

Community Themes and Strengths Assessment
Health and Transition Services
Northeast Florida

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?

- Having physicians who care about the patient and are willing to probe the patient to understand underlying conditions or areas of concern (frequently, there are conditions that are not severe or bothersome enough for a patient with disabilities to convey to a doctor, spending a little time and probing for things would prevent conditions from becoming more serious)
- Patients with disabilities will have symptoms like thinning hair or body rashes but because they do not cause pain, they will not seek treatment of them or even mention it to a doctor. Visual evaluations are critical to the care of patients with developmental disabilities or those without sufficient communication skills.
- Having a written record of health issues to carry with you to appointments with physicians - also a written record of meds.
- Scheduling regular well care visits.
- Mental health issues are frequently caused by physical issues - again, having a physician to probe and CARE to find the underlying reason for erratic or bizarre behavior. Too often, bad behavior is chalked up to the disability without looking further to see if it might be cause by something else.
- Mental health issues are almost never treated or finding a physician who understands the intellectually disabled population so they can assess mental health issues is virtually impossible.
- Finding a physician who has knowledge of their disability and the effects on their health care and one who will see them for themselves and not their disability.
- Uninterrupted access to specialty care

- Adult providers who have an interest in taking care of chronic complex disease in young adults
- An office staff that treats them the way their pediatrician's office did
- Access to quality medical care for their condition
- Being able to live as normal a life as possible with their condition (doing what other young adults do)
- Being as independent as possible
- Direct contact with the physician's office
- Coordination of visits so more than one visit can be done in a day
- Kids not feeling that they are different than their peers
- Smooth/seamless transition to adult providers of healthcare
- Have adult healthcare providers (specialist and sub-specialist) to recognize the need to follow patients
- Have available a clinic type of care where primary, specialist and sub-specialist can collaborate on plan of care
- Probably most important is the knowledge of funding streams, how to obtain coverage for healthcare, or access to healthcare
- Consistency/availability of assistance. Cannot abandon either age group. Assistance with care is needed
- Ability to earn money, jobs
- Access to adult providers in needed specialty services
- Transportation
- Someone with whom health concerns can be discussed.
- Maintaining Health Insurance
- Having a PCP and specialists who are knowledgeable about their diagnoses
- Normal physical development.
- Peer relationships that do not highlight their disability or medical condition.
- Education limits due to physical and medical conditions.
- Adult physicians who feel competent to manage their illnesses
- Health insurance

- Fitting in with the “normal” youth
- Making progress toward their life goals
- Finding a provider that will listen to them
- Getting the care they need to do the things in life they want to do—minimize the intrusion of health issues on their life

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?

- Most of what was said above pertains to families as well. The greatest concern is when a parent is no longer around - who will insure that the “clues” of poor health or problems, are seen. Also, who will remind the person of appointments and convey the findings of one physician to another.
- Same as above as well as someone who will listen to them and take into account what individuals know about themselves and their past experiences with treatment of their disability.
- A responsive office staff like the one they have become accustomed to
- Uninterrupted access to specialty care
- Adult providers who have an interest in taking care of chronic complex disease in young adults
- An office staff that treats them the way their pediatrician’s office did
- Provider who understands the parents’ desire to continue to be a big part of their adult child’s healthcare system
- Access to quality medical care for their family member’s condition
- Having insurance coverage for #1
- Will my child be able to take care of themselves independently
- More coordination with the physicians
- Coordination of visit times
- The same as above with the addition for families of Y/YA with communication disorders or intellectual disabilities - adult healthcare providers and their offices more accepting of caregivers, especially their long term knowledge of

being the primary caregiver and sometimes the expert on some rare conditions, but also, respecting and directing the communication to the patient.

- Continued reliability of assisted help.
- Families need reliable resources to learn how to provide assistance for loved ones and need a consistent source of encouragement along with
- help in finding the funds to manage long-term conditions
- Access to adult specialists
- Confidence that Y/YA are taking responsibility for health issues
- Insurance coverage
- Maintaining health insurance
- Having accessible adult doctors who are knowledgeable of the Y/YA conditions
- Access to care
- Funding sources/insurance
- establishing a medical home, “one stop shop”
- comprehensive care
- communication
- Adult physicians who are competent to treat their youth’s medical illness.
- Health insurance
- Care coordination
- Adult physicians who are competent to treat their youth’s medical illness.
- Health insurance
- Care coordination

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?

- Knowledge of the person, the disability, how to best communicate with the individual, and who assists them with their medical care
- Adequate understanding of the disease process in their patient
- Knowledge of provider network that will accept referrals of chronic patients
- Comprehensive medical history of the patient with chronic disease

- That they will be able to provide (or arrange) the care that the Y/YA needs for their condition
- That they will receive reimbursement/funding for #1
- That the services that the Y/YA needs are available in the community.
- Parental support
- Coordination between the providers treating the Y/YA to prevent overlap
- Adequate funding
- Easy access to expert/current information about conditions and care that are primarily pediatric that have moved into the adult realm
- Possibly a network/clinic that would support chronic care follow along
- Possibly a way to see a few patients with Medicaid funding that would not impact their entire practice
- Relevant health history
- Y/YA or support person that can carry out orders/advise
- Compensation for care
- Ability to communicate with Peds providers to learn how the condition was managed in peds.
- Reimbursement for services
- Time commitment
- Funding sources/Insurance
- Access to care
- Providers outside of UF/Shands who are willing to provide Primary Care services to clients who live in other counties outside of Duval.
- Research
- Safety
- Research
- Pain management
- Feeling competent to take care of the disease entities
- Getting paid for what they do, particularly coordination of care
- Being allowed the necessary time to manage these youth

