

Parents' Module for Keeping It Real: How to Get The Support You Need for the Life You Want

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THE ELIZABETH M. BOGGS CENTER
ON DEVELOPMENTAL DISABILITIES

Department of Pediatrics



ROBERT WOOD JOHNSON
MEDICAL SCHOOL

University of Medicine & Dentistry of New Jersey

*A University Center for Excellence
In Developmental Disabilities Education, Research, and Service*

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Introduction:

“Transition” means changing from one thing to another. The transition we are talking about in the curriculum called, Keeping It Real: How to Get the Support You Need For the Life You Want, is the one that has to do with leaving high school and moving into the adult world. This is obviously a huge change for all young people to think about, and most students experience some mixture of excitement and nervousness as they approach graduation.

But what about the parents? What is this time like for them? The fact is, the students aren’t the only ones who are going through transition. Their parents, too, must face changing expectations about the role they will play in their child’s life. How will they walk that fine line between being there when their child needs them, and encouraging their child to become an adult? This is true for parents of children with or without disabilities, but parents of children with disabilities often have additional concerns. Will my child have the supports she needs to succeed at college? Has my child really learned the basic job skills he needs? And if so, who will hire him? Is my child able to care for herself on her own? And if not, who will help her? Will my child have friends?

Parents of children with disabilities sometimes wonder who will continue teaching their child the life skills he may not have learned while in school. They see their child moving from an education system which is required by law to provide services, to an adult system that has no such legal mandate. The services that are there for adults with disabilities can often seem complicated and hard to understand. Many parents also worry about what will happen when they’re not around to protect and care for their child. They are uncertain about what kinds of supports their child is going to need as an adult. They want to find a way to help their child, while at the same time respecting their child’s need for more independence. They see their child growing up, and ask themselves, “What it will mean to be a parent of an *adult* with disabilities?”

“I would like him to live a typical, happy life, but it’s going to take work, a lot of work, on my part.”
Parent

“John has a nice life, but we’re case managing the whole thing. And that’s certainly not an option down the road.” *Parent*

“After I graduate from high school, my parents will charge me \$200 rent. Plus I have to buy my own food...Knowing that...is enough to get me to do whatever I need to do to get out.” High school student

“My mom is completely the opposite. She wants me...to stay home, but I don’t want to.” High school student

Of course, different parents think about their child growing up differently. What sort of adult life parents imagine for their child depends on many things, including the child’s personality, the specifics of her disability, the parents’ personalities, family and cultural expectations, and the community where they live. Some children can’t wait to move into their own homes; others want to keep living with their families for as long as possible. Some parents believe their child should move out on her own as soon as she leaves school; others prefer that their child continue to live at home until she has a certain amount

of money saved, or marries, or is a certain age. Something as basic as transportation needs might influence how parents think about their child’s future. Does the family live in a place where there is good public transportation that their child can use, or will the parents be expected to drive their child to and from work every day? Again, each individual, and each family, will have a different vision of the future, and that vision will depend on all these factors, and many others, besides. As parents help their child prepare for her future, it’s important for parents to understand what their child’s vision, and their own vision, of that future is.

When families think about the future, it is also important to understand that how services are being provided for adults with disabilities is changing. It used to be that individuals with disabilities were told how to live their lives, including where they lived, where (and often if) they worked, whom they spent time with, and what they did for fun. Now there is an expectation that services will be “person-centered” and “self-directed.” What does that mean? It means each person is supposed to be in charge of his own supports, and those supports will be based on that person’s own goals, needs and preferences. This is an exciting change, and one that respects the rights of individuals, no matter what their disability, to choose the kind of life they want to live. As with many big changes, however, it brings with it some new challenges. Knowing how to get the supports someone needs so that he can live the life he wants to live is one of those challenges. This curriculum was written to help students learn the skills they need to meet this new challenge successfully.

This parents' module was written to go along with the Keeping It Real curriculum, and its purpose is to help parents understand what's involved with getting the right kinds of supports. This is important because their child will need their help to both learn and use the new skills she is being taught. The help each student will need to get through this curriculum will vary. Some students will need a teacher or parent to read or summarize the material out loud and then guide them through the activities. Other students will be able to read and do the activities without any help from their parents, but they will still need encouragement as they practice using the skills they learn in the "real world."

It's important that parents understand that knowing how to get the right kinds of supports is a *lifelong* skill. It is not something that their child will use for high school and transition planning and then forget about. Rather, it is a skill that will be practiced over and over again, each time their child sets a new goal for himself or needs to solve a new problem.

Our hope is that as young adults with disabilities learn how to get the supports they need, they will be able to look forward to a future in which they can reach the goals that matter most to them. As parents, your understanding of what supports your child needs, and how to get those supports, is essential to your child's dreams becoming a reality. And remember, parents need supports, too, and these are skills that everyone can use to meet their own unique challenges in life.

