A resource for families and others interested in Down syndrome & related disabilities

Disability Solutions

A publication of the Enoch-Gelbard Foundation

Volume 6, Issue 1 September/October 2004

Thinking About Tomorrow

The Transition to Adult Life

by Jo Ann Simons

The period of time between high school and what comes next is not a transition. That sounds like something that gets you from one place to another—like a bridge. It even sounds easy. In my experience, transition has been nothing short of a free fall. This article will illustrate some ways to survive. Families are surviving and thriving, though they have had to work hard.

Turning 21 or 22, or getting a diploma—whatever point your state has determined is the end of a free public education—is the beginning of the rest of your life. Everything will change. Nothing will be the same, but believe me, you will survive.

There are many skills you have learned in the years leading up to this transition that will become even more important. Skills that will help you navigate a daunting maze of rules and regulations regarding what is available to your child. The biggest difference between the years your child is in school and adulthood is that your child is not "entitled" to services. There is no national or state law that entitles your child or your family to any assistance because your child has Down syndrome. There may not be any lawyers to hire or advocates to line up. Laws that do exist are carefully crafted with language such as "if funded" or "depending on allocation" and other jargon alerting you that anything you receive is subject to change depending on your state's budget process.

So, what's a family to do?

Prepare, prepare and *act*.

What is *Transition*?

My son, Jon, is 25 and he has been my best teacher. My first advice to you is to *listen* to your children. They will lead you. Several years ago, after graduating from our local high school, Jon moved on to a post-graduate program, two hours from our home on Cape Cod. His birthday was approaching and I called to make plans for us to celebrate with him. He seemed hesitant to commit to a dinner with us. He asked an interesting question: "How many birthdays have you celebrated with me?" Nineteen was the obvious one since the birthday approaching was his twentieth. He paused for a moment and replied, "Then I think it is time for a change." I was aghast, but not speechless. I came back with a quick, "It will be hard." And his thoughtful reply was, "You'll get used to it." Transitions are a time of great change. You *will* get used to it.

Every year, millions of people around the world finish their secondary or high school studies and go on to something else. But, if you have Down syndrome or a related disability, we have named it. We have named it *transition*. Otherwise, it is just "What are you doing next year?"

Have you gone through the college application process with another child recently? If so, you looked at college catalogues, visited campuses, edited essays, fine-tuned resumes, sought out connections, and spent countless hours listening

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In this Issue

Welcome

Letter from the Editor

Everything Will Change.

Joan Guthrie Medlen, R.D.

Change. We love it. We hate it. Life is full of it. Parents of children with Down syndrome and related disabilities constantly manage dramatic changes. When things remain the same, it is cause for suspicion. We wonder what lies in wait around the next corner?

When you think about it, families of children and adults with Down syndrome are not asked to cope with a greater number of transitions. All children move on to preschool, kindergarten, elementary school, middle school, high school, create plans for when school ends, and make multiple career changes. Why do these natural steps feel more difficult for us?

Maybe it is the affect significant change has on children and adults with Down syndrome and their families. Maybe it is because the system turns what should be a natural process into a contrived science filled with meetings, papers, and assessments. Or maybe it is due to the innate anxiety related to change. Whatever the reason, transitions are filled with time-consuming fret, negotiation, and work.

No stage of life is more challenging than the transition out of a Free and Appropriate Education (FAPE) to “whatever comes next.” If what is available isn’t acceptable for your child, you must act. Nothing changes what is or is not available in your community better than your own creativity and effort. Regardless of what is currently available through traditional sources, parents must proactively devise an *enviable life** for their child to lead. This last transition from school to adulthood is the least structured, most time-consuming, and most important transition your child will make. In my opinion, it begins when they are babies and never ends.

In this issue of *Disability Solutions*, two parents of young adults share their expertise and experiences with the process of creating an enviable life for their children. In her article, *Thinking About Tomorrow: The Transition to Adult Life*, JoAnn Simons shares a comprehensive list of things to consider and coordinate as you contemplate this stage of life. Use her information and experiences to guide your own creativity for your child’s adult life. She reminds us that the process takes years and each family chooses a different area to focus on first. Some will focus on living arrangements, while others will focus on employment. In her article *Beginning a Career: Stefanie’s Story*, Chery Ward shares her daughter’s experience preparing for a career.

Both articles have one motif: proactive planning, with room for creative change, is essential to reduce everyone’s stress. Both families learned nothing goes as planned; everything must be flexible. Things are often better for it. As JoAnn says, “everything will change, nothing will be the same, and you will survive.”

Take care,
Joan

*For information about the concept of an “enviable life,” visit www.beachcenter.org.

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Disability Solutions is published six times yearly by The Enoch-Gelbard Foundation, a nonprofit, independent, private foundation. If you would like to continue or stop receiving this free publication, please write to the publication address.

