

1. What two or three things do you think are most important to *Youth and Young Adults (Y/YA)* with disabilities and chronic medical conditions in regard to health care transition?

General

- It depends upon the development level
- Issues of puberty, (delayed) autonomy, personal identity, sexuality, educational and vocational choices.
- Essential role of the family

Payment for Medical Care and Insurance Coverage

- Finding providers that accept the insurance they have who has experience with their diagnosis.
- Knowing that their health care coverage will continue without interruption.
- Knowing that they will be able to obtain the same (or equivalent) medications/treatments through their new health care coverage at a similar cost.
- Having the financial means to pay for adult medical care. When I transitioned from pediatric care (At Shriners's Hospitals for Children) to adult care, suddenly my family and I were responsible for paying not only for doctor's visits, but for any medication, adaptive equipment, etc that I might need.
- Appropriate health care coverage that meets the patient's specialty services needs.
- Recipients are forced to switch to an HMO and NOT given the opportunity to change or stay with medipass prior to the change or stay switch after CMS Network is closed at the date the recipient turns 21.
- Obtaining or maintaining a funding source for health care.

Continuity and Coordination of Care

- Knowing that they will have the same doctors or that the doctors under their new health care plan will be as good as the ones that they currently have.
- Some continuity or consistency of care so the patient doesn't have to worry more about bureaucracy than caring for his or her condition.
- Finding an adult health care system that can provide continuation of health care services i.e., primary/specialty care at a level necessary for medical condition.
- The fact that at 18 years of age quite a few services are stopped with no effective counterpart in the adult system.
- Need for true medical home that can coordinate care among specialists and services.

- To access, maintain and or improve the same level of medical care in order to be able continue to maintain or improve their quality of live, this affects every aspect of their life (ability to participate in the community, go to school, work achieve independence).
- Collaboration between CMS and AHCA before Y/YA turn 21 years old.
- Continuation of proper health care.
- Better communication form pediatric Medipass provider to adult Medipass Provider.
- Being able to transition to a managed health care plan that best fits their medical needs.

Relationship Building

- A provider who listens to them.
- Finding specialist physicians willing and interested in caring for them.
- Establishing trust with new providers.
- Feeling wanted and respected as a person.
- Giving private time to speak with the doctor regarding their concerns/issues.
- Finding a "medical home" that will meet their needs-both medical and emotional and a provider knowledgeable, compassionate and sensitive to their special needs.
- Awareness of cognitive and emotional levels of the patient
- Having a family practitioner who can follow them through their lifespan.

Education/ Empowerment

- Honest conversation on the process of transition.
- Some sort of assistance to families as new roles as they pertain to on-going care are being defined (i.e.: parent possibly leaving role of primary person to consult regarding a procedure).
- Having a list of contact information of competent adult physicians that have an understanding of their diagnosis. Often times Y/YA and their families don't know which physicians will be best equipped to take on their patient case.
- Knowing their diagnosis/disease/illness including symptoms and management thereof.
- Knowing how to take their medications.
- Knowing how to make medical/dental/mental health appointments when and as needed.
- If child is cognitively able, then they should begin participating in decisions about their care.
- Communication about transition for one to two years in advance.
- Understanding the policies and procedures for transition.

Need for Support Services

- Resources to help them navigate how to get the things they need (i.e. medication, wheelchair, etc) which will improve their health status.
- The fact that at 18 years of age quite a few services are stopped with no effective counterpart in the adult system.
- In conjunction with this, there is great difficulty accessing what services are available.
- Reassurance that the same level of medical care and social support will be available when they become an adult.
- Collaboration between CMS and AHCA before Y/YA turn 21 years old.
- The Y/YA and their family being able to have all the necessary resources to make the best health care choices.

Eligibility for Services

- I often say the worst thing I ever did for myself was get an education and get married because I am told by insurance companies, Medicaid, etc that I have a double income (due to being married) so I make too much money and that I am disabled but not “disabled enough” to qualify for many “perks” that may be available to others.

2. What two or three things do you think are most important to the *families* of Y/YA with disabilities and chronic medical conditions in regard to health transition?

