



Summary Findings as of January 2009

HRTW National Resource Center Questionnaires 2006-2008

State Title V CYSHCN Agencies	42 of 59
NACHRI Hospitals	19 of 162
Shriners Hospitals	20 of 22
Family to Family Health Information Centers (F2FHIC)	26 of 45
Physicians/Medical Homes	52

MANDATES

- State Title V agencies and F2F HICs are responding to mandates of the 6 NPMs in the Block Grant, including transition programming.

PROGRESS

- Only a few states, medical homes, children’s hospitals or F2F HICs are where they want to be in their transition focus.
- Shriners Hospitals are focusing on transition as a part of care coordination emphasis.
- States, medical homes, children’s hospitals and F2F HICs want help to do transition better.
- Have expanded transition services in the past 2 years:
 - 40% of Medical Homes
 - 32% of NACHRI Hospitals
 - 71% of State Title V CYSHCN agencies

FAMILY/YOUTH INVOLVEMENT

- States are including families and youth in their planning and policy making to a much greater extent than medical homes or children’s hospitals, in part because of MCH mandates.

INFORMATION ON TRANSITION

- A greater percentage of states and F2F HICs know about HRTW and use the website and services as compared with medical homes and hospitals.
- Only 50% of the medical homes were familiar with the Consensus Statement on Transition of Youth with SHCN of the AAP-AAFP-ACP/ASIM.

OUTCOMES

- There is very little follow-up of young adults after they leave the pediatric system – we don’t know our outcomes!

- Title V agencies 7%
- Medical Homes 12%
- NACHRI Hospitals 21%
- Shriners Hospitals 25%

ACTIVITIES: Interagency or intra-agency committees or teams, notebooks and educational materials, focus groups, identifying adult providers, collaborating with community resources, adding transition coordinators/SWs, expanding age eligibility, physician and care coordinator training, website transition information, contracting for services, creating youth or family advisory groups
 * Not asked of Shriners Hospitals (we know they focus on transition as part of care coordination) or F2F HICs which are new

- **SELF RANKING ON PROGRESS - Medical Homes, NACHRI Hospitals, State Title V agencies, and F2F HICs were asked to rate their hospital/system/practice with regard to transition processes in general.**

Rating	Description	Medical Homes N=52	NACHRI Hospitals N=19	Title V CYSHCN Agencies N=42	F2F HICs N=26
1	Not interested, too busy, no resources, etc.	2%	5%	0%	4%
2	Don't have transition processes, interested in developing them	29%	21%	12%	23%
3	Beginning stages of developing transition policy and processes and finding /developing tools	25%	37%	48%	38%
4	Working on policy and processes; about halfway to where we hope to be	19%	21%	26%	23%
5	Have transition policy and processes integrated into our practice	13%	5%	12%	8%
		6 blank=12%	2 blank=11%	1 blank=2%	1 blank

Which of the following services/programs does your hospital/system/practice have in place to support transitioning of youth to adulthood and adult services?	Medical Homes N=52 26 states	NACHRI Hospitals N=19 of 162 18 states (12%)	Shriners Hospitals N=20 of 22 15 states and Canada (91%)	State Title V Agencies N=42 of 59 States/Territories (71%)	F2F HICs N=26 of 45 25 states (60%)
Designated Transition Coordinator	50%	21%	30%	48% 5 have 100%+ Coordinator	Not asked; 1 responded
Offer multidisciplinary transition clinics	Not asked	11% SB, CP, MD, CF, neuro, TBI/SCI	10% camps; seminars	29%	Not asked
Provide youth/families with an educational packet or handouts specifically related to transition needs/concerns	39%	48%	80%	74%	58%
Screen or assess to identify YSHCN who need transition services	60%	37%	90%	64%	12%

Which of the following services/programs does your hospital/system have in place to support transitioning of youth to adulthood and adult services? (Con't)	Medical Homes N=52 26 states	NACHRI Hospitals N=19 18 states (12%)	Shriners Hospitals N=20 15 states and Canada (91%)	State Title V Agencies N=42 of 59 States/Territories (71%)	F2F HICs N=19 of 34 19 states (60%)
Provide care coordination for youth with complex conditions	91%	64%	100%	81%	4%
Create an individualized health transition plan	34%	43%	25%	50%	42%
Assist youth with SHCN to make a portable medical summary (for wallet/purse/backpack)	35%	32%	50%	Not asked	23%
Promote independence in health condition management, self care, and prevention of secondary disabilities	63%	79%	95%	72%	62%
Assist with planning for school and/or work accommodations	68%	84%	100%	64%	85%
Provide or refer to transition-related mentoring, support, and skill building programs such as camps, recreation, activities of daily living skills, volunteer or paid work experiences	50%	73%	100%	69%	85%
Discuss legal responsibility for medical decisions and health records prior to age 18.	21% written policy 81% get assent	58%	100%	62%	46%
Assist youth/families to use community resources and the public benefits system	79%	74%	100%	91%	96%
Assist with planning for continuous health insurance during transition into adulthood	43%	48%	100%	72%	62%
Assist with SSI medical documentation and/or re-determination	75%	69%	100%	78%	77%
Recruit adult primary care /specialty providers to assume care of youth with special needs	56%	58%	35%	53%	Not asked
Support adult providers willing to assume care of young adults with complex health care needs with education and/or experiences in your hospital/system	64%	32%	35% 9 hospitals send transition summaries	38%	31%