The following is a brief summary of the information covered in each chapter of Keeping Real: How to Get the Support You Need For the Life You Want.

I. So, what's all this talk about "transition?"

Transition means changing from one thing to another, and high school begins the transition from being a teenager to being an adult. **Transition planning** is what should be happening *now!* It's the student, parents, teachers and other professionals getting together to talk about things that can be done today to plan and prepare for the student's future. The important thing to remember is that it is the *student's* life, and the *student* needs to take as much responsibility as possible in the planning for her future.

The student's **Individualized Education Program (IEP)** is like a roadmap that shows where the student is going and how he is going to get there. The student's IEP should reflect the goals *he wants* to achieve, and the supports *he needs* to reach his goals.

"Supports" refers to the help someone gets to do what she wants to do. Everyone, whether or not they have a disability, needs supports in their lives. The key is for each student to figure out what supports would be the most helpful to meet her own personal needs so she can reach her own personal goals. By making sure the right supports are included in the IEP, the student will be able to learn the new skills in high school that will make it possible to do what she wants to do after she graduates.

This is why it is so important that students and their families play an active role in the development of the student's IEP. This includes reading the IEP carefully, taking the time to understand what's in it, and attending IEP meetings. As a parent, here are some things you can do to help your child develop a meaningful and effective IEP:

1. If necessary, help your child read his IEP.
2. Does your child have any questions? Answer the ones you can, but also encourage your child to talk to her teacher, guidance counselor, case manager, etc. about the things she doesn't understand.

3. If your child has trouble understanding his IEP even when you read it to him, try summarizing the things he can understand. Does he feel this IEP has things in it that are important to him?
4. Do you think this IEP really reflects who your child is? If there is something that isn't clear to you about your child's IEP, don't hesitate to call her teacher, case manager, another parent, or anyone else who can answer your questions.

Self-determination means knowing what you want in life (your goals), and knowing how to get what you need in order to reach your goals. Making the decisions that are right for you is part of being a self-determined person, and high school is an ideal time to practice good decision-making skills. In fact, that's what transition planning is meant to be all about. The following are some questions to help you think about self-determination as it relates to your child:

1. What do you decide for your child, and what does your child decide for himself?
2. Are you comfortable with how decisions are made for your child?
3. Do you think your child is comfortable with how decisions are made for her? Why or why not?
4. Has your child started planning for his future? In what ways?
5. What has been your level of involvement in your child's planning?
6. Does that level feel "right" to you (not too much or too little)?
7. Do you think it feels "right" to your child? Why or why not?

Self-advocacy is actually part of self-determination. That is, once you know what you want and need, you have to be able to tell other people. Whether your child communicates using spoken words, sign language, assistive technology, gestures, or some combination of these, it's important that she lets other people know what she is thinking and feeling. The following are some questions to help you think about self-advocacy as it relates to your own life:

1. Think of a time you stood up for yourself, or spoke out about what you thought or felt about something.
2. Think of a time you didn't stand up for yourself, or speak out about something, but wish you had.
3. Think of a time you stood up for your child.
4. Which is easier for you to do, stand up for yourself or stand up for your child? Why do you think that is?
5. Remind yourself and your child that every time you let someone know what you're thinking or feeling, or ask for something you need, you are using self-advocacy skills!

The following are some advocacy organizations for people with disabilities. Your child may be interested in learning more about them:

1. New Jersey Self-Advocacy Project
(732) 926-8010
44 Stelton Rd., Suite 110, Piscataway, NJ 08854.
2. Self Advocates Becoming Empowered (SABE)
<http://www.sabeusa.org/>
3. Monday Morning (part of the New Jersey Council on Developmental Disabilities)
1-800-216-1199
<http://www.njddc.org/mm-about.htm>

II. Understanding Myself

Before your child can start planning for his *future*, he needs to understand who he is *now*, and figuring out his **likes** and **dislikes** is an important first step. As a parent, take a few minutes to think about what your child likes and dislikes. What has your child told you, or what have you observed, that has led you to think that he likes or dislikes certain things? In other words, whether or not your child is able to communicate using words, how do you decide what his preferences are? Of course that can be difficult, but the idea to remember – and help other people in your child’s life remember – is that everyone has things they like and things they don’t like, and all future planning must include a good understanding of those preferences.

Your child also has some things she does well, and some things that are hard for her to do. These are her **strengths** and **challenges**. Often when someone has a disability, other people only think about that person’s challenges. For transition planning to be successful, however, your child needs to understand her strengths so that she can build on them. What do you think your child’s strengths are? Often we don’t know if we’re good at something until we try it. Has your child had the chance to try lots of different things? If not, this may be something you want to talk about with your child and with other people, in and out of school, who are involved in her life. Also make sure that the opportunities to try different things are included in your child’s IEP.

