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**HRSA/MCHB
Performance Goal
6**

Youth with special health care needs (YSHCN) will receive the services to make necessary transitions to all aspects of adult life, including adult health care, work, and independence.



E-mail
completed
questionnaire to
survey@hrtw.org

Questions?

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Title V CSHSN Programs
Healthy & Ready to Work Services

"Short & Sweet Questionnaire"

E-mailed early September with Due 9/27/02
E-mailed early January 2003 to non-responders
Faxed to nonresponders on 3/4/03

NOTE: Results and % calculated are based on returns from 39 states
Not all states answered all questions
Reported as of June 9, 2003

The Maternal and Child Health Bureau's Division of Services for Children with Special Health Needs (MCHB/DSCSHN) is interested in learning about the Healthy & Ready to Work (HRTW) services and materials your agency uses to promote successful transition for children and youth with special health care needs (CYSHCN).

A policy paper (2000) from the Institute for Child Health Policy's Center for Policy & Partnerships shared information that was obtained through a survey of state Title V Programs and a review of state Block Grants. The document identified the status of states' efforts provide HRTW & transition services for CYSHCN. So what has happened in states since that time?

As part of our continuing effort to support state activity in this area, MCHB/DSCSHN's new HRTW National Center is emailing this Short & Sweet Questionnaire to solicit ideas, promising practices and materials that can be shared with other state programs.

In response to your input the HRTW National Center will create a web resource of selected recommended materials and will also developed products to meet the issues you identified.

Q What's a "Short & Sweet Questionnaire?"

A Recognizing that your time is valuable, this questionnaire (13 check off questions, 3 open ended questions) is estimated to takes less than 5 minutes to complete.
We appreciate your time and value your input.

Thank-you for your dedication to assure that all of our children and youth receive the services necessary to lead healthier lives!

HRTW SHORT & SWEET - QUESTIONNAIRE

Due: 9/27/02

Estimated time to complete less than 5 min



E-mail to: survey@hrtw.org

STATE: NAME: EMAIL: **Results of Returns from 39 states, June 9, 2003, Kathy**

Respondents are 16 CSHCN Directors; 2 parents; 2 combination CSHCN Director and parent; 17 Other – CHOICES contact, transition coordinator, other staff (missing who responded in couple cases)

GOAL 6: All youth with special health care needs (YSHCN) will receive the services to make necessary transitions to all aspects of adult life, including adult health care, work, and independence.

GOAL 6: Action Step 1 - Use Title V to facilitate the development of HRTW/Transition systems for children, youth, and young adults with special health care needs and their families.

1. Why type of transition services does state Title V CSHCN Program provide?"

Direct Indirect None Not Sure
13=33% 26=67% 2=5% 3=8% (MI, FL, CA)

There is some confusion about the terms. Changing personnel and dwindling institutional memory lack knowledge of previous service base. Some states do limited clinics and mostly infrastructure building and payment for services.

2. HRTW /Transition Services in my state begins:

From Birth After EI -identification At time of diagnosis
6=15% 2=5% 1=3%

4-6 6-12 13-15 16-18 18-older Not Sure
0 2=5% 14=36% 8=21% 1=3% 3=8% (MI, CO, LA)

Most states are targeting mid-teens in concert with age of education transition mandate and AAP/AAFP/ACP-ASIM Consensus Statement (2002) recommendation. Only 23% of states target from birth or identification; 64% target prior to age 16.

3. Agencies and policies may dictate at what age HRTW services are to begin, but in your personal, professional opinion, at what age would you recommend these services start?

From Birth After EI identification At time of diagnosis
13=33% 1=3% 7=18%

4-6 6-12 13-15 16-18 18-older
0 8=21% 8=21% 2=5% 0

This is an interesting difference from state practice to professional belief. 54% believe services should initiate from birth or time of diagnosis. 95% believe services should begin prior to 16. Respondents believe transition services should start much earlier than they actually do.

