

# Navigating Healthcare Transitions: Pediatric to Adult Medical Care

*For Professionals*



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Cornelia de Lange Syndrome Foundation  
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# INTRODUCTION

Cornelia de Lange Syndrome (CdLS) is a genetic disorder present from birth which causes a range of physical, cognitive, and medical challenges. CdLS is caused by a genetic mutation in one of the five genes; NIPBL, SMC1A, SMC3, HDAC8, or RAD21. At present it is estimated that the incidence is approximately 1 in 10,000 live births.

While there have been many advances in the diagnosis and treatment of CdLS, many challenges remain. One of these challenges is the transition from pediatric to adult medical care and the continuation of comprehensive health care services. The goal of this guide is to provide medical providers and healthcare professionals with the tools needed to facilitate the transition process. As you read through this guide, keep in mind that all of the suggestions may not apply to all youth with CdLS and their families. CdLS is not a “one size fits all” condition, and everyone’s experience with the transition process will be unique and specific to the young adult and his/her family.

*See Appendix for chart of CdLS Characteristics.*

For additional information about CdLS please visit [www.cdlsusa.org](http://www.cdlsusa.org) or contact the Foundation to request informational materials.

1.



# TRANSITION PLANNING

## THE FOUR STEPS TO CREATING A MEDICAL TRANSITION PLAN

*Adapted from Cooley et al 2011*

### **STEP 1** OFFICE TRANSITION POLICY

Every pediatric practice should have a well-defined policy that clearly states the expectations for the health care transition to an adult model of care. The office transition policy should include:

- The expected age of patient transfer to an adult model of care
- The patient's responsibilities in preparing for the transition
- The parent's, family's, and/or caregiver's responsibilities in preparing for the transition
- The medical provider's responsibilities in preparing for transition

*See Appendix for Sample Transition Policy.*

### **STEP 2** INITIATE A JOINTLY DEVELOPED TRANSITION PLAN

The pediatric primary care provider should initiate the discussion about transition planning with youth and parents/caregivers as early as age 12. Once the discussion occurs, the next plan of action should be focused on creating a written transition plan, sometimes also known as a plan of care.

A formal written transition plan should be kept in the youth's chart for review during future office visits.

A healthcare transition plan should include:

- Documentation of the youth's current readiness/capabilities to assume a greater role in self-management of his/her health care
- May include a completed readiness and/or skill assessment tool that reveals areas of strengths and challenges on which patient education and skill building can be focused
- Documentation of the steps to be conducted by youth, parent/caregiver, and provider in order to achieve a successful medical transition
- Documentation of transmittal of information between youth, parent/caregiver, and provider

*See Appendix for Sample Transition Plan and Provider Transition Timeline and Checklist.*

### STEP 3


## REVIEW AND UPDATE TRANSITION PLAN

The transition plan should be reviewed and updated with the youth, parent/caregiver, and provider at least annually. This will help promote the recognition by the youth, parent/caregiver, and provider of successes and/or deficits in readiness preparation for transition to the adult health care model. It may also be appropriate to reprioritize goals and/or reevaluate the existing plan with respect to changes in the youth's medical status and/or concerns on the parent's/caretaker's part. In addition, as the youth reaches 16-17 years of age and is closer to the age of expected transition, it may not be feasible to accomplish existing goals with annual reviews, and the frequency may have to be adjusted as appropriate.

### STEP 4

## IMPLEMENT ADULT HEALTH CARE MODEL

Before the implementation of the adult health care model, the youth, parent/caretaker, and pediatric provider should jointly prepare a portable medical summary which should be delivered to both the patient and new adult provider. All medical records should also be delivered to the adult provider prior to the transfer, alongside all the other items found in the "Transfer of Care Checklist" below. It is also very common for pediatric providers to make themselves available to the adult providers as a resource for any needed information or assistance during the immediate post transfer period.