It’s also important to remember that a person needs to understand his own disability if he’s going to fully understand himself. This can be hard for your child to do, because he might be embarrassed or uncomfortable about having a disability. As a parent, you can help your child realize that there are many negative stereotypes of people with disabilities that are simply not true. Attitudes are changing, and people are beginning to see that individuals with disabilities can live full, productive lives in their communities, just like everyone else. With the passage of the Americans with Disabilities Act, people have also come to realize that individuals with disabilities have the same rights as everyone else, and cannot be discriminated against simply because they have a disability. To help you think about your child’s disability, try answering the following questions:

1. Do you feel you have a good understanding of your child’s disability?
2. Do you think your child understands her disability? Why or why not?

3. Do you talk with your child about his disability?
4. Who else does your child talk with about her disability?
5. Who else do you talk with?

The following are some organizations that can give you and your child information about specific disabilities:

1. ASPEN (Asperger Syndrome Education Network, Inc.)
On the web: www.aspennj.org
2. Brain Injury Association of New Jersey
Call (732) 738-1002
On the web: www.bianj.org
3. C.H.A.D.D. (Children and Adults with Attention Deficit Disorders) –
this is a national organization with local chapters
Call 1-800- 233- 4050
On the web: www.chadd.org
4. Cerebral Palsy of New Jersey
Call (609) 392-4004
On the web: www.cpofnj.org
5. COSAC (New Jersey Center for Outreach and Services for the Autism
Community)
Call 1.800.4.AUTISM, or 609.883.8100
On the web: www.njcosac.org
6. Epilepsy Foundation of New Jersey
Call 1-800-EFNJ-TIE, or (609) 392-4900
On the web: www.efnj.com
7. Learning Disabilities Online - this site has information about state
resources for learning disabilities
On the web: www.ldonline.org

8. New Jersey Association of the Deaf-Blind, Inc.
Call (732) 805-1912
On the web: www.njadb.org
9. Spina Bifada Association of the Tri-State Region
Call (908) 782-7475
On the web: www.sbatsr.org
10. The Arc of New Jersey (serving individuals with mental retardation)
Call (732) 246-2525
On the web: www.arcnj.org

Your child may also want to talk with someone who has recently graduated from high school, and who has a similar disability. That can be a good way to learn from someone else's experiences. You may also want to talk with an adult who has a similar disability as your child's, and to a parent of an adult with a similar disability. Try to find out what they've done since leaving high school, and what supports have been helpful. Two places that can put you in touch with recent graduates are:

1. Local Centers for Independent Living (CILs), also known as Independent Living Centers. CILs are run by adults with disabilities who have made living independent, productive lives a priority.
<http://www.ilusa.com/links/ilcenters.htm>
2. The New Jersey Self-Advocacy Project
(732) 926-8010
44 Stelton Rd., Suite 110, Piscataway, NJ 08854.

Parents sometimes feel a little overwhelmed by the responsibility of helping their child establish a happy, healthy adult life. Keep in mind that you don't have to do this alone. A **Circle of Support** is one way to get the help you need. A Circle of Support is made up of a group of people who know someone well, and who want to help that person to live the life that's best for him. It's important that a Circle of Support be made up of people that both you and your child like and trust, and that will help your child find the supports he needs to achieve his goals. The idea is that the Circle commits to meeting on a regular basis to help figure out solutions to new challenges as they arise.

III. Understanding Supports

There are different kinds of supports that people use to get the help they need. **Natural supports** are family, friends and neighbors who know you and can help you out sometimes. **Community supports** are things in your community that are meant to help everyone, not just people with disabilities. These include libraries, public transportation, places of worship, YMCA's, and adult education classes. **Formal supports** are designed specifically to help people with disabilities. Formal supports can be public agencies, like the New Jersey Division of Developmental Disabilities (DDD) and the New Jersey Division of Vocational Rehabilitation Services (DVRS), as well as private, non-government businesses. Formal supports can also be individual people (sometimes called personal assistants) who are paid to help someone with a disability. **Assistive technology** is any tool that helps someone do what she needs to do. **Environmental adaptations** are changes in how things are set up to make it easier for a person to get things done (for example, putting a desk in the front of the classroom to make it easier for someone to hear the teacher).

Which kind of support your child will use will depend on what exactly he needs help with. For example, if he doesn't drive and needs to get to a dentist's appointment, a family member or friend might be able to give him a ride. However, if your child needs to get to work everyday, public transportation, including disability-specific services like New Jersey's Access Link, might make more sense. The idea to keep in mind is that friends and family are not the answer to every need, but neither are formal supports like DDD and DVRS. Each goal your child wants to reach, or problem he needs to solve, will involve a different support, or a different combination of supports.

