



Roadmap to Transition

A Handbook for Autistic Youth
Transitioning to Adulthood



Roadmap to Transition:

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Chapter 1: Introduction	7
What is this?	7
How can I use this?	8
Transition: What's it all about?	10
Transition planning is for everyone	12
What now?	15
Chapter 2: Self-Determination and Self-Advocacy	17
Overview	19
Self-determination	20
Self-advocacy	24
How does this fit into my transition plan?	28
Summary	29
Chapter 3: Know Your Rights	31
Overview	33
Individuals with Disabilities Education Act	34
The Family Educational Rights and Privacy Act	37
Americans with Disabilities Act	43
Section 504 of the Rehabilitation Act	48
Olmstead	50
Fair Housing Act	55
Protection & Advocacy Agencies	58
How does this fit into my transition plan?	59
Summary	60

Chapter 4: Making Your Transition Plan	61
Overview	63
What is transition planning?	64
IEPs and Transition Planning	66
What if I didn't have an IEP?	70
Your Transition Planning Notebook	71
Step 1: Transition Assessments	76
Step 2: Creating measurable postsecondary goals	87
Step 3: Identifying transition services	93
Step 4: Write the course of study	97
Summary	98
Chapter 5: Getting the Supports You Need	99
Overview	101
Support networks	102
Supports and support needs	108
Before you start	110
Figuring out your support needs	114
How will I get supports?	118
How does this fit into my transition plan?	123
Summary	124

Chapter 6: Supported Decision-Making	125
Overview	127
During transition	128
Self-determination & self-advocacy	131
Decision-making	132
What is supported decision-making?	134
Forming a support network	138
Making a decision with supports	142
What if...	152
Supported decision-making & the law	159
How does this fit into my transition plan?	160
Summary	161
Chapter 7: Post-Secondary Education	163
Overview	165
During transition	166
Self-determination & self-advocacy	169
Education pathways	170
Choosing your educational path	178
Accommodations & supports	191
Legal protections	194
How does this fit into my transition plan?	197
Summary	198

Chapter 8: Employment	199
Overview	201
During transition	202
Self-determination & self-advocacy	205
Working with a disability	206
Types of employment	212
Supports & accommodation	215
Researching jobs	220
Applying for jobs	228
Interviews	230
Workplace culture	234
Employment and the law	236
How does this fit into my transition plan?	242
Summary	243
Chapter 9: Housing and Independent Living	245
Overview	247
During transition	248
Self-determination & self-advocacy	251
Housing options	252
Choosing where to live	263
Making the move	266
Hidden costs	275
Legal protections	276

How does this fit into my transition plan?	278
Summary	280
Chapter 10: Health Care	281
Overview	283
During transition	285
Self-determination & self-advocacy	288
Building your medical home.....	289
Understanding insurance	293
Health care providers	307
Managing your health	313
Health care and the law.....	333
How does this fit into my transition plan?	339
Summary	341
Chapter 11: Appendix.....	343
Glossary of Terms.....	345
Resources by chapter	355
National Resources	377
Resources by State	385

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What is this?

This is a handbook to help autistic young people transition into adult life.

transition

The process of changing from one way of life to another way of life

A **transition** is a change. Transitioning means lots of new responsibilities and challenges. In many situations it can be hard to know what to do.

Transitioning into adulthood can be an especially tough transition. There are lots of new beginnings and also a lot of endings to deal with at the same time.

It may feel good to start out on your own and live independently. But it's also normal to feel uncertain, scared or frustrated at this stage in your life.

You may spend a lot of time worrying about your purpose, or what you're supposed to be doing with your time. While it's important to explore your interests, and to try to find a job in a subject area you like, the most important thing to focus on is enjoying your life day by day.

Focus on small achievements and celebrate little victories. This will help to prepare you for bigger decision-making and moving forward in life.

The support network you are used to may change. You might not see your school friends as much anymore. Or, you might move away from living with your parents, which can feel isolating. It's important to know that you are not alone, and asking for help with things that you need is okay.

self-advocacy

The act of speaking up for what you need and want

This handbook teaches **self-advocacy**. Self-advocacy means figuring out your wants and needs, and how to get them.

This is an essential tool for transitioning into adulthood. Self-advocacy is a big part of giving you control over your life. In a way, this book is a guide on how to be a self-advocate.

There is a chapter on what self-advocacy and **self-determination** mean and why they are important. But every chapter will encourage and teach you to **self-advocate** in specific ways, based on the issues you are facing during your transition.

self-determination

The idea that each person has the right to decide how to live their life

self-advocate

The action of speaking up for your own wants and needs

How can I use this?

Standalone chapters

You can use this tool in different ways. You can read it from beginning to end, or you can go right to the sections you want to know more about. Each section can stand on its own and will include its own overview, list of key terms, and summary of information. Because of this, you may see some of the same information in different sections.

Chapters 2-6 lay the groundwork for transition planning. Chapters 7-10 go in-depth about different areas of your life that you'll have to think about when making your transition plan.

Chapter 5 is called "Making Your Transition Plan." This chapter will help you use the information from the other chapters to make your own transition plan. You can make a transition plan for some parts of your life but not others. What you include in your transition plan is up to you!

Glossary

In each chapter, you will see words or phrases that are **bold and magenta**. You can find definitions of these words and phrases in the Glossary section of Chapter 11.

Resources

Chapter 11 is the “Appendix” section. This chapter has more resources, grouped by chapter. It also includes national resources and state resources.

Using this outside of the United States

If you’re outside of the United States, a lot of the information about specific laws and programs won’t apply to where you live. However, you can still use a lot of the information in this handbook!

For example, no matter where you live, you can still:

- Make your own transition plan
- Figure out what your support needs are
- Use the general information in the topic chapters to think about your current and future goals
- Read about what the U.S. laws do and look up what similar laws your country has
- Make a support team

If you want to help us make a version of this handbook for your country, you can send an email to idempsey@autisticadvocacy.org. Tell us about what laws your country has or what kinds of programs are similar to the ones in this handbook.

Transition: What's it all about?

Autistic youth in transition

A **transition** is a change. “Transition” means the process of changing from one way of life to another way of life. For autistic people, there are many different transitions to face.

Some examples of transitions are:

- changing schools
- moving to a new house
- moving out of your parent’s house
- finding a job.

Transitions can be hard for anyone. Most people take comfort in familiar settings. Autistic people often use routines to better navigate life. A sudden change, like starting school or getting a new job, can be unpleasant. Preparing autistic people for change, and making the change less sudden, makes this easier.

Many changes in life are unavoidable. The good news is that you can cope with these changes. A transition plan will help you cope with big life changes.

transition

The process of changing from one way of life to another way of life

Transitions can be hard for anyone.

Individualized Education Program (IEP)

A plan for how a student with a disability will get the services and supports the need in school

Individuals with Disabilities Education Act (IDEA)

federal law that makes sure students with disabilities get a free public education that includes the supports they need

IDEA & transition planning

When you were in school, you may have had an **Individualized Education Program (IEP)**. There is a law called the **Individuals with Disabilities Education Act (IDEA)**. This law makes sure that your IEP includes services to help you with transition planning.

What is transition planning?

Transition planning means figuring out two main things:

1. What your support needs are
2. How you will get the supports you need

IDEA has a specific definition for “transition planning.” According to the IDEA, transition planning for a student with a disability is:

- A process to make a plan of supports, services, and goals that all work together
- Focused on improving your skills in school subjects and activities of daily life (ADLs) to make your transition easier
- Based on your individual needs, strengths, preferences, and interests

It is also a way to learn more about the options you have after graduating, such as:

- Continuing your education
- Learning professional skills
- Getting a job alongside people without disabilities
- Getting new support services
- Living independently
- Participating in your community

At the end of transition planning, you will have a detailed **transition plan**. Your transition plan includes details about the services and supports you will need.

According to IDEA, your transition service plan must focus on these main areas:

1. Instruction
2. Related services
3. Community experiences
4. Employment or other post-school adult living goals
5. Daily living skills and a vocational evaluation

Don't worry if you don't know what some of these things mean right now! We'll go over each one of these 5 areas and explain what they mean in the next section.

Transition planning is for everyone

Overview

If you had an IEP in school, your transition planning will be part of the regular meetings that you have with your IEP team. Because of the IDEA law, nobody on your IEP team can plan your transition without you.

If you didn't have an IEP, that's okay! You can still form a team of people you trust (parents, teachers, other family members, etc.) and create your own plan for your transition to adulthood.

Remember, the plan you and your team make for your transition services must be based on your:

- Needs
- Strengths
- Preferences
- Interests

*See **Chapter 3: Know Your Rights** for more information about your rights under IDEA.*

First, let's talk about what each one of these things means.

Needs, Strengths, Preferences, Interests

Needs

What are your "needs" when it comes to transition planning? Your needs could be related to school, like "I need to learn how to solve word problems in math class."

Your needs could also be about the kind of life you want to lead as an adult, like "I need to learn how to use public transportation."

Your needs could also be what kinds of supports you must have in order to meet the goals you set in your transition plan.

Strengths

Your strengths are the things that you are good at. Maybe you are good at doing activities in your science class, or maybe you are good at taking care of animals.

Figuring out what your strengths will help you and your team make a plan that lets you use your strengths in the future. An example could be if you are good at taking care of animals, maybe you want your transition plan to include going to veterinary school.

Preferences

Your preferences are what you want to do. When you and your team are making your transition plan, your team has to listen to what you want your future to look like and what goals YOU want to make for yourself. It is important to be a **self-advocate** and tell your team what your preferences are.

self-advocate

somebody who speaks up for their own wants and needs

Interests

Your interests are anything you like doing or learning about. You could be interested in flying airplanes, cooking food, reading about history, studying animals, or any number of things!

Thinking about the things you are interested in can help you figure out what your goals are for your transition plan. Maybe you want to go to college to study your interests. Maybe you want to get a job related to one of your interests. This can be part of your transition plan!

Goals

Making a transition plan is all about setting goals and figuring out how you will reach them. Your goals have to be clear and focused. Your goals also have to be measurable, which means there has to be a way to find out if you have reached your goal or not.

In each chapter of this handbook, there will be a section about the kinds of goals you might set for each area. Because of that, we won't go into too much detail about specific goals here.

What now?

Whether you have an IEP or you're making your own plan, it's important to understand what transition planning is all about. Transition planning is about setting goals and making plans for your adult life.

Your transition plan should reflect your needs, strengths, preferences, and interests. We discussed the 5 areas that an IEP transition plan must have, but that doesn't mean that you can't or shouldn't make plans and set goals for other areas of your life.

Each of the next chapters in this handbook will give you more information and resources about transitioning to a specific part of adult life. This handbook will help you figure out:

- what options you have
- what kind of goals you could set for yourself
- how you will reach those goals, and
- what kinds of supports you might use.

With a good transition services plan and support team, the transition to adulthood doesn't have to be scary at all. This is the time you get to figure out what kind of life YOU want to have!

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2

Self-Determination and Self-Advocacy



Image: A miniature person crossing a string finish line on a running track. The track is a close-up guitar neck.

“The only person you are destined to become is the person you decide to be.

—Ralph Waldo Emerson

What you'll learn in this chapter

- ▶ What self-determination is
- ▶ What self-advocacy is
- ▶ Why self-determination and self-advocacy are important
- ▶ How to be a self-advocate
- ▶ What to do if you need help self-advocating

Key terms

- ▶ self-determination
- ▶ advocate
- ▶ self-advocacy
- ▶ self-advocate
- ▶ vocational rehabilitation

Outline

▶ Overview

What are self-determination and self-advocacy?

What is the difference between self-determination and self-advocacy?

▶ Self-Determination

What does it mean?

Why is it important?

How can I do it?

What if I need help?

▶ Self-Advocacy

What does it mean?

Why is it important?

How can I do it?

What if I need help?

▶ How does this fit in to my transition plan?

▶ Summary

Overview

What are self-determination and self-advocacy?

self-determination

The idea that each person has the right to decide how to live their life

Self-determination means that you get to choose how to live your own life. Nobody else gets to make decisions for you about:

- What supports and services you need
- How you participate in your community
- How you spend your money
- Where you live, or
- Anything else!

self-advocacy

The act of speaking up for what you need and want

Self-advocacy means learning how to be in control of your own life and speaking up for your rights. To be an “advocate” means to be a person who speaks up in support of something. To be a “self-advocate” means to be a person who speaks up for yourself and what you want!

What is the difference between self-determination and self-advocacy?

Self-determination is being able to decide what you want in life. It can be choosing your hobbies, making plans to see a friend or picking a career path. It is figuring out what would improve your life and having the desire and motivation to do so.

Self-advocacy is a process by which you get the things you want and need. Self-advocacy means speaking up for yourself. It means telling people what your wants and needs are and working to get the supports and services that you need.

Self-advocacy is self-determination in action.

Having self-determination is the first step to becoming a self-advocate. When you are self-determined, you decide for yourself what you want and need. Self-advocating means telling people what decisions you have made about your wants and needs. It means working with parents, teachers, coworkers, support staff, or anybody else to get your wants and needs respected and met.

Self-advocacy is self-determination in action.

Self-determination

What does it mean?

Self-determination is being able to make your own decisions. It is when you set your own goals and give yourself the means to achieve them.

You take part of important decisions.

You take action when you want something so you can get it.

You learn to solve problems.

You make your own choices and deal with their consequences.

Compare these two examples:

Example #1:

Someone tells you that they will give you a soda if you clean the table. Then, you decide to clean the table.

It is **not self-determination** because you did not take the action in the first place. You would not have decided to clean the table if that person had not told you.

“You control your destiny — you don't need magic to do it.

—Merida, *Brave*

Self-determination is not the same thing as being on your own. You can still have help.

Example #2:

You see that the kitchen counters are dirty. You don't want to make food in an unhygienic environment. So you go out, get some surface cleaner and sponges, and spend some time cleaning up the kitchen. You reward yourself with a can of your favorite soda.

This is self-determination. You made the decision to clean on your own. You thought about the consequences of having a dirty kitchen. You saw what needed to be used to get the kitchen clean. You set yourself a goal, and gave yourself a reward.

Self-determination is not the same thing as being on your own. You can still have help.

Self-determination means that the final choices you make come from you.

You start to learn self-determination skills when you are a child and as you grow up. Those skills improve your life, education and employment.

Why is it important?

Because we are autistic, we are often stopped from making our own choices as we grow up. People make choices for us and assume we cannot do it ourselves. Some people assume that we are not able to think by ourselves at all. That is why we need to learn self-determination.

It is important to be able to make our own choices and have people treat us with respect. It is also important when we are entering adulthood. It helps dealing with all the changes. It will make our life better.

When we do not feel listened to or respected, it can get frustrating and painful. We are happier when people respect our voice and our decisions. It means they respect us as a person and hear our voice.

Self-determination skills mean to make that easier.

When we are able to self-determine, we are safer from abuse, neglect, or discrimination. In the end, it has many positive results and helps us becoming adults.

When we are able to self-determine, we are safer from abuse, neglect, or discrimination.

How can I do it?

Not everyone is the same with self-determination. Your will have different levels of skills over time. You might want to control all decisions, like where you live or what work you do. You might also want more support to be able to take responsibilities.

You should be able to take part in any planning meeting that focuses on your care and needs. It includes, for example, IEP meetings. This way you will be able to discuss your own preferences and needs. You will be able to take part in decision taking.

You learn self-determination with real-life experience, like taking risks and making mistakes. When you make mistakes you will deal with the result and reflect on it. This is how you test what is hard for you and what may be more difficult.

To be self-determined, you have to know yourself. It includes knowing how autism might affect your life and the decisions you take.

Failure should not block you. Instead, it should be an opportunity to try again in another way and learn.

What if I need help?

Self-determination skills are learned by practicing them. It does not mean that you have to learn on your own. You can get help by looking for a mentor.

Mentors can be older people with disabilities. They can share their experiences with you. They can help you deal with problems and give you advice. They also encourage you if you need.

For help finding a mentor program, check the Chapter 2 Resources starting on page 355.

Community agencies have programs which will pair a young person with an older mentor. Some focus on people with disabilities.

Your family can help you. Your parents can give you advice when you are the one making a decision. In the end, they have to be ready to let you make decisions yourself. It also means allowing you to make mistakes.

Learning from a mentor: Jane's story

Jane is 20 and autistic. She wants to be a web developer. She got a degree in computer science, but is having a hard time figuring out what to do next to pursue her career. She seeks out a mentor through a local agency, and meets Cynthia. Cynthia is also autistic and has been working as a web developer for over 5 years. Jane talks to Cynthia about how to go about getting a job and where to start. She is also concerned about how being autistic will affect being in a work environment.

Cynthia helps Jane strengthen her résumé and practice what to say during job interviews. She also offers Jane support and reassurance about being autistic at work. Cynthia explains that although it was scary at first, she found that many of her coworkers were supportive. She and her co-workers shared common interests, and they listened to Cynthia about the things that she finds difficult. After meeting with Cynthia, Jane feels more confident.

Self-advocacy

What does it mean?

Self-advocacy means making your needs known. It means trying to get your needs met by other people or organizations.

For self-advocacy to work, you have to be willing to communicate your needs and **advocate** for what you need to succeed. Advocating means defending your choices. You may have to fight to make sure that your needs are taken into consideration.

Self-advocacy happens whenever disabled people try to get their wants or needs met by communicating them to others. Self-advocacy can happen in a group setting, or in one-on-one conversations. The only necessary thing for a person to be a self-advocate is that they attempt to make their needs known to another person.

Self-advocacy can be something small, like saying “no” or asking someone to explain an instruction in an easier way. Self-advocacy can be bigger as well, such as attending a protest or sitting in on a town hall meeting. The bigger types of advocacy are usually called activism.

In summary, self-advocacy means that you know what you do and don’t want, and you speak up for those things. “Speaking up” doesn’t mean that you have to actually say words out loud—however you communicate, you can advocate for yourself!

self-advocacy

The act of speaking up for what you need and want

advocate

To defend something or to argue for a certain thing to happen

“Speaking up” doesn’t mean that you have to actually say words out loud—however you communicate, you can advocate for yourself!

Self-advocacy is important because people need to know what you need in order for you to succeed.

self-advocate

Somebody who speaks up for their own wants and needs

Why is it important?

Self-advocacy is important because people need to know what you need in order for you to succeed. They may not be aware that you don't like doing a certain thing or need something explained in a different way, until you communicate that to them.

Self-advocacy can also build self-confidence. When you are able to stand up for yourself, you are confident to do so. Self-advocacy also makes things better for all people. It allows people to know that certain activities will not be tolerated by the autistic community.

How can I do it?

A **self-advocate** is somebody who does self-advocacy.

If you have any type of disability, you can be a self-advocate!

- You can be a self-advocate by speaking up for your needs. This could come in the form of communicating to a parent or caretaker that something they are doing is not something that you like.
- You can be a self-advocate by talking to a teacher, professor, or boss when you need help completing a task.
- You can be a self-advocate when you attend a protest about autistic rights.
- You can be a self-advocate when you blog online about your feelings.

There are many ways to be a self-advocate!

Self-advocacy: Wally's story

Wally has a hard time understanding and remembering verbal instructions. In class, his teacher tells the students out loud what their homework is.

Wally raises his hand and asks if the teacher can write down the assignment on the blackboard. That way, Wally can see the assignment and copy it down. Wally **self-advocated** by asking for the instructions to be given in a way that he can understand.

What if I need help?

Sometimes, self-advocacy can be hard. In that case, you may need some help. Starting with an action plan of what exactly the problem is and ways for you to solve it may be helpful. You can get an outline of questions [to ask yourself here](#).

Try communicating to a friend or some other person that you trust who isn't involved directly in the problem that you have. They may be able to help you figure out a way to communicate with the people that you are having trouble with or come up with an action plan.

Before you try to self-advocate, make sure that you thought through what you want to communicate.

If you're uncomfortable using verbal communication, try writing down what you want to say. Writing down what you need instead of verbally communicating it can get rid of some of the anxiety.

At times, people may not understand or agree with what you are saying. If this happens, don't get discouraged. Take a breath, take a break and stim if you need to, and then try again. You may need to reword how you are communicating your problem.

Before you try to self-advocate, make sure that you thought through what you want to communicate.

It's okay to have help: Kara's story

Kara wants to convince her workplace to change her hours to accommodate her disability. Sometimes Kara has difficulty explaining her thoughts. She asks her friend Avram to help her practice the points she will make, because he is a good public speaker.

Avram asks Kara to explain what she wants to say to her boss, so he can give her advice. But, Kara finds it hard to put her thoughts into words. Avram has trouble following what Kara is saying. So, Avram asks Kara questions to try to understand.

Kara starts over and tries to explain again. But, it is still difficult for Avram to follow along. After several tries, Kara gets overwhelmed and starts to get discouraged. She tells Avram that if she can't even figure out her thoughts, there's no way her boss will listen to her.

Avram suggests that they take a short break and then try a different approach. Kara takes a few minutes to get up and walk around the room.

While she does this, Avram gets some paper and markers for them. Avram says that instead of trying to explain everything at once, Kara can go point by point.

Together, they write an outline of Kara's points. Kara finds out that writing out her thoughts helps a lot. Once Kara has her outline, Avram helps her practice what she's going to say.

When she goes to talk to her boss, she brings her outline with her. The outline helps Kara to make her argument without getting overwhelmed.

How does this fit into my transition plan?

No one has a bigger stake in the outcome of your transition plan than you do. It is important that your transition plan is something that builds up to what you want, not what someone wants for you.

Being a young person with a disability means that decision making is complicated by sometimes limited choices, and the tendency for others to tell us what to do.

You need to be able to:

- Express your thoughts in a way that others listen to them.

- Explain why you want or need things.

- Express concerns or preferences about your options.

The transition process is a good place to start learning how to do these things, around people who you trust and who are there to support you. Learning these skills means your views will be heard and respected.

Your transition plan is also about helping you figure out who you are and who you want to become. So, it is okay to change your mind about what you want, and it does not make what you want any less valid.

No one has a bigger stake in the outcome of your transition plan than you do.

It is okay to change your mind about what you want, and it does not make what you want any less valid.

Summary

- ▶ **Self-determination** means that you get to choose how to live your own life.
- ▶ **Self-advocacy** means learning how to be in control of your own life and speaking up for your rights.
- ▶ Self-advocacy is self-determination in action.
- ▶ A **self-advocate** is somebody who does self-advocacy.
- ▶ When we are able to self-determine, we are safer from abuse, neglect, or discrimination.
- ▶ Self-determination skills are learned by practicing them. You can have a mentor to help you.
- ▶ Self-advocacy is important because people need to know what you need in order for you to succeed.
- ▶ Before you try to self-advocate, make sure that you thought through what you want to communicate.
- ▶ It's okay to change your mind about what you want.

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3

Know Your Rights



Chapter 3: Know Your Rights

Image: Three miniature people holding signs. They are standing on a page that says "civil and political rights."

