

# Impact

**Feature Issue on Parenting Teens and Young Adults with Disabilities**

Published by the Institute on Community Integration (UCEDD) · Research and Training Center on Community Living

Volume 19 · Number 2 · Spring/Summer 2006



*Katherine Carol and her daughter Mikelle are navigating the transition to adulthood and a new stage of life for both of them. See story below.*

## **How to Avoid Being Roadkill on the Road to Transition**

*by Katherine Carol*

My back is a little stiff this morning. Sleeping on my daughter Mikelle's couch has that effect. It has been a week since I have slept in my own bed and I am not sure when I will lay my head once again on my own pillow.

The calendar seems to have picked up the electronic pace of the digital world as Mikelle leaps towards her 23rd birthday. Her life moves forward at 21st century speed while her systems of support crawl out of the 20th century.

Mikelle graduated in 2004 as an outstanding senior at East High School in Denver, Colorado. Mikelle, her team at school and I worked hard to develop a solid transition plan to follow graduation. We had our challenges, particularly with having five vocational rehabilitation counselors in three years while that system was going through major changes in our state. All the counselors had good intentions, but each was dancing the slow dance of catch-up. And, everyone had to catch the vision Mikelle had for her life, which was to not just have a typical life, but an exceptional one – one that was based on prosperity, not poverty. Too many times we accept poverty as an implied goal during transition. I can't say I have ever seen a goal on a transition plan that addresses getting people out of poverty. It is assumed – wrongly – that you have to be poor to get certain services. With Social Security work incentives like PASS Plans and strategies for developing small businesses, poverty no longer needs to be assumed.

My expectation for Mikelle, despite the limitations of significant cerebral palsy,  
*[Carol, continued on page 27]*

### **From the Editors**

*The passage from childhood to adulthood is a passage for families as well as individuals. As young people with disabilities move from their teen to adult years, they and their families experience many growing pains in common with all families at that stage of life. In addition, there are often milestones, questions, concerns, needs, and challenges unique to individuals with disabilities and their families. In this issue of Impact we explore strategies for families of teens and young adults with disabilities to consider in navigating the transition years with their young person, and share stories of those who are in the middle of it or have come out the other side.*

*For the generation of young people with disabilities reaching adulthood today there are ever-expanding opportunities to pursue adult lives that reflect their goals, dreams, ambitions, values, and life visions. And there are still barriers to that achievement – limitations in services, supports, resources, and options. It's our hope that the articles in this Impact will provide a glimpse of what is possible, offer useful ideas for moving past some of the limitations that get in the way, and support families, teens, and young adults in dreaming big and realizing those dreams.*

### **What's Inside**

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## Youth with Disabilities Just Want to Grow Up

by John Agosta

I was once told that good parenting is the art of graciously giving ground. So it goes. Children challenge their parents as they age, steadily asserting their own identity. A two-year-old refuses to drink her milk. A ten-year-old protests his bed time. Teens forget their chores, but remember to ask for money.

Eventually, teens grow into young adults, and along the way, make great discoveries about themselves. They develop dreams and aspirations about what sort of work they want to do, where

*They want real jobs, a place of their own, and someone to love. Some even want tattoos and piercings. Oh my!*

they want to live, and what they like doing for fun. Discoveries are also made about one's sexuality. Boyfriends and girlfriends eventually come around, as do thoughts of love, marriage, and having a family of one's own.

Youth and young adults with developmental disabilities come through these same transitions. Overall, the tensions around "transition" do not exclusively center on education or employment, but to a greater extent involve life issues related to a passage from "child-to-adult."

Certainly, no two people are alike and individual transitions vary. Many considerations must be factored into how parents think about their son or daughter becoming an adult. These include the individual's age and level of disability, and the significance of the life decisions that must be made. The challenge is not to discount this passage due to the individual's disability, but to embrace it and find ways to mentor youth with disabilities to grow into strong men and women.

In our work with self-advocates, that

is, people with disabilities who speak-up for themselves, we often ask about their dreams and aspirations. Some are shy at first and have difficulty thinking beyond their present lives. They do not immediately think past their sheltered workshop or community residence, or the routine of their family life. Others are quicker to describe imagined acting careers, vacations to Hawaii or owning their own homes. After some discussion, almost all eventually reveal a range of life ambitions still to be achieved.

When we ask who is the greatest help to achieving their dreams, participants will quickly answer "my parents," and share stories of moms and dads doing their best to help their children grow into adults. When we ask, however, who stands most in their way, participants just as quickly answer back with "my parents," and also share their stories of overbearing, controlling parents who seemingly can't give ground.

There are plenty of reasons to explain why parents have difficulty with the child-to-adult passage sought by their sons and daughters. Some of this resistance is rooted in the typical struggle that exists between teens and young adults and their parents. More telling, however, is the underlying dynamic that exists between loving parents and their children with disabilities, one that is often based on parents' sober view of the impacts of disability on life functions and practical concerns for their children's well-being. Parents may not be enthusiastic about their child with disabilities wanting to work nights in a strange part of town or move into their own apartment.

Parents can also get nervous about relationships. I once asked a man with a cognitive disability if he had ever been in love. "Oh, no," he said, "my mother would never let me fall in love." Meanwhile, a mom expressed to us her concern that if her daughter became sexually active and became pregnant, that she would have to take care of her daughter

and her new grandchild.

Plainly put, the more significant the cognitive disability, the more supervision and oversight parents believe they must provide. Parents worry, and often with good cause. As a result, because of the perceived risks, parents may shy from offering the type of opportunity and mentoring individuals need to grow into adults. They may opt instead to direct their sons and daughters into sheltered life activities, stabilizing these activities over time.

Many people with disabilities do not complain about life circumstances like these, playing a generally passive role in their lives. Increasingly, however, self-advocates are seeking to live lives like anyone else. More than that, they say that they want to be "the boss of my own life." They want real jobs, a place of their own, and someone to love. Some even want tattoos and piercings. Oh my!

For young children, family support systems promote the idea that families must be empowered to identify their own needs and direct how these needs will be addressed. Families seek control of the supports they receive. As children age, however, personal empowerment themes gain in importance. The wishes of parents slowly, but surely, must give way to the preferences of their adult children. The challenge is to find means for offering supports to individuals that honor their preferences as emerging adults, but factor in real concerns for their well-being. After all, good support can set a person free. Inevitably, moms and dads, while graciously giving ground, are essential to helping their sons and daughters with disabilities to imagine a full life in their community and make a safe passage from child to adult.

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# Expectations, Reality, and the Road Ahead

by Kerri Melda

Youth with disabilities increasingly want, expect, and demand meaningful lives in the community, just like their friends and family. Likewise, their communities are coming to expect this, as well. But it wasn't always this way.

## Changing Expectations

Not too long ago, institutions were seen as the only service option available to many children with disabilities and their families. The other alternative was to care for their children at home, without many, or any, supports. Thank goodness our nation's response to disability has evolved! This evolution, generally, has been a slow but steady progression – from institution-based models, to segregated community options (such as group homes and sheltered workshops), to more progressive options that promote supported living arrangements, meaningful work, and fuller inclusion into our communities. In addition, people with disabilities are also demanding to have control of their own lives and over the resources allocated to their support.

Today's youth with disabilities attend neighborhood schools and play with neighborhood kids. They want and expect opportunities to go to dances and watch football games. Beyond high school, some expect to attend college while others seek a real community job. They think about where they will live as the years unfold, and not surprisingly, they don't all want to continue living with their parents. Many speak of friendships, relationships, and romance. Yes, the extent of one's disabilities factor into such expectations. Not all those with disabilities have expectations like these, or are capable of voicing them in these terms. Increasingly, though, people with disabilities are speaking up for themselves and telling us that they simply want the same life as anyone else, nothing more and nothing less.

## Realities of Service Systems

Unfortunately, in reality, families and youth too often discover that the service system falls short of these expectations. To some degree, the disability service system has evolved to keep pace with emerging expectations. It has reinforced these expectations by placing an emphasis on person-centered planning practices and service systems that increasingly find flexible ways to fund supports so that people can live diverse lives in the community. But, is the present service system up to the challenge? There are, indeed, many challenges. They include budget shortfalls, waitlists, and a legacy of older, outdated service options competing with newer, more progressive ones for a limited set of resources.

During the past few years, nearly every state has experienced substantial budget shortfalls, putting a strain on all human services, disability services included. These shortfalls renewed states' vigor in accessing federal Medicaid dollars to lessen the impact of budget cuts. Still, many eligible youth and families find themselves on long waiting lists for needed services. There simply are not enough resources to meet everyone's needs. So, by lottery, level of disability, date of application, or some other means some individuals and families receive services, while others wait. In addition, when policymakers decide to maintain a "living museum" of services, that is, create new services while holding on to all of the old ones too, they limit the availability of more progressive, flexible service and support options. Valuable, limited resources continue to be spent on outdated, non-inclusive services. Further, many service systems are unprepared to respond to and support the various cultural, disability, and language differences within their communities.

When the expectations of today's youth and families meet the realities of today's service systems, there is often disappointment. Years of hopeful expecta-

tions collide with the realities of underfunded, unprepared, and outdated service structures. Youth and young adults are often faced with proceeding without supports or settling for what the system has to offer.

## Moving Ahead

So what must this new generation of young people and parents do to continue their plans for a "better" future? There are a number of things:

- We must continue to press for change and make our needs and expectations known. We must pressure state leaders to invest in strategies that support people to live the lives they want in the community. We must exert pressure for better collaboration and coordination between government agencies and with the community.
- Progressive uses of Medicaid funding will be critical to moving forward. Medicaid waivers must shift from institutional to community-based models of support. We must advocate for waivers that fund more flexible and inclusive service options.
- We must look around, in likely and unlikely place, for allies. Yes, we must look to government, but let's remember too, to look to how we can mutually support one another within our communities.

So much progress has been made in recent years, but there's a lot more to do. The best thing we can do is continue helping our children with disabilities dream and have the highest expectations about the life they can live. In the end, these children will grow into adults who expect nothing less. And *that* will be a powerful force for change.

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# The Family Life Cycle and Significant Intellectual Disability

by Ann Turnbull and Rud Turnbull

Have you ever commented that a person is “going through a stage?” Probably. But have you thought about “stages” as they relate to families, especially those who have adolescents and young adults with significant intellectual disabilities?

There are between 6 and 24 stages representing the family’s passage through time, but let’s keep it simple and consider only these stages:

- Marriage and the new couple
- Families with young children
- Families with adolescents
- Families with children launching to adulthood
- Families in post-parental years
- Families with parents who are elderly
- Death of parents

These stages occur in most families, can be anticipated at certain defined times in the family life cycle, and are generally symbolized by age-appropriate “punctuation marks” such as confirmation, bar and bat mitzvah, a driver’s license, graduation from high school, and marriage. That’s the norm. But what happens to your family life cycle when your child has a significant intellectual disability?

Families often get mixed messages. Many people expect you to live your life by pretending that your child’s significant intellectual disability does not exist. On the one hand, there are the messages about normalization, self-determination, independence, and community inclusion. On the other hand, families of individuals with a significant intellectual disability do not have the same “punctuation marks” nudging them along to recognize their child’s increasing competence as their son or daughter moves from being a child to an adult. Confusion, ambiguity, and being “frozen in time” at an earlier stage can occur.

We will illustrate this mixed-message

dilemma during the teen and early adult years by using our family as an example. Our son, Jay (JT), is 38 years old and has intellectual disabilities, autism, bipolar disorder, and an irregular heart rhythm. His sisters, Amy (31) and Kate (28), have no disabilities.

## Adolescence

JT was 8 when his sister, Amy, was born and 11 when his sister, Kate was born. His birth order made him the oldest child, but in his teen years he was the youngest developmentally. At 16 years of age, Amy and Kate were getting their drivers’ licenses; at the same age, Jay was still learning to be dry through the night and had not mastered (and still has not) crossing the street safely by himself. We had to raise our typical children and raise an exceptional one, simultaneously. In some ways it was like having two family life cycles to negotiate.

