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

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# The Path Forward



**CdLS Foundation**

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## INTRODUCTION

Welcome to

# *The Path Forward*

Through advances in research, treatment and education, individuals with CdLS are often living longer and fuller lives than ever before. In fact, 50% of the families the CdLS Foundation serves have a son or daughter who is age 14 or older.


We understand that adolescence and adulthood are times of major change for you and your loved one — what we call “transitioning”. In fact, your loved one may have already gone through many transitions over the years, from early intervention, preschool, school and now on to adult life. This also is a time of change for you as a parent/caregiver. Your role transitions from being your young loved one’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.

To better understand how we can best support you as your child reaches these important milestones, the Foundation 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 only 27% of respondents reported that “Residential Options” is a critical aspect to successfully leading life as an adult with CdLS. However, after the first issue of *The Path Forward*, the number went up to 47%. Feedback we received included: “Providing information about housing options in the community from state to state is important.” As well as, “Older parents with their child with CdLS still living at home [need resources] to keep [their] child active in the community, assistance with caring for their child at home, etc.”

This issue will give you an overview of living arrangements for individuals with developmental disabilities. 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 making the decision of moving their child to a group home, keeping them at home and everything in between. We hope you enjoy the stories from community members just like you.

In this edition, we dive into the topic of  **Living Arrangements** and share stories from the CdLS community who have gone through the process.

Scan let us know what you think of this issue of *The Path Forward*.



THE PATH FORWARD

# The Six Core Areas of Transition



**EDUCATION**



**MEDICAL TRANSITION**  
(from pediatric to adult medical care)



**LIVING ARRANGEMENTS**



**SOCIALIZATION**



**LEGAL ISSUES & GUARDIANSHIP**



**RESOURCES**



Scan here to learn more  
about the six core areas of  
transition and other services  
on these topics.





# Head Over Heart Moving to a Group Home

BY BRIAN RUBIN, ESQ., RUBIN LAW, A PROFESSIONAL CORPORATION

Deciding whether or not an adult child with disabilities should move from the family home into a supported, community-based residence can be a wrenching experience. Aside from a desire for their loved one to live as fulfilling and independent a life as possible, mom and dad must plan for the time when they will no longer be around. Even if a brother or sister is willing to be an onsite caregiver, circumstances may change, and I have witnessed few sibling situations that played out as envisioned by the parents. It's likely that, at some point, an individual with significant disabilities will need to live in a professionally supported home, and making that transition while parents are alive will be easier for them.

## HOW WE HANDLED THE MOVE

My son Mitch, the oldest of my three kids, has severe autism, and shortly before his 22nd birthday, I approached the parents of one of his friends, suggesting that we look at residential options together. That way the guys would start out knowing at least one of their housemates.

We were fortunate and rather quickly found a place where Mitch could have his own room and a private bath, but as I began filling out paperwork, the emotion set in. I'd always thought he'd be the last—not the first—of my kids to leave home. It also turned out that he misunderstood the situation and believed that his new home was like the overnight camp he'd been attending for years. After a couple weeks, he expected to come back. When we'd drop him off at the residence following a visit home, he'd run after our car. This broke my heart, the tears flowed, and my wife and I began to have second thoughts.

So began a period during which he'd stay overnight with us twice each week. The residential staff tried to discourage this, saying we shouldn't get him used to a routine that his siblings would be unlikely to continue. But we persisted, reducing the visits to one per week, and eventually two or three times per month. The turning point came one night when he announced that he wanted to leave ahead of schedule. Perplexed, I called the residence and learned that everyone else was going to a party that night. He was building a life elsewhere and didn't want to miss out on the fun!

But the situation isn't perfect. Living in a group home is not the same as living with family members. Mitch's time is more scheduled than it would be otherwise. His caregivers change, which can be a problem for a person who craves consistency. When I notice a stain on the residence carpet or that his shirt is more frayed than it should be, I feel guilt. On the other hand, he has a fuller social life, and he's lost weight because the group home's staff is more nutrition-conscious than we are. Most importantly, I know that when his mom and I are gone, he'll be cared for in a familiar environment with support, as needed, by his caring brother and sister.