“I learned a long time ago the wisest thing I can do is be on my own side, be an advocate for myself and others like me.

—Maya Angelou

What you'll learn in this chapter

- ▶ What the IDEA and IEPs are
- ▶ What FERPA is and what your rights are
- ▶ What the ADA is
- ▶ What Section 504 and 504 Plans are
- ▶ What the *Olmstead* decision is
- ▶ What the Fair Housing Act is
- ▶ How these laws apply to you
- ▶ What to do if you feel your rights have been violated
- ▶ What Protection & Advocacy agencies are and how to contact them

Key terms

- ▶ Individuals with Disabilities Education Act (IDEA)
- ▶ Individualized Education Plan (IEP)
- ▶ The Family Educational Rights and Privacy Act (FERPA)
- ▶ Section 504
- ▶ 504 Plan
- ▶ Americans with Disabilities Act
- ▶ institutions

Outline

- ▶ Overview
- ▶ Individuals with Disabilities Education Act
- ▶ The Family Educational Rights and Privacy Act
- ▶ Americans with Disabilities Act
- ▶ Section 504 of the Rehabilitation Act
- ▶ *Olmstead*
- ▶ Fair Housing Act
- ▶ Protection & Advocacy Agencies
- ▶ How does this fit in to my transition plan?
- ▶ Summary

Overview

self-advocacy

The act of speaking up for what you need and want

In this chapter, we will talk about your legal rights.

Knowing your legal rights is an important part of **self-advocacy**. It helps you get the fair treatment and respect you deserve. It is useful to know when your rights are being violated, and to know what to do in that situation.

First, we will explain the Individuals with Disabilities Education Act. We will discuss the history of the act, who it covers, and how it relates to you as a young autistic person. We'll also explain some of the important terms used in the Act.

Next, we will talk about the Americans with Disabilities Act. We'll cover what it is, how it applies to you, and what to do if you think that your rights have been violated.

After that, there is a section about the *Olmstead* decision. We'll cover how community-based services for people with disabilities became a legal requirement to stop people being unfairly put in institutions. Again, we will see how the decision applies to you, and what to do if you feel like your right to live in your community is not being respected.

We then move on to the Fair Housing Act. This Act gives you the legal right to live in a building with suitable accommodations, and to live in your house free from discrimination and harassment. We will explain which accommodations landlords have to give you as a tenant with a disability.

Last, we will talk about protection and advocacy agencies and how they can help. We will explain how you can find a P&A agency in your area.

“Disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society.

—The Individuals with Disabilities Education Act

Individuals with Disabilities Education Act

Overview

The **Individuals with Disabilities Education Act (IDEA)** is a national law. It was passed in 1975.

All U.S. public education systems must follow the rules of IDEA. Some states or cities may have their own disability education laws as well.

IDEA makes sure children and young adults with disabilities get proper services in school.

Individuals with Disabilities Education Act (IDEA)

federal law that makes sure students with disabilities get a free public education that includes the supports they need

Who is covered by IDEA?

Kids and young adults with disabilities, and their families, from age 0 to 21, are covered under IDEA. Any condition considered a disability may qualify. Part C of the law covers infants and toddlers aged 2 and under, and part B covers children and youth aged 3 to 21.

Important terms

Free and Appropriate Public Education

The U.S. government guarantees free public education. All K-12 students, disabled or not, must get a public education at no cost to their families.

IDEA also guarantees appropriate public education. This means that students with disabilities must get accommodations to make sure they can learn effectively.

IDEA makes sure children and young adults with disabilities get proper services in school.

The least restrictive environment means you are in classrooms with non-disabled students.

Least Restrictive Environment

The least restrictive environment means you are in classrooms with non-disabled students. Under IDEA, a student with a disability should be able to take the courses of the general curriculum of the school. They should also get the aid they need to perform on the level of their classmates without disabilities.

Comprehensive Evaluation

A comprehensive evaluation of disability status means that the evaluators must consider many factors. One test is not enough. A student with a disability should get accommodations according to several tests. This helps get a complete picture of your needs. It also reduces prejudice in judging disabilities. The people who make the evaluation include:

- parents
- teachers, and
- medical professionals

These people all work together.

Individualized Education Programs (IEPs)

An **IEP** is a set of educational goals for a student with a disability. This includes:

- how you learn best
- what accommodations you need
- how you can be evaluated, and
- what learning material is appropriate for you

Individualized Education Program (IEP)

A plan for how a student with a disability will get the services and supports they need in school, including specialized education

“Education is the key to unlock the golden door of freedom.

—George Washington Carver

An IEP cannot include mandatory medication. No student can be forced to take any controlled substance to get accommodations.

IEP meetings

Before you turn 16, IEP meetings don't have to include you, but they do have to include:

- Your parent/guardian

- At least one of your general education teachers

- At least one of your special education teachers

- A school district representative

- An expert to interpret your evaluation results

- An interpreter, if one is needed

Once you turn 16, you have the right to participate in your IEP meetings as a self-advocate.

For more information, check out [Understood.org's IEP resources](https://www.understood.org/en/school-learning/special-services/ieps):

<https://www.understood.org/en/school-learning/special-services/ieps>

Transition Plan

By age 14, your IEP should include a statement of your transition service needs. Transition planning must begin before you turn 16.

You have the right to be included in all meetings where postsecondary goals and transition planning are being discussed.

You have the right to see your needs, choices, and preferences reflected in your transition plan.

You have the right to see your needs, choices, and preferences reflected in your transition plan.

The Family Educational Rights and Privacy Act

What is it?

The Family Education Rights and Privacy Act (FERPA)

is a federal law that protects the privacy of student education records. FERPA lets your parents see your records from school until you:

- turn 18, or
- attend a school beyond the high school level.

When either of these things happen, you become an “eligible student.” That means the rights your parents had under FERPA transfer to you. We’ll talk about these rights on the next page.

Education records

FERPA has a specific definition of what is included as part of your “education records.” Education records are records that are directly related to a student.

These records include:

- grades
- transcripts
- class lists
- student course schedules
- health records (at the K-12 level)
- student financial information (at the postsecondary level), and
- student discipline files.

Your education records might include more information than the things on this list.

How does it apply to me?

Before you become an “eligible student,” your parents or guardians have these rights under FERPA. **They can do these things without your consent.**

Your school must give your parents the opportunity to look over your education records.

Your parents have the right to request that wrong or misleading information in your records is corrected. If the school denies that request, your parents have the right to a hearing about the denial.

If the school still doesn’t make the changes that your parents want, they have the right to add a statement to your record. This statement would have your parents’ views on what they think should be changed in the record. That statement becomes a permanent part of your educational records.

Your school can only share your records with somebody besides your parents if they give the school written permission. There are some exceptions.

For example, your school can share basic “directory” information without your parents’ consent.

“Directory” information can include:

Name	Honors and awards received
Address	
Telephone number	Dates of school attendance
Date/place of birth	

But, schools must tell parents about directory information. Your parents must be given a reasonable amount of time to request that the school not share directory information.

FERPA requires that schools notify parents of their FERPA rights every year. But, the school doesn't have to individually reach out to them. They might put the annual notification:

- in the student handbook
- in the school newspaper
- on the school website

Your rights as an “eligible student”

Once you turn 18 or start attending college, all of the rights listed above get transferred to you. You get the right to:

- see your educational records
- request corrections to your record
- ask for a hearing if the school denies your request to make corrections to your record
- add a statement to your record about what changes you think should be made
- keep your records private unless you give written consent for them to be shared

Once you're an “eligible student,” your parents no longer have the right to access your educational records.

For example, your parents can't ask your school to tell them what your grades are or what classes you're taking unless you give written consent.

But, you can sign a form giving your parents permission if you want. You can also have a parent or someone else help you in your IEP meetings.

There are still some exceptions. Your school can share your information with your parents without your consent if:

- Your parents claim you as a “dependent” on tax forms
- You have a health or safety emergency
- You’re under 21 and break a law or school policy about underage use of drugs or alcohol

Accessing your educational records

FERPA gives you the right to request a copy of your educational records. At the college level, this is usually done through the University Registrar’s office. Your school has to provide you with a copy of your records within 45 days.

FERPA also says that you have the right to ask school officials to explain or interpret any part of your educational records.

Requesting corrections

You have the right to request corrections to your educational records. You can request corrections if you believe that the information is:

- inaccurate
- misleading, or
- in violation of your privacy rights.

Usually, you will have to submit this request in writing, explaining why you think the changes should be made. Then, the school has the choice to either approve the changes or to reject them. If they reject your request, you have the right to a hearing.

Hearings

A hearing is similar to a court case. At the hearing, you will have the chance to explain and defend your request for changes to your educational record.

FERPA says that you have the right to a fair hearing. You have the right to bring and explain any evidence to support your claim.

After the hearing, the school must make its decision in writing. This decision must:

- be made within a “reasonable period of time” after the hearing
- only be based on the evidence presented at the hearing
- include a summary of the evidence
- give the reasons for the decision

The school might still decide not to make the changes you want. If that happens, FERPA gives you the right to add a statement to your educational record about

- the part of your record you wanted to change, and
- why you disagree with the decision that was made

This statement becomes a permanent part of your educational record. If the school shares your record with anybody, your statement will be included.

What do I do if I think my rights have been violated?

You have the right to file a complaint if you think your FERPA rights have been violated.

You might file a complaint if your school:

- Doesn't provide you with a copy of your educational record within 45 days after you request them

- Denies you the right to correct inaccurate information in your record

- Doesn't offer you the opportunity for a hearing about the corrections you want made

- Inappropriately discloses information about you without your consent

Complaints are filed with the Family Policy Compliance Office. Complaints must:

- be in writing

- be filed within 180 days of the incident

- be clear and to the point

- include specific information explaining how the school has violated FERPA.

You will have to fill out an official complaint form.

You can get a FERPA complaint form from the Family Policy Compliance Office by calling (202) 260-3887.

The Department of Education's FERPA guidance for eligible students is here:
<http://www2.ed.gov/policy/gen/guid/fpc/ferpa/students.html>

Americans with Disabilities Act

What is it?

Americans with Disabilities Act (ADA)

a federal civil rights law that protects people with disabilities from discrimination

“Most importantly, ADA is a landmark commandment of fundamental human morality.

It is the world's first declaration of equality for people with disabilities by any nation.

It will proclaim to America and to the world that people with disabilities are fully human

—Justin Dart, Jr.

Section 504 of the Rehabilitation Act

Section 504 makes it illegal for organizations that get money from the federal government to discriminate against anyone based on disability

The **Americans with Disabilities Act (ADA)** makes discrimination against people with disabilities illegal in:

- jobs
- transportation
- schools, and
- all public and most private spaces (except homes and some other places)

The ADA became law in 1990. It is an important piece of legislation in our country. The ADA's purpose is to make sure people with disabilities have the same rights and opportunities as everybody else.

It is based on two other laws:

- The Civil Rights Act of 1964
- Section 504 of the Rehabilitation Act of 1973

The Civil Rights Act “prohibits discrimination on the basis of race, color, religion, sex, or national origin.”

Section 504 banned disability discrimination by any organization that gets money from the federal government. This prevents exclusion and segregation of people with disabilities.

Neither of these laws were easy to make happen. It took many years to draft the ADA and have it become law. People with disabilities fought to make sure that local governments followed the new laws.

The ADA has a specific definition of who is considered disabled. The ADA only protects people who fit this definition. The definition is:

- a physical or mental impairment that substantially limits one or more major life activities
- a person who has a history or record of such an impairment, or
- a person who is perceived by others as having such an impairment.

For more information about the ADA's definition of "disabled", see this page:
<https://www.illinoislegalaid.org/legal-information/who-has-disability-under-ada>

How does it apply to me?

There are three main areas where the ADA will apply in a person's life:

- employment
- public services, and
- private institutions.

In all three areas it does not mean that you get preferential treatment over others.

Employment

As mentioned above, discrimination is not allowed. This means that a potential employer cannot deny you a job only because of your disability. The employer must offer you **reasonable accommodations** if you qualify for the position. The ADA also makes sure that you get the same wages as your co-workers. You will also get the same benefits and opportunities to advance.

reasonable accommodations

changes made to a work environment, living space, or other building to make it accessible to people with disabilities

Public services

Public services refers to transportation. The area you live needs to provide either:

paratransit

door-to-door transport service for people with disabilities who can't use fixed bus routes

- a fixed bus route, or
- special accommodations to get you where you need to go. These accommodations are known as **paratransit**.

Public transportation has to be accessible. Public transportation vehicles must have ramps or lifts for wheelchairs. These vehicles include:

- subways
- trains, and
- buses.

There are some limits to who can use paratransit. It depends on if you have special difficulty using the fixed bus route.

Disability Rights Education & Defense Fund has a webpage that explains more about how to show a transit agency that you should be able to get paratransit. That page is here:

http://dredf.org/transportation/paratransit_eligibility.html

Private institutions

The last area is private institutions. This covers a wide variety of places, including:

hotels	museums
restaurants	libraries
theaters	parks
stores	schools
gas stations	social service centers
laundromats	exercise centers
professional offices	

Anyone with a disability must be allowed to take part in an **integrated setting**. Sometimes a building can't be modified to make it accessible. In that case, the business should provide another method of delivering its service.

Example: a restaurant in a historically important building.

The restaurarant isn't allowed to convert a flight of stairs to the entrance into a ramp.

Instead, the restaurant can provide takeout out or delivery service. The restaurant could also install an accessible entrance in another location.

Accommodation options should be clearly marked. This makes it easier to find out how to use the accommodations.

All employees at the business should be trained in how to provide these accommodations.

“I strongly believe that it is important to level the playing field and give eligible individuals equal access to community-based services and supports.

This vital legislation will open the door to full participation by people with disabilities in our neighborhoods, workplaces, our economy, and our American Dream.

—Senator Tom Harkin,
on passing the ADA

integrated setting

places where people with disabilities are equal and included with people without disabilities, rather than being in a separate place

What do I do if I think my rights have been violated?

If you think your rights have been violated, you can file a complaint. You file the complaint with the U.S. Department of Justice.

There is a form at <http://www.ada.gov/complaint/>.

You can also mail, fax, or email your complaint.

You can find out where to do this here:

http://www.ada.gov/filing_complaint.htm.

Remember to supply:

- your name
- your address
- your phone number
- the name and address of the person or organization who committed the discrimination
- information on the act of discrimination
- when the discrimination happened
- documents supporting your complaint, if you have any
- how to communicate with you, such as if you need written communication or to be contacted by a TTY phone.

If you need help filing a complaint, you can contact the U.S. Department of Justice for help.

Section 504 of the Rehabilitation Act

What is it?

Section 504 is another law that protects people with disabilities. It applies to all organizations that get money from the federal government. This includes all public schools.

It is illegal for these organizations to discriminate based on disability.

Section 504 of the Rehabilitation Act

Section 504 makes it illegal for organizations that get money from the federal government to discriminate against anyone based on disability

Who is covered by Section 504?

IDEA only protects certain young people with disabilities, because it has its own definition for “child with a disability”. You have to come under one of 13 specific conditions. Many young people with disabilities do not meet its definition. But, they are still protected by Section 504.

Read more about who's covered under IDEA at [Understood.org](https://www.understood.org/en/school-learning/special-services/special-education-basics/conditions-covered-under-idea):

<https://www.understood.org/en/school-learning/special-services/special-education-basics/conditions-covered-under-idea>

If you no longer meet IDEA criteria, you may be able to get accommodations under Section 504.

504 plan

A plan for how a student with a disability will get the accommodations they need for a general education in school

“It matters not what someone is born, but what they grow to be.”

— Albus Dumbledore,
Harry Potter and the Goblet of Fire

How is Section 504 different from IDEA?

Section 504 comes under a different category of law.

It is a civil rights law. IDEA is a special education law.

This is why IDEA covers fewer people. IDEA only covers the people written into special education laws.

Your school is not required to give you an IEP under Section 504. Instead, if you are eligible, you will get a **“504 Plan.”**

A 504 plan is usually shorter and less specialized. But, it's still designed to help you.

An IEP is for students who need specialized education. A 504 plan is not. It is a plan for the supports you will need for your general education.

You can get a 504 Plan if you have a disability that interferes with your ability to learn and study, or to access school programs, even if it's not listed under IDEA's criteria.

While IDEA protects you with classroom activities, Section 504 also protects your rights outside of the school day, such as extracurricular activities, sports, and after school care.

Olmstead

What is it?

In 1999, the Supreme Court made a decision on community integration. This Supreme Court case was ***Olmstead vs L.C.***

When the Supreme Court makes a decision, it affects the laws. Supreme Court decisions can make some laws illegal. They can also clarify how the law must be followed.

Olmstead was about the **Americans with Disabilities Act (ADA)**. The ADA says that it's illegal for public entities to discriminate against people with disabilities. Public entities are:

- State governments

- Local governments

- Any departments or agencies part of these governments

The Supreme Court had to decide how the ADA applied to **institutions** run by state governments.

On the next page, we'll talk about what institutions are. Then, we'll talk about what happened in *Olmstead vs L.C.* and what it means for us today.

Olmstead vs L.C.

Supreme Court case that decided it is discrimination to force people with disabilities to live in institutions rather than their communities

Americans with Disabilities Act (ADA)

a federal civil rights law that protects people with disabilities from discrimination

institutions

places where people with disabilities live but don't have control over our own lives

institutions

places where people with disabilities live but don't have control over our own lives

What is an institution?

Institutions are places where people with disabilities live but do not have control over our own lives. They are places where we are not in the community. We don't have control over:

- where we live
- who we live with
- when and what we eat
- when we go to sleep
- if we can lock our doors
- if we can leave
- our support staff
- having access to a phone or computer
- being able to see friends or family
- our relationships

Institutions are bad for people with disabilities. Institutions take away our right to self-determination. They deny us the right to live in our communities.

The “**burrito test**” is a quick way to figure out if a place is an institution or not. Here's the test:

If you're not allowed to get up in the middle of the night to microwave a burrito, you live in an institution.

The Supreme Court case *Olmstead vs L.C.* was about the right of people with disabilities to live in our communities instead of institutions.

On the next page, we'll talk about the details of the case.

What happened?

The case centered on the treatment of two women in a Georgia state psychiatric hospital. These two women were Lois Curtis (L.C.) and Elaine Wilson.

Lois and Elaine checked themselves into the hospital. They were hoping to get appropriate treatment for their mental health and intellectual disabilities. Then, they would both leave to go home.

But, Lois and Elaine had no supports in place at home. They would end up going back to the hospital to get help. This ended up in a spiral of going home, getting ill, going to the hospital, feeling better, and then going home again.

Lois and Elaine were tired of only being able to get treatment at the hospital. So, they asked the state of Georgia for community-based treatment. Their doctors agreed that, with appropriate supports, they would be able to live in their community and not rely on the hospital.

But there were no community supports in place for Lois and Elaine. They were on a waiting list for years. Lois and Elaine were still institutionalized. Being institutionalized means that you're forced to live in an institution.

Lois Curtis filed a lawsuit. Lois demanded that she had the right to return to her community. The case reached the Supreme Court as ***Olmstead v. L.C.*** "Olmstead" was Tommy Olmstead, the Commissioner of the Georgia Department of Human Resources.

“Unnecessary segregation of persons with mental disabilities perpetuates unwarranted assumptions that such persons are unfit for or unworthy of participating in community life.

—Justice Ruth Bader Ginsburg, delivering verdict in *Olmstead vs L.C.*

Check out *OlmsteadRights'* "I Am Olmstead" stories:

<http://www.olmstead-rights.org/iamolmstead/>

Olmstead vs L.C.

Supreme Court case that decided it is discrimination to force people with disabilities to live in institutions rather than their communities

segregated

being set apart from the general population

The decision

The Supreme Court decided that the state had discriminated against Lois and Elaine. The state had **segregated** them and forced them to live in a mental health hospital. The Supreme Court ruled that Lois and Elaine should have been able to get treatment in the community.

What does the decision mean?

The conclusion reached in *Olmstead* is important. It means that the government decided that:

- People with disabilities have the right to get supports and services in their community instead of institutions, and
- that the support would be state-funded.

Even though *Olmstead* only focused on psychiatric hospitals, the decision has expanded. New court cases change the way *Olmstead* is applied. Now it includes:

- Psychiatric hospitals
- Institutions funded by states and Medicaid
- Forensic hospitals
- Nursing homes
- Some sheltered workshops
- People who live in the community, but might be forced into an institution

“The *Olmstead* ruling was a critical step forward for our nation, articulating one of the most fundamental rights of Americans with disabilities: Having the choice to live independently...

I am proud to launch this initiative [“The Year of Community Living”] to reaffirm my Administration’s commitment to vigorous enforcement of civil rights for Americans with disabilities and to ensuring the fullest inclusion of all people in the life of our nation.”

—President Barack Obama,
remarks on anniversary of *Olmstead*

There are three requirements for Olmstead to apply:

1. Your treatment professionals determine that community supports are appropriate
2. You do not object to living in the community, and
3. Getting services in the community would be a reasonable accommodation.

States have to pay for these accommodations. If you needed a wheelchair ramp built to a public building, the state can't make you pay for it.

The Civil Rights Division of the U.S. Department of Justice (DoJ) made enforcing Olmstead a priority in 2009. That means the DoJ is getting tougher on state governments that are not doing the best that they can for people with disabilities.

The Department of Justice is getting tougher on state governments that are not doing the best that they can for people with disabilities.

How does it apply to me?

When making your transition plan, you have to figure out what supports and services you will need. People with disabilities have the right to live and get supports in our communities.

Olmstead means you have more control over your life. You won't be forced into an institution. Your state has programs that help you to live in the community.

For more information, check out [OlmsteadRights.org](http://www.olmsteadrights.org)'s [How Olmstead May Assist You to Live in the Community](http://www.olmsteadrights.org) quiz:

<http://www.olmsteadrights.org/self-helptools/assessment/>

What do I do if I think my rights have been violated?

Protection & Advocacy (P&A) agencies

State-level organizations that protect the rights of people with disabilities

You can file a complaint on the website here:

www.ada.gov/filing_complaint.htm. You can also mail, fax, or email your complaint.

Each state has a **Protection and Advocacy agency (P&A)**.

The P&As provide advocacy and legal services to people with disabilities. You might want to contact a P&A if:

- you need a lawyer, or
- you're seeking legal advice

You can find a full list of Protection and Advocacy agencies at <http://www.acl.gov/programs/aidd/Programs/PA/Contacts.aspx>.

Fair Housing Act

Fair Housing Act

a federal law that protects people buying or renting property from discrimination

The **Fair Housing Act** (FHA) is a law that makes sure everyone can rent housing. It prevents housing discrimination against protected classes of people. People with disabilities are a protected class under the FHA.

