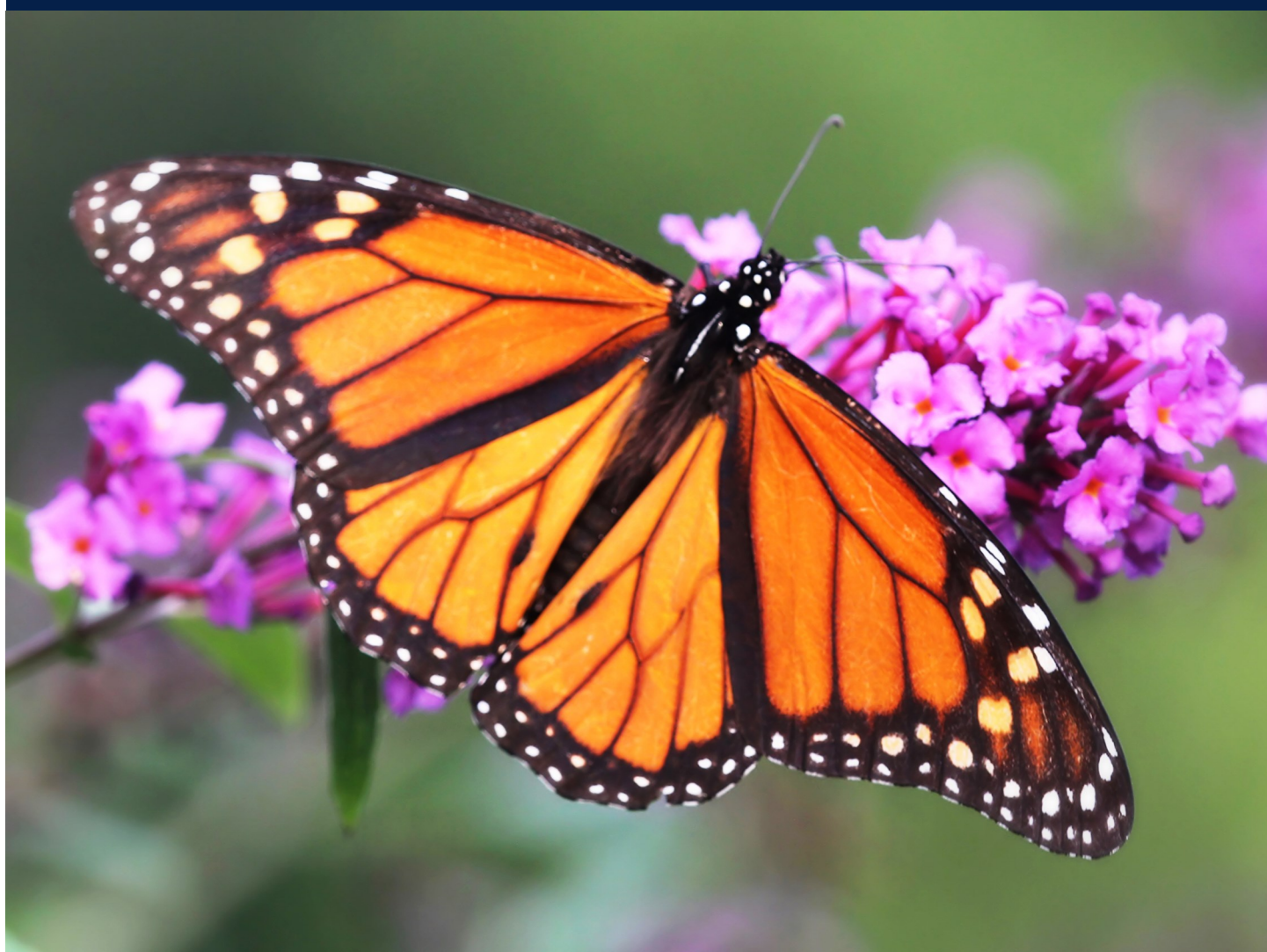


What's Next? :

A Self-Advocate's Guided Tour through
Transition for Parents and Other Supporters



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Improving outcomes for people with developmental disabilities



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A Self-Advocate's Guided Tour through
Transition for Parents and Other Supporters

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About the Author



Hello, I'm Melissa Crisp-Cooper. I am a forty-one year old woman with moderate athetoid cerebral palsy. My disability primarily affects my coordination and my speech. I navigate the world outside of my front door in a jazzy, purple, power wheelchair. My husband, Owen has a milder form of cerebral palsy. We live in Oakland, California along with our three, furry, feline friends. I have two fabulous attendants that help us keep a tidy house and assist with other tasks. Owen and I love to travel, spend time with family and friends, and hang upside down in our adaptive yoga class.

In this guide, I will share many stories from my adolescence. Let me start by painting you a brief picture of these years. I grew up in a Southern California suburb. My parents were big believers in stretching the boundaries of my physical limitations. They pushed me to dream up adaptations to accomplish the everyday, activities of daily living. I remember figuring out creative ways of doing tasks like getting dressed and climbing into my wheelchair. They instilled a strong ability to adapt and solve problems that has served me well. My parents had high expectations even when they did not know what to expect.

Still, my mom and dad had their own struggles raising a daughter with a disability. They had a difficult time trusting that I was ready to use these hard learned skills in real world situations. I had after school care all the way through my senior year of high school – long after I felt I was ready to stay home alone. They also struggled to find a balance between meeting my physical needs during family events and their desire to pursue their own interests. Perhaps if they had received a little more support, I would have felt a little less left out and isolated.

I attended the University of California, Riverside from 1993 to 1997. I earned my Bachelor's Degree in Human Development, a combination of psychology and sociology. As Owen likes to say, I take great pleasure in trying to figure out people's and societies' inner motivations. I have used this degree along with some advocacy to try to make a positive difference in the community of people with disabilities.

About this Guide

Adolescence is both a time of change and a time for everyone to make bold plans for the future. As your teen celebrates each passing year, you both may wonder what the future will hold. Will they become happy and healthy members of their chosen community? As a teen, I remember having these same questions bounce around the back

walls of my mind. For those of us with disabilities, and the people who love us, the transitional years between adolescence and adulthood can present a set of unique challenges. With a bit of creative planning and extra preparation, your teen will be more empowered to begin their journey as a self-directed young adult. This guide will pose questions, offer concrete tips, strategies, and resources as your family ventures down this path.

In these pages, I hope to broaden your sense of what is possible for your teen in the years to come.

In these pages, I hope to broaden your sense of what is possible for your teen in the years to come. I should add here that I am only one person with a disability. I have taken one path and speak from my own perspective. Of course, this is not necessarily the perspective of others in the large and varied disability community. I have lived in California my entire life. Many of the specific services and programs discussed in this guide are California based. Other states may offer different services under other names.

Not everything I say here will apply to your teen or young adult. With your support, they will choose their own unique and colorful path. So, with that disclaimer, I encourage you to push beyond your expectations and tear up the picture others have painted of your teen's capabilities.

Helping Your Young Adult Understand and Exercise their Rights (A brief overview)

The Lanterman Developmental Disabilities Act and the Regional Centers

In 1977, the California legislature passed the Lanterman Developmental Disabilities Act. This law entitles everyone with a developmental disability, no matter how profound our needs, the right to a meaningful life in the community. It also entitles those of us in this population to the services and supports we need to achieve our maximum potential. The act mandates a system of Regional Centers. These twenty-one centers are required to respond to our needs, this may include the needs of our family. Under this law, we must have leadership roles in directing our services. The array of available services should be sufficient to meet our needs. They should give us choices and support our integration into the community. In short, this act is intended to enable us to approximate everyday living of people without disabilities. It mandates services like supported living and other appropriate community living arrangements. We decide where and with whom to live, how to spend our time, and pursue our future.

The Lanterman Act places California ahead of most states when it comes to providing services, although we still have a long road to travel before we get all the services we need to become full members of our chosen community. This act forms the foundation for all Regional Center services. If your young adult has a problem with the services outlined in their Individual Person Plan (IPP), it is useful to understand the basics of this act and the *Olmstead vs. L.C.* Supreme Court decision which requires states to eliminate segregation of people with disabilities. In addition, the *Olmstead* decision ensures our right to receive services in an integrated setting.

If your loved one has been denied a Regional Center service or a certain service was ended without their express consent, their primary service coordinator should be notified. The Regional Center is required to notify you or your young adult of all changes and decisions in writing. If the service coordinator cannot resolve the issue, it may be time to request an in-person Individual Program Plan meeting. If you are not satisfied with the outcome of this meeting, you may want to submit a written appeal. Successful appeals require good documentation. I have found email trails are helpful when I am asking for something I need from any social service agency, but you may want a more formal letter. This appeal may

lead to a “Fair Hearing” before anyone comes to a final decision. To understand more about the appeal process and important deadlines, please visit this informative link <http://www.disabilityrightsca.org/pubs/506301Ch12.pdf> created by the Disability Rights California organization. Remember to share this information with your loved one in the way they learn best. Once they understand their rights, they can help to advocate on their own behalf. You can provide support. The bottom line is that these rights have no value unless your teen understands them to the greatest extent possible and has the support they need to exercise them.

The Individuals with Disabilities Education Act and Special Education

Public schools have specific procedures for handling disputes involving Special Education students. The Individuals with Disabilities Education Act (IDEA) guarantees your loved one the right to receive a free and appropriate education in the least restrictive environment. If this right has been violated, I suggest contacting your local Parent Training and Information Center (PTI). In some areas they are referred to as Community Parent Resource Centers. Many of the knowledgeable staff members at these centers also have children of all ages with disabilities. They can assist you in learning about school policies, researching options, and developing a list of questions for school officials, to name just a few of their invaluable sources of support. Although each center would like to directly help each parent, only certain centers are authorized to accompany you and your child or young adult to an Individual Education Plan (IEP) meeting. Their presence and advocacy on your loved one’s behalf can produce positive results. If your local center is unable to provide this service, consider bringing friends or family to assist you. If you are not satisfied with the services offered, consider retaining a professional advocate or attorney.

