.

Central to thoughtful planning is *clarity on mission*. While Beth Swedeen at the Waisman Center in Wisconsin determined their "service" to be resources distribution to a wide audience, Indiana's Mary Ciccarelli declared that their mission is "to serve primary care doctors throughout the state." In 2002, when Ohio began planning, discussions revolved around adding clinics to the already-existing clinics operating under the Division of Developmental and Behavioral Pediatrics within Cincinnati's Children's Hospital Medical Center. In addition to improving clinics devoted to adult down syndrome and spina bifida, the planners suspected there was a need for a brand-new transition clinic. With grant money, the planners decided to develop a pre-screening questionnaire to understand both CYSHN/family need and whether pediatricians would even use a transition clinic, refer CYSHN unnecessarily or too often. By starting to take internal provider referrals only and mailing the questionnaires home to families to fill out, transition clinic planning staff were able to follow up with families who mailed the surveys back. Staff learned that some youth already had begun to think about transition and with their feedback were able to identify the three areas the clinic would need to focus on: 1) pediatric to adult care; 2) school to work or placement; and 3) living at home with parents to living on own (or other arrangement like a residential setting). This helped clarify the clinic's mission and purview.

As in other health care settings, a *cohesive team* contributes greatly to excellent care. Transition program leaders stressed the importance of diversity of staff on a team, in respect to training (physician vs. youth advocate) and responsibilities (diagnose/manage medical condition vs. help with employment opportunities). All five clinical sites use an assessment or intake form that each team member fills out a portion of and has regular access to. Additionally, JaxHATS, CYACC and Gillette are able to document transition care through their electronic systems, facilitating up-to-date, accessible internal communication.

*Youth or family member input* only strengthens the clinic's services. Individuals can be part of the transition care team, as in the case of Nebraska's Consumer/Family Coordinator, or, also in Nebraska, the project has formed a youth advisory group that it looks to for input on clinic issues. The group suggested that the Transition Clinic be called the Transition Consultation, a more welcoming name. Gillette relies on a group of adults with disabilities to advise their clinic, while JaxHATS clinic has youth, parents and community and advocacy staffs sit on an advisory committee together.

All five clinics benefited from *economies of scale* and were able to adapt existing billing and appointment-making systems to ease the strain that accompanies start-up. In the case of Cincinnati, the hospital and its various clinics have provided developmental disabilities services through its various clinics for so long that staff has become adroit at billing. "Every visit is billed, so the clinic can pay for itself," said Katherine Thoman-Godshalk at the Children's Hospital's transition clinic. Also being under the umbrella of Children's Hospital means the transition clinic team can request an interpreter if needed. Once past its pilot phase, Gillette moved to its own space a mile away from the hospital but was still tied into all recordkeeping systems. Similarly, through their relationship with University of Florida, the JaxHATS team was led to a space away from the hospital but still part of the overall system. CYACC in Indiana was offered a space at the county hospital (Wishard) while the faculty practice group, through Indiana University's Medical Group, provided administrative structure for billing and pediatric and medical care support.

Comprehensive transition services require systems and staff in place but also *time*. CYACC attempts to collect as much data as possible on a youth before the first appointment. The program manager asks questions on the phone before the visit and encourages parents to forward copies of case management notes, an IEP, etc. Once there, the intake visit is two hours in length with various members of the team filling out sections of a comprehensive assessment form. JaxHATS follows a two-visit intake. Both CYACC and JaxHATS teams meet afterwards to discuss cases. Cincinnati's team, though very much a medical "counseling" one, has come to understand about 20 percent of the patients they see to be just "med-check people and very stable" and have appointments once a year. The other 80 percent are seen at the clinic every three months with some seen monthly. At Gillette, a youth new to the clinic can expect to meet the whole team and the visit to be an hour in length.

## **Critical Success Factors**

Ideally, a transition program will have the core components of a thorough planning process, clear mission, cohesive team, CYSHN/family input, economies of scale and time. Program leaders emphasized other factors that will only strengthen a program and lead to its success. The most often mentioned critical success factors are presented below.