How does it apply to me?

reasonable accommodations

changes made to a work environment, living space, or other building to make it accessible to people with disabilities

- You can't be turned down for housing or kicked out because of your disability.
- Your landlord has to allow certain changes to your living space. These changes are **reasonable accommodations**.
- You can't be turned down for housing because you might need accommodations.

What is a reasonable accommodation?

A **reasonable accommodation** is a change made so that people with disabilities can use a house or common space. This could be a change in:

- rules
- policies
- practices, or
- services

For example, even buildings with no-pet rules have to let people keep service animals. Also, a landlord would have to let someone put in grab bars for the bathtub.

reasonable accommodations

changes made to a work environment, living space, or other building to make it accessible to people with disabilities

Wheelchair access

Under the FHA, certain buildings have to be completely accessible to wheelchair users. This includes any building:

- Built after 1991
- That has at least four apartments, and
- That has an elevator.

Accessibility for wheelchair users means that:

- Hallways and doorways are wide enough for wheelchairs
- Wheelchairs can get into the building using ramps
- Light switches and thermostats can be reached from a wheelchair height.

“Never be afraid to raise your voice for honesty and truth and compassion against injustice and lying and greed.

If people all over the world...would do this, it would change the earth.

—William Faulkner

What do I do if I think my rights have been violated?

Go to http://portal.hud.gov/hudportal/HUD?src=/topics/housing_discrimination and fill out the complaint form.

You'll need to give them:

- your name and address
- the name and address of the person you're complaining about
- the address of the building that had the problem
- an explanation of the problem, and
- the date the problem happened. Send the form to your local HUD (Housing and Urban Development) office. You can also call that office directly.

Protection & Advocacy Agencies

What do they do?

Protection and Advocacy (P&A) agencies provide advocacy services such as:

- legal representation
- monitoring conditions in group homes and other institutions,
- ensuring access to inclusive education
- making sure health care services are accessible
- helping find accessible housing, and
- help with employment.

Protection & Advocacy (P&A) agencies

State-level organizations that protect the rights of people with disabilities

How can I find a P&A agency?

First, go to <http://www.ndrn.org/ndrn-member-agencies.html>.

On the sidebar, click on your state. This will take you to a page with the contact information for your state's P&A organizations.

It will usually include a phone number and email address. Contact them at one or both of these addresses, or have someone you trust do it for you.

How does this fit into my transition plan?

self-advocate

The action of speaking up for your own wants and needs

The more informed you are of your rights, the better you can self-advocate.

To **self-advocate**, you need to know what your rights are, so that you can stand up for them.

The more informed you are of your rights, the better you can self-advocate.

For example, if you get denied medical treatment by a doctor, knowing that you have the right to that treatment can help you to fight for it. Then, knowing you have the right to a second opinion from another doctor, you can ask for one.

For another example, knowing you have the right to live with suitable accommodations and supports in your house can make it much easier to live there. If you need something you don't have in your house, being able to contact the landlord and request it means knowing that you have the right to that support.

If you find it hard to understand what rights you have or who to contact when your rights aren't respected, you can put that in your transition plan, too.

- Who do I complain to if someone is discriminating against me at work?
- What are the signs of someone discriminating against me?
- What should I say if a police officer starts asking me questions?

Try making a list of all the things you know that you need and have the right to. Then, underneath each example, write down what to do or who to contact if that right is not respected, or you are stopped from exercising it.

Summary

- ▶ You are entitled to get community-based support and not be put in an institution.
- ▶ You have the right to vote, and to vote for whichever candidate you like best.
- ▶ You have the right to accommodations and supports that you need in your home.
- ▶ In education, you have the right to accommodations that mean you can study effectively.
- ▶ You have the right to not be abused or controlled.
- ▶ You have the right to be treated like everyone else at your job.
- ▶ You are not expected to intensively study the law. You do not need to know extremely specific examples of what you can legally do. You just need to know how to access the things you need, and live free from harassment, discomfort, or a person or institution having unfair control over you.
- ▶ If you're unsure - in most cases where knowledge of your rights is an issue, you will be able to get legal help. Much of this chapter is a guide to which people can inform you of, and fight for, your legal rights.

There are many resources in the appendix of this book to help you understand your basic rights, and all of the links provided above.

4

Making Your Transition Plan



Image: Two miniature people walking across a monthly calendar.

“A goal without a plan is just a wish.

—Antoine de Saint-Exupéry

What you'll learn in this chapter

- ▶ What transition planning means
- ▶ How to start transition planning
- ▶ What transition assessments are and how you can do them
- ▶ How to write good transition goals
- ▶ What transition services are and how to get them
- ▶ How to keep all the documents related to your transition organized

Key terms

- ▶ Individuals with Disabilities Education Act (IDEA)
- ▶ Individualized Education Program (IEP)
- ▶ vocational rehabilitation
- ▶ transition services

Outline

- ▶ Overview
- ▶ What is transition planning?
- ▶ IEPs & transition planning
- ▶ What if I didn't have an IEP?
- ▶ Your transition planning notebook
- ▶ Step 1: Transition assessments
- ▶ Step 2: Creating measurable postsecondary goals
- ▶ Step 3: Identifying transition services
- ▶ Step 4: Write the course of study
- ▶ Summary

Overview

This chapter is a detailed guide to making a transition plan to adulthood. The path to becoming an independent adult requires lots of planning. This chapter will give you a guideline to make that easier.

First, we will look at all of the usual transition steps you would go through with an Individualized Education Program. Then, we'll show you how to make a transition plan that is similar to one you would get if you had an IEP.

We will show you how to gather and store information about yourself to build a picture of what your future might look like. You will also learn how to set goals, and how to know if you are progressing with those goals.

Throughout the chapter, we will follow the story of Nikki, a young autistic person who is transitioning to adulthood. We will show how Nikki figures out the things she is good at and enjoys. Then, we will show how she uses that information to decide what she wants to do in the future. Nikki figures out the supports she needs, and the skills she needs to learn, to achieve her goals.

Meet Nikki

Nikki is a high school student. She is autistic. She has sensory needs, and finds it hard to perform some **activities of daily living**, like brushing her teeth and feeding herself.

Right now she lives at home with her mother, who takes care of her. She provides emotional and financial support for Nikki. She also prepares Nikki's food and does her laundry.

What is transition planning?

Creating your vision for the future

Transition planning helps you create your vision for the kind of future you want to have after you leave school. Maybe you want to go to college. Maybe you have a specific job you want to get. Maybe there's somewhere you want to move to.

Transition planning is all about figuring out:

- What goals you want to accomplish in your life
- How you're going to achieve those goals

Maybe you don't know **what** you want to do after you leave school. That's okay! Transition planning is also a way to learn more about the options you have after graduating, such as:

- Continuing your education
- Learning professional skills
- Getting a job alongside people without disabilities
- Getting new support services
- Living independently
- Participating in your community

At the end of transition planning, you will have a detailed transition plan. Your transition plan includes details about the services and supports you will need.

“Without leaps of imagination or dreaming, we lose the excitement of possibilities.
Dreaming, after all is a form of planning.

—Gloria Steinem

Nikki's transition assessment portfolio

Now that Nikki is becoming a young adult, her mother tells her she needs to start thinking about what she wants to do when she graduates.

Nikki doesn't know what she wants to do. So her mother tells her to make a list of the things she's good at, enjoys doing, and what types of work she prefers doing.

Nikki's mom calls this a "transition assessment portfolio."

To help fill it in, Nikki should explore different interests to discover her strengths. She should think about doing some extracurricular activities or some new hobbies.

IDEA's definition

Individuals with Disabilities Education Act (IDEA)

federal law that makes sure students with disabilities get a free public education that includes the supports they need

IDEA has a specific definition for "transition planning."

According to the IDEA, transition planning for a student with a disability is:

- Based on your individual needs, strengths, preferences, and interests
- A process to make a plan of supports, services, and goals that all work together
- Focused on improving your skills in school subjects and activities of daily life (ADLs) to make your transition easier

IEPs and Transition Planning

Transition planning is part of your **IEP**. IDEA lays out a lot of specific legal requirements for your IEP transition plan. The main focus is on coming up with what **goals** you want to achieve.

Individualized Education Program (IEP)

A plan for how a student with a disability will get the services and supports they need in school, including specialized education

What the law says

According to the IDEA, your IEP transition plan must be based on four things:

1. Age-appropriate transition assessments
2. Measurable post-secondary goals
3. Transition services
4. Courses of study

Let's break these down.

Age-appropriate transition assessments

What does it mean?

"Assessments" are ways to gather information about you. Transition assessments are different ways of collecting information about your:

Needs

Preferences

Strengths

Interests

"Age-appropriate" just means that the kinds of assessments make sense for your age.

For example, figuring out whether or not you'll be able to drive is a kind of assessment. But, it's not an assessment you would do when you were 12 years old. That wouldn't be age-appropriate.

What kinds of transition assessments are there?

There are lots of different transition assessments. If you've taken a standardized test in school, that's an assessment. If you've filled out a list of questions to figure out what kind of career you might be interested in, that's a transition assessment too!

Some transition assessments are more informal. These aren't based on your answers to a list of questions. Informal transition assessments might be things that your parents or teachers have noticed about you.

Nikki's informal assessment

Nikki knows she's good at detail work. Sometimes she takes her lunch period to help the school librarian, Ms. Miller, file books. This lets her use that skill.

While working in the library, Ms. Miller points out she is also good at creating displays. The library now has bright but informative bulletin boards and fun displays highlighting the non-fiction section.

What can I learn from my transition assessments?

Overall, your assessment results will give you a better idea of your needs, strengths, preferences, and interests. More specifically, you might learn more about your:

- Academic skills
- Learning style
- Communication preferences
- Physical strengths
- Social skills
- Career interests
- Independent living skills
- Ability to self-advocate

Everything you learn from transition assessments helps you and your IEP team develop your post-secondary goals.

Measurable post-secondary goals

What does it mean?

Your goals are what you want to achieve in life. “Post-secondary” means after high school. “Measurable” means breaking your goal down into steps you can measure, like a timeline. It means there is a way to see if you are making progress towards your goal.

So all together, measurable post-secondary goals are:

What you want to achieve after high school

Written in a way that makes it easy to see if you’re getting closer to your goals

We’ll go more in-depth on how to write measurable goals later in this chapter.

Your goals are what you want to achieve in life.

What kinds of goals should I set?

There are three main categories of goals to write in your transition plan. These are:

1. Education
2. Employment
3. Independent living

This divide helps you to focus on the different areas of your life, instead of putting all of your energy into just one area.

We’ll come back to setting goals in each area of your life later on in the chapter. There are also suggested goals in all of the content chapters.

Once you’ve got your goals, the next step is to identify transition services.

“What keeps me going is goals.

—Muhammad Ali

transition services

activities that help you develop the skills you'll need to live independently

Transition services

Transition services are activities that help you develop the skills you'll need to be an independent adult.

You and your team have to figure out what transition services you'll need to prepare for achieving your goals.

So, transition services are the different kinds of activities or supports you'll need to get ready for education/training, employment, and independent living.

The last part is the course of study.

Course of study

What is it?

Your course of study is a multi-year education plan. It shows what you're going to do while you're still in school to start working towards your goals.

What's included in the course of study?

Your course of study might look sort of like a class schedule for the rest of the time you're in school. You'll make a plan for what classes you'll take each year that will:

- Make sure you meet your school's graduation requirements
- Help you learn more about subjects related to your goals for college or employment
- Help you develop important life skills

What if I didn't have an IEP?

You can still make a transition plan! In this chapter, we'll show you how to make a transition plan that is similar to one you would get if you had an IEP. But, your transition plan doesn't have to follow the exact same format.

Whether you had an IEP or not, your transition plan should include:

- What your adulthood goals are, and
- What services and activities you'll need along the way to help you prepare.
- How you're going to get those services and take part in those activities

In the rest of this chapter, we will make a parallel of the IEP plan. We will explain all of the steps you'll need to go through with your transition plan, just like you would with an IEP.

Your Transition Planning Notebook

What is it?

Your transition planning notebook or portfolio is the place where you keep all the information related to your transition. This is where you collect and store everything you learn about your strengths, your needs, and your interests.

You use it to write down your goals, so you can come back to them later and see how far you've come.

You can use it to record more formal achievements, like any honors or awards you got from school. Plus, you can use it to store useful information about the supports you might need, and handy resources and links.

As you can tell, there are going to be a lot of important things in your notebook!

- The best way to store everything is by getting a 3-ring binder. That way, you can easily sort things into order. And if you want to change the order, you can simply open the rings and switch things around.
- Use something with a hard cover, so that none of your documents get bent, ripped or damaged by water.

Why should I keep one?

Your notebook will be very useful if you apply to post-secondary education or adult services, or apply for a job. It's great for keeping track of which of your transition goals have been completed, like a really cool to-do list. It can give you a great rewarding feeling to see evidence that you are progressing and working towards your goals.

It provides a way to keep all of your career development and transition related information in one place, regardless of who gathered it.

A notebook helps to build a picture of your interests, strengths, abilities and needs.

Managing your own notebook is a great way to learn and practice self-advocacy, self-determination and organizational skills.

When you move from grade to grade, or if you move to another school, the notebook would give your new teacher a record of what has been done, and what the next steps would be. That way, they don't have to start over from the beginning.

The notebook would be useful when you're being referred to an adult agency. They might want certain documents to make sure you're eligible, and they can also help you work on your transition.

A notebook would allow someone in your support network to see how your other supporters are helping to prepare you for adulthood. That way, if anything is being overlooked, it can be easily picked up on.

How should I organize it?

- ▶ You can organize it into either 8 or 5 categories, so you can use a standard set of tabbed binder dividers.
 - You can get these from most office supply stores.
- ▶ You can do whatever works best for you, but we recommend this way.



8 Tabs

Tab 1: Personal Information

This section might include:

- A list of information about you (name, date of birth, address, etc.)
- A copy of your state ID and/or Social Security Card
- Your transition planning worksheets
- Student questionnaires

Tab 2: Education

This section might include:

- Your transition plan goals
- Learning styles inventories
- Information about your post-secondary education options
- Any school awards or honors
- A course planning worksheet

Tab 3: Career

This section might include:

Information about what careers you're interested in

Skills inventories

Sample resumes

Letters of recommendation

Summaries of any job shadowing or work experience you've done

Information about **vocational rehabilitation** programs

vocational rehabilitation

A process that helps people with disabilities overcome barriers to finding and keeping jobs

Tab 4: Community/Independent Living

This section might include:

Independent living skills inventories

Summaries of community experiences

Activities of daily living worksheets

Tab 5: Adult Service Agencies

This section should have information about different state agencies that will provide transition services and adulthood services. It could include:

list of state agencies and what they do

summaries of any meetings with agency representatives

copies of printed materials from agencies

[agency planning charts](#)

**augmentative
and alternative
communication (AAC)**

any way of
communicating that
doesn't involve speaking
out loud

Tab 6: Communication/Social Interaction

This section might include:

- copies of handouts you can give people to tell them about your communication preferences
- information about any **AAC** tools you use
- helpful scripts to use in different social situations

Tab 7: Recreation and Leisure

This section might include:

- information about local recreational facilities
- list of any community classes or activities you've participated in
- interest worksheets

Tab 8: Other

This section could include any information that you want to save that doesn't fit in any of the other categories.

**5 Tabs**

Alternatively, you could organize your transition notebook into five tabs:

- **Tab 1:** Personal Information
- **Tab 2:** Education
- **Tab 3:** Career
- **Tab 4:** Community/Independent Living/Agencies
- **Tab 5:** Communication/Social/Recreation

As you go through the steps in this chapter, you can gradually build up your transition notebook.

Step 1: Transition Assessments

What are they?

Transition assessments are a way to figure out your:

- Needs
- Preferences
- Strengths
- Interests

But you don't just figure these out one at a time! All the transition assessments you do work together to help you figure out all four of these areas.

How can I do them?

You might not have access to the same tests and assessments that your school does. But, there are different ways that you can do your own assessments. There are four main ways that you can gather information and learn more about your needs, strengths, preferences, and interests. These are:

1. **Making lists** of what you already know about yourself
2. **Asking people** who know you, and who you trust, to tell you what they think you are good at, and what they think you might need support with
3. Filling out **tests or worksheets** (for example, a test that tells you different careers you might be interested in or what your learning style is based on how you answer the questions)
4. Your own **experiences**, like trying out a new hobby, or practicing budgeting money

We'll talk more about each one of these in the next few sections.

Your transition plan is all about you.

Making lists

Why should I do it?

Your transition plan is all about you. There are probably some things you already know about your needs, strengths, preferences, and interests. You might already know that planning a fun day out is a strength of yours, or that budgeting is something you'll need to learn how to do. You may not have to spend a lot of time figuring out what you already know about yourself.

How can I do it?

Here are some questions you can think about and write the answers to if you get stuck.

Needs

- ▶ What do you wish you could hire somebody to do for you?
- ▶ What are some tasks you know that you ought to do, but don't want to?
- ▶ What are some things you wish you knew more about?
- ▶ What are some hobbies or activities you want to learn how to do?

Strengths

- ▶ What subjects am I good at in school?
- ▶ What are some things I often do for friends or family because they're easier for me than they are for other people?
- ▶ What have you done that you're proud of?
- ▶ What do you wish you could get paid to do?

Preferences

- ▶ Think about your favorite teachers or classes. Why do you like them better than others?
- ▶ If you ruled the world, what kinds of changes would you make?
- ▶ What things really get on your nerves?
- ▶ What would your dream house look like?

Interests

- ▶ What would you do if you had more time?
- ▶ Do you have any special interests?
- ▶ What do you like to do when you have free time?
- ▶ What are some things you absolutely want to do before you die?

How can I add this to my notebook?

You can add the lists that you make to your transition planning notebook. But, the answers you write down might not be straightforward, or maybe they're messy. It might be helpful to go through the lists you've made and try to clean them up.

You might need to sit and think for a while about how your answers show your needs, strengths, preferences, and interests.

Nikki makes a list to help figure out her needs

Nikki decides to take some time making lists in her notebook. She starts with "What do you wish you could hire somebody to do?" Nikki gives this some thought. She writes down some things she really struggles with.

I wish I could hire someone to...

- Budget my money
- Go grocery shopping for me

This helps Nikki figure out what her needs might be. She makes sure to tell her transition team about the lists she writes.

Asking people

Why should I do it?

There are some things that other people might notice about you that you don't notice.

There are some things that other people might notice about you that you don't notice. Maybe you're really good at something that wouldn't be written on your report card. Maybe you struggle with something you didn't realize you could get help with. Asking other people for their input can give you another perspective.

How can I do it?

Picking the right people

You'll get more helpful information from some people than you would from others. You should talk to people who:

- **Know you well.** For example, a teacher you've had for many classes, family members, or friends you've had for a long time.
- **Come from different areas of your life.** For example, your classmates at school will have a different perspective than the people you know from your after-school karate lessons.
- **Are honest and trustworthy.** It might be nice to hear someone tell you that you're good at everything, but that won't be very helpful for transition planning.

Nikki chooses people to ask about herself

Nikki makes a list of people who know her well. Her list includes:

- ▶ The school librarian, Ms. Miller
- ▶ Her older sister, Gloria, who is already at college
- ▶ Her biology teacher, Mr. Stickler, who also sponsors the Science Olympiad team Nikki is a part of

These are people Nikki knows she can trust and ask for help. They have known her for long enough to know what she is good at and what she needs extra help with.

What should I ask?

You can start by telling the person that you're trying to figure out your needs, strengths, preferences, and interests. People who know you well might have several things that they can tell you off the top of their heads.

If you need some prompts, here are a few questions you could ask:

- What am I good at?
- What activities do I seem happiest while doing them?
- What words would you use to describe me?
- What things do I get excited about?
- What kind of job do you think I would be good at? Why?
- Let's say that there's a machine that can summon anybody in the world by putting in 5 objects that represent the person. What 5 things would you put in to summon me?

How can I add this to my notebook?

You can take notes on what answers you get. It can be helpful to record the conversation you have so you can get all of the details later. Or, you can have the people you ask write down (or type) the answers to specific questions.

You can make up a worksheet for them to fill out.

Regardless of how you get the written information, there are a few key things you should be sure to include:

- The name of the person you talked to
- How you know them
- The date you talked to them

It can also be helpful to go through and make a note of anything new you learned that you didn't know about yourself, and anything people said that you had included in the lists you made before.

Nikki adds to her transition notebook

Nikki loves dinosaurs. She also really enjoys spending a long time working on the detail of things. She decides to ask her biology teacher, Mr. Stickler, what he sees as her strengths. She also asks him what kinds of jobs he thinks she might like.

Mr. Stickler mentions that Nikki always does really well at the Earth Science events in the Science Olympiad. He tells her about many different Earth Science careers, like oceanographer or paleontologist.

Nikki writes all of these careers down so that she can research them later. She adds the notes to the "Career" tab of her notebook.

Tests and worksheets

Why should I do it?

Filling out tests and worksheets can help you learn things you didn't realize about yourself that other people might not be able to see either. Also, the answers you got from yourself and other people might not answer specific questions you have.

There are tests and worksheets that have a specific purpose. You could take a test that will ask you about different situations or tasks and then give you a list of careers you might be well-suited for. You could fill out a worksheet that will help you better understand what your learning style is. Or, you could take more general personality tests.

You might already have some results from tests you took in school. You can add those in with other test results, and then look for patterns in the kinds of results you got.

How can I do it?

There are a lot of tests and worksheets online. Some of them are free, and some of them make you pay for your full results. You can start by asking your school guidance counselor about any online test tools that they can recommend.

Seattle University also has a collection of different transition assessments here:

<https://www.seattleu.edu/ccts/resources/assessment/>

Not all the tests you'll find online are based on science, especially personality tests. Some are just for fun. But, they can still be a starting point for thinking more about yourself.

The main scientific personality test is called the "IPIP Big Five" test. There are multiple versions available for free online.

You can find online tests and worksheets by doing a search using common key words, like:

- Assessment tool
- Inventory
- Career strengths
- Self-assessment

How can I add this to my notebook?

One of the big benefits to using online tests and worksheets is that you don't have to re-write the information. You can print out your results from a test, or add a completed worksheet to your notebook.

In addition to the **date** you did the assessment, you should also include a **link to the webpage** you got it from. This is important because you might want to go back and re-take the exact same assessment. Or, you might want to look up how reliable the test results are from a certain site.

Learning from experience

Why should I do it?

There are some things we only find out about ourselves through actually trying to do a task. This especially applies to figuring out your needs and preferences. Something that sounds easy or enjoyable on paper might turn out to be completely different once you actually do it. It's better to find those things out sooner rather than later. That way, you have more time to make plans so that you don't end up stuck in a difficult life situation that makes you miserable. It's a lot harder to dig yourself out of a hole than it is to avoid it in the first place.

Something that sounds easy or enjoyable on paper might turn out to be completely different once you actually do it.

How can I do it?

