

Understanding Supports

The Big Ideas:

Different kinds of supports:

Natural supports

Community supports

Formal supports

Assistive technology/

Environmental adaptations

Resources

Evaluating your supports

Managing your supports

What does it mean to “get the supports I need?”

We’ve already talked about the fact that we all need support, or help, to reach our goals. There are many different kinds of supports that you can use. Getting the supports you need means figuring out which ones will help you do whatever it is you want to do.

“So I think students need to be taught to ask for help, because a lot of times I know they’ll get frustrated or do it the wrong way, or just try to do it the best they can without saying, ‘Can you help me figure this out?’” Peer Mentor

“Even not considering the language, Susan has real trouble asking for help because she feels like she doesn’t want to ask you for help, because people have been trying to help her her whole life when she doesn’t need it. So even when it might be helpful to her for you to help her, she’s not going to ask you, ever, and if you tried she might even get mad at you.” Peer Mentor

Activity:

- Either on your own, or with your classmates, look at the worksheet called “What Kind of Support Would Be Most Helpful?” and answer the following questions:

This is the goal I want to work on (or the problem I want to solve):

Tasks to be done (These are the things you have to do to reach your goal or solve the problem. Try to think out what has to be done, one step at a time, and write those steps down.):

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____

Where can I go to get the help I need?

The whole point of this book is to teach you about what supports there are, and how to get those supports. Here are the **four different kinds of supports** that we'll be talking a lot about.

Natural supports: These are your family, friends and neighbors who know you and can help you out sometimes.

Community supports: These are things that are near your home that are meant to help everyone, not just people with disabilities. They include libraries, public transportation (buses and trains), places of worship (churches, temples, mosques, etc.), YMCA's, and adult education classes.

Formal supports: These are supports that are meant to help people with disabilities.

- Formal supports can be public agencies that are managed by the government. New Jersey's Division of Developmental Disabilities (DDD) and Division of Vocational Rehabilitation Services (DVRS) are two examples of public agencies. Medicaid and Social Security are also supports that are paid for by the government.
- Formal supports can be private service providers. These are non-government businesses that are paid to provide services for people with disabilities.
- Formal supports can also be people (sometimes called "personal assistants") that are paid to help you with whatever tasks you need help with.

Assistive technology and environmental adaptations:

- Assistive technology is any tool that can help you do what you want to do. Examples of assistive technology are wheelchairs, assistive communication devices that can help you "speak," and computers that read words out loud.
- Environmental adaptations are changes in how things are set up to make it easier for you to do what you need to do. An example of an environmental adaptation is putting your desk in front of the classroom so you can hear the teacher better.

"I really don't think it matters who it is, as long as you have that support, someone there with you giving you motivation to keep it going." High school student

"So in his life I see that he has two needs. He needs someone to take care of his health and safety needs, and someone else to take care of his social needs." Parent

**Resources are
the places and
people you can
go to for help.**

Activity:

- **Either on your own, or with your classmates, complete the “Resource Activity” at the end of this chapter. Keep in mind that this book will teach you about many different resources that you might not know about yet.**

How do I know which of the different kinds of supports to use?

What supports you use depends on what you need help with. For example, if you don't drive then you might need help getting from place to place (that's called "transportation"). Needing help with transportation, however, doesn't mean you'll always need the *same kind* of help with transportation. If you need to go to the doctor's, a family member or friend might be the best person to ask for a ride; if you need to get to work everyday, the bus might make more sense.

The following are five steps to think about when deciding what kinds of supports to use:

Step #1: Often the easiest way to get something done is to do it yourself. Remember, *before you ask someone else for help, you should think about what you can do for yourself.* Not only is it often easier to do it that way, it is an important part of becoming an adult.

Activity:

- **Either on your own, or with your classmates, look at the worksheet called “My To Do List.” The important points to remember are:**
 - **Write down everything you plan to do, and when you are going to do it.**
 - **If you have a hard time getting something done, use the “What Kind of Support Would Be Most Helpful?” worksheet to decide which kind of support might be helpful for solving this problem.**

Step # 2: Once you've figured out what you can do for yourself, it's usually easiest to think about the people you're closest with (**natural supports**) and what they might be able to help you do.

Keep in mind that family and friends can't do everything. They'll usually try their best, but if something takes a lot of time, or is hard to do, they may have to say "no." Not asking too much of your family and friends is one way to show that you care about their needs as well as your own.