In Keeping It Real, your child is learning how to take the following steps so that she can get the supports he needs:

1. Decide what goal he wants to work on or problem he needs to solve.
2. Write down the tasks she needs to do to reach that goal or solve that problem.
3. Decide which of those tasks he can do himself.
4. Decide which tasks she needs help with, and who or what would be most helpful to her.

5. Often it's easiest to start by thinking about natural supports, then community, then formal. Assistive technology and environmental adaptations can be helpful no matter what other supports someone uses.
6. When your child is asking someone for help, he needs to be as clear as possible about what he needs help with. He also needs to ask the person he's speaking with to be as clear as possible about what help that person can, and can't, provide for him.

Remember, getting the supports she needs is a skill your child will use her whole life. It's not something she will do once and forget about it. Your child is always growing and learning and changing. That's a good thing! The challenge for both her, and you, is to make sure her supports are changing along with her needs. That's called **evaluating** supports, and the easiest way to evaluate supports is for your child to ask the question: "Am I getting the help I need to do what I want to do?" The fact is, your child might be getting some help, but it might not be the help she needs to reach her goal. If either you or your child has some doubts about the supports your child is receiving, don't hesitate to speak up!

If your child is getting the help he needs, than **managing** supports involves thanking the people who are helping him. It also means finding ways your child can give back. This encourages your child to understand that he isn't the only one in the world who needs help, and that sometimes he can be the one to give that help to others.

If your child is not getting the help she needs, managing supports involves thinking about what the problem is, asking the person who is providing the help what they think the problem is, and then figuring out a solution everyone can agree to try. Talking honestly about a problem, and listening carefully to what the other person has to say, are important skills for managing supports.

IV. Employment and Careers

People used to think that if someone had a disability they could not work. Fortunately, attitudes are changing, and more and more people are realizing that is not true. It also used to be the case that in order to receive any financial support from the government (like Social Security or Medicaid) you could not earn any money of your own. Fortunately, that is beginning to change, too, so that now there are **Work Incentive** programs that help ensure that people are better off working at real jobs and earning money for themselves.

1. You can learn more about federal Work Incentive programs by going to the Social Security Administration's website at:
<http://www.ssa.gov/work/ResourcesToolkit/redbook.html>
2. You can also read about the Plan for Achieving Self-Support (PASS), which is a Social Security program that allows people with disabilities to set aside money for items or services needed to reach a specific work goal. Go to:
<http://www.ssa.gov/work/ResourcesToolkit/elements.html>
3. New Jersey's Division of Disability Services (DDS) has a toll free hotline that responds to requests for Information and Referral Assistance on many different issues, including employment issues, affecting people with disabilities in New Jersey.
Call: 1-800-285-3036 (TTY: 609-292-1210) or go to:
<http://www.state.nj.us/humanservices/dds/>

Barriers to employment are those things that keep a person from getting a job. Not knowing what he wants to do, not having the skills he needs for a particular job, not having any real work experience, being scared of doing something new, and not knowing where to go to get help, can all be barriers to employment. What barriers to employment do you think your child is facing now, or might have to face in the future? What barriers does your child think he is facing, or might have to face?

Transportation is often a big barrier to employment for people with disabilities, and can have a big impact on the lives of other members of that person's family. What are the transportation options that you know of in your community? Do you think transportation is, or will be, a barrier to

employment for your child? What is the impact on your life of your child's transportation needs?

Again, talking with other adults with disabilities and their families can be a helpful way to hear about different ways people have overcome barriers to employment. Don't forget your local Center for Independent Living, and the New Jersey Self-Advocacy Project, which are both good resources if you want to get in touch with adults with disabilities.

Building a career means thinking about the kind of work someone would enjoy doing, not just for today, but in the future, too. To think about jobs your child might like to try, as well as possible careers, it can be helpful for her to hear about the different kinds of work you have done. Encourage your child to also talk with other family members and friends about their work, and learn about what kinds of jobs there are in your neighborhood and town. Are any of these of interest to your child? Why or why not?

The following are a couple of websites that can help your child learn about different careers:

1. www.careeronestop.org (go to the CareerInfo Net webpage)
2. Access CAREERS website at www.washington.edu/doit/Careers (look for Resources for Students)
3. There are also a number of free internet supports available to help your child create a resume. Try checking out www.onetacademy.com
4. New Jersey's Division of Vocational Rehabilitation Services (DVRS) helps people with disabilities prepare for and find jobs. Go to www.state.nj.us/labor/dvrs and click on "Community Program Resource Directory" for a listing of DVRS offices, including phone numbers, in your county. You can also look in the Blue Pages of the phone book.

V. Post-secondary Education and Training

In the past, young people with disabilities were often discouraged from attending post-secondary education and training programs, but that's also changing. More and more students are going on to both two and four year colleges, as well as other kinds of vocational training schools. There are some important federal laws that you should know about that require these programs to provide students with disabilities with supports that will help them be successful.