First, you'll need to identify a type of skill that you'll have to do as part of everyday independent living. This could be for a particular kind of job you think you might like to do. Or, it could be something like grocery shopping or taking public transportation.

- ▶ This is probably something you've had support with when you were young, but you need to try to do it on your own (to the extent that you are able), and then assess how well it goes. You'll need to write down which parts you found hard and which parts you felt you were good at.
- ▶ A good place to start is to watch how someone else does that thing. You could try making a shopping list with someone else and then going shopping together, or taking the bus somewhere with a friend, or helping someone else to pack for a trip. That way, you can see someone else's process, and it won't seem as scary or alien when you do it yourself.

Job skills

For job skills, you can ask your guidance counselor or do your own research to find **“job tryout”** or **“job shadowing”** opportunities. These experiences will let you see what it will be like working in the actual place of employment.

If there aren't any programs like that near you, you still have options. Try reading interviews on JobShadow.com about different aspects of a career. Or, you can work with your transition team to set up a simulation of some of the important job conditions.

For example, if you want to be a barista at a coffee shop, you could have friends and family members give you specific “orders” to make, or you could practice making change.

What now?

At the end of all this, you should have lots of information about your skills, interests and needs. The next step is for you and your team to look at all of this information together. You can start to identify patterns about yourself, and talk about what you think you might want to do after high school, jobs or education-wise. You should talk about what kinds of needs you'd have for the options you chose. This includes talking about the independent living skills you need to work on, or get support in.

Then, you can take what you have discussed and learned, and use them to set smaller, measurable, manageable goals for yourself.

All of this takes time. Remember, these are decisions about the rest of your adult life. They require time, careful planning and patience.

Nikki starts to create a vision for the future

After she talked with Mr. Stickler, Nikki did a lot of reading about paleontology online. Nikki has decided that she wants to get a degree so that she can be a paleontologist.

She would also like to attend field schools in the summer. Field schools are a chance for paleontologists to get experience on the ground before they finish their degrees.

She tells Mr. Stickler about her decision to become a paleontologist. She tells him she wants to get a degree and go to field schools, and eventually work in a museum.

Mr. Stickler tells Nikki he will email his paleontologist friend, Dr. Eugene Crawford. He will ask Dr. Crawford if he wouldn't mind talking to Nikki about what it's like to be a paleontologist. Dr. Crawford emails Nikki a couple of days later and describes his job and how he got there.

Learning about Dr. Crawford's experience makes Nikki realize she might struggle with certain aspects of being a paleontologist.

For example, she would have to study a lot of math. Nikki didn't realize how much math you have to use as a paleontologist!

Nikki tells her transition team about her goal to become a paleontologist. But, she also mentions the things that she is worried about. She is worried that she isn't cut out to be a paleontologist.

Nikki's transition team tells her not to give up just yet. They'll work together to make goals to help Nikki get closer to her dream. And, to make sure she has the supports she'll need along the way.

Step 2: Creating measurable postsecondary goals

Goals in a transition plan need to be measurable.

What does it mean?

The most important part of your transition plan is your post-secondary goals. These are the things that you are planning to do after high school (also known as “secondary school”). Goals in a transition plan need to be measurable. A measurable goal is one that you know whether you have reached it or not.

Using your transition assessment portfolio

Your post-secondary goals will be based on everything you’ve collected in your portfolio so far. So if you have identified a need, your next step will be to write a goal for how you’re going to get that need.

The goal-writing process

Goal-writing takes time

It can be hard to write good goals, or know exactly what all your specific goals are going to be! It’s okay if you start out with very generalized goals, and then gradually refine them to be more specific. Unless you know exactly what you want to do, this is probably what will happen.

Additionally, let’s say you set one big goal, and then you figure out all the smaller goals you’ll have to do between now and then to get it. It’s still okay to change your mind and set a completely different goal instead. You don’t need to have your whole life decided right now! That’s the whole point of this process.

Goals aren't set in stone

In an IEP plan, you have to write annual IEP goals. These are the yearly, smaller goals that help you build towards your larger goals. Every year, you look at these goals, see how far you've come, and then set yourself new goals. You should try to write goals like this in your plan. They should be at least yearly. But, they can also be more frequent than that.

One of your goals might turn out to be a lot more than you can accomplish in the timeframe you've set. When it comes time to review your progress towards your goals, it's perfectly fine to revisit them and adjust them. Your dreams might not seem to match up to your goals, and that's okay - your goals are just the checkpoints along the way to your bigger dreams.

What might a transition goal look like?

Here's an example goal:

After graduation from high school, Nikki will enroll at Harold Washington College (a community college) and take a library science class to improve their work-related categorizing skills and to advance her career in paleontology. Nikki knows that this will be an important skill to have in the off season.

What makes it a good goal:

Enrolling in the course at a community college is the focus of the goal.

The goal fits with Nikki's other goal to become a paleontologist.

The goal reflects Nikki's strengths in detail work.

Here's a bad example of a goal:

Nikki plans to apply to Harold Washington College.

What makes it a bad goal:

The goal is **not measurable**. With this goal, we don't know:

- When Nikki will apply
- If Nikki actually intends to go to college
- What she plans to study
- How it ties in to her other transition goals.

Once you've got your goals set, it's time to break them down. What are the steps you need to take along the way to reach your goal? How will you measure progress?

You can write SMART goals to make a plan for how you'll get closer to your main goal starting right now.

Setting SMART Goals

The goals you set for yourself should be SMART goals.

SMART is an acronym that stands for

- **S**pecific
- **M**easurable
- **A**ttainable
- **R**elevant
- **T**ime-bound

Let's look at what each one of these means.

Specific

For a goal to be specific, it has to be clear. What exactly do you want to do?

Non-specific: I want to learn to play music.

- What kind of music?
- What instrument?

Specific: I want to learn to play I Think I Need A New Heart by The Magnetic Fields on the ukelele.

Measurable

For a goal to be measurable, you have to be able to tell how you're making progress. You also have to know when you'll have met the goal.

The example goal from above is specific, but it's not measurable: it doesn't show how you'll know you're making progress.

To make the goal more measurable, you could add:

- I will get a ukulele.
- I will sign up for ukulele lessons twice a week.
- I will learn all the songs in the beginner's song book.

Attainable

Is your goal realistic? Is it actually possible? For example, let's say you added "I will practice the ukulele every day for 10 hours a day." That isn't realistic. There will be days when you have other responsibilities. You would burn out fast if you tried to practice for that long every day. You could get tired or bored.

When you set unattainable goals, it's easy to get discouraged.

To make this goal attainable, you could instead say that you will practice for a half hour every day. Or, that you will practice for at least 5 hours each week.

This gives you more flexibility. That makes it more likely that you'll be able to meet your goal.

Relevant

Does this goal relate to your needs, strengths, preferences, and interests? Does it make sense as a goal for you during transition?

Remember, these are the goals you want to reach as you become an adult. Goals like "I want to retire to the Bahamas when I'm 70" or "I want to own a pet monkey named Marcel" are not immediately relevant to how you're going to:

- Get a job you like
- Learn the daily life skills you need
- Access health care, or
- Other aspects of adult life

Before you can retire to the Bahamas with your pet monkey and ukulele, you'll need to figure out how you're going to learn the skills you need to get the job you want so you can afford to do the other things you want to do in life.

Time-bound

Finally, your goals need to be time-bound. Our example goal still doesn't say when we want or need to do it by. "I'm going to sign up for ukulele lessons." By when? Will you sign up for them by August 15th? Will you sign up for them before the school year starts?

Without adding a time-frame, your goals will be open-ended. When your goals are open-ended, it's hard to make a plan for really accomplishing them.

You can add a blank calendar inside your transition notebook and write on it. This will help you keep track of starting and completing your goals.

Now you've got:

- Goals for adult life

- Sub-goals to build towards your main goals

What if I need help?

Remember, your transition team is there to help you make this plan. You can ask the members of your team or your high school guidance counselor to help you refine your goals.

*Take a look through **Chapter 6: Supported Decision-Making** for more information on getting help with your planning.*

There are also lots of resources online specifically designed to help you with writing postsecondary goals. These are usually found on websites about IEP transition planning. But, you can still follow these guides even without an IEP. You can find these resources in the Chapter 4 section of the Appendix at the end of this book.

Step 3: Identifying transition services

What does it mean?

Transition services are activities that help you develop the skills you'll need to be an independent adult. You and your team have to figure out what transition services you'll need to prepare for achieving your goals. So, transition services are the different kinds of activities or supports you'll need to get ready for education/training, employment, and independent living.

For more information on planning your supports, see Chapter 5.

Individuals with Disabilities Education Act (IDEA)

federal law that makes sure students with disabilities get a free public education that includes the supports they need

According to **IDEA**, your transition service plan might include some or all of these:

1. Instruction
2. Related services
3. Community experiences
4. Employment or other post-school adult living goals
5. Daily living skills and a vocational evaluation

Let's go through what each of these means.

Instruction

“Instruction” is a transition service that means anything that you need to learn in order to reach your goals. Here are some examples of instruction that you might include in your transition services plan:

- Learn money management skills

- Take specific classes in school

- Learn how to drive a car

- Research colleges or careers

Related services

“Related services” are the supports you need to access work, school, and independent living environments. Maybe you need counseling services or speech therapy, and you need to include in your plan how you will get these things in the future.

Here are some examples of related services that you might include in your transition services plan:

- Get new equipment for the future (like wheelchairs or communication devices)

- Find community health centers to work with

- Visit therapy providers that you could use after you graduate

- Finding people who can support you at college or a job

Figuring out your “related services” might include getting in contact with specific agencies that will support you after you graduate. That information should be included in your plan.

Community experiences

“Community experiences” are activities that happen outside of school. They might have to do with exploring options for jobs, going to college, or transitioning to independent living.

Here are some examples of community experiences that you might include in your transition services plan:

- Touring colleges you might like to go to
- Practicing using public transportation
- Looking at apartments or other housing
- Participating in an internship where you learn more about a job

Employment or other adult living goals

Transition services related to “employment” and other “adult living goals” are services that center on helping you develop the skills you need to participate in adult life. Employment transition services are services that will help you to find a job, but this part of your plan can include many areas!

Here are some examples of employment or other adult living goals that you might include in your transition services plan:

- Opening your own bank account
- Applying to colleges
- Practicing interviewing for jobs
- Registering to vote and learning about how to vote

Daily living skills and a functional vocational evaluation

Daily living skills are the basic skills you will need in your everyday adult life, like paying bills, taking care of personal hygiene, and feeding yourself.

Here are some examples of daily living skills that you might include in your transition services plan:

- Taking cooking classes
- Learn how to use a washer and dryer for laundry
- Managing a daily schedule
- Learning how to manage your own medication

You might need supports in some areas of daily living skills. This is where the “functional vocational evaluation” comes in. A “functional vocational evaluation” is a process to figure out which of these areas you will need support in. One way that your support needs can be determined in a functional vocational evaluation is by practicing actually doing these activities.

Who provides transition services?

There are different state agencies that might be involved in providing you with transition services. Since each state has its own set of agencies, you’ll have to do some research to find out:

- What agencies your state has
- What programs those agencies have
- How to get involved with these agencies

A good starting point would be to search for “[your state] Department of Human Services” or “[your state] disability services.”

Step 4: Write the course of study

What does it mean?

Your course of study is a multi-year education plan. It shows what you’re going to do while you’re still in school to start working towards your goals.

What's included in the course of study?

Your course of study might look sort of like a class schedule for the rest of the time you’re in school. You’ll make a plan for what classes you’ll take each year that will:

- Make sure you meet your school’s graduation requirements
- Help you learn more about subjects related to your goals for college or employment
- Help you develop important life skills.

Nikki's course of study			
Freshman	Sophomore	Junior	Senior
Algebra 1	Geometry	Algebra II/Trigonometry	Strategic College Reading
English I	English II	American Lit/Comp	Contemporary Lit
Health / P.E.	Driver's Ed / P.E.	Outdoor Education	Personal Fitness
Biology	Chemistry	Physics	Zoology & Botany
Geography	World History	U.S. History	Economics
Spanish 2	Spanish 3	Spanish 4	AP Biology
Culinary Prep I & II	Creative Writing	Environmental Science	

Summary

- ▶ In order to have control over your life, you need to make plans.
- ▶ The clearer and more defined these plans are, the more likely it is that you can stick to your plan.
- ▶ Planning your transition well takes:

Time	Careful decision making
Patience	Support from people around you.
Organization	

- ▶ You need to figure out what your needs are, so that you don't end up in a situation where you are struggling.
- ▶ You also need to figure out what you enjoy and are good at, so that you end up doing something that makes you happy.
- ▶ This process is called self-assessment, and it comes in many different forms.
- ▶ Even if you have set some goals and started down a particular path, it's always okay to change that path and set a completely different goal instead.
- ▶ As long as you plan your transition carefully and don't make decisions on a whim, you can change your goals whenever you like. It doesn't matter whether they are your larger goals, like picking what career you want, or smaller goals, like joining a club, or deciding that a support isn't right for you.
- ▶ Your dreams might not always seem to match up to your goals, and that's okay - your goals are just the checkpoints along the way to your bigger dreams.

5

Getting the Supports You Need



Image: Miniature people work together to fill up a giant bowl with candy.

“You can do anything as long as you have the passion, the drive, the focus, and the support.”

—Sabrina Bryan

What you'll learn in this chapter

- ▶ How to form a support network
- ▶ What supports are
- ▶ How to figure out your support needs
- ▶ Three ways you can get supports

Key terms

- ▶ support network
- ▶ activities of daily living (ADLs)
- ▶ instrumental activities of daily living (IADLs)
- ▶ supports
- ▶ Personal Care Assistant
- ▶ independent living
- ▶ spoons
- ▶ Medicaid
- ▶ Medicaid expansion
- ▶ vocational rehabilitation

Outline

- ▶ Overview
- ▶ Support networks
- ▶ Supports & support needs
- ▶ Before you start
- ▶ Figuring out your support needs
- ▶ How will I get supports?
 - Government-funded programs
 - Natural supports
 - Paying out-of-pocket
- ▶ How does this fit into my transition plan?
- ▶ Summary

Overview

This chapter is a guide to meeting your support needs. Here we will find out what support needs are and why you need to figure out what your individual support needs are going to be.

support network

a group of people you can depend on for help both on an everyday basis and in an emergency

activities of daily living (ADLs)

the basic tasks necessary for day-to-day functioning

instrumental activities of daily living (IADLs)

tasks that help you live independently but are not essential for basic functioning

Before you start making big decisions about your life, you will need to build a **support network**. A support network is a group of people who you trust, talk to and get advice from. They can also be people who offer different kinds of support, like fun, or comforting words. The first section of the chapter is about identifying, and building on, your team of supporters.

You will need to figure out which **activities of daily living (ADLs)** and **instrumental activities of daily living (IADLs)** you are able to do and to what degree. This is just a fancy way of saying the tasks that you need to do on a daily basis. We will look at the differences between ADLs and IADLs, and what supports you can get for them.

Once you've figured out where you need extra support, you can then start to plan suitable supports for getting those needs met. We'll show you examples of how you can figure out your support needs.

There are many ways of meeting your support needs. We have categorized sources of support into three areas:

- ▶ Government programs that can support you.
- ▶ Natural and informal supports - this could be help from people around you that you don't need to apply or pay for, or it could be free apps or other free resources that help you manage your life.
- ▶ Supports that you pay for out of your own money.

Support networks

What is a support network?

A personal support network is a group of people you can depend on for help both on an everyday basis and in an emergency.

To be effective, a support network usually needs to include all kinds of people, like:

- friends
- relatives
- co-workers
- neighbors
- health care providers

Many people may be able to help in some situations but not others. Having a diverse network will make it more likely that you will be able to turn to someone who can help.

Why is it important to have a support network?

- ▶ **It eases stress.** Your support network can ease your stress by providing many kinds of practical and emotional support. This could be things like:
 - bringing you homemade soup when you're sick, or
 - talking with you when you're feeling low.
- ▶ **It helps you enjoy life.** Everybody needs both time alone and time with others, and a strong personal support network will help to ensure that you'll have companionship when you would prefer to share an activity with others.

- ▶ **It gives you a sense of belonging.** You're less likely to feel lonely if you spend time with people who value and care about you.
- ▶ **It makes you more secure.** You'll have a stronger sense of security if you have people in your life whom you know would be willing to do things like:
 - pick up a prescription for you, or
 - keep an eye on your home when you're away.
- ▶ **It builds confidence.** Having a support network doesn't just help you - it lets you help others, too. Even if you're doing fine, you may gain self-confidence from helping others who are still struggling with challenges you've overcome.
- ▶ **It improves your health.** Many studies have found that having strong ties to others can improve your health and even help you live longer.

Building a support network

Starting from scratch: Identifying potential supporters

Make a list of the people who you think could be a part of your team of supporters. Include:

- people to have fun with,
- people to study with,
- people at home or who you grew up with,
- people to get advice from,
- people you live with, and
- anyone else you can think of.

When you're writing the list, be realistic about what each person can offer. For example, you can't expect just one friend, or your partner, to be your constant or only support. It is not fair on them. It also doesn't give you the security of a range of support options.

Growing your network

Why do I need to grow my support network?

- ▶ Having a variety of perspectives can help you make decisions.
- ▶ Sometimes, one person will notice something important about you that someone else wouldn't.
- ▶ It's too difficult to be one person's only support. One person can't support you with everything.
- ▶ Different people offer different styles of support because of their individual experiences.

Maybe a teacher would know better learning resources than your parents would.

Maybe a younger person that's closer to your age would be more fun to do a hobby with.

Some people are good for doing things with and distractions, others are good for listening and understanding.

Some things are best dealt with by a professional.

How can I grow my support network?

- ▶ **Be open to relationships with a variety of people.**
Don't limit your network to just people who share all your interests and values.
- ▶ **Reach out.** Take the first step to launch new relationships. If you keep running into someone you'd like to know, suggest that you have lunch or coffee. Or, ask about their interests, or how they're doing.
- ▶ **Take part regularly in an enjoyable activity with other people.** The more you see people, the easier it will be to ask them for support, and for them to know what you need, too. You could:
 - take a class
 - get involved in a volunteer organization
 - start a group, such as a Friday night movie club or a Sunday afternoon football group.
- ▶ **Explore the Internet.** Many social networking or other sites have forums, discussion groups or blogs for people with particular concerns. A good way to find helpful sites is to search online for a national organization devoted to issues that concern you, such as having a disability.

Online relationships can't always substitute for face-to-face conversations. But, they may be helpful if you:

- have a specific need your network can't meet
- don't like face-to-face interaction
- want to talk about some issues under the privacy of a screen name.

Strengthening your support network

The strongest personal networks are based on a mutual appreciation and desire to help. Their members give as much as they receive. So, strengthening your network starts with being willing to go out of your way to help others.

Think about your current relationships. Are you giving others the kind of support that you would like to have or may need someday? If not, look for ways to start doing more for people who may need your help. Here are some tips:

- ▶ **Keep in touch.** Try to call, write or send emails or text messages often. If you don't keep in touch, your supporters may not stay up to date on the kind of support you need. You may also find it harder to ask for support when you need it.
- ▶ **Consider joining online networks that your friends and family enjoy.** Online networks can strengthen your support system. These sites let you see the news posted by your friends even if you post rarely or not at all.
- ▶ **Remember special days.** Write or send a card on birthdays, anniversaries, holidays and other days that are important to people in your network. Keep in mind that even if you would prefer to ignore your own birthdays and some holidays, many people need extra support at these times.

- ▶ **Limit the time you spend with negative people.** Build your personal support network on a foundation of people who make you feel good. If you need to keep in touch with a friend or relative who drags you down, try sometimes to see the person in a group so that you don't become the sole focus of the negativity.
- ▶ **Show family and friends that they are important to you.** Return their calls or messages and respond to invitations. Tell them often that you appreciate them. Even people who support you strongly may back off if they think that you aren't interested in the relationship.
- ▶ **Don't wait for people to tell you that they need support.** Keep in mind that people may be reluctant to ask for help. If you know a friend is going through a tough time, ask them if they need anything.

Supports and support needs

What are supports?

Supports are the help you get to accomplish everyday tasks. Support comes in many different forms. Anything and anybody that help you to accomplish tasks in your life are supports.

supports

the help you get to accomplish everyday tasks

What can I get supports for?

You can get support in any area of your life! For example, you can get supports to help you with:

- Learning in the classroom
- Doing the tasks needed for a job
- Participating in your community
- Independent living skills, including household chores

What might my supports look like?

Sometimes support can come from a person helping you to do a task.

For example:

- A **Personal Care Assistant** who you hire to help you with household chores
- A family member coming over once a month to help you make a budget
- An employee at a fitness center who helps you participate in a group exercise class

Personal Care Assistant

a kind of support staff that you can hire to help you with non-medical care tasks, like meal preparation or chores

Support can also come in the form of accommodations. Accommodations are changes made to a work environment, school environment, living space, or other environment to make it accessible to people with disabilities.

For example:

- A sign language interpreter helping you to participate in an integrated classroom
- Getting your doctor to write down important information in plain language
- Working from home part of the week instead of coming into the office every day

Supports can also include other tools or apps that help you to accomplish tasks.

For example:

- An alarm on your phone that reminds you to take your medication every day
- Text-to-speech software that reads webpages and documents out loud
- An app that motivates you to complete your to-do list by making it into a game

Support needs

Support needs are just that: the areas of your adult life where you will need to get supports.

There are two main categories that you will have to think about during transition planning:

1. Supports that you have now that will stop being available to you as an adult
2. Supports that you might need to take on new tasks and responsibilities in adulthood

This chapter is all about getting the supports you need. We'll go more in-depth about:

How to figure out what your support needs are,
and

Different ways to access supports.

support needs

the things you need help with, and the kinds of help that work best for you

Before you start

Figuring out your support needs can take a while. It might seem abstract. Or, you might feel like some of your needs are hard to put into words. If that's the case, don't worry! You're not alone.

There are two important concepts that might help you get started thinking about your support needs. These are:

independent living skills

spoon theory

We'll explain these terms in the next section.

independent living

living in the community and having control of your life, including your support services

“Independent living is not doing things by yourself. It is being in control of how things are done.

—Judy Heumann

activities of daily living (ADLs)

the basic tasks necessary for day-to-day functioning

instrumental activities of daily living (IADLs)

tasks that help you live independently but are not essential for basic functioning

Independent living skills

What does independent living mean?

Independent living means that you are in charge of your own life. Independent living means that you live the kind of life you want to live in your community. It means that you choose and control your own supports and direct your own life. Independent living means that you are free to make decisions about your own lives instead of somebody else making decisions for you.

It doesn't mean living alone or not having help.

ADLs and IADLs

What are they?

Activities of daily living, or ADLs, are basic self-care tasks. These are tasks that are considered necessary for your ability to function from day to day.

