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

The Path Forward



INTRODUCTION

Welcome to

The Path Forward

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

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

Another good option is connecting with other parents with children with special needs who may know of other opportunities for social participation, such as horseback riding, swimming classes, etc.

A state waiver program or other government services may support these. In addition, be aware that if your child is receiving any government services, there may be a care manager or coordinating agency you can contact for resource information and for help in planning for your child's future.

This issue of *The Path Forward* will give you in-depth stories from parents whose adult children with CdLS dealt with socialization. It also includes helpful tools and resources that will assist you in planning for tomorrow.

In this edition, we discuss the topic of  **Socialization** and share resources that will assist you on your journey.

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.





Programs to Help Adults Socialize

JEANINE GERACI, SPECIAL NEEDS SERVICES COORDINATOR, PROTECTED TOMORROWS

Socialization is an incredibly important part of our human existence. It provides a sense of belonging, reduces loneliness, helps to increase happiness, and can even strengthen memory and cognitive skills. When we're children, our socialization comes mainly from family gatherings and schooling. As adults, we foster friendships and plan for activities. Still, many of us can find it more difficult to socialize and make friends in our adult years. This can be especially true for adults with special needs. However, programs exist that can help provide opportunities and outlets to participate with peers.

One option is to apply for services provided through a community-integrated living arrangement (CLIA) in your state. CLIA programs are joint federal and state programs that provide long-term care services and support for those with developmental disabilities or mental illness, living in a group home, at home with family or with a host family. These programs are funded through Medicaid waivers, such as a Home and Community Based Services (HCBS), or 1915(c) waiver.

Under the Social Security Act, states have the option to submit plans to the federal government that request some of the federal Medicaid requirements be waived to start a program that better serves a targeted part of the population. Each state can develop its own waiver programs, so eligibility and services vary from state to state and from waiver to waiver. Each waiver targets a particular population, such as those with developmental and intellectual disabilities, autism, cerebral palsy, epilepsy, or traumatic brain injury. What

is true of all state waiver programs is that the individual applying must demonstrate their need for services. Under a waiver program, a state asks the Center for Medicare and Medicaid Services (CMS) to waive certain federal Medicaid requirements.

Standard Medicaid programs can have asset and income limitations as part of their eligibility requirements. But some state waiver programs serve those with medical need, even if their income or assets are higher than the limits of the state's standard Medicaid program. While Medicaid provides health insurance, a waiver program, like a Home and Community-Based Services waiver, or a CLIA Program can provide wrap-around services such as adult day care, opportunities for educational or vocational training, or help locating leisure and recreational activities. Some waiver programs provide housing subsidies, case management support services, or allow for self-directed care where a budget is provided that can be used not only to hire personal assistants but also for personal recreation or leisure activities.

These services foster appropriate behaviors, greater independence, and personal choice. All of these can help an individual expand their daily living and social skills.

To learn what state waivers exist where you live, visit: bit.ly/CdLS-waivers.

Your state may have a waitlist to participate in a waiver program. For more information contact your state's lead agency for Medicaid. If you are not sure of your state's lead agency visit: bit.ly/CdLS-states.

Families want their loved ones to be happy, safe, and independent. Among other services, Medicaid waiver programs can help individuals achieve these goals.

After all, we all want and need to be integrated into our communities with our peers, living our most independent lives. The best way to build relationships and experience life is to be around people with shared interests.

Individuals with disabilities need just as much socialization, conversation, exercise, and inclusivity as anyone else. With some research and some creativity, these programs can be accessible and affordable.

Individuals with disabilities need just as much socialization, conversation, exercise, and inclusivity as anyone else; thankfully, government funding exists to help make these programs accessible and affordable.



SOCIALIZATION

Starting on the Right Foot

LINDA PIERCE, M.S.W., PROGRAM DIRECTOR, FAMILY SERVICE, CdLS FOUNDATION

Identify All the Key Players

Recreation and leisure activities are necessary for our well-being, developing mind and body, interacting with others, relieving stress, and expressing creativity. These activities also provide opportunities to learn transferable skills used in other settings, such as school or employment.

One of life's biggest joys comes from the comfort and confidence we find in the companionship of others. We all benefit from connecting through shared interests, friendship, family, romance, and work. At times, forming and sustaining relationships can be difficult for everyone. But, for individuals with disabilities, developing these meaningful relationships can be more challenging.