General

- Financial stability

Payment for Medical Care and Insurance Coverage

- Freedom from financial responsibility for their child's healthcare.
- Knowing that health care coverage will continue without interruption.
- Knowing that their child will be able to obtain the same (or equivalent) medications/treatments through their new health care coverage at a similar cost.
- Learning, or understanding insurance implications or procedures.
- Knowing where to turn to so you feel confident of the care your child will receive as an adult and figuring out how to financially cover their medical expenses.
- To keep the same insurance.
- Keeping Medipass and system that is consumer friendly for the family.

Education/Empowerment

- Guide to insurance information for transitioning youth/young adults.
- Working with family members/caregivers who have cognitive disabilities themselves and are overwhelmed by intimidating and incomprehensible demands put on them.
- Learning how roles change and how support may also change as this occurs.
- Learning, or understanding insurance implications or procedures.
- Knowledge of their child's condition.
- Feeling the child can effectively manage their own healthcare needs.
- Educational opportunities to improve health literacy.
- Teaching regarding coordination of care and how that will change as child ages out of youth services and into the adult system.
- Involvement of schools in planning for long term vocational/education needs.
- Assistance with training their youth/young adults about their disease, medications and making appointments for care.
- Families being able to let the Y/YA make more decisions in their health care as they transition into adulthood.
- Emphasizing to youth that they will eventually be responsible for their own care.

Continuity and Coordination of Care

- Finding providers that are knowledgeable about and eager to treat their child.

- Knowing that the doctors under their new health care plan will be as good as the ones that they currently have.
- To access, maintain and or improve the same level of medical care in order to be able continue to maintain or improve their ability to continue care for their child and achieve the child's goal, whether that is to maintain care at home, participate in the community, go to school, work, achieve independence.
- Finding a "medical home" that will meet their needs-both medical and emotional and a provider knowledgeable, compassionate and sensitive to their special needs.
- New providers have adequate skills and training as well as compassion and needed resources.
- Having a smooth hand-off and not having to repeat everything.
- Overall plan that recognizes their child's unique situation.
- Primary Care Provider (PCP) to be able to follow inpatient and outpatient for continuity of care.
- Background in pediatrics patient training (Ex: Med-Ped program trained).
- Identify a group/provider for a family to meet before sending the patient.
- To keep the same doctor.

- Having health navigators assist families in developing transition plans.
- The opportunity to maintain an active relationship with the Y/YA and their care coordination.

Accessibility of Care

- To access, maintain and or improve the same level of medical care in order to be able continue to maintain or improve their ability to continue care for their child and achieve the child's goal, whether that is to maintain care at home, participate in the community, go to school, work, achieve independence.
- Central location/ accessible to wheelchair/stretchers.
- Proximity to other specialists so 2-3 visits on same day.
- Transportation options.
- Having health navigators assist families in developing transition plans.

Support Services

- Support services to families once their youth are 18, and for Exceptional Student Education, once the young adult is 22.
- Having health navigators assist families in developing transition plans.

3. What two or three things do you think are most important to *providers* of care for Y/YA with disabilities and chronic medical conditions in regard to health care transitions?

General

- A change in thinking where we professionals would see our patients through a life cycle approach as opposed to children, then youth, then young adult.

Payment for Medical Care and Insurance Coverage

- Reimbursement equivalent to the time it takes to treat the patient.
- Knowing that the Y/YA health care coverage will continue without interruption.
- Knowing that the Y/YA will be able to obtain the same (or equivalent) medications/treatments through their new health care coverage at a similar cost.
- Helping families negotiate or understand reimbursement issues.
- Adequate funding source to cover all levels of care required.
- Appropriate funding for providing care in a medical home based practice model.
- Providers have to be more receptive to taking Medicaid and/or find ways to make health care affordable for youth who are in transition from pediatric services to adult services.
- That there is no interruption in medical healthcare insurance.
- Adult care givers need to accept Medipass as a funding source.
- Ability to pay/funding for needed services.
- Healthcare financing.

Information Sharing/Communications

- Information that is readily available to assist the providers in care and treatment of the patient.
- Pediatric providers to provide a summary and next steps prior to the first visit and the opportunity for ongoing collaboration after assuming care of the patient.
- Availability of all medical records of prior primary care provider and all sub-specialists caring for teen/youth.
- Being understanding of the families as they learn their new roles and how they may be able to leverage the support of family members.
- To have an understanding that individuals with disabilities are not all “difficult cases” and there shouldn’t be a concern of taking on their case because of the time they may take compared to “normal” patients.
- Ability to quickly and efficiently communicate/share information with other providers, easier access to medical records, to be able to find up to

date info about child's condition (particularly difficult to those with rare disorders).