		<b>Sample Transfer of Care Checklist</b>
Patient Name: _____	Date of Birth: _____	
Primary Diagnosis: _____	Transition Complexity: _____ <small>Low, moderate, or high</small>	
<b>-Prepared transfer package including:</b> <ul style="list-style-type: none"><li><input type="checkbox"/> Transfer letter, including effective of date of transfer of care to adult provider</li><li><input type="checkbox"/> Final transition readiness assessment</li><li><input type="checkbox"/> Plan of care, including transition goals and pending actions</li><li><input type="checkbox"/> Updated medical summary and emergency care plan</li><li><input type="checkbox"/> Guardianship or health proxy documents, if needed</li><li><input type="checkbox"/> Condition fact sheet, if needed</li><li><input type="checkbox"/> Additional provider records, if needed</li></ul>		
<b>-Sent transfer package</b> _____ <small>Date</small>		
<b>-Communicated with adult provider about transfer</b> _____ <small>Date</small>		

*See Appendix for Sample Transition Transfer Letter.*

## PORTABLE MEDICAL SUMMARY

A portable medical summary is written information about the youth's health history. Portfolios can be used to describe chronic health condition or disability in both words and photos and should be created with input from both the provider and parent/caregiver.

A portable medical summary can include:

- CdLS informational material (e.g., Medical Treatment Guidelines)
- Impact of CdLS and how it affects the youth
- Diagnoses
- Medications, including what they do, how long the youth has taken them, side effects, who prescribes them, and which pharmacy fills them
- Allergies
- Dietary restrictions
- Seizure information, including what kind, how long they last, how often the youth has them, how to keep the youth safe during a seizure, and how to help the youth afterward
- Medical equipment information (feeding tubes, oxygen tanks, etc.): who maintains, refills, and recharges the equipment and what should be done if the equipment fails
- Accommodations to help the youth manage their health
- Communication strategies
- Emergency Care Plan

2.



# IMPORTANT CONSIDERATIONS FOR TRANSITION PLANNING

## ASSESSING YOUTH'S ROLE IN TRANSITION PLANNING

Age alone may not always be an appropriate factor in determining the time and/or extent the young adult will be involved in the transition planning discussion. It is important to keep in mind that this discussion will need to be tailored to the unique needs of each young adult and family. Providing youth with information, support, and opportunities for making choices will help him/her be an active participant in the process.

Providers and parent/caretakers should determine the extent of youth's capabilities in the following areas:

- Youth's judgment and reasoning skills
- Youth's understanding of his/her medical condition(s) and treatment
- Youth's level of participation at medical appointments
- Youth's self-care skills, including the ability to fill prescriptions, follow prevention and treatment regimens, and seek assistance in an emergency
- Youth's self advocacy skills
- Youth's medical status and stability

*Adapted from the Institute of Medicine US Committee on Disability in America 2007.*

## INCREASING YOUTH'S SKILLS

Skills such as self-advocacy, self-determination, and autonomy play an important role in the transition process. The ultimate goal of teaching these skills is to allow young adults with CdLS to have as much input as they are capable of in the transition planning process as well as their future life goals.

No matter what the child's developmental level may be, every child should have the opportunity to make choices and take control of their life in a way that is appropriate for them because this gives them an opportunity for growth and learning.

Ways to increase youth's skills:

- Teach youth about his/her special needs related to CdLS
- Allow youth to participate in making choices
- Encourage youth to participate in self-care
- Assign youth with appropriate responsibilities

- Encourage youth to speak for themselves
- Promote youth's interactions with health care providers
- Encourage youth to participate in organized activities that build social skills and confidence
- Provide youth with an opportunity to find his/her own solutions to problems