Here are a few examples of ADLs:

- Feeding yourself
- Bathing
- Getting dressed

There is a second category of ADLs. These are **instrumental activities of daily living**, or IADLs. These are not essential tasks to your ability to function. But, they are important tasks that help you to live independently.

Here are a few examples of IADLs:

- Managing money
- Shopping
- Housework and laundry

How can this information help me?

When you're making your transition plan, you might get caught up on making plans for a career, higher education, or other big changes. It's important to remember that before you can do any of those things, you have to make sure that your basic needs are met.

When you were growing up, your basic support needs may have been met without you ever having to think about it. You might not have known that there were even names for these basic tasks.

Now, you can do a search for "activities of daily living" or "instrumental activities of daily living" and find lots of helpful resources that you can use while planning for your transition.

Spoon theory

What is it?

Spoon theory is a metaphor to explain that people with disabilities have a limited amount of energy, or "**spoons**", that we can use each day. The idea came from [an essay written by Christine Miserandino](#) in 2003.

In the essay, Christine's friend asked her what it feels like to have her disability. So Christine came up with a way to explain.

Christine gave her friend twelve spoons. Then, Christine asked her to list out the things she does on a typical day. Each time her friend listed an activity, Christine took away a spoon. Each spoon represented a unit of energy.

Christine used the spoons to help show how people with disabilities have to carefully use our energy, or "spoons", in a way that non-disabled people don't.

spoons

the amount of energy
people with disabilities
have to complete tasks
each day

As people with disabilities, we usually have to put a lot more energy into everyday tasks. We have more limitations. So we have to think about where we will spend our energy, or “**spoons.**”

Spoons aren’t just physical energy. Your spoons include mental and emotional energy as well. Doing household chores uses up spoons. But, spending time comforting a friend or getting into an argument would also use up spoons.

More and more people are learning about spoon theory. You might hear somebody say that they “don’t have the spoons” to do a task right now, but they’ll come back to it later. It’s a helpful way to quickly explain a pretty complicated concept.

How can this information help me?

Spoon theory gives us a concrete way to understand and think about our energy and abilities from day to day. It helps us measure how much we can manage in one day. It helps us understand our limitations. It helps us accept that we cannot always do everything a person without disabilities could do in one day, and that that is okay.

What happens when you run out of spoons is different for every person with a disability. For autistic people, running out of spoons could lead to burnout or a meltdown.

Spoon theory is very helpful when you’re figuring out your support needs. Some days you will be able to do a task without any support. But, some days you might not have the spoons to do the task. You can make plans for what kinds of supports you might need on days that you’re low on spoons.

Figuring out your support needs

Start with the basics

The first step is to figure out what you'll need to do to meet your basic needs. Your transition team or members of your support network can help you make a list of everything you will need to do regularly in your adult life. These are your **activities of daily living (ADLs)** and **instrumental activities of daily living (IADLs)**. There are also many checklists and worksheets available online to help you make this list.

activities of daily living (ADLs)

the basic tasks necessary for day-to-day functioning

instrumental activities of daily living (IADLs)

tasks that help you live independently but are not essential for basic functioning

Advice on using worksheets

There are many worksheets online to help you figure out your support needs for ADLs and IADLs. These worksheets often look something like this:

ADL/IADL	Can always do without help	Needs some support	Needs a lot of support	Does not do
Bathing	✓			
Feeding self	✓			
Cooking			✓	
Managing money		✓		

These worksheets are usually for people with disabilities that impact their life the same way all the time. As autistic people, our disabilities can impact our ability to do tasks at very different levels from day to day. So, you might run into trouble filling out a worksheet like this.

Worksheet workarounds: Mary Angela's story

Mary Angela and her big brother Joey are filling in a worksheet to identify her daily support needs. Here is part of their conversation.

Joey:

Okay, so far we've figured out that you need a lot of support with budgeting and saving money, but you don't need any support with making your own appointments or doing your laundry.

Next section is about food. Can you make sure you have enough to eat every day?

Mary Angela:

I don't know. Some days I could cook a whole casserole.
But there's other days where I don't even eat at all.

Joey:

Why is that?

What happens on those days to stop you being able to eat?

Mary Angela:

On my bad days I barely have the spoons to get out of bed, so I can't go to the grocery store and get food or go to the kitchen and cook.

And sometimes I *could* do those things, but it means I won't have the spoons to do anything else at all.

Joey:

Let's check "Needs some support" for this one.

We should try to come up with some fixes that help you on your bad days, so that at least you get to eat something!

After finishing the worksheet, Mary Angela gets out a notebook and a pen and writes down all of the things she marked "needs some support" or "needs a lot of support."

Joey then helps Mary Angela brainstorm a list of all the different tasks that could go into being able to do each activity.

She makes her own chart for each area.

Here's part of one of Mary Angela's charts:

Feeding myself

<u>Tasks</u>	Easy for me	Need to learn how	Hard if I'm low on spoons	Hard all the time
Making a grocery list	X			
Going to the grocery store			X	
Budgeting money for food		X		
Ordering food over the phone				X

Mary Angela uses the ADL/IADL worksheet together with the new charts she made herself. This helps her to figure out what specific tasks she will need support in.

independent living

living in the community and having control of your life, including your support services

supports

the help you get to accomplish everyday tasks

Next steps

It may take a while to make the initial list of everything you'll need to do as an adult, but it is important that you think carefully about all of the activities that are important to **independent living**.

- ▶ You can figure out your support needs for the other things in your life, and for the things you want to do in the future.
 - List the **supports** you already have for whatever it is you want to do.
 - Then ask yourself, when I go to college/get a job/move somewhere new, how am I going to get those supports?
 - What are new things I will need supports for?
- ▶ This is less straightforward than ADLs and IADLs. So you will need to discuss it with your support team to find out what you're going to need in your individual situation.
- ▶ The different content chapters (Chapters 7-10) of this book will help give you clues about things you might need in the different areas of your life.
- ▶ Then, using the resources you already have, such as your supporters (and this book), you need to figure out how to get your support needs met when you transition.

How will I get supports?

Three ways of accessing supports

There are three ways that you can get the support services that you need:

Government-funded programs

Natural/informal supports

Paying out-of-pocket

Government-funded programs

Government-funded programs are paid for by the government. Sometimes this means you get these services for free, or only have to pay part.

This includes:

Medicaid

Supplemental Security Income (SSI)

Housing vouchers

Home and Community-Based Services

vocational rehabilitation

You have to meet certain requirements to qualify for government programs, and not everybody will be able to use them.

Medicaid

government-funded insurance for low-income people

vocational rehabilitation

A process that helps people with disabilities overcome barriers to finding and keeping jobs

State differences in government-funded programs

The services that you can get through government programs are different in different states. Government programs are administered on a state-by-state basis. This is important to know if you're planning to move out of your state.

Medicaid expansion

part of the Affordable Care Act which makes more people eligible to get Medicaid, if their state chooses to be part of expansion

- ▶ For example, you should know if the state you plan to move to is a part of **Medicaid expansion**. If you're moving to a state that didn't opt-in, you might have much less access to essential health care.

[Here is a state-by-state guide](#) to where the Medicaid expansion applies.

- There is more information on Medicaid and the Medicaid expansion in Chapter 10.

Government programs differ by state. Because of this, instead of just searching for "housing vouchers", you should search for "[**your state**] housing vouchers." For example, if you live in Michigan, you would search for "Michigan housing vouchers."

There are many websites with state-by-state guides on how and where to apply for benefits, like:

www.disability-benefits-help.org

There are some government agencies that don't have a strict application process, but this process still differs from state to state.

Looking up state agencies and finding out what programs they have may need to be a part of your transition plan. You can start by searching for:

- ▶ “[your state] department of human services”
- ▶ “[your state] social security disability programs”
- ▶ “[your state] Centers for Independent Living”

Natural/informal supports

Natural/informal supports are the personal relationships you have with friends, family, peers, and other trusted people. They can act as informal supports, fulfilling some of the roles you might have hired paid support staff members to fill.

These are also supports that you do not pay for. Other informal supports can come in the form of free apps that help you manage your life, or websites and online resources that encourage you to study, plan, budget or cook.

Paying out-of-pocket

Paying out-of-pocket is the last way you can access needed supports. Some of the services you may need might be very expensive to pay for out of your own money, depending on what kind of living arrangement you have.

Let’s take accessing the community as an example of an area of your life that you might need support in, and look at three of the different ways of getting that support.

Example: Accessing the community

- ▶ **Government-funded program:** ADA Paratransit is a special type of transportation that can pick you up at home. You have to meet certain requirements to qualify for a paratransit program.
- ▶ **Natural or informal support:** Using fixed public transit routes or asking a friend for a ride somewhere.
- ▶ **Out-of-pocket support:** Ordering a ride using on-demand services, like Uber, Lyft, Hailo, or taxicabs.

Mixing and matching supports

spoons

the amount of energy people with disabilities have to complete tasks each day

When planning your day, you need to think about your energy levels. Everybody has limited energy levels, but for autistic people, many everyday tasks use up more of our energy, or “**spoons**”. When we run out of spoons, it can mean burnout or a meltdown.

If you find you run out of spoons quickly, it’s important to prioritize your to-do list. Don’t spend a lot of time cleaning your room if you need to go shopping for food.

If you didn’t manage to fulfill a task, don’t worry! Try to figure out why it was hard, and whether you could get help with doing it, or make it easier to do. It’s okay to need help with something, no matter how easy you think it should be.

It’s also important to remember that your support needs will vary from day to day, and situation to situation.

Some days you'll take the bus, some days you'll need to use an Uber.

Sometimes you might need help to carry out an ADL or IADL, even if other times you can do it independently.

If you need support, there are a lot of options available to you. There is no right or wrong way to meet your support needs. You shouldn't feel guilty about how your support needs are met. A support can be, and often is, something you enjoy doing.

Also remember: Not having the exact same support needs from day to day does not mean your support needs are not needs. Nor does it mean that they're somehow less important, or that you are 'less autistic'.

Using this handbook

- ▶ It would be impossible to list every possible source of support. But, each of the 4 transition plan content chapters (Chapters 7-10) will have suggestions for sources of supports.
- ▶ There are also even more ideas for supports, plus contact numbers, links to legal information and many more helpful links in the resources section of the appendix.

How does this fit into my transition plan?

Your transition plan is something that you do as part of a team of people. As we said in the beginning - before you start making big decisions about your life, you will need to build a support network. Your transition team and your support network will most likely overlap.

So before you start your transition plan, you should make sure you have a network of supporters to help you make transition decisions.

After you've done that, a big part of your transition plan is figuring out:

- what your support needs are, and
- how you'll get the supports that you need.

Getting supports might involve lots of smaller goals, like:

- learning about your options,
- figuring out what you can afford,
- researching what services are available in your area.

Summary

- ▶ When we don't have our needs met, we can't focus on what we want, because our needs take priority.
- ▶ If you need support to get the things you need, you have to figure out what those things are to make sure you get them.
- ▶ When you can have your needs met, you can start working on what you want out of life and pursuing your goals.
- ▶ You need supportive people around you during this phase of your life. You will be dealing with changes, getting new responsibilities and making decisions.
- ▶ You may not need help with everything, but you will still need to have people you can ask for help.
- ▶ To be effective, your support network needs to include all kinds of people.

6

Supported Decision-Making



Image: Miniature people standing around a drawing of a square split into halves. One half says “yes” and one says “no.”

“Not making a decision means forgoing an opportunity.

—Auliq Ice

What you'll learn in this chapter

- ▶ What supported decision-making is
- ▶ How supported decision-making can help you
- ▶ How to form a support network
- ▶ What kinds of supports are available
- ▶ How to make a decision with supports

Key terms

- ▶ transition
- ▶ support teams
- ▶ guardianship
- ▶ self-determination
- ▶ self-advocacy
- ▶ regular power of attorney
- ▶ durable power of attorney
- ▶ representative payee
- ▶ joint bank account
- ▶ HIPAA release
- ▶ augmentative and alternative communication (AAC)

Outline

- ▶ Overview
- ▶ During Transition
- ▶ Self-determination and self-advocacy
- ▶ Decision-making
- ▶ What is supported decision-making?
- ▶ Forming a support network
- ▶ Making a decision with supports
- ▶ What if...
- ▶ Supported decision-making & the law
- ▶ How does this fit into my transition plan?
- ▶ Summary

Overview

Throughout your life, many of the decisions about your life might have been made by other people. Maybe other people decided:

- what you ate
- what doctors you visited, or
- how much money you were allowed to have.

Maybe you disagreed with these decisions and have been waiting for the freedom to make your own choices.

Maybe you were okay with other people making decisions for you, and the idea of making your own decisions is frightening!

As you transition into adulthood, there will be many decisions to make. Some decisions relate to your transition, like:

- “Where do I want to live?”
- “Do I want to get a job?”

Some decisions are part of adulthood for everyone, like:

- “How should I manage my money?”
- “What do I want to do with my free time?”

Some decisions may take more careful consideration than others.

This chapter focuses on supported decision-making, a system that can help autistic people and people with other disabilities tackle some of the decisions we face as we enter adulthood.

Using supported decision-making, we can form **support teams** to help us make choices about our own lives.

The most important part of supported decision-making is that *you* are ultimately the decision-maker. You are in control of what happens in your life. That might sound scary—or exciting!

Let's take a closer look at what supported decision-making is and how you can use it in transition and adulthood.

support team

a network of people who help guide you in your decision-making

During transition

Overview

Transition means the major changes that youth with disabilities go through as we become adults. These changes can include:

continuing education

finding a job

finding a place to live

This chapter is about the transition from having decisions made for you to supported decision-making.

In supported decision-making, you are in control of the decisions about your life.

transition

the process of changing from one way of life to another way of life

Rights

As an adult, you should have the right to:

- Make decisions
- Sign contracts
- Vote
- Defend your rights in court
- Choose your own medical treatments
- Form a support team to help you make decisions
- Change the people in your support team
- Have people you trust act as your supporters
- Have situations explained to you in a way that you can understand before being asked to make a decision about them
- Have the final say in what you want
- Take risks
- Change your mind about a situation
- Be free from exploitation and abuse

guardianship

a legal arrangement where you are given a “guardian” who can make decisions for you

But, **guardianship** can take away some or all of these rights. Guardianship is a legal procedure that takes your decision-making rights away. Supported decision-making is a model that lets us keep all of the rights that we should have.

We’ll talk more about the differences between guardianship and supported decision-making later on in this chapter.

Responsibilities

Being able to make your own decisions is an important part of adulthood! Everybody has certain responsibilities anytime they make a decision.

When you make a decision about something, you have the responsibility to:

- Think carefully about all decisions and how they will affect you or other people

- Think ahead about any risks or potential negative effects of the decisions you make

- Accept the results of the decisions you make and not blame the results on somebody else

Goals

Your transition can help you achieve important goals. If you seek to live on your own, you must transition out of your parents' or guardian's home. If you seek to find a full-time job, you must transition out of high school or college.

Supported decision-making can help you in your transitions. The support of your parents or guardians during childhood can help you to move from home to a college dorm or new apartment.

The ultimate goal is to make the transition successful by having a good support team and making sure your needs are met.

The support team does not just give physical or emotional support. The support team also may give advice in navigating services. The support team will be ongoing even after the transition is complete.

Self-determination & self-advocacy

self-determination

The idea that each person has the right to decide how to live their life

self-advocacy

The act of speaking up for what you need and want

Self-advocacy is self-determination in action.

What are self-determination and self-advocacy?

“Self-determination” and “self-advocacy” mean people with disabilities have control over their lives.

Self-determination is the power to decide what you need and want.

Self-advocacy is the action of making your needs and wants known. Self-advocacy is self-determination in action.

Autistic people may need help from outside sources. Nonetheless, we get to decide what that help may be and who we wish to get it from. This is self-advocating.

For more information, see Chapter 2 of this handbook.

Self-advocacy and supported decision-making

Self-advocacy is very important when it comes to supported decision-making. You have to make it clear what you want.

If people try to do something that you didn't say that you wanted, you have to speak up for yourself.

You need to make it clear that you have the right to make decisions about your own life.

Decision-making

Overview

As you transition into adulthood, you'll start to be able to make choices about your life that other people used to make for you. Instead of somebody telling you what's best for you, you'll get to look at all the choices and decide for yourself which ones you want.

Decision-making comes up in every area of your life.

In the morning, you might have to decide if you want to eat cereal or pancakes for breakfast. To make this decision, you might ask yourself questions like:

How much time do I have for breakfast this morning?

Do I have a clean bowl and spoon for cereal?

Do I have all the ingredients to make pancakes?

You could ask a lot of questions just to decide what you want for breakfast. And that's just one decision!

As you transition into adulthood, there will be even bigger decisions to make with much more to think about and many more questions to ask.

Decision-making comes up in every area of your life.

What kinds of decisions will you need to make in transition?

The kinds of decisions you might need to make include:

- Will I need to get a new doctor?
- What kind of daily schedule will I have?
- Do I need staff to support me in my everyday life?
- Where do I want to live?
- What skills do I need to learn?
- How do I become a better self-advocate?
- What should I do to participate in my community?

What kinds of decisions will you need to make as an adult?

Here are some of the decisions you might need to make as an adult:

- What do I need to do to get the kind of job that I want?
- What living arrangement is best for me?
- Do I want to get married?
- Do I want to have children?
- What do I want to do in my free time?
- How will I save money for the future?

What is supported decision-making?

Overview

It can be scary to think about all the big decisions you'll have to make as you transition into adulthood. Many of them might be too big to try to handle on your own. That's where supported decision-making comes in.

This section will discuss:

- what supported decision-making is

- who supported decision-making is for

- the differences between supported decision-making and guardianship

What is it?

Supported decision-making is a model for helping us to make decisions about our own lives.

Under supported decision-making, we can form **support teams** made up of people we trust.

Our supporters can be:

- family

- friends

- community members, or

- anyone else that we trust.

These supporters might be able to access private information (such as information about our medical records) that they would otherwise not be allowed to see. Our supporters are only allowed to see our personal information if we decide that they can.

support team

a network of people who help guide you in your decision-making

Our supporters are only allowed to see our personal information if we decide that they can.

After consulting with our support teams, the final decision is still up to us.

When we have a decision to make, we can get help from our support teams. Here are some things a support team could do:

- Explain the situation/decision to make sure that we completely understand what's being asked of us
- Provide more insights or information about the situation
- Help make a list of pros and cons
- Help compare the options we have to choose from

After consulting with our support teams, the final decision is still up to us.

Who is it for?

Supported decision-making is for anyone!

Sometimes the supported decision-making process is more formal. You can keep written records of who helped and what was decided.

Most of the time, it's much more informal than that. Have you ever asked a friend for their opinion before buying something? That's supported decision-making!

People who make most of their decisions by themselves can use supported decision-making. Non-speaking Autistic people can use supported decision-making. High school seniors can use supported decision-making. Grandparents can use supported decision-making.

Everyone has the right to make their own decisions and to have the support they need to do so.

Everyone can use supported decision-making!

Everyone has the right to make their own decisions and to have the support they need to do so.

What is the difference between supported decision-making and guardianship?

Supported decision-making helps us get help with making big life decisions without losing the ability to have the final say.

Guardianship is a legal procedure that takes your decision-making rights away. A guardian gets the right to make decisions for you.

Some guardians do their best to avoid making decisions for people without asking them first. But, if you have a guardian it can be hard to stop your guardian from making a decision for you that you don't agree with.

People who have supported decision-making always have a say in what happens. Your decision team has to respect the choices you make, and the lifestyle you choose to live.

You don't choose your guardian. The court chooses your guardian. If you don't want to have a guardian anymore or want a different guardian, you can't change it without permission from the court.

There are different types of guardianship. Some types give the guardian the ability to make only some types of decisions for you. Other types allow the guardian to make all kinds of decisions about you.

In some cases guardianship could mean that you aren't allowed to:

- see people without the guardian's permission
- choose whether you want to leave an institution
- keep the money you earn.

guardianship

a legal arrangement where you are given a "guardian" who can make decisions for you

You don't choose your guardian. The court chooses your guardian.

Supported decision-making has several key features that allow people with disabilities more freedom. In a supported decision-making agreement, you get to keep all your legal rights. You may choose to stop supported decision-making at any time. You have to approve all decisions.

Why is guardianship bad for people with disabilities?

Guardianship is bad for people with disabilities because it takes away choices.

Guardianship is bad for people with disabilities because it takes away choices. It allows someone to have complete control over some or all parts of your life. It takes away your rights and freedoms. Almost everybody wants to have control over their lives. So, a lot of people under guardianship aren't happy with their situation.

It is hard to prevent abuse by guardians. This is because the guardian has control over the person in their care. Your guardian is supposed to make decisions that are in your best interest. But, it is hard to stop them from making bad decisions without going to court. Even if you do complain and go to court, it can be hard to convince the court that your guardian is being abusive. It can be especially hard if you have a hard time expressing yourself and collecting proof of the abuse.

With supported decision-making, you can make sure that you'll always be able to get support from someone you trust.

Some guardians have a good relationship with the person they support. But, they could have the same type of relationship with supported decision-making instead of guardianship. With supported decision-making, you can make sure that you'll always be able to get support from someone you trust.

Forming a support network

Overview

This next section discusses the actual formation of a support network for decision-making. It covers:

- who would support you
- what qualities a supporter should have, and
- what kinds of people would not make good supports.

Everyone is different. We all have different life situations. Only you can decide what supports, if any, you need when making decisions. Only you can decide who to trust to help you with your decisions.

Only you can decide what supports, if any, you need when making decisions.

What qualities should a supporter have?

A good supporter is somebody that you can trust to help you make informed decisions and choices. A good supporter focuses on what you want and need.

They might be a:

- friend
- partner
- family member
- caretaker, or
- someone else that is close to you.

“I think most of us are raised with preconceived notions of the choices we’re supposed to make.

We waste so much time making decisions based on someone else’s idea of our happiness—what will make you a good citizen or a good wife or daughter or actress.

Nobody says, “Just be happy—go be a cobbler or go live with goats.”

—Sandra Bullock

There are many qualities a good supporter should have. The following is a list of some (but not all) the characteristics to look for in a good supporter:

A good listener: A supporter should be able to listen to your concerns and feelings when making choices. They should also be someone that you can have a constructive conversation with.

A person like this won’t:

- ignore you
- interrupt you, or
- invalidate what you have to say.

Respectful: A good supporter makes sure that they are making decisions with you, not for you.

A good supporter respects:

- you
- your opinions, and
- your **autonomy** (ability to make decisions for yourself).

Trustworthy: Sometimes the decisions a supporter is helping you make are personal. These might be decisions that you want to be kept confidential. Confidential means the decisions are private between you and your supporter.

For example, you might need a supporter to help you make financial or medical choices.

That means that good supporters must be able to be trusted with personal information sometimes.

Understanding: A good supporter understands that they might disagree with you on what choice to make. But, they also understand that the decision is yours to make, not theirs.

