

# Navigating Healthcare Transitions: Pediatric to Adult Medical Care

*For Parents and Caregivers*



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Cornelia de Lange Syndrome Foundation  
302 West Main Street, #100  
Avon, CT, 06001  
[www.CdLSusa.org](http://www.CdLSusa.org)



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Core Clinical Advisory Board (CAB), CdLS Foundation

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Dayla Culp

Grace Dixon

Amy Franco

Tami Hamblen

Lorrie Keammerer

Lynnette Miller

Diane Neary

Juanita Parkhill

Donna Rodgers

Emily Turner

Sandra Turner

Debbie Walks

Angie Young

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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. 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 healthcare and the continuation of comprehensive services.

The goal of this guide is to provide parents or caretakers and young adults with the tools they need to understand the healthcare transition process to prepare for what lies ahead. This guide contains information from multiple sources including other transition guides, research articles, and tips from family members who have gone through the process themselves.

As you read through this guide, keep in mind that all of the suggestions may not apply to your child/family. CdLS is not a “one-size-fits-all” condition – everyone’s experience with the transition process will be unique and specific to the young adult and his/her family. However, having a general idea of the medical transition process may make the experience less daunting.

1.



# HEALTHCARE TRANSITION PLANNING

## WHAT IS HEALTHCARE TRANSITION PLANNING?

Healthcare Transition Planning is the purposeful, planned movement of young adults from a child-centered to an adult-oriented healthcare system (Antosh et. al., 2013).

The goal of transitioning from pediatric to adult healthcare services is to maximize lifelong functioning and potential through the provisions of high quality, developmentally appropriate healthcare services – services remain uninterrupted as the individual moves from adolescence to adulthood (Institute of Medicine US Committee on Disability in America, 2007).

It should also be noted: a smooth transition does not result from the mere physical pediatric to adult healthcare transfer, but rather the consideration and incorporation of the young adult's physical, psychological, and social development (Crowley, Wolfe, and McKee, 2011).

## WHAT TO EXPECT AS A PARENT OR CARETAKER

The transition from pediatric to adult healthcare is a critical stage of life for all individuals involved. This time period can present many factors that can drastically change the daily lives of both the young adult and their family. As a result, the transition period may be an especially stressful time. As a parent or caretaker, it is important to consider using all available tools and resources to make the transition successful and to minimize potential stress (Neece, Kraemer and Blacher, 2009).

For some parents or caretakers of young adults with CdLS who have severe intellectual disabilities, little change may occur in the care-taking tasks as the child grows into an adult. However, both legal and changing medical needs in adulthood will require parents or caretakers to assume new responsibilities as the young adult begins the healthcare transition process.

In addition to the healthcare transfer, some parents or caretakers may also take part in changes such as moving youth to adult daycare facilities, or moving out of the home to a group home environment or other residential care (Bindels-de Heus, 2013). Collaboration with the young adult, the family, the service provider(s), and the community will be beneficial in creating meaningful outcomes for all who are involved in any transition.

## CdLS FOUNDATION'S RESOURCES FOR A SMOOTH TRANSITION

Get in touch with one of our volunteers:

- **Regional Coordinators:** Parents or caretakers who volunteer welcome new families into the Foundation, provide information about resources in their state, and offer emotional support
- **The Education Resource:** Parents or caretakers who volunteer to serve as a support to other parents with concerns about their child's educational experience
- **The Transitional Resource:** Parents or caretakers who volunteer to serve as a support to other parents or caretakers planning a transition to adulthood healthcare

Other ways to obtain support:

- **Connect with Families Service:** Utilize the Foundation's "Connect with Families" service to get in touch with other families who have gone through/are going through the transition process for feedback and support
- **Family Gatherings:** Attend "Family Gatherings" in your state and use the opportunity to discuss transitioning with other parents/caretakers, especially ones who have already gone through the process
- **Family Service Coordinators:** Contact a "Family Service Coordinator" at the Foundation for additional support, feedback, and resources
- **Social Media:** Consider connecting with other CdLS families on various social media sites and ask them for recommendations and tips for smooth transition

CdLS Website: [www.CdLSusa.org](http://www.CdLSusa.org)

*"Speaking with other parents helped me to know what was out there."*

– Debbie W.



2.



# WHEN TO BEGIN HEALTHCARE TRANSITION PLANNING?

## START EARLY

Although healthcare transition planning should be flexible and specific to the young adult's needs, it is recommended that the process of healthcare transitioning should begin no later than 14 years of age (Gorter, 2009). It has been found that the conversation about transitioning to an adult healthcare model can be initiated as early as 12 years of age (Got Transition, 2014).

Since transitioning is considered a process and not a single event, it is important that the young adult and his/her family are prepared well in advance, and have all the necessary tools and skills needed to make the process a positive experience (Gorter, 2009).

*“We really started thinking about transition when Emily hit puberty; she had some complications and was referred to a reproductive endocrinologist. That’s when I started thinking that we might need to begin transitioning to more “adult” doctors.”*

– Sandra T.

## THINGS TO CONSIDER AT ANY AGE

- Is my child eligible for Supplemental Security Income (SSI)?
- Is my child receiving service coordination services (case management) through the Medicaid Waiver?
- Is my child involved in recreational/leisurely activities?
- Are medical needs being addressed?

It's also important to have copies available of the following documents at any given time:

- Birth certificate
- Social Security card
- Immigration papers
- Medical records, including immunization record
- Latest IEP and psychological report