## TRANSITION TIPS

If your loved one has the capacity to participate in residential decision-making, identify friends who are currently living in group housing. Tour the homes, attend their social activities and, if possible, arrange for an overnight stay. Give your kid a chance to understand that this lifestyle offers new opportunities.

In preparation for your adult child's move, develop a version of your letter of intent for support staff. I actually created a page-long, bulleted list that his "staff" fixed to Mitch's door. On the back was more detailed information, as well as references to the full document. This shorthand version is especially important for staff members who are substituting for the regulars. It explains things like how to handle a meltdown and what words to avoid.

If your loved one rejects the idea of a group home, investigate other residential options. Are they capable of living on their own with scheduled visits from caregivers? Will a Medicaid waiver program cover such support? Sometimes condo-like housing is available, with onsite supervision, but alternatives vary greatly from state to state.

Any move will likely be difficult for the entire family. But keep reminding yourself that this increased independence is in your child's best interest. This is a situation in which a parent really must separate head from heart.





# Aging Research in CdLS

BY ANTONIE D. KLINE, M.D., CdLS FOUNDATION MEDICAL DIRECTOR

With advances in medical care and nutrition, along with early intervention therapy and ongoing physical activity, individuals with Cornelia de Lange Syndrome (CdLS) are living well into adulthood.

Through the generosity of the hospital where I work, Greater Baltimore Medical Center (GBMC), my growing team of health care providers and I have been focusing on assessments of adolescents and adults with CdLS. Since 2001, we have held multidisciplinary aging clinics, which have served over 160 individuals with CdLS and their families. Through these clinics and the efforts of the team, we have learned much about aging in CdLS.

It is probably most important to note what we have **not seen**. We have seen only a few people with hypertension, and some with high cholesterol or lipids, and often there was also a family history of these. There have only been two cases with heart failure, both treatable, and no one with a heart attack or sudden cardiac death. In the older patients, there have been two instances of cancer and several benign tumors, but no consistent types. This is difficult to sort out with other possible genetic influences unrelated to CdLS.

To put all of this into perspective, according to the Center for Disease Control in Atlanta, 29% of the population in the USA has hypertension and 2-3% has heart failure. Furthermore, according to the National Cancer Institute, 4.5% of all men and women develop cancer every year and 39.5% will be diagnosed with cancer at some point in their lives. Thus, our numbers for all of these in CdLS are relatively low, which is quite reassuring. **We have found that adults with CdLS are very strong, healthy and generally disease-free.**

We have noticed continued involvement of several specific body systems. **The gastrointestinal (GI) system is always one of the most commonly involved** through adulthood. Gastroesophageal reflux is present in nearly every individual with CdLS. If not, it should be assessed in the event that there is new onset abdominal pain, or a change in or worsening of behaviors. Some GI complications can occur in adulthood at an earlier age than in the general population. One such GI complication is Barrett's esophagus, a direct complication of untreated reflux. This has to be managed and treated because of a risk for becoming cancer. Bowel obstruction may occur during adulthood. All individuals with CdLS should have an upper GI series to rule out malrotation when they are younger. If malrotation is found, it should be surgically repaired.

The urinary tract and genitalia remain stable, and we have not seen adult kidney complications. Vision can worsen, like in everyone who ages, and if individuals with CdLS have been very near-sighted, they are at risk for retinal detachment as they age. Menopause in women appears to be at a typical age. Men can have prostate enlargement earlier than the general population. The bones can lose their density earlier than expected as well, and a bone density scan is recommended to assess in the 40's rather than older, as is recommended in the general population. We have noted 3.5% of our group having bone fractures, which are associated with decreased bone density.