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Feature Story

Beginning a Career

Stefanie's Story

by Cheryl Ward

My daughter has always been a unique girl. She is talented, charming, smart, and clever. We have advocated for her education to fit her abilities and desires, which isn't always easy. Planning for her life at the end of her Free and Appropriate Education (FAPE), hasn't been any different. It has required some compelling discussions to promote individualized planning. As usual, when we listened to Stefanie and advocated with her for experiences that fit her abilities and interests, we made the most of the opportunity.

When Stef was in middle school, we began to listen more closely to her dreams about the future. She wanted to be a movie star, live in a house at the beach, and be married to a cute husband. While being a movie star isn't the most practical career goal, it was a similar goal to many of her girlfriends who did not have Down syndrome. So was having a cute husband. Her friends' parents saw this dream as a natural part of growing up. So did we. There was no need to squelch her dreams with our idea of practicality. Instead, we decided to use them to our advantage. Yet when the I.E.P. Team met to discuss her eventual transition, her dream didn't fit in any of the multiple-choice boxes on the form.

We have been skillful and lucky when it comes to educational placement. Stefanie has always been included in general education. This means her curriculum was based on general education goals other students learned rather than solely on life skills. Stefanie was able to pursue her dream of being a movie star in drama classes. She also enrolled in the Teen Living Classes offered to all students where she learned cooking, sewing, and budgeting skills alongside her childhood friends.

Over time her dreams began to change. Or, I should say, her career choices changed. She still dreamed about living in a house at the beach with a cute husband, but she realized—just as her friends did—that she probably wasn't going to be a movie star. At the same time, she found her high school classes more challenging. We decided to enroll her in some classes in the special education department. In these classes, her education focused on her transition goals, expanding her plan and the areas where she needed to add more skills such as money management.

At the same time, her interest in self-advocacy also increased and she began to attend her IEP meetings armed with specific goals of her own. Where did she gain the knowledge and strength to recognize and express her desires like this? How did she know what choices were available? Sure, we

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as your child chose the setting that fit his dreams, interests, and personality.

You will have to have the same level of involvement with your child who has Down syndrome as he leaves public education also. Unfortunately, there are not many guidebooks to help. But, as always, we have each other and lots of families have gone before you to pave the way. Your job is to repair, refine, and redirect the path as needed for those who follow you.

My goal is to simplify this time in your life and demonstrate to you that you already have all the knowledge and most of the tools to support your son or daughter during this transition. This article provides a general road map and some useful tips to use along the way.

What Are the Options?

Think back to your own experiences. Recall your own high school years or, if that is too distant, perhaps you have a child who has recently graduated from high school.

Somewhere in your junior year you began to think about what you were going to do when you graduated. But most of us waited until our senior year to do the thinking. So what did everyone decide?

Here is what happens to a typical senior class:

- Some of our classmates went directly to work.
- Some of our classmates went to trade schools.
- Some of our classmates joined the armed services.
- Some of our classmates went to community colleges and lived at home.
- Some of our classmates went off to 4-year colleges.
- Some of them lived at home others lived on campus.
- The majority of our classmates stayed within a 1-2 hour drive from home.

In every graduating class, people with developmental disabilities will make a variety of choices for their life after the end of their public education.

Expect the same for people with developmental disabilites:

- Some will go directly to work.
- Some will go to trade schools.
- Some will go to community colleges and live at home.
- Very few, if any, will join the armed forces, though they may want to.
- Some will go to 4-year colleges or other post secondary programs.
- Some will live at home; others will live on campus or in apartments.
- The majority will stay within a 1-2 hour drive from home.

Outside of the initial diagnosis, families believe the most difficult time in the life of a parent of a child with a developmental disability, is the transition from school to adult life. What makes this so difficult is that the process is really a series of decisions and transitions that take many years. It requires much effort, planning, and time on the part of families.

A Vision for Life After High School

We all have to start somewhere and a vision is good place to begin. What is your vision for your child after high school? What is your child's vision? Are they the same, or even close? A vision begins with, and focuses on, your child's interests, abilities, and dreams. Some families have a vision they share throughout their child's life, altering it as his interests change. Other families need more structure and discussion to begin to develop a vision. Many families use a process called *person centered planning* to develop a vision and a series of action plans

Expect the same for students with developmental disabilities.

to reach that vision. Person centered planning is a process of learning what your child's dreams are, assessing what needs to be accomplished, and creating action plans that lay out steps toward each goal. Some better known methods for doing this are called, *mapping* (MAPS) and *group action planning* (GAP). Resources for person centered planning tools are available on page 15.

We did not use a formal process to determine a vision for Jon. Instead, we listened to Jon**.** His vision began taking root in his early years of high school when he expressed his preference for an inclusive education setting. As a sophomore, he began to ask about taking the SAT's and going to college. Inclusive education meant he spent his days in our local high school surrounded by students planning to go to college. In a high school that sends 87% of its students to college, Jon did not meet too many kids who were planning on work or the military after high school.

