

# ASSESSMENT OF CHILDREN'S HEALTH SYSTEM AND UAB DEPARTMENT OF PEDIATRICS TRANSITION OF CARE OF CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

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## Children and Youth with Special Health Care Needs (CYSHCN)

- 17.1% of Alabama's children have special health care needs (estimated 187,263)
- 61.7% of these CYSHCN report that they have not received services necessary for transition to adult health care (estimated 40,714)

• 2005/06 National Survey of Children with Special Health Care Needs

## Children's Health System & UAB Department of Pediatrics

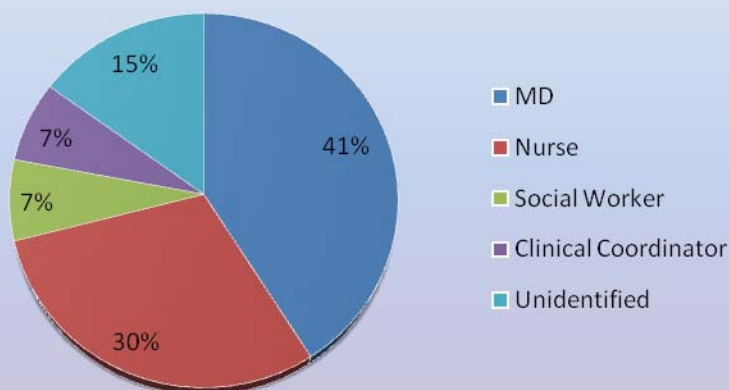
- Alabama's single, largest provider of specialized pediatric services
- One of the nation's largest outpatient centers
- Serves as the medical home for a large percentage of Alabama's CYSHCN

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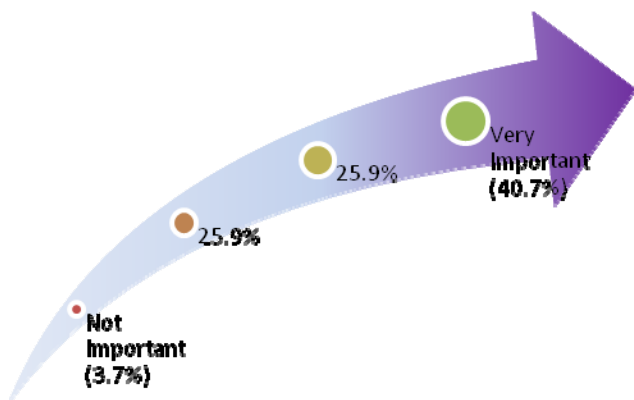
## ABOUT THIS SURVEY

- Survey was distributed to 52 physicians, nurses and social workers in the Departments of Pediatrics and Pediatric Surgery in June 2009
- A total of 27 surveys were returned for a response rate of 52%
- Distribution of respondents: 11 MDs (41%), 8 nurses (30%), 2 social workers (7%), 2 clinic coordinators (7%), and 4 unidentified (15%)

## Distribution of Survey Respondents



# COMMITMENT TO TRANSITION



How important does your practice consider the transition process of youth with special health care needs to adult care an important part of helping adolescents and their families achieve adult milestones?

Survey Results regarding Commitment to Transition	All (n=27)	MD (n=11)	Nurses (n=8)	Other (Social workers, Clinical Coordinators, & unidentified) (n=8)
Are considered as medical home to complex patients	78% (21)	91% (10)	75% (6)	75% (6)
Have a specific adult provider to whom patients are transferred	56% (15)	64% (7)	38% (3)	63% (5)
Have a transition coordinator	33% (9)	55% (6)	13% (1)	25% (2)
Utilize a mandated transition policy	15% (4)	18% (2)	25% (2)	0% (0)
Have a written transition policy	11% (3)	18% (2)	0% (0)	13% (1)
Utilize a special clinic time for transitioning adolescents	7% (2)	18% (2)	0% (0)	0% (0)
Have received transition training	7% (2)	0% (0)	0% (0)	25% (2)



**AGES OUT** – Leaves practice upon reaching an age determined by the practice  
**DROPS OUT** – Stops coming for care and is lost to followup  
**FORCED OUT** – Leaves for reasons not controlled by patient or practice  
**HANGS OUT** – Continues with practice after age limit of practice  
**MOVES OUT** – Leaves practice to seek care from other provider  
**TRANSFERS OUT** – Coordinated transfer to adult health care provider