Parent Training and Information Centers also offer workshops on many topics related to youths, families, and disability. In addition, they provide families assistance navigating other programs and services such as the Regional Center and Department of Rehabilitation. These groups offer many tools to help families advocate and find their way through the maze of disability-related services. They can be powerful allies if you find yourself in the middle of a dispute with a school district or other service agency. To discover more about these centers, please follow this link: <http://www.parentcenterhub.org/>

Transition Planning

I started attending all of my Individual Education Program meetings in middle school. This felt awkward at first. I suddenly had to make decisions about my life that the adults had always made for me. Gradually, I saw these meetings as more than just good excuses to get out of class. By high school, I had grown more comfortable with using my voice to plan for my future.

The decisions made at these meetings will greatly impact the course of their life.

If your adolescent receives special education services, they should have a component of transition planning included in their Individual Education Program (also referred to as an Individual Transition Plan or ITP). These plans are intended to help your teen prepare for life after high school. Transition planning should start by age sixteen or earlier and can continue until the student turns twenty-two. It is extremely important for your teen to have an active role in this planning process. Everyone in attendance should have a clear understanding of what your teen wants their future to look like after high school. They need more than just a single vote or to be physically present at meetings. Since the decisions made at these meetings will greatly impact the course of their life, they should have a strong leadership role.

To help them prepare to take this lead, explain the process, ask for their input, and encourage them to attend all of their transition planning meetings. With support for communication and decision-making, almost all adolescents with disabilities can make decisions for themselves. As they start to make more decision, they will learn from these experiences. Even bad decisions can provide potential opportunities for learning and growth.

Everyone makes and communicates their choices in different ways. If your teen happens to have limited expressive communication for example, the two of you could visit potential classrooms or programs. Request that an educator who has intimate knowledge of their talents and support needs attend this site visit as well. Together, it may be possible to observe how they respond to a particular environment.

If your teen has a different set of functional abilities, they may make choices about their future using alternative methods. They may need explanations in plain language or with the use of visual aids. My main point is that every student has the right to be given all of their options and voice their opinion in any style of communication that works best for them.

Give them information, presume competence even if you aren't sure how much they understand, or even if you are sure they don't yet understand. Often, they understand more than we think. Also, that is the only way they will increase their understanding.

Certain decisions made at these transition planning meetings have the power to influence much more than just their high school education. Here are some examples to illustrate this point:

- The decision to pursue a standard diploma versus a certificate of completion will have a significant impact on their future earning potential.
- The decision to place your teen in a sheltered workshop means they will earn below minimum wage and have fewer opportunities for personal growth and advancement. Other integrated, supported employment options may be more appropriate.

If at all possible, they should understand the weight of these decisions and have a voice in mapping out a future that aligns with their preferences, hopes, and dreams.

Tips for Successful Transition Planning

Below are suggestions to help with the transition planning process.

- Explain the process of transition planning.
- Ask for your teen's input.
- Encourage your student to attend all of their transition planning meetings.
- Offer choices and allow your student to voice their opinions using the communication style that works best for them.
- Provide your teen information, presume competence even if you are unsure how much they understand, or even if you are sure they don't yet understand.
- Give your loved one a voice in mapping out a future that aligns with their preferences, hopes, and dreams.

Meeting Your Teen's Transition Goals and Needs

Transition planning is also the time for everyone involved in this process to evaluate your teen's specific support needs. This process may require additional assessments by a variety of agencies.

Questions: Evaluating Specific Support Needs

Below are some questions to help you evaluate your teens specific support needs:

- Are they receiving the appropriate services now to help them meet these stated transition goals?
- Do they have input into these decisions?
- Would they benefit from additional services, programs, or equipment such as:
 - An augmentative and alternative communication (AAC) device
 - A laptop with adaptive software
 - Physical or occupational therapy sessions

Under the Individuals with Disabilities Education Act, the Individual Education Plan team must consider Special Factors such as low incidence funding to purchase some of these adapted support needs. This equipment may need to be returned to the Special Education Local Plan Area (SELPA) or district when the student exits special education. If the equipment must be returned, request that the Regional Center, the Department of Vocational Rehabilitation, private insurance or a combination of resources fund a replacement. They will probably require an independent evaluation, so now is the time to look into all those extra bells, whistles, and features that could prove useful in the future.

Young adults with disabilities will need to advocate for themselves their entire lives. Why not start to guide them through the process now?

Advocating for these needs is not an easy task.

Make sure your teen is involved in every possible way. Can they help you write letters or speak directly to the decision maker who controls the budget? Are they present at every meeting? Even teens with significant communication and behavioral disabilities fully deserve a seat at this table. The “squeaky wheeler” or most persistent users of communication devices can get amazing results. Besides, young adults with disabilities will need to advocate for themselves their entire lives. Why not start to guide them through this process now?

At this point, I’m sure many of you are anxious about your teen’s young adulthood. Will the current programs offered by the school district actually prepare them for a happy and fulfilling future? To answer this question, try connecting with the parents of older kids. Then ask what programs and resources have worked for their teens. Do not rely solely on what the district or Regional Center has to offer if these options do not make sense. If you hit a snag or come across a road block, contact a parent advocacy group.

Looking Forward

In addition to other academic or skill-based goals, a transition plan can also place an emphasis on a wider array of post-secondary goals which can include:

- Communication
- Transportation
- Employment Training
- Continuing Education
- Independent Living Skills
- Building Circles of Support
- Working with Paid or Unfamiliar Supporters
- Practice with Making Decisions

*Everyone has the right
and basic human need to
communicate.*

Of course, these are incredibly broad areas. Specific goals and objectives must be based on your son or daughter's individual wants and needs. Here are a few practical topics and examples for everyone to consider when creating a plan.

Communication

Everyone has the right and basic human need to communicate. Strong communication skills are a key component of autonomy and self-direction. Your teen or young adult should be supported to use communication skills both at school and at home. Some school districts and day programs may suggest that young adults who use electronic forms of Augmentative and Alternative Communication (AAC) leave their device locked up inside the building. If a school district or day program wants your young adult to leave their device, perhaps an argument can be made for home and community use based on their communication, educational, and social goals. Teens want to talk to their family members and maybe even gossip on the phone with their friends. They should have every opportunity to develop communication skills, particularly in comfortable environments such as home.

Features of a Speech and Language Assessment

A good speech and language assessment should examine some of the following areas:

Access to Current or Appropriate Vocabulary

- Does your teen have access to vocabulary through their preferred method of communication?
- Do their word and icon choices match the current curriculum?
- Can they address friends and other important people by name?
- Are they able to discuss their favorite music, TV shows, or relevant events with friends?
- Can they learn to program their own device? (This may require additional learning and

practice or may not be feasible yet for some teens).

Ask speech pathologists or teachers to have regular check-ins with your teen, their friends and supporters. Everyone should be encouraged to suggest new vocabulary.

Access to Self-Advocacy Vocabulary

- Can your teen advocate for their own wants and needs?
- Do they use words or recognizable patterns to indicate when they are unhappy, sick or need something else?
- Are they empowered to speak up when something does not feel right or they are being mistreated?
- Do new supporters understand how to interpret these messages?
- Are these messages acknowledged and respected?

Nothing will disempower your teen more than not being heard. Let them know it is okay to say no, have an opinion, or express a desire.

Access to Real Life Communication Experiences

- Can they order food at a restaurant or ask for directions?
- Everyone needs some sort of voice in the world, even if that voice does not make typical speech sounds.

Increasing Self-Advocacy and Decision Making Skills

Like most adolescents, many teens with disabilities want to experience a certain amount of freedom away from the bounds of their nuclear families. By the beginning of high school I was incredibly ready to explore life away from my parents. Many of my friends were also eager to see what life had to offer. You probably will have some valid concerns about your teen's safety and well-being when they start making decisions with real consequences. Fortunately, this transition towards independence and autonomy usually occurs on a gradual continuum. Every teen is different. Some teens are ready and able to take on the world while others may require some gentle prodding.

When your adolescent is beginning to test the deep waters of adulthood, consider shifting your primary role from advocate to ally.

Moving from Advocate to Ally

At certain points in our lives, all of us need experiences which test our preconceived limits. These opportunities will allow your teen to take risks, succeed, and sometimes fail. These are the experiences that often expand their capabilities and allow them to grow. Your teen will not always make the best choices or the choices you would have made. That's okay. I

doubt that any of us always make ideal decisions even after decades of adulthood. These decision-making attempts should be encouraged. They may lead to tough conversations when things don't quite turn out as planned.

When your adolescent is beginning to test the deep waters of adulthood, consider shifting your primary role from advocate to ally. Sometime during my first week of college, my dad went with me to see my new academic advisor about a problem with my schedule. He automatically started speaking to the woman on my behalf. She quickly interrupted to remind him that I was a college student now and needed to speak for myself. This obvious piece of truth took us both by surprise.

Teens need opportunities to discover new things about the world and themselves and make a few mistakes along the way. If your adolescent has a plan that you do not fully support, could you voice your opinion, then let them test out their plan? You don't necessarily need to offer any type of physical, logistical, or financial support. Figuring these things out is one part of the learning process. The other part of the process is learning how to deal with the consequences of a bad decision.

Learning How to Solve Problems

So much of living successfully with a disability has to do with being able to solve everyday problems and compensate for challenges. By now, you and your teen have come up with dozens of amazing, innovative solutions to complete countless activities of daily living. Here's an example of such an innovative solution: A young man with autism at the day program I worked for had trouble understanding the abstract concept of money. He made it a practice to never leave home on weekdays without a ten dollar bill in his wallet. This amount generally covered his lunch and a small incidental as he traveled throughout the community with this program.

Independent or supported problem solving is a critical skill. Perhaps start helping your teen to develop this skill by trouble-shooting a simple problem. Ask them to describe the problem and type of help they need. Have them identify who they can ask for help. Role-play this conversation by having them state their problem and describing their ideal solution. Remind them not to get discouraged if the problem isn't solved immediately. Persistence often yields big rewards. Learning self-advocacy skills during these transition years will empower your teen for a lifetime.

Self-Advocacy Groups

There are many in-person and on-line self-advocacy groups and resources. The majority of these groups use peer mentors and leadership roles to promote public policy and empower members to have a strong voice in the world. Larger groups have statewide conferences and run advocacy summer sessions or other programs throughout the year. Often a peer with a disability can make a great friend and teacher.