Jon's roadmap included visits to 4-year colleges, community colleges, and specialized post secondary residential programs. We filled out applications, went on interviews, took tests and we "marketed" him to prospective schools. It was a long and thoughtful process and it took several years. In the end, all our work and effort paid off as Jon had choices in May of his senior year. He decided to attend the GROW (Getting Ready for the Outside World) program of the Riverview School in East Sandwich, MA and co-enrolled at the Cape Cod Community College in a program designed for students with developmental disabilities. In doing so, he turned down the opportunity to become the first and only student to attend a four-year college in Massachusetts as a non degree-seeking special student, an opportunity to attend a college in New York, or stay in our community and get a job.

Everything will change. Nothing will be the same. You will survive.

The Transition Checklist

Along with the vision, it is important to have a tangible idea of your child's skills related to the real world to help you identify what to address. To help you with this, one version of a checklist is included on page 6. This is not a test or assessment. It is an opportunity to see the skills your child has and what areas you may have overlooked. It is helpful to use when you need to describe your child to an admissions officer or whoever is the gatekeeper to whatever it is you and your child decide you want for a transition. This checklist provides some general areas to consider.

Use the transition checklist to identify goals to build into your child's I.E.P. and your home routines during the transition years (age 14-21). Keep in mind the checklist is very broad. Some areas your child has already mastered. Others will require some thought regarding the steps involved and which of those your child needs to work on. Although some of these areas may not be important to you, they are likely the types of questions others will have for you about your child when considering life after public education.

Other transition checklists that break categories down in more detail are listed in the resource section on page 15.

Choices About Graduation

Another important aspect to leaving school is graduation. The first item to consider is when does secondary school education in the high school environment end? Like everything in your child's life, this is specific to each individual. For some students with developmental disabilities, it ends after four years of high school and for others it may end after five, six or seven years. It might depend on how old

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Thinking About Tomorrow

Transition Skills Checklist

Vocational Skills

Can your child:

- ☐ Get to and from work, on time.
- ☐ Perform work satisfactorily.
- ☐ Work cooperatively with others.
- ☐ Take break or lunch appropriately.
- ☐ Wear suitable clothing.
- ☐ Use appropriate safety procedures.
- ☐ Follow directions.
- ☐ Accept supervision.

Community Skills

Can your child:

- ☐ Use public transportation.
- ☐ Shop for groceries, clothing.
- ☐ Make necessary appointments.
- ☐ Use phone.
- ☐ Use bank accounts.
- ☐ Be safe in traffic, among strangers.
- ☐ Know how to seek help.
- ☐ Handle money.
- ☐ Use an ATM.
- ☐ Use vendine machines (laundry machines, fare cards, and so on).

Domestic Skills

Can your child:

- ☐ Plan menus.
- ☐ Make shopping list from menus.
- ☐ Prepare breakfast, lunch, supper, snack, or pack a lunch.
- ☐ Wash dishes, pots, and pans
- ☐ Clean up apartment (bathroom, living areas, kitchen, and so on).
- ☐ Clean own room.
- ☐ Do laundry: use washer, dryer, and iron.

Social & Personal Skills

Can your child:

- ☐ Supply appropriate personal identification.
- ☐ Greet people appropriately.
- ☐ Use contemporary style of dress, hair, make-up.
- ☐ Use good grooming, hygiene skills consistently.
- ☐ "Talk" with friends and co-workers.
- ☐ Be courteous.
- ☐ Be responsible.
- ☐ Be happy.

Recreation & Leisure

Can your child:

- ☐ Use free time for pleasure.
- ☐ Choose reasonable activities.
- ☐ Pick a hobby.
- ☐ Perform required activities.
- ☐ Use community resources.
- ☐ Call friends to make plans with them.

Other Useful Skills

Can your child:

- ☐ Use cell phone.
- ☐ Use a datebook.
- ☐ Take prescriptions as directed.
- ☐ Use over-the-counter medications appropriately.
- ☐ Use sunscreen when needed.
- ☐ Use insect repellent when needed.

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your child is and that may depend on decisions you made many years ago. Some families kept their young children back several years and others wanted their children to stay with their peers. Each of us made different decisions then and each of us will make different decisions now. Our guides will be our children and our own personal values.

Every state establishes guidelines for issuing a diploma. They usually consist of completing a certain set of courses and some tests students must pass to prove competency in educational standards. Most students eagerly anticipate the earliest graduation date possible. For many students in special education who have significant needs, and almost all of those with Down syndrome, "graduating" has several definitions. "Graduating" may mean walking across the stage to receive a diploma. But in many communities, once a student—even those in special education—receives a diploma, it means you agree that a Free and Appropriate Education (FAPE) is complete.

However, for most families of children with Down syndrome, "graduating" is an important life cycle event rather than an acceptance of a diploma or the end of FAPE. It is very important to know the local rules and customs so you are not caught off-guard. Make sure your choices are informed ones.