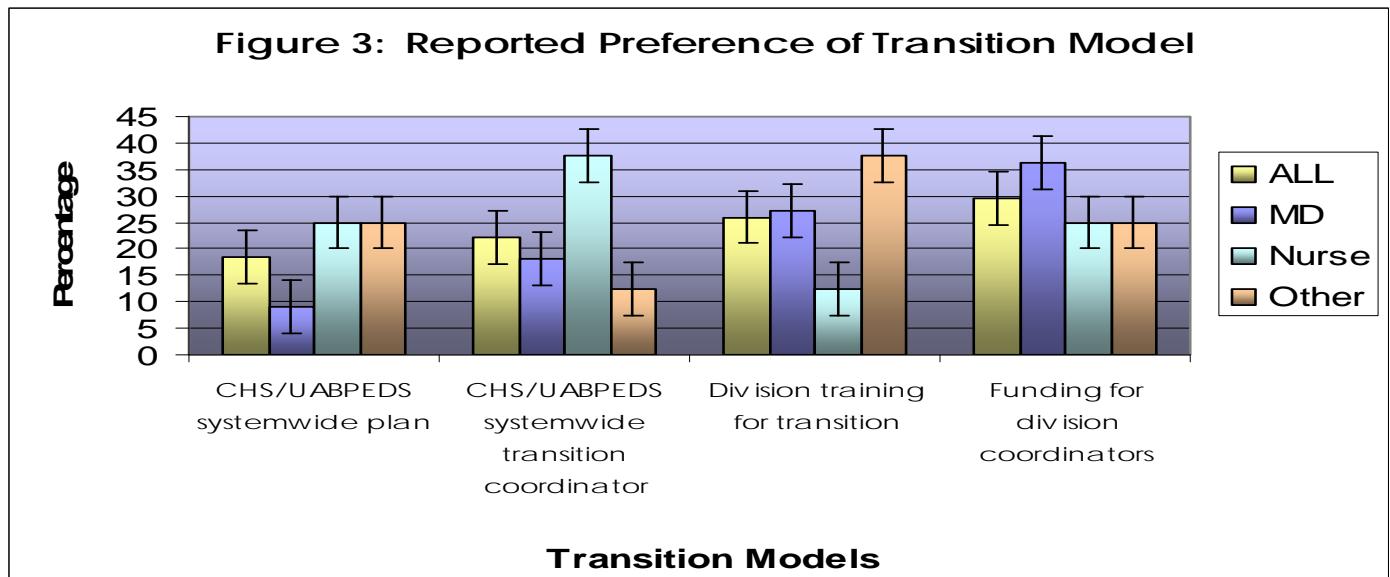
\*Based on estimates made by survey responders

# BARRIERS TO TRANSITION

Survey Responses Regarding Barriers to Transition	All (n=27)	MD (n=11)	Nurses (n=8)	Other (Social workers, Clinical Coordinators, & unidentified) (n=8)
Lack of available, appropriately trained, or willing adult providers for complex patients	67% (18)	64% (7)	75% (6)	75% (6)
Unwillingness of families to leave pediatric practice	63% (17)	45% (5)	88% (7)	75% (6)
No written transition policy within the practice	56% (15)	45% (5)	63% (5)	50% (4)
No recognizable CHS/UAB PEDS system infrastructure supporting transition	48% (13)	55% (6)	25% (2)	63% (5)
No institutional-wide transition policy	44% (12)	45% (5)	38% (3)	63% (5)
Time constraints of existing personnel	41% (11)	45% (5)	38% (3)	38% (3)
Lack of training for personnel regarding transition	37% (10)	36% (4)	38% (3)	38% (3)
Lack of individual division infrastructure to support transition program	37% (10)	36% (4)	25% (2)	50% (4)
Lack of funding for transition coordinator position	37% (10)	45% (5)	25% (2)	38% (3)
Concerns of financial impact of losing patients	4% (1)	0% (0)	13% (1)	0% (0)