- Access to technology!!!!
- An “off-service” note. Pertinent past information that is important as well as current plans.
- If there are any “hot button” issues to avoid or be sensitive about.
- To be realistic with patient regarding outcome expectation/condition.
- To have updated medical records, medications and specialists involved.
- Patient and/or family to understand condition well.
- Coordination of transition efforts.
- Being an integral part of transition team.
- Providers need to be willing to assist families and schools with helping students with disabilities to transition from pediatric care to adult care.
- The proper and accurate transfer of patient records to create a successful transition from pediatric to adult health.
- Better coordination between inpatient/outpatient beyond medical record information.

Care Coordination/Case Management

- Care Coordination or case management for multiple issues, including psychosocial.
- Provision for ancillary services that will assist in care coordination, such as nurse case managers.
- Opportunities and programs that coordinate and integrate services for those Y/YA with multiple needs.
- Help with case management.
- Adult providers creating a provider/patient relationship that coincides with their previous pediatric care.
- Better coordination between inpatient/outpatient beyond medical record information.
- Having checklists that can be used in transitioning youth.
- Knowledge of patient's health and social background issues prior to treatment.

Training

- A change in thinking where we professionals would see our patients through a life cycle approach as opposed to children then youth then young adult.
- Improved teaching at the medical school and residency training level in regards to care of patients with complex medical needs.
- Training physicians in the developmental approach.
- Holding patients accountable for their care.

4. Describe what elements of the current health care transition work well for Youth and Young Adults (Y/YA).

- Not sure or nothing seems to work - 5 responses out of 18 (28%).

Availability of providers

- Finding primary care for YSHCN when they have private funding.
- Medical specialties show competencies in knowledge regarding complex medical problems.

Payment for Medical Care and Insurance Coverage

- If the Y/YA is on SSI disability than services can continue.
- Easier if patient has Med-Waiver prior to age 18.
- Funding for youth with disabilities exists.

Coordination/Communication

- Sending of medical records/radiological studies to next provider.
- A program with a good track record of effectively dealing with Y/YA in the Child Welfare system is Connected by 25.
- Current technology exists to help with health care needs of patients with physical disabilities.
- School systems have systems in place for evaluation and planning for educational needs of youth with health care needs.
- Many patients have developed strong relationships with both primary care and specialists during their childhood years.
- CF model USF pediatric pulmonology and Adult CF Center at Tampa General
- CMS multi-disciplinary staff in place.
- CMS has a good transition program for their patients.
- Social services are the most vital component in the transition system.
- The major element of the current health care transition that seems to work well for Youth and Young Adults is the care coordination from CMS that they receive.

5. Describe gaps in health transition services for Y/YA that currently exist. Please list as many gaps as you can and be as specific as possible. Gaps can be disease specific, specific to a population, or a gap that exists in services to all Y/YA with chronic or complex medical needs.

General

- For a Child Welfare situation, a lot of Y/YAs are on the streets or in jail at 18.

Continuity and Coordination of Care

- The major gap of the current health care transition in my opinion would be the loss of care coordination once the Y/YA are no longer age eligible for the CMS program. Y/YA and their families need to be given information on how to independently coordinate their own care once they are no longer affiliated with the CMS system to maintain healthcare services and a routine that best fits their individual needs.
- There is not consistent approach to moving patients between primary care for youth and primary care for adults. No consistent mechanism for compiling the medical history of the patient other than getting this information from the patient and their family and reading the medical chart.
- Transportation needs.
- Lack of education to adult medical community about transition needs.

Communications

- Communication barrier exists between specialists and primary care. Very limited ability to group plan regarding patients, even when that patient is in an in patient setting. This seems to be due to time constraints and a reimbursement system that make it hard to get payment for this type of “work”.
- Need to see the other side (pediatric/adult).
- Pediatric and adult centers need to agree on workable plan.
- Difficulty in making appointments with new providers.
- Y/YA and there families are used to a more paternalistic system of care (team approach, team clinic visits, CMS umbrella, specialty provider communication), adult providers (specialty) operate more in silos. Communication gaps between adult specialists and PCP.
- Don’t treat patients like they are dumb or will break.
- Speak to the patient, not the parent (if able).

