

Transition to Adult Health Care Guide

(April 2012)

Created by
Family to Family Health Information Center
a program of Family Voices of Alabama



1050 Government St., Mobile, AL 36604 ♥ Phone: 877-771-3862
www.familyvoicesal.org



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Goals of this guide

This guide will help you in:

- ♥ Realizing the importance of health care transition
- ♥ Identifying barriers to health care transition
- ♥ Developing the skills necessary for successful health care transition
- ♥ Getting the timing right
- ♥ Starting your health care transition plan
- ♥ Discussing a health care transition plan with your child's medical provider
- ♥ Partnering with providers in strategies to support the health care transition process
- ♥ Identifying insurance issues related to health care transition
- ♥ Sharing advocacy skills to pass on to your child to increase his/her self-management of health care
- ♥ Discovering resources and sources of support to help you and your child with the transition process as well as how to mentor other parents as they experience transition with his/her child
- ♥ Learning from the transition stories of others (Appendix C)



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Realizing the importance of health care transition

There are many transitions in life, including school, work, independence, and health. The focus of this resource is on health care transition. Optimal health care is achieved when each person, at every age, receives medically and developmentally appropriate care. The goal of a planned health care transition is to maximize lifelong functioning and well-being for all youth, including those who have special health care needs and those who do not.¹ Although health care transition often leads to transfer of care from pediatric to adult providers, patients of family practice physicians and combined internal medicine/pediatric physicians can undergo transition without transfer of care. Changing doctors is never easy. When you're a teenager new to advocating for your own health care, or one who has a chronic illness like diabetes, spina bifida, cerebral palsy, or cystic fibrosis, it can be even more challenging to make the transition.

Transition realities for Children and Youth with Special Health Care Needs (CYSHCN*)

- ♥ 90% of CYSHCN reach their 21st birthday
- ♥ More than one-third of youth in the US have some form of chronic illness.²
- ♥ 17.8% of children in Alabama have special health care needs according to the 2009/2010 [National Survey of Children with Special Health Care Needs \(NS-CSHCN\)](http://www.childhealthdata.org), www.childhealthdata.org
- ♥ Some young adults lack a payment source for needed health care
- ♥ Many youth lack access to primary and specialty providers who are familiar with his/her special health care need or disability

Advances in medical care have given physicians the ability to prolong life in children who previously had limited life expectancies. In the early years of the 21st century, the American Academy of Pediatrics (AAP) recognized transition as a natural goal for sustaining wellness for all of our nation's youth and is a process that should be effortless and seamless, yet more than half of youth with special health care needs in the United States fail to receive the support they need for a smooth transition from pediatric to adult health care.

** Children and youth with special health care needs (CYSHCN) are defined by the Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau (MCHB) as:
"...those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."*

Successful health care transition is related to:

- ♥ Better health as an adult
- ♥ Self-sufficiency and independence
- ♥ Prevention of secondary conditions
- ♥ Decreased emergency room use and overall medical costs

Health care transition is a process:

- ♥ Different from transfer of care which is an event
- ♥ Requires preparation and planning
- ♥ Occurs in phases

Health care transition is individualized:

- ♥ Movement from one phase to the next depends on when the individual youth is developmentally ready
- ♥ Timing of transition may be different for youth depending on needs



Transition is NOT achieved in just one way.

Identifying barriers to health care transition

Even with increased awareness of the importance of health care transition, there are many CYSHCN that are still not prepared to take responsibility of his/her own health needs as they enter adulthood. There are often barriers that prevent youth from receiving the necessary services to support a smooth transfer to the adult health care provider. These barriers are broken down into 3 categories:

- 1) personal;
- 2) structural;
- 3) service.

Personal barriers – Youth

- ♥ Fear, anxiety, sense of loss or risk with transfer to an adult provider
- ♥ Opposition to healthy life styles choices in:
 - ☆ Diet
 - ☆ Exercise
 - ☆ Relationships
 - ☆ Smoking
 - ☆ Alcohol or illegal drug use
- ♥ Progression of chronic conditions and health concerns
- ♥ Understanding of sexual development and the responsibilities of planning parenthood.

Personal barriers – Family/Caregiver

- ♥ Ability to support and to “let go” (relinquishing control of the day-to-day management)
- ♥ Trust that your young adult can manage his/her own health care
- ♥ Having input without interfering with doctor/patient relationship (between youth and doctor)
- ♥ Family members working together toward a common goal with agreement and support among caregivers

Structural barriers (External factors related to care)

- ♥ Transportation
- ♥ Employment
- ♥ Living independently (the ultimate goal)

Service barriers (Access to care)

- ♥ Finding age appropriate, quality and approachable health care providers
- ♥ Lack of accompanying medical documentation
- ♥ Lack of training on transition for physicians
- ♥ Paying for health care
 - ☆ Insurance
 - ☆ Payment for transition activities
 - ☆ Availability of public assistance programs

Most primary care pediatricians do not believe transition planning needs to begin before age 18, do not provide portable medical summaries, and do not make a direct connection for his/her patients with adult health care settings.