Section 504 of the Rehabilitation Act makes it clear that post-secondary programs cannot discriminate against students on the basis of a disability. Section 504 requires any college or school that receives federal funding to provide accommodations for qualified students. Most colleges and schools receive federal funding. That means that if a student can document that he is a person with a disability and is otherwise qualified to attend the program (for example, has finished high school and/or has taken the appropriate coursework), the program must provide that student with reasonable accommodations, or the supports that will help him to succeed.

The **Americans with Disabilities Act (ADA)** requires that people with disabilities be provided with equal access to public programs and services. The ADA adds to the rights of students with disabilities protected by Section 504 by requiring post-secondary programs to make their physical sites accessible. For example, there have to be ramps on buildings and reserved spaces in parking lots. The ADA also requires that programs make information about their programs accessible. That means that if a program uses the internet for communication, the web-site must be accessible for students using adaptive technology. Informational materials and software for coursework must also be accessible.

An accommodation is something that helps someone do what they want to do. Section 504 and the ADA require post-secondary programs to make what's known as "**reasonable accommodations**" for students with disabilities. This means programs have to provide certain supports, but they do not have to change their academic standards. Some reasonable accommodations might include:

- Changes to the classroom environment or task

- Removal of physical barriers
- Testing accommodations (more time, alternative formats)
- Adaptive technology services
- Other supports such as interpreters, note-takers, scribes and readers

Post-secondary programs are not required to provide personal devices such as wheelchairs, hearing aids or glasses, or personal services such as assistance with eating, toileting, dressing, etc.

Four year colleges and universities, as well as community colleges, are required to have an office that coordinates services for students with disabilities. They are called by different names like the Disability Services Office, Office of Differing Ability Services, etc. The important difference between the services and supports a student receives in high school (the things described in his IEP) and the supports that post-secondary schools are required to provide, is that the student must apply and be found eligible for the supports in post-secondary schools.

Another important difference is that the student must be able to advocate for the supports he needs to be successful. There won't be a case manager or teacher who is taking care of all that for the student; it will be up to the student to let the post-secondary school know what he needs. Being an effective self-advocate in post-secondary programs means:

- Knowing yourself and understanding your disability
- Knowing your rights and responsibilities
- Knowing where to go to get help
- Taking action

VI. Living Arrangements

Where someone lives is a key part of that person's happiness and well-being. Where do you picture your child living a year from now? How about ten years from now? Where does your child picture herself living a year from now? Ten years from now? How do you know what kind of picture of the future your child has? Is your picture the same as your child's? How do you handle it if your child's picture of her future is different from yours? These can be tough issues to think about, but knowing about some options for living arrangements can help you and your child get started.

Buying and renting are the two living arrangement options that most people are familiar with, but there are others. **Residential services** are provided by service providers who are paid to support people with disabilities. Residential services can be expensive, and usually require that the person with a disability applies for government funds (for example, funding through the Division of Development Disabilities) to help pay for the services. The following is a brief description of residential services:

- **Group homes** are owned and operated by service providing agencies. A number of people live together and are supported all day, everyday, by agency staff that is hired by the agency. This staff is trained to keep the residents of the group home safe and healthy, and to provide them with recreational and learning activities. Residents generally do not have much privacy, and are expected to follow the rules of the group home.
- **Supervised apartments** are living arrangements where a couple of people share an apartment. Support staff does not live in the apartment, but they live nearby and are available to help out. For example, the support staff helps people do the things that are difficult for them to do, like paying bills, or making sure they have the right food to eat. They also are there to help in an emergency. This option generally gives a person more privacy and independence than a group home. However, there may not be a choice of roommate, and the service-providing agency decides who the support staff will be.

- In **foster or sponsor families**, the person with a disability lives with a family or a trained support provider. The foster or sponsor family provides the care and assistance the person needs. There is some privacy, but the person is living with a family and like other families there are rules, shared space, etc.
- **Supported living** programs are designed to provide just as much support as a person needs and wants in the living arrangement of his choice. In this option, the person chooses where he lives and whom he lives with, though his support staff might still be hired by the agency providing the supports.

Some people choose to go the route of **independent living**. That means the person doesn't necessarily have to go through a service provider agency to arrange for the supports she needs. Either on their own, or with the help of family and friends, many people with disabilities choose this path. It takes work and a lot of self determination, but people have found that having the control they want over their own living arrangements is worth the effort.