My son graduated with his class, received several senior awards, and over $6000 in scholarships. But he did not receive an actual diploma. He walked across the stage and was handed a folder that looked the same as everyone else's, but rather than having a diploma inside, it was a "certificate of attendance." When Jon turned 22 years old—the age FAPE ends in Massachusetts—I picked up his actual diploma in the principal's office. We did not take the actual diploma when he graduated with his friends to ensure our school district would continue to provide him with the educational supports he continued to need.

Your choice will depend on several factors: financial, emotional, and practical. What is important is that you understand why you are choosing one over the other and the implications of making that choice.

After Graduation

After you decide how long your child will be in high school, it is time to plan for what comes next. Don't wait until your child graduates to begin thinking about these topics. Each one requires considerable time and effort from parents and those who support your family. It is wise to begin researching what is available and building partnerships with others to create a situation that is unique for your child.

There are several areas to think about that fit into three main categories: employment, living arrangements, and leisure time. Each category is filled with choices, options, and financial needs to consider. There is no right or wrong order to tackle them. Some families will focus on living arrangements first while others will work on finding stable employment or leisure opportunities. These decisions will likely depend on programs and waiting lists for those programs in your community. Start early, ask questions of friends and professionals, and make informed decisions that support your child's vision for their life.

Employment

Competitive employment is one option after high school. In the United States, many typical students go to work when their secondary studies are completed. For young adults with Down syndrome and other disabilities, employment may be appropriate if they have both good work skills and previous work experience. Competitive employment is just that—competitive—and it is often a goal that can be reached with limited job supports. Many people benefit from what can best be described as a long orientation to their job. In the service world, it may have a different name such as "employment supports" or "job coaching." An individual called a "Job Coach," "Employment Specialist," or something similar accompanies the person to work for several hours, weeks, months, or until the person is successful independently in the work place.

Another approach to supporting people in competitive employment is *fading*. Fading is a technique where the support person slowly fades from the job site. They stay involved just enough to ensure the person continues to be successful as with decreasing support that is finally eliminated.

One essential aspect to successful employment is having someone serve as a *Follow-Up Specialist*. This person, in a mutually agreed upon interval with the employer, checks in with the supervisor and the employee, to ensure that the workplace expectations continue to be met and any problems are identified early enough to be addressed. Too often, this important component is overlooked causing people to lose their jobs when a little bit of intervention might have resulted in continued success.

The most overlooked opportunity in employment is the use of *natural supports* in the workplace. This means providing guidance to co-workers that gives them confidence in assisting, prompting, and providing general help to your child—just as they would anyone else. If you think about it, we all use natural supports in our work.

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That being said, job loss is a fact of life, especially for persons with disabilities. Supervisors' change, corporate expectations rise, and under-performing workers are often the first to go.

Job development is very important for successful, competitive employment. You want to not only ensure a job is identified for your child, but that it is the right job. A noisy environment will not work for someone with sensory issues and a job in an office won't work for a person who needs more physical activity.

There are many ways to evaluate what jobs your child will enjoy and thrive doing. The article, *Beginning a Career* (page 3), describes in more detail the process one family is using. Career Interest Inventories are a tool to consider. A brief list of inventories is listed in the resource section on page 15.

It is important to consider the need for physical activity in the lives for people with disabilities when we are looking for employment. Knowing that my own son benefits from more physical activity rather than less, we looked at jobs that he would enjoy and would give him opportunities to burn some calories. Jon seems to have found this in the maintenance department of the YMCA of Cape Cod. An added benefit, in addition to the health benefit of the physical nature of his job, is that he is employed by an organization that is dedicated to the well-being of individuals and families.

Supported employment is similar to competitive employment in that is occurs in the community in real work locations. The major difference is that the individual requires long term or on-going support to be successful. Hence, the term, *supported employment*. In supported employment, any individual with any disability can be successful because the person receives whatever support is needed for however long it is required. However, many agencies and governments have imposed time limits to how much support they will provide because of the expense it incurs. This usually means that persons with more challenges require more support and resources for longer periods of time. Agencies may not be able to afford those resources, even though they are needed.

If this offends you, vote for the brave politician who is willing to raise taxes to meet the needs of those who need services. Don't forget that your family member should be registered to vote, too. Remember, if you vote for tax relief, it may come at the expense of programs your child uses or would benefit from.

Sheltered employment is a softer term for sheltered workshops. These are settings where people with disabilities attend on a daily basis and have the opportunity to do sub-contract work (usually mailings, packaging and assembly) and are paid according to how much they can accomplish compared to workers without disabilities. The Department of Labor regulates it to ensure that accurate time studies are done for each job and payment is accurate.

Sheltered workshops are often criticized for being segregated settings. Some workshops do have workers without disabilities because the amount of sub-contract work cannot be completed without the addition of these workers. However, even when they do include nondisabled employees, there is little mixing between groups.