Self-advocacy also means knowing how to communicate with people outside of the protective environment of family and school in order to receive assistance. Some of this communication will involve explaining to a new supporter how to meet their specific needs. More than anything, teens need choices about who they hang out with, who supports them, and how they spend their free time. Remind them that they have the right to be treated with respect and dignity.

Opportunities to Strengthen Self-Advocacy Skills

Some opportunities to strengthen self-advocacy skills include:

Going to Camp: Attending summer camp is a great way to practice asking for assistance from unfamiliar supporters. Camp also has the power to expose your teen to many different types of social interactions and physical experiences. These camps can either be disability-specific or attended by teens in the general population. The Regional Center may be able to provide funding if camp attendance is a stated goal in your teen's Individual Program Plan. I loved the freedom and adventures camp offered. It also gave my parents and grandparents a valuable summer respite period.

Group Membership: Joining an after-school club may give your adolescent a sense of belonging to a group with a common interest or cause. If they have a paraprofessional assistant during the school day, could they get help from a fellow group member for the hour or two during the meetings? If they need more support during these after-school activities, request an assistant as a part of their Individual Program Plan or their Individual Education Plan.

Allowance: An allowance or job can give teens with disabilities a sense of pride and responsibility. Control over some money will place your adolescent on equal footing with their able-bodied siblings and peers. An allowance can teach them important life skills like budgeting and prioritizing their wants and needs. Money is usually a great teacher of life lessons about the positive or negative consequences of certain choices.

Chores: Chores provide teens with an important role in a family structure and give them a sense of responsibility. If your adolescent has a significant physical disability, their chores might include activities tailored to their unique skill set, such as maintaining a weekly grocery list, helping a younger sibling with their homework, or planning meals.

Real World Experience

Regardless of your teen's academic skills, they still need exposure to everyday experiences. I was surrounded by the protective walls of school and home until I left for college. I did not roll across a busy intersection in my power wheelchair independently until midway through my freshman year at University of California Riverside. Some teens may take the bull by the horns and figure out ways of safely navigating the world. Others may need extra support in acquiring certain life skills. Goals can be created to help these students negotiate real world situations. A student in a wheelchair, for instance, may want help to map out transit routes while a student with autism may need additional practice with social encounters.

Allowing your teen to venture somewhere without you will open up their whole world!

Some school districts may offer summer programs to help students with disabilities enhance these skills if they have been on an academic track during the traditional school year.

Transportation

Nothing gave me a greater sense of freedom and independence as a teenager than the first time I took a Paratransit bus home from school by myself. My parents did not think I was ready to take other forms of public transportation, but we felt I was ready to conquer this smaller goal. Now, I love the challenge of figuring out how to get to new places using all forms of transportation.

Going somewhere without parental supervision is an excellent way to promote independence, increase social interactions, and boost self-confidence. Allowing your teen to venture somewhere without you (in whatever way makes sense) will open up their whole world! This can mean anything from going to camp to hanging out at the mall with friends after school.

Travel training comes in all different shapes and sizes. Each approach will depend on your adolescent's readiness and functional abilities. For teens that may not have the current capacity to travel alone, perhaps they can practice other skills, like choosing a destination, giving directions to a supporter, or practicing pedestrian safety skills. Everyone needs opportunities to expand their possibilities.

If your teen has the potential to travel independently, the most important skill for them to have in their toolkit is the ability to seek help if they get lost or into trouble.

Tips for Seeking Help

Below are tips to help your teen travel safely independently:

Asking for Help

- Can they ask for directions or assistance?
- If they have difficulty with expressive communication, can they use a rehearsed script, a programmed sentence on a communication device, a text, or another written method? I will type out messages on my iPad if someone is unable to understand my speech.
- Other travelers with communication challenges have programmed frequent transit stops loaded into their personal devices and are at the ready for bus drivers or anyone else. These methods of communication should be prepared ahead of time.

Technology

- Smart phones have locators that can be turned on with the consent of the user. This can enable someone else to find your family member if they become lost or have an emergency.
- Phones also have easy-to-use map and direction apps.

Travel training can start with small goals. Ask them where they would like to go or have them choose from a select number of options. This might be a group or class decision. Here are a few questions and comments to help everyone think of creative ways to kick-start these travel adventures:

- Do they want to walk/roll with a friend to a neighborhood store?
- Who can help plan a route?
- Can they practice taking this route with a supporter?

Paratransit (PT) is a door-to-door, shared-ride, bus service for people with disabilities and seniors who are unable to use other fixed-route, public transportation sources. Riders can travel alone or with a companion. This service goes by different names depending on the city or town. Although this service helps many of us navigate our communities, we often experience elements of frustration when riding these buses. There is a lengthy application process and drivers frequently pick-up or drop-off passengers late. That said, Paratransit is a positive step towards independence.

Considerations about Paratransit

The questions below can help you think about whether Paratransit is a good option for your family:

- Does the person qualify for Paratransit?
- Are they registered for Paratransit?
- Can they plan or get support to plan the logistics of a trip?
- What is the location, day, and time of their trip? It's helpful to write this information down along with pick-up times.
- Can they schedule a ride or use support to make this call?
- Can they contact Paratransit or someone if they miss the pick-up window or their bus is running late?
- Do they need support once they arrive at the destination? If yes, can someone meet them there?

I have seen people with a vast range of abilities learn to use various forms of mass transportation. This process may include some trial and error, but with patience and persistence it can yield big rewards. Many school transition programs, transit systems, and centers for independent living offer travel training services. The Regional Center may be able to fund some forms of travel training if an IPP goal has been created. In addition, most transit agencies offer people with verified disabilities reduced, and sometimes free fare.

Tips: Traveling in the Community

Below are some additional thoughts on traveling in the community:

- Travel training should teach teens safe routes to and from transit stops. This could involve learning how to safely cross major streets and follow other safety rules.
- Under the Americans with Disabilities Act, public transportation is required to be fully accessible for people who use most types of mobility equipment. This does not guarantee that station elevators and bus lifts will always work or that drivers will always secure your equipment. Advocacy skills are often necessary!
- People with a wide spectrum of physical, intellectual, and communication capabilities use public transportation on a regular basis to travel to work, school, and community outings.
- Learning even a limited number of specific routes or traveling with a companion can enhance independence.
- Literacy is not an automatic requirement of traveling on public transit. Operators generally announce stops. Riders should be able to identify landmarks, know their direction of travel, or have enough information to ask questions.
- Processing transit payments and adding fare are not always easy tasks, even for people

without disabilities. Your teen may need to follow an explicit set of instructions.

- When well-intentioned strangers offer unwanted help, teens should be prepared with a courteous, yet firm response. Usually a simple reply such as, “No thanks.” “I’m okay.” or “I got it.” will do the trick.

Civics

All teens need opportunities to find meaningful ways of participating in their community. The suggestions listed below barely scratch the surface of possibilities. I hope they will help both of you get your creative juices flowing.

Today, many high schoolers must perform some type of community service project. If this practice exists at your teen’s school, having a disability should not give them an automatic exemption. All teens should have the opportunity to make a meaningful contribution to their community. After all, everyone has something valuable to offer. These projects should take advantage of your teen’s strengths, interests, and abilities. They may need a little extra help to figure out ways of either completing an individual project or making a significant contribution to a student team.

People with all forms of disabilities are greatly affected by how the government funds social services, creates public policy, and enforces laws. We must make our voices heard by casting our ballots. Teachers, parents, or other support team members may need to find creative ways of helping their students keep informed and understand the issues. You can help by discussing current events or asking questions about the nightly news. Teens can disengage from the world around them. We can help them stay connected.

If your adolescent could benefit from a greater sense of purpose; suggest that they use supports to help identify volunteer opportunities. Local animal shelters, senior centers, and skilled nursing facilities are some places to investigate. Of course if they have a particular passion or interest, let this guide their search. Could the local motorcycle shop use an extra set of hands? Maybe the library really needs someone to read to a children’s group. Is the animal shelter looking for volunteers to cuddle with the dogs and cats? Can they create artwork to sell at a fundraiser or festival? Can they become more active in their religious community?

Suggestions for Community Participation

The suggestions below can help your teen find meaningful ways to participate in their community:

Community Service Projects: Community service participation and volunteer work can be outlined and measured in their IEP's.

Voting: If your adolescent will turn eighteen while still in special education, registering and learning how to vote should be a highlighted goal in their IEP.

Volunteering: Resource teachers, service coordinators, and website listings are just a few great resources for finding such opportunities to volunteer.

After school and summers make for lonely times for many teens and young adults in this population. Finding a cause that is close to their heart will help fill this social void by providing opportunities to make new friends and broaden their circle of support. Plus, volunteering has the potential to build job skills and increase network connections which may lead to future employment.

Continuing Education

Investigating options to improve skills or continue a lifetime of learning after high school means different things for different people. It can mean looking into options for pursuing a degree, building functional skills, or discovering a new passion. The transition program I worked for enrolled participants in classes at the local community college. They took art, gym, and dance classes. It was a great way for these students to participate in their community as young adults and get a taste of the college experience.

Today, a number of higher education programs exist for students with a range of intellectual disabilities. Some programs focus on functional skills, while others focus on encouraging students to take regular college courses. To learn more and view an outstanding video on attending college for students with intellectual or developmental disabilities, please visit: <http://www.thinkcollege.net/training/rethinking-college-the-film> Participating in higher education may also mean taking an on-line course of interest or identifying other learning sources in the community.

If your teen wants to pursue a higher education after high school, request that this be a stated transition plan goal as early as possible. Their special education program should refer them to the California Department of Rehabilitation. Usually, I simply refer to this state agency as Rehab. If your teen meets all the disability status and financial qualifications, Rehab will cover college tuition and learning materials. Please see this helpful information document published by Disability Rights California for further details:

<http://www.disabilityrightscalifornia.org/pubs/557201.pdf>. Since the main goal of Rehab is to help people with disabilities find employment, some students who use Rehab services work towards a degree with future employment in mind; however Rehab eligibility and services are based on whether the person is eventually “employable.” Employment is possible for people with a wide range of disabilities. Rehab can also fund adaptive equipment, supported employment, and other types of vocational training programs. They have specific programs for people with visual impairments, including orientation and mobility training. If something is work-related, Rehab can provide it.