***Start transition early.*** Some leaders that JSI interviewed emphasized that children are never not in transition, and that comprehensive health care planning, moving from pediatric to adult care, must be addressed for all children, regardless of health conditions. Each program leader acknowledged AAP's guidance for pediatricians to create a written health plan for a CYSHN by age 14, however JaxHATS targets 16-year olds and older. CYACC explained, "Transition planning starts at point of diagnosis or birth, but we limit ourselves to start transition planning at 11." Gillette's policy: by age 16, providers should be talking to a patient and have a plan in place (which, ideally, they sat down to write when the patient/youth was 14). Nebraska targets 15-year olds and up, while Cincinnati tends to start seeing youth at the end of their high school years (though it will depend on how they're referred to the clinic.) EPIC IC in Pennsylvania project and the Waisman Center both said that transition planning should begin at age 14.

On the other end, JaxHATS aims to complete transition by 25. CYACC doesn't "close off at the upper end, but we just don't consider them in transition if over 50." Gillette and EPIC IC didn't name an upper age limit. Cincinnati promises to "serve until successfully transitioned," while the Waisman sees the upper end of transition to be age 21. Some leaders talked about "graduating" their youth into primary care, but also acknowledged returning phone calls to answer questions even after someone has an adult care provider.

***Remember that transition is iterative.*** Mary Ciccarelli at CYACC said, "Not everyone needs total adult care. It could be a mix of pediatric and adult care, especially if a youth is still going to a pediatrician and you can't find an adult specialist. Adult care needs to be part of a person's care, but the care doesn't have to be all adult or none." Ronna Linroth at Gillette said that there is a need for gradual change and not designing a program that tells a patient that "you have to do this, you have to go there by next year." Starting a CYSHN off with one new provider can often be enough for that individual. Every three to six months, the JaxHATS team reviews the transition forms they have used to assess a youth. They discuss the scores they assigned to the youth on the forms and whether "we graduate him from our program and plug them into primary care beyond our transition program," explained David Wood.

***Establish goals with youth.*** This means not just focusing on the medical aspect of transition. Cincinnati's Katherine Thoman-Godshalk explained, "There's never a visit where we don't counsel. We always ask, 'How's school? How's work? Have you looked at your transition plan lately?'" Mary Ciccarelli at CYACC's comment: "A theme of success is that you don't just focus on the medical."

***Always encourage youth and families to be involved in transition.*** CYACC gives CYSHN and family a copy of the transition plan. Nebraska provides the family with a

transition plan and resource book after the visit to refer to when seeking more care (usually through the assigned service coordinator). The Cincinnati clinic now provides CYSHN and families with a so-called portable health notebook. “This came from our parents saying, ‘We would have kept better track,’” explained Ms. Thoman-Godshalk.

***Get to know everybody in the community.*** The list is long: primary care physician practices, specialty practices, community-based organizations, case management services, disease-specific nonprofits like the March of Dimes, vocational rehabilitation, schools and community colleges. David Wood at JaxHATS reported some success working with specialists. “We don’t necessarily have to be next to the specialists but need to get into and be seen in their systems. So now when we make referrals, it comes from their internal (ambulatory) clinic. They get a transition clinic referral like they would any other adult referral and start to treat you like one of their customers. Get the word out by infiltrating the system.”

***Aim to have an internal medicine and pediatric medicine trained physician working in the transition clinic.*** This is an ideal fit for this setting. If there is no such person available to work in the clinic, at least be able to refer to her/him. The JaxHATS clinic has benefited from sharing space with internists, as “people needing transition have complicated diseases... We’ve been able to bring in a mix of medical expertise when we’ve needed to,” said Dr. Wood. CYACC, too, has set up its services to be able to draw on such expertise when necessary.

***Have a physically comfortable space.*** Surprisingly only Gillette and Nebraska emphasized the efforts they had made to have wide hallways, examination rooms with tables that go up and down, lifts to move transition patients, etc. Cincinnati did mention that their clinic space is tight and not “developmentally friendly.” The hospital is now building them a new space! JaxHATS emphasized the ease with which their transition patients can see other physicians and specialists in the ambulatory clinic the transition clinic is co-located in. At the same time the space is not ideal, as youth are now the youngest sitting in the waiting room with senior citizens (unlike in a pediatric setting where they were the oldest). The 20-year old building, itself, has exam rooms that can accommodate wheelchairs but no exam tables that go up or down.