- Knowing how to communicate effectively and support growth in their independence with health and health care
- 2. Getting paid for what they do, particularly coordination of care and being allowed the necessary time to do a good job

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

- I don't know that it works well - but, having a supported living coach is supposed to answer the problem with follow up and conveying nuances of change in behavior so that a doctor might be able to diagnose problems - the problem is that providers change so frequently that they do not have the benefit of history or in-depth knowledge of the patient to be able to share that information with the medical provider.
- Consultation with the former health care provider regarding the needs of the individual. What types of intervention work best. What to expect on the first visit. General information about the person.
- Care for those conditions that have traditionally been present in the adult, as well as pediatric population, such as diabetes, asthma, thyroid disease, seizures, uncomplicated shunts
- Care within a system of providers that includes both pediatric and adult providers, such as UF
- Care where there are providers who appreciate and are committed to the need for effective transition—only present in a few subspecialties
- JaxHATS Clinic
- Touchstone Village
- Children's Medical Services
- Location of current clinic
- Physicians in the current program
- I have heard nothing but good things about JaxHATS from the families that I talk to who have used their services.

- A medical home model work well because the supportive staff is always available to the Y/YA and caregivers.
- JH-PCP
- Referral resources to specialist at Shands who are adjusting to the needs of our pt population
- Medical Home
- Increased number of community resources or activities
- Care coordination
- CMS care coordinators
- Organizations/programs that promote transition
- CMS care coordination within JaxHATS
- Organizations/programs that promote transition in other areas of life such as education, vocation.

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. (Example: only one adult cardiologist who has an understanding of congenital issues; physicians are hesitant to provide care to developmentally disabled Y/YA; not enough Spanish speaking providers; little understanding of cultural issues among service providers.)

- We do not have providers of mental health counseling or psychiatric care.
- Health care providers, including dentists are not always well prepared to work with adults who have behavioral issues or who do not communicate well.
- Multiple areas where adult providers have no comfort level in dealing with conditions that previously ended life in childhood—CF, neuromuscular disorders, genetic syndromes, complex congenital heart disease, neurodevelopmental conditions associated with extreme prematurity
- Poor reimbursement for services provided and resources consumed in the care of these patients
- Transportation services for chronically ill patients
- Respite care

- Nemours providers' inability to care for kids beyond 18-21 years of age
- Specialist resources for adults on Medicaid are limited in many communities.
- Medicaid does not cover the same services for adults as it does for children (<21)
- Medicaid reimbursement is low, so patients with special health care needs that require extended time/care don't always receive it.
- Deaf patients - ADA requirement for interpreter services, but they charge \$48-\$53/hour, which is more than Medicaid reimburses the provider for the visit (\$30), so the provider may not want to see them.
- A psychologist trained to work with Y/YA
- There seems to be a great need for Y/YA to receive access to some services that help them adjust to their disability/chronic health care needs - they are usually a little more complex than the typical Y/YA but not totally different enough to warrant a mental health diagnosis, they need professionals who can assist with a transition from professionals that have an understanding of their unique circumstances. For example some who have gone to centers that specialize in a particular chronic health diagnosis or disability come back with additional understanding of the healthcare needs/disability as it relates with typical young adult adjustment/issues moving to independence and adulthood.
- Peer support for medical/disability. Sometimes Y/YA will hear or listen from someone else who has gone through what they are going through.
- Not enough Psychiatrists or mental health professionals who treat Y/YA with Medicaid, medipass, etc.
- Need more adult physician providers willing to manage chronic and complex conditions in Y/YA.
- Need to have City Contract equivalent in surrounding NE FL counties as that is a limiting factor in caring for many Y/YA with chronic conditions who live in the surrounding counties.
- Disease Specific: a. ER visits; b. mental health; c. drug seeking stereotype among inpt facilities(pt feedback); d. cultural competencies

- Population: a. socioeconomic; b. high school drop outs; c. geographic elements; d. cultural
- Services: a. Transportation; b. Funding sources; c. legal aid; d. SSI/SSDI; e. No. of specialists who do not accept MCD or MCR; f. 6. No. of Primary Care providers: FP, IM
- Insurance coverage gaps
- Inadequate numbers of PCP's with the time or skill set to manage these complicated young adults
- Gap between pediatric and adult specialists in dialogue about transition
- Lack of care coordination in the adult medical model
- Inadequate preparation of the youth and their families by the pediatricians and pediatric subspecialists for the transition from pediatric providers to adult providers.

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

- Health systems that currently include adult and pediatric providers, such as UF and Baptist Primary Care
- Family medicine training programs that could be used to support transition education
- UNF and its College of Health programs
- Need to get the participating medical providers that are providing most of these services to come together and organize better.
- Need case management providers to work with #1 above.
- Location of clinic
- A pretty strong pediatric community of providers
- I think that our community has all/most of the necessary parts- first class medical care/facilities, professionals in many different areas of expertise, etc. However, I believe that there is a need for information/training/support,

unfortunately, about a very small population who have extraordinary needs that do not bring additional funding to the table.

- Several interagency groups in community that are focusing on assisting Y/YA in various areas of transition (vocation, education, independent living and healthcare)
- JH clinic, IM department UF/Shands and CMS is an integral part of promoting the importance of quality of life for clients who participate in a transition program.
- JH unique model that provides collaborative and comprehensive care. Providing care coordination to clients who require assistance with insurance, legal issues and vocational rehabilitation.
- Access to the staff of JH via phone, web page and community referral resources. Clients are willing to communicate effectively when they understand there is someone who will listen and provide guidance, day to day.
- On call providers who can manage urgent/emergent situations by communicating with caregivers or clients that require assistance after hours.
- Patient advocate groups
- CMS
- State legislators who are interested
- Physician advocates like Dr. Wood
- Models like JaxHATS
- Physician advocates