Volunteer work is a great option if earning a paycheck is not essential or to gain some additional job training. Some families use volunteer work as a way to get around waiting lists for supported employment programs. It is important to note, however, that a person may not *volunteer* where others are *paid* to do the same job. You can volunteer at a library or Meals-on-Wheels where others volunteer to do the same, specific tasks, but, you can not volunteer at McDonald's or the local bookstore.

Post Secondary Education

The idea of attending a college program is not new. However, what it means to be included in post-secondary education is changing every year. Not long ago a post-secondary program for young adults with Down syndrome meant a segregated program for people with disabilities. However, families are constantly challenging their communities to include students with disabilities in degree and non degree-seeking programs at community colleges and universities. It is important to recognize that a post-secondary program is not essential for your child. However, if your child dreams of going to college like his brother or sister, here are some options to consider.

Four-year colleges have recently been explored as options for individuals with Down syndrome. A handful of young adults with Down syndrome have attended four-year universities. At least one young man has received an undergraduate degree. Families are also approaching local colleges and universities for an opportunity to attend classes without seeking a degree. Remember, however, that universities are not required to accommodate or provide supports for your child. You may need to be creative when it comes to support in the classroom.

Community colleges are excellent resources for individuals to consider for post secondary education. The breadth and variety of opportunities in both degrees and certificate programs abound. From Bakersfield Community College in California, to Portland Community College in Oregon, to Cape Cod Community College. In Massachusetts, community colleges are welcoming students with disabilities in a wide range of classes.

College-based programs are programs that are located on college campuses that share their resources with the post-secondary program. There are many of these programs such as the Threshold Program at Lesley College in Cambridge and programs at the University of Alabama at Birmingham and New York Institute of Technology.

Programs based at special education schools sometimes offer post-graduate programs for students who have finished their high school studies at their school or elsewhere. These schools include the Riverview School's GROW program in Massachusetts, Maplebrook School in New York, and Chapel Haven in Connecticut.

When considering post-secondary program options, you must be prepared to foot a good portion of the bill. Just like any other young adult going to college, these programs can be expensive. Some of the specialized schools or programs may be subsidized, however, most will not. In addition, if you choose a program in a different state, your child may not be eligible for any financial assistance from that state.

Leisure Based or Dayhab Programs

Some families may prefer a program that places few demands on their family member. These programs are generally operated by a private vendor under contract with a government-supported agency such as the Department of Mental Retardation and are usually supported by Medicaid. Activities may include community outings, recreation, and life skills.

Community Living Options

Another area to consider for your child's adult life is where he will live. Even if he is living on the campus of a college or post-secondary program, you will need to plan where he will live when he is done with that program. The number of options is growing, particularly as people with disabilities are encouraged to take control of their lives and support services. The following are some of the options to consider.

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"The importance of controlling your own living environment cannot be overstated."

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Privately, Personally Owned Housing

Some individuals live in *personally owned or controlled* apartment or house. The *Home of Your Own Program* has helped to initiate and expand these opportunities. The importance of individuals owning or controlling (through lease agreements) their living environments cannot be overstated since so many decisions (roommates, furnishings, house routines) should be in the hands of the individual. Information about this program is available on page 15.

Vendor-Owned

Vendor owned homes or apartments are the most available and recognizable living environments. Over the years, we have called them group homes, community residences, congregate housing, etc. While many of these provide excellent opportunities for growth and deliver good services, some other entity (provider, management agent, state agency, etc.) makes many important decisions about the house and choosing the support people who work there. This limits the amount of input or control families and the people who live there have on their living situation.

Shared Living

Shared living is where two or more people live together in the house or apartment. Those who do not have a disability provide support for the person who does. For example, my agency supports a young man with Down syndrome who needs more support than he would receive living alone in an apartment. His family wanted more individualized support than a group home would be able to provide. Their solution was to find a roommate for him who is a student at the community college and provides the safety net that "Eric" needs to live in his own apartment. Eric's roommate is compensated for his time and support with a salary and reduced rent. Some families pay a direct salary to their child's roommate and others provide other compensation such as food or transportation.

Social Security Income (SSI) guarantees a monthly income. It does not guarantee self-respect.

Foster Homes

Some people do best in family units. For these individuals adult foster care may be a great opportunity. This model is sometimes hard for families to consider because we have been conditioned to think that when our children are ready to leave our home, it must be to go live in one of the options described earlier. Families are reluctant to embrace the possibility that the growth and independence of their child might be achieved within another family. I believe this is a missed opportunity for some individuals who would thrive in a family that is not their own. This does not mean that the person's own family is lacking. It means that most of us are not able to create the opportunities for risk and growth in our own family that our children need.

As with everything in our lives, the right option for your child and family is probably some combination of the above options. Do not be held back by anything you have seen or read. Create the vision that best fits your child, your family, and you.