For example, a good supporter might sometimes disagree with you on a decision and tell you their opinion. But, they will still let you make the choice for yourself.

What kinds of people would not be good supporters?

Not everyone can be a good supporter. These kinds of people would not work to keep your best interests and wants in mind. Some people that might be bad supporters include people that are:

Condescending: Bad supporters might be condescending. That means they act like they are smarter or better than you.

A supporter like this might try to act as though you cannot make decisions for yourself at all. When looking for someone to be a member of your support network, remember that they are your equal and should treat you like that. Anyone who treats you as if you are beneath them is not good for your support network.

Disrespectful: Bad supporters might also not respect your decisions, choices, or opinions. A disrespectful supporter might ignore what you have to communicate. They might ignore what you want or need when making a decision with you.

Not everyone can be a good supporter.

Untrustworthy: People you can't trust with personal information are not good supporters.

For example:

Sometimes you might need help making medical or financial decisions. A supporter might need to know some details about your medical or financial history to help you.

But, these are things that you might not want a lot of people to know. You have to make sure that your supporters are people that you can trust with information like this.

Who might support me in making a decision?

- Family
- Parents
- Siblings
- Cousins
- Aunts/uncles
- Friends
- Co-workers

You have the right to decide at any time that someone in your support team is no longer a good supporter.

In other words, anyone that you know and trust would likely support you in your decision-making.

You have the right to decide at any time that someone in your support team is no longer a good supporter. If they start to disrespect your wishes or try to push you towards/away from certain choices because of their own beliefs, it's okay for you to stop including them in your support team.

A good support team will provide you with help and resources while still allowing you to make the choice you want to make.

Making a decision with supports

Overview

We talked about forming your support team. Now, it's time to take a look at how your own supported decision-making process might look.

You can use supported decision-making in different ways.

Maybe you only need to quickly consult with one member of your support team about a small decision.

An example of a small decision could be which brand of batteries to buy.

Maybe you have a big, complicated decision to make. You might want there to be formal contracts involved.

An example of a big decision could be a decision involving your medical care.

No decision is too big or too small for supported decision-making. You don't have to call your support team for every single decision if you don't want to. But if you do need them, they're there to help you!

No decision is too big or too small for supported decision-making.

What kinds of decisions might I make with supports?

Your support team can help you get a better idea of all kinds of situations you might have to make a decision about, including:

- Where to go to school and what you want to study
- Buying your first car
- Planning your wedding
- Buying groceries for yourself
- Medical procedures

What might the decision-making process look like?

The bare outline of the decision-making process would be something like this:

1. Identify the decision you must make.
2. Identify your options.
3. Gather and process information on your options.
4. Make your decision.

Making a decision with supports: Felipe's story

Felipe is trying to make a decision about what kind of car to buy.

He asks his support team about their experiences with the cars they have. His cousin Marisa tells him about some of the tricks car salespeople might try to use to overcharge him.

Felipe's dad tells him about a couple of websites that he can use to find and compare different kinds of cars and car dealerships in the area. His dad also tells him about the different cars that he has owned and what he liked about them.

After looking at some of the websites, Felipe decides that he's going to go look at a couple of cars at a nearby dealership. He asks Marisa to come with him to the car dealership to help him talk to the salesperson.

Felipe looks at a couple of cars at the dealership. He remembers the advice his dad gave him, and makes a final decision.

Felipe is glad that he asked his supporters for their input. The advice he got helped him to make a better, more informed decision than he could have otherwise. But, the final decision was up to him.

How can supported decision-making help me?

Supported decision-making is an idea designed to help people with disabilities. The team of people who agree to support you can help in any situation where you need to make a decision. It could be making decisions about:

- where and how to live
- paying taxes
- budgeting
- healthcare issues
- employment
- buying an expensive item, or
- planning for the future.

The members of the team can guide you through the process of making a decision, step by step.

First, you have to decide that you need to make a choice. Then, you have to find out what the options are. This step might take a little research or talking with people to find the information you need.

It is good to know the details of each option. You should tell your team what kind of options you are looking for.

Then, you weigh the different options and make the final decision. After that, you and your team may need to do other things to make sure the plan is working as expected.

Making better decisions together: Sahra's story

Sahra is looking for a room to rent. She has looked at several different places. She's also asked around on the Internet to see if anyone she knows has a room for rent.

After doing this, she narrows her options down to two rooms. Both of them become available in around a month. One room is more expensive and a little out of town, but she'd be living with her best friend.

The other room is considerably cheaper for the same size, and a little prettier. Sahra found out about the room from someone she kind of knows from school. He seems nice enough, but Sahra was never that close to him.

Sahra tells her support team about the different options she has. She asks for their help in making a decision.

Together, they weigh the different options.

- ▶ What would be the benefits of living in each house?
- ▶ What would be the drawbacks?
- ▶ What is Sahra uncertain about?

Sahra writes all her thoughts down. She gives herself a time limit of 5 days to figure out what she wants to do.

Finally, Sahra decides it's worth paying the extra money to live with someone she knows and trusts.

She and her support team have looked at her budget carefully. They figured out that she can still afford the room with enough to spare for food, clothes and fun. So she contacts her friend and lets them know her decision.

Sahra's support team helps her out with the rest of the move wherever she needs help. They help her decide what she needs to pack. They go through the tenancy contract with her. By the end of the month, Sahra is all moved in and planning a housewarming party with her best friend.

What kinds of supports can I use?

Power of attorney

Granting someone power of attorney is different than legal guardianship. You get to decide how much decision-making power the agent actually has.

“Power of attorney” is a legal document. Giving somebody power of attorney means that they can make legal decisions and take care of your money or other issues on your behalf.

The person granting power of attorney is the **principal**. The person you give these rights to is your **agent**.

Granting someone power of attorney is different than legal guardianship. You get to decide how much decision-making power the agent actually has.

For example, you can just give your agent the right to use your bank account to pay your rent and bills.

Or, you can also give your agent the right to sign leases, buy and sell things for you, or even take out loans for you.

regular power of attorney

a legal agreement where you give decision-making power to someone else until 1) you take the power away or 2) you can't make decisions for yourself anymore

durable power of attorney

a legal agreement where you give decision-making power to someone else, and this power lasts even if you can't make decisions for yourself anymore

You can revoke, or take away, the power of attorney at any time. Under guardianship, only the court can revoke the guardianship.

There are two kinds of powers of attorney: regular and durable powers of attorney.

A **regular power of attorney** will stop working if you ever become unable to make decisions for yourself. For example, if you get sick and can't understand things as well as you normally do.

A **durable power of attorney** will allow your agent to keep doing things for you when you're sick or otherwise unable to make decisions. In fact, some durable powers of attorney only allow your agent to do things for you when you're too sick to do them yourself!

It's important to think about when you want your agent to help you, and decide whether you want the power of attorney to be durable.

Representative payee services

A **representative payee** is someone who manages your benefit money on your behalf.

You can use a representative payee if:

You get financial disability benefits from the government, and

You need support to manage your money.

There are many regulations that representative payees must follow. These regulations are to make sure that they are not mismanaging your money.

Sometimes, the government will decide you need a representative payee even if you do not want one. If this happens, you may be able to get the government to stop using a representative payee for you.

You will have to show that you can manage your own money, with or without help from your support network.

representative payee

a person who gets your disability benefit money and manages it for you

Other tools

You can get support from people without having to sign anything naming them as your agent or representative payee. Maybe you want to get help from different people at different times. Maybe you can get the help you need without having to name anyone as your agent.

Support plans

You and your supporter can make a plan where they agree to help you with decisions, but don't have the power to make decisions for you.

For example, your supporter may agree to come over once a month to help you pay your rent and bills. Or, your supporter can help you when you have to buy something expensive, like a car. You might give your supporter your bills and bank statements so that they can help keep track of things.

Supported Decision-Making Agreements

These are agreements that let you name a support person to help get information and help you make decisions. They are like powers of attorney, but they do not let your supporter make decisions for you. They only let your supporter give you advice and help.

Right now only Texas has a law that specifically recognizes these agreements. But, that doesn't mean that you can't sign one anyway.

ASAN's Model Supported Health Care Decision-Making Legislation has an example supported decision-making agreement.

You can find that resource here:

autisticadvocacy.org/policy/toolkits/healthtransition/

Prepaid Cards

If you have trouble keeping track of your spending money, your supporter can help you decide how much money you can afford to spend every month. That way, you will still have money left over for your rent and bills. Then, your supporter can help you get a prepaid card.

You can use prepaid cards like credit cards. The difference is that prepaid cards will only let you spend as much money as you've put into the prepaid account. This way you won't get punished by your bank for spending more than you have in your account.

NerdWallet has a guide to prepaid cards. Check it out here:

<https://www.nerdwallet.com/blog/banking/prepaid-debit-cards-what-you-should-know/>

Credit Card and Bank Alerts

You can tell your bank to keep track of your account and to email or call your supporter whenever you spend a lot of money in one day.

This might be helpful if:

You have a habit of spending lots of money without thinking it through, or

If people sometimes try to talk you into giving them lots of money

That way, your supporter can check in with you and make sure that you are ok. Some banks will even let you set up your account so that you can't spend too much money at once unless your supporter says it's ok.

This is something that you should only do if you actually want someone to help stop you from spending money. You should choose a supporter you trust.

joint bank account

a type of bank account that lets two people own and manage it

Joint Bank Accounts

If you get support from someone who also shares your money—like a spouse—you can set up a **joint bank account**.

Your supporter can make decisions about how to spend your shared money. But, you still have the ability to also make decisions about the shared money.

If you set up a joint bank account, the money in it will belong to the other person and not just to you.

You shouldn't start a joint bank account with someone unless you trust them. You should also have an agreement about how to spend the money in the account.

HIPAA Releases

As an adult, you have a right to privacy for your health care. Except in special cases, your doctor can't talk to your family members about your health unless you say it's okay. But, you might want your doctors to talk to your supporters. That way your supporters can help you make decisions about health care.

HIPAA release

a form you can sign that lets your doctor share your medical information with somebody else

If you want your doctor to talk to your supporter, you can sign something called a **HIPAA release**. Every doctor's office should be able to give you the right form to sign.

What if...

I can't talk?

Talking isn't the only way to communicate. Many Autistic people make use of different kinds of **augmentative and alternative communication** (AAC) to tell people what they want. AAC just means communicating in ways other than speaking out loud.

There are two kinds of AAC: unaided and aided.

Unaided AAC includes:

- Gestures

- Body language

- Sign Language

Aided AAC includes the use of tools or devices, for example:

- Writing on a piece of paper

- Text-to-speech devices

- Communication boards with symbols and letters that you can point to

If you can't talk, you can still communicate.

Your support team should be made up of people who will both understand and respect whatever way you choose to communicate what you want.

Your supporters should respect your non-verbal communication. They should respect it the same way they would respect verbal communication.

augmentative and alternative communication (AAC)

any way of communicating that doesn't involve speaking out loud

“I celebrate being non-speaking because it is the only me I know, and because I can still “say” what I want to say, and fight for my rights, without oral speech.

—Amy Sequenzia

Some of us only use AAC occasionally. Some of us rely on it as our main way of communicating.

You might want to have a trusted translator as part of your support team. A translator can help make sure that all your supporters can understand what you have to say about the decision. You might not want a translator. It's up to you who you want to have as a part of your support team.

You can use supported decision-making no matter how you communicate with others. Being able to speak is not necessary for supported decision-making.

There are many ways to communicate in supported decision-making. This includes ways that do not rely on verbal communication.

There are no "right" or "wrong" ways to communicate. All that matters is that everyone in the decision-making process is able to express themselves and understand each other.

I need a lot of support?

All people with disabilities have the right to make decisions for themselves. This includes:

- people with intellectual disabilities
- people with more than one disability, and
- other people with disabilities that may need extra support.

If you need a lot of support, there are many government programs that can help you. These programs include:

Medicaid

Social Security Disability Income (SSDI)

Supplemental Security Income (SSI).

Programs like these can help you pay for caretakers, or people to help you in day to day life.

Medicaid

government-funded insurance for low-income people

Example: Let's take a look at the case of an older woman who has dementia and is hard of hearing.

She has a caregiver that visits her a few times a week to help her do things that she otherwise might not be able to do on her own, such as:

- ▶ run errands
- ▶ cook
- ▶ do chores around the house

But, she is still able to make choices in these activities herself. The caregiver just provides help to her when she needs it.

Even if you need a lot of support, supported decision-making can work for you too.

I can't understand what's going on?

One of the roles your supporters play is making sure that you understand the decisions you are expected to make.

If you can't understand what's going on, reach out to your support team. They should work with you to help you understand what the decision is that you need to make and what the effects could be.

self-advocacy

The act of speaking up for what you need and want

Self-advocacy is very important if you don't understand what's going on. You have to let somebody know that you are confused or have questions. A good support team is there to help you, not to judge you for not understanding something! Your support team is on your side.

I want something bad for me?

self-determination

The idea that each person has the right to decide how to live their life

Self-determination gives you the freedom to make your own decisions in life. With that freedom comes risks. There is a risk that you may make bad or unhealthy decisions. You might make a bad decision for any reason.

While other people may have excellent advice or poor advice, you must make the final decision about the course of your life.

If you do make a bad decision about housing, health care, or school, you can talk to your parents, or a counselor, or a teacher or a health care professional about other options to reverse your decision. If reversing your decision is impossible, then you can figure out together how to move forward.

Supported decision-making may allow you to make bad decisions in the first place. Supported decision-making will also help you to undo those decisions with help from your friends and family.

“I made decisions that I regret, and I took them as learning experiences... I'm human, not perfect, like anybody else.

—Queen Latifah

I'm already under guardianship?

You can use supported decision-making even if you're under **guardianship**. Your guardian can support you in your plans to move towards independent living. Your guardian can make sure to talk to you about every decision and respect your decisions even when they disagree with you.

Supported decision-making includes the ability to make decisions that your guardian doesn't agree with. Supported decision-making is the best way of planning for your future and to eventually move out from under guardianship.

If you are currently under guardianship, you may lack certain legal rights. These are the rights that you need to move towards independent living without their help. Your guardian can provide you with whatever help you need, including financial support or advice. But, unless you can get the court to end the guardianship, you will need your guardian's help to transition to the life you want.

Sometimes a guardian has control over important things, like:

- how or whether you can spend money
- your medical treatment, or
- where you live.

You might not be able to sign a lease or start your own bank account without your guardian's signature. To live independently, you must rely on your guardian to support your decision to change how you live your life.

guardianship

a legal arrangement where you are given a "guardian" who can make decisions for you

Sometimes guardians might not be supportive. In some cases, your guardian may even be a volunteer who doesn't really know you!

Just remember that all people with disabilities, even ones with guardians, can self-advocate and make their own life choices. Even if you need a lot of help to make your own choices, you deserve to have the final say in decisions about your life.

If you do not feel that you are getting support, you may need to try and get the court to take away guardianship. You can also try to get a new guardian. Every state has a different system for this.

You might also get support from other people who know you. These people could include your service workers and other family members.

You can get help from your state's [Protection and Advocacy \(P&A\) agency](#) or from [Adult Protective Services](#) if:

- you are in immediate danger
- your guardian is abusing you
- your guardian is stealing your money

You might want to have someone you trust contact them for you if you are concerned that your guardian might try to stop you from getting help.

There is more information on the next page about how to find contact information for these groups.

To contact your P&A agency:

1. First, go to <http://www.ndrn.org/ndrn-member-agencies.html>.
2. On the sidebar, click on your state.
3. This will take you to a page with the contact information for your state's P&A organizations, usually including a phone number and email address.
4. Contact them at one or both of these addresses, or have someone you trust do it for you.

To contact Adult Protective services:

1. First, go to <http://www.napsa-now.org/get-help/help-in-your-area/>. This will bring you to a picture of a map of the United States.
2. Click on your state.
3. After you click on your state, there will be a sidebar labeled **"To Report a case in your area call:"** with the contact information for your state.

Supported decision-making & the law

Texas

Right now, there are no official national supported decision-making laws in the United States. But, changes are happening on a state-by-state level.

Some states are starting to prefer a supported decision-making model over guardianship. Texas has a supported decision-making law. You can read more about [the Texas law here](#).

Around the country

Other countries, like Canada and Australia, have decided to make national laws recognizing the supported decision-making model. They recognize it as a positive alternative to guardianship.

Disability rights advocates in the United States are working to get laws like the ones in Canada and Australia.

The Autistic Self Advocacy Network has created [model health care supported decision-making legislation](#). This would work as a law in the United States.

The model legislation has a supported health care decision-making agreement form. You can use this form when making your own supported decision arrangements.

Because it is not a law yet, other people might not have to cooperate with your supporter. But, it can still be useful to think through how you want your supporter to help you.

How does this fit into my transition plan?

You can use supported decision making during the transition planning process itself.

You should make your transition plan with input from people you trust who support you. But, they should let you make your own decisions about what you want in life.

You can also include supported decision-making in your transition plan as a support that you'll need in the future.

You can think about how supported decision-making could improve how you live, work and study.

For example, you might need somebody to help you make healthy grocery decisions.

A good goal is to ensure you have supporters who are good for you in your future. You should be able to ask questions, raise concerns, and be able to sometimes express disagreement with someone who is supporting you.

Summary

- ▶ There are lots of different types of support you can get while making decisions. There are people who can help you with your finances, who can give you legal support, or help you make decisions about your education, for example.
- ▶ Having the right to make your own decisions is an important part of adulthood.
 - This is the case no matter how many disabilities you have, or how much support you need.
- ▶ If you're nonverbal, you can use **augmentative and alternative communication (AAC)** to tell people what you want. AAC means communicating in ways other than speaking out loud.
- ▶ With that freedom comes risks. There is a risk that you may make bad or unhealthy decisions. That is okay.
- ▶ Supported decision-making can help you undo bad decisions with help from your friends and family.
- ▶ You should be able to ask questions, raise concerns, and be able to sometimes express disagreement with someone who is supporting you.
- ▶ You have the right to have things explained to you in a way you understand, before being asked to make a decision about it.
- ▶ **Guardianship** is a legal procedure that takes your decision-making rights away. A guardian gets the right to make decisions for you.

- ▶ Supported decision-making is a model that lets us keep all of the rights that we should have. Sometimes, guardianship can take these rights away.
- ▶ You can still use supported decision-making if you're under guardianship.
- ▶ People in the U.S. are fighting to get laws changed, so that more people can have supported decision-making, as opposed to guardianship.

7

Post-Secondary Education



Image: Miniature people standing on towers of colorful building blocks.

**“Education is our passport to the future,
for tomorrow belongs to the people
who prepare for it today.**

—Malcolm X

What you'll learn in this chapter

- ▶ The different education pathways you can take after high school
- ▶ How to choose your educational path
- ▶ How to apply to and pay for college
- ▶ What to do if a school doesn't accept you
- ▶ What kinds of supports you can get at college
- ▶ How the Americans with Disabilities Act and Section 504 protect you from discrimination

Key terms

- ▶ transition
- ▶ Americans with Disabilities Act
- ▶ Individuals with Disabilities Education Act
- ▶ Section 504 of the Rehabilitation Act
- ▶ self-determination
- ▶ self-advocacy
- ▶ 504 plan
- ▶ Individualized Education Program (IEP)

Outline

- ▶ Overview
- ▶ During transition
- ▶ Self-determination and self-advocacy
- ▶ Education pathways
 - Traditional college
 - Modified college
 - Community college
 - TPSID
 - Trade school
 - Online courses
 - Community classes
- ▶ Choosing your educational path
- ▶ Accommodations and supports
- ▶ Legal protections
- ▶ How does this fit into my transition plan?
- ▶ Summary

Overview

This chapter is a guide to the education system. It will help you understand your rights and responsibilities as a student. You will learn how to access the education you want.

There are many different options for education. This chapter will help you to explore your options and learn how to apply for a college.

Once you have settled on a type of college, this section can help you pick a specific college, taking into account its price, size and location.

You will learn how to apply for courses, deal with interviews, and get the accommodations and supports you need at college.

We will discuss the different ways you can pay for college.

There is a section about how the Americans with Disabilities Act and Section 504 of the Rehabilitation Act of 1973 can protect your rights while you are a student. It will discuss what is considered discrimination under these laws.

We will also help you with what to do if you weren't accepted to the college you picked.

During transition

Overview

Transition means the major changes that youth with disabilities go through as we become adults. These changes can include:

continuing education

finding a job

finding a place to live

This chapter is about the transition from attending high school to pursuing higher education.

Rights

Your rights in education are protected by:

Title II and Title III of the **Americans with Disabilities Act**

The **Individuals with Disabilities Education Act**
Section 504 of the Rehabilitation Act

These laws are discussed later on in this chapter. You can read about them in more detail in Chapter 3: Know Your Rights.

You have the right to any accommodations or supports you need for:

- studying and learning
- participating in a lecture or other college environment
- getting to or around your college.

transition

the process of changing from one way of life to another way of life

Americans with Disabilities Act (ADA)

a federal civil rights law that protects people with disabilities from discrimination

Individuals with Disabilities Education Act (IDEA)

federal law that makes sure students with disabilities get a free public education that includes the supports they need

Section 504 of the Rehabilitation Act

Section 504 makes it illegal for organizations that get money from the federal government to discriminate against anyone based on disability

Individualized Education Program (IEP)

A plan for how a student with a disability will get the services and supports they need in school, including specialized education

You have the right to be free from discrimination from your professors and other students. .

If you have an **IEP**, you have the right to be included in all meetings where your post-secondary goals and transition plans are being discussed.

You have the right to choose what you do after you leave school.

Responsibilities

Your responsibilities are the things that it is up to you to do. You can get support and encouragement to fulfill your responsibilities. But you have to be the person who ultimately does these things.

If you know you need help and support with your responsibilities, it's also up to you to seek that help.

Before and during your post-secondary education, you are responsible for:

- Choosing your major
- Choosing your educational path
- Your own budgeting and finance
- Going to class and doing your work
- Reading any recommended material
- Seeking out accommodations and supports
- Doing your own research
- Submitting papers and course work on time

Goals

Your goals are the things you are aiming to do, or be able to do, as part of your transition to adulthood.

You need to figure out what your goals are, and write them in your transition plan, making sure you also write down how you plan to achieve them.

Your goals can be small and everyday, or they can be larger objectives for further in the future.

Some goals related to your education might be:

- Decide on a major you love and really want to do

- Pick a college that is ideal for you in terms of location, size, and your budget

- Prepare yourself for an interview

- Make some friends who have similar interests to you

- Become qualified for your ideal job

- Learn all the necessary skills of a trade

Self-determination & self-advocacy

self-determination

The idea that each person has the right to decide how to live their life

self-advocacy

The act of speaking up for what you need and want

What are self-determination and self-advocacy?

“**Self-determination**” and “**self-advocacy**” mean people with disabilities have control over their lives. Self-determination is the power to decide what you need and want. Self-advocacy is the action of making your needs and wants known.