## PRACTICAL CONSIDERATIONS FOR MULTIPLE STAKEHOLDERS IN THE TRANSITION PROCESS (RACINE ET AL 2014)

Practical Consideration	Youth	Parents	Pediatric Providers	Adult Providers	Other Healthcare Providers
<b>Transition as a process of skill building over time</b>	Understand transition as a normal and ongoing process that begins early in adolescence.	Encourage progressive skill building and responsibility of youth.  Understand and appreciate youth's preferences and life goals.	Educate oneself and teach trainees to identify youth's decision making capacity and to speak with them about their health care role as appropriate.	Educate oneself and teach trainees to identify youth's decision-making capacity and to speak with them about their health care role as appropriate.	Build sustainable relationships with youth to facilitate transition.  Appreciate the different models of autonomy dependent on youth's special health care needs and wishes.
<b>Preparation for decision making</b>	Participate in early skills building activities that are developmentally appropriate.	Encourage early skill building—allow youth to communicate about disability and preferences in and out of medical encounters	Break down stigma regarding CdLS to help promote self-esteem in the youth.  Recognize youth's decision-making capacity and encourage decision making where possible.	Avoid misconceptions about the decision making capacities of youth with CdLS.	Discuss and support choices of youth during transition.
<b>Relational aspects decision making</b>	Participate in and/or develop peer groups who will also transfer at the same time.	Teach youth self-advocacy skills and build self-esteem and confidence.	Encourage early skill building and educate family about the importance of promoting choices and decision making of youth.	Improve understanding of CdLS and knowledge of individual's abilities for participating in decision making.	Facilitate stronger relationships with the health care team to help increase confidence of youth in health care services.  Facilitate communication with schools about the child. Drive continuity of care across transition.



## COMMUNICATING EFFECTIVELY

Individuals with CdLS with cognitive and developmental limitations on the more severe end of the spectrum are at a greatest risk for not being given the opportunity to express their needs, wants, and feelings. Health care providers have the opportunity to empower their patients and provide them with the opportunity to actively participate in their care as appropriate. Providers can achieve this by utilizing communication skills and techniques that fit the different communication needs of individuals with CdLS.

*See Appendix for Suggested Communication Tips and Strategies.*

## TRANSITIONAL BARRIERS

### YOUNG PERSON

Young people, particularly young people with complex conditions, have spent years with the same pediatric care team and may perceive the transition process as abandonment and feel uncomfortable or threatened by the style of practice of physicians who care for adults.

### FAMILY

Parents, too, may see the transition from pediatric care team as abandonment. They can also feel threatened by the loss of authority over care for an adult child, especially if the adult health care provider is not sensitive to parental anxieties and to parental involvement in their child's ongoing process of achieving independence.

### PEDIATRICIAN

Pediatricians may be reluctant to initiate a transition. They may also see physicians who care for adults as less prepared to provide comprehensive, developmentally appropriate patient and family centered care.

### ADULT HEALTH PROVIDER

Physicians who care for adults may have had little training for many conditions that were once fatal in childhood and may have little experience working with young adults with disabilities and their parents. Many will be subspecialists with a less comprehensive, less interdisciplinary approach to care than is characteristic of providers in pediatric and family practice.

*Adapted from the Institute of Medicine US Committee on Disability in America 2007*

3.



# TRANSITIONING

## EMOTIONAL ASPECTS OF TRANSITIONING

Although families make multiple transitions during their child's life, providers must recognize that for some individuals, the pediatric to adult transition can mean many losses—loss of relationship with pediatric team, loss of control, and loss of a comfortable context and known history of how decisions about health and care management have been made.

The provider's goals should be to normalize the transition process, address family's anxiety or questions, and foster a team approach to help facilitate the acquisition of skills and tools that the youth can use both in transition and beyond.

Providers should also assess youth's and family's coping mechanisms associated with stressors of transitioning and provide referrals for additional support, as appropriate (Colet et al. 2011).

## TERMINATION

Given that termination can be an emotional process for families, it is important providers give attention to and create an opportunity for saying goodbye. It may be helpful to set aside time on the last visit for therapeutic closure for everyone as well as to share how the patient and family can reconnect with pediatrician if needed and how to update the pediatric team how the young adult is doing (Schluter 2014).

## YOUTH'S EXPERIENCE WITH LOSS AND GRIEF

As youth transitions to adult medical care he/she may experience multiple layers of loss as they are introduced to new providers. It is important to recognize that children with CdLS do experience grief and that having limited communication skills does not mean that the child is unaffected by loss but rather will express his/her grief in distinct ways.

Symptoms of loss may include somatic complaints, relationship difficulties, social withdrawal, increased compulsivity, intensified frustration, and self-injurious actions. When children with CdLS or other developmental disabilities experience disruption in their lives such as a loss associated with transitioning, symptoms of increased anger, confusion, compulsivity, and ritualization are patterns that may be seen in daily activities (Sormanti and Ballan 2011).