Finding local opportunities as children age into their teenage years and when the school services end, it can be challenging. Securing the right services at the right time is essential; this takes time and planning.

Transition into adulthood centers around fostering self-determination, allowing your child to gain as much control as they are able over their future. To maximize their success, assess your child's needs and give yourself adequate time to research available services.

Take full advantage of resources available through special education services and community resources. Depending on where you live, transition planning at school should start between the ages of 14 and 16. Many schools have a designated transition coordinator; this may be part of IEP meetings in other schools. Remember, the plan is to develop skills and access services needed after your child graduates.

Identifying Strengths and Interests

Both families and schools should take a person-centered approach that uses student likes, interests and needs as a basis for planning. Your child should be as involved as possible in these planning meetings. You and your child can start by identifying four major categories that must be addressed. They are:

- My Strengths
- My Interests
- My Preferences
- My Needs

Focusing on these four items can bring clarity to your child's goals. It can help you and your child become active and engaged participants in planning and help develop self-advocacy skills.

For more information or assistance, contact Family Service at the CdLS Foundation at 800.753.2357 ext. 9391 or email familyserVICESTeam@CdLSusa.org.

If you do not feel you are getting the support and service your child deserves from the school, consider contacting your local Center for Parent Information and Resources and enlist the help of an advocate. Find your local Center for Parent Information and Resources here: www.parentcenterhub.org.



Benefits of Adult Day Programs for Individuals with Disabilities

ADAPTED FROM: COVEY.ORG

Day service programs for adults with disabilities can do wonders for their overall happiness and well-being. It is designed to help build meaningful relationships and gain self-confidence. Day programs offer adults the tools and opportunities to foster personal growth. Of the many positive outcomes of Adult Day Programs and Services, some of the stand-out benefits include:

Development of Life Skills

Day programs allow participants to develop their real-world skills. Through activities such as exercising, creating personal schedules, and volunteering in the community, adults with disabilities can grow their confidence and knowledge in new facets.

Relief for Caregivers

Being a caregiver to your loved one is more than a full-time job. It's your life. Adult day programs offer respite for caregivers and peace of mind that their loved one is in good hands.

Community Connections

Adult day programs often bring participants into the community to volunteer, connect with businesses, and socialize with new people. Frequently, many resources are available in the community for individuals with disabilities that they may not have known about before exploring. Allowing adults to go out of their comfort zone safely is vital in helping them build independence.

Daily Socializing

Attending day programs with peers is like having a built-in group of friends. A supportive group of like-minded individuals surrounds participants, and these new found friends can bond over similar interests, differing abilities, and ways to help each other grow.

Fun for Everyone

Day programs allow participants to try new things. From playing sports to making art, there's an activity for everyone to enjoy! These services are designed to be both educational and fun.

Safety and Support

Safety is always of the utmost importance. Adult day services provide a safe environment for individuals to learn, grow, and be themselves. Adults with disabilities can appropriately explore their interests and talents with support.

Boosts Overall Well-being

Social activities and events can do wonders for a person's overall well-being. Plus, when an individual finds a new talent or hobby, their confidence grows exponentially! Adult day services can significantly improve mental and physical health through socialization, physical activity, and mentally stimulating games.

On *The Path Forward* Together

Welcome to our fourth edition of *The Path Forward*. We hope you have enjoyed the articles and insights you have read so far.

The topic detailed in this issue is socialization. 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.

Some tools parents/caregivers should have to help their loved include:

- Develop self-determination and self-advocacy skills.
- Expand social and community support networks.
- Build a work resume.
- Learn “soft” employment skills.
- Visit postsecondary training and education programs.

In the next few pages, you will find some of this information in detail from parents of individuals with CdLS who have experience with socialization.

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**.

Warmly,



Bonnie Royster
Executive Director

A last thought...

Being social is such an important component of our everyday lives. Being an adult with CdLS can bring challenges in any social situation. One of those situations can be a living environment.

Organizations like We Built are so important to people and their families in the special needs community. Their focus is creating opportunities for new life experiences and friendships that empower individuals to be successful in community living.

They have locations across the United States and are building in more states!

To learn more, visit: **www.webuilt.info**.

WORD OF WISDOM: SOCIALIZATION

Cheryl Davis and daughter Rebecca (Age 26)

ILLINOIS



Friends and sports – are Rebecca’s two favorite things. She has been fortunate to participate in several programs that have allowed her to enjoy both.