*Adapted from Deverux (2015)*

## TRANSITION TIMELINE

| Age 14 or Before  | Age 16   | Age 18   | Age 21  |
|---|--|--|---|
| Initiate conversation about the healthcare transition plan with pediatric provider(s) and your child  | Continue to promote your child's self-advocacy skills, as applicable   | Legal documents for guardianship, power of attorney and/or medical directives should be in place   | Transition to adult healthcare provider(s) should be complete unless special provisions are made                                  |
| Work with pediatric provider(s) to create a Healthcare Transition Plan/Plan of Care that is to be kept in your child's medical chart and updated annually | IEP needs to include a "Transitioning Section," which should include healthcare transition goals and be updated yearly<br><br>Healthcare Transition Plan/Plan of Care continues to be updated with medical provider at least once a year | Reapply for Social Security benefits and other entitlements<br><br>(see pg. 42 for details)        | Prepare and make plans for when the last year of entitlement to Special Education Services through public schools comes to an end |
| School conducts first IEP-Transition Meeting  | Gather information regarding how to file for guardianship in your state  | Finalize healthcare coverage as an adult   |   |
| Assess your child's skills and work on enhancing self-advocacy, as applicable   | Identify adult health care provider(s)   | Adult medical home should be identified and put in place, unless other arrangements have been made |   |
|   | Investigate SSDI/SSI eligibility requirements for adults<br><br>Look into opening a trust fund for your child prior age 18   | Acquire an identification card for your young adult through the local Motor Vehicle Department     |   |
|   | Explore options for healthcare coverage  | Develop Portable Medical Summary Portfolio   |   |
|   | Explore alternative living arrangements and/or transportation, if applicable   |  |   |

*Adapted from Wisconsin Community of Practice on Transition (2014) and Children's Special Health Care Services Transition Timeline for Youth and Families (2005)*



3.



# OVERVIEW OF TRANSITION PLANS

As you continue reading this guide, you will find information on both the Healthcare Transition Plan and the Individualized Education Program (IEP) Transition Plan. These are two separate plans and both have importance and value. Below you will find a breakdown of each plan:

| IEP Transition Plan   | Healthcare Transition Plan  |
|---|---|
| <ul style="list-style-type: none"> <li>• Plan is focused on the transition to adulthood and encompasses all areas of transitioning such as education, employment, housing, financial, healthcare, etc.</li> <li>• Per IDEA, it is the law to include a transition plan in your child's IEP by age 16</li> <li>• Planning should be initiated by age 14</li> <li>• Plan is created with educational professionals, child, parents/caretakers, and anyone else who plays a part in child's transition to adulthood</li> <li>• Plan is updated annually</li> </ul> | <ul style="list-style-type: none"> <li>• Plan is focused on goals specific to the transition to adult healthcare</li> <li>• A written healthcare transition plan is not required by law</li> <li>• Planning should be initiated by age 12-14</li> <li>• Plan is created with pediatrician, parent/caretaker, and child</li> <li>• The original copy is kept in child's medical chart</li> <li>• Plan is updated at least annually</li> <li>• Having a written plan keeps young adult, parent/caretaker, and pediatrician/medical professionals on task throughout the healthcare transition planning phase</li> </ul> |

## THE FOUR STEPS TO CREATING A HEALTHCARE TRANSITION PLAN

*Adapted from Cooley et al, (2011)*

### STEP 1 ASK YOUR PEDIATRICIAN ABOUT THE OFFICE TRANSITION POLICY

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

- The expected age of patient transfer to an adult healthcare model
- The patient's responsibilities in preparing for the transition
- The parent or caretaker responsibilities in preparing for the transition
- The medical provider's responsibilities in preparing for transition

## **STEP 2**

### **INITIATE A JOINTLY DEVELOPED HEALTHCARE TRANSITION PLAN**

The pediatric primary care provider should initiate the Healthcare Transition Plan by age 12-14. If this is not the case, the young adult and parent or caretaker will need to address this topic with their provider(s) at the appropriate time. Once the discussion occurs, the next plan of action should be focused on creating a written plan, sometimes also known as a Plan of Care.

A formal Healthcare Transition Plan should be kept in the patient's chart for review during future office visits. The plan should include:

- Documentation of the young adult's current readiness/capabilities to assume a greater role in self-management of his/her healthcare
- May include a completed readiness and/or skill assessment tool showing areas of strengths and weakness on which patient education and skill building can be focused
- Documentation of the steps to be conducted by young adult, parent or caretaker, and provider(s) in order to achieve a successful healthcare transition
- Documentation of transmittal of information between young adult, parent or caretaker, and provider(s)

## **STEP 3**

### **REVIEW AND UPDATE HEALTHCARE TRANSITION PLAN**

The plan should be reviewed and updated with the young adult, parent or caretaker, and provider(s) at least annually. This will help promote the recognition by the young adult, parent or caretaker, and provider(s) of successes and/or deficits in readiness preparation for transition to the adult healthcare model. It may also be appropriate to re-prioritize goals and/or re-evaluate the existing plan with respect to changes in the youth's medical status, and/or parent or caretaker concerns. Additionally, as the young adult reaches age 16-17 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 appropriately.

## **STEP 4**

### **IMPLEMENT ADULT HEALTHCARE MODEL**

Before the implementation of the adult healthcare model, the young adult, parent or caretaker, and pediatric provider(s) should jointly prepare a Portable Medical Summary and a Healthcare Transition Plan that should be delivered to both the patient and the new adult provider(s). All medical records should also be delivered to the adult provider prior to the transfer, along with all the other items found in the Transfer of Healthcare Checklist below. It is also very common for the pediatric provider(s) to make themselves available to the adult provider(s) as a resource for any needed information or assistance during the immediate post transfer period.

## TRANSFER OF HEALTHCARE CHECKLIST

- Transfer letter (including date of transfer to adult provider)
- Final transition readiness assessment
- Healthcare Transition Plan and Plan of Care (including transition goals and pending actions)
- Updated Portable Medical Summary
- Guardianship or healthy proxy documents, if needed
- Medical records

*Adapted from Got Transition (2014)*

## WHAT IS A PORTABLE MEDICAL SUMMARY?

A Portable Medical Summary is written information about a patient's health history to help medical professionals quickly learn more about the patient. Portfolios can be used to describe chronic health conditions or disabilities with both words and photos, to tell medical professionals how the patient best communicates, what supports the patient needs, and more (Brown, 2013).

A Portable Medical Summary can include:

- CdLS informational material (e.g. Medical Treatment Guidelines)
- Impact of CdLS and how it affects the young adult
- Diagnoses
- Medications, including what they do, duration of prescriptions, side effects, who prescribes them, and which pharmacy to get them from
- Allergies
- Dietary restrictions
- Seizure information, including what kind, how long they last, how often they occur, how to keep safe during a seizure, and how to help 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 manage the young adult's health
- Communication strategies
- Emergency Care Plan

*Adapted from Got Transition (2014)*

*“One thing that has helped me is keeping a notebook with Emily’s medical records, growth charts, IEP’s, and business card from all of her specialists. I take it with me when visiting a new doctor that way I have all the information at my fingertips.”*

– Sandra T.