Children with CdLS are also more likely to use coping strategies such as increasing negative, repetitive behaviors which may include self-stimulatory actions like twirling, rocking, head banging, or flapping which may progress to the point of self-harm.

## SEEKING SUPPORT FROM SOCIAL WORKERS

Social workers can be a valuable resource when it comes to transition planning. Social workers are knowledgeable about community resources and can make necessary referrals for support in the transition to adult medical care (Carvalho 2012).

*See Appendix for additional information on how Social Worker can facilitate the transition process.*



4.



# INDIVIDUALIZED ASPECTS OF TRANSITIONING

## STRENGTHS BASED PERSPECTIVE IN TRANSITION PLANNING

Understanding the individual strengths and needs of youth with disabilities is an essential aspect of high quality transition planning. The emphasis on strengths-based assessment affirms that strengths coexist alongside needs in every person. Identifying both will ensure a more comprehensive approach to addressing the multiple dimensions of the young adult as he/she transitions to adult health care.

A central element of conducting a comprehensive assessment involves the integration of perspectives of multiple individuals who know the young adult. A multi-informant approach may be particularly important when planning for youth with complex communication challenges who may have difficulties articulating their own goals, interests, strengths, and needs (Carter, Brock, and Trainor 2014).

## STRENGTHENING THE PROFESSIONAL-FAMILY RELATIONSHIP

One of the most important aspects of family support is the relationship between the professional serving a child with a disability and the family. A professional's understanding of the coping strengths of families and the positive contributions of people with disabilities has major implications for strengthening the relationship.

It is important for professionals to be aware that a sense of mastery or control is a vital coping strategy for families who have a child with a disability. Professionals need to take every possible opportunity to point to progress that the child is making. Even more importantly, professionals should try to link that progress to some action taken by the family.

Helping families identify positive contributions of their experience with a child with a disability and enhancing self-esteem through the appreciation of positive aspects of the situation requires that professionals themselves hold a positive attitude. Professionals should examine their own feelings about the value of people with disabilities and should be able to identify the ways in which children and adults with whom they have worked have enhanced their own life.

There is no way to pretend a positive attitude; families and people with disabilities can spot insincere statements as easily as anyone else. Therefore, the extent that professionals actually enjoy their work and believe in the intrinsic worth of people they serve, the better they will be able to engage the family's ability to see positive worth in both themselves and in their child with a disability (Summers and Turnbull).

## CULTURE AND TRANSITION PLANNING

Cultural competence supports the autonomy of the patient in health care encounters such as the medical transition to adulthood. The process of becoming culturally competent is one of building a patient approach that acknowledges and respects patient values, beliefs traditions, and other aspects of the individual's culture, with the ultimate goal of improving the patient's health status (Robey et al 2013).



## USEFUL RESOURCES

“Health Care for Adults with Intellectual and Developmental Disabilities: Toolkit for Providers,” Vanderbilt Kennedy Center. <http://vkc.mc.vanderbilt.edu/etoolkit/>

“Access to Medical Care for Individuals with Mobility Disabilities,” U.S. Department of Health and Human Services. Last modified July 2010. [http://www.ada.gov/medcare\\_mobility\\_ta/medcare\\_ta.pdf](http://www.ada.gov/medcare_mobility_ta/medcare_ta.pdf)

“Healthcare Transition Resources for Providers.” <http://www.gottransition.org/index.cfm>

“Transition to Adulthood: resources for Physicians,” American Academy of Pediatrics Illinois Chapter. <http://illinoisAAP.org/projects/medical-home/transition/resources-for-physicians/>