For me, setting higher education goals was a great motivator to do well in high school. I longed to experience the freedom that going to college promised. Higher education goals can encompass a wide variety of areas. In order for teens to feel invested in their future, they need the resources and support to drive this exploration.

I will dive into a deeper conversation about attending college later in this guide.

Goal Setting for Higher Education

The list below includes a small selection of sample goals for higher education:

- Maintaining or improving GPA.
- Meeting with a guidance counselor to ensure you’re taking the right courses.
- Signing up for SAT preparation classes and requesting test accommodations.
- Researching schools of interest – Does their high school have a college prep program or academic advisors?
- Deciding between a trade school, community college, or four-year university.
- Attending college information fairs.
- Scheduling campus tours.
- Shadowing a current student – maybe even spending the night in a dorm.
- Emailing or calling college personnel for information.
- Comparing various campus programs and services for students with disabilities.

Sexuality Education

Sexuality education is sometimes incorporated into a general health class. If your teen will not take a health or biology class in high school, this curriculum still needs to be a part of their education. It should be a strongly stated goal in their Individual Education Plan. Teachers may need to tailor the instruction for your teen. However, understanding how their body works should definitely fall under the category of enhancing self-direction. This hot topic of discussion strikes different chords for different people. However, I think the ultimate goal of any type of sexuality education curriculum should be to teach teens about their bodies and ways to keep themselves safe and healthy. Their bodies and thoughts are changing just like those of their able-bodied peers. They have questions, think about sex, and sometimes act on these thoughts. These thoughts and feelings may be expressed differently, but they probably still exist. We are sexual human beings; this is a simple fact of life.

*Teens have questions,
think about sex, and
sometimes act on these
thoughts.*

Knowing that your teen has a unique constellation of physical abilities and ways of processing new information, I would like to outline a few basic things every teen (especially teens with disabilities) should have.

Thoughts on Sexuality Education

The thoughts below are basic things every teen (especially teens with disabilities) should have:

The power to lead these conversations. They will have questions and need to feel safe enough to ask them. It's okay if you start the conversation, just try being as open and honest as possible when talking about their bodies and sex. They may not have accurate information or a way to process the information they've gathered from other sources. You can ask for help with these sensitive conversations. Resources and support are available on-line, from their school, doctor, or the Regional Center.

An understanding of puberty and why their bodies are changing. This includes learning the proper names of reproductive organs and private body parts and having access to these terms on communication devices. Able-bodied kids are taught this information sometime around age ten. Why not begin these lessons for kids with disabilities around the same age? Teachers and parents may need to use visual aids, books, or other resources and techniques to explain difficult concepts. Some preteens will need frequent repetition and reinforcement to fully grasp this information.

A clear notion of how their body works. Try giving explicit explanations in plain language about what happens during and after sex. Explain some of the possible physical and emotional consequences of sex. Demonstrate using models how to use condoms and

other forms of birth control, and protect against sexually transmitted diseases. Ask them to practice using the models. Tell them that safe sex is the responsibility of both parties. Give your teen permission to trust their body if something does not feel right. Be honest and frank. Remember, this is an ongoing conversation.

Acknowledge that human connections through sex and intimacy are not bad things.

Many teens with disabilities receive negative messages about the dangers of sex and intimacy. These messages always make me sad. They are important parts of how we bond. With the right person, at the right time they have the power to make us feel loved and secure.

A concrete and practical understanding of the unwritten rules of sexual encounters.

These unwritten rules may include obtaining consent from their partner and knowing when to stop or slow down. Sometimes it can be hard to figure out what topics and actions are socially appropriate. When and where can these conversations or actions take place? Who is appropriate to flirt with or ask out? Other topics that revolve around gender and sexual orientation can be hard to understand.

Acceptance. Since teens with disabilities can fall along the same gender and sexuality spectrum as their able-bodied peers, you should be prepared to go through a similar process of acceptance. Your messages can shape their developing self-image. A good friend recommends the book: *The Ultimate Guide to Sex and Disability* to anyone interested in these topics, regardless of how they identify.

A strong voice and self-advocacy skills. These are powerful tools when it comes to having autonomy over their own bodies. Every teen should have a way to say NO and report any unwanted touch. This includes invasion of personal space in the form of pats on their head, the unauthorized use of assistive equipment, and, of course, all forms of sexual abuse.

Health

As your young adult matures, they should be strongly encouraged to take more control over their own health. Here are some basic questions to ask when planning new goals for this area.

Topics for Setting Health Goals

Some basic questions to ask when planning new health goals include:

Nutrition

- Do they have the information and the practice they need to choose healthy food options?
- Can they help plan menus and make grocery lists using words or pictures?
- Does their transition program include a cooking class?
- Can they help cook at home?
- Do they understand the negative consequences of an unhealthy diet?

Exercise

- Do they have the opportunity to move, gain strength, and improve their over-all health through exercise? Even teens with significant physical limitations need opportunities to move their bodies. Adaptive physical education is the most obvious, school-based structure for exercise during the day. Try thinking outside this standard adaptive curriculum.
- Can they be included in sections of general physical education classes or on after-school sports team?
- If they are interested in an activity outside of school, is there a local Special Olympics program, or an adaptive swimming or yoga class?
- Would the neighborhood martial arts teacher be willing to modify their instruction?
- Sometimes having the self-confidence to move in public, even if those movements are a little unconventional, can build confidence in other areas as well.

Explain Disability and Support Needs

- Can your teen explain their health condition or disability to a variety of people?
- How would they explain it to a new friend or their classmates?
- What would they tell a new doctor?
- Could they tell a new assistant at school how to meet their specific support needs?
- If this goal cannot be accomplished verbally, do they have input into these conversations through alternative methods of communication?
- Are their preferences noted, acknowledged, and followed?

Actively Participate in Monitoring Their Own Health Status

- Is your teen able to communicate with unfamiliar supporters when they do not feel well?
- If this communication is primarily nonverbal, are there clear, written explanations of their communication signs or behavior patterns?
- If a daily medical log travels between home and school, can the log be modified (perhaps using plain language or graphics) so they can record the information?
- If feasible, can the student self-report changes in their health status without a log? A link to sample health tracking forms is available in the resources section of this guide.

Perform Basic Health Procedures and Activities of Self-Care

- Can your teen take an active role in either doing certain tasks like taking medication, catheterizing, or monitoring glucose levels, or give clear instructions to new assistants? This is a key step towards any amount of independence. During the school day, perhaps your adolescent could perform these tasks (or some portion) under the supervision of a trained professional.

Healthcare Transition

Hopefully, by now your teen's primary care provider has started a conversation with the both of you about moving towards an adult model of healthcare. These conversations should start when your teen is around age twelve. They are intended to be broken down

into gradual steps that occur over a number of years. A well-timed, organized transition will play an important part of how consistently their health needs are met during this period. If your child has a pediatrician, you may be nervous about leaving this pediatrician who knows your teen's unique medical history and personality so well. Yet, as they mature they will have adult health concerns and questions.

If your teen currently sees a family physician, this physician will need to transition into an adult style of interacting with more appropriate model of care for your maturing adolescent. If they see a pediatrician, this practice should remain actively involved in finding a competent adult physician

All teens and young adults deserve to experience a self-directed model of medical care.

who understands your teen's condition and how to care for their medical needs. Both physicians should work together to ensure a smooth transition. If your teen has difficulty with change or meeting new people, it may be helpful to visit the adult physician while still under the care of the familiar pediatrician. Often, it takes time to build a trusting doctor – patient relationship.

In addition to establishing this new adult provider or model of care, your adolescent's transition should cover several basic areas. These might include:

- Changes in their care needs
- Changes in insurance coverage
- Moving them towards self-direction

Other topics will include issues of informed consent and confidentiality. This physician should also help the both of you investigate the possibilities for the future. Ideally, an adult provider should be able to point the both of you towards resources in areas such as education, employment, and living options. If your teen's new doctor does not already know what resources are available, they should be willing to learn right along with you.

If your teen is growing like a weed during these years, they may need more frequent assessments of their durable medical equipment:

- Do their wheelchair, braces, walker, or crutches still fit their growing body?
- Is it time for a more advanced communication device?

A yearly, comprehensive health assessment can lead to the detection of other types of unmet health needs as well. They will help the physician get to know your teen and understand their specific needs.

Everyone involved in this process should also keep in mind the current and future access needs of your adolescent. What you and your teen might be able to work around now could eventually become a physical barrier to their health care. As a preteen, my dad would carry me onto the scale whenever I was weighed at the doctor's office. The medical assistant would then subtract his weight to determine my weight. This only worked for so long. I was not weighed for a good twenty-five years after I became too heavy for my dad to lift.

Questions for Selecting an Adult Health Care Provider

Below are a few questions to consider when selecting an adult health care provider:

- Are the building and office wheelchair accessible?
- Does the practice have a high/low adjustable exam table and accessible medical equipment?
- Can the office staff modify the environment to meet their sensory needs?
- Will they provide your teen medical information in a format that matches their level and style of communication (through sign language interpreters, print materials in alternative formats, visual aids, plain language explanations, etc.)?
- Does the office staff use respectful and effective communication practices when treating patients with disabilities?
- If you have a specific issue regarding access and/or accommodations, do not hesitate to file a formal complaint with the patient advocate of your medical group.

These accommodations will help your teen develop increased autonomy over their own health care. One of the major differences between pediatric care and adult based care is who is legally able to give informed consent for treatment. You have the legal authority to give this consent until your teen reaches the legal age of adulthood. Perhaps you have already begun to encourage your teen to test out their communication and decision-making skills with their pediatrician. This physician knows them well. They acknowledge and respect their decisions and value your input as a parent. Your teen may have even requested a private appointment to ask questions about their changing body.

All teens and young adults deserve to experience a self-directed model of medical care. This holds true even if your loved one has significant intellectual or communication challenges. Many people with disabilities can make decisions and express preferences with the right support. Some families and other important caregivers already use many of the principles and practices which make up a concept known as Supported Health Care Decision-Making, although they might not recognize this system of support by name.

In short, Supported Health Care Decision-Making is a recognized alternative to conservatorship. This collection of principles and practices is intended to give people with a

variety of disabilities control over their own health care. Under this concept, your young adult could name any number of trusted supporters to assist them in communicating with their doctors, following treatment plans, and making medical decisions. However, they would retain the power to make any and all final decisions about their body and health.