Making It Happen

The leap from knowing what options exist to making your vision a reality is often very difficult, but as David Lloyd George said, "Don't be afraid to take a big step if one is indicated. You can't cross a chasm in two small steps." It is very important to take a moment and dwell on this. As families, we have been told to appreciate the small steps, the small achievements and the small successes of our child. The truth is that sometimes, big things require big steps. They require risk.

Suppose you have a vision. You have even developed a *Person Centered Plan*. You know what you want and maybe even how to get there. How do you pay for it? Here is where you have to be creative and a little luck is helpful.

Funding Options

First of all you need to know what sources of income you have at your disposal. The following are some categories for potential sources of funding to consider to identify income you have presently and areas where you might be able to find additional support:

- Wages
- SSI(Supplemental Security Income)/SSDI (Social Security Disability Income) *www.ssa.gov/about.htm*
- DMR or other state agency support (including Voc. Rehab)
- Family contributions
- Section 8 or other housing subsidy
- www.hud.gov/offices/pih/programs/hcv/index.cfm
- Food stamps
- www.fns.usda.gov/fsp
- Medicaid or other health insurance *cms.hhs.gov/medicaid*
- Medicaid Waiver Programs: Each state has a variety of waivers designed to promote community living. The waivers are specific to each state.
- Personal Care Attendant Program http://www.centerlw.org/PCA/Intro.htm

Each of these funding options is a complex and sometimes confusing maze to navigate that goes beyond the scope of this article. Be a good investigator and know what the limitations of each funding program are so you are not caught off-guard and lose that money or the benefits you are depending on. Ask other parents as well as those within the programs. Let their experience and knowledge guide you.

Friendships and Free Time

Now comes the hardest part: developing a satisfying and sustainable social network. To put it simply, this means having something to do and some people to do it with. Most families find the loss of the activities of school life difficult to replicate. Too often TV becomes a time-consuming friend. This is the time that you will need to seek out community and specialty social activities. Most of us have come to realize that the friendships we had hoped would sustain our children never materialized. Some of us encouraged relationships in unique and creative ways and others are grateful for Special Olympics, parks and recreation programs, and recreation programs of the Arc's. In some areas there are Ameri Corps volunteers and personal assistants working with recreation programs to encourage community inclusion. Check with your local program to see what support they have available to include your child if needed. Most of us have used a combination of all these options.

In our situation, Jon has developed a social network of work friends, friends with disabilities, paid staff, and family members. The Massachusetts Department of Mental Retardation, his salary, SSI, Section 8, and food stamps support him. He has a valued job at the Camp Lyndon Center of the Cape Cod YMCA and lives with a roommate in a community, supported by LIFE, Inc. in his own home. He helps direct support from his personal care attendant, Mary, who he considers a friend. A cell phone provides all of us with some increased measure of comfort. It helped when he was lost at the Fleet Center and when he lost power in his house. But, everyday, since he lives two hours from us, Jon is allowed to take the risks that come with increased dignity and for that he is very proud.

We usually visit Jon at least twice a month, but during football season it can increase to weekly, so he can watch the New England patriots with his father. They give me a shopping list for the grocery store. Recently, he requested that I not visit. He told me, "I need a break from you". When I pressed

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Thinking About Tomorrow

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him, he said, “When you were my age, didn’t you need a break once in awhile from your mother?” I resisted my temptation to make him feel guilty and while I was a bit hurt, I celebrated his ability to advocate for his own needs.

Final Words of Advice

Finally, I have some advice to dispense to you. Like the hit song several graduation seasons ago, I’ll start off by telling you to use sunscreen because it is the only advice that has been scientifically proven. The rest is based on my observations over the past 20 years of being both a parent and someone who is responsible for providing services to individuals with developmental disabilities.

- Teach your children how to use a bathroom-by themselves.
- Resist the temptation to assist your child in the bathroom at an age when he should be doing it himself.
- Make sure your child knows how to shower—ALONE. It is not a group activity.
- Make sure your child knows that showering is, however, a **daily** activity. It’s also a rule. Make no exceptions to this rule. If in doubt, shower twice a day.
- Wearing clean clothes is essential. Changing them every day is important.
- Teach your child to do his laundry. Show him stains on clothing so he knows what to look for and not to wear clothes with stains.
- While I am on the subject of clothes, if there is a choice, buy the next larger size. If someone hasn’t told you this yet, let me be the first: people do not look good in clothes that are too tight.
- Food is fuel. The wrong types slow you down and good food gives you energy. If your child eats the wrong food, he will look wrong. If he eats the right foods, he will look right. It’s that simple.
- Do not let anyone tell you that your child cannot learn to read, or learn more, or read better than they do today. Learning never ends.
- Respect. We all want it. Many of us want our children to receive it but, truth be told, you and your child must be willing to give it. Then it will come.
- Make sure your child knows he needs to do what the boss tells him, whoever the boss may be.
- Remember daytime is for being awake and nighttime for sleeping. Some people still don’t get it.
- Adults work. Many teenagers work, too. Your child should work. Somewhere.
- SSI guarantees a monthly income. It does not guarantee self-respect.
- Don’t blame someone else for mistakes. You set a bad example. Mistakes are inevitable. Learn from them and move on.
- Don’t expect siblings to be the parents. Brothers and sisters want information-lots of information. That is not the same thing as wanting responsibility.
- Finally, if you don’t teach your child to cross the street, he will never know what’s on the other side.