## REFERENCES

- Carvalho, M., Shanske, S., Rein, J., & Arnold, J. (2012). Social workers as transition brokers: Facilitating the transition from pediatric to adult medical care. *Social Work in Health Care*, 51(4), 279-295. doi:10.1080/00981389.2011.638419
- Cooley, W. C., Sagerman, P. J., Transitions Clinical Report Authoring Group, American College of Physicians, American Academy of Family Physicians, American Academy of Pediatrics, & American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians, Transitions Clinical Report Authoring Group. (2011). Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*, 128(1), 182-200. doi:10.1542/peds.2011-0969
- GotTransition. (2014). Six Core Elements of Health Care Transition 2.0. Retrieved June 4, 2015, from <http://www.gottransition.org/resourceGet.cfm?id=208>
- Institute of Medicine (US) Committee on Disability in America. (2007). Health Care Transitions for Young People. In M. Field & A. Jette (Eds.), *The Future of Disability in America*. Washington (DC): National Academics Press (US).
- Racine, E., Bell, E., Yan, A., Andrew, G., Bell, L. E., Clarke, M., . . . Yager, J. Y. (2014). Ethics challenges of transition from pediatric to adult health care services for young adults with neurodevelopment disabilities. *Pediatrics & Child Health*, 19(2), 65-68.
- Schlucter, J. (2014). Patient- and Family-Centered Transitions From Pediatric to Adult Care. *Pediatric Nursing*, 40(6), 307-310
- Sormanti, M., & Ballan, M. S. (2011). Strengthening grief support for children with developmental disabilities. *School Psychology International*, 32(2), 179-193. doi:10.1177/0143034311400831
- Vanderbilt Kennedy Center for Excellence in Developmental Disabilities. (2015). Communicating Effectively with Adults with Intellectual and Developmental Disabilities. Retrieved July 28, 2015, from <http://vkc.mc.vanderbilt.edu/etoolkit/general-issues/communicating-effectively/>

# APPENDIX

## CHARACTERISTICS OF CdLS

### BIRTH WEIGHT, GROWTH, AND HEAD SIZE

- average birth weight is 5lbs. 1oz
- average birth length is approximately 18 inches
- microcephaly

### DEVELOPMENTAL DELAYS

- intellectual disabilities
- learning disabilities
- language delays

### GASTROESOPHAGEAL REFLUX DISEASES (GERD)

### BEHAVIORAL ISSUES

- self-injury
- compulsive repetition
- autistic-like behaviors
- anxiety
- obsessive compulsive disorder
- attention deficit disorder and attention deficit hyperactivity disorder

### FACIAL FEATURES

- synophrys
- long eyelashes
- short upturned nose
- thin downturned lips
- low-set ears
- high-arches palate or cleft palate

### LIMB DIFFERENCES

- small hands and feet
- clinodactyl
- partial joining of the second and third toes
- proximally placed thumbs
- upper limb abnormalities

### OTHER SYSTEM ABNORMALITIES

- blepharitis
- faulty or nonexistent tear ducts
- ptosis
- myopia
- hearing loss
- communication delays
- feeding difficulties
- seizures
- heart defects
- bowel abnormalities
- undescended testes
- cutis marmorata



## Sample Transition Policy

[Pediatric Practice Name] is committed to helping our patients make a smooth transition from pediatric to adult health care. This process involves working with youth, beginning at ages 12 to 14, and their families to prepare for the change from a “pediatric” model of care where parents make most decisions to an “adult” model of care where youth take full responsibility for decision-making. This means that we will spend time during the visit with the teen without the parent present in order to assist them in setting health priorities and supporting them in becoming more independent with their own health care.

At age 18, youth legally become adults. We respect that many of our young adult patients choose to continue to involve their families in health care decisions. Only with the young adult’s consent will we be able to discuss any personal health information with family members. If the youth has a condition that prevents him/her from making health care decisions, we encourage parents/caregivers to consider options for supported decision-making.

We will collaborate with youth and families regarding the age for transferring to an adult provider and recommend that this transfer occur before age 22. We will assist with this transfer process, including helping to identify an adult provider, sending medical records, and communicating with the adult provider about the unique needs of our patients.

As always, if you have any questions or concerns, please feel free to contact us.



## Sample Plan of Care

**Instructions:** This sample plan of care is a written document developed jointly with the transitioning youth to establish priorities and a course of action that integrates health and personal goals. Motivational interviewing and strength-based counseling are key approaches in developing a collaborative process and shared decision-making. Information from the transition readiness assessment can be used to guide the development of health goals. The plan of care should be dynamic and updated regularly and sent to the new adult provider as part of the transfer package along with the latest transition readiness assessment, medical summary and emergency care plan, and, if needed, a condition fact sheet and legal documents.