## **Barriers and Challenges**

JSI staff considers the seven transition program leaders they interviewed to be positive, entrepreneurial in spirit and able to maintain perspective when asked what the barriers and challenges to setting up their programs were. Yet, some themes did come through.

***Successful transition programs need time.*** When the team does not have adequate time to prepare for CYSHN clinic visits and to discuss them afterwards, transition planning suffers. The team needs time to follow up with care coordinators (CYACC) or service coordinators (Nebraska). It needs time to acquaint primary care physicians with a youth’s issues (Cincinnati) and it needs time to assess a youth’s readiness to transition (JaxHATS). Gillette prides itself on its reliance on an adult model of care in a pediatric

hospital, but it only works when both parties have access to each other and time to discuss individual patient's usually complex needs. Counseling is another component of transition services that takes time. Undoubtedly, comprehensive transition takes time. Yet, time constraints exist within all health care delivery systems and are not unique to CYSHN transitioning from pediatric to adult health care.

***Relationships can be unpredictable.*** Some adult medicine physicians may be reluctant to collaborate, and pediatricians don't always want to "let go" of their patients. Parents, too, don't always know how to, nor do they want to "step back." Professionals working in transition need better peer-to-peer support; it can be draining work.

***Good adult care can be hard to find.*** Cincinnati has a tri-state scope and not far from the clinic's in-city location are rural areas with few adult medicine physicians familiar or comfortable with CYSHN. The EPIC IC attempts to match pediatricians with family medicine providers in the same geographic areas of the state. It gets harder the more rural the state becomes, and Nebraska tries to involve rural physicians through video conferences and by offering transition consultation services via telehealth. If a clinic operates in a varied (or in Cincinnati's case a tri-state) setting, it can be difficult to identify all the individuals and agencies the transition clinic should be collaborating with, and, equally challenging, to then establish working relationships.

***Transition clinic can become a safety net.*** There are youth/families who can't find a provider to prescribe medications, for example. Once a youth starts getting medication through the transition clinic, the youth and family have no interest in going elsewhere for medication or care. The idea that this youth deserves more comprehensive attention and is of an age that she/he would be best served in an adult medicine setting is unwelcome.

***Physician capacity to serve CYSHN must be increased.*** As summarized by a Massachusetts pediatrician and adolescent medicine specialist serving on the Committee on Disabilities for the MA Chapter of the AAP, "We are trying to develop more physician capacity and figure out where the needs are for more physician education. Massachusetts is home to nearly 220,000 kids with special needs."

***Special needs vary according to type and the extent of disability.*** An individual could need a wheelchair, ventilator or medications for mental health issues. Which becomes the priority? How does care get coordinated? Has the transition clinic assigned a team member to be responsible for all details regarding a youth with multiple concerns? In rural settings, it isn't easy to have CYSHN geographically close to transition care.

***Literacy, proficiency in English and cultural competence can not be assumed.*** Before launching its website, JaxHATS had youth review it. The team tested their transition tool for readability and literacy level. Gillette, being part of a major hospital, has the benefit of interpreters and its advisory committee vetted their transition materials.

***Health insurance coverage is limited.*** Not all CYSHN have health insurance, therefore hindering access to all necessary services. Coverage and other available financing vary

from state to state. Surprisingly all program leaders interviewed said that they were usually able to bill for and obtain payment for transition services. This probably reflects sophistication with naming diagnoses and billing codes.

***Trust between transition team and family is difficult to establish.*** Finally, trust between the physician/transition team and a youth/family can take a while to establish. Once established, it is also difficult for the family to “let go” as they look to their transition program as a safety net of services.

### **Program Sustainability**

All the transition programs have successfully established themselves to address the need for services for CYSHN facing or going through transition. Yet, none of them would flourish without the expertise and services of other providers and agencies. So, how will these programs sustain themselves? How can others? Beth Swedeen at the Waisman Center which began as a Healthy and Ready to Work demonstration project and relies on multiple funding now stressed the importance of not waiting until the end of a grant cycle to decide next steps. If a project is not working, don't waste further resources on it or correct what's wrong. Swedeen's third point: You have to give a project your full attention in order to sustain it; don't take on too many things at once. Other program leaders referred to the following approaches:

***Think holistically about transition and keep building relationships.*** CYACC has been successful at utilizing existing resources within Riley Hospital as well as within the community. The JaxHATS team has begun to establish its transition services as equal to adult services offered in the same building. Cincinnati team members call individual rural primary care providers to introduce the transition clinic, the youth receiving services and to figure out a collaborative care plan. Nebraska reminds both physicians and services coordinators about their transition consultation through monthly teleconferences. Gillette arranges for co-visits, so that a youth can be seen by an adult provider and pediatrician in one visit.