Neither will you.

Jo Ann Simons is the Executive Director of the East Middlesex Association for Retarded Citizens (EMARC). JoAnn resides with her husband in Swampscott Massachusetts while her children, Jon, who has Down syndrome, and Emily, create their own, independent lives.

> “Don’t be afraid of taking a big step if one is indicated.”
>
> David Lloyd Jones

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discussed things at home as a family, but most of her information—and often the best information—came from another source: her friends in general education. Over lunch she heard what everyone else was planning to do. In classes, vocational plans were often topics for projects. On the bus they talked about the choices their brothers and sisters were making after graduation. In short, she learned about her options the way most teenage girls do: endless talking.

Our plan was for Stefanie to take as many academic classes in general ed as she wanted, to stay on the same schedule at school as her friends, participate in graduation with her class, and then return to school for the remaining years until she turned 21 focusing on vocational classes, skills, and programs. But, as usual, Stefanie had other plans. Her schedule included a special education class with a focus on basic vocational skills followed by a work experience program. The school received a grant to establish a partnership with a local business to create a coffee shop in one of the school administration buildings. The plan was for the students to take on all the responsibilities of a small food service company. Stefanie wanted to participate. The students created job descriptions and outlined the responsibilities for each position. They rotated through the positions so they had a wide range of experiences. In the end, the students exceeded the program goals. They successfully, traveled to the job site, set up the shop, handled the inventory on computers, expanded their menu based on customer demand, made orders with the shop vendors, and planned and catered meetings for large groups.

She learned about her options the same way other teenage girls do: endless talking.

During this experience it was clear that Stefanie's inclusion was her best ally. In general education, she learned to rise to challenges, be independent, meet deadlines, make new friends, and be flexible. In addition, her academic background provided her with skills that were invaluable in the coffee shop such as basic math skills for making change and following recipes. Her experience in drama and giving class presentations gave her the poise she needed when they expanded their marketing to door-to-door sales throughout the building. This door-to-door service became a very lucrative part of the shop's business and provided even more opportunities for everyone involved.

We were proud of her and her classmates. We knew that this experience would lead Stefanie to dream of something more. But what would it be?

It didn't take long for us to learn she planned to be an office assistant. She learned of a work experience program that offered an opportunity for her to try that job, but she would need to move on after one quarter. Led by Stefanie, we negotiated for her to stay in that position if she chose. Last fall she began work as an office assistant in an elementary school. She loved the work and the people. She earned glowing reviews for her attitude, independent learning skills, dependability, and her strong work ethic.

In addition, Stefanie chose to sign up for a program for students with disabilities at Old Dominion University. She passed the entrance exam and signed up for business as her area of study. The program requires students to be employed in a part-time job. Stefanie convinced them to consider her experience at the elementary school as her job. She

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kept work journals, was evaluated by instructors and staff at her job site, and kept up with schoolwork at the high school and the university. Being a student at Old Dominion was exciting to her. She felt connected to her community even more and she had achieved a milestone of college just as other students did.

As we watched this process, we became aware that the high school program had some weaknesses. It lacked intense job training or skill acquisition by the high school staff connected to the program. In other words, the job coach merely collected data and kept track of the students. Co-workers at the job site help students learn how to perform a task, but there are no corresponding goals on the student's IEP to ensure this occurs. We adjusted her IEP to include goals we felt were important for an office assistant For instance, we wrote goals regarding how to operate specific office equipment, how to do corresponding actions with the equipment such as sending a fax and printing a confirmation report, how to take proper phone messages, and appropriate conversation topics for the workplace. However, we were told this was an exception to the typical process. In the end, we were the ones who reinforced these goals by discussing her day and offering advice for situations she encountered.

This year Stefanie's transition plan has changed again. Originally, she planned not to return to school for her last year of a free and appropriate education in order to search for a job in the "real world." We all felt she was ready. However, the school district offered her a unique opportunity. They found a way to offer her work experience as an office assistant with a paycheck to boot!

Our school system has a Co-operative Education (COE) program where students attend class for part of the day and work in an approved business office location for part of the day. The teacher-coordinator along with an on-the-job training sponsor develop an individualized training plan that identifies learning experiences according to the student's career objective. There are pre-requisite courses required to participate in this program. The COE program is thought to be for students in general education. However, the staff pointed out Stefanie was eligible and had taken the necessary pre-requisite classes, which is another example of the benefits of inclusive education.