Name:	Date of Birth:				
Primary Diagnosis:	Secondary Diagnosis:				
What matters most to you as you become an adult? How can learning more about your health condition and how to use health care support your goals?					
Prioritized Goals	Issues or Concerns	Actions	Person Responsible	Target Date	Date Complete



## Sample Transfer of Care Checklist

Patient Name: _____	Date of Birth: _____
Primary Diagnosis: _____	Transition Complexity: _____ <small>Low, moderate, or high</small>
<p>-Prepared transfer package including:</p> <ul style="list-style-type: none"><li><input type="checkbox"/> Transfer letter, including effective of date of transfer of care to adult provider</li><li><input type="checkbox"/> Final transition readiness assessment</li><li><input type="checkbox"/> Plan of care, including transition goals and pending actions</li><li><input type="checkbox"/> Updated medical summary and emergency care plan</li><li><input type="checkbox"/> Guardianship or health proxy documents, if needed</li><li><input type="checkbox"/> Condition fact sheet, if needed</li><li><input type="checkbox"/> Additional provider records, if needed</li></ul>	
<p>-Sent transfer package _____ <small>Date</small></p>	
<p>-Communicated with adult provider about transfer _____ <small>Date</small></p>	



## Sample Transfer Letter

Dear Adult Provider,

Name is an age year-old patient of our pediatric practice who will be transferring to your care on date of this year. His or her primary chronic condition is condition, and his or her secondary conditions are conditions. Name's related medications and specialists are outlined in the enclosed transfer package that includes his or her medical summary and emergency care plan, plan of care, and transition readiness assessment. Name acts as his or her own guardian, and is insured under insurance plan until age age.

I have had name as a patient since age and am very familiar with his or her health condition, medical history, and specialists. I would be happy to provide any consultation assistance to you during the initial phases of name's transition to adult health care. Please do not hesitate to contact me by phone or email if you have further questions.

Thank you very much for your willingness to assume the care of this young man or woman.