Activity:

- **Either on your own, or with your classmates, look at the worksheet called "Getting the Natural Supports I Need." The important points to remember are:**
 - **Be very clear about what you need help with.**
 - **Ask the person you are talking with to be very clear about what they can (and can't) help you with.**
 - **When possible, offer to do something for that person in return. Helping other people is an important part of taking care of the people who care for you.**

Step #3: After you've thought about natural supports, the next thing to think about are the places that everyone can use, whether or not they have a disability (**community supports**). Let's say you need a computer, but you don't have one at home. The local library might have a computer you can use, and the librarian might be a good person to show you how to get the information you need.

Activity:

- **Either on your own, or with your classmates, look at the worksheet called "Getting the Community Supports I Need." The important points to remember are:**
 - **Be very clear about what you need help with.**
 - **Find out if this place has provided supports for other people who have needs like yours.**
 - **If this organization has never provided the supports you need, try using your self advocacy skills and see if there's someone to talk with about creating those supports!**

Step #4: If there aren't any natural or community supports that can give you the supports you need, then it's time to think about **formal supports**. These are the services that are there to help people with disabilities. This will involve finding a public agency or private service provider to work with. It might also involve hiring a personal assistant.

Activity:

- **Either on your own, or with your classmates, look at the worksheet called “Getting the Formal Supports (public agency or private service provider) I Need.” The important points to remember are:**
 - **Be prepared to talk about what your disability is, and the kinds of things you need help with.**
 - **Find out what services this organization provides.**
 - **Find out what you need to do to get these services.**

- **Look at the worksheet called “Getting the Formal Supports (paid support person/ personal assistant) I Need.” The important points to remember are:**
 - **Be very clear about what you need help with.**
 - **Find out if this person has already worked with people who have needs like yours.**
 - **Ask the person to be very clear about what they can (and can't) help you with.**
 - **Be honest with yourself about whether or not you feel comfortable with this person. If so, great! If not, don't be afraid to keep looking for someone who feels right for you.**

Step #5: Tools such as wheelchairs and touch screens for the computer (**assistive technology**), or taking tests in a room by yourself (**environmental adaptations**), can be helpful no matter what other supports you are using.

Activity:

- **Either on your own, or with your classmates, look at the worksheet called “Getting and Evaluating the Assistive Technology/ Environmental Adaptations I Need.” The important points to remember are:**
 - **Be very clear about what you need help doing.**
 - **Ask other people what kinds of assistive technology or environmental adaptations might be helpful.**
 - **Be honest with yourself about whether or not this assistive technology or environmental adaptation really is helping you do what you want to do. If so, great! If not, don’t be afraid to try something else.**

What happens once I get the supports I need?

Evaluating your supports means asking yourself, “Are the supports I’m getting helping me do what I want to do?”

It would be nice if once you got the supports you needed, there wasn’t anything else you had to do. But the fact is, you will always be learning and growing and setting new goals for yourself. It’s important that your supports change along with you. Otherwise, the help you get may not be the help you need. Evaluating your supports means deciding if the supports you have are still the right ones for you.

“Transition is ongoing. John’s life is going to evolve just like our lives have evolved. I’m not doing what I did 30 years ago, and I’m not going to assume that John will be doing what he’s doing now 30 years from now.”
Parent

What happens if my supports aren’t helping me do the things I want to do?

Managing your supports means finding ways to make sure your supports really are helping you do what you want to do.

When you evaluate your supports, the big question you’re going to ask is, “Are the supports I’m getting helping me do what I want to do?” If the answer is “yes,” then that’s great! If the answer is “no,” then you’ll want to do something to change that. Maybe the person who drives you to work is always late. Or maybe the person who helps you do your job is really nice, but you’re mad at her because whenever someone asks *you* a question at work, *she* answers. Being able to handle problems like these is an important part of managing your supports.

Activity:

- **Either on your own, or with your classmates, look at the worksheet called “Evaluating and Managing My Supports.” The important points to remember are:**
 - **Be honest with yourself about whether or not you are getting the help you need.**
 - **If you are, make sure you thank the person who is helping you.**
 - **If not, talk with the person about what you both think the problem is, and what solution you can both agree to try.**
 - **Remember, if you can’t find a solution that works, think about other supports that might be helpful.**

What if I'm not sure I can do all this myself?

It's important to understand that different people will need different kinds of help in order to get, evaluate, and manage their supports. One person might need important information read out loud and explained. Another person might need a family member or friend to help make sure other people understand what she likes and doesn't like. Everyone needs the people they are close with to encourage them as they practice these new skills.

