WE LISTEN TO YOU

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THE KEY TO INDEPENDENCE

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WORDS OF WISDOM

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A SPECIAL EDITION OF *REACHING OUT* FOR OLDER INDIVIDUALS WITH CdLS AND THEIR FAMILIES

The Path Forward

EDITION #1

CdLS Foundation
Cornelia de Lange Syndrome Foundation, Inc.

INTRODUCTION

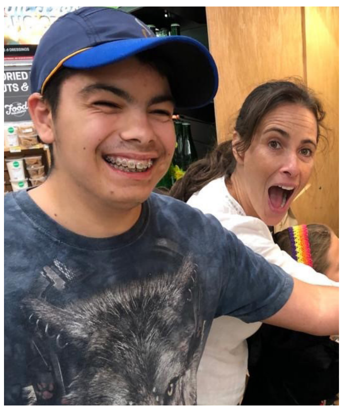
Navigating the Road Ahead

Through advances in research, treatment and understanding of CdLS, our children are often living longer and fuller lives than ever before. In fact, 50% of the families the CdLS Foundation serve have a son or daughter who is age 14 and older. Your family is one of them, which is why we're sending you our new newsletter, *The Path Forward.*

We understand that adolescence and adulthood are times of major change for you and your child —what we call "transitioning." In fact, your child and family have already have gone through many transitions over the years, from early intervention, pre-school, school and then now on to adult life. This also is a time of change for you as a parent. Your role transitions from being your young child's provider and manager to one of supervisor or counselor to your adult son or daughter.

The Path Forward was created to help you jumpstart the planning process for transitioning from adolescence into adulthood. It's for everyone—whether you're just starting out or you're well on your way to helping your child develop independence as an adult.

This issue will give you an overview of the challenges and opportunities to consider as you move forward. It includes information about useful tools and resources that will help you plan for tomorrow. In these pages, you'll also hear from parents just like you who share their experiences, triumphs and insights they've gained from helping their children transition from child to teen and teen to adult.



WELCOME TO THE PATH FORWARD

We Listen to You

To better understand how we can best support you as your child reaches these important milestones, the Foundation recently emailed a survey to parents/guardians of individuals with CdLS who are age 14 or older.

We gained many valuable insights from this survey, including learning that over 85% of parents/guardians that responded reported that it is "extremely important" or "highly important" that the Foundation expands our support to individuals and families as they transition into adulthood. Survey respondents also had the opportunity to tell us about challenges they face as their child becomes a teenager or adult: *"Services completely change as our kids transition into adulthood. I felt like I was starting all over again as I did when my daughter was an infant/toddler."*

To review all the results from this important survey, please visit our website at www.CdLSusa.org.

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What You Told us About Your Needs in our Survey

"Help us figure out how to have an adult child become as independent as possible to survive beyond their parents passing and live a full life."

"Guidance on steps required to apply for guardianship, social security, medical assistance."

"Provide easy access guidance on what to possibly expect medically and provide webinars regarding aging topics, such as changes in personality and moods as (our children) age, health issues that statistically arise and at what age."

"Knowing you are there with information is a huge relief. Being a storehouse of good, up-to-date information would be #1."

85%

of parents/guardians that responded reported that it is "extremely important" or "highly important" that the Foundation expands our support to individuals and families as they transition into adulthood.

A Great Journey Begins with Good Planning

We understand that parents in our CdLS community are in different stages of life and planning. The good news is, it's never too early — or late — to begin!

While it may sound a bit intimidating at first, planning for your child's future is key to reaching precious goals and dreams for a fulfilled life. Good planning gives you all-important peace of mind. It also gives your family a valuable roadmap that can be amended and adjusted over time. And please remember, you're not alone! Hundreds of families are dealing with many of the same struggles and issues you're experiencing — and many of them have discovered effective ways to support their maturing child that they can share with you. This newsletter features just a few of many stories and families that are part of your circle of support. As always, the CdLS Foundation staff is here to help connect you to our wide-ranging community, along with providing expert information, insight, and compassionate support.

The CdLS Foundation has a vast library of publications including the comprehensive, 60-page *A Guide to Adult Transition*. You can get your free copy just by contacting anyone in Family Service. This Guide provides in-depth information on what we call the "six core areas" to prepare your child to successfully transition into the adult world.