Are YSHCN/families involved in the development of your hospital/ system/ practice's services to support transitioning?	Medical Homes 42%	NACHRI Hospitals 47%	Shriners Hospitals 35%	State Title V 88%	F2F HIC 100%
Family advisory group	14 of 22 practices saying Yes	6 of 19 Hospitals saying Yes	6 of 20 Hospitals saying Yes	37 of 42 states work with parent groups	Programs are run by families
Disease-specific family advisory group	1	1			
Youth Advisory group	3	3	3	2009: 24 states <i>variety of sources</i>	4 HICs
Family Support Group	4	2			
Youth Support Group	2	1	13		
Topic Specific Focus groups	1	4			
Consumer Advisory group	2 practices	1			

Barriers to Transition * <i>rated extremely important or very important (combined)</i>	Medical Homes	NACHRI Hospitals	States	F2F HICs
Lack of capacity of adult providers to care for youth/adults with SHCN	83%	85%	95%	92%
Inability to access adult specialty care	73%	84%	92%	89%
Fragmentation of care among systems providers	87%	73%	89%	100%
Lack of services for adults with special health care needs	89%	85%	88%	85%
Limited coverage for services by insurance or Medicaid	75%	58%	85%	92%
Inability to access adult primary care	73%	84%	81%	84%
Lack of staff time	85%	68%	81%	81%
Low reimbursement levels for transition services	61%	63%	71%	96%
Lack of computer technology to identify and track	56%	37%	55%	58%
Lack of understanding of reimbursement eligibility differences between adults and children with special health care needs	65%	63%	Not asked	Not asked
Pediatric providers unwilling to transition care to adult providers	43%	42%	53%	62%
Lack of knowledge about or linkages to community resources that support youth in transition	85%	58%	50%	96%

**Not asked of Shriners Hospitals*

Areas of technical assistance most requested by states and F2F HICs:

- Youth Advisory Councils
- Recruiting and supporting adult health care providers
- Transition planning (including emergency plans and portable medical summaries)
- Tools for youth, families, and professionals
- Regional conferences to connect states and F2F-HICs

Materials states and F2F HICs would like developed (in order of frequency mentioned):

- Training materials and tools for adult providers (including reimbursement)
- Information on YACs – structure, function, working hands-on with youth consultants
- Materials for youth/young adults with cognitive disabilities and lower functioning families and youth
- 1-page materials: transition and person-centered planning
- Articles for newsletters
- Materials promoting interagency collaboration – especially with schools
- Evaluation of transition systems and outcomes
- Fitness; sexuality; motivation for children and parents

Requests for help by Medical Homes and Hospitals:

- Develop recommendations and resources for training pediatric, family physicians and internal medicine residents on transition
- Educational forums; CD-Roms; websites to refer to when have YSHCN
- Provide assessment tools for when to transition and map out transition plans – systematic examples to follow; brief interventions for a busy office; handouts
- Coding for reimbursement
- Help deal with payers to get organized system of payment and responsibility for this population
- Lists of resources – state and area specific and info on who does what, lists of adult providers willing to accept YSHCN
- Family/youth education
- Facilitating study of patient outcomes
- Staffing for transition activities

Suggestions for MCHB and HRTW by states:

- MCHB or partner agency could sponsor a national summit for Title V-sponsored Youth Advisory Councils and Parent Advisory Councils
- Focus on developing the *systems* that will support successful transition (including health education in schools, interagency collaboration and coordination of a service care plan that is electronically driven and accessible)
- Need for evidence-based, peer reviewed research to evaluate transition systems and outcomes
- Collaborative efforts with Family Physicians and Internists around primary care for youth and adults with SHCN

HRTW Technical Assistance offered:

INFORMATION & TOOLS

- Website: www.hrtw.org
- Tools for screening, assessment, planning, teaching, evaluation, life span skills
- HRTW e-News
- Promotion of tools/materials for adult health care providers

PEER MENTORING

- HRTW Topical Conference Calls / resources and transcripts at HRTW-U on website
- Promote transition in ALL 6 National Performance Measures
- Connect states: Peer to peer, mentors

PROGRAMMING

- Transition support in all phases of programming
- Planning for adulthood early and promoting health and wellness

FAMILY / YOUTH INVOLVEMENT IN HEALTH CARE DECISIONS

- Increase skills for individuals: self care and accessing health care
- Increase informed decision-making: Assent to Consent
- Patient hand-held medical records, portable medical summary
- Increase transition skills of F2F-HIC leaders

YOUTH LEADERSHIP IN HEALTH POLICY

- Promote Youth Advisory Councils and youth leadership with:
 - Resources www.hrtw.org, click on HRTW-U
 - Connection of states developing YACs with experienced states
 - Consultation by youth to HRTW National Resource Center
 - Youth participation in conferences and trainings

NETWORKING & COLLABORATION

- Recruitment and support of adult health care providers
- Outreach to American Academy of Family Physicians and other groups
- Collaboration with other MCHB National Centers, MCHB funded projects

Have used HRTW Website:

83% of State Title V agencies

81% of F2F HICs

21% of NACHRI Hospitals

17% of Medical Homes

Have used HRTW services

60% of State Title V agencies

31% of F2F HICs

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