4. My state program has used or does use the materials developed by the HRTW Projects.
(ie. KY HRTW Life Maps, ME Service Tapestry, etc.)

Yes No Not Sure
13=33% 18=46% 7=18%

This response indicates need for greater marketing efforts for materials that have been produced through MCHB and other grant projects. The goal is to distribute the information developed and replicate good practices and avoid or lessen duplication of effort.

5. (a) What format do you prefer to receive transition policy papers?
- | | | | | |
|-----------|------------------------------|-----------------------------|-----------------------------------|------------|
| Via web | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Not Sure | 24=62% yes |
| Via email | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Not Sure | 30=77% yes |
| Hard Copy | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Not Sure | 21=54% yes |

It appears that our State Title V colleagues are truly a “click away” from obtaining needed resources, yet there is still a preference for hard copy materials. Some states may need assistance with printing and dissemination costs in this time of tight budgets. The fact that we got e-mail responses from only 22 (of 39) of the states on the e-mail survey is also revealing of the lack of skill and comfort and possibly state technology for e-mail and the web.

- (b) Has your state program created transition materials for: (check all that apply)
 If yes, are these materials available on a web site? Please provide web address.
- | | | | | | |
|-----------|------------------------------|-----------------------------|-----------------------------------|------|------------|
| Youth | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Not Sure | URL: | 13=33% yes |
| Families | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Not Sure | URL: | 11=28% yes |
| Providers | <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Not Sure | URL: | 10=26% yes |

This is a promising trend and demonstrates that states with and without HRTW funding are taking some initiative, yet few have materials on their state web pages nor have a vehicle to share/disseminate nationwide.

GOAL 6: Action Step 2 - Assure that youth with special health care needs participate as decision-makers and as partners.

6. Does your state program participate on an interagency council that is targeted to youth and transition?
- | | | | |
|------------------------------|-----------------------------|-----------------------------------|--|
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Not Sure | If yes, which agency is the designated “Lead.” |
| 21=54% | 15=38% | 2=5% | |

While it appears that over half of the respondents participate in an interagency activity at the state level, an in-depth follow-up is needed to determine the mission, funding base and role of Title V and Health.

Dept of Education is most frequently mentioned lead agency; Title V leads in New Mexico, and leads for data collection in Colorado.

7. Does your state program currently have a Youth Advisory Council (YAC) in place?
- | | | |
|------------------------------|-----------------------------|-----------------------------------|
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Not Sure |
| 9=23% | 24=62% | 6=15% |

If no, would you like to information or TA from other states who do? Yes No Not Sure
24 say yes (1 no and 3 not sure)

It took almost a decade, even though it was federally mandated, to implement Family-Centered Care practices – and states are still not 100% in compliance. HRTW will need to develop an expedited implementation plan to ensure that youth have the skills and the opportunities to have their voices/ideas heard to shape policy and influence changes in practices.

GOAL 6: Action Step 3 - Provide youth with special health care needs with accessible and affordable health insurance coverage. **39 states 6/9/03**

8. This age group has several options for health care coverage before and upon turning 18. Are there special waivers in your state to wrap around services for 18 and beyond?

Yes No Not Sure
14=36% 12=31% 9=23%

The percentage of respondents who don't know if these services are available indicates that Title V staff do not know about the adult health care and social service systems to which their clients are transitioning. The supports required for individuals who are attempting independence from their families necessitate a broad range of services available at the community level. This question needs to be further defined to assess scope of eligibility and actual range of coverage for which populations – all or select - in the states.

9. Is your state program participating in the Ticket to Work (Medicaid buy-in)?

Yes No Not Sure
18=46% 9=23% 12=31%

Again it is interesting that almost one third of respondents do NOT know if their state is participating in Ticket to Work. Insurance coverage will continue to be problematic for this age population (ages 18-25), as this group is more vulnerable to not being insured than any other age group. In addition, their eligibility status can fluctuate due to change in education status, start of a new job, change in residence away from family, and income due to government support programs.