THE PATH FORWARD

The Six Core Areas of Transition

EDUCATION

SOCIALIZATION

MEDICAL TRANSITION
(from pediatric to adult medical care)

LEGAL ISSUES & GUARDIANSHIP

LIVING ARRANGEMENTS

RESOURCES

In this edition of *The Path Forward*, we'll give you a snapshot of these different core areas and highlight why each is so important for a secure future for your loved one.

LEGAL ISSUES & GUARDIANSHIPS

Mapping out your child's educational plan

It's important to be aware that there is a specific timetable of important milestones to be accomplished at specific ages, once your child goes on to high school.

Here are just a few of them:

- At age 14 or entering high school, create a Transition Plan as part of the IEP process and review this every year with your child's school.
- Look at graduation options since graduation can vary by state - anywhere from 18-22 years of age.
- Identify and explore areas of interest to your child that can help guide what life after high school will look like. For instance, identify life skills, job opportunities such as training, work programs, job coaching, additional education, various Day Programs, etc.
- Research other options open to you, by contacting Adult Services Programs in your area.

A Guide to Adult Transition provides a wealth of detailed information on the educational and training component of your plan for your child's future.

SOCIALIZATION

Enjoying an Enriching Life

No one knows your child as well as you do. You've learned what they enjoy, their challenges, their interests and how to engage them in various activities. Discuss these at the IEP meeting (or with teachers, other parents, school social worker) and find out what social opportunities the school provides, such as a Best Buddies Program.

Or, tap into local special needs groups for social activity options including Special Olympics. Local programs such as dance studios, music lessons, various sports and art studios that often offer classes specifically designed for people with disabilities.

Another good option is connecting with other parents who have children with special needs who may know of other opportunities for social participation, such as horseback riding, swim classes, etc. Be aware that these may be supported by a state waiver program or other government services.

In addition, be aware that if your child is receiving any government services, there is a case worker assigned to your child and this person can be a great help planning for your child's future.

LEGAL ISSUES & GUARDIANSHIPS

The Key to Independence

Before your child reaches the age of

18

MEDICAL

From Pediatric to Adult Healthcare Services

The transition from pediatric to adult healthcare is a critical stage of life for everyone involved. This time period can present many challenges that can drastically change the daily life of both a young adult and their family. The medical goal of your plan is to maximize your child's lifelong functioning and potential by coordinating high quality, developmentally appropriate healthcare services. It's also critical that these all-important healthcare services remain uninterrupted as the individual moves from adolescence to adulthood

Here are a few steps to a seamless transition:

1. Between ages 12 and 14, ask your pediatrician about the office transition policy
2. Initiate a jointly developed a Healthcare Transition Plan
3. Review and update the Healthcare Transition Plan as needed
4. Implement an Adult Healthcare Model by creating a Portable Medical Summary

The Guide to Adult Transition also provides information in great detail on a wide variety of physical and behavioral healthcare issues, such as puberty and sexuality. These important insights give parents and physicians a better understanding of what to expect and how to better manage the different stages of a maturing individual with CdLS.

Healthcare Transition Questions To Think About:

Have I identified all the key players in the process?

Have you begun to discuss the transition with your child?

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?

Have I identified transition barriers?

establishing a legal guardianship is often necessary so that the family members continue to have a vote in decisions on essential matters including medical care or where the individual with CdLS will reside.

If guardianship isn't already in place by age 18 and your child needs medical/government supports, etc., she/he will likely be asked to prove they have a guardian. If you can't provide the right paperwork, you may not have any say or be able to implement services/supports.

At the age of maturity, other legal issues typically arise such as whether the adult child with CdLS will continue to be covered under parents' medical plans. In addition, various benefits, like Medicaid and Social Security Insurance (SSI) may become available to the adult child at this time. Many decisions have to be made at this juncture, so establishing a guardianship for your adult child is extremely important.

During this legal proceeding, someone (usually a family member) asks the court to determine that a person is unable to manage his or her affairs effectively because of a disability. A guardian steps into the shoes of the person with a disability and makes the decisions for them.