## IEP TRANSITION PLAN

Health-related goals should be included in the young adult's Individualized Education Program (IEP). A transition plan is required for students enrolled in special education who have an IEP, and goals specific to the healthcare transition should be included (Stanberry, 2010).

According to the Individuals with Disabilities Education Act (IDEA), an IEP must include a transition section by age 16. Healthcare transition planning should be addressed as early as age 14. All transition planning meetings should include the student, family members, teachers, and other school staff. Parents or caretakers are the most important players in the transition planning process because they know the young adult best and can advocate for the young adult's best interest, goals and wishes, especially if the young adult is unable to vocalize these themselves.

Below you will find a list of possible skills that should be considered in an IEP's Transitional Section, especially in regards to the medical transition.

- Communication skills
- Self-awareness
- Self-advocacy
- Activities of daily living
- Safety
- Vision/hearing
- Nutrition and fitness
- Recreation and socialization
- Transportation
- Legal and financial issues
- Managing medical care
- Locating adult health care providers
- Establishing a medical home
- Insurance and care coordination
- Managing appointments
- Managing medications
- Managing medical equipment and treatments
- Managing medical information

*Adapted from Wisconsin Community Practice on Transition (2014)*



4.



# HELPFUL TOOLS FOR HEALTHCARE TRANSITION PLANNING

## IDENTIFYING ALL PLAYERS

The best place to begin when creating a Healthcare Transition Plan is to identify all key players in a young adult's current medical team or medical home.

It may be worth noting the common misconception of whom and what a medical home entails. A medical home is not one specific place, but rather a healthcare model for the delivery of accessible, continuous, comprehensive, person- family-centered, compassionate, and culturally sensitive healthcare services (American Academy of Pediatrics, 2002).

The medical home is a partnership between the patient, family, and primary healthcare provider in cooperation with specialists and support from the community (U.S Department of Health and Human Services, 2015). Given geographic location and availability of services, not all families will be able to achieve the same type of medical home for their child.

*“We live in a rural area with virtually no services for Matthew. Our medical transition has been difficult due to this.”*

– Dayla C.

Side note: Why is an adult medical home important?

Young adults with chronic conditions and disabilities who have an adult medical home are better able to take care of their healthcare needs and are more likely to pursue opportunities related to education, employment, and independent living, as well as participate more fully in the community (U.S. Department of Health and Human Services, 2015).

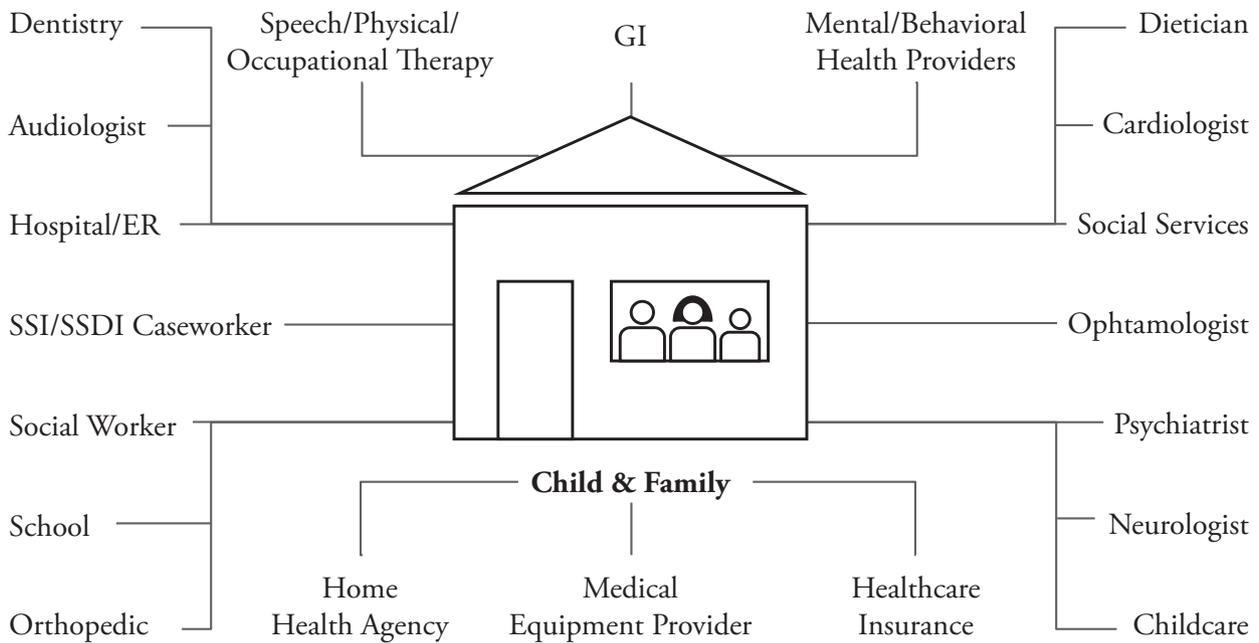
In addition, people with chronic medical conditions or disabilities are at risk of developing other serious health problems known as secondary conditions. Receiving up-to-date medical care and preventive services as part of the medical home is crucial in preventing secondary conditions that could greatly impact the individual's quality of life (Gorter, Stewart and Woodbury-Smith, 2011).

Side note: What does person-family-centered care entail?

- The person and their family are informed
- The person and their family choose services and supports
- The person and their family choose and attain their goals
- The person and their family exercise their rights

When the person and their family receive care that is focused on relationship-building, is responsive to families' strengths and needs, families' cultural context for realizing health and illness, and the necessity for long-term continuity of care, it forms and nurtures relationships between the provider(s), families, and the patient that bring about mutual trust (Duke and Scal, 2011).

Below you will find an example of what an adult medical home may encompass. This can help you identify who is in your child's current medical home to start planning for the healthcare transition process, searching for adult provider(s) and establishing the adult medical home. Please note this is not an exhaustive list.