For more information on living arrangements, contact the following organizations:

1. Centers for Independent Living (also known as Independent Living Centers)
<http://www.ilusa.com/links/ilcenters.htm> (look for the contact information for your local CIL)
2. County Offices for the Disabled
<http://www.wnjin.state.nj.us/services/cofd.htm> (look for the contact information for your County office)
3. New Jersey Division of Disability Services
1-888-285-3036
<http://www.state.nj.us/humanservices/dds>

VII. Recreation and Leisure

When your child is not in school or at work, what does he do with his time? Does he seem satisfied with that? One of the problems that adults with disabilities sometimes experience when they leave school is not having enough to do for fun and relaxation. This is especially true for people who need supports to participate in activities. Often recreation and leisure activities are not seen as important areas of adult life, but not having enough to do outside of work or school can lead to boredom and frustration. Our behaviors show people a lot about what we're feeling, and one of the things to consider if your child is "acting up," or "misbehaving," is that he doesn't have enough to do with his free time.

In this chapter, we talk about the problems that sometimes come up with the people who are providing your child with the supports she needs. For example, let's say your child really enjoys going to karate lessons, and the person in charge of taking her there keeps showing up late. That means your child is getting to her lessons late, and her frustrations about that are making it hard for her to participate in class. How should this problem be handled? There is no one right way, of course, but here are some useful guidelines for you and your child to think about:

1. Talk honestly with the person who is providing supports, and listen carefully to what that person has to say.
2. Come up with a solution to the problem that everyone can agree to try.
3. If no one can think of a solution to the problem, it might be time to think about using another kind of support.

VIII. Moving Forward

Keeping It Real was written to give your child a basic idea of how to deal with supports, so that the next time he has a new goal he wants to reach, or a new problem he has to solve, he'll know where to start. This booklet was written to help parents better understand what their child is learning, and to help their child get the supports he needs. Nobody is expecting either you or your child to be an expert at this! The fact is, the more someone practices using these new skills, the easier it gets. Remember that getting, evaluating and managing supports are skills your child will use his whole life, and the good news about that is he will have lots of chances to practice!

The following section lists **resources** that might be helpful as you and your child look into the different kinds of supports that are available. As much as possible, phone numbers and web links are included to make it easier to contact these organizations.

One of the things your child will be doing is putting together a **portfolio** of information about herself. This portfolio will contain "Official Information" (that's the information like a copy of her IEP, a resume, and professional documentation of her disability) that she will share with other people to get the supports she needs. Her portfolio will also include "Personal Information" (that's the information that helps your child understand herself better, and it will be up to her to decide what of that information she wants to share with other people). Your child will be encouraged to take responsibility for her own portfolio, and update it whenever she has new information to add to it. There may be times when you will need to help her with this, but as much as possible, think of it as her job.

This curriculum uses different worksheets to help your child break down the process of getting, evaluating, and managing supports into smaller steps. This booklet includes these worksheets, and you're free to make as many copies of them as you want.

Keeping It Real has a lot of information in it, but if your child is able to do the following three things, he will have gone a long way in getting the supports he needs:

1. Decide what she wants to do
2. Think about what he can do on his own and what he needs help with
3. Let other people know what she wants to do and what she needs help with

Remember, every time your child lets someone know what he is thinking or feeling, or asks for something he needs, he is using self-advocacy skills... and self-advocacy is *the key* to living the life that's right for him. As his parent, the more you can support your child's efforts to speak up for himself, the more you will help your child live an independent, productive and fulfilling life.

IX. Information About Resources

Arc of New Jersey:

The Arc of New Jersey is made up of one statewide office and nineteen county offices. The Arcs provides many different services and programs to people with developmental disabilities and their families. In addition, the Arc of New Jersey's website has a lot of good information about ways you can advocate for people with disabilities at the state and federal level.

Want to learn more?

Call: 732- 246-2525

On the web: <http://www.arcnj.org/> (use this to get contact information for your own county Arc)

Association for Persons in Supported Employment (APSE):

APSE: The Network on Employment works to make it easier for people with disabilities to work in their communities. It does this through advocacy and education.

Want to learn more?

Call: 804-278-9187

On the web: <http://www.apse.org/aboutapse.html>

Centers for Independent Living (CILs), also known as Independent Living Centers (ILCs):

Centers for Independent Living (CILs) are also known as Independent Living Centers (ILCs). People with disabilities are in charge of CILs. Their goal is to help people with all kinds of disabilities live as independently as possible in their own communities. They do this by providing information and by helping people advocate for themselves. There are nearly 500 CILs in the USA.

Want to learn more?

On the web: <http://www.ilusa.com/links/ilcenters.htm> (look for contact information for your local CIL)

Cerebral Palsy of New Jersey:

Cerebral Palsy of New Jersey provides many types of services to people with all disabilities. The supports they offer include rehabilitation services, help with finding jobs, family support, and advocacy.

Want to learn more?

Call: 888-322-1918

On the web: <http://www.cpofnj.org/>

Commission for the Blind and Visually Impaired (CBVI):

The Commission for the Blind and Visually Impaired (CBVI) provides supports for people in New Jersey who are blind or visually impaired. It has many different educational services for children, job services for older teens and adults, and independent living services for people of all ages.

Want to learn more?

