

## **Healthy and Ready to Work (HRTW)/Transition Activities of State Title V CSHCN Program**

### **Results for Selected Questions Summer/Fall 2000 HRTW/Transition Survey**

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While rapid advances in medical science have enabled over 90 per cent of children born with special needs to reach adulthood, youth with special health care needs are much less likely than their non-disabled peers to finish high school, pursue post-secondary education, get jobs, or live independently. Few coordinated services have been available to assist them in their developmental transitions from school to work, from home to independent living and from pediatric-based care to adult-based health care. The result of this lack of focused, coordinated, well-funded services is that many adolescents and young adults remain dependent on family members, pediatric service providers and public programs such as SSI, Welfare and Medicaid rather than striving to become independent, productive members of society and part of the workforce.

Since 1996, the Maternal and Child Health Bureau (MCHB) has funded nine "Healthy and Ready to Work" (HRTW) grants to develop, implement and evaluate strategies and mechanisms for improving access to health care and other services needed by children and youth with special health care needs to make necessary transitions. The goals of one or more of these projects are to a) increase understanding by the medical community and others of the special problems of youth with special needs concerning transition; b) maintain and develop partnerships to maximize availability of services, work readiness and work opportunities; and c) improve the transition of youth with disabilities to healthy, productive lives and maximize financial independence. Four of these nine projects are being carried out through a State Title V CSHCN Program.

In recognition of the importance of transition/HRTW services, MCHB's Division of Services for Children with Special Health Needs (DSCSHN) added a HRTW performance outcome in its 1999 update of the National Agenda for Children with Special Health Care Needs. This outcome states that all youth with special health care needs will receive the services needed to make necessary transitions to all aspects of adult life, including adult health care, work and independence, as they so choose.

Following is a summary of data collected through the 2000 survey, which provides information about the HRTW/transition activities of forty-four (44) state Title V CSHCN Programs.

1a. Does your state Title V CSHCN Program provide HRTW/Transition services to youth with special health care needs?

**Yes = 21                      No = 22                      Don't Know =1                      N=44**

1b. If yes, what is your state Title V CSHCN Program's operational definition of "healthy and ready to work" (HRTW)/transition services"?

See Appendix A (Operational Definition)

1c. **Of the 20** Title V Program that do provide HRTW/transition services, the specified number of Programs provide and/or pays for individualized services and supports that:

**18** prepare children and youth to transfer to adult health care services

**16** prepare children and youth to transition to independent living/self determination

**13** prepare children and youth to self-direct their care

**9** promote employment (including training and supported employment)

**5** assure inclusion of "health and wellness" in educational and accommodation plans developed in the schools

**3** other

2a. About how many children and youth received HRTW/transition services through your program in 1999?

**Of the 20** Title V Program that do provide HRTW/transition services, **14** states provided estimates of the number of children and youth that received regarding the number of children and youth receiving such services. Numbers served are presented in ascending number served:

<u># served</u>	<u>State</u>
120	MD
131	OR
200	MS
238	MO
250	AR
300	VA
318	ND
350	SC
400	MA
409	WV
1215	IL
2900	AZ
3000	TN
15181	KY

2c. States indicated that the age range of children and youth to whom the program provided transition services are as follows:

<u>From</u>	<u>To</u>	<u>State</u>
0	18	SD
0	21	IN, KY, OK, TN
6	25	MD
11	20	MA
12	21	AL, OR
14	21	AR, CT, IL, LA, MS, NY, WV
14	22	UT
15	21	AZ
16	21	ND, NM, SC
17	22	CA
18	21	HI, NH, VA
19	21	MO

2d. **Nine** states provided estimates of the amount of funds that were allocated by the state Title V CSHCN Programs to HRTW/transition services, supports, and system development activities in 1999. Data is presented in ascending amounts of funds.

Amount	State
\$14,000	NM
\$20,000	MS
\$25,000	NC
\$30,000	LA
\$40,000	HI
\$70,000	MD
\$103,320	WV
\$349,739	KY
\$500,000	AZ

2e. **Fourteen** states provided estimates on the amount of Title V CSHCN Program staff time and effort devoted to HRTW/transition services, supports, and system development activities in 1999.

FTE	State
0.01	WV
0.02	HI, ND
0.03	ME
0.05	MS, TN
0.25	CT, LA, OH
0.75	NC
1.0	AZ, MD, VA
3.0	KY

2f. Data not included in this report

2g. **Of the 21** Title V Program that do provide HRTW/transition services, **15** states provided a description of the strategies and mechanisms used by the program to assure the cultural competence of HRTW/transition services and cultural diversity among consumers involved in HRTW/transition services, supports, and system development activities.

(See Appendix B: Strategies to Assure Cultural Competence)

3a. Do you measure the outcomes of the HRTW/transition services provided and/or paid for by your Program?

**Yes = 9      No = 21      Don't Know = 2      No Answer = 21      N = 44**

3b. The **nine** states that measure HRTW/Transition, use the following methods.

AR CHOICES survey, CMS Parent Satisfaction survey.