Note: Some states have begun to expand their state SCHIP programs to include adults with disabilities and chronic health conditions (ME). Other states continue to maintain creative buy-in plans (MA Common Health). As further budget woes reduce existing services, there is concern that some of the progress in providing coverage to this age will be arrested or backslide.

There are five health coverage scenarios that youth with disabilities face. Some of these scenarios can become life threatening or certainly negatively impact health status if coverage is lost, lessened or threatened. The scenarios are:

NEW TO MEDICAID

- Child did not qualify for SSI under 18 due to family income. At age 18 may qualify for SSI and Medicaid as an adult single head of household.

NEW or MAINTAIN MEDICAID

- Emancipated Minor - by marriage or court decision may qualify or continue Medicaid due to income and/or disability status.
- Youth age 18, single head of household, former child SSI recipient, meets new SSI disability criteria, continues to receive Medicaid.

LOST MEDICAID

- Child was a SSI recipient; at redetermination at age 18, became ineligible for services and lost his/her Medicaid coverage.

PRIVATE INSURANCE

- Youth over age 18 may continue on family plan until age 22-25 if full time student
- Youth over age 18 may continue on family plan if is determined to be an adult dependent for life (with annual re-certification)
- Youth receives/purchases health insurance though college/vocational school
- Youth receives health insurance as benefit of employment or purchases plan through employer.

MEDICAID BUY-IN - via TICKET TO WORK

- Program is too new to assess if states are providing full benefit packages and at what level of sliding fee.

GOAL 6: Action Step 4 - Assure that all youth with special health care needs have medical homes responsive to their needs.

10. Does your state program have a written protocol or guidelines in place for transition to adult services?

Yes No Not Sure
11=28% 22=56% 5=13%

If you answered yes, does protocol or guidelines include **raw numbers (2 said they did not have protocols but say they refer to VR and adult med providers)**

- a) referral to Voc Rehab Services ? 13 Yes 2 No 1 Not Sure
b) referral to adult Medical Provides & Services ? 12 Yes 2 No 1 Not Sure
c) personal attendant services? 6 Yes 7 No 2 Not Sure

It is anticipated that the AAP-AAFP Transition Consensus Statement when broadly disseminated will be helpful to states as they coordinate care. It will be helpful to obtain e-copies of existing protocols to share with other states (mount on the HRTW National Center Web Site: www.hrtw.org)

11. Does your state program provide assistance in gathering medical evidence for SSI application at age 18 (during redetermination) ?

Yes No Not Sure
21=54% 7=18% 9=23%

Just over 50% of states indicate they assist in gathering medical and other evidence for SSI applications. Is the assistance limited to copying of medical records or does it include family/youth education in how to create a concise application?

Interesting to note that 41% of respondents indicated they did not or were unsure if they assisted with SSI applications. MCHB funded an extensive effort on gathering medical and other evidence for SSI applications (1990-1997). With the documented rejection rate of 60% during redetermination, what role does/should Title VCSHCN programs play in assuring that cash benefits and the Medicaid connection are not jeopardized. Should this be a component of transition services?

Another issue: As states lower the age eligibility due to budget cutbacks or policy changes, what other agencies are in a position to close this need gap? Are families and youth being taught how to prepare a concise medical summary that meets the SSA requirements, thorough without being documentation dense?

Comments from states:

- MN cut off age is 16
- MO delegates this to Protection and Advocacy
- ND and NE assist upon request
- CO has local offices for limited numbers
- SSI is not available in VI

Action Step 4: Assure that all youth with special health care needs have medical homes responsive to their needs.