Adult primary and specialty care providers express discomfort with childhood onset conditions, particularly those other than asthma, diabetes, or hypertension. They worry about the extra time that may be required and are more likely than pediatricians not to be Medicaid providers. Adult providers say that they want care plans, portable medical summaries, and condition specific information sheets—all of which are rarely provided by pediatric health care settings.³

Meanwhile, young adults with chronic conditions experience more emergency room visits, hospitalizations, complications, and even deaths than they should, partly because of disruptions in their continuity of care.⁴

Many adult providers feel unprepared to care for young adults with complex chronic conditions. In some cases, there is no identified adult primary care or specialty provider to whom care can be transitioned.

Developing the skills necessary for health care transition

Every CYSHCN should understand that addressing his/her health needs, first and foremost, is the key to having a more productive life as an adult. Health care transition is an important process that helps youth build the necessary skills that can lead to positive health outcomes. Remember, it is never too early to start discussing independence. Adults can look for opportunities to talk about transition issues.

Assess your individual situation (the variables)

- ♥ Age of youth, age appropriateness of tasks and skills
- ♥ Informed consent: age of majority in Alabama and guardianship
- ♥ Consider your youth's developmental, cognitive, physical, emotional, and social abilities

- ♥ Remember, he or she is a teenager, help them understand his/her own priorities
- ♥ Determine how much time you have to plan
- ♥ Discuss how your culture/beliefs impact how your family receives care
- ♥ Availability of family support; get help from family members to develop a plan
- ♥ Find out if your physician is willing to do a formal transition plan and help to develop a portable medical summary
- ♥ Ask your youth what he/she wants you to do - do not just assume you know the one's wishes.

Many readiness-assessment tools and skills checklists exist for conducting this assessment; one is provided in Appendix A and others are included within "RESOURCES."

"All adolescents face unique health issues and have complex needs when it comes to care, but this is particularly true for teens dealing with chronic disease or disability."

Roland Goertz, MD

Some of these health management skills include:

- ♥ Scheduling appointments with health care providers (who to see and when)
- ♥ Medication management (what, why, when and how)
- ♥ Record keeping and documentation - our Care Notebook can really help with this skill. Get a notebook at www.familyvoicesal.org or by calling 877-771-3862.
- ♥ Ability to have one-on-one dialogue with medical providers to make informed medical decisions
- ♥ Knowledge of health condition
- ♥ Knowledge of insurance options

Health care self-management skills are related to the youth's ability to manage his/her own health care. By learning these important skills, CYSHCN will have greater confidence in managing his/her health issues as an adult.



Getting the timing right

Generally, discussion of health care transition should begin early in adolescence. It is important to remember that it is never too early and never too late to begin the process. The pediatric physician, parents, youth and adult health care provider should all be in agreement about when the actual transfer of care should occur. The actual transfer of care occurs when everyone feels it is time.



It's never too early to start talking about independence and the transition to adulthood.

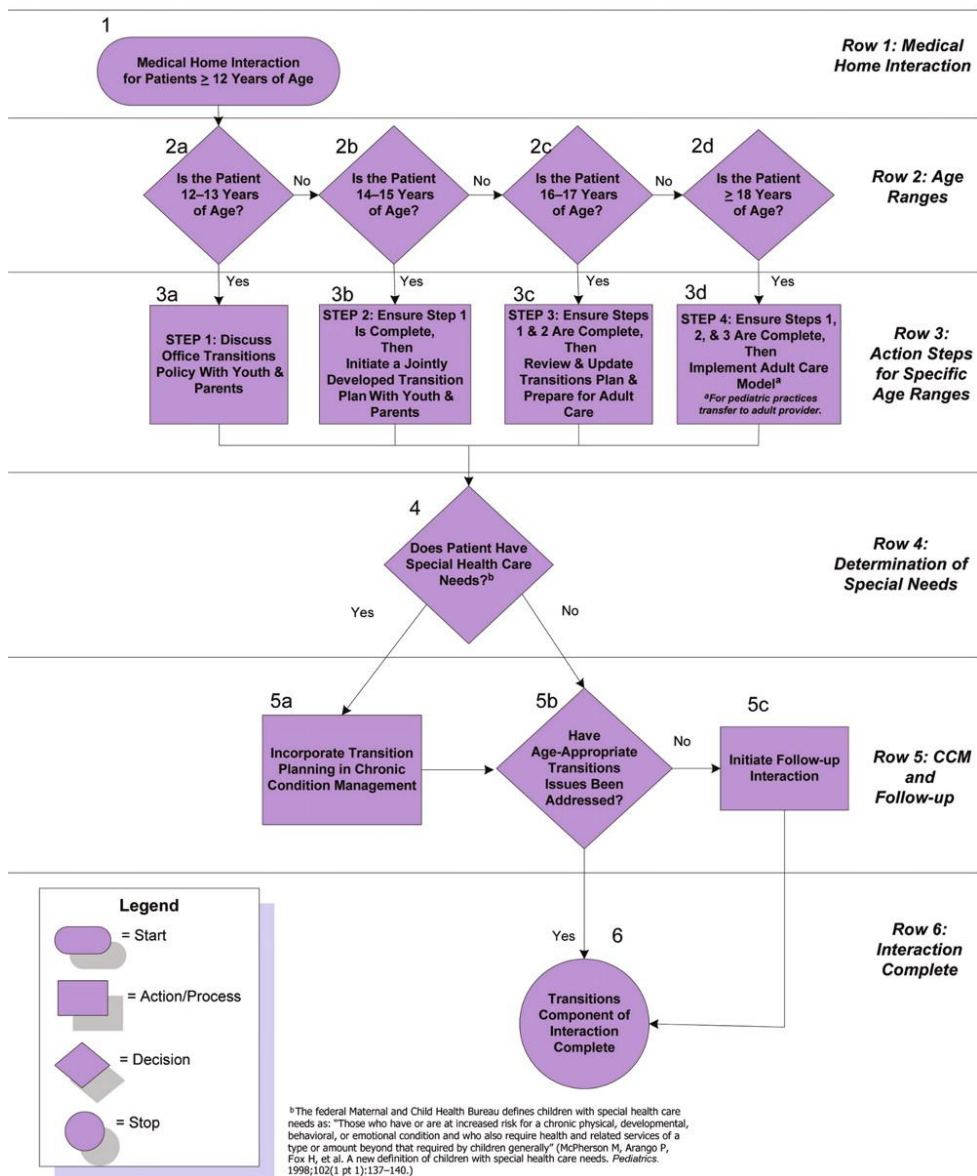
Make sure your child knows:

- ♥ About her or his condition or disability
- ♥ What qualifies as symptoms of concern
- ♥ How to determine an emergency
- ♥ Who to call in case of an emergency
- ♥ How to schedule his or her own appointments
- ♥ How to arrange for her or his own transportation
- ♥ How to keep track of and order his or her own medication refills
- ♥ To write down questions before she or he visits the doctor
- ♥ To speak up and ask questions (advocacy)
- ♥ That he or she can talk to the healthcare provider about difficult subjects that may be hard to discuss with family in the room, like relationships, sex, and birth control
- ♥ To ask for an explanation of medical tests and reports
- ♥ To carry her or his insurance card and portable medical summary
- ♥ How to order and care for medical equipment and assistive technology

Starting your health care transition plan

The *CLINICAL REPORT - Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home* (see REFERENCES page item #1) provides a decision-making algorithm (Fig 1 - below) for all youth, beginning at 12 years of age. The algorithm includes a branch with expanded, generic guidelines for transitioning youth with special health care needs. Much more detail is provided within the report.

Figure 1
Health Care Transition Planning Algorithm for All Youth and Young Adults
Within a Medical Home Interaction



While the algorithm can be overwhelming to some, all should focus on the CLINICAL REPORT's four recommended components for a transition plan:

1. Assess for transition readiness.
2. Establish youth's goals and capture in a written transition plan. The written transition plan should account for cultural, developmental, organizational, and contingency-related concerns. Include:
 - a. plan's main goal(s)
 - b. identification of who within the medical home will be responsible for overseeing and/or coordinating the plan
 - c. time line for accomplishing stated goals
 - d. skills required by the youth to achieve maximum self-management
 - e. families' or other caregivers' role
 - f. proposed financing of the youth's adult health care.
3. List action steps to achieve written goals.
4. Document progress to enable ongoing reassessment and movement of medical information to the receiving (adult care) provider. We recommend that you begin using our Care Notebook (downloadable at <http://www.familyvoicesal.org/resources-frm-CareNotebook.php>) and discuss this with your youth at each appointment as soon as possible. You could also take your Care Notebook to interview appointments with the adult providers, so they can see your youth using this resource tool.

As implementation of the transition plan progresses, responsibility for care evolves from parental management to shared parent-child management, to adolescent management with parental oversight, and then to independent young adult management. Throughout the plan clear communication of roles, expectations, and responsibilities for care is necessary. A template to guide you in drafting your own plan is found in Appendix B.



Discussing a health care transition plan with your provider

Although inclusion of health related needs as part of transition planning is growing within the health-care community, putting this principle into practice continues to be a challenge.

Interviewing a potential provider may be an important step in developing a successful transition to a new health care provider. You may want to use our [Questions to Ask a New Health Care Provider](#) tip sheet to guide your interview. Interviews create an opportunity to discuss communication options such as the use of communication technology (e.g., phone text messaging, e-mail, phone, electronically accessible reports). Utilization of such communication methods in adolescents with chronic conditions may increase essential contact with the medical system without increasing his/her frequency of office visits which is especially important for those without reliable transportation. If lack of transportation to medical appointments may create a barrier to quality health care for you, you should factor a provider's openness to pursue non-standard communication into your decision about which provider to select.