Advocates want to further develop this concept by creating agreements which would outline the types of requested support and give supporters a legal status. Until this happens, there are steps you can take to help your loved one access information and understand their options. If they sign a HIPAA release, you or another listed supporter will be able to communicate with their doctors, have access to their medical history, and other sources of vital information. Other more restrictive options such as health proxies and conservatorships will limit the power and control your loved one has over their body.

Support Health Care Decision Making

Broadening your teen's circle of support and using Supported Health Care Decision-Making practices will:

- Empower them to take an active role in their own health care.
- Help them learn to make decisions with the support of others.
- Ensure they have the support they need, even if you are unable to fulfill this role.
- Establish healthy adult boundaries between you and your loved one.

To learn more about supported decision making you can visit:

<http://odpc.ucsf.edu/supported-health-care-decision-making>

Who can they trust to help them make important decisions about their health?

You may have qualms about someone else helping your teen make medical decisions. You have probably been to every doctor's appointment, and made sure every treatment plan was followed. Yet, you will need to let someone else help them at some point. Identifying and learning to work with other chosen supporters before it becomes a necessity will make this transition easier and more successful in the future. Your teen may still choose to list you as one of their supporters.

Of course, your young adult must have a positive relationship with all of the individuals who support them in this role. They definitely should not have a conflict of interest (such as their doctor or care home owner) and they must respect and communicate the decisions of your young adult. One way to let a new supporter get to know their medical history, likes, and dislikes is to ask them to complete a health passport together:

http://odpc.ucsf.edu/odpc/html/for_self_advocates/index.html. You should remain available to answer questions and fill in gaps.

Who should fulfill these roles?

Filling the Role of Health Care Supporter

Below are considerations to help your young adult identify potential healthcare supporters:

- Are they close to a sibling or another family member?
- Do they have a good relationship with a staff member from their day program
- Is there a reliable friend or neighbor?
- Do they have a support coordinator through their independent or supported living agency who knows their medical history and preferences well?
- Do they receive services from an organization that offers health advocates such as the Arc of San Francisco?
- Health advocacy services can be included in your teen's individual Program Plan.

My support coordinator has gone with me to almost every medical appointment. She helps me with physical tasks like undressing and transferring onto the exam table. She also helps me communicate with medical staff and doctors when they are unable to understand my speech. Often, we have to redirect doctors back to me when they ask her questions about my body and health. I ask people I value to support me when I have to make major medical decisions.

Adolescents with disabilities should be empowered to talk to medical providers. Many teens with disabilities have multiple doctors. This interdisciplinary care should be team-based, with your loved one and their supporters at the center of this team. The doctors should communicate with each other. These physicians should respect the authority of your teen over their body. They will need to work with your teen and their supporters to find appropriate, functional methods of communication.

Suggestions to Nurture Health Care Autonomy

Below are a few ideas to suggest to doctors and their staff to nurture your teen's autonomy:

A Single Point of Contact

- Is there an extra kind, competent staff member who communicates well with your teen?
- Are they available through a backline phone number to answer their questions or relay messages to the doctor?

- If your teen wishes to practice scheduling their own appointments, can they contact this person?

A Way to Respect their Privacy

- If your teen has a private concern and cannot attend an appointment without support, can they contact the doctor from home?
- Is the doctor available via phone conversation, Skype chat, or through a secure email?

An Alternative to Long Waits and Appointments

- If your teen cannot handle long wait times or appointment blocks, can forms be filled out at home?
- Can appointments be scheduled either during the first morning slot or immediately after the lunch break, before the doctor gets backed up by other patients?
- Can the bulk of the conversation occur before the appointment?

A Longer Appointment Time

Conversely, your teen may need a longer appointment to accomplish physical tasks or communicate with the doctor.

- Can the office schedule a double appointment or during a time when the doctor has a little more flexibility?
- Can forms be completed at home?

A Chance to Practice Setting Their Own Health Care Goals and Priorities

Your teen needs opportunities to express what is important to them.

- Do they think current treatments and therapies are beneficial?
- For example, would they rather use a power wheelchair at school to keep up with their friends or maybe swap a therapy session for more hang out time?
- Do they know about alternatives and the consequences?
- Can they make their choices known?

A friend and wise physician once wrote, *“Wellness is more than being free of illness; it is being in balance, participating, and being included in all aspects of life.”* For me, this means having control and a voice in the world. It means getting the support I need, being treated with dignity, and having the final say over what happens to my body. It means the people who know and support me, including my doctors, do not make assumptions about my capabilities. They understand what is important to me and that I want to lead a productive life. They know I have many of the same dreams and concerns as my able-bodied peers.

What Will Life Look Like After High School?

For some young adults with disabilities, life during these transitional years may look a little different from their able-bodied counterparts. Your teen may not have earned their driver's license at sixteen, gone to junior prom, or hit other milestones at the prescribed age. Yet, they have conquered many hurdles and achieved some amazing accomplishments during these years. Focusing on these hard-earned successes will motivate them to aim for their future goals.

Adults with disabilities need new experiences to change, grow, and experience a variety of stimulating experiences.

Many of your adolescent's customized educational services will end upon graduation or when they complete their allotted years in special education. If a solid transition plan was put into action beforehand, the new services and programs outlined in this plan should fall into place. If this road map does not lead to an ideal destination, you may want help identifying different types of support services.

Person-Centered Planning

A good way to start your investigation is with a Person-Centered Planning meeting. These meetings are similar to their Individual Education Plan meetings in school, but can have broader implications for their quality of life. These planning meetings have a variety of names depending on the agency involved. However, the main focus of any single meeting must be the direct wants and needs of your teen and your family. They should be encouraged to invite anyone they wish to these important meetings.

Qualities of Person-Centered Plans

Person-Centered Plans should:

- Help define a vision and plan for the future.
- Acknowledge the right to self-directed services.
- Use a team approach; giving your young adult a leadership role.
- Recognize their unique constellation of talents, abilities, and support needs.
- Assist them in developing relationships, participating in the community, and taking more control over their lives.
- Aim to solve problems.

Many principles of Supported Health Care Decision-Making discussed in the previous section can be put into practice for other areas of adult life. If given the right support and information in an accessible manner, your young adult may be able to make other life decisions about where they live, how they spend their money, and what they do during the day. This is just a short list of countless choices they can make with support.

All of the activities listed in the sections below are by no means meant to be mutually exclusive. Like everyone, young adults with disabilities need new experiences to change, grow, and experience a variety of stimulating activities. Your young adult may not be happy or fulfilled if they are simply plugged into a single, existing activity. With some creative person-centered planning, the right combination can be found.

Of course, your family member may need additional support to envision their future and create objectives.

Questions to Aid Creative Person-Centered Planning

Below are questions to answer with your family member to help guide the process of discovery:

- What do they see as their greatest strengths and weaknesses?
- What are their hopes and dreams?
- What are their support needs?
- What do they like to think, talk, or learn about? What are they drawn towards?
- Do they have special skills, passions, or talents? (Art, computers, music, writing, cleaning, organizing, engaging in conversation, playing with children, cooking, etc.)
- Do they have an ultimate goal? If this goal is unrealistic, can it be modified or broken down into smaller steps?
- Do they have the prerequisite classes, training, or skills to meet their goal?
- What is their optimal schedule? Are they active in the mornings or do they function better in the early afternoons?
- What are your pressing family considerations? Do you need to work during the day? Can you afford the extra expenses associated with certain programs? Are other funding sources available?

Finding a meaningful activity to occupy the previous hours spent in high school is crucial for the mental health and motivation of your young adult. You may need to work or fulfill other commitments and duties during this time. Fortunately, there are a wide variety of available options within this category, ranging from college, work, customized or supported

employment, volunteer opportunities, and adult day programs to name just a few options. They can choose a single option or a unique combination depending on what appeals to their interests and meets their specific needs. In a perfect world, support needs would not factor into these choices. In reality, however, it sometimes takes a while to put all the pieces together to create the life your young adult wants.

Going to college is about so much more than just earning a degree.

Going to College

Going to college is about so much more than just earning a degree. My college years were about meeting new, interesting people, finding a passion, and figuring out how I fit into the world. Owen always says college did not teach him what to think; instead it taught him how to think. If nothing else, college will expand your young adult's view of the world. They will learn how to think independently, solve problems, establish networks, and question beliefs. People from so many different backgrounds and walks of life attend college, so it is often a great place to find your niche.

I have heard stories of parents attending college classes with their young adult children with disabilities. Please, if you are considering this, I beg you to look into other options! This should be the time when they build a network of friends and discover who they are without your constant support. Under The Americans with Disabilities Act and Section 504 of the Rehabilitation Act students are protected from discrimination based on their disability. Unlike high schools, colleges and universities are not required to provide these students with a free and appropriate education. They are however, required to provide "appropriate academic adjustments" (<http://www2.ed.gov/about/offices/list/ocr/transition.html>) in order to prevent discriminatory practices. Many campus disabled student service programs have a variety of ingenious ways of meeting all types of academic and personal support needs. Each program offers slightly different services, but common services are likely to include the following:

Common Campus Disabled Student Service Programs

Each disabled student service program offers slightly different services, but common services are likely to include the following:

- Accessible student housing
- Priority course enrollment periods
- Academic advising based on disability (help deciding on a courseload)
- Auxiliary Services

- Note-takers
 - Readers
 - ASL interpreters
 - Assistive listening devices
 - Alternative media formats
- Academic accommodations such as extended time on tests
 - Attendant referral lists
 - Basic mobility equipment repair services

I met my awesome best friend during my freshman year. She has a visual impairment and I have various mobility impairments, so together we each used a wide swath of the services listed above. We each lived in accessible dorm rooms for our first three-years of school. We both received extra time on tests. I had assigned note-takers in most of my classes. She was escorted to her classes by someone in mobility services and received print material in Braille or via an audio format. She loved how her dedicated readers would sometimes use different voices if a book had multiple characters.

We had many slightly older friends with disabilities to show us the ropes during these four years. They each had creative ways of making college work for them. Some hired attendants who they met on campus at designated times and locations. Their attendants helped them use the restroom, eat lunch, or run errands. Others scouted out accessible off-campus apartments.

