

Supporting the transition of Children and Youth with Special Health Care Needs (CYSHCN) from Title V CSHCN agencies to adult health care and services is not just a good idea—it’s an integral part of our job! The tables below provide some ways to assess and promote transition services.

<p>PERFORMANCE MEASURE 1:</p> <p>Early and Continuous Screening</p>	<ul style="list-style-type: none"> ▪ Ensure screening mechanisms that include developmental and transition skills are a regular part of health services for young people of all ages. ▪ Develop referral and communication linkages with early intervention and school districts to ensure problems are identified early and treatment begun. ▪ Transition assessment and planning are essential aspects of direct services, care coordination, and contracts with community providers. AAP/AAFP Policy directs health transition planning at age 14 by physicians (<i>Pediatrics, 2002</i>). IDEA mandates beginning transition planning in schools at age 14. A written individualized health plan can be part of each of these or written separately by families/youth with assistance of Title V CYSHCN staff.
<p>PERFORMANCE MEASURE 2:</p> <p>Families & Youth are Partners in Decision-Making.</p>	<p>The emerging generation of youth needs mentoring and then assistance to develop confidence in their roles as partners in decision-making, to the greatest extent possible.</p> <ul style="list-style-type: none"> ▪ Youth serve as compensated advisors to ensure no decisions about them are made without them. ▪ Families serve on Advisory and Planning Committees to focus on global and local issues in transition. Youth leaders are mentored as they serve on policy councils. ▪ Families serve as paid staff of Title V agencies involved in intake, coordination of contract work with parent groups, transition programming, information dissemination, and other clinical and administrative activities. Parent and youth consultants are compensated for their time and expertise when assisting the program. ▪ Collaborate with Family and Youth Leadership Organizations: Encourage and provide connections that will build competencies and self-confidence in working with issues and agencies for their children and their special needs. National youth leadership groups such as KASA—Kids As Self-Advocates (www.fvkasa.org) and The National Youth Leadership Network (www.nyln.org) provide a network to skilled youth leaders who have chosen to become involved in policy shaping and decision-making. Parent Training Information Centers (www.taalliance.org) and Family Voices Coordinators (www.familyvoices.org) develop leadership abilities and help families with children with special needs with their specific concerns.
<p>PERFORMANCE MEASURE 3:</p> <p>Medical Home</p>	<ul style="list-style-type: none"> ▪ Communicate promptly with community physicians about specialty care and transition teaching and experiences the Title V agency provides. ▪ Offer information on medical aspects of pediatric-onset conditions and community resources for youth with special needs in a variety of mediums: conferences, Medical Society newsletters, one-page information sheets for the offices, web sites, and others. ▪ Involve physicians in planning and implementing Healthy & Ready to Work programming.