There are a number of different types of guardianships and laws that govern them, and these can vary from state to state. Prior to seeking guardianship in your state, be sure to check the applicable laws and/or consult with an attorney specializing in guardianship issues. You can also access informative articles on the CdLS Foundation website, such as Planning for the Future for Your Loved One with CdLS, authored by Beth Dixon, District Court Judge and former CdLS Foundation Board Member. You'll find this helpful article at: bit.ly/cdlsfuture

There are also other Internet sites such as: www.ProtectedTomorrows.com that offer webinars covering many of the topics discussed in this publication, exclusive access to valuable resources, including an interactive planning tool that guides you through a holistic, step-by-step approach to planning.

You can also consult the Special Needs Alliance (SNA) that is in all states for guidance on legal issues for people with special needs. SNA is a national organization of attorneys that specialize in the practice of disability and public benefits law. Individuals with disabilities, their families and their advisors rely on the SNA to connect them with nearby attorneys who focus their practices in the disability law arena.

LIVING ARRANGEMENTS

Feeling Right at Home

Just as you would do for a typical child, as your son or daughter with CdLS moves into adulthood, it's a natural time to consider a more independent lifestyle for him or her. And this may involve living at home with greater independence or moving away from home and living more on their own. The goal is to have your child be in a happy,

appropriate and safe environment –– one that you as a family feel comfortable with.

A few examples of different types of living arrangements include:

- Living with parents or family members
- Group homes/ supportive housing
- Assisted living facilities/ skilled nursing facilities
- Trust ownership of a home/ beneficiary
- Independent living

So how do you select the right living option for your loved one?

First, do your research and get involved with your community. If you're able, do this while your child is young. Get familiar with your community so that you can see what options are available in your area as far as living arrangements. Also, take time to see what other families with children similar to yours have done.

Second, consider all your options and make a plan with your family about the future. It may be hard to think about, but planning for where your child will live when you're older is an important step in caring for them and their future.

Next, decide which type of living arrangement is best for your child's level of functioning and their daily needs. Start the process toward finding a place nearby so you can easily visit your child and still be a large part of her/his life.

Then, look into what insurance will cover and plan the payment of the living arrangement. A lot of this payment may be covered depending on the state you live in.

Finally, make a decision for your family and move your child into their new living environment. Or, if your child is remaining at home, decide what other aspects of their lifestyle can be altered to provide them with more independence under your roof.

RESOURCES

Government Services & Supports

The good news about your child wanting more independence as they get mature is that there are so many resources available to you and your adult child.

However, be mindful that these resources and benefits vary state by state. That's why it's so important that you do your research and find out what is available to help support your child.

Here are a few steps that will help you find services and resource where you live:

STEP 1

Do your research, find out what is available in your state and in your community. SSI/ SSDI covers quite a bit and is available everywhere, so it is well worth your time to investigate all the options that may be offered. For example, If you are of retirement age, your child may be eligible for one-half of your Social Security income amount to be paid to them separately. Make sure you check with the Social Security Administration or a financial advisor. More information can be found on the site: bit.ly/CdLSbenefits

STEP 2

Look at other resources in your state, find out what other families are utilizing in your area specifically. Places like ARC are available in most states and can be a huge resource that will help with activities and pay for things for your child in some cases.

STEP 3

Call each of the places that you've found and ask what paperwork is needed and verify that you qualify and set up the application. This sometimes can be a process and take some time, but it's worth it.

STEP 4

Check to see for how long benefits last and when re-approval dates are so that you can make sure benefits won't lapse. Utilize these benefits and make sure to check the age requirements and find out if things change in your state after your child turns 18. If that is the case, reapply for this as soon as possible so that your child is always covered.

On *The Path Forward* Together

You and your family are transitioning into a new phase of life — and so are we. All of us at the CdLS Foundation are absolutely committed to helping you, your transitioning child and family have the best life possible. We see this as a challenging yet exciting new chapter in your life story as well as ours.

This newsletter is just a start. Finding more ways to help you navigate, plan and make good choices for your child as she/he transitions into and through adulthood is a major focus of the CdLS Foundation today.

If you'd like more information, please contact the CdLS Foundation for your free copy of our recently updated The Guide to Adult Transition. And please, do not hesitate to reach out to Family Service or directly to me with your thoughts, questions and ideas about how we can best serve our rapidly growing adult community.

Individuals with CdLS are living longer. Our hopes and possibilities are rising. And everyone at the Foundation is dedicated to meeting the moment. As our maturing community continues to expand, the CdLS Foundation will continue to walk The Path Forward alongside you — every step of the way!