Autistic people may need help from outside sources. Nonetheless, we get to decide what that help may be and who we wish to get it from. This is self-advocating.

Self-advocacy in post-secondary education

Here are some examples of self-advocacy in post-secondary education:

- Requesting accommodations, like an alternate test format
- Telling your parents what college you want to attend
- Doing your own research on colleges
- Asking questions about a school you’re touring

Education pathways

Overview

This section will explore the different education pathways you can take. There are several different types of college. There are some ways of getting education that do not require going to college.

- ▶ **Traditional colleges** are for people who have graduated high school and are eighteen or older. They are one of the most popular types of post-secondary education.
- ▶ You can **modify your traditional college pathway** to suit you - you can take fewer classes to lighten your workload, for example.
- ▶ A **community college** is another option for after you graduate high school. They offer degrees, and also job training programs. You can study full time or part time. They are less expensive than traditional colleges.
- ▶ For students with intellectual disabilities, there are transition and post-secondary programs, known as **TPSIDs**.
- ▶ **Trade schools**, career schools or vocational schools, last around 2 years or less. They focus on teaching the hands-on skills needed for specific careers.
- ▶ **Online courses** are another alternative. You can learn very specialized skills at your own pace. You need to be able to motivate yourself to keep up with the classes.
- ▶ **Community classes and workshops** are a great way to learn a variety of skills. You can take classes to learn basic cooking, clay sculpting, self-defense, karate, swing dancing, sign language, and more. There's no homework, grades, or pressure to earn a certificate.

“No matter what anybody tells you, words and ideas can change the world.

—John Keating,
Dead Poets Society

GED

a test you can take if you didn't graduate high school that gives you a certificate

Traditional college

Traditional colleges are a type of school that people go to after high school graduation. Students are almost always eighteen or older.

Being accepted into most traditional colleges requires a high school diploma or a **GED**. People who want to go to a traditional college usually look up many different colleges online, and choose some colleges that they like best. This is usually based on things like:

- where the college is located: its distance from where they live, etc.
- what subjects the college is best known for teaching
- how “good” the college is in general
- what sorts of clubs or student socialization groups exist

You then apply to all these colleges. This involves sending them information, like a high school transcript or test scores. Applying often also involves writing an essay. Then, you wait to see if the schools accept your applications.

Sometimes more than one school will accept your application. In this case, you choose one school from your options. Sometimes none of the schools will accept your application. In this case, you can try to figure out what went wrong, and re-apply the next year, perhaps to more schools.

Colleges give people who have studied for long enough degrees. The type of degree you get is based on how many credits you have completed. College classes are worth varying amounts of credits.

This amount is usually between one credit and four credits. It takes about sixty credits to get an associate's degree. An associate's degree usually takes two years. Bachelor's degrees take about four years to complete.

You can find a traditional college to get just about any kind of degree you can imagine. What you choose to study depends on:

- what you personally find interesting
- what kind of job you want to have, and
- what kind of job you think will be the best fit or earn the most money.

Degrees do not correlate perfectly with future jobs. For example, someone who wants to hire a writer might hire someone with a creative writing degree, or someone with a world-building degree.

Traditional college is often expensive, unless you can earn a scholarship or grant that pays for your education. Scholarships and grants are money awarded for things like:

- good grades
- participation in an extracurricular activity in high school
- being part of a historically underrepresented community
- athletic ability

Scholarships can pay for either some or all the costs of college. If you cannot get a scholarship or a grant, student loans are an option for paying for college. Loans are easier to get, but you have to pay them back in the future with interest.

Modified college

Most people who go to college go to get a degree. It usually takes about two years to get an associate's degree, four years to get a bachelor's degree, and six or eight years to get an advanced degree.

But, there are other possible goals and other timeframes that someone might use in college.

You may choose to take fewer credits than most students do. A full time student usually takes around twelve credits per semester. That's three or four classes. You might choose to take fewer classes. You might choose to take classes that are easier and are worth fewer credits, if you work best when you have a lighter workload.

Community college

Community colleges are a higher education choice. Students go to community college after high school graduation. Students are eighteen years old or older; many adults go to community colleges.

Some people attend full time and finish an associate's degree in two years. Other students take only a few classes at a time. When a student finishes all the classes in some programs, they get an associate's degree.

In some states, when a student gets an associate's degree, they are automatically accepted into a 4 year college program. Or, you can transfer the credits you got at community college to a 4 year college. Then you would only have two more years of study to get a Bachelor's degree.

Community colleges also have job training programs. You don't have to go for two years to finish some job training programs with a certificate. The certificate says a student

has completed training in a career field.
The certificate can help you get a good job.

Most community colleges do not have dorms. Students usually live at home or in an apartment near the college campus. Students go to classes, go to the library, study, and meet friends on campus. They go home when they are done.

A community college may be a good place to continue learning after high school and getting skills for a job.

Community colleges cost much less than four year colleges.

For autistic students or students with other disabilities, there may be help with tuition and other life skills. A student may be able to learn about things like first aid, personal safety, housing, finances, and medical care.

Transition and Postsecondary Programs for Students with Intellectual Disabilities (TPSID)

These are high quality, inclusive programs for college students with intellectual disabilities. They provide individual supports and services. TPSID projects focus on:

- academic enrichment
- socialization;
- independent living skills, including self-advocacy skills; and
- integrated work experiences and career skills that lead to gainful employment;

You can [search here](#) to find schools with programs supporting students with intellectual disabilities.

Trade schools

These schools are also known as career schools or vocational schools. There are both public and private trade schools. The programs of study generally are two years or less.

Trade schools focus on teaching the hands-on skills needed for a specific career. At the end of a trade school program, you'll get a license, certificate, or associate degree.

There are trade schools for many professions. Some examples are:

- Professional chef
- Hair stylist
- Automotive repair
- Electrician
- Legal assistant
- Makeup artist
- Registered nurse
- Medical laboratory technician
- Welder
- Airplane pilot
- Locksmith
- Carpenter

One of the biggest benefits to attending a trade school is you'll only focus on the skills you'll need to get a job in that field. This is different than a college or university.

Colleges and universities usually require that you take general education courses. Someone who goes to college to become a museum curator might have to take calculus and physics classes. At a vocational school, you only study the hands-on skills that you'll need.

Online courses

Online courses can be a great alternative to going to college. They are often overlooked as a valid educational pathway, because the qualifications are less official, and usually are for a specific subject area. This may be something you want to consider, if the career you want requires an official qualification. But, passing an online course will show an employer that you have a specific ability, or an in-depth knowledge about a specialized topic.

Benefits

It is usually much cheaper to take an online course—instead of the thousands of dollars you might spend on a college, a certificate for an online course could cost you under \$100.

It is free to audit a class, so you can try out a subject before you decide you want to commit to it and pay for it.

You can manage your own time and study when you want, instead of having to get up early for a lecture.

You can take breaks whenever you need to.

You do not have to move house, or search for, or pay for, accommodation.

You don't have to worry about crowds or social anxiety.

If you find something hard to understand, or you miss something, you can go back and re-read course material, or re-watch an online lecture.

You can study very specific in-depth subjects, that you would usually only be able to study as an aspect of more generalized courses.

Downsides

One possible downside to online classes is the lack of social interaction with your classmates and teachers. Depending on what your needs are in social situations, this can sometimes be a positive thing. But without the social aspect of studying, it can be hard to motivate yourself. You could ask a friend if they'd like to do the same class alongside you. Or, you could see if the website has a forum where you can talk about the class with other people.

Community classes and workshops

You may prefer to get involved in a community class or a workshop. These are usually much less expensive than college. The environments are often more relaxed and informal. A class could be a one-off session or it could be several. Community classes are smaller than college classes, but this can mean there is limited space for the class.

Community classes take place in different community centers in your neighborhood. You will need to figure out how to get there.

You are not assigned homework in community classes. They are not graded, which means you are more free to work at your own pace, but also means you won't get a qualification at the end of the class.

Your local park district might offer classes. You might have to prove that you live in the district by bringing a piece of mail to the park district office. Park district classes are much cheaper if you live in the district.

Community classes are a good option if you don't want to move away from home or don't have much money. Especially if you find it hard to motivate yourself to take an online class. They are also a great way to make friends.

You can find community classes online. Try searching "YMCA classes" or "park district classes" to find programs near you.

Some restaurants and coffee houses have bulletin boards for community events. You can try checking these boards for flyers about upcoming classes.

Choosing your educational path

Overview

There are several aspects you need to think about when picking a college. These are:

Price - this is more than just the price of college itself. Remember, you will probably need to pay for meals, any equipment or textbooks you need, plus extra money for occasionally going out with friends, or buying yourself nice things every now and then.

Size - how big the school is and how many people are attending. A smaller campus can help you connected you feel to your tutors and other students, and may be easier if you have difficulty with crowds or busy places. A bigger campus could mean there is a larger community, and you might be more likely to find others going through similar issues to you.

- **Location** - will you be happier in a small town, or in a large city? Maybe you will want to go to college that's not too far away from a big city, but in a quieter area. That way you can access lots of help and resources, but without the sometimes chaotic environment of the inner city.
- **Available programs** - which major you will pick and what the course requirements are.
- **Housing** - where and how you will need to live. Will you live at home? Will you share a dorm room?

Once you have picked a place, you will need to start applying to universities.

In the application section later in this chapter, we will cover the following topics:

- Traditional applications
- The Common Application
- Recommendation letters from your high school teachers
- Interviews with the college or alumni

Finally, we'll talk about the different ways to pay for your education, including:

- Free Application for Federal Student Aid (FAFSA)
- Scholarships and grants
- Student loans
- Part-time jobs

Picking a college

Price

Unless you get a full scholarship, you (or your parents) will have to pay for college. These costs can include:

Tuition

Housing

Meal plan

Textbooks

Materials like chemistry or art equipment

tuition

the cost of college classes, separate from the costs of course materials

Many people take out student loans to pay for college. The average student debt of a graduate in 2014 was \$33,000. Some people graduate with student loan debts of over \$100,000.

You have to start making payments on these loans after you graduate. Here are some things to keep in mind:

Do you qualify for any scholarships?

Does the school offer financial aid?

Does your financial aid offer have requirements attached?

Will your major have additional costs for materials?

Will you be paying for housing/a meal plan?

Are there on-campus jobs available?

Size and location

Some schools may only have about 1,000 undergraduate students in total. The largest school in the United States has over 50,000 undergraduate students.

Benefits of a smaller school can include:

- Feeling more connected with professors and peers
- Easier to ask questions in class
- Ability to get more in-depth with course material

Benefits of a larger school can include:

- Ability to focus more on yourself and what you need to get done
- A sense of anonymity
- Larger campus community

Campus visits are very important. You can get a better feel for the school's atmosphere from visiting. A small urban school will have a much different atmosphere from a large rural school. Also, a school can have a large campus without having a very large student body.

It's important to think about what's important to you. Some things to keep in mind:

- Will you need to drive or use public transit to get around?
- Would you prefer to attend a large school with its own community, or a smaller school within a larger city community?
- How big is the campus? How close are the buildings?

Available programs

You may find that the subject you want to study comes under a different major. Don't get too caught up on the title of the major. The titles of majors differ from school to school. Look at the course curriculum, so that you're sure what you will be studying. That is the most important thing to know.

Make sure you also know the course requirements, and pick up any recommended reading so you won't feel out of your depth when term starts.

It's a good idea to pick a school with a wide range of choices, in case you change your mind about your major. It's okay to be undeclared or to switch majors. Lots of people do this.

Many people think that if they don't go to college, they will be stuck in an unsatisfactory or low-paid job forever. It is not always the case. Also, don't feel pressured to go to a four-year college or to pick a major just because it's considered academic.

If you already know that the field you want to work in is something you can study at a trade school, it will be a much easier way in to that line of work. The amount of time you spend studying will usually be much shorter which can save you a lot of stress.

Housing

You might want to find out where you'll be living once you go to college. Some colleges require that you live in the dorms with roommates for the first year or two.

Some things to keep in mind:

- Will you be living on campus?
- Is off campus housing available?
- Will you be living with a roommate?
- How big are the dorm rooms?
- How many people are you comfortable sharing a room with?
- Are there nearby places that are quiet and/or open late, in case you need to get away from your room?

Applying to universities

Traditional applications

Here are some tips that apply to all applications:

- Apply as early as possible. It's easy to lose track of deadlines.
- Put all application deadlines on your calendar or in your phone.
- Double-check everything. You want to catch any mistakes before you send it!
- Have a few people check over your essay. These should be people willing to give you honest feedback.
- Don't lie on your application.
- Make sure you have all the necessary documents ready. This can include test scores and high school transcripts.

The Common Application

The Common Application is used by almost 700 colleges and universities. You fill out the application one time and can send it to any of the schools that accepts it.

The [Common App website](#) helps you keep track of application deadlines. The deadlines may vary between schools.

Some schools may require that you send a separate essay. Be sure to keep track of each school's requirements. The Common App website has [a form you can print out](#) and use to keep track of different requirements.

Recommendation letters

Many colleges will require that you have letters of recommendation. These letters usually come from high school teachers.

You can ask your former high school teachers for letters of recommendation even if you've been out of high school for a few years.

If you have an idea what major you want to study in college, it can be good to get a letter of recommendation from a teacher you had in related subject.

Interviews with college or alumni

Some colleges require an interview. These interviews generally focus on:

- Your thoughts about college
- Your academic background
- What you do in your free time
- Personality traits
- Your goals and plans

You'll also have time to ask any questions you have about the school. It's a good idea to have some questions prepared.

For example, you could ask:

- What does the college do to help students with career planning and internships?
- What advice would you give me as an incoming student?
- What preparations has the college done to handle emergencies?
- Can you tell me more about your study abroad program?

You can find more resources about preparing for admissions interviews in the Appendix.

Paying for college

Free Application for Federal Student Aid (FAFSA®)

Filling out the FAFSA can make you eligible for multiple types of financial aid, including:

- grants
- scholarships
- student loans
- work-study programs

The FAFSA asks about 100 questions. It can take anywhere from 20 minutes to 3 hours to fill out the form. You'll finish it quicker if you have the documents you need ahead of time. These can include:

- Your Social Security Number
- Your driver's license or state ID (if any)
- Your most recent W-2 forms
- Your most recent Federal Income Tax Return
- Your most recent untaxed income records
- Your current bank statements
- Your parents' Federal Income Tax Return
- Your parents' most recent W-2 forms
- Your parents' bank statements
- Your parents' untaxed income records
- Your parents' current business and investment records

NerdWallet has a helpful [guide to the FAFSA here](#).
You will never have to pay to file the FAFSA.

Scholarships and Grants

The words “scholarship” and “grant” are often used to mean the same thing. But, there are some differences. The difference is how they are awarded. “Awarded” means given. Scholarships are awarded on academic talent, and sometimes for extracurricular activities too. Grants are awarded based on need.

Governments, colleges, and private institutions like charitable foundations can all award grants and scholarships.

To apply for a grant or scholarship, you need to find out what paperwork you have to do and fill it out correctly. The process is often complicated. For example, you may have to contact several people. But, help with that is available on many campuses.

Read award letters carefully—financial aid awards may have conditions attached to them.

For example, you may need to have a certain GPA, or get an on-campus job.

In the appendix, you will find resources on finding and applying for grants and scholarships.

Student loans

You don’t have to pay back grants and scholarships. You do have to pay back student loans. Usually, student loans have an interest rate when you pay them back. That means that the amount you owe increases over time. The longer it takes to pay back your loans, the more you’ll end up paying.

There are different kinds of student loans. Some come from the government.

Anybody can get student loans from the government.

You might be able to get a private loan. But, government loans usually:

- Have lower interest rates

- Work with you to figure out a payment plan

- Don't need to check your credit score

- Can be consolidated when you graduate

Consolidation means that if you have multiple government loans, you can group them all together. Then, you can choose whether to make payments on all them at once or pick specific ones.

You can read more about the types of student loans at [Big Future](#) or [Debt.org](#).

Part-time jobs

You might be able to find a job on campus or in the community. On-campus jobs will work with your class schedule. Jobs off-campus might not be as flexible.

It's important to remember that the money you get from a job, even an on-campus job, doesn't go directly towards your tuition. You get your paycheck and can spend it on whatever you want. You will have to budget the money yourself.

Making a decision

There are a lot of factors to take into consideration when choosing a college! Some things you may be considering:

- Physical location
- Landscape and weather
- Community
- Cities you want to be near
- How close you want to be to home
- Diversity of student body
- Type of college
- Number of students
- School personality
- Available programs
- Campus facilities
- Athletics
- Financial aid available

Admission Possible has a great worksheet to help you figure out what you're looking for in a college. That worksheet is [here](#).

You can have other people help you make the decision. Chapter 8 is all about forming a support team that can help you with big decisions.

What to do if you weren't accepted

Competition for college admission is growing. More people are going to college now than in the past. If you were not accepted to a college you applied to, you still have options.

Talk to your high school guidance counselor.

They might be able to help you figure out why your application wasn't accepted.

Apply to another school. Many schools have "rolling admissions." This means they accept applications much later than most schools.

You can find a list of colleges with rolling admissions here:
<http://blog.prepscholar.com/colleges-with-rolling-admissions>

Consider community college. Community colleges are much cheaper than 4-year colleges. Most community colleges have arrangements with state schools. These arrangements let you transfer the credits from your community college classes to a 4-year university.

Take an online course. There are lots of online courses available from websites like edX, Coursera, and Udacity. You can take courses in the subject area you want to study for free. Some courses let you earn a certificate or even college credit for a fee.

Accommodations & supports

Disability services

504 plan

A plan for how a student with a disability will get the accommodations they need for a general education in school

Individualized Education Program (IEP)

A plan for how a student with a disability will get the services and supports they need in school, including specialized education

What is it?

When you get to college, you will no longer have a **504 plan** or an **IEP**. This does not mean you will no longer be eligible to accommodations and supports.

Every college will have an office for Student Disability Services. Different colleges will call this office different things, but every school will have one. Student disability service offices can help students with disabilities. They can help you identify and get the accommodations and supports you need to succeed.

In college, it is not the responsibility of disability services to find you.

It is your responsibility to identify yourself and seek them out. Most student disability service offices will have contact information available on the college website.

To be eligible for student disability services, you may need to provide documentation of your disability.

Requesting accommodations

It is your responsibility to seek out accommodations.

You will need to make an appointment with the disability office at your school. These can have names like “Student Disability Services” or “Office of Disability Concerns.”

Your school should have a webpage for the disability office. This webpage will explain what you need to do to start the process. It may also tell you what accommodations are available.

What accommodations can I get?

Here are some examples of accommodations:

Note takers in class. Having a note taker means you can focus on listening to lectures.

Copies of visual aids the professor shows during class.

Extra time for taking exams.

Taking exams in a separate and less distracting environment, away from the rest of the class. For example, fluorescent lighting might be a problem for you. You can request a room with non-fluorescent lighting for exams.

Receiving course materials in alternate format if you have difficulty reading text. This can include electronic files or audio recordings.

Small changes to assignments or exams.

Sometimes autistic or learning disabled students get extra time to complete assignments and projects. But, this can backfire. You might end up falling behind with lots of unfinished assignments.

Reduced course load. This means taking fewer classes than a typical full-time student. That way, you can spend more time on each class, and keep up with your assignments. Taking fewer courses at a time also means fewer shifts in attention between different courses.

This list was adapted from Jim Sinclair's Introduction in Navigating College: A Handbook on Self Advocacy Written for Autistic Students from Autistic Adults, [available here](#).

Documentation required

You should bring up-to-date documentation of:

- your disability, and
- your functional limitations.

Your functional limitations are the impact your disability has on your ability to function in college.

If you had an IEP in high school, it would be helpful to bring a copy of your latest IEP. But, that alone is not enough. A letter from a doctor or psychologist documenting your diagnosis is not enough either. If you had an evaluation in the last three years, you can bring that. Otherwise, you should request an updated report from a doctor or psychologist. This report should explain your functional limitations.

Your doctor or psychologist might suggest particular accommodations that would help you in college. They should explain how those accommodations relate to your functional limitations.

*You can read more about accommodations in our resource **Navigating College: A Handbook on Self Advocacy Written for Autistic Students from Autistic Adults**, [available here](#).*

Legal protections

The Americans with Disabilities Act

Title II and Title III of the **Americans with Disabilities Act (ADA)** protect you. Title II makes it illegal for public colleges and universities to discriminate against you based on your disability. This includes community colleges. Title III of the ADA makes it illegal for private colleges and universities to discriminate against you.

The ADA does not apply to religious universities or colleges. But, most religious universities and colleges still fall under Section 504. We discuss Section 504 in the next section.

Americans with Disabilities Act (ADA)

a federal civil rights law that protects people with disabilities from discrimination

Section 504 of the Rehabilitation Act of 1973

Section 504 makes it illegal for any program getting federal money to discriminate against you based on your disability.

This means that if the school accepts students who are getting financial aid from the federal government, Section 504 applies to them.

Section 504 of the Rehabilitation Act

Section 504 makes it illegal for organizations that get money from the federal government to discriminate against anyone based on disability

What kinds of actions are discriminatory under these laws?

Some examples of discriminatory prohibited by the ADA or Section 504 include:

- Denying you admission solely because of your disability

- Excluding you “from any course, course of study, or other part of its education program or activity” because of your disability

- Counseling you toward more restrictive career objectives than other students because of your disability

The Family Educational Rights and Privacy Act

The Family Education Rights and Privacy Act (FERPA)

is a federal law that protects the privacy of student education records. FERPA gives your parents certain rights related to your educational records until you:

- turn 18, or
- attend a school beyond the high school level.

When either of these things happen, you become an “eligible student.” That means the rights your parents had under FERPA transfer to you.

At that point, your parents can only see your education records if you let them. For example, your parents can’t ask your school to tell them what your grades are.

Your rights as an eligible student

You have certain rights as an eligible student under FERPA.

Your school must give you the opportunity to look over your education records.

You have the right to request that wrong or misleading information in your records is corrected. If the school denies that request, you have the right to a hearing about the denial.

If the school still doesn’t make the changes you want, you have the right to add a statement to your record. This statement would have your views on what you think should be changed in the record. Your statement becomes a permanent part of your educational records.

Under FERPA, a school can only share your records if you give written permission. There are some exceptions.

Under FERPA, your school can share your information without your consent if:

- You have a health or safety emergency
- You're under 21 and break a law or school policy about underage use of drugs or alcohol
- It's basic information to be used in a directory of students

Schools must notify eligible students of their FERPA rights every year. But, the school doesn't have to individually reach out to you. They might put the annual notification:

- in the student handbook
- in the school newspaper
- on the school website

You can file a complaint if you think your FERPA rights have been violated. You might file a complaint if your school:

- Doesn't provide you with a copy of your educational record after you request them
- Denies you the right to correct inaccurate information in your record, or doesn't offer you the opportunity for a hearing about the corrections you want made
- Inappropriately discloses information about you without your consent

Complaints must be filed within 180 days of the incident. You can get a complaint form from the Family Policy Compliance Office by calling (202) 260-3887.