Youth and families need to learn strategies to effectively manage health issues. For example, youth may benefit from having a filing system to keep medical records organized (see our Health Care Notebook at www.familyvoicesal.org), to know when to make follow-up appointments, and to know how to find historical information about diagnoses and treatments.

The American Academy of Pediatrics identifies four elements that are key to a successful transition:

1. Including health-care providers along with other service providers in transition planning.
2. Promoting opportunities for youth to be active in their own health-care decision-making.
3. Parental support for giving youth more responsibility and independence—striving to balance the need for safety with the adolescent's need to become an adult.
4. Continuity between pediatric and adult health-care providers.

Partnering with providers in strategies to support transition process

One of the most important keys to successful collaboration between youth, families, and health care providers is communication. As a parent of a youth (teenager) with special

needs, you should discuss his/her concerns and priorities and how these may change as they are going through the transition process. Any assessment tools (e.g., checklists) you and your child have completed should be shared with your child's provider. This will give the provider a good idea about how to support your family through the health care transition process. Make sure the pediatric provider is involved in educating your child about life-long transition skills such as proactive planning, problem solving, self-advocacy, and negotiation.

There are many differences in pediatric health care versus adult health care. These differences are important to remember during the transition process. Some examples of these differences include:

PEDIATRIC HEALTH CARE	ADULT HEALTH CARE
One doctor provides almost all medical care	Different doctors for different health needs
Informal and relaxed	Business-like, more formal setting
Warm, optimistic	Rigorous exams for health problems
Scheduling is more flexible	Advance planning for appointments required
Family management of health needs	Patient self-management
Family centered	Patient centered



Identifying insurance related transition issues

The 2010 Affordable Care Act (ACA), health care reform legislation, has already impacted access to care and care coordination. Specific provisions of the ACA expand children's and youth's access to coverage and ongoing care, including changes that permit children to remain on their parent's insurance until the age of 26; eliminate insurers' ability to exclude coverage on the basis of preexisting conditions; improve coverage portability; create a high-risk insurance pool for people who cannot access coverage through other sources; enhance payment to physicians; and mandate that nearly all people (including young adults) have coverage. Although these changes are likely to prove beneficial, it is likely that parents, caregivers, and transitioning youth alike will need assistance to understand this complex legislation and its impact on their lives and the transition process.

Families must become educated on age eligibility and coverage requirements for programs such as Title V, Medicaid, Supplemental Security Income (SSI), and Social Security Disability Income (SSDI).

Sharing advocacy skills toward self-management

When a youth has serious health challenges, it's easy for the youth and/or family to feel overwhelmed and helpless. Self-management can help. It means that the youth takes responsibility for doing what is necessary to understand and carry out the treatment recommendations that his/her and his/her doctor have agreed upon.

The youth and his/her doctor can work together to set goals that will lead to better health. As part of self-management, it is necessary to ask for help if it is needed. Support can come from friends, family, a support group, your doctor, or other medical staff. Additional information can be found on the "RESOURCES" and "REFERENCES" pages of this guide.

Skills that lead to effective self-management:

- ♥ Making the decision to take an active role in managing your own health care
- ♥ Working with your doctors to set goals that lead to better health
- ♥ Planning ahead for possible challenges that may block achievement of your goals
- ♥ Making life-style changes needed to accomplish your goals
- ♥ Taking a realistic look at your goals and how you are doing, then modifying them if necessary
- ♥ Giving yourself credit for your successes and working on your self-confidence

Discovering resources and support

Although youth with special health care needs require a broader range of considerations during their transitions, all youth need education, guidance, and planning to prepare to assume appropriate responsibility for their own health and well-being in adulthood.⁵ Other families may have a wealth of knowledge about adult practice physicians that may be a good match for your family.

Where to find and how to search for additional resource materials may include:

- ♥ "RESOURCES" and "REFERENCES" pages of this guide.
- ♥ Internet based health resource websites.
- ♥ Peer support (friends or support groups).
- ♥ School-based health center or school nurse.
- ♥ Local family support agencies.

One of the best sources for support and ongoing education are your youth's primary care providers - both the pediatrician and adult/family physicians. The physician's role in the health care transition process should include:

- ♥ Provide preventative care and teach healthy life-style choices
- ♥ Identify and treat common medical conditions
- ♥ Assess the importance of medical problems and give proper direction for that care
- ♥ Provide information on insurance options as an adult

Record keeping (<http://www.familyvoicesal.org/resources-frm-CareNotebook.php>)

While working with your youth's health care provider or pediatrician, it is important to keep records of your visits and conditions that are being treated. By keeping a record of your youth's important medical treatments, you can provide them with enough information to help them transition to the adult health care provider at the appropriate time.