Call: 973-648-2412

On the web: www.state.nj.us/humanservices/cbvi

DisabilityInfo.gov:

DisabilityInfo.gov is a website that makes it easier to find disability-related resources that are provided by the federal government. It includes a listing of web links that are helpful to people with disabilities, their families, employers, service providers and other community members.

Want to learn more?

On the web: <http://disabilityinfo.gov/>

Division of Developmental Disabilities (DDD):

The New Jersey Division of Developmental Disabilities (DDD) serves more than 33,000 people with developmental disabilities. These disabilities include mental retardation, cerebral palsy, autism, epilepsy, spina bifida, traumatic brain injuries, and certain neurological impairments. DDD offers case management, residential services, family support services, day programs, and employment services.

Want to learn more?

Call: 1-800-832-9173

On the web: www.state.nj.us/humanservices/ddd

Division of the Deaf and Hard of Hearing (DDHH):

The Division of the Deaf and Hard of Hearing (DDHH) advocates for people in New Jersey who are deaf or hard of hearing. DDHH helps people with social, legal, medical, educational and recreational issues. It is also in charge of New Jersey's main sign language interpreter referral service.

Want to learn more?

Call: 800-792-8339 V/TTY or 609-984-7281 V/TTY

On the web: www.state.nj.us/humanservices/ddhh

Division of Disability Services (DDS):

Through its toll free hotline and its publication called *New Jersey Resources*, the Division of Disability Services (DDS) helps people with all types of disabilities figure out where to go to get the services they need.

In addition, DDS runs programs, such as the Personal Assistant Services Program, that help make it possible for people with disabilities to live more independently in their communities.

Want to learn more?

Call: 1-800-285-3036 (TTY: 609-292-1210)

On the web: <http://www.state.nj.us/humanservices/dds/>

Division of Mental Health Services (DMHS):

The Division of Mental Health Services (DMHS) serves adults with mental illnesses and children and adolescents with emotional and behavioral disorders. Services are available to anyone in the state who feels they need help with a mental or behavioral health problem.

Want to learn more?

Call: 1-800-382-6717

On the web: www.state.nj.us/humanservices/dmhs

Division of Vocational Rehabilitation Services (DVRS):

Most states have their own services for helping people with disabilities both get and keep jobs. In New Jersey, employment-related services for individuals with disabilities are provided through the state's Division of Vocational Rehabilitation Services (DVRS).

Want to learn more?

On the web: www.state.nj.us/labor/dvrs (click on "Community Program Resource Directory" for a listing of DVRS offices, including phone numbers, in your county)

Job Accommodations Network:

The Job Accommodations Network (JAN) is a free consulting service that is meant to help people with disabilities get and keep jobs. It does this by: 1) helping people figure out worksite accommodations, 2) helping people understand the American with Disabilities Act (ADA) and other disability related laws, and 3) educating people about self-employment options. This is a free service of the Office of Disability Employment Policy, U.S. Dept. of Labor.

Want to learn more?

Call: 800-526-7234 (V/TTY)

On the web: <http://janweb.icdi.wvu.edu/>

Medicaid:

Medicaid is a way to help pay for health care for people who have disabilities and who don't have a lot of money. Medicaid will also pay for certain kinds of non-medical long-term care for people with developmental disabilities.

Funding for Medicaid services is provided by *both* the federal *and* the state government. This means that each state has its own unique Medicaid program, and you will have to get in touch with your state's Medicaid offices to find out what services are available and how to apply.

Want to learn more?

Call (for New Jersey Medicaid): 1-800-356-1561

On the web (for New Jersey Medicaid):

<http://www.state.nj.us/humanservices/dmahs/dhsmed.html>

On the web (for regional offices throughout the country):

<http://www.cms.hhs.gov/RegionalOffices/>

New Jersey Association of County Offices for the Disabled:

New Jersey has 18 County Offices for the Disabled. Their mission is to empower people with disabilities to become self advocates and to live independently in their communities. The Offices for the Disabled provides information, and helps people figure out where to go to get the services they need.

Many Offices for the Disabled administer the Personal Assistance Services Program (PASP). This program helps people with physical disabilities get the supports they need so they can live as independently as possible. These supports include help with daily living tasks such as bathing, dressing, making meals, doing laundry, shopping, and getting from place to place.

Want to learn more?

On the web: <http://www.wnjp.in.state.nj.us/services/cofd.htm>

New Jersey Council on Developmental Disabilities:

The Council's goal is to influence social policy to improve the lives of people with disabilities. The Council does this in a different ways. It serves in an advisory role to the Governor and the State Legislature. It also provides training to so that people with disabilities and their families can more effectively advocate for themselves.

Two examples of Council programs are Monday Morning, which is made up of people with disabilities who work with local, state and federal officials on public policy issues like transportation, and Partners in Policymaking, which is an intensive advocacy training program for people with disabilities and parents of children with disabilities.