Bonnie Royster

Bonnie Royster
Executive Director
CdLS Foundation

A last thought…

One step the CdLS Foundation believes is very important is to document your child's life. Think of all the things you've filed away in your head that are specific to your child—from the very small to those things that may be complex.

Write down what makes your child so special in a notebook, journal or whatever works for you. This "instruction book" is useful now and it will be there to inform others about your wonderful child, if you can't be there someday.

While this may seem like just one more things to do, in the long run, it's well worth the effort!

WORDS OF WISDOM

Amy Loftus and son, Eric (Age 24)

NORTH CAROLINA

As Eric, now age 24, approached adulthood, Amy Loftus and her family thought long and hard about the decisions they would make to support Eric's future independence. Amy reports that Eric is more severe than many individuals with CdLS, is self-fed, walks but is non-verbal, is in diapers and has serve SIB. He also loved the daily routine of school and once he graduated, the family was not sure what would they do for a routine. Due to Eric's behaviors they struggled with finding a day program that was a good fit and staff who can manage and deal with his behaviors.

"Initially, we set up an apartment for Eric with a 24-hour companion. When the companion decided to get married and had to leave the position, we realized that the impermanence of this situation over time would be a problem for Eric. We then turned to finding a group home that would also enable Eric to roam when he wanted to and most importantly, to create friendships with other residents.

Amy and her family researched and tried different living options before selecting a group home environment that meets Eric's needs and where he is happy. The journey the family took to get there has informed Amy with many insights that she is happy to share with other parents just starting out

Amy remarks, "The first thing I'd recommend is before you start looking at group homes, is to make a list of all the things that are important about your child: their needs, likes, dislikes and so on. Then, when you're visiting homes, listen to your gut. A place can look perfect but not be right for your child. Also, keep in mind though that there is no such thing as a "perfect" place; but only make compromises that your comfortable with. Trust yourself.

"Also, it's NEVER too early to start looking. The earlier you begin, the better your understanding will be of what's available and what's right for your child. And—this is really important— the more comfortable you'll be when the time comes. Letting go of your daily caregiving responsibilities in some ways can be very difficult. The rest of your family can feel this too, and they need time to process and adjust to the new situation.

"Today Eric, like all other young adults, wanted and now has more independence and lives where he wants to be. He recognizes the difference between his family who loves him and the friends that he has his own relationships with. We are hopeful that this will be a long-term solution but if anything changes, we understand that the plan can change as well.

"Frankly, it's hard to make the decision to have your child move out and live away from you. But it's also a time for you as a caregiver to have a break and some of your own independence back. If you make these decisions early and carefully, everyone can benefit."

WORDS OF WISDOM

Beth Dixon and daughter, Grace (Age 25)

NORTH CAROLINA

After high school, Beth and Glenn Dixon's daughter Grace very much wanted to continue her education. A major factor in making Grace's dream come true was their discovery of the University of North Carolina's program, Beyond Academics

"This remarkable program enabled Grace to live independently both on- and off-campus. It's a 4-year Certificate program, rather than a standard college degree program, and it's specially designed for individuals with development disabilities and special needs. Students learn both professional and life skills they need to live more independent lives. For example, the program taught Grace about personal finances and how to use public transportation plus gave her a wide variety of job skills, since the aim of the program is for graduates to become employed.

"When Grace was diagnosed 25 years ago, we had no idea something like this would ever be possible. We never though she would be able to have this kind of educational experience, and live on her own. She consults with us on many issues but she is living her own life, on her terms, which we are thrilled about.

"Programs like Beyond Academics are offered through over 200 colleges and universities throughout the country. You can go to the website ThinkCollege. Net and find information about where these programs are and how to prepare your child for them.

"One thing to prepare yourself for is letting go, if and when the time is right for your child to move out. You know we're all 'mama bears' when it comes to our kids! After Grace went to UNC, we learned that she would get in touch with us when she needed us and we had to stop hovering. And while Grace has gained independence, so have I. I am a judge and a mother of four and now have more time for these aspects of my life.

"So don't let your fear stand in the way of your child's advancements. Let them spread their wings in the way that's right for them."