Availability of Providers

- Limited adult providers comfortable caring for these kids, insurance issues, lack of time in busy practice.
- Very limited as to who treats chronic or complex medical diagnosis and there is no “one area” to go for the information.
- There is a lack of primary care specialists to transition to in both the private sector as well as in the university training programs. This seems to be due both to inadequate training as well as low payments from the insurance industry and Medicaid.
- Disparity and lack in communities for specialty services.
- Lack of Medicaid Physicians
- Most do not want to take Medicaid
- Medipass specialty providers for adults are very limited w/o support from AHCA.
- Very few primary care physicians who are willing to take care of this type of patient. The ones we have referred to will take a few and then refuse anyone else.
- The resources just don't exist for adults with special medical needs.
- Not many doctors accept Medicaid, hardly any specialty providers accept Medicaid. Many will not see children with complex or rare disorders.
- Lack of desire in adult provider network to take care of young adults who have chronic medical and/or developmental needs - comfort level is in pediatric specialists not adult specialists for many childhood conditions.
- Adult neurologists are hesitant to see patients with CP and other developmental disabilities.
- Limited adult sub-specialists for consultation.
- Not a solid knowledge of how to care for chronic or complex medical diagnosis.
- Adult medical system is skewed to specialists so biggest gap is in general practice or primary care clinic receiving a Y/TA from their existing medical home.

Cultural/Linguistic Issues

- Not enough Spanish speaking providers-1/3 of our patients are Spanish speaking-even when they speak English-conversationally, they often do not understand.
- Language barriers-Spanish.
- Cultural awareness.
- Not enough Spanish speaking providers.
- Cultural barriers.

Payment for Medical Care and Insurance Coverage

- Type of insurance can limit which providers will treat patients-may not get to see provider with the most expertise.
- Financial incentives are lacking.
- Finances not there.
- Change in benefit package in Medicaid when client turns 21 - unable to have funding for services that were previously considered medically necessary, i.e. nursing care in the home.
- Medicaid coverage stops and Medicare coverage may not pick up coverage for certain medical conditions (unless it affects the persons ability to work).
- Lack of affordable medical care for youth with disabilities to transition to in terms of the adult medical care world.
- Limitations for health care funding, and identification of appropriate resources.
- Adequate funding for adult primary care.
- Once patient turns 18 Medicaid does not cover the same services even though the patient continues to have the same chronic medical issues (Ex: nursing home is not covered). This can create a huge problem/crisis for families.
- Med-Waiver needs to get patients off of waiting list before they turn 18.

Support Services

- Support services are not available like they are for pediatrics (for example, no more CMS, social worker's in Doctor's offices, no child life in hospitals.
- Families need Guidance on how to complete guardianship-no resources for this.
- Limited social workers in private sector.
- Case management expensive-who pays.
- Lack of education to adult medical community about transition needs.

Developmental Issues

- Little acceptance and toleration for that group from 18 to about 23. Especially in a Mental Health setting.
- Pediatric providers are focused on developmental milestones, social issues, educational/vocational goals and challenges and the importance of improving functional status throughout childhood. Adult providers are more concerned about disease management. Developmentally delayed patients may still have potential to improve physical, cognitive, and social functioning as young adults.
- Difficult years for teens/young adults.

Examples

Two different neurologists refuse to accept a new client because she has a diagnosis of a rare disorder.

Client needs an evaluation for Baclofen pump but can not find a surgeon that accepts Medicaid.

Client requires emergency gallbladder surgery and can not find a surgeon that accepts Medicaid; parent had to pay out of pocket.

Client has an insulin pump and can not find a doctor that has equipment to download information from the pump.

Client is on a ventilator has been in the ICU but is stable, for 9 months parents have not found a pulmonologist willing to release client to home care even though all services required are in place.

6. What assets do we currently have that can be used to improve the quality of life for Y/YA in transition?

Access

- Urban setting allows for easier transportation.
- Excellent pediatric programs for YA with special care needs.