## Launching

Research on families of children without disabilities has found that they tend to experience the greatest stress at the launching stage of the family life cycle because they have to plan for life after high school. A challenge for Amy and Kate was picking among the many different colleges that would have welcomed them as students. The challenge for JT was finding even one program that offered the kind of “typical living” that he wanted for himself (and that all of us as his family endorsed). We had to discover and often create opportunities, networks, and funding streams that offered Jay dignity, interdependence, inclusion, and productivity/contribution. It took a number of “trials and tribulations” in order to choreograph how JT, especially given his significant intellectual disabilities, could have a home of his own, a real

job, a circle of friends, regular opportunities to be with his girlfriend, and essentially a life he loved. With six postsecondary degrees between us, a national network of leading disability advocates ready to help us, and enough money to purchase what we needed, it still took us nearly 10 years of partnership with Jay in order to create the life he wanted.

## Post-parental Years

Right now, we are in the post-parental stage – somewhat. Amy is married, has a 15-month-old son, and is moving through her own family cycle. Kate is in graduate school, has a strong circle of friends, and her acting career is as well mapped out as any such career can be. We talk to them frequently, visit as much as possible, and miss their daily and weekly presence in our lives. Yet we are relieved to not have as much parental responsibility for their daily and weekly well-being as we have had in the past. This is typically what the post-parental stage of the family life cycle is all about.

Although JT is 38 years old, we are still intimately involved in orchestrating the supports in his life so that he can live what we call an “enviable life” – a life that is not in any way characterized by second-class citizenship and that enables him to truly be a full citizen of his inclusive community. Weekly, we oversee the maintenance and upkeep of JT’s house; provide support to his housemate who, in turn, provides the key support to JT; address challenges that arise due to the significant mood shift that JT experiences in a bipolar cycle; complete the myriad forms from Medicaid, Section 8 housing, and SSDI related to JT’s benefits; handle his insurance and property taxes; often go to his doctors’ appointments with him; and problem-



solve when unanticipated behavioral and mood challenges prevent him from carrying out his typical routine. We have arranged for Jay to work at the Beach Center (which we co-direct); thus we also have ultimate responsibility for orchestrating his job supports. JT has great job coaches and co-workers who provide support to him, and he also has a wonderful housemate and nearly a dozen young adults who support him in one way or another weekly. JT also enjoys coming to our home and chooses to be there for a portion of almost every weekend and all holidays. His presence is a joy in many ways in terms of not being separated from him by long distances as we are with his sisters; however, during our post-parental years we still are tethered to JT and arrange our schedules so we are home on weekends and do not disrupt the security of his regular routine.

Many self-advocates, as well as professional leaders in the area of self-determination, frequently advocate for families of individuals with disabilities to pull back and encourage their son or daughter to be in charge of managing his or her own funding, hiring and supervising his or her staff, and accessing community resources of choice. We are certain that if we had not advocated so strongly for JT to be able to participate in self-determination funding, and if we did not provide such significant and practical support, this clearly would not be an option for him. In our community there are no support brokers or agencies proactively pursuing self-determination funding opportunities for individuals who are not able to choreograph their own supports.

### **Tips for Keeping the Cycle Moving**

Negotiating the many mixed messages that occur in the family life cycle when an individual has a significant intellectual disability is challenging for families. It can be easy to let the atypicality of problems such as chronic bedwetting, intense problem behavior, and a lack of capability to cross the street safely keep an individual with a disability and the family from progressing throughout the typical

expectations of the family life cycle. Some of the lessons we have learned along the way are incorporated in the following tips for keeping the family life cycle moving forward:

#### **Adolescence**

- Foster your child's friendships with peers and a wide range of people of all ages across the community.
- Seek to have your child participate in inclusive school settings, which will enable you to stay in touch with typical age-appropriate expectations.
- Seek extracurricular activities at school and/or community organizations that enable your child to be with same-age peers.
- Emphasize skill development related to self-help and activities of daily living (for example, waking up to an alarm clock rather than to parents).
- Learn about various occupations for your child and seek experiences that will provide prerequisite skills for and exposure to those occupations.
- Explore the use of assistive technology that will support greater degrees of adolescent and adult independence (see [www.ablelink.com](http://www.ablelink.com)).
- Explore options for your child to use public transportation.
- Seek advice from siblings about how they believe the independence of their brother or sister with a disability should be facilitated and ways in which you as parents should ensure that none of you over-protect.
- Foster friendships with adults with similar disabilities. Explore the options of your child visiting them in their homes (perhaps even spending the night occasionally) and shadowing them on their jobs.
- Visit young adults who have various types of housing and encourage your child to express preferences related to each.

#### **Launching**

- Based on the preparation that you have done related to future housing

and employment, implement options with the greatest likelihood of success and be prepared to provide extensive support, especially during the beginning phases.

- Pay attention not only to the residential and work experiences of your son or daughter, but also help foster social connections in the community and friendships.
- Take one step at a time, do not get overwhelmed, and realize that supporting the creation of a whole enviable life can take years.
- Encourage your son or daughter to express feelings and preferences about the new experiences that they are having. When there is limited communication or cognitive understanding of some situations, pay close attention to behavior, energy levels, and mannerisms that can indicate ranges of satisfaction to dissatisfaction.
- Enlist ongoing advice and guidance from brothers and sisters to help gauge how things are going, what needs to be improved, and how quality of life can best be manifest.

These tips are for families like ours who find that predictability is a rare part of life, typical assumptions don't necessarily apply, and creativity, hard and constant work, and daily diligence must be embraced as the norm. Not that we would have it any other way! Jay is our teacher of how to live well (and he does live exceedingly well), a guide in our work, an inspiration for much of our writing, a brightly shining light in our hearts, a balm for our spirits, and a beacon for our religious and ethical selves. And more.

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# Supporting Healthy Adolescent Development for Youth with Disabilities

by Kris Peterson

Family support is key to healthy adolescence. Families enable children to experience attachment, belonging, competence, and self-esteem, as well as success and failure, adventure and retreat, independence, and interdependence. For families who have teens with disabilities, adolescence can be especially challenging because, like most parents, they often find themselves at odds with the teen who wants to experience life, develop individual values, and achieve independence (Tempke, 1994). At the same time, when a child is vulnerable, parents may view control as a responsibility to ensure safety. Parents may have extensive fear of how the world will treat their child, and may hesitate to give-up their primary role as protector and advocate. In spite of this, teens with disabilities want and need to experience the same things as all adolescents, no matter how significant their disability.

Transition assessment and planning during adolescence often focus on academic and vocational development, yet moving into adulthood is more than that. It also includes psychological, social, emotional, and sexual development. As Gerber and Okinow (1994) put it:

Adolescents with chronic illness or disability experience the same developmental transitions as their peers without disabilities, yet their illness or disability places them at risk for certain psycho-social problems as they move into adulthood. The risk is not solely in the medical complications of the illness or disability... rather risk is more often related to the degree of fit between the adolescent and his or her environment: family, school, peers, health care services, work, and societal attitude. The fit can lead to optimal integration and development, or it can result in isolation and low self-esteem (p.1).

Families play a pivotal role in supporting healthy adolescent development in all these areas, and in fostering positive connections between teens and their environments.

## What Families Can Do

It is important for teens with disabilities and their families to have information from physicians, teachers, social workers, and other families about adolescent development, and to receive encouragement to create a vision of adulthood. It is also vital that they experience opportunities to share their dreams and hopes, fears and frustrations, and to dialog about their visions for the future. Autonomy, independence, problem-solving, and constructive role-related changes will increase if families can build safety nets amid the fear of life-threatening decisions and risk-taking that are part of the teen experience.

The National 4-H Council has identified eight "Keys for Kids" (University of Minnesota Extension Service, 2006), experiences that are essential to healthy youth development. They are:

- Security: Youth feel physically and emotionally safe ("I feel safe").
- Belonging: Youth experience belonging and ownership ("I'm in").
- Acceptance: Youth develop self-worth ("What I say and do counts").
- Independence: Youth discover self ("I like to try new things").
- Relationships: Youth develop quality relationships with peers and adults ("I care about others").
- Values: Youth discuss conflicting values and form their own ("I believe...").
- Achievement: Youth feel the pride and accountability that comes with mastery ("I can do it").

- Recognition: Youth expand their capacity to enjoy life and know that success is possible ("I feel special").

It's important that all adolescents, with and without disabilities, have opportunities to establish these building blocks through experiences within and outside the family context.

## Conclusion

Adolescent development is more than high academic expectations, career development, and independence. Families play a pivotal role in supporting teens to explore their identities and make connections with peers and other adults. Understanding all aspects of adolescent development helps families of youth with disabilities and those who work with them address these critical issues and support the transition from childhood to healthy adulthood.

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*This article is excerpted and adapted with permission from "Information Brief: Supporting the Dynamic Development of Youth with Disabilities During Transition: A Guide for Families" (March 2004), published by the National Center on Secondary Education and Transition, University of Minnesota. The full article, with more detailed information on youth development, is online at [www.ncset.org/publications](http://www.ncset.org/publications).*

## Graduation and Beyond: Beth's Story

by Cathy Ficker Terrill

My daughter's dream was to walk across the graduation stage after four years of high school and receive her diploma with her friends. It was important to Beth to be able to celebrate with her classmates. She had to use her self-advocacy skills to fight to walk across that stage, but fight she did and she walked proudly across it. We used that experience to talk with Beth about the difference between those first four years of high school and how we could best use the next three years of high school in another way.

For so many students with disabilities, high school might be the last step in their

*My daughter's dream was to walk across the stage after four years of high school and receive her diploma with her friends.*

formal education process. While there are new opportunities for young adults with developmental disabilities to access higher education, we know that for many the barriers are substantial. We used the graduation moment to find a way to maximize opportunities for Beth. Rather than thinking about what she needed to do to get ready for the next school year, Beth tried looking at it from a different perspective. We had her pretend that it was June 2008 and we asked her, "What was the most memorable moment of the past three years? What new friend did you meet? What life lesson did you learn? Which job made a lasting impression on you? What mistake did you make that taught you a valuable lesson? What obstacle was in your path that you never thought you'd overcome...until you did? What experience helped you decide what your new dreams will be for the future?"

Successful outcomes take a lot of planning. Beth decided to use the start of the school year as an opportunity to plan for positive and important outcomes in her life. We looked at what is important to Beth, rather than looking at her as someone with a disability who needs to have the year "planned." The focus was geared toward making sure that Beth reached life goals meaningful to her while still in school. Beth decided to take a class at the local junior college, try out two part-time jobs, and take a few classes at the high school. She now starts her day at the high school with a class on life skills, where she is learning more about budgeting, maintaining her checkbook, and meal preparation. She's creating a step-by-step cookbook with her digital camera; Beth intends to have a home of her own some day and she knows she needs to be able to cook to move out. Beth's paychecks are automatically deposited, but she is learning to use a cash station card with a modified tracking system. Some days she attends the local junior college where she not only takes a class, but she also stays on campus two days a week for lunch, so she can build new social capital. Other days she goes off to one of her part-time jobs.

Technology and self-advocacy have been effective tools for Beth. Although the high school offered a minimal self-advocacy curriculum, we were able to ask the local park district to offer a session on self-advocacy. They used parts of the curriculum *My Voice, My Choice* from the Self-Advocate Leadership Network. Beth learned how to send effective communication to government leaders. Although she can't write, she now has software from [www.ablelinktech.com](http://www.ablelinktech.com) that reads all of her received e-mails and enables her to dictate her responses back. Beth can now correspond with her friends in college, legislators on policy issues important to her, and her family. She is not only using her voice – people are hearing her voice. Beth can also com-



Beth (left) with her cousin Lauren.

municate with her cell phone. Technology has created cell phones that are easily pre-programmed. Beth's cell phone is her link to friends, but it is also her link to safety. It has global positioning so if she can't find us, we can find her. It is pre-programmed for quick emergency response. Although Beth can't read street signs, she feels comfortable venturing out in the community with her cell phone as a key support. At home she uses a Teleface™ photo phone. It features 10 large memory keys with photo windows, so with a touch of someone's face or the fire truck graphic, Beth can speed dial for fun or for safety.