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WORDS OF WISDOM

Mary Levis and son, Josh (Age 38)

DELAWARE

Mary Levis and her late husband, Lee, were both psychologists who were familiar with the social and educational systems for people with special needs. Yet, when their own son, Josh, began transitioning into adolescence and then adulthood, they both were challenged by "the system" to find services and support.

"Transition is such an important time for your child and family, but it's not aways easy," Mary says candidly. "The social services system varies not just state by state but often county by county — and it changes all the time. You really have to get in there and be persistent to be sure your child's special needs get met. A good first step is writing down the goals your child and you have about their future. Even if some of the goals seem a bit aspirational, keep the door open. You can always scale back your plan if you need to. But you may be surprised how much farther your child can go. We certainly were!"

"Josh finished high school and wanted to go to college like his siblings. We applied for a scholarship to Community College through the Division of Rehabilitative Services (DORS) and we were thrilled he received a $15,000 grant. However, the workload was more than he could handle. But the good news was that he could apply this grant to start a small business—which was his dream all along. Josh took a small business course, wrote a business plan and made a presentation. He was granted to use the $15,000 scholarship money to start up his online business that sells tee-shirts, hats, sweatshirts with a skateboard theme (skateboarding is big here in Ocean City!) Over time, with the money from his business (and his ongoing job as a short order cook at a local restaurant) Josh was able to purchase a condo where he now lives independently. He consults with us and we are always here for him. But our son has come farther than we ever dreamed 30 years ago."

"Every child is different, of course, and each has their own challenges. But the best advice I can give another parent is to help your child believe in themselves. When other people would sometimes stare at Josh or say unkind things, my son would always say, 'That's their problem, not mine.' Of all the things Josh has achieved so far, this belief in himself is his greatest achievement."

WORDS OF WISDOM

Priscilla Amor and daughter, Carolina (Age 24)

FLORIDA

Priscilla and her husband Fernando are devoted parents to Carolina, who has no language and needs constant care from them. Yet they were shocked to find out that before their beloved daughter turned 18, they would have to be declared legal guardians for her.

"I was attending a Family Gathering around the time Carolina was 14," recalls Priscilla, "and someone there informed me that we would have to be named as legal guardians by the time our daughter would be considered a legal adult. I simply had no idea! I also learned that the time to start this process was way before Carolina's 18th birthday. In fact, it was time to start immediately.

"We decided to consult with a lawyer because the process can be quite involved. If you cannot afford a lawyer, there are many pro bono legal aid services that can help. And, make sure this guardianship is established well before your child's 18th birthday as it takes some time to do all this and you will run into problems if you wait until after they turn 18. We also set up a trust for Carolina and I was glad we had expert advice.

"Another eye-opener concerned the Medical Waiver process that enables you to access programs and services for your child. Our family has been fortunate enough to be financially secure, and our attitude was always if we can pay for a service we will, and this will enable someone with fewer means to get support they need. I learned this was not the best way forward for this reason: If something were to happen to me and my husband, the trust would only go so far. If our daughter required access to services down the road, she must already be registered in the social and healthcare benefits system. Again, the sooner you do this, the better.

"A few years ago, I had to deal with some health issues and had to be hospitalized for a while. We knew then that we needed to find the right place for our daughter outside the home. After a couple of trys, we found a group home that works well for her. I am so glad we didn't wait to get this in place. Because we made this decision before something happened to us, we could ensure that Carolina is living in a good place. We are able to bring her home often for visits and she knows we are always here for her.

"In short, the best thing I can say to any parent, is to think about and plan for your child's future today — even though they may still be very young. It's never too early to start making sure that your precious child will be taken care of even if you cannot be here.

CdLS is:

RESILIENT

SMALL HEAD

CAPTIVATING

EYEBROWS THAT MEET

ENGAGING

LONG EYELASHES

LOVELY

SHORT UPTURNED NOSE

CHARMING

THIN DOWNTURNED LIPS

GRACEFUL

SMALL HANDS + MISSING ARMS, FOREARMS OR FINGERS

THE ANATOMY OF CORNELIA de LANGE SYNDROME

The Cornelia de Lange Syndrome (CdLS) Foundation provides a host of services for anyone touched by this little-known genetic syndrome and other isolating conditions.

Learn more about us, visit: **cdlsusa.org**

CdLS Foundation
Cornelia de Lange Syndrome Foundation, Inc.