The nervous system also has continued involvement. Seizures may occur in adults if they were present in childhood, and occasionally if they were not. Intellectual disability and autistic features will persist

into adulthood, but there is **continual learning of new tasks and skills** well into adulthood. In terms of psychiatric diagnoses, both depression and anxiety can develop, and several individuals will have decreased interest in outside activities and increased desire to stay at home. Behavioral problems persist as well, sometimes amenable to behavioral modification or other treatments; these include outbursts, aggression and self-injury, and often subside in the 20's and older.

For some people, the skin and face appear older than would be expected based on age. Hair tends to become grey at an earlier age than other family members. The oldest individual attending the clinic was 54 years old at the time, but we know a number of men and women in their 50's at this point. Causes of deaths have mainly been related to the GI tract, bowel obstruction, but also include respiratory causes, complications of anesthesia, and natural causes.

**Of all the individuals we have seen through the clinics, 93% are still living.** This gives us hope that continued research and education about CdLS allow this number to increase.



Scan QR Code to learn more about **Treatment Protocols** for Individuals with CdLS.





INSPIRATIONAL

CAPABLE

RESILIENT

STRONG

# On *The Path Forward* Together

Welcome to our second issue of *The Path Forward*. In the next pages, you will hear from parents as well as a few adults who have gone through the process of finding their homes. Each story is unique and offers insight, as well as guidance that can help you and your loved one with CdLS navigate this part of your journey.

There are many different options to consider when looking for appropriate living arrangements, including; living with parents or family members; group homes/supportive housing; assisted living facility/skilled nursing facilities; trust ownership of a home/beneficiary; and independent living.

Here are a few helpful tips for you to select the right living option for your loved one:

1. Do your research and get involved with your local community. Make friends with others in your community who have children with a developmental disability. Create a social circle for yourself and your child. Learn about available programs and services in your hometown or region. If you're able, do this while your child is young.
2. After considering all your options, decide which type of living arrangement is best for your child's level of functioning and their daily needs.
3. Learn what insurance will cover and plan the payment structure for the living arrangement you choose.
4. Importantly, share your plan for the future with your family and/or close friends.

As the CdLS Foundation grows older and individuals with CdLS live longer, it is our hope the resources provided here and parent stories deeply resonate with you. There is no one right answer. Just know there are many *paths forward*.

If you have thoughts or suggestions you would like to share on how we can best serve our rapidly growing adult population, please contact me at [Outreach@CdLSusa.org](mailto:Outreach@CdLSusa.org).

Warmly,



Bonnie Royster  
Executive Director

## A last thought...

At the CdLS Foundation, we not only care for the individual with CdLS, but for the entire family. Many times, parents and caregivers are burnt out and especially after the last year, you need to take a moment to yourself and regroup.

Taking care of yourself is essential. While putting yourself first for a few minutes a day may seem hard, it is crucial for the long run. Take a walk, go to bed early, read a funny book for 5-minutes. Your health is important...you are important.



## SUPPORTIVE HOUSING

# Susan Leone and son Frankie (Age 28)

NEW YORK



I started to think about adult options when Frankie was around 10 years old. I knew the transition would be hard knowing there is very limited space in a good adult residence. I was also very nervous about the world of appropriate day program options. Frankie does not have any behavioral issues at all. However, I believe it is in the individual's best interest to reside among peers. I knew Frankie would continue to grow and develop in the adult world if he did live in a community of like peers.

When Frankie was 20, we were contacted by the local Developmental Disabilities Services Offices (DDSO) office about considering placement for him and if so, it was time to act. At that time, Frankie was in a residential school placement (age 15-21) Frankie's IEP was sent out to different facilities that I thought I may like to tour and have him evaluated by. I do have a background in adult placement working in a Public Health community setting so I knew what I did not want for my child. I knew it would be difficult to find the appropriate placement for him too.

The process for him was seamless. We had about six different group home agencies contact the residential school - to complete this evaluation on Frankie - I was not impressed with some of the placements and I just crossed them off my list - all but one accepted him. I was looking for a placement close to my home where I can pop in and see him as often as I want.