As adults, when we look back at our high school years, it's often the relationships we formed and the life lessons we learned that remain with us. While the facts and figures and technical skills we mastered laid the foundation for what we've achieved as adults, those usually aren't the memories that flood our minds. With Beth, we try to use the opportunity of each new school year to make sure that when she looks back at the current year she will have memories of relationships and life lessons that will stay with her for a lifetime.

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## Eight Effective Steps to Employment Success

by Cary Griffin and Dave Hammis

Alicia\* received her Certificate of Attendance from public school and faced unemployment. Luckily, the local community rehabilitation program leveraged Vocational Rehabilitation and Developmental Disabilities funds to assist her in finding a job. Alicia made no secret of her love for children, but her school program only offered training in office skills and short unpaid work experiences bussing tables at a restaurant. With assistance from an employment specialist, Alicia visited several day care centers but found no jobs for individuals without experience. Digging deeper into her interests revealed that she enjoyed using computers with basic math and reading software. Even with minimal reading and math skills, the software served as her guide, and her ability to use the programs and her enthusiasm led the employment specialist to suggest that Alicia become a computer tutor for children.

Alicia worked with her team locating a pre-school program that needed computer equipment and an instructor. Using personal funds set aside for employment she brought a new computer and software into a day care facility, becoming their newest employee. The business charges families extra for computer tutoring, and Alicia is paid for her work. Three years later, the initial investment in equipment and software, along with job coach support setting up the operation, has paid off, allowing Alicia the success she dreamed of, and increasing the profitability of the business.

Alicia's story is not typical. Today, only 26% of adults with developmental disabilities are working (Hall, et al., 2006). However, with a bit of planning and an understanding of employment options, transition-aged youth can attain vocational success.

Alicia's story serves as an inventive, but simple, approach to creating employment. Traditional competitive employment fails people with disabilities. There are many entry-level jobs available for

people with disabilities, but career advancement and doing what one loves are less common for individuals with significant disabilities. Therefore, changing our understanding of employment and approach to getting jobs is necessary. The following eight steps are a starting point:

- **Raise expectations.** Families are often discouraged from having dreams and setting high expectations for their children with disabilities. Expecting children to grow-up and work is a crucial first step to success. Make certain that children have household chores, after-school jobs, and summer employment.
- **Follow expectations with action.** One critical activity is saving for the future. Families should consider establishing an "employment fund" for their child just as they might for a sibling expected to attend college. This fund can be used for advanced training, buying tools, securing transportation or starting a business.
- **Advocate for real work experience.** Work experiences should be paid either by the school, an arrangement through a youth employment program sponsored by the local Workforce Center or One-Stop, Vocational Rehabilitation or the employer. These time-limited try-outs can help clarify the interests of the individual, and reveal the supports necessary for success, the best teaching approaches, and future options for work and study. Wages build a work ethic, garner peer status, and reinforce the connection between labor and reward.
- **Augment exploitable resources.** The best jobs go to those who offer the greatest potential benefit to an employer. Having equipment or tools that enhance employability can help career advancement. Alicia's talents were augmented by computer equipment. Using these assets, a new job was created. Using valued resources

to secure employment is analogous to using a college degree to get a job.

- **Apply for Social Security.** As graduation approaches, parents should investigate eligibility for the Social Security system programs. Social Security provides a variety of work incentives available to individuals with disabilities.
- **Arrange for a smooth transition.** Many states have waiting lists for adult services, so graduating with work experience and a paid job are crucial. In addition, it is also critical to apply well before graduation to the state for case management services and for vocational supports at the local One-Stop center.
- **Consider self-employment.** Business ownership is the fastest growing employment option in America and many people with disabilities have ideas and interests that easily translate into money-making opportunities. Consider starting early and remember how young most children are when they open their first lemonade stand.
- **Use the family network.** Most people get their jobs through personal contacts. Families consume local goods and services and have friends and colleagues. Use these contacts to help your child locate appropriate work experiences and jobs.

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\* Alicia's story is a composite of several people's experiences

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# SSA Employment Support Update

by Mary Hoover

All youth need support as they transition from adolescence to adulthood. The Social Security Administration (SSA) recognizes that young people with disabilities face particularly challenging transitions. In addition to maintaining ongoing work incentives and programs, SSA continues to add new employment supports to help youth with disabilities make a successful transition from school to employment.

## Ongoing Work Incentives

The following is a brief description of some of SSA's ongoing work incentives and supports most likely to be used during the transition planning process:

- **Ticket to Work Program.** This program provides individuals who want to work with vocational rehabilitation, employment services, and other support services at no cost. While an individual is using a Ticket to Work, we will not conduct a continuing disability review to see if his or her condition has medically improved.
- **Impairment Related Work Expenses (IRWE).** SSA deducts the out-of-pocket costs of certain impairment-related items or services needed to work. These expenses are subtracted from gross earnings when SSA decides whether work performed is at the Substantial Gainful Activity (SGA) level. These expenses are also subtracted from earned income when figuring the SSI monthly payment amount.
- **Blind Work Expenses (BWE).** For Supplemental Security Income (SSI) beneficiaries who are statutorily blind, SSA does not count any earned income that is used to meet expenses needed to earn that income. The expenses do not have to be related to the individual's blindness.
- **Plan to Achieve Self-Support (PASS).** A PASS allows an SSI disability applicant or beneficiary to use income and resources to pay for things needed to

reach a work goal. A PASS can establish SSI eligibility or increase or maintain the SSI payment amount by excluding the income or resources.

- **Special SSI Payments for People who Work (1619a).** An SSI beneficiary can receive cash payments even when earned income is at the SGA level.
- **Medicaid While Working (1619b).** An SSI beneficiary can keep Medicaid coverage even if earnings become too high for an SSI cash payment.
- **Extended Medicare.** Medicare coverage continues at least 8 1/2 years after an individual first returns to work as long as his or her disabling condition continues.
- **Expedited Reinstatement (EXR).** If benefits were terminated due to work activity, an individual can have benefits restarted without a new application within five years if unable to work at SGA due to a medical condition and the impairment is the same as, or related to, the previous impairment.

## New Supports and Provisions

The following work incentives and provisions have recently been changed or implemented by new regulations:

- **Student Earned Income Exclusion (SEIE).** The SEIE was increased in 2006. If an SSI beneficiary is under age 22 and regularly attending school SSA will not count up to \$1,460 of earned income per month up to \$5,910 a year. In April 2005, SSA removed the restriction that a student had to be unmarried and not head of a household to use the SEIE. This makes the SEIE available to people who are married, have children or live independently.
- **Substantial Gainful Activity (SGA).** The maximum amount of earnings a person can have and continue to re-

ceive Social Security Disability Insurance (SSDI) payments was increased in 2006 to \$860 per month for disabilities other than blindness. For blindness, the SGA was increased to \$1,450 per month.

- **Trial Work Period (TWP).** The TWP allows an SSDI beneficiary to test his or her ability to work for a minimum of nine months over a five-year period. During those months, the beneficiary will receive full SSDI benefits regardless of earnings as long as he or she continues to have a disabling impairment. In 2006, the monthly earnings used to determine if a month counts for the TWP was increased to \$620.
- **Continued payment under a program of vocational rehabilitation, employment services, or other support services (Section 301).** In July 2005, SSA extended the continuation of payments for students whose disability or blindness medically ceases if they are age 18-21 and participating in an individualized education program (IEP). Benefits will continue until they complete the IEP or stop participating for any reason. This provides students with the opportunity to continue receiving benefits while they complete school.

## Conclusion

SSA continues to improve ongoing provisions and plan for new supports to enhance the transition process for young people with disabilities. Families who would like more information on work incentives can refer to *The Red Book* at [www.ssa.gov/disabilityresearch/redbook.htm](http://www.ssa.gov/disabilityresearch/redbook.htm). For specific questions about the benefits your child is receiving call 800/772-1213 or your local SSA office.

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## ***Involving Youth with Disabilities in Community Service Activities***

by John G. Smith, Ann Mavis, and Julia Washenberger

The youth and young adults of America have long engaged in community service activities through churches, scouting, schools, and a myriad of other organizations, as well as on their own or with their families. With appropriate opportunities and support as necessary, young people with disabilities can join their

to include service learning as part of a student's individual educational plan. Service learning combines community service activities that meet community needs with student learning and academic requirements. Students may carry out projects as a group or individually. Including service learning opportunities as part of the school day for students with disabilities can provide new avenues to pursue interests, develop skills, and prepare for employment, postsecondary education, community participation, and other experiences of adulthood.

Another way for youth and young adults with disabilities to become involved in service is through the volunteer activities available outside of school to all community members. These include volunteering with faith communities, nursing homes and hospitals, crisis services (such as food banks, homeless shelters), arts organizations, political campaigns, animal shelters, community beautification projects, civil rights/human rights organizations, nature centers, and neighborhood block clubs, to name a few.

Whichever type of opportunity is chosen, it's important for youth and young adults to first think about their interests and what kind of contribution they feel would be important to make to their community. They should also gather information about the service activity being considered, including where it takes place, what is expected of the volunteer, who they'll work with, what training and guidance is provided to volunteers, what supports the youth or young adult may need to fulfill the expectations of the activity, and what supports and assistance are available.

Youth and young adulthood is a time when it is important to build the relationships and develop the skills that will translate into success in adult life. Instill-

ing an attitude that values service to the community, while developing useful skills and a sense of making a difference to the community, cannot be underestimated in contributing to successful adult lives for all young people, but especially for those with disabilities. Schools, community organizations, governmental agencies, parents, and young people themselves need to become aware of the opportunities available for individuals with disabilities to participate in service activities, and to make the commitment to support the participation of youth

***Young people with disabilities can join their peers in contributing to their communities and enriching their own lives by participation in voluntary service.***

peers in contributing to their communities and enriching their own lives by participation in voluntary service.

Youth and young adults with disabilities need encouragement and support to become involved in all types of activities that will foster their success in later life. Involvement in service activities in the communities where they live has the potential to provide many benefits, both to young people with disabilities and to their communities. To ensure such benefits occur for both parties however, it is important that service activities/opportunities be chosen and arranged to match the capacities, support needs, and interests of each individual. This is the key to ensuring that such activities truly support youth in making a successful transition to adult life, while also allowing the communities where they live to benefit from their efforts and gifts.

One way for young people with disabilities to connect to and have successful experiences with service activities is

***It is important that service activities/opportunities be chosen and arranged to match the capacities, support needs, and interests of each individual.***

and young adults with disabilities. In this way we will develop a system where everyone benefits, and where individuals with disabilities will feel valued and will contribute to their communities.

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## Postsecondary Education for Young Adults with Disabilities: What Families Can Do

by Kelly D. Roberts and Robert A. Stodden

Postsecondary education is becoming more and more important to obtaining meaningful employment for individuals with disabilities. The most recent data indicate that only 15.6% of persons with disabilities with less than a high school diploma participate in the labor force. However, participation doubles to 30.2% for those who have completed high school, triples to 45.1% for those with some postsecondary education, and climbs to 50.3% for those with at least four years of college (Yelin & Katz, 1994).