Teaching your youth to maintain his/her own records will also support their success in the health care system as an adult. We recommend using our Care Notebook.

Work on the notebook together with your youth to strengthen his/her knowledge about his or her health history and condition. This will also help him or her to become responsible for his/her own health information.

The Care Notebook can be used in a hard-copy format, or electronically, and can be personalized to meet each individual's needs.

Work with others to help youth in health care transition:

- ♥ Schools, counselors, school nurses, Individualized Education Plan (IEP) team
- ♥ Pediatricians and pediatric specialists
- ♥ Dietician/nutritionist
- ♥ Coaches or health teachers
- ♥ Other parents and other youth

Teen Transition Clinic is a Specialty Evaluation Service of the Alabama Department of Rehabilitation Services. The clinic assists adolescents and young adults in planning for transition into adult life, to include adult health care, functional independence, mobility, independent living and work. The multidisciplinary team members provide client/parent counseling and education on all phases of transition and in understanding and coping with the youth's special health care needs. To be referred, the youth must be between the ages of 12 and 21.

The successful transition of youth depends upon the relationships among the youth, family, supports and service providers. If these individuals work well together, successful transition becomes more likely. It is the purpose of the Teen Transition Clinic to support the transition process of our youth with special health care needs by providing a setting where all team members, including the youth and family, can plan and work together towards an individualized transition to all areas of adult life.



APPENDIX A - HEALTH CARE TRANSITION CHECKLIST

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Age 12-15		Things my child needs to know or do	Will someone else have to do this for my child?	I will finish by (date)	Done
1.	My child understands his/her health care needs.	Y N	Y N		
2.	My child explains his/her special needs to others.	Y N	Y N		
3.	My child tells the doctor how he/she is doing and can answer his/her questions.	Y N	Y N		
4.	My child knows the name of his/her doctor(s). <i>* We recommend using our Care Notebook available at www.familyvoicesal.org to help with this step.</i>	Y N	Y N		
5.	My child takes his/her medicine with supervision.	Y N	Y N		
6.	My child knows the name(s) of the medicine he/she takes and possible side effects.	Y N	Y N		
7.	Child knows when he/she is sick.	Y N	Y N		
8.	My child carries a copy of his/her insurance card.	Y N	Y N		

APPENDIX A - HEALTH CARE TRANSITION CHECKLIST

Age 12-15 (continued)		Things my child needs to know or do	Will someone else have to do this for my child?	I will finish by (date)	Done
9.	My child carries a summary of his/her medical information with him/her. <i>* We recommend using our Care Notebook available at www.familyvoicesal.org to help with this step.</i>	Y N	Y N		
10.	My child is learning to schedule his/her own appointments.	Y N	Y N		
11.	We are reviewing eligibility for adult services and when to apply.	Y N	Y N		
12.	We are investigating obtaining a Medical Power of Attorney	Y N	Y N		
13.	Before a doctor's appointment, my child prepares written questions to ask.	Y N	Y N		



APPENDIX A - HEALTH CARE TRANSITION CHECKLIST

Age 15-18		Things my child needs to know or do	Will someone else have to do this for my child?	I will finish by (date)	Done
1.	My child manages his/her doctor visits, explaining any problems and concerns.	Y N	Y N		
2.	My child knows he/she can meet alone with his/her doctor for part of the visit.	Y N	Y N		
3.	My child keeps a record of his/her appointments and knows the reason for them. <i>* We recommend using our Care Notebook available at www.familyvoicesal.org to help with this step.</i>	Y N	Y N		
4.	My child calls the doctor to schedule or reschedule appointments as needed.	Y N	Y N		
5.	My child takes his/her medicine and does treatments as scheduled.	Y N	Y N		
6.	My child takes part in making medical decisions.	Y N	Y N		
7.	My child informs family of when medicine needs to be ordered or calls in his/her own refills.	Y N	Y N		

APPENDIX A - HEALTH CARE TRANSITION CHECKLIST

Age 15-18 (continued)		Things my child needs to know or do	Will someone else have to do this for my child?	I will finish by (date)	Done
8.	My child has talked with his/her doctors about choosing a doctor for adult care when he/she turns 18.	Y N	Y N		
9.	My child knows about his/her health insurance and how it works.	Y N	Y N		
10.	My child is learning what health insurance coverage he/she will have when he/she is 18.	Y N	Y N		
11.	We have started talking about moving from pediatric to adult health care providers.	Y N	Y N		
12.	My child assists with filing his/her medical records and receipts at home. <i>* We recommend using our Care Notebook available at www.familyvoicesal.org to help with this step.</i>	Y N	Y N		