Sincerely,

## COMMUNICATING EFFECTIVELY

Goal	Suggested Communication Tips
<b>Establishing Rapport</b> <ul style="list-style-type: none"> <li>• Speak directly with the patient</li> <li>• Avoid talking to an adult as if he/she were a child</li> </ul>	<ul style="list-style-type: none"> <li>• Consider not wearing the white coat.</li> <li>• Speak directly to the patient, not to his/her caregiver(s).</li> <li>• Ask the patient: “Do you want your support worker/caregiver to stay here for this visit?”</li> <li>• Ask simple introductory questions (e.g., name, reason for visit).</li> <li>• Explain the process and purpose of the visit in simple terms.</li> <li>• Gain the patient’s attention and eye contact, if possible, by using his/her name or by touching his/her arm prior to speaking.</li> <li>• Determine how the patient communicates: “How do you say Yes? No?” “Do you use a device? Can you show me how to use this book/machine?”</li> <li>• If the patient uses a communication technique or device, involve a caregiver who is familiar with it.</li> <li>• Show warmth and a positive regard.</li> <li>• Encourage the use of “comforters” (e.g., favorite item the patient likes to carry, or a preference for standing and pacing rather than sitting).</li> <li>• For individuals with autism and related disorders, respect the preference to avoid eye contact.</li> <li>• Use positive comments and positive reinforcement.</li> <li>• Focus on the patient’s abilities rather than disabilities.</li> </ul>
<b>Choosing Appropriate Language</b> <ul style="list-style-type: none"> <li>• Use concrete language</li> <li>• Avoid shouting</li> </ul>	<ul style="list-style-type: none"> <li>• Use plain language. Avoid jargon.</li> <li>• Use short, simple sentences.</li> <li>• Use concrete as opposed to abstract language, for example: “Show me”; “Tell me”; “Do this” with gesture; “Come with me”; “I’m going to...”</li> <li>• Say “Put your coat on” instead of “Get ready.”</li> <li>• Say “Are you upset? Are you sad? Are you happy?” instead of “What are you feeling?”</li> <li>• To make the concept of time more concrete, use examples from daily and familiar routines (e.g., breakfast-time, lunchtime, bedtime).</li> </ul>
<b>Listening</b> <ul style="list-style-type: none"> <li>• Listen to what the patient says</li> <li>• Allow enough time</li> </ul>	<ul style="list-style-type: none"> <li>• Let the patient know when you do and do not understand.</li> <li>• Be sensitive to tone of voice and nonverbal cues.</li> <li>• Differences in muscle tone for some individuals may complicate reading their facial expressions or body language. Check/validate your perceptions.</li> <li>• Be aware that the visit will likely take more time than usual.</li> <li>• Several consultations may be required to complete a full assessment.</li> </ul>
<b>Explaining Clearly</b> <ul style="list-style-type: none"> <li>• Explain what will happen before you begin</li> <li>• Tell and show what you are going to do and why</li> </ul>	<ul style="list-style-type: none"> <li>• Speak slowly. Do not shout.</li> <li>• Pause frequently, so as not to overload the patient with words.</li> <li>• Give the patient enough time to understand what you have said and to respond.</li> <li>• Rephrase and repeat questions, if necessary, or write them out, if the patient is able to read.</li> <li>• Checking for understanding is essential. For patients who can speak in sentences, ask questions such as: “Can you tell me what I just said?” “Can you tell me what I am going to do and why?”</li> </ul>
<b>Communicating without words</b> <ul style="list-style-type: none"> <li>• Use visual aids</li> <li>• Act or demonstrate</li> </ul>	<ul style="list-style-type: none"> <li>• People with limited language ability and understanding rely on familiar routines and environmental cues to understand or anticipate what will happen next.</li> <li>• Use simple diagrams and gestures.</li> <li>• Use pictures when communicating; find signs in the patient’s communication book or point to familiar objects (e.g., “It looks like...”)</li> <li>• Some people with IDD may express themselves only in writing.</li> <li>• When possible and safe, allow the patient to handle and explore equipment.</li> <li>• Point to body parts and act out actions or procedures (e.g., checking ears).</li> </ul>

*Adapted from Vanderbilt University 2015*

## SOCIAL WORKERS AS TRANSITION BROKERS

Developmental Framework	Resource Facilitation	Patient/Provider Relationships
<b>Normative Child Development and Impact of Chronic Illness</b> <p>Social workers educate members of health care team about the social and emotional development.</p> <p>Social workers have understanding of the complex layers chronic illness adds to a child's social and emotional development and the impacts it has on the individuation of an adolescent from the parents.</p> <p>Social workers consider the impact of chronic illness on the family dynamics and role definition within the family.</p>	<b>Activities of Daily Living</b> <p>Social workers can begin to engage families in thinking about the future in terms of daily life.</p> <p>Social workers provide information and guidance in many areas of social and emotional growth as well as facilitate access to programs and services that are needed.</p>	<b>Empowerment</b> <p>Social workers provide interventions that teach competencies inherent to the transition process in order to allow for optimal empowerment of the youth and family.</p> <p>Social workers in a multidisciplinary system also integrate the empowerment perspectives in order to allow youth to utilize their maximum capabilities.</p>
<b>Impact of Developmental Delay</b> <p>Social workers help families and providers understand and navigate the challenges associated with significant developmental delays.</p> <p>Social workers provide families with support beyond the school years such as providing resources and referrals for day programs and long-term care options.</p>	<b>School</b> <p>Social workers are well versed in education laws and entitlements programs, and advocate on behalf of children in order to ensure that these services are provided and the specific needs of the child are being addressed.</p> <p>In complex situations, social workers can refer families to advocates in the community.</p>	<b>Self-Awareness Promotion for Providers</b> <p>Social workers are trained and able to process not only their own feelings and relationships but also to serve as a support for other members of the multidisciplinary health care team.</p> <p>Social workers help the health care team to be prepared, capable and willing to manage the range of emotional and psychological feelings within the transition process.</p>
<b>Social Work Assessment Within Biopsychosocial Model</b> <p>Social workers provide ongoing assessments with the understanding of complex factors including normative development, the interplay of chronic illness, the length of time since the diagnosis of a medical condition, and the family's developmental stage, resources, community support, and coping abilities in evaluating for well coordinated transitions.</p> <p>Social workers mentor and teach patients and families necessary self-care skills for collaborative transition planning and transfer of care.</p>	<b>Work</b> <p>Social workers assess readiness to work issues and their effects on Social Security benefits and other entitlement programs.</p> <p>Social workers can help an individual identify his/her strengths and challenges in finding employment, and provide them with information about their rights in the workplace.</p>	<b>Self-Awareness Promotion for Youth</b> <p>Social workers' awareness of the developmental stages within the adolescent allows them to guide the medical team on how to and when to offer a sense of self as a separate individual with rights to privacy that help to empower the youth and promote a trusting patient/provider relationship.</p> <p>Social workers have skills in assessing maturity, health literacy level, and socio-emotional functioning in order to help the medical team in determining when a patient is capable to receiving and process individualized and detailed information.</p>