For parents of teens and young adults with disabilities it's necessary to start planning during high school – the earlier the better – for postsecondary education. While postsecondary education may seem a long time away, that time will go quickly. In order to start planning, we recommend families address the following considerations:

- Your child needs to start thinking about what they want to do when they graduate from high school and 10 years beyond. Is their desired career something that requires a degree? If so, do they need a degree from a vocational school, two-year college or four-year college/university?
- Has your child taken the courses they need in high school to enter the postsecondary option(s) of their choice? If not, their schedule needs to be revised as soon as possible. If you are not sure what courses are needed, talk to a school counselor and find out.
- Is your child's individualized education program (IEP) written to help them prepare for postsecondary education? Is there a transition plan in place? Are IEP goals aligned with what your child wants after high school?
- Are staff from the agencies that may be able to assist your child in postsecondary education included in the IEP? Such personnel could include staff from the Office of Vocational Rehabilitation Services; staff working within programs funded under the Workforce Investment Act; higher education support personnel; and health, transportation, and adult community living support personnel.
- Postsecondary institutions often have requirements for admission, including specified scores on tests such as the SAT or ACT, math and English courses, and GPAs. Make sure these pieces are in place. Information about the requirements should be used to plan students' secondary coursework.
- Which schools align with what your child wants to do? Do they want to move away from home or go to a local school? Do the institutions they are interested in have the disability supports they need to succeed? Set up some campus tours. Are the campuses accessible? While there, meet with the disability services staff.
- What are the disability supports your child needs in order to succeed? Does your child know what these supports are? Can your child explain to others (e.g., a disability support person at a college) what accommodations they need in order to be successful?
- Is transportation an issue? If so, is there accessible transportation at the school of choice and in the community? Does your child know how to use the public transportation system?
- Is your child independent in the ways that may be necessary on campus? For example, do they know how to use an ATM machine, use a computer, manage money, use the course catalog, read a campus map, and schedule and keep appointments?
- Is financial assistance necessary? If so, find out when you need to submit the financial aid forms or apply for scholarships. Check with a high school counselor to find out what scholarships are available and get the financial aid forms. You can also look online for scholarship options.
- Does your child have the skills to make new friends? This is important because school can be very lonely without a network of friends.
- Does your child need accessible housing? If the school provides housing to students without disabilities, it must provide comparable, convenient and accessible housing to students with disabilities, at the same cost.
- Is there a back-up plan if postsecondary education doesn't work out?

Parents should be aware that when their children are ready to exit high school and their eligibility for special education services is ending under IDEA 2004, a summary of their academic achievement and functional performance, including recommendations on how to assist them in meeting postsecondary goals, should be prepared. It's also important to know that postsecondary education institutions are not like high school; disability service personnel make decisions based on the "reasonable accommodations" requirement of the Americans with Disabilities Act (ADA) and the Rehabilitation Act, section 504. Even if a request is made, it does not have to be provided unless it is deemed reasonable. So, start gathering information, exploring options, and planning for postsecondary success now!

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## Ways to Enhance Social Inclusion

by Brian Abery

Teens and young adults with disabilities who have positive social relationships with peers, and participate in community activities they enjoy and value, are on the path to greater satisfaction and success in adult life than those who are socially isolated and uninvolved in recreation and leisure activities. Young people who have opportunities to develop and practice social skills, and engage in activities of their choosing with peers of their choosing, demonstrate improved coping abilities, increased independence, and greater self-determination, self-esteem, and self-confidence. Social inclusion also has the potential to strengthen leadership skills, promote acceptance between young people with and without disabilities, and support development of age-appropriate, socially-valued behaviors.

Determination, creativity, and effective planning by families can support teens/young adults with disabilities to develop and maintain valued social relationships with persons of their own choosing. What can families do to facilitate social inclusion? Below are a number of suggestions:

- **Believe that social inclusion is possible.** If inclusion is seen as a “doable” challenge, it is much more likely that all involved, including teens/young adults with disabilities, family members, and persons in the community, will be motivated and willing to work toward it.
- **Identify the activities for which your teen/young adult has a passion.** We typically develop friendships with those we view as similar to ourselves and with whom we have common interests. A good place to start facilitating inclusion is to provide young people with opportunities to engage in activities that they enjoy with others who are also passionate about the activities. Based on conversations with and observations of your teen/young adult, figure out what they really enjoy doing. Using such interests as a starting point ensures that they will be motivated to engage in the activity on a regular basis, which enhances the likelihood of social relationships developing.
- **Identify and communicate to others the strengths, gifts, and capacities of your teen/young adult.** It is too often assumed that young people with disabilities have few, if any, strengths or gifts. Uncovering, acknowledging, and letting others know the personal capacities of your teen/young adult not only has the potential to begin changing attitudes of peers, but increases the likelihood that your young person will experience belonging and valuing in the community.
- **Create an action plan.** Given that social inclusion is a crucial developmental outcome, it is appropriate that it is included in the IEP, Transition, and/or person-centered plan of your teen/young adult. Making inclusion happen is hard work and takes supports. Plan ahead to insure that the necessary resources are available.
- **Let your teen/young adult do the choosing.** All of us desire to choose our own friends and to be chosen by others. Respect the right of your teen/young adult to choose their own friends whether these are individuals with or without disabilities.
- **Develop knowledge of resources and how to access them.** Learn about programs, organizations, and activities available in your community that might present opportunities for social connections through shared recreation and leisure experiences. Talk with other parents of teens/young adults with disabilities to find out what worked (or did not) for them; keep a notebook with your young person of ideas and experiences.
- **Develop an awareness of the skills that will support participation.** Talk to those individuals who will be staffing or supervising clubs, programs, or events and ask about the specific skills that teens/young adults are expected to have that will facilitate their full or partial participation. Assess the extent to which your young person possesses those skills/capacities and problem-solve what supports they will need to meet any challenges that they are likely to experience. If there are barriers to participation, identify the staff who are most likely to be able to help remove the barriers. Talk to them about the need to support inclusion, on how it “fits” with the mission and vision of the organization, and the specific needs that have to be addressed.
- **Assess the extent to which your family is able to support participation and inclusion.** Family support must be present to make social inclusion happen and working toward this goal does not come without some risks. Determine the extent to which you are willing to support your teen/young adult taking some risks and engaging in activities that might be new; be open to them developing social relationships with peers you do not know; and provide concrete support (e.g., program fees, transportation).
- **Find a bridgebuilder.** Whenever your teen/young adult begins a new experience, stay on the lookout for someone who might be interested in serving as a bridge-builder. Such individuals are socially skilled, connected, and can be enlisted to help your teen/young adult become familiar with the activity and setting, and to introduce them to other participants.

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# Sex, Dating and Disability: How to Help Youth Make Healthy Choices

by Rebecca Hare

Sex. Sexuality. Sexual identity. These are words that can make people squirm. When you add “and individuals with disabilities,” people are often perplexed. Why? Society doesn’t think of people with disabilities as sexual.

Growing up with two parents, both of whom had disabilities, I never thought that there was anything weird about sex and disability, or disability and dating. As I met people outside the family and engaged in conversations with other youth and young adults with disabilities, I quickly learned that sex was a taboo subject. Having sessions about sex and relationships at a conference for youth leaders with disabilities caused a stir among everyone *but* the youth. “We don’t really need to talk about that” was the response of some support personnel, and parents said things like, “My son/daughter doesn’t need to be exposed to that!”

Generations X and Y have grown up with the cliché, “Knowledge is power!” When looking at the five identified areas of youth development/youth leadership in which all youth need information, *thriving* is one of them (Pittman & Cahill, 1991). It’s especially critical to youth with disabilities. Thriving includes mental and physical health, preventing secondary conditions, and maintaining overall well-being. Unfortunately, most people do not think about thriving as including dating, healthy relationships, sex, and forming healthy sexual identities.

## Myths About Disability and Sex

Some common myths about people with disabilities and sex (Kaufmann, Silverberg & Odette, 2003) say that people living with disabilities and chronic illnesses:

- Are not sexual.
- Are not desirable.
- Can’t have “real” sex.
- Are pathetic choices for partners.

- Have more important things to worry about than sex.
- Are not sexually adventurous/are perverts.
- Shouldn’t have sex if they live in institutions, group homes, or with parents.
- Don’t get sexually assaulted.
- Don’t need sex education.

These myths are why students with disabilities are kept out of sex education classes and why they are not taught self-defense, and these myths perpetuate the idea that youth with disabilities are less than or different than other youth.

## What Can Parents and Families Do?

Parents and family members can support healthy sexual development of youth with disabilities by taking the POWER Approach, developed by the National Consortium on Leadership and Disability for Youth. Its components are Preparation, Open Attitudes, Where Are You?, Exposure, and Reality Check:

- **Prepare yourself and your youth.** Having youth-friendly information available can help the young person in your life make healthy and positive choices. Preparation also means giving them the whole picture and including information that may make you uncomfortable. If you need help with a topic, you can find an expert. Many counties, schools, and clinics have health professionals and sexuality educators available to answer questions from young people and parents.
- **Open attitudes.** Family is the first place where we learn expectations for our own lives and how to have relationships with others. Families need to have an informed, open, and supportive relationship with their youth. This means being comfortable talking about disability as a normal function of life,

and that life itself includes sex, dating, and relationships.

- **Where are you?** Present! An informed and involved family is a prepared family. Know who your young person hangs out with. Know where they go. Know who they have problems with. If you don’t know, ask. Youth may not want to share these sorts of things, but make them aware that you’re asking because you’re concerned for their well-being.
- **Exposure.** Youth with disabilities need to see and interact with people with the same and different disabilities from a young age and be able to see them in relationships, as parents, as professionals. In addition, involving youth with disabilities in youth development and youth leadership programs, both disability specific and general youth programs, helps them develop healthy relationships and healthy self-images.
- **Reality check.** Family members need to remember that first and foremost youth with disabilities are youth. They are going to develop crushes, they are going to experiment with dating and sexual behavior, they are going to hang out with other kids you may or may not like. *Do not* treat youth differently or have different expectations for them because they have disabilities. Rather be prepared to do the research and have frank (and even uncomfortable) conversations with them.

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## Learning Life Skills: The Resources Found in Centers for Independent Living

by David Hancox

Rearing children is tough. Rearing *teenagers* at times seems impossible. And, rearing a teenager with disabilities can be downright overwhelming! Added to the usual rigors of high school for all parents and students is the need for extra effort to ensure that they are appropriately and adequately prepared for life after high school, effort that includes

***One resource that can be invaluable in this transition process is a local Center for Independent Living (CIL).***

managing the IEP in a way that ensures the maximum benefit and preparation for the student.

One resource that can be invaluable in this transition process is a local Center for Independent Living (CIL). If you have never heard of Centers for Independent Living or are unsure how they can help you and your child, this article may provide some answers.

CILs were originated in the early 1970s by people with disabilities to provide others with disabilities with an alternative community-based resource to assist with independent living skills development, advocacy supports, peer mentoring relationships, and general information and referral. CILs were developed as an alternative to the traditional medical model that far too often viewed people with disabilities as needy and helpless and kept people with disabilities dependent. The founders of the CIL movement believed that individuals with disabilities were capable of managing and directing their own lives if they were provided with the proper and effective supports. The mantra of the inde-

pendent living movement has become, "Don't make people with disabilities dependent on you."

Services at CILs are available to all individuals with disabilities, their families, and interested others. There are no restrictions based on disability diagnosis, age, income level, gender, ethnicity, racial identity or sexual identity. Services are consumer-directed, individually-designed, and delivered by adults with disabilities who themselves have faced many of the same challenges your child may be facing. And services are tailored to meet the specific needs of the individual, rather than requiring the person to choose from a limited list of options.

CILs provide independent living skills development – those skills needed to live successful self-directed lives. The following are a few of the many skill development areas with which they can assist:

- Cooking, menu planning, and comparison shopping
- Money management
- Self-advocacy and assertiveness training
- Resume preparation, job search preparation and support
- Hygiene
- Supervising personal assistants
- Academic skills

Clearly, independent living skills cover a vast array of competencies.

Many CILs provide transition services specifically designed to assist students between the ages of 18-21 to be more active participants in their IEPs and transition processes. Several CILs have also developed leadership and personal development training curricula specific to assisting students in preparing for life after high school. Many also offer peer mentor services that match an

young person with a disability with a trained mentor who also has a disability and can support personal development and social skills building. And a number of CILs offer personal assistant services to assist with personal needs.

You can locate the CIL nearest to you by contacting the National Council on Independent Living at 877/525-3400 or on the Web at [www.ncil.org](http://www.ncil.org). They can connect you with information about CILs and the independent living movement, and link you to local CILs in your community or nearby.