## TIPS FOR FINDING AN ADULT PROVIDER(S)

Successful healthcare transitioning requires the identification of an adult healthcare model. Once the young adult and parent or caretaker select an adult provider(s) (usually with the help or guidance of the pediatrician), it is the pediatrician's responsibility to ensure proper communication of all medical needs to the receiving provider(s). This is a critical step in the transition process, as the adult healthcare personnel may be unfamiliar with any pediatric conditions.

- Ask current doctor for a referral
- Consider current adult providers used by family/friends
- Call insurance company
- Check with local support groups
- Call large medical and specialty rehab hospitals to ask for referral line
- Ask case manager for suggestions
- Ask adults who have similar health needs for recommendations
- Call a "Family Service Coordinator" at the CdLS Foundation for resources

*Adapted from UIC-Division of Specialized Care for Children and Families and the Illinois Chapter, American Academy of Pediatrics*

*"The most important piece of advice I have is to find doctors that you trust, doctors that you know will take good care of your child. If you don't trust the doctor you are with you have to keep searching."*

– Tami H.

## SEEKING SUPPORT FROM SOCIAL WORKERS

Given that the healthcare transition from pediatric to adult healthcare has many moving parts, having someone on your team with the knowledge and understanding of these "processes" may relieve some confusion and stress.

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 healthcare (Carvalho, 2012).

Where to find a social worker

- Schools
- Hospitals
- Medical offices
- Community agencies
- State programs
- Current or former social worker

Social workers can:

- Mentor and teach young adult and family the self-care skills necessary for transition planning
- Assist in identifying young adult's and family's areas of strengths and challenges
- Provide information and about education laws
- Assist in navigating entitlement programs
- Advocate on behalf the young adult and family
- Provide resources and referrals to appropriate programs and organizations
- Provide young adult and family with emotional support
- Coordinate collaboration with other professionals who are part of the transition process (e.g. courts, schools, insurances, medical professionals)

## CULTURE AND TRANSITION PLANNING

Culture involves a number of elements, including personal identification, language, thoughts, communications, actions, customs, beliefs, values, and institutions that are often specific to ethnic, racial, religious, geographic, or social groups. As a result, culture plays an important role in defining the values, beliefs, and practices surrounding when and how young adults transition into adulthood (National Institutes of Health, 2015).

Some transition polices, practices, and services may assume that all young adults with disabilities or special healthcare needs value similar outcomes (Antosh et al, 2013). It is important to incorporate cultural values in transitional planning because it will help create goals and objectives that are meaningful.



5.



# HOW TO INVOLVE YOUR CHILD IN THE HEALTHCARE TRANSITION PLANNING?

## DISCUSSING TRANSITION PLANNING WITH A YOUNG ADULT

As mentioned earlier, ages 12-14 appear to be an appropriate time to begin discussing healthcare transition planning. However, age alone may not always be the appropriate factor in determining the time and/or extent to which the young adult will be involved in the discussion about healthcare transition planning. 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 the young adult with information, support, and opportunities for making choices will help them be an active participant in the process.

Parent or caretakers should determine the extent of the young adult's capabilities in the following areas:

- Judgment and reasoning skills
- Understanding of their medical condition(s) and treatment
- Ability participate in medical visits
- Self-care skills, including the ability to fill prescriptions, follow prevention, and treatment regimens, and seek assistance in an emergency
- Self-advocacy skills
- Medical status and stability (Institute of Medicine US Committee on Disability in America, 2007)

## INCREASING YOUR CHILD'S SKILLS

Skills such as self-advocacy, self-determination, and autonomy play an important role in the transition process. Teaching these skills will 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 developmental level may be, every young adult should have the opportunity to make choices and take control of their life in a way that is appropriate for them because this provides an opportunity for growth and learning (Autism Speaks, 2011).

Ways to increase your child's skills:

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

- Encourage your child to speak for themselves
- Help your child to interact with health care providers
- Encourage your child to participate in organized activities that build social skills and confidence
- Give your child the opportunity to make mistakes
- Provide your child with an opportunity to find their own solutions to problems

*Adapted from Stewart et. al., 2009*

## SELF-ADVOCACY

Self-advocacy or “having your own voice” is an important skill because it allows a young adult to communicate to others who they are, what they like and don’t like, and gives them the ability to exercise choice and control. It is important to emphasize that having a voice does not necessarily mean having a literal voice. People who are non-verbal are able to communicate themselves - their likes and dislikes, their wants and needs - in ways other than words (Downer and Owen, 2002).

## SELF-DETERMINATION

Self-determination is a process in which a person chooses how to live life consistent with their own personal choices and preferences. Some individuals with CdLS who have severe intellectual disabilities may have cognitive limitations to independently make quality of life decisions. In these circumstances, they may need to rely on a variety of supports such as their parents or caretakers who know them well, are concerned with their best interests, and are willing to work with the person on enhancing their quality of life in order to actualize self-determination (Kim and Turnbull, 2004).

## AUTONOMY

Autonomy refers to a person’s ability to think, feel, and make decisions on their own. Young adults develop autonomy when challenged with a new level of self-reliance, which increases their sense of self-governance, responsibility, independence, and decision-making (Russel and Bakken, 2002). In the context of CdLS, this goal is valuable but should be open to interpretation. Due to the wide range of symptoms associated with CdLS, autonomy goals may look different for each young adult. Young adults and families may benefit more from identifying the skills needed for functioning in the medical care process rather than total autonomy or independence (Carvalho et al, 2012).

## HELPFUL TIP

Look in the appendix section of this guide to find the “Assessment Tool for Parents and Caretakers,” which will help you identify your child’s areas of strengths and challenges in terms of skills needed for healthcare transitioning. You will also find a similar version of the assessment tool for your child. If he/she is able to utilize the tool, compare your child’s self-assessment to your assessment of them to better understand which areas require more attention.

*“Sometimes things don’t go as planned but you have to speak up for your child and their needs.”*

– Donna R.

6.



# HEALTHCARE TRANSITIONING

## TRANSITIONAL BARRIERS

The healthcare transition process is complex because it requires ongoing coordinated involvement from multiple players. In order to be best prepared for this process familiarizing yourself with potential barriers may help you avoid hurdles along the way. Below you will find examples of possible barriers that can impact some of the key players in the transition process.