If your teen thinks these accommodations may be useful, they will need to submit written documentation of their disability. We graduated nearly twenty years ago. Much progress has been made during those intervening years. Today, the college experience is possible for a wide variety of students with disabilities and health conditions. Certain two-year and four-year schools now offer newer programs specially designed for students with intellectual disabilities.

Community colleges are a great place for any student to either begin their journey or simply take an interesting class or two. I fell in love with a creative writing program at a local community college. These classes allowed me to sharpen my writing skills and stay engaged with the world as I searched for employment.

Financial assistance via scholarships or grants is available for many students with disabilities at almost all educational levels. This assistance is intended to help cover the cost of tuition and educational materials such as books and other supplies. In some cases, The Department of Rehabilitation will cover these expenses.

Working

Potential new employees should have big dreams and be ready to conquer their corner of the world. They should know that sometimes there are ways to make the system work for them. First, they will need to do the hard work of finding a job. I would be lying through my teeth if I said your young adult will have an easy road to employment. Convincing a potential employer to look past their limitations and see their remarkable talents will be a difficult, uphill challenge. When these attempts are unsuccessful, the rejection will be painful, especially when your young adult suspects it might be due to a disability that they cannot change or control.

Yet, I know so many people with significant disabilities who have jobs they love. They all shared the unshakable belief that they had something important to contribute. They had faith that they would eventually find an employer willing to think outside the conventional box. If your loved one can hang onto those two basic beliefs even if the job market has locked multiple doors, they will have the best chance of coming across an unlocked door. They don't have to find these unlocked doors alone. They can receive support and resources from organizations focused on employment for people with disabilities.

My best advice is to start down this path in high school and college.

Tips for Establishing a Work History

Below are some ideas to help establish a work history:

- If they have a unique skill or interest, perhaps they could set up an informational interview with a professional in this field.
- If a paid position is not available or realistic, could they contribute to a project or perform a customized set of work tasks?
- Could they work or volunteer some place for a few hours after school or during the summer?
- Does their day or transition program include work opportunities?

If they can establish a work history now (show future employers what is possible) it will be easier to travel down this path later. In other words, can they get a foot or wheel through the front door?

If your young adult wants to find a job, there are a variety of services to help them achieve this goal. Select high schools in California have established Transition Partnership Programs (TPP). High school students must qualify for Department of Rehabilitation services. A Rehab counselor can authorize funding for community based instruction, vocational and work-site

training, job placement, and follow-up services upon graduation. I wish this program had been around when I attended high school. I would have loved a summer job. To learn more about this program, please visit: <http://www.dor.ca.gov/public/factsheetdocs/TPPFactS.pdf>

Many high schools, community colleges, and four-year universities also offer students “pre-employment services.” In California, these services are sometimes clustered into “Workability” programs. I have participated in several Workability type programs throughout the years with varying degrees of success. These programs however, have had extremely positive outcomes for many of my friends.

Typical Pre-Employment Services

Pre-employment services typically enable participants to prepare for the job market by:

- Offering techniques on creating networks
- Guiding job searches
- Assisting with resume writing
- Practicing interview skills
- Suggesting ways to disclose a disability to a potential employer
- Evaluating work place accessibility and ergonomics

Newer programs are beginning to focus on the power of building a network. The Center for Independent Living director spoke of an innovative approach they are now trying in their employment program. He said that their first goal is to encourage young adults to reframe their thoughts on employment. Then, ask them to imagine the possibilities. Next, help build their network by matching them with professionals in their chosen field. These meetups not only give the participants a more positive picture of the job market in their desired area, it also allows potential employers to see these young adults as realistic job candidates.

Customized Employment

If an employee with a disability cannot meet all the standard requirements of a particular job, some employers can customize or carve out a set of tasks that align with the employee’s unique skills and capabilities. For example, an employee with a disability may lighten the workload of their coworkers by performing office management type tasks or take on quality control tasks which require a high degree of singular focus and attention. The possibilities are endless. Job placement counselors may help some employers to think outside of their standard box. They can also assist your young adult in creating lists that both emphasize their skills to potential employers and offer a set of job duties they are able to perform.

Work Incentives

Both of you may worry that the person with a disability will become ineligible for government benefits such as Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) when they enter the work force. Advocates are pushing for changes in the system to protect these benefits for employees with disabilities. Certain programs already exist. The Social Security Administration has created a number of work incentive programs which allow people to explore their work options and receive job placement assistance without immediately losing their medical insurance and income benefits. One well-known example is the Ticket to Work program. Social Security has published a pamphlet on their website summarizing Ticket to Work and the other work incentives currently available. Yes, these incentive programs have many flaws. They will not meet everyone's needs in terms of income stability and medical insurance coverage. Still, it is always good to understand the available options. To learn more, visit: <https://www.socialsecurity.gov/pubs/EN-05-10095.pdf>.

Supported Employment Services

In the past, employment for people with significant intellectual and physical disabilities typically meant placements in segregated workshops and shelters for subminimum wages. Today, we are not satisfied with these arrangements. In fact, several states have successfully eliminated these workshops altogether. They have found integrated employment placements for individuals with all types of support needs. Your young adult has the right to work at a real job that pays a real wage. The tenets of supported employment are based on the belief that anyone has the ability to work given the proper supports. If they are consumers of the Regional Center and/or the Department of Rehabilitation, they can request these services.

Many of the consumers I interviewed for my quality-assessment job worked at various supported employment job sites in the community. These consumers worked on janitorial crews, in bakeries, at recycling venues, hospitals, and animal shelters to list just a few examples. They either worked in groups or individually with a job coach. The coach usually was employed by a specific agency that provided these services. Each consumer who utilized these services needed support to function in a competitive job.

If your young adult wants to receive supported employment services, an agency will do a comprehensive evaluation to find a job site placement that matches with their skills and interests. Don't be afraid to ask for a little more creative thinking on the part of the chosen agency when it comes to finding the right job site for your loved one, even if the placement lies outside their standard practice. They should be willing to work with your young adult to find a job site that keeps them productive, challenged, and engaged in their work.

Ideally, these customized services should:

- Place a high value on your young adult's preferences
- Provide trained job coaches and specialists
- Offer work-site training and support
- Build in enough flexibility to last indefinitely or be phased out gradually over time

If your young adult has expressed an interest in working, supported employment may be the perfect starting point. Some programs and agencies provide consumers with a higher level of intense job site training and a host of other supports to enhance employment success.

Attending an Adult Day Program

I have quite a bit of first-hand knowledge about adult day programs based on my roles as an observer, volunteer, and employee. These programs provide daily activities for people with disabilities of all ages. They may be in a fixed location, centered out in the community, or some combination of these two settings. Thankfully, the newly implemented Home and Community Based Services Settings regulations state that Medicaid (MediCal in California) will not fund services that promote segregation and isolation. I volunteered at a program where participants were bussed to an aging building in a remote location. When this program began, segregation of people with disabilities from their community was the norm. The current regulations require that a strong community integration component and choice of activities be built into all existing and planned day programs.

Examples of Types of Adult Day Programs

Below is a small sample of the types of programs which exist:

Life Skills and Transition Programs: Foster the development of everyday living skills such as cooking, community access, and money management.

Creativity Based Programs: Allow participants to explore the arts. Certain programs have galleries which display and sell the artwork created by the participants.

Interest Based Programs: Offer a spectrum of activities and classes such as adult education, physical enrichment programs (like special needs yoga classes and swimming), or access to adapted computer labs.

A quality day program should provide your teen or young adult with a framework to build and maintain friendships and pursue select areas of interest. Some programs serve participants with specific disabilities or functional levels. For programs that serve people

with intense support needs, staff members generally assist them with any health maintenance and personal care tasks.

Since it is important for them to keep learning and have opportunities to practice new skills throughout adulthood, successful day programs will tailor parts of their curriculum to help your young adult meet their individual goals. My friend Monique, for example, uses the skills she learns in the micro-business incubator class at her program to grow her own graphic art business.

Skills Successful Day Programs Can Foster

Below are a few skill categories successful day programs can help foster in people with disabilities throughout adulthood:

Basic Functional Academic Skills: Learning to use and budget money or identifying basic road signs.

Activities of Daily Living: Developing hygiene skills.

Communication: Expressing wants and needs or communicating in public.

Use of Assistive and Adaptive Devices: Using devices appropriately or maintaining devices (asking for support to keep them clean, charged, and repaired when needed).

Healthy Lifestyle: Meal planning, basic cooking skills and opportunities to exercise.

Self-Advocacy: Tools to say no, express an opinion, and fulfill needs.

Functional Life Skills: Travel training or community access – participate in new and novel experiences, adapting household tasks.

Self-Care: Increased independence in self-care or practice instructing supporters.

Social Skills: Opportunities to make new friends and stay in contact with old friends and learning unwritten social rules.

Vocational Skills: Volunteer opportunities, chances to practice taking responsibility, researching job possibilities or internships.

In order for your young adult to experience personal growth, day programs, like all types of support services, must be:

- Flexible
- Align with areas of interest
- Promote goal achievement, and
- Allow for choice

The single biggest gripe I have about many day programs is that they can become Bermuda Triangles or black holes of disability services for some participants. They are placed in a program after high school and are left there for the next thirty years. People change and need new experiences to grow. Sometimes, a program is a great fit for a person. They have found a niche and love the staff. They may not want to leave. Other times, they may not know about their options, alternatives have not been created or explored, or someone in their circle of support thinks it's easier to not rock the boat. I have seen boredom and apathy towards a program lead to regression and anger. If your loved one cannot express these emotions verbally, are they trying to communicate through their behavior or actions? If a particular program no longer fits their current interests or needs, please ask for help to identify and test out new options.

Both of you will need time to establish new and healthy boundaries.

Living Options

Planning for their future also means considering the best living option. These options range from living in your home to living independently with appropriate supports in another location of their own choosing. Your young adult could choose to live in a licensed community care home with three to five other adults with similar functional abilities. Large institutional care facilities and “intentional communities” are rapidly being phased out in favor of smaller, neighborhood-based residences. Or, they could choose to live with you or receive individual services from either an independent living agency or a supported living agency and live in their own home or apartment.