CILs offer a valuable combination of services that will provide meaningful assistance through the difficult teen years, as well as throughout adult life.

***Services at CILs are available to all individuals with disabilities, their families, and interested others. There are no restrictions based on disability diagnosis, age, income level, gender, ethnicity, racial identity or sexual identity.***

Effective preparation for life after high school is the goal, and consumer-directed CILs may be the answer for you and your child.

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## The Ups and Downs of Finding a Support Person: Andreas' Story

by Susan Yuan

Andreas lives for other people. He smiled at three weeks old, and hasn't stopped since. Without spoken language, he reigns king of communication. In that world of connection, in school or in the years since, the key has been his support person/companion – the person who keeps the balance, who opens up opportunities yet helps Andreas keep his exuberance within bounds.

Andreas moved into high school surrounded by friends. His social studies teacher had a sister with disabilities, and took it as his challenge to make the entire class advocates for Andreas – and succeeded. Andreas was in regular classes, in a local school, in a small town, in a small state, where everyone knew him. In that microcosm, Andreas knew how to fit, and how to move. Then his class graduated. Andreas stayed on, and on, and on, with fewer and fewer friends. In his last year, recognizing his shrinking world, his school hired a beautiful young woman as his paraeducator. She naturally drew the other students in the school to her, and at the center of that magnetic field sat Andreas. He graduated to a standing ovation, and partied all night with his classmates.

We had everything in place – a Medicaid Waiver for activities in the community and a decent salary for a person to carry them out; funding for a life outside our home, plus four part-time jobs, one for pay. We had done a good job planning for transition, and still it fell apart.

In a community-based, individualized model of supports, everything rises or falls with that key support person, and we couldn't find one. We joke now about those first couple of years. There was Elmer from Maine, who had a 10-year gap in his resume, and wondered, in passing, if there would be any problem with Andreas' playing with the fishhooks in his truck. A politician's son announced that they had had a marvelous

day – Andreas had hugged every person in downtown Burlington! A very disturbed young woman reported that Andreas was suicidal; he had been trying all day to hang himself with his seatbelt.

One by one, Andreas lost all his jobs. He had a job walking dogs for a local pet daycare business until his supporter of the day walked into the room full of people delivering their dogs and announced that she would never leave her dog in a dump like that! A couple of jobs he lost because those boundaries of exuberance weren't maintained, and he overwhelmed co-workers with bear hugs. The paying job he lost because it was just too much trouble to get him there. There was no point in trying to develop new jobs when there was no way to guarantee that he would show up.

To be fair, Andreas tended to give new support people a run for their money, especially at first. One time, his service coordinator, a savvy experienced woman, volunteered to fill in. An hour after he was supposed to be home, I got a call from a town 40 miles away. Andreas had been sitting in a booth at McDonald's for four hours, and wouldn't budge. When I arrived and walked in the door, he popped right up and out. The woman sputtered, "You little s—!"

Stability came within reach as a young mother looked for a way to work and still be with her children. Andreas loved her and her babies, and she would load him and her children in her van and cruise all over northern Vermont. He watched Barney videos, but at least he was occupied, happy, and, we thought, safe. After three years, we learned that his social circle had grown to include crack addicts, pill poppers, and methamphetamine "tweakers." How ironic that I worked in the field of disability, yet Andreas wasn't safe, even when he returned home every night. I felt guilty that I loved my job, and didn't want to



Andreas and friends at a club.

give it up to become his permanent companion. The time he spent with us on weekends was boring for him, but at least I knew where he was and what he was doing, even if he was doing nothing.

Despair had almost taken over when Jason entered our lives. A year older than Andreas, he'd felt empty and Andreas has filled his life. Half the time, Andreas lives with Jason and his five dogs. They swim and kayak in the summer, but more than anything, they party at nightclubs and concerts. Jason says Andreas is a babe-magnet, who sorts out only the right women.

We didn't do anything to find Jason, he found us. No matter how hard we try to control life, we can't. We didn't when Andreas was born, and we don't now. But that doesn't mean that life isn't good. It may not last, but we've learned how to appreciate it while it does!

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# The Power of Community

by Henry Barclay III

All of us want to have a bright and wonderful future, the kind of future that you talk about happening when people get together. But I have to confess, as a parent of an individual with a disAbility\*, that there came a time when I might have settled for anything. I was discouraged and hopeless. How were great expectations ever going to be on the game board of life, much less realized? The truth is that all of us are literally standing on the threshold of tomorrow. There is a key and I want to share it with you: *Hope* is the most powerful tool we have! *Hope* is the key to the future. You can have it and success can be achieved!

What we need is the ability to tap into unlimited potential. That is exactly what I want to share with you: that in the community around us, there are resources that are *unlimited, awesome and available!*

## Tapping the Power

At the Full Life Ahead Foundation we use a process called Full Life Ahead Planning Process (FLAPP). There are other methods by other names, but this is the process that we have found produces consistently positive results. In the FLAPP process, we help individuals bring together family, friends, service providers, and a vast array of community members to brainstorm, power-think, and link to possibilities. It is a process of Hope, Dreams, Action Planning, Action Steps, and Renewal. It takes courage on the part of an individual and their family to reach out to the community – to friends and family members, acquaintances, business people, faith-based support people, political leaders, school leaders, and others. These folks participate in a learning process about the FLAPP and the individual with the help of a facilitator (note: it is *not* a parent). The invitees *choose* to participate. The focus can be literally anything, from roadblocks in school, to social situations, to finding a job or career, to a way to live in the community with

supports. But in my experience, the focus is on discovering and helping implement what a specific individual wants to do in life, where he or she fits, and what we (as a group) can do to help make it happen. Let me tell you briefly about two recent FLAPP experiences.

## Jurdy's Experience

Jurdy is a delightful young lady with cerebral palsy who also has visual impairments. She truly wanted to work, but she had become “lost” in the “system” and had been sitting at home since leaving school at age 21. Her family made every connection they could, but Jurdy needed some supports they couldn't provide on the job. Time had passed and success had become impossible and seemed beyond hope.

Jurdy and her family heard about the successes that others were having with FLAPP and opened themselves to the encouragement and support of people who believed that Jurdy could have the life she dreamed about. Courageously, Jurdy and her family reached out to the community and her FLAPP began in October 2004 (at age 26). The members of Jurdy's Board of Director's (as her family chose to call it) are family members (mom, dad, brother), friends of the family (several are godmothers, one works at BellSouth and another owns a wine company; non-profit directors; a graduate student; a couple of chefs; a technology specialist; a photographer; a physical therapist), selected service providers (a Vocational Rehabilitation supervisor, the Full Life Ahead Foundation staff, a chosen facilitator, her VR counselor), and others including friends of the initial board. The FLAPP enthusiastically examined her gifts and strengths and ultimately her strong interest in animals became the driving force. A young FLAPP member took Jurdy to visit the Birmingham Humane Society where she asked if they needed any volunteers.

They were thrilled and she started right away. Ten days later, she was hired to be the full-time receptionist and greeter. She had her first check in hand in February just four months after that first FLAPP meeting! ClasTran (our para-transit, which was initially furnished through the VR counselor) picks Jurdy up and takes her home each day, freeing her mother for the first time in 27 years from being the sole source of transportation. Next on Jurdy's list of goals is her own log cabin on some family acreage. Jurdy is currently participating in Partners in Policy Making in Alabama, is very excited about her life, and is definitely “on the move.”

## David's Experience

David, a dynamic young man, is a recent graduate of Georgia Tech University with a degree in Mechanical Engineering. He uses a power wheelchair for mobility (he has spinal muscular atrophy). During school he actively participated in the Mini-Baja Off-Road Team designing, building, and racing cars across the U.S and Canada. Just before David's senior year, the team trailer with all tools and the car was stolen. David, the team captain, took the lead in raising over \$100,000 to replace the lost equipment and put the team back in competition. They wound up with not one, but two cars that season! David has designed modifications to his own Suburban and has the only vehicle like it in the world (gull-wing rear door).

David was offered a position designing prototypes for GM in Michigan upon graduation, but could not accept the job because he could not find accessible housing in the area or a cost effective solution to attendant care. David moved home to Stockton, Alabama to live with his parents while he looked for work.

A good friend at the Alabama Department of Rehabilitation Services introduced David to the Full Life Ahead Foun-

\* We use the word “disAbility” to show that we believe the Ability to be the most important factor, not the “dis.”

dation. We invited several national experts into an e-mail round robin and the group began working with David on some essential planning pieces. David's first FLAPP meeting was held at a regional two-day workshop by Full Life Ahead for parents and individuals with disabilities. The group consisted of David's parents and the participants. In David's words:

I must admit that going into it, I was skeptical about how a [FLAPP] could help me since I am quite independent and "established" in the way I deal with my abilities and disabilities, education, future plans, etc. I was not skeptical that it would work for most people, but I thought that the issues that I am working through may be too complex for what I imagined a [FLAPP] could handle. I could see how a [FLAPP] could help create a support group and help with disability-related problems, but not how to get a job or start a company. Basically, it is easy to see how it will work for small-scale, somewhat contained personal obstacles, but not business plans that involved many people, legal issues, detailed plans, and a lot of money. But then [K]atherine Carol gave an example of how a [FLAPP] is working for a friend who is self employed and wants to grow her business (who I think is not disabled) which made me realize that a [FLAPP] is not really a system that is JUST for [people with disabilities] to deal with disability-related problems, but a system that happens to work well for [people with disabilities] and works great with "normal" problems too.

Then, we held a [FLAPP] for me, which made it obvious that a [FLAPP] could work for more than just finding an attendant, working out problems at school, finding housing, or figuring out how to drive. It can also work for issues that affected multiple people in many BIG ways, such as starting a company. And no, I am not talking about a small company with \$500 of startup capital, but the potential of hundreds of thousands of dollars of startup capital. That is big, and, it

seemed to work great at my [FLAPP] Friday night. We are now working to schedule a [FLAPP] in January, which will include many local businessmen, friends, family, equipment suppliers, etc. My unfinished invitation list has over 30 people, and that doesn't include my parent's list, or the people who may come with Full Life Ahead.

David's dream is to have his own business modifying all types of vehicles for all individuals (think hot rod) with a side business designing and modifying adaptive equipment for individuals with disabilities. A few key investors and he will be on his way with this unique concept! At the January FLAPP meeting we discussed the resources David needs in the community and specific individuals we will invite for future meetings. The FLAPP is free to add people (bankers, business owners, entrepreneurs, investors) and adapt to goals as it goes along. There is strong community interest in this work-in-process. Meanwhile, David has accepted a job working for a shipbuilding company. Through members of his FLAPP, he made contacts for and has received approval of his State of Alabama Independent Living waiver to assist with personal care. Next will be the challenge of finding attendants, then housing and independence. David is definitely a rising star and one of the true success stories!

### Conclusion

In our experience, the community *wants* to help – they simply do not know how. What they need is a way to become aware of specific needs for specific individuals in a friendly setting with fun, food, fellowship, and networking opportunities. That is the FLAPP. It works, it's worthwhile, and it is definitely worth taking a chance!