Frankie is in the most amazing placement at this time. Mayor Frankie - resides in a co-ed home of a total of 8 individuals. He loves the staff and appears to tolerate the housemates. He was always much better with able individuals. Frankie does not really gravitate to his peers; he would rather hang out with the staff. There is nothing I would change if I had to do it all over again with his placement, except maybe open up my own group home for him and peers.

I recommend parents create a list of questions to have answered. I would concentrate on what you are looking for in the adult placement and also what you are not looking for.

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Frankie is in the most amazing placement at this time. Mayor Frankie - resides in a co-ed home of 8 total individuals.



## SUPPORTIVE HOUSING

# Jesse Bassett, Adult with CdLS (Age 34)

MINNESOTA



I started thinking about moving out on my own around the age of 18. Before that I lived in a group home, which I call my foster home, with other individuals with special needs. I knew that I didn't want to be in the foster home any longer and it took 15 years to get to the point of being ready to be "on my own". In my group home, the adults that lived there had more freedom and structure to do things they wanted to

do, they could attend events that were on the schedule or not.

However, there were issues that began with the foster care provider. The staff and provider were supposed to help the residents with life skills, such as budgeting or how to cook and they were not providing these services. There were also issues with new staff not being trained properly, not having appropriate staff to handle caseloads or not being qualified to work with the residents. There were even times when I was left alone for 8 hours a day because the foster care provider did not want to pay for an extra staff person.

All of these red flags, pushed me and my external care team to really look for alternative living arrangements. My guardians were fine with me looking for an apartment as long as there were staff onsite. My social worker began the search for me, but I was getting impatient because of the immense stress I was feeling living at the foster home. When my social worker wasn't getting any calls back from the apartment, I took the initiative to find one. Within a week, I had a new apartment.

The whole process was extremely stressful and the week of moving was really bad. I had lived in a room and was now going to a whole apartment – a very overwhelming experience. My old room was a mess, with holes in the walls that my guardians had to fix, not the best time of my life.

Now I have a great roommate and I am extremely comfortable in my home. I have even taken over the living room! My roommate doesn't mind, in fact he doesn't care what I do as long as I don't burn down the apartment. I enjoy rearranging the apartment when I feel like it. I am extremely thankful my team gave me the opportunity to do this. I am able to meet with my team to make sure I stay on track and that I am



managing to live "independently" and making wise decisions.

The apartment I live in has on site staff which I am able to receive services that include mental health, coping strategies, learning how be mindful, cope with what is going on internally, teach me

how to cook, budgeting and take me places in a set distances (5 miles)... many of the things that were lacking at my previous foster home. I also was set up with a homemaker through the county.

My social worker is great and was able to set me up with a companion and the first thing he is going to do with me is to teach me how to use my walk fit (treadmill) properly. My social worker also helps diffuse any issues so they do not escalate. I know I lack communication skills and this is where my social worker really helps.

My advice to any other adult with CdLS who wants to move out on their own would be, be patient. Be mindful that things are not always what they seem. People are here to help and make use of the resources around you. Always remember there are going to ups and down in life. You need to take one day at time when you are living on your own. If it sounds too good to be true it probably is.

# The Path Forward

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## SUPPORTIVE HOUSING/GROUP HOME

### Kari C-R and daughter Iselen (Age 28)

WASHINGTON



We started to think about the future for our daughter when she was 16 years old. At the time, we didn't know about housing options available in our community. The first impetus for planning for the future was when we attended a presentation about social security and guardianship.

Our daughter developed serious behavioral problems after she finished high school and the transition program. She didn't have structure to her day and my husband and I both were working. She became self-injurious, assaultive and destructive. We had requested a behavioral support professional to help us in our home. She was the first person to tell us our daughter needed to move out for our emotional health.