**Young Adult.** Young adults - particularly young people with complex conditions, have spent years with the same pediatric care team - may perceive the transition process as abandonment, and may 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 a young adult, especially if the adult healthcare 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 Provider.** Physicians who care for adults may have had little training for many childhood-onset conditions and may have little experience working with young adults with disabilities and their parents. Many could be sub-specialists 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)*

*“I think one of the hardest things was finding good dental care for Ben when he became an adult. A lot of it was trial and errors until we found someone who took good care of Ben and met all his special needs.”*

– Lorrie K.

## TERMINATING WITH PEDIATRIC PROVIDER(S)

The ultimate transfer of care, as well as the gradual and ongoing discussion in anticipation for the transition, may evoke feelings of abandonment, anger, and grief for both the young adult and parent or caretaker. Families may relive the initial diagnostic experience and its implications (Carvalho, 2012).

It is important to give attention to and create an opportunity for saying goodbye. It may be helpful to set aside time during the last visit for therapeutic closure, as well as share how the patient and family can reconnect with the pediatrician and how to update the pediatric team on the young adult's progress (Schlucter, 2014).

## COMMUNICATION TIPS FOR MEETING WITH NEW PROVIDER(S)

- Ask provider(s) about their background/experience
- Request a long enough appointment
- Allow the young adult to tell the doctor everything about themselves, what they do and how they feel (if appropriate)
- Provide additional information about the young adult (if needed)
- Bring a list of questions
- Be honest and open
- Be assertive/express the young adult's needs
- Take notes

*Adapted from Porter, Freeman and Griffin, 2000*

*“Don't be afraid to “interview” doctors and try them out. Change if you aren't happy!”*

–Sandra T.

## EDUCATING ADULT PROVIDER(S) ABOUT CdLS

Some adult provider(s) may lack training or experience with childhood-onset and congenital medical conditions. CdLS is not only a genetic condition present from birth but it is also rare, increasing the odds that a provider(s) may not be familiar with its symptoms and treatment management.

Parents or caretakers need to take an active role in providing adult provider(s) with information about CdLS, and how it impacts the patient. It is crucial that adult provider(s) receive medical records, as well as consult with the pediatric provider(s) to obtain information necessary to understand the patient's medical needs.

Parents or caretakers are encouraged to reach out to the CdLS Foundation or visit the CdLS website to obtain CdLS materials for the adult provider(s) who will be taking over the young adult's care.

## ADAPTING TO NEW SERVICES

Meeting with the adult provider(s) for the first time may evoke anxiety for both the parent or caretaker and the young adult. Individuals with CdLS are likely to experience anxiety, communication frustrations, and social confusion (all possible scenarios that can take place during a doctor's visit) in situations that cause a change to daily routine.

Below you will find tips and strategies to ease possible anxieties related to meeting with a new provider(s). Some suggestions may need to be adjusted to fit the specific needs of the young adult.

- **Quiet Days:** If your schedule is flexible, request a day and time that is quieter. This will be less overwhelming, especially in the waiting room.
- **Get the Details:** Find out exactly what will happen at the appointment so that you can come prepared.
- **Give the Details:** Speak with the provider ahead of time and provide information that will help make the visit less stressful for your child.
- **Do Paperwork in Advance:** If there is any paperwork that you need to complete, find out if the forms could be sent to you first, so you can complete them at home.
- **Practice:** Practice what will happen during the doctor's appointment. Use dolls or role-play with a toy doctor's kit to help your child anticipate what is happening.
- **Stay Calm:** Consider doing a relaxing activity prior to the appointment.
- **Bring Reinforcements:** Bring a friend or relative with you to the appointment if you need to talk with the doctor and your child has a difficult time sitting for long periods of time.
- **Fidget Toys:** Bring fidget toys or small comfort objects so your child has something to do in the waiting room. These toys can also provide some comfort or distraction when the doctor is completing his/her exam or while you are talking to the doctor.
- **Provide Demonstrations:** If your doctor is comfortable, have him/her explain and demonstrate what they are about to do, on themselves or you first.
- **Expect the Unexpected:** Be prepared for events such as parking issues, the doctor running late, or changes in appointment procedures.
- **Get help from professionals:** They can provide suggestions about the types of questions to ask, as well as reports or other developmental information that is important for the doctor to know.

*“Parents need to know that the world of adult medicine is very different from pediatrics. You don't seem to get the same level of interest, concern, and accessibility with adult doctors.”*

– Angie Y.

## LOSS AND GRIEF

Loss and grief are difficult subjects for us all. However, young adults with CdLS may have an especially difficult time with adjustment to loss. As your child transitions to adult medical care he/she may experience multiple layers of loss as they are introduced to a new provider(s).