Living with Family

If you and your young adult have chosen to live together during these transitional years, there are several things to consider when planning for a future that will work for your family. You should have opportunities to pursue your own interests. Both of you will need time to establish new and healthy boundaries. Most of all, you need and deserve assistance with caregiving responsibilities. Don't be shy about asking for help when you need a break. Your primary care provider or Regional Center coordinator should be able to help you identify community resources.

Below, I've listed some ways of getting support and other ideas to consider. I am sure there are many things I missed. Please, just think of this list as a jumping off point.

Supports and Considerations for Living with Family

Below are ways of getting support and other ideas to consider when living with family:

Natural Supports. In addition to using siblings and other family members as care providers, is there another nearby family of a person with a disability? Perhaps they are friends from school or their day program. My sister and another mom friend often swap care duties with each other for things like date night or errands. This not only benefits both moms, it also provides both teens more time to hang out with a familiar friend. If both friends happen to use similar mobility equipment, they may already have the necessary home accommodations.

Respite Care. If your loved one is a consumer of the Regional Center, either of you can request a certain number of respite hours from their service coordinators. These hours are meant to prevent the physical and emotional burnout you may feel as a result of your own intense daily caregiving responsibilities. These respite care hours will also provide your loved one with a chance to receive support from someone else and enjoy their company. The Regional Center will fund these hours and in some cases help find a qualified care provider.

Personal Assistance. If your young adult lives in California and meets certain requirements, In-Home Supportive Services will pay direct support workers to provide them with personalized assistance. Family members, friends, or other individuals can fulfill this role. Many families use this income to replace at least a portion of the wages they may have earned in lieu of their current caregiving duties.

Home Adaptations. As your adolescent grows into a larger adult, routine tasks such as bathing and transferring to and from a wheelchair may become more difficult. At some point, home adaptations and select pieces of durable medical equipment such as ramps, grab bars, Hoyer Lifts, roll-in showers, accessible bathrooms, and shower/toilet chair combinations can become extremely helpful. They may also give your young adult a greater sense of independence. The Regional Center or other not-for-profit organizations may be able to fund these adaptations. Some cities have home modification funds or other types of funding sources such as the Community Living Fund in San Francisco. These designated funds allow residents with disabilities to remain safely in their homes. If funding is not available, some organizations actually loan equipment on a trial or semi-permanent basis. Occupational therapists from the Regional Center or other agencies can help brainstorm other ideas to make daily living a bit less challenging.

Preparing to Live Independently. Another option exists if your young adult still lives at home, but would like to receive independent living services in order to move into their own apartment or house. Regional Center Service Coordinators can authorize a limited number of hours to help them gain functional life skills and identify resources to prepare for this move. This move must be a stated goal planned for their near future.

Subsidized Housing Lists. The Housing Choice Voucher Program known as Section 8 can have a long waiting period. If your young adult meets the income eligibility requirements, ask their service coordinator for information about this program as soon as they are seriously considering moving.

Independent Living Services (ILS)

Support is also available if your young adult can perform most of their own activities of daily living (bathing, feeding, dressing, toileting) with minimal assistance and want to live in their own home or more independently in their family home. For people who may need a little more assistance performing these tasks, arrangements for additional hours of support can sometimes be made through In-Home Supportive Services or another agency. Flexible and tailored supports should be offered to your loved one if they do not fit perfectly into a structured model.

Independent Living Services (ILS) Coaches can help your young adult learn how to budget their money, pay bills, and schedule appointments. They can assist them in learning to cook, accompany them to medical appointments, and help with a host of other important tasks. They will receive a certain number of hours each month. These hours can be increased, remain consistent, be decreased, or phased out entirely over time depending on their needs and goals. All independent living services should be designed to help them achieve their goals and promote the greatest level of independence possible.

These services can occur in the community, in their home, or at the independent living services agency office. The location frequently depends on the practices of a particular agency. This can be good information to know before you both decide on an agency. If the practice is to provide instruction from an office setting, will your young adult be able to transfer these learned skills to their home environment? Personally, I do not feel this general strict practice embodies the spirit of flexible and tailored services.

Many consumers choose not to live alone. Your young adult may want roommates to share the financial responsibilities of independent living, provide a buffer against loneliness, and compensate for one another's weaknesses. If, for example, they want to live with a friend from their community day program, they might enjoy cleaning, while their friend loves to cook. Together, they will make a fierce team. They each have separate service coordinators, but perhaps share an ILS coach who supports them in maintaining their apartment and in other areas of their lives.

Supported Living Services (SLS)

I use supported living services (SLS) to help me live the life I want. These types of services are designed for consumers who wish to live in a home of their own, but may require a higher level of assistance. If your family member requires help with common activities of daily living, has intense behavioral needs, or a combination of support needs, then supported living services may be the right fit. My support coordinator recently told me these services often work well for people who have experienced problems with other types

of living arrangements since all of the supports are created around the person. In other words, your loved one will receive individualized attention and services that revolve around their world.

Supported living services work much the same way as independent living services with a few intentional differences:

- Independent living services focus more on teaching consumers life skills in order to increase their ability to function independently and possibly decreasing their need for paid support.
- The main goal of supported living services is to enhance independence through the utilization of tailored levels of significant support.

This support is generally provided by a supported living agency. Some agencies provide both independent living services and supported living services. For consumers who also qualify for In-Home Supportive Services, their total number of allotted hours will be combined. Many supported living services consumers receive support twenty-four hours a day, seven days a week. They often have a paid roommate – a staff member who lives with the person and provides support for designated shifts.

A supported living services agency will assign each consumer a support coordinator (sometimes referred to as a service coordinator or other similar job title). Laurel plays an important role in my life. She helps me trouble-shoot problems, advocates on my behalf, and provides an in-depth degree of oversight for my direct support staff. A good coordinator will be able to assist your loved one in a variety of other areas as well.

Support Coordinator Assistance

A good support coordinator should be able to assist with:

- Hiring and supervising direct support workers
- Handling finances
 - Making sure bills get paid
 - Structuring a budget
 - Accounting for money
 - And more
- Tracking medical needs
 - Scheduling and attending medical appointments
 - Keeping medical histories
 - Helping to coordinate other health maintenance tasks
- Serving as a liaison between your young adult and other support programs
- Keeping the Regional Center up-to-date on status changes and annual reports
- Identifying and accessing community resources
- Advocating for services

A good support coordinator can make a huge difference in their quality of life. The first step to finding this coordinator is to identify a quality supported living services agency. These agencies come in all different shapes and sizes. There can be trade-offs depending on the size of the agency. Smaller agencies tend to support fewer consumers and can often provide more personal attention to each consumer. Yet, larger agencies tend to employ a greater number of direct support workers and can have an easier time finding back-up coverage when an employee has to miss a shift. Make sure the agency you both choose has a designated twenty-four hour, on-call staff member who can be reached in emergencies.

Direct Support Workers

Direct support workers are sometimes called attendants or home care workers. Your young adult can ultimately hire these assistants through In-Home Supportive Services, via a supported living services agency, or by another means. Regardless of the funding source, they should remember that the person actually works for them. This can imply all sorts of unfamiliar freedoms and responsibilities. Before I discuss this crucial working relationship, maybe I should back up and start at the beginning of the hiring process.

Where to Find Direct Support Workers

Once your loved one has determined their support needs (including things like specific tasks and the number of hours or shifts), they can participate in the process of looking for qualified workers. Even if they only have a limited number of support hours, it's usually a good idea to hire more than one person. Different attendants can bring a variety of strengths and talents to this job. Another benefit of hiring multiple attendants is their ability to cover for each other if one person must miss a shift.

Where to Find Direct Support Workers

Below are potential ways to find direct support workers:

Word of Mouth: Often, the best way to find a good worker is by word of mouth.

- Does your young adult know someone who loves their attendant or do you know another parent who has found a great supporter for their loved one?
- Is this supporter looking for more hours?

List Serves and Websites: Believe it or not, sites like Craig's List are popular places to find attendants. My favorite attendant answered a help wanted ad that someone from my supported living services agency posted on Craig's List. Other websites such as MySupport.com focus on matching the right supporter with your young adult. State agencies like In-Home Supportive Services frequently maintain a list of current workers, but they tend to provide little to no background information.

Job Board Postings: College students can make great attendants. Consider posting an ad on a college or university job board.

Their supported living agency may already have the perfect supporter on their staff. If not, they should help your family member find several ideal candidates to interview. Your loved one will need to remain involved in these interviews to the greatest extent possible, even if this involvement means being present in the room during the interviews. Some agencies try to skirt this step by assigning workers to their clients based simply on hours and availability. In my experience, this match-up never works out for very long. The nature of this position is intensely personal. Attendants will spend a great deal of time with your loved one and know intimate details about their lives. Each party should agree to this match-up or have the clear option to say, “No,” and look for another candidate or potential client.

Many of the thoughts and interview questions I’ve listed below are based on my own experience. They are based on things and ideas that are important to me. Your young adult will have a different set of priorities, but this list might spark a few ideas.

Questions for Interviewing Direct Support Workers

Below are thoughts and potential interview questions for hiring a direct support worker:

- Does the person speak directly and respectfully to me or do I get a bad/condescending vibe?
- Are they okay with doing things differently/how I want them done? (Allowing for some flexibility with regards to how tasks get done is important.)
- Are they typically on time to their work obligations?
- Can they take initiative, but not overstep my personal boundaries? (This is a hard balance, and usually takes training and a willingness to learn and adjust. Maybe ask for past examples.)
- Are they willing to help me with things that they might not personally condone as long as there are no negative consequences for them? (Like pouring me a drink made with alcohol.)
- Do we share any common interests?
- Do they like pets, and are they comfortable with pet care?
- Have they worked with anyone with cerebral palsy or a speech impediment?
- Are they comfortable doing the personal and household tasks I need done?
- Do they enjoy cooking? Do they have any objections to cooking meat?

Usually, candidates are prescreened by the quality assurance manager of my supported living services agency. She asks candidates for references and if they have CPR/First Aid certification. If they are hired by the agency, they can become certified before they start working. Laurel almost always attends these interviews with me. By now, she knows me well enough to help me judge if a candidate might be a good fit, but I always have the final say over who gets hired.