***Keep collaborating and getting the word out.*** The Waisman Center's statewide Community of Practice on Health and Transition Workgroup has four groups (employment, post-secondary education, youth leadership and health/transition) meeting to discuss issues; the health/transition group is working to disseminate materials that its members have developed. Beyond collaboration, it is important to publicize the work that a transition project is doing. Potential partners will know that your work becomes their work, and this will help avoid duplication of services.

***Make services available to youth*** by training physicians in rural areas, teaching them about complicated medications regimens and offering telehealth.

***Figure out how to bill for all services.*** As discussed above in relation to Gillette and Ohio, sometimes economies of scale and being part of a larger organization will allow a newer program to pay for its services. The JaxHATS Clinic made Title V part of its pilot

project while Nebraska is attempting to finance itself through the state's waiver program. CYACC has paid for some staff time through Title V. If a project can identify an aspect of its care (whether its equipment, staff or certain services like service coordination in Nebraska), sometimes a state entity, like Title V, will contribute funding.

***Remember that Title V can be a partner.*** The role of Title V will vary by state. For example, CYACC's transition program benefited from grants, while JaxHATS used seed money to launch a pilot. Find and work with those Title V professionals who are knowledgeable about transition and want to be part of the planning process to establish transition services in a state.

***Never forget CYSHN and their families.*** One of Cincinnati's team members is able to seek out family- and youth-driven services by working with Project SEARCH, a program dedicated to matching young adults with developmental disabilities to jobs in the community. All seven programs value the input of the CYSHN and families they care for and not only make time for their questions after appointments and to make proper referrals, but also involve them in advisory committees, materials review sessions and ask them to serve as resources at conferences.

***Evaluate, evaluate, evaluate.*** The JaxHATS team circulates patient satisfaction questionnaires after the first visit and six months later and does a routine quarterly check to see how it's doing with overall clinic processes. The team is beginning to track outcomes, i.e., has a youth made the transition to adult services successfully. Some team members suspect that emergency room and hospital bed utilization has gone down since the clinic started but are relying on self-reports and need to start collecting data formally.

CYACC is in the process of developing a baseline and annual survey, looking at outcomes related to state-, MCHB- and Healthy People 2010 goals. The team has adapted Dr. Richard Antonelli's care coordination tool for CYACC and plan to have it programmed into handheld devices for ease of data collection and uploading to an Access database. Gillette is starting to put together a formal evaluation. Gillette Children's Specialty Healthcare, the overarching organization, has signed a contract with an outside agency to conduct a satisfaction survey with individuals being served at all its clinics. Surveys are being distributed both at time of visit and mailed out afterwards. Also, once a year, Gillette Lifetime Specialty Clinic staff attend a retreat where they discuss program development, successes, failures, and areas for improvement. Patient visit numbers increased 35 percent from 2006-2007, which Ronna Linroth interpreted as a good sign and a reflection of the strong word-of-mouth influence in the community. She and her staff are considering the design of a comprehensive cost-benefit study which Ms. Linroth suspects will reflect savings.

Nebraska's "Program Evaluation Summary" (see page 44 of *V. Appendices/Supporting Materials*) circulated satisfaction surveys to youth/family, physicians and service coordinators, and documented the number of participants in the project. Nebraska was motivated to carry out a comprehensive evaluation, as it was one of only two states

selected to pilot the development of the new waiver service (discussed above) that could, ultimately, serve as a national model.

Ohio relies on the parent advisory committee that gives feedback to the Hospital's Division of Developmental and Behavioral Pediatrics, with which the transition clinic is affiliated. As mentioned earlier, portable health notebooks are now being offered; this decision came directly from parents making this request during committee meetings. Periodically, the transition clinic team has set up quality surveys to be completed via SurveyMonkey, but the results have been inconclusive as not all youth/families have Internet access.