My husband, our daughter and I met the director and associate director of the agency. They were so welcoming and it was clear they felt passionate about their agency and the work they were doing. They suggested a certain house and described the living situation there. Two young adult women lived there with one-on-one support during the day and a person overnight. The model is called supported living. We met with the other young ladies, their families and some of the staff. Together it was decided that the household would be appropriate for our daughter. My daughter has been living with one housemate since she moved in which has been stabilizing for her.

The first few weeks were a nightmare. Our daughter did everything she could think of to get kicked out. The staff kept reassuring us that they had made a commitment to her and her safety. We realized she needed someone at the house to help her make the transition. We hired her high school teacher who had taken a leave from teaching. This was key to our daughter's success.

We are happy about where our daughter is living and the people who work with her. We appreciate what the staff do for our daughter and I feel like we are a team. We value them and try to let them know that often.

Our daughter has lived in the same house since she moved almost seven years ago. She doesn't live in the same city as we do and we travel to visit her twice a week. Every other week she comes to stay with us from Friday to Monday. We enjoy each other and can have fun together again. She continues to have challenges and her staff work from her behavior plan so they can all be consistent.

My advice for another family who is about to start the journey of transition is to give yourself love and care. The challenges can be overwhelming but the benefits for our loved ones and for us are important considerations.

The first step is to talk to your case manager about what you need. In many states, funding for housing is limited and is allocated based upon the urgency of the situation. It is hard to present our children in a negative light, but I encourage you to be open about what is going on. We had to get to a crisis point for our daughter to qualify and I wish we could have been proactive rather than reactive.

Find out what kinds of housing options are available and talk to the different agencies. When we were considering our daughter's agency, I asked to talk to other parents whose children were being served by that agency. It was helpful to talk to other parents and to hear about their experiences.

There is an agency in Washington State called Community Homes. The agency provides Adult Family Homes for adults with IDD. What is unique about this model is the choice aspect. The adults with IDD are not placed there. They choose to live with the other adults with IDD in a home that is appropriate for them.



## LIVING WITH PARENTS

# Sandra Turner and daughter Emily (Age 28)

ALABAMA



From the time Emily was young, my husband and I had conversations about Emily's future. We were told that college was not likely to be in her future, but I never wanted to limit Emily based on what others said to expect. Emily pushed herself to get an advanced academic diploma and started exploring college options as part of her high school transition. With our support and after visiting several different colleges,

Emily decided to attend a small private college about an hour from home. With the help of some great friends and dorm mom, Emily was successful living in the dormitory with other students. Her time at school solidified our beliefs that Emily could live somewhat independently, but would need support close by. Trying to find the right balance of independence and support has always been a challenge for us.

When Emily graduated from college our thoughts turned to "what next?". Although Emily was a college graduate, we knew she couldn't get a job that would provide full support for her. We were also faced with her aging out of our insurance coverage. Emily began working at a local retail store, but the stress of working caused her anxiety to increase substantially. For the first time in Emily's life, we applied for government support so we could help relieve some of her stress. After three years and appeals, Emily was approved for Social Security. This allowed us to keep her on our insurance. She quit her retail job and found a job working part time in a private preschool.

Throughout this time, we knew Emily needed to be pushed towards independent living. Her brother and sister had both moved out and started their own adult lives. We wanted Emily to have that same experience. We live on about an acre lot outside the city limits, so we began researching "tiny house" options. Emily was a part of this



process in every aspect. She knew she didn't have the confidence to live completely alone. She agreed that the tiny house option was best.

The process was easier than we thought. Because we live outside of city limits, we were able to purchase a pre-made 14x40 metal building and have it converted to a one bedroom "apartment". It is considered a portable building, so no permits were required. We had water and electricity run from our house and the bathroom was connected to our septic system. Emily has been able to do a lot of the inside work on her own. We had insulation and interior walls installed and a small air conditioner mounted. It has been the perfect blend of independence and oversight.