AZ Occasional special studies

KY State performance measure

MA We look at grant outcomes - parent/teen satisfaction, medical transitions completed, with pilot projects.

MS We do receive feedback from participants, and their families. Outcome measured through questionnaires given to family members, CSHCN, and other staff participants.

ND We mailed information to 318 families/children age 16-21

OR Evaluation package completed when youth enter the Community, Solutions Project and updated every 6 months; gather information on access to health care, employment, preparedness for college, transition t

SC The SC Division of CSHCN has developed a Continuous Quality Improvement (CQI) tool that provides eight indicators that will measure and monitor the progress and success of transition services. This tool will tell staff when a treatment plan has been completed, if transition services have been initiated, vocation referral made to SC Vocational Rehabilitation Department.

UT A survey was conducted with youth and families who completed the formal transition program offered through the Interagency Collaboration Transition Center.

3c. Are reports of other documentation available about these outcomes?

**Yes = 7      No = 0      Don't Know = 2      N=9**

4a. Does your State Title V Program provide training, technical assistance, or other "systems development" services that promote and support the transition of children and youth with special health care needs to self-directed care, employment, independence, and adult health care services?

**Yes = 19      No = 17      Don't Know = 1      No Answer = 7      N=44**

4b. Of the 19 Title V Program that do provide HRTW/transition-related systems development services, the specified number of Programs provide training and technical assistance materials to the following groups:

- 17 to children and youth
- 17 to families
- 15 to professionals
- 11 to community-based and consumer lead organizations and agencies
- 4 to employers

4c. Of the 19 Title V Program that do provide HRTW/transition-related systems development services, the specified number of Programs provide technical assistance services to the following groups:

- 15 to children and youth
- 14 to families
- 9 to primary care pediatricians and other pediatric primary care providers
- 8 to schools (teachers and school nurses)
- 6 to specialty care pediatricians and other pediatric specialty care providers
- 5 to community-based and consumer lead organizations and agencies
- 4 to managed care organizations and other provider networks.
- 3 to primary care adult providers (family-physicians, internists)
- 3 to specialty care adult providers (cardiologists)
- 1 to employers

4d. Of the 19 Title V Program that do provide HRTW/transition-related systems development services, the specified number of Programs support HRTW/transition by:

- 15 assuring that youth with special health care needs currently have a medical home (i.e. access to ongoing routine health care from a primary care physician that is coordinated with specialty care and other services)
- 12 operating and/or coordinating an interagency coordinating council or other networking entity that promotes collaborative efforts among multiple agencies and organizations to develop, provide and coordinate transition services for children and youth with special needs
- 11 assuring that youth with special health needs who are not Medicaid eligible have adequate insurance to pay for the services and supports that they require
- 11 assuring that youth are satisfied with the services that they receive
- 10 assuring that services are organized so that youth can use them easily
- 8 supporting and promoting the role of youth as partners especially in planning, implementing, and evaluating HRTW/transition programs and their related policies and practices

5a. Does your State Title V Program have a State Negotiated Performance Measure (in your Title V Maternal and Child Health Block Grant Application) that is related to transition of youth with special health needs?

**Yes = 6      No = 33      Don't Know = 3      No Answer = 2**

- 5b. The HRTW/Transition-related State Negotiated Performance Measures, as reported by five states, are:
- AL Percent of CSHCN enrolled in the State CSHCN Program who are referred to the Adult Vocational Rehabilitation Service for services upon their sixteenth birthday (FY 199 Status: 24% FY 2001 Target: 25%)
  - IL The proportion of CSHCN ages 14 and above and their parents who receive comprehensive transition planning services to promote awareness of adult services. This is measured by reviewing the client records of all recipients 14 and over for documentation of transition activities.
  - KY Degree to which CCSHCN provides opportunities for young people to develop skills for transition at critical developmental stages.
  - LA Percent of CSHS patients with case management from a nurse, social worker or nutritionist.
  - SC The degree to which the State assures a transition system for is developed for those children aging out of the CSHCN program

6a. Does your State Title V Program have any Memorandum of Understanding (MoU) with other agencies in support of assisting successful transitions of children and youth with special health needs to self-directed care, employment, independence, and adult health care services?

**Yes = 11      No = 28      Don't Know = 2      No Answer = 3**

(See Attachment C for a listing of agencies included in transition-related MoU's)

7a. Does your CSHCN program have a representative on your state's Interagency Workgroup on Transition/ School to Work issues?

**Yes = 9      No = 23      Don't Know = 5      No Answer = 7**

8a. In your opinion, what are the major barriers in your state to the successful transitioning of children and youth with special health needs from pediatric to adult health care and from school to work? (Briefly specify up to 5 barriers).

**See Attachment D (Barriers)**

8b. Please describe the strategies and mechanisms that your Program is using to address these barriers (attach additional sheets).

**See Attachment E (Strategies)**

**NOTE: For a description of selected HRTW/Transition-related activities of selected state Title V CSHCN Programs, see Attachment F (Program Activities)**

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