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## Person-Centered Planning for Students

*The Individuals with Disabilities Education Act (IDEA 2004) requires that a student's Individualized Education Program include transition planning by age 16 or earlier, if appropriate. This plan should reflect a student's interests and preferences, current accomplishments and skills, what they still need to learn, as well as what they want to do in life. This can include a range of goals – everything from the type of career the student would like to pursue to the kind of living situation he or she hopes to have. Person-centered planning is a way to identify a student's individual goals and to help students, families, and professionals craft plans that will support students as they strive to achieve their dreams....*

*Despite growing interest in using person-centered planning to drive the transition process, it is not yet common practice. One reason for this may be that many people believe this process is too time-consuming. What they may not realize is that person-centered planning may be more efficient in the long run. The best transition plans truly reflect student-family goals for the future, which helps the team avoid time-consuming guesswork....*

*Many different person-centered planning tools have been developed that could be used in the transition process: MAPs, Personal Futures Planning, PATH planning, Essential Lifestyle Planning, and Dream Cards are a few examples. The following are online resources with more information: PACER Center (<http://www.pacer.org/tatra/personal.htm>), PEATC ([http://www.peatc.org/NEXT\\_STEPS/Intro/brief.htm](http://www.peatc.org/NEXT_STEPS/Intro/brief.htm)), IMPACT: Transition to Empowered Lifestyles Project Person-Centered Planning (<http://www.ptimpact.com>).*

Excerpted and adapted with permission from *Parent Brief: Person-Centered Planning – A Tool for Transition* (2004), published by the National Center on Secondary Education and Transition, Institute on Community Integration, University of Minnesota. The entire brief is online at [www.ncset.org](http://www.ncset.org).



# Supporting Self-Advocacy for Youth

by Chester Finn

*Chester Finn is the Chair of Self-Advocates Becoming Empowered, a national organization of self-advocates. He is also special assistant to the Commissioner of the New York State Office of Mental Retardation and Developmental Disabilities. He has been an advocate for people with disabilities since 1992. Here he shares his responses to questions about youth and self-advocacy.*

- **What does self-advocacy mean for transition-age youth?**

Self-advocacy is people advocating and speaking up for what they want in their lives. It is the same for youth, but yet a little different. Youth still have to listen to their parents and teachers if they are under 18 years. Therefore, they must talk with their teachers and parents about things that they want. They must also ask their parents to include their opinion in decisions that affect them.

- **Why is it important for youth to learn how to advocate for themselves?**

Youth need to speak for themselves and learn advocacy skills because when their parents are gone they need to know how to be independent. Learning leadership skills gives them this opportunity. Hopefully, they are the ones who will be taking over the self-advocacy movement from us.

- **What opportunities do youth have to learn self-advocacy and leadership skills at present?**

The National Youth Leadership Network (NYLN) teaches youth leadership skills. The NYLN has chapters in most states. Youth with disabilities also participate in state and local People First chapters and other self-advocacy organizations.

- **What kind of supports do youth need to learn self-advocacy skills? What can families and schools do to help them learn these skills?**

Building self-esteem is an important

part of teaching youth self-advocacy. Participating in organizations such as YMCAs/YWCAs, 4-H, and scouting can be important in building confidence. I remember participating in Cub Scouts, Boy Scouts and 4-H. I loved those activities and they helped me become confident. I won awards for growing the biggest watermelon and best garden. These awards and activities built my self-esteem and taught me leadership skills. Competition is good for young people; it builds character. We tell youth with disabilities that it is okay to lose as long as they tried. But we need to teach them to play to win. Participating in sports, arts and crafts, and church activities are other ways youth can build self-esteem.

Parents should let youth take chances and experience different activities. When I was younger I wanted to go downtown by myself. My parents were reluctant and I had to talk to my parents for months before they allowed me to do it. But once I convinced them and showed them that I could do things independently I gained their trust and had more freedom to try things.

Further, parents have to listen to their children to understand what they want. I met a mother who was making future plans for her daughter in a way she thought her daughter would like. When her other daughter told her that her sister wanted something different, she realized that she didn't really know what her daughter with a disability wanted. It surprised her because she had lived with her daughter all her life and hadn't really understood what she wanted. This story illustrates to me that it is very important to keep talking to young people to understand what they want for their future.

Another issue that might arise for some younger individuals is that they

are uncomfortable with their disability. They may consider it "uncool" to advocate for their own needs. They don't want to stand out in the crowd in school or "hang out" with other youth with disabilities. Youth need support to understand that everyone is unique and that differences can be good.

- **What is Self Advocates Becoming Empowered (SABE) doing to help youth leadership?**

Tia Nelis, another member of SABE, and I have spoken at the NYLN national conference. Additionally, youth with disabilities have come to a couple of SABE meetings and have spoken at our conferences. We also accept them in our groups. For example, the statewide president of New York's self-advocacy group is in her late 20s. We also have members in their early 20s.

We talk to youth about forming separate groups or joining existing groups. A lot of youth can't participate in our meetings because their issues are school-related and they don't understand our issues enough to participate actively.

- **What actions need to be taken by all of us in the future to facilitate youth leadership?**

We need to encourage youth, answer their questions, and set examples. We must accept them and tell them it's okay to fail as long as you try to win again. Sometimes we just need to be there to listen. We must communicate with youth early in their development as self-advocates.

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# Assistive Technology and Transition Planning

by Thomas J. Nurse

These are exciting times in which we live. The opportunities to use assistive technology as a tool to support the activities of youth and adults with disabilities have never been better. When assistive technology is combined with transition planning, the scope of opportunities for achieving life goals broadens greatly.

*Assistive technology* refers to “any item, piece of equipment, or product system that is used to increase, maintain, or improve functioning of individuals with disabilities”; it can be as simple as a pencil grip or complex as a touch-screen computer (Family Center on Technology and Disability, 2006a). This brief article offers some ideas, resources, and things to consider related to assistive technology and transition. This is a topic of particular passion for me as a parent of a wonderful 14-year-old daughter, Shelby, who has cerebral palsy and utilizes assistive technology every day. Shelby’s assistive technology success story was recently highlighted in an article posted on the Family Center for Technology and Disability Web site ([www.fctd.info/](http://www.fctd.info/)).

## Start Early, But it’s Never Too Late

As a child learns new skills, those skills build the foundation for acquiring related higher-level skills. For a child with a disability, development may be slower, requiring more time, more repetition and a willingness to learn other ways to be successful, including utilizing assistive technology. For example being able to answer a yes-or-no question is the start to being able to engage in conversation, yet if a disability creates a barrier to communication then assistive technology may be a valuable tool to help make communication possible.

By law, a student’s assistive technology needs must be considered in development of their individualized education program (IEP); it may be referred to as “assistive technology” in some IEPs, while in others it may be “accommoda-

tions, supports, program modifications or supplementary aids and services” (Family Center on Technology and Disability, 2006b).

Under IDEA 2004, transition planning must start no later than the first IEP to be in effect when the child turns 16. However, in reality earlier is often better. IDEA 2004 also states that a Transition IEP broadens formally to “a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child’s movement from school to post-school activities...” (National Dissemination Center for Children with Disabilities, 2005). Assistive technology needs should be included as part of the discussion to determine if a Transition IEP may be needed earlier than age 16, as well as included in the IEP itself.

## Think Across Settings

Children and youth learn in all their environments, not just in school. Therefore, it’s critical to consider utilizing assistive technology in all the child’s environments including, home, school, and in the community. For example, independent living skills include tasks such as turning on lights, calling for assistance, changing the TV channel or talking on the phone. Typically these are more frequently part of home life, not the school day. However, often the expertise on how assistive technology could be utilized to develop these skills exists with the school-based assistive technology professionals. Successfully combining assistive technology considerations in all the child’s environments requires communication between the family and school, which allows everyone to share their perspectives and expertise.

## Let’s Get Started

The steps below do not always occur in the same order and sometimes you have

to go back and try again. But, they provide a starting point for evaluating how assistive technology can benefit a child in school and beyond into adult life:

- Establish an understanding of the child’s present level of academic performance by utilizing your state’s standardized grade level student expectations to identify both areas of strength and where additional assistance may be needed.
- Establish an understanding of the child’s present level of functional performance by utilizing a tool such as the *WATI Assistive Technology and Transition* forms ([www.wati.org/products/freematerials.html](http://www.wati.org/products/freematerials.html)).
- Develop a written vision of life after high school in a detailed post-school outcome statement. This statement can help the Transition IEP team identify needed supports and services.
- Consider whether assistive technology can help achieve the outcomes.
- Identify who’s going to do what in acquiring the technology, providing training in its use if needed, and funding it. Also determine whether the funding source will allow the technology to go with the student into post-high school education and work.

Finally, as the old saying goes, “The harder you work, the luckier you’ll get.” Good luck.

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# Making a New Home: Options for Young Adults to Live Away From the Family Home

by Bob Prouty

If families are to help their young adult son or daughter successfully transition to life away from the family home, it is important that they have accurate information about the realistic options available. The systems for providing housing and support services for persons with intellectual and developmental disabilities (ID/DD) vary among the states and within individual states, as does the terminology describing the different options. It is very important to establish a good relationship with your young adult's county case manager (if your son or daughter has none, contact your county social service agency to request that one be assigned) so that you can get a clear and complete picture of all the services and supports for which your son or daughter is eligible, as well as their availability.

## Minimum Standards

In your planning, you should know that publicly-funded services for persons with ID/DD have specific standards set forth in law and court decisions, and you should expect and accept no less:

- Services must be provided in a timely fashion.
- Services must be provided in the "least restrictive alternative" (i.e., the most integrated and inclusive setting and circumstances possible within the general community).
- Services, including supervision and oversight, must be provided in such a manner as to assure the health, safety and welfare of the recipients.
- Services must provide opportunity for training and support to reduce the recipients' dependence and to provide an improved quality of life.
- Services must be provided in a manner fully respectful of the individual

worth and dignity of each recipient and of their desires and preferences.

- Persons with ID/DD may appeal decisions affecting them in a formal social services hearing before an independent hearing officer.

## First Planning

In planning for life outside the family home it is useful to think of two major factors: 1) living expenses and 2) residential services:

- Living expenses (housing, food, personal needs) are generally funded by monthly federal Supplemental Security Income (SSI) allotments to your son or daughter, as well as any state supplemental allotments and personal income from work and/or family.
- Residential services are generally paid for by Medicaid (a state-federal program) funds, but some persons receive services wholly funded by state and/or county dollars. Service funds may not be used to pay living expenses.
- A single agency may provide both room and board and specialized services for an individual, but this is unnecessary and, increasingly, separation of a person's living arrangements and the specialized services they receive is seen as desirable (e.g., it becomes possible to change the service provider without having to move from the residence).

## Where People Live

Nationally, there are many different names for residential settings and arrangements where persons with ID/DD receiving publicly-funded residential services may live. Excluding family

homes, generic nursing homes, and psychiatric hospitals, they fall into three broad categories: *congregate care residences*, *foster care/host family residences*, and *their own homes*. As of June 2004, the following was true of persons with ID/DD living in these settings:

- Almost two-thirds lived in congregate care residences in which a number of people with ID/DD lived, residences that were owned or rented and managed by the residential services provider.
- Nearly one-tenth lived in foster care/host family residences, where one or more persons with ID/DD lived with a family not their own, with additional services provided by an outside agency or, in some cases, by the family members.
- More than one-fourth lived in their own homes, which they or their family owned or rented and managed. They may have chosen to live alone or with others. They may have chosen their service provider(s).

In the past, with the nearly total reliance on congregate care settings, it was common practice to place people with ID/DD in existing residential settings to "fill the beds." In the early 1980s, with the advent of the Medicaid Home and Community Based waiver, that practice became outdated and ill-advised. It then became possible to provide specialized services to persons with ID/DD in settings of their own choosing. Thus, deciding on a living arrangement first and then arranging necessary services to be brought into that living arrangement is a logical and far more desirable approach than placement simply to fill an empty bed. This does not mean, of course, that there are no limitations to choice. Affordability, availability, and eligibility are all real-life factors that must be considered.



However, for an increasing number of families and individuals, housing chosen and controlled by the residents, with services selected and managed by the recipients, are worthy goals and realistic options.

### Selecting a Residence

In helping your son or daughter to choose a place to live, as you look at each possibility, there are questions you may wish to consider. As you discuss your options later, you can use these points and whatever else you choose to add in making comparisons:

- Does your son or daughter want to live here?
- Can your son or daughter afford to live here?
- Do the other residents, if any, seem compatible with your son or daughter and he or she with them?
- Does the residence seem safe (e.g., door and window locks, fire extinguishers and smoke detectors, on-site building manager)?
- Does the neighborhood seem safe (e.g., traffic, crime, street lighting, general state of the area, natural hazards)?
- Is the location convenient to family and friends, employment or other day activities, shopping, places of worship, social and recreational activities, health care, and public transportation?
- Is the service provider also the building manager?
- Who owns the building?
- What rent/lease arrangements are required for your son/daughter?
- What things, if any, bother you about the residence?
- What are the positive factors about this residence?