<p>PERFORMANCE MEASURE 3:</p> <p>Medical Home (con't)</p>	<ul style="list-style-type: none"> ▪ Offer transition concepts, such as those found in AAP's Medical Home Training Transition Component, in medical meetings or interdisciplinary conferences. ▪ Offer opportunities to attend Title V multidisciplinary clinics for youth with complex conditions to medical school students, medical center residents, and community physicians. ▪ Develop a Speakers' Bureau of physicians, family and youth leaders, and others who can talk with physicians in groups or with their office staffs about transition issues. ▪ Recruit physicians into a network of pediatric and adult medical care providers who offer information and support in caring for young people with complex conditions.
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<p>PERFORMANCE MEASURE 4:</p> <p>Health Insurance</p>	<ul style="list-style-type: none"> ▪ Develop a matrix of insurance plans and enrolled physicians willing to care for youth with disabilities. ▪ Plan early with youth on age-specific waiver programs (such as Katie Beckett or other home and community-based waivers) for transition to another program when they age out at age 18. ▪ Know the resources in the community that might help youth without insurance (federally funded clinics, special state programs, etc.) and teach youth and families how to use these resources appropriately. ▪ Consider providing care for adults with complex conditions (hemophilia, cystic fibrosis, spina bifida) or creating a source of support from pediatric to adult services that includes periodic sharing of treatment protocols and experience. ▪ Develop and distribute "Primers on Health Insurance" in a variety of community settings including schools, parent resource groups, and others concerned with youth.
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<p>PERFORMANCE MEASURE 5:</p> <p>Organization of Services</p>	<ul style="list-style-type: none"> ▪ Mission statement: Make it clear to all constituents that you value working in partnership with families and youth to plan for and manage developmental transitions and prepare youth for transition to adult health care and services. Assure that programs are—and will continue to be—responsive to a wide range of disabilities and to cultural, ethnic, gender, geographic, and economic diversity issues and needs. ▪ Collaborative focus at administrative level: No single agency has the expertise or funding to cover all aspects of transition. Establish interagency workgroups with physician and other health care provider groups; the education field (day care through college), and programs focused on workforce development, business, health care funding, transportation, personal support, and poverty. Include such involvement in the job descriptions of state and regional office administrators. Establish Memoranda of Agreement or Understanding to strengthen commitment to collaborative efforts. ▪ Policies and procedures: Transition issues are included in documentation, quality assurance, outcome measurement, and personnel description and evaluation mechanisms. ▪ Care coordination: Professionals and families constantly learn how to work with the "system". Coordination of transition services' multiple funding streams (health, education, business, multiple private organization) is critical. The focus of services for people with disabilities should be on primary, secondary, and tertiary prevention of disabilities; transportation; housing; access to quality health care and insurance especially for the working poor; personal care assistants and job supports; and assistive technology that is affordable and portable.
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PERFORMANCE MEASURE 5:

Organization of Services (con't)

- **Data systems and evaluation:** Develop data collection and tracking mechanisms to follow progress of youth through systems for children and adults. Continuous quality improvement programs can track effects of programming and inform program development.
- **Partner for school success:** School is where young people spend a great deal of time, learn habits that foster healthy behaviors, and develop work ethics, skills, and expectations for their futures. Collaborate with the Early Intervention system to help families start early in planning for the future. Establish local community inter-agency agreements to assure good transition planning for children transitioning from early intervention to the school system. Help families and youth negotiate the sometimes-difficult transitions into middle school and high school. Initiate or support programs that help students to maintain and sustain wellness to reduce absenteeism and increase opportunities for more consistent learning experiences.
- **Dedicated position with responsibility for transition programming:** Establish a transitions specialist position in the Title V/CSHCN agency that has the ear of administration, does outreach to leaders of state organizations, and is approachable to front-line staff. This person sees that:
 - **Transition issues** are addressed at every contact from birth through discharge, screening and teaching mechanisms are in place, and teaching materials are available. (Issues such as: self-care, working with health care providers, school progress, work readiness, independence building)
 - **Staff development** is continuous and everyone is seeking, collecting, and transmitting transition information and resources among colleagues.
 - **Evaluation activities** determine outcomes of services and transition status of graduates and evaluation information feeds new programming.
- **Community transition liaisons:** Someone in each community office is responsible for keeping the transition focus in the local office and encouraging high expectations for families and youth. Activities might include: discussion in staff meetings; keeping resource files updated; outreach to community agencies and physicians, school nurses, schools (especially special education teachers and counselors); organizing mailings or activities in the office for youth and families; working with community agencies on specific activities (such as family camps or Disability Mentoring Day); and asking transition-related questions during care coordination conferences.
- **Web site:** Information is easily accessible through this cost-effective, public relations effort. Update transition items regularly; coordinate and link to other web-based resources. Assure the availability of alternative formats, and ADA/Section 508 compliance (www.section508.gov). Offer generic, easy to remember e-mail addresses, such as, info@xxx.gov
- **Information Dissemination:** Newsletters to professionals, to families, to youth; newspaper articles describing activities; presentations to community groups working with youth and families; professional journal articles; presentations to university classes; collaboration with university professors in development of courses implemented in the classroom or in "distance learning" mechanisms; participation in conferences focusing on youth by presenting sessions or posters. Consideration must be given to assure written materials are available in different formats: readability, languages, ADA compliance and graphics are culturally diverse and represent the program population.
- **Collaborate with mental health professionals** to develop and sponsor community and family/youth education about mental health issues for all ages. Although critical for successful transition, often families or young people are reluctant to seek or accept mental health care, and funding and waiting-list issues loom large. Emotional or behavioral difficulties should be caught early to prevent their becoming secondary disabilities.