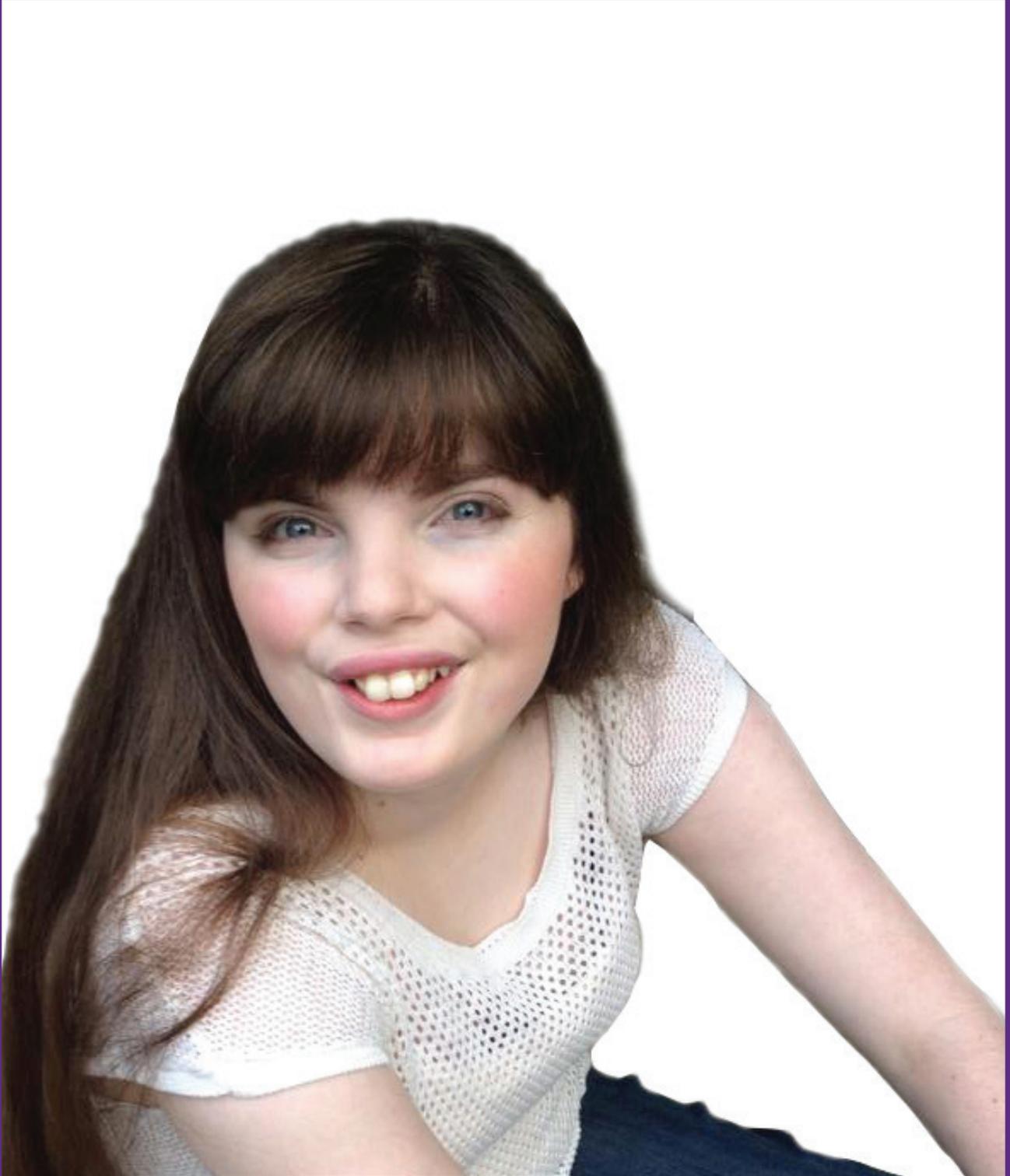
Your child may respond to loss in many different ways. This can include somatic complaints, relationship difficulties, social withdrawal, increased compulsivity, intensified frustration, and self-injurious actions. When young adults with CdLS or other developmental disabilities experience disruption in their lives such as a loss associated with transition, symptoms of increased anger, confusion, compulsivity, and ritualization are patterns that may be seen in daily activities.

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

When dealing with events related to loss and grief, it is important to recognize that young adults with CdLS experience grief and that having limited communication skills does not mean that they are unaffected by loss, but rather will express grief in distinct ways (Sormanti and Ballan, 2011).



7.



# FINANCIAL AND LEGAL ASPECTS OF HEALTHCARE TRANSITIONING

As the young adult transitions to adult healthcare, it is crucial to research all options for covering medical expenses. As mentioned earlier, connecting with community resources and/or professionals who have knowledge and expertise in this arena may be very helpful.

## INSURANCE OPTIONS

### MEDICAID

### MEDICARE

### PRIVATE INSURANCE

- Through employment
- Through college
- Staying on parent's plan
- Purchasing individual health plan

### OTHER

It is possible that an individual may have more than one health plan in place at a given time.

## OVERVIEW OF MEDICAID AND MEDICARE

**Medicaid** – A state run medical assistance program for certain individuals and families with low incomes and resources. Medicaid eligibility is limited to individuals who fall into specific categories. Although the federal government establishes general guidelines for the program, the Medicaid program eligibility requirements are actually established by each state. In addition to paying for some medical services and prescriptions, Medicaid may also pay for residential facilities, workshops, and other programs. This program has asset limitations similar to the SSI limitations. Check with your state or local social services agency to see if your child qualifies. SSI recipients automatically qualify for Medicaid in most states.

**Medicare** – A federal health insurance program for people 65 years of age or older, certain younger people with disabilities, and people with End-Stage Renal Disease (permanent kidney failure with dialysis or a transplant). Medicare does not cover everything, and it does not pay the total cost for most services or supplies that are covered.

Medicare has four different parts:

**Part A**, which covers hospital, skilled nursing facility, hospice, and home healthcare costs. Most people do not have to pay a monthly premium for Part A.

**Part B**, which covers doctor and other healthcare provider services and supplies (e.g. wheelchairs and walkers) considered medically necessary to treat a disease or condition. Most people pay a monthly premium for Part B.

**Part C**, which are also called Medicare Advantage plans. These are health plan options run by private insurance companies and approved by Medicare.

**Part D**, which helps cover the cost of prescription drugs.

For More Information: <http://www.medicare.gov>.

*Adapted from Protected Tomorrows (2015)*

*“They (pediatric providers) tell me they have doctors to send us to but I have heard horror stories of no one taking Medicaid. Miranda will stay on our insurance for as long as possible so that will help us in any transitions.”*

– Dianne N.

## OVERVIEW OF SSI AND SSDI

**SSI – Supplemental Security Income.** A federal income supplement program funded by general tax revenues (not Social Security taxes). Its purpose is to help the aged, blind, and disabled who have little or no income. It provides a maximum of \$733 per month in 2015 to be used for basic needs such as food, clothing, and shelter. It is generally for people who have little or no work history. An SSI applicant must limit their assets in order to qualify for this benefit. Basically, the allowable assets for a person applying for SSI are a home, one car, a pre-paid funeral, and \$2,000. Of course, understanding what is considered an asset is important, as well as which is the appropriate asset for your family member to own.

Once your child turns 18, you must re-apply for SSI benefits. The SSI benefits eligibility criteria are different for children and adults with disabilities, and SSI benefits are not automatically rolled over once the child turns 18. If your child is receiving SSI benefits, contact their current caseworker and ask about the adult eligibility criteria, as well as how and when you need to begin the adult re-determination process.