### Finally...

Rarely, if ever, can a parent assume that the essential contacts with adult service programs will be made during the transition process from high school to adult life without the active involvement of the parents. Informed assertiveness on your part is significantly more likely to achieve the desired result as you seek to help your son or daughter find a home in the community with services they need and want.

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## What Does Health Have to Do with Transition? Everything!

*It is not common practice to identify health-related needs and goals when developing a statement of transition services within a student's IEP. However, lack of attention to health needs and health management can jeopardize goals for learning, working, and living safely in the community. For this reason it is important that young people with disabilities know how to manage their own health care and work with appropriate professionals as partners in their care.*

*Health is an important factor to include even if chronic health concerns do not exist. All people must deal with health problems and learn how to maintain good health.*

*Transferring responsibility for self-care to an adolescent is a complex process. It requires assessing a variety of factors, including the complexity of a youth's health needs, his or her physical and cognitive abilities and degree of self-determination, as well as*

*family factors (Kelly, Kratz, Bielski, & Rinehart, 2002). Cultural factors such as values, health care practices, and beliefs about disability must also be considered (Geenen, Powers, & Lopez-Vasquez, 2001). The IEP lends itself well to evaluating factors needed for successful health outcomes as youth transition from special education to the adult world...*

*Because it is not yet common practice, families may find they have to bring health-care concerns to the attention of the IEP team in order for their son or daughter's health needs to be addressed. It can also be very difficult for parents to give full responsibility for health issues to a young adult because of the obvious dangers of mismanagement...It is beneficial to clearly identify concerns and discuss best- and worst-case scenarios. Support and emergency plans can be developed, and youth can become aware of the impact of certain behaviors on their health in order to*

*make informed choices. This approach has been successful in alleviating some fears and providing teens with a better understanding of how to maintain their health. These and other health-care issues can be addressed in the statement of transition services in a student's IEP...*

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Excerpted and reprinted with permission from *Parent Brief: What Does Health Have to Do with Transition? Everything!* (May 2006), by Ceci Shapland, Co-Director of the Healthy & Ready to Work National Center. Published by the National Center on Secondary Education and Transition, University of Minnesota. For the full article go to [www.ncset.org/publications](http://www.ncset.org/publications).

## Honoring Values and Needs: Personalizing the Transition Planning Process

by Pam Stenhjem

The transition planning process for young adults with disabilities is based on federal legislation requiring the development of an Individual Education Program (IEP). Certain activities must take place and specific guidelines must be met in order to fulfill the legislative requirements. However, the rules and regulations can many times make the transition planning process generic and rigid, rather than flexible and customized to a particular individual and family. Despite this obligation to meet the letter of the law, there are many ways in which young adults and their families can work with school staff and service providers to personalize the transition planning process to reflect their unique family values, culture, and needs.

Below is a list of activities that take place within a typical transition planning process, as well as a list of suggestions about how families and young adults can help the transition team to respond to their values and needs. The success of these suggestions is in part dependent on how receptive the case manager, IEP team members, and school are to them. Parents and young adults may have to be assertive and persistent in advocating for these options, and unfortunately may not always be successful. Yet, these suggestions are intended to help the process fulfill its purpose of supporting the successful transition of the young adult by ensuring that it respects those things that are important to the individual and their family:

- **Transition Process:** *Inform young adults with disabilities and their families about the IEP transition planning process by providing written information developed for this purpose.*

**Family Suggestion:** Speak with the case manager about your family, including important family and individual values, expectations, and needs

that must be considered when planning with your young adult for post-school life. Share views and needs in relation to transition planning, such as how the process can be respectful of family values and characteristics, as well as needs for information in alternative formats such as Braille or languages other than English.

- **Transition Process:** *Send a letter notifying families of the IEP transition planning meeting date, time, and place. Hold the IEP meeting at the school during regular school hours.*
- **Family Suggestion:** Speak with the case manager about where and when you prefer to meet. Is it better for you if the meeting is held in your home, workplace, or a community location other than the school? Is it better if it's held in the evening?
- **Transition Process:** *Invite service providers and key school staff to attend the meeting.*
- **Family Suggestion:** Tell the case manager who you would like to invite to be part of the transition planning process. For example, you may want to include friends, grandparents, aunts and uncles, community elders, or interpreters.
- **Transition Process:** *Review the previous IEP at the meeting in order to familiarize team members with goals, objectives, and progress made toward meeting those goals. Develop IEP goals based on legislated mandates that reflect student preferences.*

**Family Suggestion:** Review the IEP ahead of time to prepare for the meeting and to identify the goals your young adult wants to work toward. Generate a list of questions, concerns, or needs that you want to discuss. Identify ways in which goals need to be stated to reflect your young adult's

and family's preferences, values, and culture.

- **Transition Process:** *Implement the IEP as stated.*
- **Family Suggestion:** If problems, concerns or questions arise as the IEP is implemented, contact the case manager to discuss ways to address them in light of your views, values, and preferences. Suggest alternative ways of implementing goals that are respectful of your beliefs, traditions, and culture. Invite IEP team members to attend events with your young adult and family in your community so that they can learn more about you and what is important to you.
- **Transition Process:** *Review the IEP at the beginning and ending of each school year and add or modify goals as needed with input from the student and family.*
- **Family Suggestion:** Contact the case manager to review and modify the IEP as often as needed, and make your needs and concerns known. Help the IEP team understand how your young adult and family view the world, as well as the transition planning process, so that they can understand how you approach the revisions.

Transition planning can be a wonderful experience when the IEP team, the young adult, and their family work together to address each young adult's goals for the future through attention to unique needs, family values, and cultural heritage. When we address the transition planning needs of youth in a creative and sensitive way, everybody wins!

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## Supporting Culturally Sensitive Transition Planning for American Indian Youth

by Vern Zacher, Jean Ness, and Dennis Olson

*The values expressed in strategies used by transition services and supports for young people with disabilities may at times be in conflict with the values of families from a number of cultural communities. This article presents one example of how families might experience and navigate those services and supports.*

The path from school life to adult life is not easy for anyone. For American Indian youth this transition can be compounded by many factors in their lives. Often public school was not a pleasant place for American Indian parents, while grandparents have memories of boarding schools. These institutions historically represent places where one's culture was not allowed. These memories are still alive and well with parents and grandparents of many. Therefore, being involved in school activities does not bring memories of positive events.

Unless family members have been through the process of transition from high school to postsecondary life, they may not have necessary skills to work with the systems that support the transition process. American Indian youth in transition need an adult who has time, who they trust, who knows how to advocate on behalf of the student, and who knows how to work with agencies. Often students need "hand holding" to actually lead them through the college admissions and financial aid process, or employment-seeking process. It is essential that the goal is the youth's and not the support givers'. If the youth does not develop the ownership of those goals, there may be a total loss of interest and the student drops out of school or work.

Here are some key points for parents and family members to consider in supporting their youth in transition:

- Find someone you trust at the school and start learning about the options available after high school.
  - Search for extended family members who can be positive role models in the transition process. These are individuals who have had experience with systems and can give you and your youth strategies to use.
  - Help youth understand their strengths in and out of school to help them determine interest areas for careers. Help them realize that grades are only one measure of their performance. It is likely the youth has developed skills by being involved in cultural and community activities. Stress the importance of pursuing these areas as part of their transition exploration.
  - If the youth expresses interest in a career area, help them find ways to have experiences in that area. Maybe a family or community member works in a related field and can help provide a job shadowing experiences.
  - Parents can also work with school staff to assist with searching and applying for summer internship positions in career interest areas.
  - Help the youth find a trustworthy community member, perhaps an elder, who can listen to the youth and be a mentor or positive role model.
  - Help youth learn how to ask for what they need in an appropriate way. Role model positive ways to advocate in your community. Have them practice it at home and then in situations unfamiliar to them.
- Here are some key points to consider when transition planning for life after high school:
- Get to know your high school guidance counselor. Encourage your youth to let the counselor know what his or her interests are so they can offer specific ideas about how to pursue those interests after high school. If your school doesn't have a counselor, the American Indian advocate, Home School Liaison, or Indian Education Director can also provide direction.
  - Look for the scholarship office on your reservation. Scholarship counselors are available on many reservations to not only help youth access money for college, but for guidance and direction.
  - Encourage your youth to talk to relatives and others in your community who went to college or conducted a job search, and ask them for tips on how they did it.
  - Talk to elders in your community and ask them about how they feel about education. Have them explain to your youth the important role of educated members of the tribe. Ask elders for guidance.
  - Parents and family members need to get involved in the planning process so they can help youth accomplish their goals. For many family members, college is a foreign concept, so youth and other family members will need to learn the steps together.
  - If you do not have a family member who can offer support for your youth's postsecondary planning, ask your school for a mentor, someone who has experience with college and/or your youth's career interest area who can give ideas and support.

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## If I'd Known Then What I Know Now...

by Julia Washenberger

I have taken a lot of time recently to reflect on my life, my accomplishments, and challenges. A reflection that continues to come to mind is that I would *not* have had as many accomplishments had it not been for the services and support I have received throughout my life.

My support started with early childhood services at 16 months of age. Those services helped me to bridge the gap between the level I was at and that of other 16-month-old infants. I was born with spina bifida and hydrocephalus. The cerebral spinal fluid that didn't flow correctly put pressure on areas surrounding my brain. It resulted in what is essentially a form of brain injury. The brain injury led to cognitive complications and issues with learning. This was finally formally documented much later in my life at the age of 18. At the time, I really didn't realize the profound impact hydrocephalus would have on my life.

Instead, for years I believed what others told me: that I was unintelligent, lazy, inattentive, and that I would have to settle for less in life because I was not "smart enough." While I am of below average intelligence, I struggle with learning and auditory processing. For years I struggled with how I felt about myself. I did not do well academically. I knew that there was something different about me, but I didn't know what it was. At one point I let professionals convince me that I was depressed as a result of not "accepting my physical disability." I also began to believe that I just wasn't trying hard enough. It turned out that with learning I could be successful if the information was relayed to me in a manner that I could interpret. What I really needed was appropriate accommodations and to understand my learning disability.

Support services are an extremely important part of the transition process. They are intended to be used as a stepping stone to achieve self-sufficiency. I have seen first-hand how difficult life can

be for those who choose not to utilize this support (as needed) in order to make a successful transition to adult life. As a result of support services – such as vocational rehabilitation and transition programs – and the support of my family I live a successful life. Expectations were set very high for me. There were consequences when I did not work to my potential. One thing that would have been more helpful as I made that transition to adult life would have been the belief that I had what it took to move forward. Young adults need to be better prepared to know they can succeed. I continue to stay connected to people who have been part of my support network for years. I discovered that they were not just involved because they had to be, but they are invested in whether I succeed or not. They have turned into life-long friends and my life-long support system.

Today I have much to celebrate! I have a bachelors degree in Human Services Administration, and I am pursuing a certificate in Disability Policy and Services at the University of Minnesota. I'm planning on getting my masters degree in public policy, and I have worked at the Institute on Community Integration as a community program associate for six years. I own a home, am not on financial assistance, and contribute much of my free time to a number of organizations. I have learned that life is a series of transitions. As I go through each new life transition, I am searching for tools that will help me to move forward in a positive direction. I do not look at challenges in life as mistakes, but rather as something that I need to learn from; there is value in change. Whether your disability is acquired later in life or you are born with it, acceptance is important. With acceptance though does not have to come a lowering of expectations. Expectations can be met with the right support and accommodations.