[The biggest challenge since leaving high school was] "learning how to live on my own, and hiring attendants...Before I lived in the dorms, I was so used to having my parents doing my laundry and preparing food and all that stuff and then I had to rely on other people to do it. And hire attendants. And sometimes they were really flakey and didn't show up. And so that got really frustrating." Recent high school graduate

All of this can feel new and a little scary, but it's important that you keep in mind that these are skills you will use your whole life. Just like the self advocacy skills we talked about earlier, they get easier with practice. A lot of what we've talked about comes down to two basic things. If you can do these two things, you'll be surprised at how far you can go in living the life that's right for you.

#1. Take the time to understand yourself!

All planning for your future, including getting the supports you need, starts with this.

#2. Let other people know what you want and need.

The more other people understand these things, the easier it will be for them to support you in ways that help you reach your goals.

Learning from Leaders

Ed Roberts was born in 1939, and became sick with polio when he was a teenager. For the rest of his life he couldn't move much, and had to use a machine to help him breathe, but Roberts never let this stop him. As a young man, Roberts fought to go to college. Once there, he became a leader in the independent living and disability rights movements.

Like other people with disabilities at the time, Roberts had to learn how to handle discrimination (being treated unfairly because he had a disability). In 1961, California's Vocational Rehabilitation agency refused to serve him because they said his disability was too severe for him to work. Not only did Roberts fight successfully to have that decision changed, but 14 years later he was appointed by the governor to be the state director of that same agency.

Roberts helped to start the independent living and disability rights movements because he knew - and wanted other people to know - that individuals with disabilities have the right to direct their own lives. He died in 1995.

Questions to think about:

1. What do you think it means to "direct your own life?"
2. Look up the word "independence."
 - What does "living independently" mean to you?
 - Think about people you know who live independently. Do they still need help sometimes? What kind of help?
3. To learn more about Ed Roberts and the independent living movement, go to <http://www.ilusa.com/links/ilcenters.htm>

Kristen's story continued:

Kristen really likes an aide at her school named Leslie. Leslie is very funny and makes Kristen laugh a lot. Every year she bakes cookies for Kristen's birthday. Kristen wants to invite Leslie to be a part of her Circle of Support (a group of people who will help Kristen live the life she wants). The problem is that when Kristen's mother visited the school, she noticed that there were a number of times when Kristen was trying to show Leslie something and Leslie just rolled her eyes and walked away. Kristen didn't seem to notice this, but her mother feels that Leslie doesn't really respect Kristen. She isn't comfortable asking Leslie to be part of the Circle. The other members of Kristen's Circle aren't sure what to do. They want to respect Kristen's wishes, but they also understand her mother's concerns.

Activity:

- Either on your own, or with your classmates, think about Kristen's story and answer the following questions:

What are the ways people show respect to one another? For example, people show respect by listening when someone is talking.

Kristen needs people whom she likes and is comfortable with. She also needs people who will respect her. Do you think Leslie would be a good person to have in Kristen's Circle of Support? Why or why not?

Activity (cont.):

If you were part of Kristen's Circle of Support, how would you handle this problem?

Let's Review:

- Getting the supports you need means thinking out what you want to do, what you need help with, and where to go to get that help.
- It's important to first decide what you can do for yourself.
- There are different kinds of supports: natural, community, and formal. It's often best to start with thinking about what natural supports you can use, then think about community supports, and then formal supports. You might use all of these supports to reach a goal.
- Assistive technology and environmental adaptations can be used along with the other kinds of supports.
- After you have some supports in place, the next step is deciding if you're getting the help you really need. That's called evaluating your supports.
- Managing your supports means thanking people when things are going well *and* solving problems when things aren't going well. It's important to come up with solutions to problems that both you, and the person helping you, can agree to try.

Additional Activities:

- **READ ABOUT DIFFERENT RESOURCES THAT MIGHT BE HELPFUL TO YOU IN THE CHAPTER CALLED “RESOURCES.”**
- Either on your own, or with your classmates, take out the “List of Resources” worksheet at the end of this chapter.
 - Write down the names and phone numbers of family and friends who might be able to help you out sometime. (Put these under “Natural Supports.”)
 - Using the phone book and/or the internet, find the phone numbers of different resources in your community. (Put these under “Community Supports.”)
 - Get the contact information for some public agencies or private service providers that might be helpful to you. (Put these under “Formal Supports.”)
 - If you need Assistive Technology or Environmental Adaptation, write down the contact information for people or places that might be able to help you get these things. (Put these under “Assistive Technology/ Environmental Adaptations.”)
 - Talk with parents, teachers, case managers, friends, etc. for suggestions of other resources you might want to include.
 - **PORTFOLIO: Put this List of Resources in the section for “Official Information.” As you learn about more resources, keep adding to this list.**

Additional Activities (cont.):

- Either on your own, or with your classmates, answer the following questions:
 - Who are the people you trust, and why do you trust them?
 - Is it ever hard to know whom to trust?
 - How do you want to be treated by the people who help you?
 - How can you tell if someone isn't being respectful to you?