The EPIC IC project focuses on quality improvement and has been collecting data and assembling patient registries in order to improve efficiency, while the Waisman Center attempts to evaluate each of its efforts separately. In summary, all the transition leaders interviewed understand the importance of evaluating their programs and collecting good outcome data. At the same time, they are still determining the most effective strategies to do this. None felt completely satisfied with her/his program's current approach. All want to collect data that reflects success in providing care and services to CYSHN. Also, some remarked that substantive evaluation results can be shared with potential funders who may then contribute money to allow programs to sustain (or expand) themselves.

The AAP 2002 Consensus Statement reached a wide audience of pediatricians and propelled many of them to begin addressing transition for their patients. The many lessons elaborated on above show that not one approach is full-proof. Rather a broader scope, involving multiple individuals and collaborations, will reach the most CYSHN. All leaders indicated that their programs had room for improvement, but by coordinating services and resources with others in the community, they have helped individuals through transition, probably not duplicated services, and perhaps saved money.

#### **IV. Next Steps**

The core components and critical success factors presented on pages 17-21 are recommended for setting up and sustaining a transition program. Transition must continue to be understood in a context with medical home, health insurance and financing, family-to-family information, screening and community integration. These six essential areas define the Maternal and Child Health Bureau's Division of Services for Children with Special Health Needs' mission. At the same time, some of what has been discussed in this report could be applied to care and services for all children. Transition is clearly becoming more and more a part of pediatricians' practices. It is not an urban or rural, large or small practice issue. Having a presence in every state gives MCHB and Title V unique opportunities to address transition. Dr. Turchi's EPIC IC project revealed that 75 percent of the pediatric practices in Pennsylvania she works with want transition programs or policies.

Despite the integration of transition services by the seven programs in this report, many pediatricians must still be reached. JSI staff heard throughout the interviews that informing, educating and training are the approaches to be relied on, in particular by:

1. Providing pediatric and internal medicine residents with written information on both the medical home and transition concepts
2. Recruiting local medical school and residency program faculty to lecture on both topics
3. Providing ongoing education to residents about pediatric “special health needs”
4. Talking to “grand rounds” organizers (and speakers) to introduce the topics of medical home and transition and requesting them to always explain the concepts in such talks
5. Involving individual adult medicine providers or pediatricians less familiar with transition by inviting them to serve as a consultant to a particular CYSHN’s care or to be part of transition clinic hours
6. Making any materials developed available through physician-related web sites. Put that same information on a listserv (or a DVD)
7. Working with the American Academy of Pediatrics and the American Academy of Family Practice to approach medical schools and residency programs with transition and medical home curricula that can be shared.

Projects should be encouraged to:

1. Incorporate the core components and critical success factors elaborated on in this report.
2. Facilitate geographical (and other) linkages between pediatricians and internal medicine or primary care providers.
3. Extend coverage to CYSHN needing transition services to age 30 (beyond the current cut-off age of 25) and begin transition services early (at diagnosis).
4. Encourage work with agencies, coalitions, schools, community and vocational rehab services to coordinate non-medical transition care.

Distinctions between rural and urban care were made throughout the interviews by program leaders; any technical assistance would have to be tailored accordingly. As with any program, materials and resources developed must always be CYSHN-oriented, culturally sensitive and written at an appropriate literacy level.

### ***Conclusion***

This report summarizes themes and findings from interviews conducted with seven transition program leaders, but certainly there are many others around the country with useful information, insight and details about their programs to share. Interviewing some of these leaders could provide further insight into developing a model for transition care.

These programs include but are not limited to the following:

Adolescent Health Transition Project  
University of Washington  
Seattle

Baystate Children's Hospital  
Springfield, MA

“Making Tracks to Transitions”  
Schwab Rehabilitation Hospital  
Chicago

Moving On  
Pediatric Pulmonary and Cystic Fibrosis Center  
Madison, WI

Program of Transition and Transfer of Youth to Adult Health Care  
Hasbro Children’s Hospital and Rhode Island Hospital  
Providence

REACH: Rapport, Empowerment, Advocacy through Connections and Health  
The Children's Hospital of Philadelphia  
Philadelphia

Transition Clinic Program  
Phoenix Children’s Hospital  
Phoenix