**SSDI – Social Security Disability Insurance.** An SSDI is a federal cash benefit program that may be available if a person is disabled. It pays benefits to the individual and certain members of the individual’s family if you are “insured,” meaning you have worked long enough and have paid Social Security taxes. Each insured individual should receive a statement from Social

Security explaining their status of eligibility. Social Security statements can also be obtained from <http://www.ssa.gov/mystatement>.

*Adapted from Protected Tomorrows (2015)*

*“Parents need to know that when a child moves to a group home or medical facility he/she may need to reapply for benefits. When Devin moved to a group home his eligibility for SSI benefits changed because he was no longer receiving kinship support.”*

–Lynnette M.

## GUARDIANSHIP

Not all young adults with CdLS will be able to make all decisions even if they had opportunities for decision-making skill building throughout their life. In certain situations additional support such as guardianship will be required, especially in the domain of medical decisions.

Guardianship is the legal process by which an individual assumes the role of decision-maker for an adult who is unable/or becomes unable to make such decisions for himself/herself.

### IMPORTANT TERMS TO KNOW

**Guardian ad Litem (GaL)** - A independent professional appointed by the court to express whether or not a guardianship is in the best interest of the respondent. In a case where the guardian ad litem disagrees with the respondent, the respondent should be appointed a separate attorney that will advocate on behalf of the respondent.

**Petition** - A formal document requesting the court to make a finding or adjudication.

**Petitioner** - Person who brought the matter (or petition) to court.

**Respondent** - The person who is the subject of the petition.

Guardianship can take several forms:

**Guardianship of the Person**, wherein decisions are limited to those affecting the person of the individual with disabilities, such as medical treatment decisions;

**Guardianship of the Estate**, wherein the guardian is responsible for managing the estate of the individual with disabilities. “Guardianship of the Estate” is required when a person with disabilities has significant assets, or in cases where an inheritance or other monetary windfall is anticipated;

## **Guardianship of the Person and Estate;** or,

**Limited Guardian of the Person, Estate or both**, in cases where the individual with disabilities is determined by the court to retain some capacity for rational decision-making.

**The process of obtaining guardianship is governed by the laws of each state.** Generally, the individual seeking guardianship must:

- File a petition for guardianship of the person with disabilities (the “Respondent”), nominating either themselves or another qualified person or entity to act as guardian;
- Arrange for personal service of the petition, the “Rights of the Respondent” and a summons on the Respondent. Service is usually performed either by the sheriff of the county in which the petition is filed, or by private service (in some jurisdictions, private service requires court approval) and must be accomplished a specific number of days prior to the hearing date;
- Provide notice by mail to the Respondent’s nearest relatives; and
- Obtain a medical report from a licensed physician detailing the reason guardianship is necessary or an investigation performed by a Guardian ad Litem.

A Guardian ad Litem may be appointed by the court in cases where the Respondent cannot, or will not, appear for personal examination by the court. The Guardian ad Litem performs an independent investigation of the facts in the case and reports to the court. After the requirements listed above have been satisfied, a hearing is then held, the evidence is presented, and the court issues a ruling.

*Adapted from Doucet (2015)*

*“I always carry proof of guardianship paperwork with me whenever going to medical appointments with Devin because they always ask for it, especially before any procedures. Some medical facilities are able to scan the paperwork and have it on file, which makes life so much easier.”*

–Lynette M.

## **SPECIAL NEEDS TRUST**

A special needs trust is a tool in the healthcare planning process that provides above and beyond the basic living needs and can maximize the benefits that the young adult receives. Having a knowledgeable special needs planner and estate attorney is an invaluable asset the parent or caretaker and the young adult. It is important to set up an appointment with a planner to discuss next steps as soon as possible.

What is a special needs trust? It is a vehicle that holds assets that are beneficial to the young adult. It is also an instruction manual for how to handle assets. It answers the question of who is in charge and if there are limits to how the young adult’s money is used. It can be set up by anyone except for the beneficiary, and it can be used for supplemental care for your child. The

beneficiary of the special needs trust cannot be changed. However, the trust can and should be amendable if the laws change.

How do you fund a special needs trust? There are three primary ways that a trust can be funded: inheritance, savings on the young adult's behalf and child support. Be sure to speak with a financial professional prior to funding a trust to learn about any potential tax consequences. Remember, anything that comes to the young adult directly may disqualify him/her from benefits and programs.

*Adapted from Protected Tomorrows (2015) and Got Transition (2012)*

*“The more research a parent can do and the earlier, the easier the (guardianship) process will be. Becoming a guardian is a must if the child is not able to make their own decisions. If a parent does not do this, the state will. Families need to tap into other families in their state for resource and information. Shop around for attorneys. A special needs trust is also a must, so the child does not risk losing all of their funding and benefits.”*

– Angie Y.

8.



## SECTION FOR THE YOUNG ADULT

You are reading this guide because you are at a very important milestone in your life: the transition to adult healthcare. Becoming an adult may make you feel many different emotions such as excitement, anxiety, or fear. The goal of this guide is to help you prepare and plan ahead for the transition process and hopefully ease some of your worries.

### WHY DO I NEED AN ADULT DOCTOR?

As you get older, your medical care needs may change. Pediatric doctors are trained to take care of children's medical care needs. Once you reach adulthood, or are between the ages of 18-21, your pediatric doctor may no longer be able to take care of all of your medical care needs and you will need to begin seeing an adult doctor.

*"I plan on going to adult doctors on my own or with a friend if it's just a regular check-up. If I have a serious problem or a medical issue I will ask my mom to come with me."*

– Grace D.

### WHAT IS THE DIFFERENCE BETWEEN PEDIATRIC AND ADULT HEALTHCARE?

| Pediatric Healthcare   | Adult Healthcare  |
|--|---|
| Parents are in charge of making medical decisions for you  | You are in charge of making your own medical decisions  |
| Doctor will talk to your parents about your medical care   | Doctor will talk to you about your medical care   |
| Parents schedule your appointments   | You schedule your own appointments  |
| Parents provide you transportation to your medical appointments                                      | You are responsible for transportation to your medical appointments   |
| The doctor's office may be colorful and have toys and games  | The doctor's office may not be as colorful and fun  |
| If you are under 18, parents need to give permission for your medical care and treatment             | If you are over the age of 18, you must give permission for parents to be in the exam room, see test results, and talk to your doctor about your medical care |
| Your relationship with the doctor may be strong because you have known him/her since you were a baby | It may take some time before you build a relationship with your adult doctor  |
| Parents advocate for you   | You advocate for yourself   |

*Adapted from the CSHCN (2011)*

## HOW CAN I PREPARE FOR THE HEALTHCARE TRANSITION?

The best way to prepare for the transition to adult healthcare is to work on learning new skills needed to take care of you.