Developmental Framework	Resource Facilitation	Patient/Provider Relationships
	<p><b>Finances</b></p> <p>Social workers assist families with navigating entitlement systems while supporting the emotional implications behind receiving benefits.</p> <p>Social workers help identify the logistical and emotional concerns of the young adult and family and help facilitate a discussion around issues of financial security and money management.</p>	<p><b>Cultural Competence</b></p> <p>Social workers recognize that diversity has a broader meaning, to include the socio cultural experiences of people of different genders, social classes, religious and spiritual beliefs, sexual orientations, ages, and physical and mental abilities—all factors that are relevant to the formulation of a tailored and realistic transition plan.</p>
	<p><b>Medical Care</b></p> <p>Social workers help interpret psychosocial information to the medical team to achieve better communication understanding.</p> <p>Social workers assist in identifying specific family needs and have knowledge of the health care system, insurance programs, and other health related benefits.</p> <p>Social workers help empower families to organize pertinent medical information and increase self-advocacy skills to better facilitate positive connection to adult providers.</p>	<p><b>Termination</b></p> <p>Social worker can help guide a very well-structured termination process that feels as settled and comfortable for the family as possible and facilitate a successful launching into a new phase of development and care.</p>
	<p><b>Guardianship</b></p> <p>Social workers guide families through the guardianship process by identifying state-specific protocols and appropriate agencies and referring to local resources for the evaluation of the person's capabilities.</p> <p>Social worker provide anticipatory guidance to families and providers and facilitate access to resources requires to ensure a through, ethical, and socioemotionally sound process.</p>	<p><b>Systems Issues</b></p> <p>Social workers are commonly the professionals who coordinate collaboration with multiple health care collaterals during the transition process, including courts, schools, employers, and insurance companies.</p>

*Adapted from Shanske et al 2012*



## PROVIDER TIMELINE AND CHECKLIST

The goal of this checklist is to assist pediatric providers in the process of transitioning by presenting actions steps in a timeline format. Please note, not all action stapes may be applicable or appropriate, and should be tailored to the individual needs of each young adult and his/her family.

Provider Action	Age 14 or before	Age 16 or before	Age 18 or before	Age 21 or before
Encourage youth to assume increasing responsibility for his/her healthcare management				
Meet with youth privately for portion of visit				
Address questions to youth and allow him/her to answer first				
Assure youth understands his/her condition and medical treatment				
Allow youth to practice decision-making skills by offering choices				
Encourage youth's increase use of self-care skills				
Promote youth's self-advocacy skills				
Assess youth's ability to determine if medical condition is worsening				
Discuss youth's/family's plan for medical emergencies				
Initiate discussion regarding the transition to adult health care with youth/family				
Create a Medical Transition Plan with youth and family, and update annually				
Identify possible adult health care providers				
Encourage youth/family to meet and interview potential adult health care providers				
Discuss confidentiality and consent with youth/family				
Discuss youth's/family's plans related to guardianship				
Discuss youth's/family's plan for adult health care coverage				
Prepare Portable Medical Summary				
Acknowledge emotional aspects of transitioning				
Complete transfer of medical records				
Be available for youth/family and adult providers after transfer if additional support is needed				







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