APPENDIX A - HEALTH CARE TRANSITION CHECKLIST

Age 18-21		Things my child needs to know or do	Will someone else have to do this for my child?	I will finish by (date)	Done
1.	We are establishing a Medical Power of Attorney and/or Guardianship.	Y N	Y N		
2.	The transition to adult health care providers is on-going.	Y N	Y N		
3.	We have applied for Social Security Insurance (SSI).	Y N	Y N		
4.	We have contacted our private insurance plans about coverage.	Y N	Y N		
5.	We are aware that some services (such as Children's Rehabilitation Service) may end	Y N	Y N		
6.	My youth co-signs the "permission for medical treatment" form (with or without signature stamp).	Y N	Y N		
7.	My youth knows symptoms that need quick medical attention.	Y N	Y N		
8.	My youth knows what to do in case of a medical emergency.	Y N	Y N		
9.	My youth helps to monitor and maintain medical equipment by doing daily/routine service.	Y N	Y N		

APPENDIX B - SAMPLE TRANSITION TEMPLATE

APPENDIX B – SAMPLE TRANSITION TEMPLATE

The template shown below (continuing on for several pages) was created from two transition templates graciously provided by Tera Bartelt (PCNS-BC, RN, 414-266-2690, tbartelt@chw.org). Tera is a Clinical Nurse Specialist currently working with the Spina Bifida Program at the Children’s Hospital of Wisconsin (www.chw.org).

WISCONSIN TEMPLATES IN THEIR CLINIC TRANSITION PROCESS

Both of the Wisconsin templates are used to put together a unique plan for each patient. Input from the family during a transition appointment is included in the plan. The plan is not meant to be an all inclusive medical history but a snapshot of care provided and what the receiving physician should know and understand about the young adult. It is stressed that each plan is “one of a kind” for an individual patient and is a “bridge” to adult care for that one person. Tera said, “Another key to successful transition here is that we have an excellent Social work department that is actively engaged with the family throughout the child’s continuum of care. Social workers are assigned based on condition; they follow the families and children when they are in the hospital and when they are in clinics. They discuss guardianship with the families on an ongoing basis and when appropriate make referrals to our free guardianship clinics.”

USING THIS TEMPLATE IN YOUR TRANSITION PROCESS

We recommend that you start your written plan by using the sections outlined in the template below. Much of the information in this template could be extracted from your Care Notebook if you are using our tool. Our Notebook is available by calling 877-771-3862 or online at www.familyvoicesal.org.

Transition Template

CONTACTS:			
Patient name:	Patient phone:	Patient address and/or email:	Patient DOB:
Parent/guardian name:	Parent/guardian phone:	Parent/guardian address and/or email:	
Power of Attorney name:	Power of Attorney phone:	Power of Attorney email:	
Primary Care name:	Primary Care phone:	Primary Care email:	
Pharmacy name:	Pharmacy phone & fax:	Pharmacy address:	
Specialty:	Specialist's name:	Specialist's phone:	Specialist's email:
Specialty:	Specialist's name:	Specialist's phone:	Specialist's email:
Specialty:	Specialist's name:	Specialist's phone:	Specialist's email:

APPENDIX B - SAMPLE TRANSITION TEMPLATE

(continued)

CHRONIC DIAGNOSES:

PAST SURGICAL HISTORY:

ACTIVE PROBLEMS/PLAN:

Problem	Plan	Responsible	Outcome

PATIENT/FAMILY GOALS (FUNCTIONAL, MEDICAL, And PERSONAL):

EMERGENCY PLAN/Common Presenting Problem -SUGGESTEDMANAGEMENT:

Problem	Suggested diagnostics	Suggested treatment

APPENDIX B - SAMPLE TRANSITION TEMPLATE

(continued)

ALLERGIES:

LATEX ALLERGY? YES/NO HX OF REACTION? YES/NO EPI-PEN? YES/NO

TYPE OF REACTION:

Allergen	Reaction
Allergen	Reaction
Allergen	Reaction
Allergen	Reaction

CURRENT MEDICATIONS:

Name of Medicine (brand or generic)	Dosage (mg, units, puffs, drops)	How often taken?	Reason for taking / treatment of	Start Date	End Date	Prescribed by	Notes on reactions / side effects

CURRENT FUNCTIONAL STATUS:

Cognitive	
Behavioral/ Mental Health	
Mobility	
Self-care	

APPENDIX B - SAMPLE TRANSITION TEMPLATE

(continued)

CURRENT FUNCTIONAL STATUS (continued):

Communication	
Vision	
Hearing	
Self-care	
Sexuality	
Patient adjustment to disability (psychosocial, spiritual)	
Other	

MEDICAL / ASSISTIVE TECHNOLOGY SUPPORTS

Communication devices: (tty, touch talker, etc)

Hearing aids:

Visual aids:

Prosthetics:

Home rehab equipment: (w/c, orthotics, positioning devices)

Miscellaneous Durable Medical Equipment (DME) supplies/issues:

Other:

CURRENT NUTRITION

Route:

BASELINE PHYSICAL EXAM:

RECENT LABORATORY/IMAGING FINDINGS:

FUTURE RECOMMENDED LAB/IMAGING:

APPENDIX C - TRANSITION STORIES

APPENDIX C – TRANSITION STORIES

In our family transition has been a process that was started at birth. Very quickly upon learning that each of our children (son now 14 and daughter now 12) had medical conditions that would be life-long and complicated we started framing our goals. For us they were the same as most families; to raise happy, independent, productive, caring adults. This goal dictated the services we engaged and how every interaction was handled. Examples of transition planning were apparent from the start and evolved and continue to evolve:

1. Our children from birth were always exposed to honest and complete information about their condition, prognosis and treatment options and outcomes
2. Our children were asked to communicate directly with medical providers to the extent that was developmentally possible (and this was often far beyond the norm
 - a. As young children, they were to give the first report on how they were feeling and changes at any appointment
 - b. By elementary school, they were to report on medication list and doses (sometime supported by list-record on phone)
 - c. In middle school, they “run” their medical appointments and hospitalizations with a parent offering information and decision making only as needed and in support
 - d. They are tasked with knowing their insurance and providing that for registration
 - e. Current emerging skills, are navigating prior authorization and in and out of network list, and Medicaid redetermination
3. We found school (starting in preschool) to be a great environment to grow self-management skills around medical issues. They have always been in fully inclusive settings with supports including access to RN for medication and assessment. Each year they have worked on improving self-reporting, and decision making around level of intervention needed for issues
4. The kids have Individual Health Plans (written documents) that capture needs, and plans and they are now tasked with maintaining and updating to the documents
5. Motor skills limit the kids' ability to self administering medication but, they are able and do direct whoever is dispensing and administering. This skill has been key to facilitating their access to community and social events.

APPENDIX C – TRANSITION STORIES

I have two sons with the same genetic disorder; they are 4 ½ years apart in age. Transition was forced upon us when we moved to Alabama with my oldest son because he was 17. My son, husband, and I all started seeing an internal medicine doctor. We were happy with the doctor, but then my son turned 18. We applied for SSI and Medicaid, he was approved right away. Well, that is when we discovered Medicaid would not pay if we continued seeing his internist and that his assigned Medicaid doctor was over an hour way from our home. We found a Medicaid pediatrician who agreed to see him for one year. I began to look for a new doctor by asking friends that also had adult children with disabilities who they used. We now have a great doctor, but I learned a lot about having to clear your own way down the transition path.

My younger son was not diagnosed until age 17. He has always had medical problems, but we had never tested him for the genetic disorder. Two years ago he started having more severe health problems which lead us to test him. After being diagnosed, he suffered from depression. Well, as any Mother would do I tried to seek mental health services for him only to find out that at 18 the medical-community considers you an adult and required that he make the appointment. I was surprised by this since in the state of Alabama you are not an adult until you turn 19. He never agreed to make that appointment, but it did give me some leverage to make him be more involved in his health care. Our pediatrician helped us transition, but we had no formal meetings. We transferred care to my oldest son's doctor. We also began to work on accommodations for college. If it was not for the support of the professional at the Office of Disabilities at the college, we would not have known what to do. Once again being the Mother I am, I jumped through all the hoops for this transition into college. Only to once again realize that I could "lead that horse to water, but I could not make him drink". He is home now going to a community college. He is slowly learning that he has to manage his health and for him it is important to have his family there to steer him to the right path. I feel that talking with your teenager/young adult is a very important step in transitioning. They need to learn how to manage their care while you are still available to guide them. My oldest son is ID, so this meant that I needed to get guardianship of him to make sure his health care was managed appropriately.

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My son has autism and a rare genetic disease that causes misfires of the adrenal gland and overwhelming responses to any stress. When he becomes over-stimulated, he quits breathing and medications work opposite or randomly from their intended effect. Therefore, we have learned to modify life experiences. All is well-documented in his medical records. When he turned eighteen, he was automatically "routed" through adult surgical services at the nearby tertiary medical center. I tried to persuade the administration to continue allowing him to use pediatric surgical services. They knew him and were always responsive to the information I shared with them. We had developed a working partnership. The hospital firmly denied my request. A fiasco then occurred. I was told to quiet him when he had to stand in line for pre-op check-in. He responded by making more and louder noises. The resident that prepped him for surgery declined my insistence that he wait until my son was asleep to place the IV, causing my son further stress. His response was to faint and fall off the stretcher. My pleas for modifying procedures were ignored, although I am his legal guardian, because I was not the patient. But between wheeling my son into surgery and his ride to post-op a miracle occurred. He was taken to pediatrics post-op rather than adult post-op. Since that point, attitudes and services have dramatically improved! There is now a team of sensitive and appropriate providers who work with me and my son to assure that whatever modifications are necessary for success are put into place before, during and after his hospital stays.

Your story can teach.