Want to learn more?

Call: 609-292-3745

On the web: <http://www.njddc.org/>

New Jersey Protection and Advocacy (NJP&A):

NJP&A's mission is to protect, advocate for and advance the rights of persons with disabilities. NJP&A operates nine federally funded programs: Protection and Advocacy for Persons with Developmental Disabilities (PADD); Protection and Advocacy for Individuals with Mental Illness (PAIMI); Protection and Advocacy for Individual Rights (PAIR); Client Assistance Program (CAP); Protection and Advocacy for Beneficiaries of Social Security (PABSS); Traumatic Brain Injury Protection and Advocacy (PATBI); Protection and Advocacy for Assistive Technology (PAAT); Assistive Technology Advocacy Center (ATAC); and Protection and Advocacy for Voter Access (PAVA).

The Assistive Technology Advocacy Center (ATAC) serves as New Jersey's federally funded assistive technology project through a sub-contract with New Jersey's Department of Labor. ATAC helps people with disabilities get the assistive technology devices and/or services they need.

Want to learn more?

Call: 1-800-922-7233 (TTY 609-633-7106)

On the web: <http://www.njpanda.org/>

New Jersey Transit:

Public transportation is mostly buses and trains. Some communities have a lot of public transportation for people to use, and others don't have much at all. The Americans with Disabilities Act (ADA) says that whatever public transportation a community has must be made accessible for people with disabilities.

Access Link is New Jersey's paratransit service. Individuals are eligible for Access Link if: they cannot get on or off a bus or ride in an accessible bus without help; they have a disability that prevents them from getting to or from a bus stop; they could use the local bus, but accessible service is not yet available in their area. You have to apply and be found eligible for Access Link.

In addition to Access Link, each of the 21 counties in New Jersey provides community-based transportation services to help meet the needs of people with disabilities.

Want to learn more?

Call: 1-800-772-3606

On the web: www.njtransit.com

NJHelps:

NJHelps is an on-line service that gives people information about 8 programs that might be helpful to them and their family. These programs include Medicaid, NJ FamilyCare, Food Stamps and Low Income Home Energy Assistance.

Want to learn more?

On the web: <http://www.njhelps.org/>

One-Stop Career Centers:

The federal Department of Labor (DOL), in partnership with states, has created something called One-Stop Career Centers. The Centers offer services like training referrals, career counseling, and job listings, all in one place, to people who are looking for work. DOL's Division of Disability and Workforce Programs helps to make sure that the One-Stop Career Center system is available to people with disabilities.

Want to learn more?

Call: 1-877-348-0502 (TTY 1-877-348-0501)

On the web: www.careeronestop.org (by typing in your zip code, you can link to information about the One-Stop Career Centers that are nearest to you)

Recording for the Blind and Dyslexic (RFB&D):

RFB&D provides audio recordings for books. RFB&D's library contains more than 98,000 books on all different topics, from literature and history to math and science. Books can also be found for all reading levels, from kindergarten to books for people who are professionals in their field.

Want to learn more?

Call: 1-800-221-4792 (member information) and 609-520-8096 (Custom Recording Services)

On the web: www.rfbd.org

Social Security:

- **Social Security Number/card:**

Everyone needs a Social Security Number when they go to work. You probably already have one by now, but in case you don't, you need to apply for one. To get a Social Security number and card, you have to complete an application. You can get this application online, by phone, or by visiting your local Social Security office.

- **Supplemental Security Income (SSI):**

SSI benefits are paid to individuals who have disabilities *and* who have little or no income. SSI provides cash to meet basic needs for food, clothing, and shelter.

Individuals who are over 18 are considered eligible for SSI if they have a medically determined physical or mental impairment that results in a lack of "substantial gainful activity" (that means, the person is unable to earn much money because of his disability). Once a person turns 18, only that person's income and savings (and not his family's) are looked at when he applies for SSI benefits.

- **Social Security Disability Insurance (SSDI):**

SSDI refers to cash assistance payments to individuals who have a disability. However, to get SSDI a person must have worked and paid taxes for about 5 years, or be the adult child of a person who has worked and paid taxes.

Want to learn more?

Call: 1-800-772-1213 (TTY 1-800-325-0778)

On the web: www.socialsecurity.gov

Statewide Parent Advocacy Network (SPAN):

Through Information Specialists, workshops, conferences and publications, SPAN provides parents, educators and service providers with up to date information about education (including transition), law and advocacy, school reform, health and disability issues. SPAN offers emotional support and information to parents through a bilingual, multi-racial staff of parents of children with and without disabilities, and supports parents and professionals working towards comprehensive, coordinated, culturally competent services for children and families across agencies.

Want to learn more?

Call: 1-800-654-SPAN or 973-642-8100

On the web: <http://www.spannj.org/>