Some people whom I have met who have children and/or adult family mem-



*Julia found the right supports and accommodations to help her successfully navigate the transition years.*

bers with disabilities tend to think that the most important thing in life is to make the person with the disability "look" typical to "fit in" and be socially accepted. They feel that accepting services and supports is not living a "typical" life. I had the support of family and friends to develop what my "normal" life would be. The challenge I find myself in is when I compare myself to others. I have to stop doing that. My "normal" and my "reality" is different than that of others my age.

I now look forward to my future challenges and accomplishments. Transitions in life will continue to come. With that will also come many more accomplishments and successful attempts at new adventures in life. I want to thank all of the support providers who believed in me.

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## Parents' Suggested Timeline for Transition from School to Life

<b><u>Student Age</u></b>	<b><u>Action Needed</u></b>
<b>11-14</b>	<ul style="list-style-type: none"> <li>Your child's IEP (Individualized Education Plan) should include social, communication, and self-help skills with at least functional math and functional reading in regular classroom settings (if appropriate)</li> </ul>
<b>By 14</b>	<ul style="list-style-type: none"> <li>Begin Transition Planning (focus on student's course of study)</li> <li>Learn about exit options to ensure that your child will be able to reach his/her goals (example: going to college or military service)</li> </ul>
<b>No Later than 16</b>	<ul style="list-style-type: none"> <li>Transition planning (focus on interagency responsibility or any needed linkages)</li> <li>Identify job interests and abilities and some job training</li> <li>Begin to identify community services that provide job training and placement</li> <li>Prepare job placement file with references and skills that have been acquired</li> <li>Begin application to adult service agencies</li> <li>Consider summer employment or participate in volunteer experiences</li> </ul>
<b>16-18</b>	<ul style="list-style-type: none"> <li>Contact Adult Services programs:               <ul style="list-style-type: none"> <li>Colleges, vocational or technical schools</li> <li>Social Security Administration</li> <li>Residential or independent living services</li> <li>Recreation/leisure groups</li> <li>Medical services</li> </ul> </li> </ul>
<b>17-18*</b>	<ul style="list-style-type: none"> <li>Begin to consider and research Guardianship</li> <li>Continue to review and update Transition Plan</li> <li>If college-bound, take ACT or SAT tests, visit colleges and their disability services offices, and register with the disability service office of your preferred school by the end of Senior year</li> </ul>
<b>18-21*</b>	<ul style="list-style-type: none"> <li>Continue to review and update Transition Plan</li> <li>Establish needed health benefits</li> <li>Develop long-term financial support plan (example: SSI)</li> </ul>
<b>21 and beyond</b>	<ul style="list-style-type: none"> <li>There is support available to adults with DREAMS for the future.</li> </ul>

\* Some students may remain in school and continue working on transition goals through age 21 or as defined by state law.

Adapted and reprinted with permission from *Full Life Ahead: A Workbook and Guide to Adult Life for Students & Families of Students with Disabilities* (2006), by Judy Barclay and Jan Cobb, published by the Full Life Ahead Foundation, Birmingham, Alabama. For further information on the entire guide visit [www.FullLifeAhead.org](http://www.FullLifeAhead.org) or call 866/700-2026.

## Resources

- **Parent Training and Information Centers/Community Parent Resource Centers.** Every state has at least one Parent Training and Information Center or Community Parent Resource Center serving families of children and young adults with all disabilities from birth to age 22. They help families access appropriate education and services for their children, train and inform parents on a variety of topics, resolve problems between families and schools or other agencies, and connect young people with disabilities to community resources addressing their needs. To find out about the parent center in your state visit [www.taalliance.org/centers](http://www.taalliance.org/centers) or contact the National Technical Assistance Center at PACER Center, Minneapolis, 888/248-0822 (toll-free), 952/838-0190 (TTY/711 Relay), or [alliance@taalliance.org](mailto:alliance@taalliance.org) (e-mail).
- **Bright Futures for Families (<http://brightfuturesforfamilies.org>).** Bright Futures for Families is a national initiative for families and communities to promote and improve the health and well-being of children of all ages. Resources on the Web site include the *Family Pocket Guide – Raising Health Infants, Children and Adolescents*; *Health Care Visit Checklist for All Children Including Children with Special Health Care Needs*; *Transitions – Growing Up and Away*; and the e-newsletter *Bright Futures: Family Matters*.
- **Family Voices ([www.familyvoices.org](http://www.familyvoices.org), 505/872-4774 or 888/835-5669).** Family Voices is a national grassroots network of families and friends that advocates for health care services that are family-centered, community-based, comprehensive, coordinated and culturally competent for all children and youth with special health care needs. It promotes the inclusion of all families as decision-makers at all levels of health care, and supports essential partnerships between families and professionals. On its Web site are resources for information and education concerning the health care of children with special health needs. In addition it provides information on the Family Voices organizations in each state.
- **Kids as Self Advocates ([www.fvkasa.org](http://www.fvkasa.org)).** Kids as Self Advocates (KASA) is a national, grassroots network of youth with disabilities and special health care needs (and their friends) speaking out. KASA youth are leaders in their communities who spread helpful, positive information among their peers to increase knowledge around various issues including living with disabilities, health care transition issues, school, work, and many more. KASA is a project of the national organization Family Voices, and on the KASA Web site are useful resources for youth with disabilities and special health care needs, and a place to share ideas and experiences.
- **The Self-Advocate Leadership Network ([www.hsri.org/leaders](http://www.hsri.org/leaders), 503/924-3783).** The network educates self-advocates to play lead roles in their personal lives and to shape disability policy. Several products are available on self-advocacy, self-determination, giving a presentation, and organizing for change. Also, the network publishes *The Riot!* a free quarterly e-newsletter for self-advocates ([www.theriotrocks.org](http://www.theriotrocks.org)). Not a typical policy rag, it tackles important issues and covers life topics, such as dating, health and everyday fun. The network is based at the Human Services Research Institute, Portland, Oregon.
- **Family Village ([www.familyvillage.wisc.edu](http://www.familyvillage.wisc.edu)).** Family Village is a Web site for children and adults with disabilities, their families, and others. It brings together thousands of online resources in a organized, easy-to-use directory, including an extensive listing of transition-related resources for teens, young adults, and their families. Family Village is operated by the Waisman Center, University of Wisconsin - Madison.
- **The National Youth Leadership Network ([www.nyln.org](http://www.nyln.org), 866/480-6565 x2, toll-free for youth only).** This network is dedicated to advancing the next generation of disability leaders by promoting leadership development, education, employment, independent living, and health and wellness among young leaders representing the diversity of race, ethnicity and disability in the U.S. It fosters the inclusion of young leaders with disabilities into all aspects of society at national, state, and local levels, and communicates about issues important to youth with disabilities. Its Web site has resources on a wide range of topics including scholarships and financial aid for students with disabilities.
- **Partners in Policymaking (<http://www.partnersinpolicymaking.com>).** Partners is an innovative, competency based leadership training program for adults with disabilities and parents of young children with developmental disabilities across the country. Created by the Minnesota Governor's Council on Developmental Disabilities, it offers numerous online and classroom training opportunities, including the following free online courses: *Partners in Education*, a six-hour self-directed course to help parents of children with developmental disabilities better understand and maximize the benefits of special education services and inclusion for their children; *Partners in Employment*, a six-hour self-directed course for adults with developmental disabilities on how to find a job, write a resume, participate in an interview, and plan for a career; and *Partners in Time*, an eight-hour self-directed course to help people with developmental disabilities, their family members, and others understand the history of society's treatment of people with disabilities.



*[Carol, continued from page 1]*

and the use of a wheelchair and augmentative communication, is that she has to earn a living and could and should get the good stuff in life. Fortunately, she assumes that as well.

During school she was fully integrated into regular classrooms, and quickly developed friendships with other students. By the time Mikelle graduated she had had four jobs, two of them paying at least \$100 per hour and two of them paying well over minimum wage. The high-paying jobs were contract jobs, but still set the expectation that she could earn good money. The others were summer jobs. We used extended school-year dollars in partnership with some

***To have a chance at accomplishing real transition into adulthood – the kind where young adults actually own their own lives – requires vision, passion, focus, and most assuredly persistence.***

limited support from vocational rehabilitation to pay for a job coach during the summer. Summer job development was a cooperative venture between friends, family, and the school.

To have a chance at accomplishing real transition into adulthood – the kind where young adults actually own their own lives – requires vision, passion, focus, and most assuredly persistence. And, the knowledge that your transition plans will most likely have to be changed and modified along the way – many times. Sleeping on the couch is how my nights are spent at the moment. It reflects some of those changes and modifications that happen along the way. In reality, both Mikelle and I have needed a Plan B, Plan C, and now Plan D. We both

have had to make adjustments and gain new insights into ourselves and the realities of successful transition.

One of Mikelle's goals on her transition plan was to live on her own. Talk about persistence; she reminded us constantly that she was determined to move out. We all thought it would be when she was 23 or 24 years old and that we would have a couple of years to make that happen. We signed her up for the Section 8 housing waiting list, figuring it would take several years, if not many years for her to obtain a voucher. Her voucher came up suddenly and we had 60 days to find her an apartment. We found her a two-bedroom apartment so close to my home she can see it from her apartment window, plus it has a great view of downtown Denver. She has two bedrooms so she can have a roommate to provide overnight support and fill in a few hours a week.

I placed an ad on Craig's List, ([www.craigslist.org](http://www.craigslist.org)) and we ended up interviewing five young women for the role of support person. We selected one and did reference checks, including a criminal background check. I stayed overnight for a week making sure they were comfortable, only to have it quickly become apparent that the arrangement was not going to work. Hence, the return to the couch. Mikelle would not even consider moving back home – I don't have cable!

So, what have we learned? As you let go and transition, have solid agreement between roommates and staff about expectations – they need to be written together and signed by all parties. No one is going to parent like you do, but they can bring new perspectives and learning experiences even if it looks like it failed. And be persistent and know that for your child's life to change, yours has to change as well. This way you will avoid being roadkill on the road to transition.

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## **Institute Online Resources**

- **National Center on Secondary Education and Transition (NCSET) Web Site ([www.ncset.org](http://www.ncset.org)).** This Web site from the Institute's NCSET offers families, educators, youth, and others over 70 free publications that support the success of transition-age youth. Among them is *Parent Brief*, which informs parents about secondary education and transition services and issues. And visitors can sign up online for *NCSET E-News*, a twice-monthly e-newsletter with information on publications, Web sites, listservs, grants and scholarships, and more.

- **Youthhood ([www.youthhood.org](http://www.youthhood.org)).** This Web site of the Institute's NCSET is a free, holistic tool that teenagers and their teachers, parents, and mentors can use to plan for life after high school. It has three main purposes: 1) To provide a curriculum for adults to use with youth to help them plan their futures; 2) to be a resource and future-planning tool for youth; and 3) to be a place where youth can learn from one another.

- **Quality Mall ([www.qualitymall.org](http://www.qualitymall.org)).** This Web site of the Institute's Research and Training Center on Community Living (RTC) offers over 1100 resources from around the nation related to person-centered supports that help people with developmental disabilities live, work, and participate in their communities. It includes a section of family resources on topics ranging from financial and estate planning, to respite, to aging.

- **Self-Advocacy Online ([www.selfadvocacyonline.org](http://www.selfadvocacyonline.org)).** A Web site launching in July 2006 that will include a directory of self-advocacy organizations and groups nationwide, and interactive lessons for persons with disabilities desiring to build their own self-advocacy skills. It's operated by the Institute's RTC.

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## **Impact**

*Feature Issue on Parenting Teens and Young Adults with Disabilities*

*Volume 19 · Number 2 · Spring/Summer 2006*

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*Impact* is published quarterly by the Institute on Community Integration (UCEDD), and the Research and Training Center on Community Living, College of Education and Human Development, University of Minnesota. This issue was supported, in part, by Grant #90DD0579 from the Administration on Developmental Disabilities, US Department of Health and Human Services; and Grant #H133B031116 from the National Institute on Disability and Rehabilitation Research, US Department of Education.

The opinions expressed are those of the authors and do not necessarily reflect the views of the Institute, Center, University, or their funding sources.

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