When she was about five, Rebecca played soccer and t-ball in our park district program with typical kids. After a couple of years, it became clear that she could not keep pace. We were fortunate to be introduced to a special needs soccer program that was part of AYSO, the American Youth Soccer Organization.

A parent from the soccer team told us about Warren Special Recreation Association (WSRA). What a blessing that was! WSRA has become Rebecca’s primary source of socialization opportunities. They have various programs, including many sports - basketball, track and field, golf, bocce ball, softball skills, soccer skills, snowshoeing, and volleyball.

These sports are part of the Special Olympics program, which allows participants to compete at regional and State games, allowing Rebecca to meet many peers outside of our community.

Rebecca was nominated by WSRA and chosen by Illinois Special Olympics to compete in track and field as part of Team Illinois in the 2022 USA Games in Orlando, Florida. It was the most fantastic experience, where she met many great people.

WSRA also has Friday Night Club, where the participants play games, do crafts, and have a snack based on the theme for the night and movie nights. Other programs include swim lessons, exercise classes, cooking classes, and art programs. They go on excursions to the zoo, the pumpkin patch, sports events, and many more places. They also have an after-school program, a summer camp for school-aged participants, and a day program for adult participants.

When the world shut down due to COVID-19, WSRA didn’t miss a beat. They figured out a way to keep the participants connected through Zoom classes. Because of this experience, Rebecca and her friends became comfortable communicating online. Now she and her friends FaceTime most days.



Rebecca’s high school has a Council for Exceptional Children (CEC) group. This group consists of kids who are typical and have special needs. They meet monthly during the school year to hang out and have fun. Her high school also has an Allied soccer team that practices in the spring and plays games against other special needs teams from nearby high schools.

The library in our community has a program each quarter called SMILE, Special Monday in the Library Event, which serves adults with developmental disabilities. Two of their programs have included Halloween and Cinco de Mayo parties!

Rebecca is living her best life, primarily due to all the great programs she participates in. They are the highlight of her week.

“Rebecca is living her best life, primarily due to all the great programs she participates in.”

WORD OF WISDOM: SOCIALIZATION

Kristin and Tony, and daughter Bianca (Age 15)

NEW YORK



Bianca, or B (as we call her) is almost 16 and is very much a teenager. Born at 5 lbs. 9 oz, the first label the doctors gave her was “failure to thrive” until we could get her properly diagnosed by a geneticist at eight months old. A once floppy girl with low muscle tone, she is now one of the mightiest petite girls you’ll ever meet. The previously silent

girl can now talk nonstop (albeit repetitively) when she wants to. Balance is no longer a problem. She can navigate obstacles in her way. One of the traits consistent with B is her love of being surrounded by people, not too close, but around her. She loves music, dancing, food, and people having fun. This girl loves to party and have all eyes on her!

We are incredibly fortunate to live in Westchester, New York, where we can choose activities and resources. We would be remiss not to take advantage of them. A few years ago, we embarked on the paperwork journey with OPWDD (Office for People with Developmental Disabilities). Last year, we started receiving self-direction funding for her community classes, respite, and community habilitation support. While the system can be tedious and frustrating, the benefits for Bianca make it worth the trouble, especially as puberty behavioral changes have made it necessary for her ‘village’ to grow.

Bianca has been taking extracurricular classes, starting with dance, since she was four. While we were concerned about how she would do in a structured environment, thanks to the fantastic teachers, she stayed for ten years until covid hit. She performed on stage with her peers in front of cheering audiences at the annual recitals and musical plays. This girl does not hesitate to perform and be in the spotlight. She has participated in musical theatre, band, art, sports, and girl scouts. Given her abilities, we can’t emphasize how lucky we are to have organizations and business owners supporting her in adaptive and regular classes. Her current high school teacher takes her to Theater Club at school, and to continue her

journey in Girl Scouts, I (mom) became a troop leader myself. She also has her Dad; Nico, her 26-year-old brother; and his girlfriend, Heather; keeping her entertained and taking her places. And thanks to technology, she keeps in touch with her Tita (aunt), Lolo (grandpa), and Lola (grandma) overseas via video chats regularly.



In addition, Bianca also has a service dog, Morla, who joined us as the lockdown hit. While Morla’s primary task is to keep track of B, due to elopement, her secondary task is to be a social icebreaker. Having Morla allows us to prompt B to speak up and engage with people who come up asking about her sweet dog. Morla also gives B that bridge for people to be comfortable enough to approach her, realizing that her dog is there to assist her.