In the Appendix section of this guide you will find a worksheet titled “Healthcare Skills Assessment Tool for Youth.” Take some time to read through the worksheet and think about the different skills listed. As you read each skill think about if 1) I can do this on my own, 2) I need some help with this, or 3) I don’t know how to do this or don’t feel comfortable doing this. By completing this worksheet, you will learn what skills you are really good at and which skills might need some extra practice or help with from a parents or caretaker. If you are unsure if you are able to do a certain skills ask your parent or caretaker for help.

## PRACTICE, PRACTICE, PRACTICE!

If you want to learn new skills and feel comfortable using them you must practice. Below are a few ideas on things you can practice with your parents, caretakers, or other adults in your life.

- Practice describing your medical conditions
- Practice asking questions you want to ask your doctor
- Practice what you will say when you call the doctor’s office to make an appointment
- Practice describing how your body feels
- Practice the names of your medications, and describe how and when you take each
- Practice what you will say when you call the pharmacy to refill or pick up your prescription

## IMPORTANT THINGS TO REMEMBER

Remember that you should always ask questions when you don’t understand something. If you don’t know what the doctor, nurse, or secretary is saying to you, you can always say, “I don’t understand what you mean. Can you please explain this to me again?”

If you don’t feel comfortable going to the doctor’s office alone, you have the right to decide who you want to go with you as an adult. You may find it helpful bringing someone you trust to your appointment. This person can take down notes during the appointment and help you process all the information once you leave the doctor’s office. Being at the doctor’s office can sometimes feel overwhelming since you are given a lot of information in a very short period of time. Having a “buddy” with you who can give you support will make going to the doctor less stressful.

Medical information and the terminology doctors sometimes use can sound very complicated and confusing. You should never have to feel like you are alone or that you might be making the wrong decisions because you don’t understand something. It is important that you tell the doctor when you don’t feel comfortable or don’t understand something. As an adult, you

must speak up for yourself and tell others what you need. You have the right to ask parents, caretakers, or other trusted adults in your life to help you with making medical decisions.

It is also really important that you know whom you can turn to for additional help. Connecting with your community can be a great way to learn new skills and meet new people who you can turn to for help. If you are not sure where to begin, you can call the CdLS Foundation to find a supportive network.

*“When I went to see a new doctor I felt a little nervous because I did not know what to expect. Having my mom go with me for the first visit was helpful. My mom answered questions I did not know the answers to.”*

– Emily T.

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# APPENDIX

## HEALTHCARE SKILLS ASSESSMENT TOOL FOR PARENTS/CAREGIVERS

| Skill  | Performs Independently | Needs Some Assistance | Needs Full Support | Comments |
|--|------------------------|-----------------------|--------------------|----------|
| Describe medical condition(s)                  |                        |                       |                    |          |
| Communicate his/her needs                      |                        |                       |                    |          |
| Ask and answer questions                       |                        |                       |                    |          |
| Advocate for self                              |                        |                       |                    |          |
| Perform daily medical care                     |                        |                       |                    |          |
| Make medical appointments                      |                        |                       |                    |          |
| Arrange transportation to appointments         |                        |                       |                    |          |
| Give consent to medical care                   |                        |                       |                    |          |
| Understand insurance coverage                  |                        |                       |                    |          |
| Obtain regular medical/dental check-ups        |                        |                       |                    |          |
| Administer medication(s)                       |                        |                       |                    |          |
| Refill medication(s)                           |                        |                       |                    |          |
| Understand side effects of medication(s)       |                        |                       |                    |          |
| Share knowledge of allergy information         |                        |                       |                    |          |
| Determine if medical condition(s) is worsening |                        |                       |                    |          |
| Understand a medical emergency plan            |                        |                       |                    |          |
| Follow an emergency plan                       |                        |                       |                    |          |

## HEALTHCARE SKILLS ASSESSMENT TOOL FOR YOUTH

| Skill   | I can do this on my own | I need some help with this | I don't know how to do this | Comments |
|---|-------------------------|----------------------------|-----------------------------|----------|
| I can describe my medical condition                                   |                         |                            |                             |          |
| I feel comfortable asking questions                                   |                         |                            |                             |          |
| I know how to answer questions  |                         |                            |                             |          |
| I know how to contact my doctor                                       |                         |                            |                             |          |
| I know how to take care of my medical condition                       |                         |                            |                             |          |
| I can schedule an appointment with my doctor                          |                         |                            |                             |          |
| I can find a way to get to my appointments                            |                         |                            |                             |          |
| I can take my medication on my own                                    |                         |                            |                             |          |
| I know how to refill my medication                                    |                         |                            |                             |          |
| I know when I have a medical emergency and need to go to the hospital |                         |                            |                             |          |
| I know if I have allergies  |                         |                            |                             |          |
| I know the names of all the medications I take                        |                         |                            |                             |          |
| I know the names of all my doctors                                    |                         |                            |                             |          |
| I know the name of my insurance plan                                  |                         |                            |                             |          |
| I can write down questions for my doctor                              |                         |                            |                             |          |
| I know that medications can have side effects                         |                         |                            |                             |          |
| I know what to do if I have side effects from medications             |                         |                            |                             |          |

## 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 |                  |                  |                  |                  |



## 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 |
|-------------------|--------------------|---------|--------------------|-------------|---------------|
|                   |                    |         |                    |             |               |

|                       |       |                     |       |                             |       |
|-----------------------|-------|---------------------|-------|-----------------------------|-------|
| Initial Date of Plan: | _____ | Last Updated:       | _____ | Parent/Caregiver Signature: | _____ |
| Clinician Signature:  | _____ | Care Staff Contact: | _____ | Care Staff Phone:           | _____ |









Cornelia de Lange Syndrome Foundation  
[www.CdLSusa.org](http://www.CdLSusa.org)