PERFORMANCE MEASURE 5:
Organization of Services
(con't)

- **Provide 1-800 numbers** and other telephone information sources and referral mechanisms.
- **Encourage attendance of parents, families, caregivers and youth at conferences.** Offer family tracks at youth conferences and youth tracks at family/caregiver-focused conferences to give each learning time away from the other.

PERFORMANCE MEASURE 6:
Transition to Adulthood

- **Youth advisory committees** give a unique perspective to program planning and build confidence and competence in the participating youth. When program planning involves youth, they are seen as more than simply patients and their voices and opinions are valued.
- **Youth are encouraged to learn skills to become spokespeople** for youth with health, work, education, and social service professionals.
- **Staff members talk directly with youth** during clinic and other encounters and encourage them to prepare questions to present at service visits.
- **Health skills development:** Address transition questions and self-care competencies and health promotion issues in a variety of curricula, health notebooks, medical teaching exams, web-based and computer programs, and other transition planning mechanisms.
- **Youth are involved in independence building and work experiences.** Connect youth with Scouts, 4-H, Winners on Wheels, Special Olympics, local parks and recreation programs and other independence and social skill building organizations to broaden their horizons beyond medical settings.
- **Person-centered planning and mentoring programs** for interested youth are offered in collaboration with condition-specific agencies (Spina Bifida Association, United Cerebral Palsy, University Centers for Excellence in Developmental Disabilities (UCEDD), youth leadership organizations such as Kids as Self Advocates—KASA (www.fvkasa.org), National Youth Leadership Network (www.nyln.org), and others.
- **Work opportunities:** State and federal governments provide funding for work preparation and employment experiences for youth with disabilities. Developing streamlined referral and communication systems to get the youth to the programs is a responsibility of all staff. Teens can learn work habits early through volunteer activities. Encourage youth to work and employers to hire youth.
- **Independent living training, transportation, and assistive technology:** State and federal programs fund agencies in all states to fund and provide access to such services. Collaboration and referral helps these agencies meet their missions and can be cost-neutral with time rearrangement for the Title V agency staff.
- **Connect youth to other youth and adult mentors** through traditional face-to-face support meetings, and electronically via list-serves, web-based programs, and other mechanisms.

BLOCK GRANT – 6 NATIONAL PERFORMANCE MEASURES

To help states develop effective mechanisms to achieve a system of care for children and youth with special health needs and their families by 2010, six national performance measures (NPM) serve as a guide to states in meeting this goal.

BLOCK GRANT GUIDANCE 2003 - New Performance Measures (p.43) [ftp://ftp.hrsa.gov/mchb/blockgrant/bgguideforms.pdf](http://ftp.hrsa.gov/mchb/blockgrant/bgguideforms.pdf)

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The HRTW National Center www.hrtw.org enjoys a working partnership with the Shriners Hospitals for Children and KASA. The National Center is funded through a cooperative agreement (U39MC00047) from the Integrated Services Branch, Division of Services for Children with Special Health Needs (DSCSHN) in the Federal Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA), Department of Health and Human Services (DHHS).
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HRTW Phase II Projects are currently active in Arizona, Iowa, Maine, Mississippi, and Wisconsin.

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