We hope this is just another step on Emily's road to complete independence. We are now looking towards Emily's living arrangements when her dad and I are gone. We will continue pushing Emily to step out of her comfort zone.

For other families considering transitional housing, I would say look outside of the box. There are grants available to help with building costs for special needs housing, you just have to be willing to do your research. Most importantly, let your child be a part of the process.



## INDEPENDENT LIVING

# Dianne Lessa and daughter Valerie (Age 41)

## MASSACHUSETTS

It was Valerie who expressed an interest in moving out on her own. I used to say she can't wait to get out of the house.

Valerie was about 24 when we started the process. We put her name on the list to receive a Section 8 housing voucher. The waiting list was quite long and I don't remember exactly how long we waited for her name to come up. But we finally got a call that they had a Massachusetts Housing Voucher available for her. We took that voucher. At that time, another



girl she knew also received one. We worked at getting one voucher for two people so they could share an apartment. They were both working with Minuteman Arc of West Concord, MA. Minuteman Arc is a national organization serving people with intellectual and developmental

disabilities. It was early in 2006 that we found an apartment for them which was in the town of West Concord.

Minuteman was going to have someone stay with them for a week to help them get used to living on their own. Although they already had the apartment, the person who was going to stay with them couldn't come right away. Valerie insisted that she was going to stay in the apartment alone. She was just too excited to be on her own that she couldn't wait. She did it. I have always told families with children with disabilities is to "expect a lot, but take what you get" meaning you won't know if they can do something if you don't let them try. She stayed the entire week all by herself and made out fine. They lived together for a year but it didn't work out so we had the voucher changed back to two separate ones and we found Valerie another apartment.

Since Valerie was going to be living alone, her Service Coordinator from

the Massachusetts Department of Developmental Disability wanted Valerie to meet with a psychologist. She remained in contact with this woman over the years. At one point, she introduced Valerie to another learning-disabled older woman named Joanne. They became good friends and Valerie would spend many weekends together. Somewhere around 2015 while my husband and I were in Florida, Valerie and Joanne started making plans to live together. There was another person from Minuteman Arc living in her building in a two-bedroom apartment. Valerie found out he was looking for a one bedroom and they started making arrangements to swap apartments.

They lived there for a few years when they found a new apartment building closer to town. Again, on their own, they spoke to the leasing manager of that building. They found out that they could use their Section 8 and luckily there was a two-bedroom apartment available the next month. They moved into the apartment in June of 2019 and there they remain.

Valerie pays all of the bills each month except for the rent which is automatically withdrawn from each of their bank accounts. Minuteman staff takes her to work, to appointments, food shopping and other things that need to be done.

If you are looking into an independent living arrangement, I would suggest that you work with an organization like Minuteman Arc. It was important to make Valerie independent and for the most part not reliant on me to do everything with her. **I will not be around forever and having Valerie learn to get along without me while I am still here is important.** This doesn't mean that I don't do anything with her or take her to appointments because I do. Minuteman is there taking care of a good part of what Valerie needs.

## INDEPENDENT LIVING

# Valerie Lessa, Adult with CdLS (Age 41)

## MASSACHUSETTS

I don't know what age I was when I started thinking about moving out, but it took a few years to get everything together. It was helpful that my parents were supportive. We had to first apply for a housing voucher. I originally received a one-bedroom voucher, which we had to turn into a two person one because I was moving in with a roommate.

The whole process of originally moving out wasn't stressful to me, but there have been a lot of changes since I first moved out. My first roommate was someone who I had known for a long time and it just didn't work out. From the first day, there were issues, we had flipped a coin on who would get the larger room and I won. My roommate was upset that she didn't win, so instead of causing a fuss, I told her she could have it. Which made me



Joanne and I were looking for a two bedroom. We were able to swap apartments, we also had to get a new voucher, a section 8 one this time. We have been living together ever since. In 2019, we moved to a building that was closer to town.