Our daughter has a number of chronic, congenital health conditions related to her primary diagnosis of Down syndrome. We learned early the importance of family advocacy and involvement. So as soon as I heard about transitions to adult providers, I have been preparing and discussing with others. During her visit to her cardiologist when she was sixteen, I reminded him I needed his insights to find an adult cardiologist that was comfortable with congenital cardiac issues. He acknowledged it would be difficult since most were familiar with acquired rather than congenital issues. When we returned to see her pediatric cardiologist a year later and I discussed the increasing urgency, he assured me that he and another doctor, a med-peds physician, had started an adult cardiology clinic for persons with congenital defects during that year. Four years later that clinic is going strong! Our daughter is a patient with a practice that understands the effects of her congenital issues and will assist her in preventing adult-onset heart disease. I am beyond pleased that someone saw the need and stepped in to answer. How blessed we are.

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I have used the same Primary Care Provider (PCP) for many years. He is a member of a large group family medicine practice. He has been aware of my daughter and her complex medical needs for many years, and when she was in her early teen years, I spoke to him about taking over her care when the pediatric practice would no longer see her at age 21. He said certainly, and even asked me to start having her medical reports copied to his as well as her pediatrician so that he could become more familiar with her case. At some point while she was about 20, I mentioned to him that we would need to meet and decide on a "formal" transition schedule. At that point, he looked at me and said, "we won't be able to take her as a patient in this practice". And that was it! No real explanation of why, or when he had come to that decision. In my opinion, this was not about money- my daughter is covered by Blue Cross/Blue Shield, Medicare (began at age 20) and Tricare. This has totally changed my own relationship with my physician. And, I have been unable to find another local physician willing to take her on-at age 25 she is still being seen at our pediatrician's office, which works for us because many of the specialists she sees are also pediatric. The only time I even worry about it anymore is every now and then when the pediatrician mentions that we really should find an adult provider!

Voices of families matter.

Recently our adult daughter saw a new provider who recommended a surgical consultation for a minor issue. I was beyond concerned about the referral because our daughter has an intellectual disability and, although I have medical power of attorney rights for her, I was unsure how the surgeon would address her as well as respect the information that I needed to share. During the check-in and waiting process, we received stares of confusion and concern from the staff. I was anticipating an uncomfortable conversation with the physician. What a pleasure to meet and work with this surgeon! She was relaxed, appropriate with my daughter as well as with me. She asked all questions to my daughter first, then silently checked in with me to confirm the response. At all times she treated my daughter with respect and was appropriately interested in what she was told. Throughout our time with the surgeon and the resident, we were actively engaged as partners in the discussion and decision. I was very impressed that an adult provider got it right when dealing with a young woman with an intellectual disability and her involved mother!

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A pediatrician might be ready to transition a youth to an adult PCP, but often finding one who will accept the youth is easier said than done! When our pediatrician said that she really couldn't continue to care for my son, who was extremely medically fragile, I asked her to help me find an adult provider. She was willing, but she soon discovered (and admitted that she was surprised) that as she spoke with various family practice and internal medicine providers in our city that none felt comfortable taking on his complex needs. In a few cases, there was some interest, but then the new practice would end up saying they would not be able to accept his third party coverage, which was Tricare and Medicaid. After almost a year of making contacts, our pediatrician finally found a family practice doctor (a personal friend of hers) who agreed to take him. Both of them committed a full afternoon to meeting with us, reviewing his records, and discussing how we would handle future events and emergencies. Some of the unanswered questions involve hospitalizations, as this practice does not admit any patients to any hospitals. They rely on hospitalists to manage all care in the hospital. So, we have made a tiny step forward on this "road to transition", but I am left feeling very vulnerable and scared about all of the unknown things that lie before us.

The road might be bumpy.

My daughter is now 24 years old and is attending a university. She has Spina Bifida and uses a power wheelchair for mobility. Throughout high school there were those in special education services that discouraged our family from college as a transition goal and others who thought it was an excellent direction to take. As a result there were conflicts amongst the faculty and with the family on occasion. There was a very helpful counselor who played a role in developing the steps that were necessary for college admission and scholarship applications. Children's Rehabilitation Service helped our family understand some of the inherent challenges with our transition goals and took part in finding strategies to deal with them. We did not have a comprehensive written transition plan because there were so many unknowns that we were facing.

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Transition planning is a very personal journey that involves the whole family. It encompasses the visions of each member of the family and is loaded with emotion. Once my daughter, along with the rest of the family, decided on the direction that we wanted to take, it then took a constant effort to fend off naysayers, develop relationships with supporters, and engage in creative problem solving. Challenges always seem to rise up along the way. It is hard to imagine implementing a transition plan without the support of the whole family. Thinking "outside of the box" helps a lot. We've been reasonably successful but each day is a new day and there are always issues that need attention. We provide all of the transportation to and from school for classes and special events. At the end of the day my daughter travels to a nearby restaurant and waits to be picked up. Relationships have grown with the staff and regulars at the restaurant which has been a very positive situation. This part of our plan also provides the flexibility needed by our family in bringing her home. Our daughter's experiences at college have allowed her to continue to learn new things and develop relationships with her peers.



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RESOURCES

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