# INSTITUTIONALSUPPORT

<b>UAB Department of Peds/CHS systemwide plan for transition using standardized protocol</b>	<b>UAB Department of Peds/CHS systemwide transition coordinator</b>	<b>Training for practice personnel to develop transition program</b>	<b>Funding for transition coordinator within practice</b>
<ul style="list-style-type: none"> <li>•All Divisions would follow the same systemwide transition protocol</li> </ul>	<ul style="list-style-type: none"> <li>•All Divisions would refer patients ready to begin the transition process to a systemwide transition coordinator who would coordinate an individualized transition process.</li> </ul>	<ul style="list-style-type: none"> <li>•Each Division would receive training on transition and guidance regarding the development of their own unique transition program.</li> </ul>	<ul style="list-style-type: none"> <li>•Each Division would receive funding for a transition coordinator to design, implement and maintain a Division-specific transition program.</li> </ul>



## IMPLICATIONS OF FINDINGS

Transition is taking place at CHS/UAB PEDS, but without structure at the institutional level

- Several responders report some sort of transition activity in their practice areas with varying levels of success
- Lack of formal CHS policies regarding transition and aging out results in divisional autonomy
- Sharing of transition strategies and methods across division could result in collaborative programs
- Sharing of transition strategies and methods for those who are not having difficulty with transition could help those who are

Transitional training needed at multiple levels

- Only 2 survey responders have received transition training
- Although the training model was the 2<sup>nd</sup> choice of survey responders, training could and should be offered through Grand Rounds presentations, CME/CEU workshops, etc
- CHS/UAB PEDS-supported parent workshops for CYSHCN
- Medical school lectures – How are young doctors being taught about the growing cohort of adults with pediatric diseases?
- Training (and subsequent program development) results in patients and families who do not resist transition
- Training results in advocacy at the state/federal level for policy change regarding reimbursement

Strong collaboration and community building with adult medicine is needed

- Pediatric model of care differs from the adult model, resulting in frustration.
- Do the patients have to be transitioned to the corresponding medical specialty?
- Do the patients have to be transitioned across the street to UAB adult providers?
- How can CHS/UAB PEDS collaborate with stakeholders throughout the state?

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## AREAS FOR FURTHER EXPLORATION

- Surveys of adult medical care providers to gain insight into their views of transition
- Surveys of families of CYSHCN regarding their attitudes towards transition
- Review of CHS/UAB PEDS policies that relate to the care of older adolescents/young adults with special health care needs
- UAB medical school curriculum review regarding transition of CYSHCN to adult medical care
- Review of transition programs in place at other children's hospitals and pediatric departments similar in size and scope to CHS/UAB PEDS

## Comments and Responses from Survey Responders

MD	We have a protocol in place but no specific written policy. We are working on creating a binder for patients as they transition out.
MD	We have a transition team for diabetes, but not other endocrinology patients.
MD	Have not received specific training, but have dealt with these issues on a regular basis in my clinical practice.
MD	No special clinic time, but do coordinate these issues on an individual basis.
Nurse	We have a specific group of providers that we transition our patients to.
MD	This survey is missing the target. It is the adult MD's who don't want complex difficult patients with little to no compensation.
MD	No one on the adult side wants to care for these complex patients with chronic conditions.
Nurse	The majority of our complex patients stay with us longer than they should.
Nurse	In our division, the nurses and social workers collaborate to help identified patients move to adult care.
MD	We follow a population of neurologically devastated individuals, many in their 20's. Despite their chronologic age, their neurologic status remains unchanged. This population probably needs more help with primary care transitioning.
SW	Unwillingness of families to leave pediatric practice plus the unwillingness of the doctors to transition these that don't want to leave.
MD	NASPGHAN has come out with guidelines, but they are not mandatory.
MD	A transition coordinator would be nice, but there are no resources available.
MD	Transition is an important aspect of my practice. Mostly hampered by lack of a coordinated effort, funding and a willing and available partner on the adult side. Funding/billing for a transition visit is also a significant barrier (who will bill for the visit – adult or peds practice, and where to house the transition program?)
CC	Insurance is a big issue – the kids age out of their insurance and have now way to finance healthcare.
Nurse	We have a great relationship with UAB Epilepsy Center and Dept. of Neurology for transition. Typically this is arranged by the patient's primary care physician or staff nurse. I don't think we have enough patients to justify hiring a full-time transition coordinator.
Nurse	We have no set age limit for when we will stop seeing patients.
Nurse	The patients with spina bifida and hydrocephalus are harder to transition because adult neurosurgeons do not want to deal with pediatric diseases.
MD	No forced age – We leave it up to the patient to decide when to transfer care and to what doctor. Do agree this should be a planned process and not just an "event". Getting pregnant, though, is an automatic referral to UAB.