The apartment buildings I have lived in are for anyone. Staff members come in to work with me. Minutemen Arc takes me grocery shopping, run errands and to doctor appointments. I was working up until last year at Marshall's and plan on start looking for jobs in the spring time. I do miss the social interactions with working. I am looking forward to when I feel comfortable riding the train again and visiting the mall.

If I had to change anything, I would have been more careful on who I selected to begin my journey with. If someone asked me what I would suggest to another adult with CdLS trying to move out on their own, I would be caution moving in with a friend, it might not work out. Also, make sure someone is on top of your vouchers and get on a waiting list. If you have a certain date or age you want to move out by, you may want to look to see what the guidelines are in your state. Make sure you are advocating for yourself and your home – that it is up to the proper standard living too.

upset and I knew that I didn't want to live in a situation where I had to compromise all the time.

Around 2007, I moved out on my own and lived in my second apartment for 12 years. During this time, I met Joanne who became a good friend and eventually my roommate. Another person in my apartment building was looking for a one bedroom and





## INDEPENDENT LIVING

# Eileen Ahearn and son Daniel (Age 32)

WISCONSIN



I am a psychiatrist and I know that from a clinical perspective it may seem like the system is against you, but try not to take it personally - it's not about you, it's about the budget. However, don't be afraid to go after what you need and don't stop advocating for you child.

For my family the hardest part of

the transition process was getting the money attached to the plan for placement in the community. Daniel was aggressive, which entailed hitting himself (SIB) as well as hitting or grabbing us if he was angry. He also liked to wander, get into and drive cars. He even got into an accident (in a neighbor's car!). It was not safe for him to remain home. The county kept telling us that we were "fine" and that we didn't need placement, but we knew better.

My husband, Mark, and I requested an order of protective placement through the court system. This order allowed us to remain guardians but the county took over responsibility for Daniel's welfare. This was for Daniel's protection and safety. A clinical report from a local expert in developmental issues was important to present to the court for gaining protective placement. The judge granted the order for placement, but there was no budget attached to it. I tried repeatedly to contact the county with no response. It took a year and additional legal action before we received money from the county.

At the age of 18, it was clear that Daniel was ready to move out. Mark and I tried renting an apartment but there were too many noise complaints. We ended up buying a duplex. Daniel lives on one side and we rent out the other side to persons with special needs. Daniel adjusted fine to the new placement, he has been out in the community for the last 14 years and is doing well.

Daniel's brother, John, is happy for him. He was clearly frustrated at home and was noticeably better after he moved. He was sad to not see him as often of course, but it was ultimately for the best. Daniel's brother, Nathan, remembers that the few years leading up to the move being extremely stressful for all of us, but especially his dad and me. He believes that puberty was an especially tough thing for Daniel and he was increasingly anxious and aggressive. His brothers regularly visit him and continue to stay in touch. He is very happy to see them and get a car ride, but he doesn't want them to stay too long!

We are responsible for all decisions regarding the adequacy of his housing, safety, health and well-being. He works 20 hours a week doing laundry for the high school, with, an onsite job coach. The county we live in has a "everyone works" mentality and a program to assist those who need extra help in the work force. We partner with a team including his job coach, home staff manager, behavioral consultant, and case manager and meet every 6 weeks to review things. Our case manager interfaces with the county on issues of budget, on Daniel's behalf. His home and work staff help him with tasks such as bathing, cleaning, and laundry. He is unable to cook or manage a budget as he has significant cognitive issues. He is cognitively at about a 4-5-year-old, does not write, read, or speak.

We all need to work in our communities to create opportunities for people with disabilities and to try and make things better. As parents, we also need to advocate for our family members with CdLS. Trust your instincts about what your child needs and don't be afraid to push your community to do the right thing for your son/daughter. In the end, you will be setting a precedent for other families and creating a path forward for them.