She is now in the throes of her teenage years. Unfortunately, recent increasing behavioral challenges have started limiting some of the classes and activities in which she can participate. Despite these circumstances, we keep her socializing in the community in other ways because she thrives on other people’s energy. A trampoline park nearby is now an excellent outlet for her desire to jump recently, enjoy pumping music, and be around peers. We are hopeful that with time and puberty passing, perhaps some medication to help, she will be able to fully participate in more classes and productions to take those bows once again and develop some meaningful friendships.

Conversation with...

The CdLS Foundation Family Service Team

The Importance of Recreation and Leisure Activities



It can be challenging to find opportunities for teenagers to socialize with others, establish healthy relationships, and develop the self-confidence to know they are valued friends and partners. School can structure a child's day and opportunities to engage with peers in the classroom and extracurricular activities. But school supports end when a child graduates. Without planning, this can leave young adults alone and without the support system

needed for their success. Exploring resources available during and after high school that match your child's strengths, interests, and needs can help maximize their success.

Building Social Skills and Relationships

If your child's strengths, interests, and preferences are building one-on-one relationships, see if your child's middle or high school offers a Best Buddies or similar program. These programs build one-to-one friendships between students with and without disabilities, building meaningful connections with peers. These programs exist in middle and high schools, colleges, and for adults in the community.

An e-Buddies program also provides a safe online space to develop friendships. Best Buddies offers leadership development programs for those that seek to become leaders and advocates in the disability

community. These connections can be vital in reducing isolation and developing self-confidence and socialization skills. Best Buddies has active programs throughout the United States and in other countries. You can learn more about their programs here: bit.ly/CdLSBest.

Surviving Lunch Time

If your child identifies a need for additional companionship during the school day, see if there is a Sit With Us movement at their school. Sit With Us was started by a student, then in high school, who was bullied and embarrassed when sitting alone during lunch. Wherever the program is present, children download the free Sit With Us app that lets students find or create a lunch event and chat with others to coordinate lunches. Learn more about this program that can make a huge difference in someone's day here: bit.ly/SitwUs. The first step to a warmer, more inclusive community can begin with lunch.

Music

Many children with developmental disabilities respond well to music. Music is a multi-sensory activity that can captivate attention and bring joy. It can enhance and encourage verbal skills, improve gross and fine motor skills, reduce anxiety, and help children remember step-by-step routines and transition from activity to activity. Learn what adaptive or inclusive music programs your school or town offers. If music is a strength or interest for your child and there isn't a specific program at your child's school, talk with a music teacher and add these accommodations to an IEP.

If your school's music teacher is unsure how to accommodate your child, use the strategies The National Association of Music Teachers offers for working with children with special needs. These strategies can create an environment of belonging where students gain self-esteem, have fun, and build positive relationships, visit bit.ly/CdLSmusic.



Sports

Many schools emphasize providing appropriate physical education and sports opportunities for all students. Physical activity can reduce symptoms of anxiety and depression, improve overall health and function, reduce isolation, and help individuals find success and build friendships. If participation in sports fits

your child's strengths and interests, consider finding inclusive or adaptive sports programs through your local park and recreation department or Special Olympics program near you. Special Olympics programs exist across the United States and in many countries worldwide. You can find them here: bit.ly/CdLSOlympics. They also offer excellent opportunities for family members to volunteer and support participating athletes.

Residential or Day Camps

Depending on your child's strengths, preferences, and interests, camping and recreation options may be important to explore. Residential or day camps can provide fun experiences that help develop confidence and independence. [Veryspecialcamps.com](https://www.VERYSPECIALCAMP.COM) can help you find a summer camp based on your location and your child's specific requirements and interests. You can also seek resources from organizations like Easter Seals, which offers multiple camping and recreation programs for children and adults.

Employment

Employment is also an excellent opportunity for socialization, self-esteem, and self-confidence. Vocational Rehabilitation programs can assist with this. A member of the IEP team or any school staff member can refer a student for vocational rehabilitation services. Students can also self-refer.

The process of accessing Vocational Rehabilitation services can be lengthy, beginning with assessing a student's work potential and completing trial work experiences with a job coach. Trial work experiences occur in a natural work environment over a sufficient length of time to determine if the student can benefit from services and succeed

in a work environment. Getting started early can help ensure a smooth transition your child may need after graduation.