This survey did not address this desired outcome. It is anticipated that findings will be shared from the AAP Medical Home National Center during the coming year

12. BUDGETS ISSUES

Post 9/11, has your state budget and service priorities for youth with special health care needs

Increased/Expanded Reduced Eliminated No Change Not Sure
5=13% 12=31% 1=3% (UT) 17=44% 3=8% (NM, SD)

Comments from states:

- **ND: Reduced 1% this biennial budget, however a 5% reduction for all state agencies has been requested by the Governor for the 2003-2005 budget**
- **WI: Has little to do with 9/11 except bioterror \$\$ for WI we included mental health a priority area. We only have MCH block grant \$ and that has increased slightly. No GPR however, have HRTW grant.**
- **MN expects reduction**

An earlier MCHB funded report from McManus and Fox reported budget woes for State Title V CSHCN Programs. Recently, the National Governors Association www.nga.org released a report saying states face the most dire fiscal situation since World War II. The National Governors Association and the National Association of State Budget Officers conclude many states have exhausted budget cuts and drawing down rainy-day funds and that the most difficult decisions still lay ahead. State by state fiscal chart (pdf) <http://www.nga.org/cda/files/NOV2002FISCALSURVEY.pdf>

It is anticipated that states will have a difficult time adding or expanding new/existing programs.

13. EXPERTS IN TRANSITION: *People, Services & Solutions*

We realize there are pockets of excellence. Is there a person or a professional group in your state that has made progress in transitioning youth to adult services and whose efforts may be highlighted as a promising practice?

(a) Who in your agency would you recommend as a contact who knows how to navigate the system?

NAME/AGENCY EMAIL PH

(b) Who outside of your agency do you call and would recommend to others?

NAME/AGENCY EMAIL PH HRTW Projects, Parent groups, Education, VR

There is a growing base of state/community-based transition expertise within the states. The names provided will be considered for inclusion to the HRTW Wisdom Council.

14. MATERIALS

(a) What transition materials would you recommend to your MCH Colleagues? List URLs (ie. AAP Medical Home training materials, MCHB funded or other sources)

- AAP Medical Home Transition materials
- NASW has new packet of transition materials
- NICHY
- HRTW Projects
- Indiana Medical Passport

(b) What transition materials would you like to have but can not find and would like developed?

- Adolescence Life Planning/Estate Planning for Youth & Families
- Transition Planning for Adolescents with Special Health Needs
- Would like to have more information about mental health and emotional disabilities
- More on transition and adult health care
- Transition booklet state specific
- Fact sheet (transition tips)
- Materials that are developed in other languages
- Transition success stories
- How to disseminate to low population states

15. **CONTINUING EDUCATION: Capacity Building for Providers and Leaders 39 states 6/9/03**

Continuing education needs to be offered to providers and those in leadership positions to better understand the complex issues related to transition policy and program development from needs assessment to program evaluation. What is your opinion of the above statement?

Strongly Agree Somewhat Agree Neutral Somewhat Disagree Strongly Disagree
30=77% 7=18% 1=3% (OH) 0 0

Overwhelmingly the states recognize that professionals need additional training in this area to be effective. Content is new due to longer survival rate and the desire for higher quality of life for YSCHN. It is hoped that the HRTW National Center will be partnering with existing education centers to augment curriculum to include HRTW and transition of care issues.

16. **Other comments?** Use next page if needed.

Region I

- DE Title V has established a partnership within the past year with the Medicaid

Region IV

- FL We are in the process of writing transition guide that can be used by
- GA Have distributed numerous materials developed by HRTW & by other sites; Transition included in Care Coordination training and services
- AL Staff person assigned to transition. Invite Title V Transition specialists to HRTW meetings!

Region V

- MI Looking to pay attention to this need as soon as get to it. Other needs higher priority at this time.
- WI through the UAP/Waisman Center received a HRTW grant.

Region VI

- NM Transition New Mexico Conference for families, youth, providers

Region VIII

- MT CSHCN Director active on statewide transition committee
- ND Resources devoted to transition for Title V CSHCN programs are scarce.

Region X

- WA Need provider pre-service, not only in-service. Need to develop information and training for teachers and health care providers.