Resource Activity

1. If you wanted to borrow a book to read, you would _____

This is an example of a:

Natural support _____ Community support _____ Formal support _____

Assistive Technology _____ Environmental Adaptation _____

2. If you could not see and wanted to read a book, you would _____

This is an example of a:

Natural support _____ Community support _____ Formal support _____

Assistive Technology _____ Environmental Adaptation _____

Resource Activity (cont.)

3. If you needed a ride to the store, you would _____

This is an example of a:

Natural support _____ Community support _____ Formal support _____

Assistive Technology _____ Environmental Adaptation _____

4. If you wanted to talk to someone about an argument you had with a close friend, you would _____

This is an example of a:

Natural support _____ Community support _____ Formal support _____

Assistive Technology _____ Environmental Adaptation _____

Resource Activity (cont.)

5. If you wanted to cash your pay check, you would _____

This is an example of a:

Natural support _____ Community support _____ Formal support _____

Assistive Technology _____ Environmental Adaptation _____

6. If you wanted to find out about apartments to rent, you would _____

This is an example of a:

Natural support _____ Community support _____ Formal support _____

Assistive Technology _____ Environmental Adaptation _____

Resource Activity (cont.)

7. If you needed help cooking your meals and getting dressed each day, you would _____

This is an example of a:

Natural support _____ Community support _____ Formal support _____

Assistive Technology _____ Environmental Adaptation _____

8. If you wanted help finding out about jobs in your community, you would _____

This is an example of a:

Natural support _____ Community support _____ Formal support _____

Assistive Technology _____ Environmental Adaptation _____

Resource Activity (cont.)

9. If you wanted help finding out about careers that might be right for you, you would _____

This is an example of a:

Natural support _____ Community support _____ Formal support _____

Assistive Technology _____ Environmental Adaptation _____

10. If you needed help understanding what you're supposed to do at your job, you would _____

This is an example of a:

Natural support _____ Community support _____ Formal support _____

Assistive Technology _____ Environmental Adaptation _____

Resource Activity (cont.)

11. If you needed a ride every day to go to work, you would _____

This is an example of a:

Natural support _____ Community support _____ Formal support _____

Assistive Technology _____ Environmental Adaptation _____

12. If you wanted to find out about colleges you would _____

This is an example of a:

Natural support _____ Community support _____ Formal support _____

Assistive Technology _____ Environmental Adaptation _____

Resource Activity (cont.)

13. If you wanted to find out about disability services at a college you wanted to attend you would _____

This is an example of a:

Natural support _____ Community support _____ Formal support _____

Assistive Technology _____ Environmental Adaptation _____

14. List one thing you have done in the past and the kind of help you used to do it: _____

This is an example of a:

Natural support _____ Community support _____ Formal support _____

Assistive Technology _____ Environmental Adaptation _____

Resource Activity (cont.)

15. List one thing you would like to do in the future, and the kind of help you might need to do it: _____

This is an example of a:

Natural support _____ Community support _____ Formal support _____

Assistive Technology _____ Environmental Adaptation _____

*Adapted from: Wehmeyer, M. (1995). Whose Future Is It Anyway? The Arc National Headquarters: Arlington, TX.

List of Resources

NATURAL SUPPORTS (FAMILY AND FRIENDS):

Name:	Phone number:
1.	
2.	
3.	
4.	
5.	
6.	
7.	
8.	
9.	
10.	

List of Resources

COMMUNITY SUPPORTS:

Name of organization:	Phone number and/or web address:	Contact person (if known):
1.		
2.		
3.		
4.		
5.		

List of Resources

FORMAL SUPPORTS (PUBLIC AGENCIES OR PRIVATE SERVICE PROVIDERS):

Name of public agency or private service provider:	Phone number and/or web address:	Contact person (if known):
1.		
2.		
3.		
4.		
5.		

List of Resources

FORMAL SUPPORTS (PAID SUPPORT PEOPLE/ PERSONAL ASSISTANTS):

Name of paid support person/ personal assistant	If connected with agency, name of agency:	Phone number:
1.		
2.		
3.		
4.		
5.		

List of Resources

ASSISTIVE TECHNOLOGY/ ENVIRONMENTAL ADAPTATIONS:

Kind of Assistive Technology/Environmental Adaptation:	Name of place and/or person to call for information:	Phone number and/or web address:
1.		
2.		
3.		
4.		
5.		