# Conversation with...

## Karen Prada

REGIONAL COORDINATOR IN CALIFORNIA

Karen, mother to daughter Brianne (Age 29), has graciously provided a treasure trove of resources that will help families in California, as well as across the United States. She has compiled a list of helpful websites to visit and tips she has learned that she believes can help in your loved one's transition. Thank you, Karen, for taking the time to help CdLS community members.

### Regional Centers in CA

There are 21 regional centers statewide (CA) all offering a variety of different services depending on their catchment area (county). We belong to the Valley Mountain regional Center serving San Joaquin, Stanislaus, and San Andreas County. They offer a wide range of services depending on the unique situation to each of our consumers we serve. For someone to begin receiving regional center services they must first go through the intake/eligibility process by calling the regional center office they belong to depending on their county. Once determined eligible they will begin receiving services.

- Housing: care homes, family home agencies, and independent living with Supported Living services in place (should consumer desire to receive such support)
- Employment: work activity programs and/or day programs offering vocational training with job coaching support. We work closely with Department of Rehabilitation (DOR) for support in finding group or individual employment to our consumers.
- Community Integration: day programs offering community integration which most of our programs offer this. To learn more about your regional center, visit: [www.dds.ca.gov/rc](http://www.dds.ca.gov/rc)

### Able Accounts and CalABLE Accounts

An Able Account is a Federal program that is a way an individual with qualifying disabilities can save and spend money without it jeopardizing any federal programs they may currently be on. Those types of programs only allow people to have no more than \$2,000. If you have more than that, you are at risk of losing your benefits. This program, if the person qualifies, alleviates that problem. The money that can be put in this account can be gifted from anyone.

In California, the program is called "CalABLE Account". For information on Able Accounts: [bit.ly/AbleAcct](http://bit.ly/AbleAcct) For information on CalABLE Accounts: [www.calable.ca.gov/](http://www.calable.ca.gov/)

### Top Steps to go Through in Order to Receive Benefits from the Government (depending on benefit and qualification)

- SSI (Supplemental Security Income) benefits prior to age 18 will depend on family income. At age 18, most individuals with developmental disabilities automatically become eligible. (unless they have income or assets exceeding \$2,000).
- If they receive SSI, they most likely will receive Medicaid. However, even without receiving SSI, (before age 18) you can receive Medicaid benefits. Brianne received Medicaid benefits at a very early age using "Institutional Deeming". Every state has a Waiver program. This also qualified her for the EPSDT program which has a variety of services available for those under age 21. After age 21, she was automatically moved into a different waiver program which includes many benefits including respite. Learn more at: [bit.ly/CAHCBS](http://bit.ly/CAHCBS)
- IHSS (In Home Support Services) - Depending on the individual needs, IHSS services can be attained at different ages, but you must be Medicaid eligible to qualify for this service. You do not need a referral for IHSS services. After they determine the needs of the person, they will also determine how many hours they are eligible for. Learn more at: [bit.ly/CAIHSS](http://bit.ly/CAIHSS)

word search

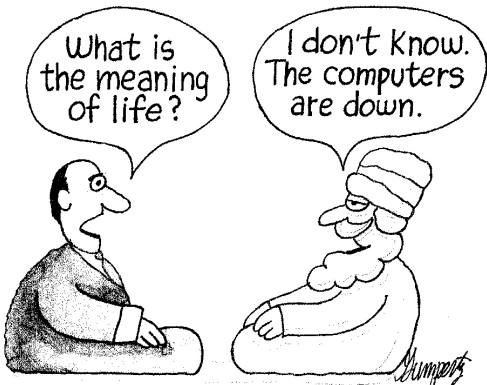
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- Graceful
- Path Forward
- Charming
- Legal Issues
- Captivating
- Transition
- Engaging
- Housing
- Advocate
- Resilient
- Adult
- Socialization
- Awareness
- Education
- Strong
- Resources
- Lovely
- Medical

The Funnies

SOMETHING TO MAKE YOU SMILE.

The Magic of “Dad Voice”



MOM OLYMPICS