All students who receive special education services in secondary school can receive vocational rehabilitation services while still in school. Vocational Rehabilitation Transition Counselors can collaborate with your school and provide services before graduation. If you invite them to participate in your school team, they must help the IEP team develop the student's IEP.

Vocational Rehabilitation Services are available in all fifty states, the District of Columbia, Puerto Rico, and four territories. You can find your local vocational rehabilitation administration agency here:

bit.ly/VRSCdLS.

If you need more information or assistance regarding vocational rehabilitation services or want to know your rights under these programs, contact your State's Client Assistance Program (CAP). To find your local CAP, visit bit.ly/NDRNCdLS and select your state.

Further Education

Work with the team in your child's high school to determine if your child will graduate at age 18 or if they will remain in school until age 21. The Individuals with Disabilities Education Act (IDEA) helps ensure free appropriate public education is available to all children with disabilities between the ages of 3 and 21. Various educational options are available after high school for students with special needs. Please work with your IEP team to identify different college options and their requirements, bit.ly/CdLS-edu is a great place to begin your search.

In addition to colleges, there are adult education and job training programs and Comprehensive Transition and postsecondary (CTP) programs in many States across the Country. CTP programs are designed to support students with disabilities who want to continue academic, career, and independent learning instruction and prepare for gainful employment. Students enrolled in CTP programs can apply for Federal Pell Grants, Federal Supplementary Educational Opportunity Grants, and Federal Work-Study programs. You can learn more about CTP programs by visiting: bit.ly/CTP_CdLS.

It's never too early to investigate programs that best suit your child's needs. As always, the CdLS Foundation is here for you!

Do not hesitate to reach out to Family Service at 800.753.2357 or familyserVICeSteam@CdLSusa.org.



Top Soft Job Skills for Adults with Disabilities

ADAPTED FROM: [UDSERVICES.ORG](https://udservices.org)

Adults with disabilities make up nearly 20% of the American workforce. Still, they often face more significant challenges in finding and maintaining employment. In most cases, this is because they don't have the opportunity to develop soft and hard job skills that characterize appealing candidates.

However, these social- and work-related attributes are essential to securing employment and maintaining a job in the long run.

Soft or interpersonal skills are core competencies that define how you work. These transferable skills are valuable regardless of your job and helpful in any professional environment. If you've already held employment, chances are you've developed soft skills.

Ultimately, soft job skills are just as essential as specific job-related competencies. They're especially crucial if your job requires you to interact with the public. However, the ability to "read" others and adapt to uncertain situations can be difficult for people with disabilities.

Below are some of the most valuable soft job skills for adults with disabilities that employers are looking for.

Attention to Detail

While the bigger picture is always important, businesses want employees who pay close attention to the details.

Communication Skills

Good communication skills help you productively engage with coworkers, superiors, and customers. They also allow you to follow instructions and effectively express your thoughts and feelings to those around you. In short, they're essential to a positive work environment where everyone feels valued.

Conflict Management Skills

Unfortunately, conflict and disagreements can crop up in any working environment. Potential employers are searching for candidates who can navigate and mitigate conflict calmly.

Problem-Solving Skills

The ability to solve problems and assess situations from multiple perspectives is another top soft job skill. Problem-solving is key to critical thinking, strategizing, and taking advantage of potential opportunities.

Professionalism

Approaching your job positively and professionally impacts how your superiors and coworkers perceive you. Professionalism includes things like showing up for work on time, dressing appropriately, and respecting the people around you.

Teamwork Skills

The ability to work as part of a team is crucial to both your success and your company. Effective teamwork also involves understanding the needs of your coworkers and supporting them for the greater good.

Time Management Skills

Knowing how to manage your time effectively allows you to prioritize and accomplish your tasks. Effective time management also demonstrates initiative and positions you as a self-starter who doesn't need to be hand-held.

Now that you know the top soft job skills for adults with disabilities, you're ready to pursue employment. As someone with a disability, it's easy to feel discouraged and disadvantaged during your job search. However, careful self-marketing allows you to turn your disability into a valuable asset.

Be confident, and remember that your disability does not define you, personally or professionally.

word search

E	E	C	D	M	A	D	U	L	T	S	C	C	L	T	I	O	I	X	H
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Special Olympics
Socialization
Music Therapy
IEPS
Awareness
Sit With Us
Advocacy
Employment
Teens
Adults
CdLS
Best Buddies
Day Camps

The

Funnies

SOMETHING TO MAKE
YOU SMILE.

THE FAMILY CIRCUS®



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

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