Working with an Attendant

After your young adult has hired personal care attendants, they will need to develop a working relationship with each individual. I have had dozens of attendants over the past twenty years. They each come into my life with a unique personality and working style. It has taken me a long time to figure out what traits work best for me, and sometimes I still have to trust my gut. I like having someone work for a no-fault, two-week trial period. This gives us time to get to know each other and establish a routine. Either of us can back out of the arrangement at the end of this period if we are not satisfied. Sometimes a trial period is more complicated if they are hired through an agency because of the costs associated with a new employee (background checks, TB testing, etc.), but the agency may be able to place the employee with another client. This might be worth asking about when investigating different supported living agencies or hiring attendants through another method.

If your young adult chooses to live in a care home, they will have the right to privacy, dignity and respect.

Many people who apply for this job see this work as a transient position. They may need part-time work while they go to school, or as they search for a better paying career. Attendants who are paid by the state or through a vendorized agency usually only earn slightly above minimum wage. Fair wages for people who help us live in our chosen communities is a large topic best suited for another forum. I mention it here only to help you understand why workers tend to leave this job. This turn-over will likely be emotionally difficult especially if your young adult has grown attached to a particular attendant. I have shed many tears as I said good-bye to some of my favorite workers. On the flip side, a few of my friends have had the same attendants for decades.

Regardless of how long they remain in any one position, most attendants are completely dedicated to their job. They know their employer/client inside and out. They know their daily routines and encourage them to lead self-directed lives. I've had so many caring attendants. Yet, this relationship is almost always tricky. The boundaries between employer and friend often become blurred. Everyone wants a positive and friendly work environment, but it is just as important to establish boundaries you will not cross. I had one attendant borrow a large sum of money. When she took advantage of our friendship by not returning my money, I learned the hard way that this was a bad practice.

Once the friendship boundary has been crossed, some attendants have difficulty taking directions. They may start showing up late for their shifts, wanting to leave early, or cutting

other corners in their assigned tasks. One simple solution to this dilemma is for your young adult to remind their direct support worker that this is the time they have to get their needs met. Sometimes, if an attendant fails to accomplish a task, it will not get done that day. It's helpful to have an assigned written weekly chore or duty list so each attendant knows what they are expected to do during each shift. Other times, apathy may be a sign of burn-out. In my experience, once an attendant has reached this phase, it's usually time to start looking for a new attendant.

A final note before I leave this topic: Sometimes it's hard to remember that attendants have their own needs and personal boundaries. They may not be able to stay later than their assigned shift or they may not feel comfortable helping someone with an activity that jeopardizes their safety, health, or job. This is a working relationship. Respect needs to travel both ways.

Licensed Community Care Homes

My work partner and I visited many community care homes, also called group homes, when I was employed by Area Board III. These typical neighborhood homes provide living accommodations for three to five individuals with developmental disabilities. The staff in these homes offered different levels of support depending on the level of medical care and behavioral needs of the residents they served. Each home had a unique vibe. Some houses we entered felt like a warm, nurturing home and the residents felt like a family. While other houses we visited felt like smaller versions of the institutions where many of the residents had previously lived. The residents did not choose their roommates, have the power to lock their bedroom doors, or decorate these shared rooms with their personal belongings. Luckily, the current Home and Community Based Service Setting regulations will strengthen the rights of these residents.

If your young adult chooses to live in a care home they will have the right to privacy, dignity and respect. This can include the right to lock their own bedroom or bathroom door and the right to choose a private room or select a roommate and staff of their choice. Your loved one will also have the right to speak privately with friends and family. They will be able to make choices about their daily activities and relationships. Of course, safety issues will be taken into consideration. For example, they will have access to food unless they have a disability where this access can substantially endanger their health, such as Prader-Willi Syndrome. Exceptions are written into their Individual Program Plan.

These new regulations will give your adult with a significant disability many of the rights and freedoms that able-bodied adults often take for granted. I am excited to see how these regulations actually change the landscape of our services once they are fully implemented.

They will apply to a wide spectrum of disability-related services in addition to care homes and day programs. I hope they lead to the development of more community-based, meaningful jobs. To learn more about exercising rights under these new regulations visit: <http://autisticadvocacy.org/policy-advocacy/policy-advocacy-toolkits/hcbs/>.

A Few Final Thoughts

An old friend with a visual impairment once said, *"I am in the world, man!"* This comment made me smile. I knew exactly what he meant. He realized that yes he perceived the world a little differently than most sighted folks, but he still wanted to explore his community, be a part of the action, and take his place in the world. This is exactly what I want for your young adult, and for the next generation of people with disabilities.

*Thank you for being a
part of this journey.*

Everyone deserves to have the support they need to live as full members of society. You, as parents and caregivers, deserve to know that this support is available when the time comes for you to take a step back from this role.

Please, have high expectations for your loved one. They will absorb so many of your words and actions. Help them find positive role models and programs that support their dreams. Teach them advocacy skills and to have the courage to ask for exactly what they want and need. Tell them that "no" is an acceptable answer, and sometimes the only answer that will give them a sense of power and control over their lives. They need a voice – whatever their chosen method of communication.

Help them to feel valued for being the (smart /funny /kind/creative/thoughtful) person they are right now. Show them that they have something awesome and important to contribute to both your family and the world. They may feel a certain sense of guilt for being disabled or having to rely on others to meet their needs. I know from personal experience that it is often hard to feel worthy of love or other good things when you feel like a burden. Remind them that we are all interconnected and rely on each other for support.

Remember that it's okay for you to ask for support and pursue your own passions. Share your caregiving responsibilities and take care of your own health. Team up with other parents or ask for more respite care hours from your young adult's service coordinator. Go on a date or join a book club. I promise your young adult will be happier if you're healthy and less stressed. Besides, this is a great time to give them some space away from you. I don't know many twenty-somethings who really want to spend all their time with a parent.

It's also okay to disagree with proposed or current services. This is how better services are developed. We need more parents to demand that society allow their young adults to participate in all aspects of life. Society can be slow to move forward, but it usually follows the lead of the available services. When institutions housed and cared for people with disabilities; it was the norm to keep us hidden behind closed doors. Now, thanks to the

parents of past generations and many other advocates, we are active participants of our community. We still have plenty of work to accomplish on this journey. Yet, these groups will continue to create a world that values all people and welcomes the gifts of diversity. Thank you for being a part of this journey. We owe so many of our accomplishments to the unwavering, boundless love and support of our parents and supporters.

Resources

The Lanterman Act and the Regional Centers

California Department of Developmental Services: <http://www.dds.ca.gov/RC/RCipp.cfm>

California Regional Center Directory: <http://www.dds.ca.gov/RC/RCList.cfm>

The Lanterman Act: http://www.dds.ca.gov/Statutes/Statutes_Home.cfm

Rights Under the Lanterman Act:

<http://www.disabilityrightsca.org/pubs/PublicationsRULAEnglish.htm>

Olmstead Rights: <http://www.olmsteadrights.org/about-olmstead/>

The Individuals with Disabilities Education Act and Special Education

California Parent and Training Information Centers: http://www.parentcenterhub.org/wp-content/uploads/2015/12/PTI-CPRC_CA_110615.pdf

Center for Parent Information and Resources: <http://www.parentcenterhub.org/find-your-center/>

Individuals with Disabilities Education Act: <http://idea.ed.gov/>

U.S. Department of Education: *Definition of Individualized Education Program:*

<http://idea.ed.gov/explore/view/p/%2Croot%2Cregs%2C300%2CD%2C300%252E320%2C>

Transition Planning

U.S. Department of Education: *Transition Services*

<http://idea.ed.gov/explore/view/p/%2Croot%2Cregs%2C300%2CA%2C300%252E43%2C>

Meeting Your Teen's Transition Goals and Needs

California Department of Education: *Low Incidence Specialized Services*

<http://www.cde.ca.gov/fg/fo/profile.asp?id=2299>

California Department of Education: *Special Education Local Plan Areas*

<http://www.cde.ca.gov/sp/se/as/caselpas.asp>

Continuing Education

California Department of Rehabilitation: <http://www.rehab.cahwnet.gov/>

Disability Rights California: *Educational and Training Services through the California Department Rehabilitation Fact Sheet:* <http://www.disabilityrightsca.org/pubs/557201.pdf>

Rethinking College: *A Film about College Students with Intellectual Disabilities*

<http://www.thinkcollege.net/training/rethinking-college-the-film>

Health

Office of Developmental Primary Care: <http://odpc.ucsf.edu/>

Office of Developmental Primary Care: *Charts & Forms*

http://odpc.ucsf.edu/odpc/html/for_self_advocates/charts_and_forms.htm#overlay-context=odpc/html/for_clinicians/charts_forms_c.htm

Healthcare Transition

Office of Developmental Primary Care: *Health Passport*

http://odpc.ucsf.edu/odpc/html/for_self_advocates/index.html

Office of Developmental Primary Care: *Supported Health Care Decision-Making*

<http://odpc.ucsf.edu/supported-health-care-decision-making>

Going to College

U.S. Department of Education: *Students with Disabilities Preparing for Postsecondary Education:*

<http://www2.ed.gov/about/offices/list/ocr/transition.html>

Working

California Department of Rehabilitation: *Transition Partnership Program*

<http://www.dor.ca.gov/public/factsheetdocs/TPPFactS.pdf>

Work Incentives

Social Security Administration: *Working While Disabled - How We Can Help*

<https://www.socialsecurity.gov/pubs/EN-05-10095.pdf>

Attending an Adult Day Program

Accessing Home and Community-Based Services: *A Guide for Self-Advocates*

<http://autismnow.org/wp-content/uploads/2014/09/9-3-14-HCBS-tool-FINAL.pdf>

Autistic Self-Advocacy Network: *Home and Community-Based Services Advocates Toolkit*

<http://autisticadvocacy.org/home/policy-center/policy-advocacy-toolkits/hcbs/>

Living with Family

California Department of Social Services: *In-Home Supportive Services (IHSS) Program*

<http://www.cdss.ca.gov/agedblinddisabled/PG1296.htm>

Licensed Community Care Homes

Autistic Self-Advocacy Network: *Home and Community-Based Services Advocates Toolkit*

<http://autisticadvocacy.org/home/policy-center/policy-advocacy-toolkits/hcbs/>