Her COE position is in a school administration building. In this position Stefanie is developing new skills and sharpening the skills she already had for her chosen vocation. She socializes confidently in her workplace with her fellow workers, most of whom do not have a disability, making that transition from student to staff. As the school year draws to a close, so does this job for Stef. She has typed up her resume and is beginning her job search. Her co-workers are concerned Stefanie may not be able to communicate the quality and breadth of her skills in an interview. They decided as a group to help her construct a resume portfolio. The portfolio contains sample work, photos of Stef performing various office tasks, and letters of recommendation. The office manager of the elementary school where Stef is working shared her letter with us. She ended it with, "I wish I could have her here now as one of my employees." What more could any employee ask for?

I have watched my daughter navigate successfully from career interests to career exploration and on to career preparation for the changing demands of the workplace and life. Although the road was rocky at times, she has done a fantastic job of making each situation the best one possible. And she has one more thing every girl dreams of: more shopping money!

Cheryl Ward is the Education Advocacy Coordinator at the Endependence Center, a center for independent living in Norfolk, VA. She has two children, one of whom has Down syndrome. She resides with her husband and Stefanie in Virginia Beach, VA.

Resources

Person Centered Planning Information and Workbooks

"What is Person-Centered Planning?"

http:/ici2.umn.edu/pcplanning/info/whatis.html

A detailed description of person-centered planning.

Group Action Planning Is a Strategy for Getting a Life

By Ann and Rud Turnbull. Published by The Beach Center on Disability, 1998. Available free as an Adobe Reader file: www.beachcenter.org/books (click on Person-Centered Planning and Friendships).

A Workbook for Your Personal Passport

Written and published by Allen, Shea, and Associates, 1780 Third Street, Napa, CA 94559. 707/258-1326. Available free as an Adobe Reader file: http://www.allenshea.com/passport.html

A person-centered planning tool for your child or student.

Full Life Ahead: A Workbook and Guide to Adult Life for Students and Families of Students with Disabilities.

By Judy Barclay and Jan Cobb. Published by Southeast Regional Resource Center (SERRC) Auburn University Montgomery, Montgomery AL 36124. Available free as an Adobe Reader file: edla.aum.edu/serrc/fulllife/fulllife.htm

Filled with positive messages such as "Knowledge is Power! Become Powerful!" this book is a good tool for students and families who need to organize a lot of information.

The Transition Process and Transition Checklists

The Parent's Role in Transition—A Checklist

Adapted from the National Transition Network, published by Parents' Place of Maryland, 7484 Candlewood Road, Suite S, Hanover MD 21076. available as an Adobe Reader file: http://www.ppmd.org/factsheets/transition_checklist.pdf

Transition Checklist

By Celeste D. Johnson © 2002. Available from *Listen-Up Web Page Specializing in Information for the Deaf and Hard of Hearing.*

Available as an Adobe Reader file: http://www.listen-up.org/rights/tchklst.pdf.

A Student's Guide to the I.E.P.

By Marcy McGahee-Kovac. Published by NICHCY, 2002. P.O. Box 1492, Wshington, DC 20013. Available as an Adobe Reader file: http://www.nichcy.org/pubs/stuguide/st1book.htm

The author shares tangible ways for students to let adults know he is interested in the process.

Adolescent Autonomy Checklists

Developed by University of Washington Division of Adolescent Medicine. Published by The Adolescent Health Transition Project, Center on Human Development and Disability, Box 357920, University of Washington, Seattle, Washington 98195-7920.

http://depts.washington.edu/healthtr/Checklists/intro.htm

Career Interest Inventories & Employment Information

Career Interest Inventories

Indiana Career and Post Secondary Advancement Center, 2805 E 10th, Bloomington IN 47408. http://cpac.indiana.edu/careers/inventories

Career Assessments for All Ages

Published by Career Consulting Corner http://www.careercc.com/career_assessment.shtml

Funding Information

Transition Age Special Education Students and SSI: What Parents Should Know.

http://www.communityinclusion.org/publications/text/witn4.html

From Stress to Success: Making Social Security Work for Your Young Adult:

http://www.communityinclusion.org/publications/text/to13.html

Social Security Disability Program

http://www.ssa.gov.disability

Post Secondary Education

HEATH Resource Center

http://www.heath.gwu.edu/

The Enoch-Gelbard
Foundation

Disability Solutions

PMB179
9220 SW Barbur Blvd #119
Portland OR 97219

Address Services Requested

Disability Solutions

A resource for families and others interested in Down syndrome and related disabilities

Share Your Thoughts

	Great	*Good*	*O.K.*	*Not Good*
Thinking About Tomorrow: ***The Transition to Adult Life***				
Beginning a Career: ***Stefanie's Story***				
Resources				

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