Technology

- We have advances in technology that can speed up communication, access, sharing and organizing medical information for both providers and families.
- State of the art conferencing technology exists.
- Move towards universal electronic health records will help in communication.
- Social networking technology
- We have advances in technology that can speed up communication, access, sharing and organizing medical information for both providers and families.
- EHR capability and possible interconnectivity in the future (ER, specialists, Medical Home provider)

Institutions

- Medical school
- Regional referral centers
- School District
- Local university system is better equipped to take lead in this type of care than standard private care systems.
- USF Health has a medical home for Y/YA in transition that is not being used.
- Vocational Rehab.
- Possible partners in service and education: USF, COPH, HCHD.
- A successful CMS (Children's Medical Services) model that could be expanded to care for adults.
- More resources for those that are trying to be contributing citizens in their community.

Personnel

- CMS personnel-nurse coordinators, social worker, nutritionist.
- There seems to be an adequate number of primary care providers in Hillsborough County.
- Refer patients to a physiatrist.

- Many pediatric providers who are willing to “hold on” to their patients until they feel ready to release them.
- I think we have many more professionals aware and sensitive to this issue. The next step is what we are doing now, which is a call to action. Support and advocacy groups such as NAMI are becoming aware of the need to focus on the population also.
- Large group of primary care providers in our community health centers already caring for a diverse population with complex medical problems.
- Emotional bonds are developed between families and health care providers.
- We utilize in CMS and Shriner’s-disease specific Care Coordinators that develop an expertise in transition issues for their specific patient populations.

Payment for Medical Care and Insurance Coverage

- Safety net of County insurance program.
- Hillsborough County Health Care Plan - probably being under-utilized for this population.
- CMS to age 21
- Social Services help grants to obtain DME that is not covered by insurance and a nurse coordinator who assists families in need.

Additional comments provided by respondents

A Personal Perspective:

I mentioned in our first meeting that I was told by an ex governor of FL that, “Typically people in wheelchairs are not smart enough to go to college so we don’t worry about you.” I was also told by my insurance company (BCBS) to commit insurance fraud to get a home health nurse to come to my place of employment to help me with the restroom once per day. I was asked if I needed catheterized or wound care. I said no. The only way BCBS would pay for this was if I needed one or both of these things. When I described that all I need is for someone to help me undress and transfer I was told to tell the agency that I need one or both of these things and then when the aide gets to me, tell her the truth. When I refused to do so and asked what other options I had, I was told to wear Depends, go to the bathroom in that and when I got home at night have my husband change me. When this is the kind of help that insurance companies are giving you, you don’t know where to turn.

I used to have Vocational Rehabilitation, whom did wonders for me. Paid for whatever my scholarship didn’t for college, paid for numerous vans to be adapted, have provided me with adaptive equipment for my home, etc. I was told once I entered the working world that VR would still assist on the big ticket items, like adapting a van. Recently I was told that because of what I make, which in the big picture of adaptive equipment is not much, and the fact that I am married, they can no longer help me.

So, the help that is needed is giving Y/YA the guidance they need for healthcare as well as being as successful and independent as they can. Stop the double standard. If I hear, yes you’re disabled, but not enough to get help or that you make too much to get help, I will scream!

My experience with doctors has been this: I do not even mention I have a disability when I sign up with a new doctor. If I am going to someone for something that has nothing to do with my disability, I don’t want them to focus on the fact that I do. I have had some older doctors try and tell me that I was having acid reflux problems because I am high risk from my “condition”. He didn’t even know what “my condition” was. He saw I was in a wheelchair and he made his assumption.

Elements to consider in a Transition Model

Models of pediatric care that can be replicated for transition:

- Patient/parent advocacy
- Care Coordination

Must be "top driven" as valuable to our society/citizens in Tampa Bay

From a Medicaid perspective there are several ways to access information that will allow the Y/YA to transition into a health care plan that will best fit their needs. There are also Medicaid waivers like the Aging Out Waiver, APD Waiver, Brain and Spinal Cord Injury Waivers. Many of the waivers have limited enrollment and/or waiting lists, but might be an option for some recipients. Care coordinators should have access and be able to guide Y/YA and families to the resources that they need.

Program models can be: disease specific

- Subspecialty model
- Adolescent health model
- Primary care model

Pediatric Model	Adult Care
Family Oriented Developmental aspects considered More help with treatment regimen More trainee supervision Paternalistic	Individual focused Specifically focused on health Less communication with social service or workplace More accepting of treatment refusal Less trainee supervision Shared treatment decisions