For more information on your rights under FERPA, see Chapter 3.

How does this fit into my transition plan?

Setting post-secondary goals is a section of your transition plan. Pursuing higher education could be one of your transition goals. It could also be a pathway to another goal, like a career you want to have.

Deciding on your goals in higher education will mean going through the Strengths and Interests parts of your transition plan. Find an option that includes one or more of your strengths and interests. That way, you can find something that might be a little easier for you to do. Even if you find it difficult, the fact that you enjoy it and find it interesting will motivate you to get better and work harder.

For some people, it will be easier to choose a path that leads to their goal. For example, animals might be a special interest of yours. This might lead you to want to be a veterinarian. So you can find out about veterinarian assistant programs, and how you could access them.

For other people, their interests and strengths may not have an obvious career or study path. Talk to your guidance counselor about what you might want to study, or what you want to do as a career and what the best pathway is. If you're not sure, you could take skills and career assessments in school.

If you decide to go to college, it's likely that a big part of your transition plan will be preparing for that life change. You may need to learn some skills before you start college, like how to:

- budget
- apply for a loan
- prepare for an interview

You may want to work on your organizational skills, or math or writing skills, while you're still in high school. These will be in the Needs section of your transition plan.

If you get stuck with knowing what you need to do, or how to set clear goals for yourself, refer to Chapter 6: Making Your Transition Plan to help you.

Summary

- ▶ You have many different options for post-secondary education, not just four-year college.
- ▶ You need to pick a solution that works for you, taking into account

- What you are good at

- Your interests

- Your learning style

- Your budget

- Where and how you want to live

- The environment you work best in.

- ▶ When you start college, you will no longer have an IEP or a 504 Plan, but there are still disability services.

- It is now your responsibility to identify yourself as a disabled student and seek out the services you need.

8

Employment



Image: Three miniature construction workers working on a computer motherboard.

“We go through our careers and things happen to us. Those experiences made me what I am.

—Thomas Keller

What you'll learn in this chapter

- ▶ What kinds of employment there are
- ▶ How to prepare and look for a job
- ▶ What kinds of supports you can get on the job
- ▶ What legal rights you have when looking for jobs

Key terms

- ▶ discrimination
- ▶ reasonable accommodations
- ▶ disclosure
- ▶ Fair Labor Standards Act
- ▶ sheltered workshops
- ▶ Employment First
- ▶ integrated employment
- ▶ Schedule A
- ▶ Vocational Rehabilitation
- ▶ essential job functions
- ▶ résumé
- ▶ curriculum vitae (CV)

Outline

- ▶ Overview
- ▶ During transition
- ▶ Self-determination & self-advocacy
- ▶ Working with a disability
- ▶ Types of employment
- ▶ Supports & accommodation
- ▶ Researching jobs
- ▶ Applying for jobs
- ▶ Interviews
- ▶ Workplace culture
- ▶ Employment and the law
- ▶ How does this fit into my transition plan?
- ▶ Summary

There are many benefits to having a fulfilling job, and being autistic should not be a barrier to this.

Overview

This section of the book is about employment. It will discuss the issues affecting autistic people when it comes to working and finding a job.

This chapter teaches you to self-advocate as an employee or potential employee. There are many benefits to having a fulfilling job, and being autistic should not be a barrier to this.

This chapter also discusses getting accommodations and support for the things that might otherwise make your job difficult. We will talk about the option to disclose your status as an autistic person to the people you work with. We will discuss the pros and cons of telling people, and the reasons behind this decision.

We will go through different types of employment, like:

- integrated and competitive employment
- working full time versus working part time
- being self-employed
- supported employment, and
- vocational rehabilitation.

There are also government programs that help autistic people get jobs. These programs include Employment First and Schedule A letters.

We will talk about the difference between a résumé and a CV and help you to write them.

We will also talk about how to prepare for an interview and what to expect, and where to look for jobs in your chosen field.

There are more in-depth resources to help you with this in the resources list at the end of this book.

We are going to talk about your rights at work and during job searches, such as:

- worker's compensation

- wage laws

- unions

- overtime

There are laws that protect you at work. For example, the Americans with Disabilities Act and laws against sexual harassment.

Lastly, we will talk about where employment fits into your transition plan.

During transition

Overview

Transition means the major changes that youth with disabilities go through as we become adults. These changes can include:

- continuing education

- finding a job

- finding a place to live

This chapter is about the transition from attending high school to finding a job.

transition

the process of changing from one way of life to another way of life

discrimination

treating a person less favorably because of bias against their race, gender, sexual orientation, or disability

reasonable accommodations

changes made to a work environment, living space, or other building to make it accessible to people with disabilities

disclosure

the act of telling somebody else that you have a disability

Rights

You have the right to apply for any job, internship, or volunteer position you are qualified for.

You have the right to not be discriminated against when you apply for a job. **Discrimination** means being treated differently because you are autistic.

When you interview for a job, the interviewers are not allowed to ask you some kinds of questions. Interviewers cannot ask you about your disabilities. They can ask you about your ability to perform the job.

For example, your interviewer **cannot** ask, “Are you autistic?” or “Are you disabled?” They **can** ask you something like: “How do you handle stressful situations at work?”

You have the right to a legal salary that is the same as an employee without a disability. Your salary is how much money your employer pays you.

You also have the right to any **reasonable accommodations** you may need. You may need to disclose that you are autistic to get these accommodations. **Disclosure** means that you tell your employer that you are autistic.

Responsibilities

You have a responsibility to always do your job to the best of your ability. Otherwise, you can be fired.

Also, if you do need any accommodations or supports, it is up to you to get them from your employer.

Goals

Your goals are the things you are aiming to do, or be able to do, as part of your transition to adulthood. You need to figure out what your goals are, and write them in your transition plan, making sure you also write down how you plan to achieve them.

Everyone has a different set of advantages and disadvantages. This means that everyone has a different set of goals in life and in the workplace. Many people have workplace goals that are pretty similar.

These workplace goals include:

- Achieving a certain degree of financial independence

- Reaching a specific point of professional development

- Getting a feeling of personal satisfaction from your work

You can use these goals as starting points. You can change them to fit your own circumstances. No two people are going to have the exact same professional goals.

Here are some examples of professional goals that a journalist might have:

- Get a job as a journalist for BuzzFeed

- Make \$40,000 a year as a freelance journalist

- Join the Society of Professional Journalists

It's up to you to choose what goals you will set for yourself. Your transition plan will help you get the supports you need to reach your goals.

Self-determination & self-advocacy

self-determination

The idea that each person has the right to decide how to live their life

self-advocacy

The act of speaking up for what you need and want

What are self-determination and self-advocacy?

“**Self-determination**” and “**self-advocacy**” mean people with disabilities have control over their lives. Self-determination is the power to decide what you need and want. Self-advocacy is the action of making your needs and wants known.

Autistic people may need help from outside sources. Nonetheless, we get to decide what that help may be and who we wish to get it from. This is self-advocating.

Self-advocacy and employment

Here are some examples of self-advocacy about employment:

- Asking for workplace accommodations
- Finding and applying for jobs that you want
- Understanding and exercising your rights in your workplace
- Taking sick days when you need to

Working with a disability

Overview

Both the **Americans with Disabilities Act** (ADA) and regular employment laws protect you as an employee with a disability. Despite that, laws surrounding disability issues can be complicated. But this shouldn't stop you from pursuing a career! You can earn a fair wage and a place in competitive employment that suits your individual talents.

Here you will learn about accommodations and how to qualify for them. We will also cover helpful agencies and particular laws that have to do with employment—some good, some bad. We will also discuss different government programs that help people with disabilities find work.

Americans with Disabilities Act (ADA)

a federal civil rights law that protects people with disabilities from discrimination

Why work?

People may choose to work for many different reasons, but there are a few general reasons that most people use to explain why they work to others:

- **“I work because I want more money”:** Most people work because they need or want the money earned from it. It allows us to achieve more independence and stability, both financial and otherwise.
- **“I work because I enjoy what I do”:** A lot of people also choose to work just because they enjoy it. Some just enjoy the chance to get out of the house and interact with others. Other people have a strong passion for their work. Also, some people experience a sense of belonging or purpose from their work.

- **“I work because I want to build my résumé”:**

Some people, especially young adults, work in smaller jobs or internships to get more experience for a future career. Many employers prefer to hire more experienced employees. They want people that have already proven themselves to be capable of working well. Often, an easy way to do this is by obtaining a volunteer position, or by working an easier job before applying for a more difficult position.

There are many benefits an autistic person can experience through employment. These include:

- earning money
- meeting people with whom you share interests, and
- enjoying your job.

Can I work?

Absolutely! Everyone has a different set of strengths and weaknesses. There are jobs available for all types of people with many different skill sets.

If you dislike social situations, you can look for a job with a company that gives you more independence. You can also look for a position where you work on your own, like driving trains. There are even some positions that let you work from home, if that is an environment you would prefer.

If you need a workspace that is quiet and comes with a routine, an office job might work for you. If you need a job that is not too physically demanding, there are jobs that don't involve physical exertion. For example, some jobs let you work with computers at a desk.

Barriers to work

Most people who look for a job face difficulties. For people without disabilities, this difficulty can come from lack of experience or a poor job market, among other things.

For autistic people, finding employment is more complicated. Autistic people face some of the same difficulties as neurotypical people in finding a job. But autistic people also face other, unique difficulties.

Job accommodations can help address these difficulties. Accommodations are changes made by an employer to help make a job easier for people with disabilities. You have to ask for accommodations to get them.

There are available work supports for people with disabilities. An intellectual or developmental disability (I/DD) agency is a state organization that funds services for people with intellectual or developmental disabilities. I/DD agencies fund different types of services.

All 50 states and the District of Columbia have I/DD agencies. [Autismnow.com has links to each I/DD agency website](https://autismnow.com/links-to-each-i-dd-agency-website/). Each state agency helps people with disabilities to find jobs.

Real jobs for real pay

Fair Labor Standards Act
federal law that
established the minimum
wage and other rules
about employment

Section 14(c)
part of the Fair Labor
Standards Act that says
people with disabilities
can be paid less than
minimum wage if their
employer gets a special
certificate

sheltered workshop
a place where people with
disabilities are employed
in a segregated setting,
and are often paid less
than the minimum wage

Many people with disabilities are still paid less than minimum wage. This practice is legal because of a loophole in the **Fair Labor Standards Act of 1938 (FLSA)**. This loophole is **Section 14(c)** of the FLSA.

Section 14(c) allows the Secretary of Labor to give employers Special Wage Certificates. These certificates let employers pay workers with disabilities wages that are less than the federal minimum wage. These certificates are usually used in **sheltered workshops**.

In sheltered workshops, people with disabilities have to work separate from people without disabilities. We are also paid much less than our coworkers without disabilities. These sheltered workshops do not have to follow the rest of the FLSA. This is a big problem for people with disabilities who work there.

There are hundreds of thousands of people with disabilities who are paid less than the minimum wage for their work. This is harmful to these workers. Many workers with disabilities do not make enough money to survive. They have to rely on government social programs. These programs can be difficult to sign up for, and often have their own limits on how much money you can get. This makes life more difficult for many people with disabilities.

If people with disabilities get the supports we need at work, we can take part in jobs just like people without disabilities. Because of this, disability advocates argue that people with disabilities should get the same wages as people without disabilities.

There are many different kinds of work environments besides sheltered workshops where people with disabilities are treated more fairly. You will learn more about other kinds of workplaces in the next sections of this tool.

Employment First

Employment First is a government program. Employment First helps people with disabilities find and keep **integrated employment**. Integrated employment means jobs that pay at least minimum wage. Your employer pays you directly. You work alongside people without disabilities.

As of 2016, there are 46 states with some kind of effort that focuses on Employment First. Nineteen states have official state policies that promote integrated employment for people with disabilities.

Employment First

government program which helps people with disabilities find and keep integrated employment

integrated and competitive employment

employment where people with disabilities make at least the minimum wage, and work alongside people without disabilities.

Schedule A letters

The United States government has two different hiring processes. One is competitive, and applicants “compete” through a review process much like for any other job. The second process, designed to be non-competitive, is **Schedule A**.

Schedule A lets government agencies pull applicants with disabilities into their own applicant line. That makes the interview and hiring process easier.

It is easier for an interviewer because they can devote more time out of their day to interviewing fewer applicants. They can give more time to applicants who move or communicate slower than someone in the “normal” line.

Schedule A

hiring process that gives people with disabilities an advantage when applying for government jobs

Schedule A was created in part because of employer discrimination against people with disabilities.

When Schedule A is used, a person isn't guaranteed a job in the government. But, if they feel that you are qualified for the position, you will be considered for the job.

Sometimes there is a "quota" that the government agency needs to meet. That means they are looking to hire a certain number of people with disabilities. Let's look at an example where a Schedule A applicant and a regular applicant are applying for the same job. Both applicants have exactly the same job history and skill sets. Whoever is in charge of hiring will look at these two applicants and not know who to choose because they are both so perfect! But then they'll see that one of the applicants is using a Schedule A letter. It's likely the applicant with a disability will get hired for the position. Don't worry about the regular applicant! Statistically, they are more likely to find a job in their chosen field almost anywhere. You aren't "stealing" a job from anyone. You are just exercising your right to get fair and equal employment.

How can you get a job through Schedule A? [This resource explains how to use USAJOBS.gov](#) (the United States government hiring portal) to get Schedule A status.

Types of employment

Integrated and competitive employment

Competitive employment means that people with disabilities will get paid at least the minimum wage for their work. You will be paid at a rate that is like people without disabilities who work in the same place as you. **Integrated employment** means that people with disabilities work alongside people without disabilities.

Integrated and competitive employment are important for workers with disabilities. It helps us to be able to make enough money to live more independently. Integrated and competitive employment can also gives people with disabilities self-confidence and a sense of acceptance in the workplace.

competitive employment

employment where people with disabilities make at least the minimum wage

integrated employment

employment where people with disabilities work alongside people without disabilities

Customized and self-employment

In customized employment, you are hired based on your strengths and weaknesses. The company that hires you will often take duties from another employee to give to you, based on what you can handle. The employer takes supports and services into consideration.

Self-employment is another form of customized employment. Self-employment lets people get help to create a small business. It would be a match between your strengths, your weaknesses, and the needs of the local market. It would also include support strategies to help your business be successful.

vocational rehabilitation

A process that helps people with disabilities overcome barriers to finding and keeping jobs

Supported employment (job coaches)

Supported employment helps people with disabilities find and keep jobs. These jobs are integrated and competitive. Supported employment provides individualized supports that help you find and succeed in the type of job you want. This support often comes from a job coach.

Supported employment is often used when you have not been able to work in a competitive setting. It can also be used if you've had interruptions in work.

A state agency pays for the supported employment. This is usually some sort of **vocational rehabilitation** agency. A community agency provides the service in a way that you prefer.

Vocational rehabilitation

Vocational rehabilitation (VR) is a service nationwide that helps people with disabilities find work. A wide range of services are available, including:

- general education
- job skills training
- funding for equipment

VR works with individuals to help you create a plan for where you want to get and how you might get there. Based on that, they can then decide how to proceed and what help they can give.

Part time vs. Full time

Most states define part-time employees as people who work fewer than 35 hours per week. Full-time employees are usually people who work 40 or more hours per week. “Full-time” and “part-time” are **not** defined by the **Fair Labor Standards Act**. Your state’s employment laws determine whether you are considered full-time or part-time.

Fair Labor Standards Act
federal law that established the minimum wage and other rules about employment

Rights

Both full-time and part-time employees have all the rights under the Fair Labor Standards Act. This includes the right to a minimum wage and the right to be paid for overtime work.

Benefits

Part-time employees usually do not get company benefits that full-time employees get. State labor laws or company policies determine which benefits part-time employees can get.

These benefits can include:

- **Health insurance** benefits
- Paid or unpaid vacation days
- Sick days

health insurance
an arrangement where a company, or the state, pays for certain health care services.

Supports & accommodation

Overview

This section is about the things that make working easier for people with disabilities. It covers disclosure and getting reasonable accommodations.

disclosure

the act of telling somebody else that you have a disability

reasonable accommodations

changes made to a work environment, living space, or other building to make it accessible to people with disabilities

Disclosure means letting your employer know you're autistic. We'll talk about why you might or might not want to disclose.

Reasonable accommodations are adjustments to your work environment that make it possible to:

- apply for a job
- perform the tasks required of the job, and
- enjoy the same benefits of employment that non-disabled people working the same job would experience.

Disclosure

What is it?

Disclosure means telling your employer that you are autistic. It is your decision whether you disclose any disabilities that you have.

This is a complex and personal decision. There is no right or wrong decision.

On the next page, we'll list some reasons for why you might want to disclose, and some reasons why you might not.

Reasons to disclose

You may want to disclose your disability because:

You have disclosed it before and it makes you feel more comfortable

You want to be honest with your supervisor or coworkers

You want to clear up misunderstandings with coworkers

Reasons not to disclose

You may not want to disclose your disability because:

You don't want to be treated differently

You find it difficult to discuss

It isn't relevant to your job

Reasonable accommodations

The **Americans with Disabilities Act** (ADA) protects you from disability discrimination in the workplace. You can have reasonable accommodations to help you do your job. The ADA protects you as long as you can perform the **essential functions** of the job.

In the next two sections, we'll talk more about what kinds of accommodations you can have, and what an "essential function" of a job is.

Americans with Disabilities Act (ADA)

a federal civil rights law that protects people with disabilities from discrimination

essential job functions

the core tasks someone must be able to do in order to do their job

What are reasonable accommodations?

Reasonable accommodations are changes or adjustments to a job or work environment. These changes would allow a qualified applicant or employee with a disability to:

- Take part in the job application process
- perform the essential functions of a job
- enjoy benefits and privileges of employment equal to those enjoyed by employees without disabilities

What kinds of accommodations can I have?

Some examples of reasonable accommodation:

- acquiring or modifying equipment or devices,
- job restructuring,
- part-time or modified work schedules,
- reassignment to a vacant position,
- adjusting or modifying examinations, training materials or policies, or
- providing readers and interpreters

It is a violation of the ADA to not provide reasonable accommodations to you if you are qualified for the job. Being qualified for the job can mean:

- Having a college degree in a certain field
- Having a license to do the work needed
- Having a certain number of years of experience

There is one exception where you can be denied accommodations. If the accommodations would impose an **undue hardship** on the employer, you can be denied accommodations. Undue hardship means that the accommodation would be difficult or expensive to provide. Whether an accommodation imposes an undue hardship to the employer is determined on a case-by-case basis.

The ADA protects you from disability discrimination if you can perform the essential job functions. You can have accommodations to perform these functions.

Which job functions are essential?

A job duty is an essential function if any of the following is true:

- The reason the job exists is to perform that function.

- Only a few employees can perform the function.

- The function is so specialized that the employer hires people just for their skill in performing that function.

If a function is essential, you must be able to perform it with reasonable accommodations.

If you cannot perform the function, then you are not legally qualified for the job.

This means that you cannot bring a disability discrimination lawsuit against the employer.

Here are some examples of cases where a disability discrimination lawsuit **would not apply** if the job functions are essential:

- If a job requires you to be able to stand and lift 50+ pounds, and you cannot.
- If a job requires answering and speaking on telephones, and you have difficulties with verbal communication.
- If a job requires driving around in a car making deliveries, and you are unable to drive due to a disability.

Supported employment

integrated employment

employment where people with disabilities work alongside people without disabilities

competitive employment

employment where people with disabilities make at least the minimum wage

vocational rehabilitation

A process that helps people with disabilities overcome barriers to finding and keeping jobs

Supported employment helps people with disabilities find and keep jobs. These jobs are **integrated** and **competitive**. Supported employment provides individualized supports that help you find and succeed in the type of job you want. This support often comes from a job coach.

Supported employment is often used when you have not been able to work in a competitive setting. It can also be used if you've had interruptions in work.

A state agency pays for the supported employment. This is usually some sort of **vocational rehabilitation** agency. A community agency provides the service in a way that you prefer.

Researching jobs

Overview

All jobs require preparation, both for the interview and for the job itself.

Depending on the job you want, it is likely you will need to do the following:

Do your **research**

Get **qualifications** for the job you want

Think about the **qualities** best suited to that work environment

Build **experience**

Have a well written résumé and/or CV.

Qualifications and qualities

No matter what job you want, there will be certain requirements you have to meet.

These fall into two main categories:

Qualifications

Qualities

Qualifications

Qualifications are formal requirements. You usually won't be considered for a job if you don't meet the qualifications.

The next page has examples of qualifications.

Qualifications can include:

- Certain level of education
- Licenses (including driver's license)
- Professional certificates
- Prior experience
- Specific abilities

Try reading job postings on websites like Indeed.com.

Here are some examples of formal requirements from three different jobs:

Linux Systems Administrator

Required Skills:

- ▶ Have 1-2 years of experience in administering UNIX/Linux based systems. Working knowledge of system management tools and logical file systems
- ▶ Knowledge of apache
- ▶ Knowledge of Red Hat Linux
- ▶ Knowledge of IP tables, dns/dhcp, syslogd, vi/vim
- ▶ General knowledge of mysql/mariadb/mongodb
- ▶ General knowledge of version control systems.
- ▶ General knowledge of Windows Desktop and Server
- ▶ Scripting: Shell
- ▶ Have effective verbal and written communication skills for the purpose of providing information to team members, management, and staff.

Tattoo Artist

Required education:

High school or equivalent

Required experience:

Tattooing: 2 years

Required licenses or certifications:

- ▶ Tattoo License
- ▶ Bloodborne Pathogens Training
- ▶ CPR/First Aid
- ▶ AED

Pizza Delivery Driver

Job requirements:

- ▶ At least 18 years old
- ▶ Valid driver's license with a safe driving record
- ▶ Own a vehicle with insurance
- ▶ Ability to read a map,
- ▶ Ability to locate addresses within designated delivery area
- ▶ Ability to navigate difficult terrain including multi-story buildings.

Qualifications are usually straightforward. Job listings might also include **qualities**, which we will talk about on the next page.

Qualities

What are they?

Qualities are more flexible than qualifications. They are traits that you have as a person. Employers often list desired qualities in job postings. Sometimes they are mixed in with the formal qualifications.

What qualities might a job listing include?

Here are some examples of desired qualities from a variety of job listings:

- Outgoing, self-motivated, enthusiastic, with a professional appearance and a passion for delivering exceptional guest and technical service.
- Friendly and welcoming individuals who enjoy providing pleasant and courteous food service to our guests!
- Position requires a confident, self-motivated, multi-tasked individual with integrity in the use of resources.
- No drama, drug free with easy going personality.
- Ability to remain effective under pressure; ability to handle stress in a manner that is acceptable to others and to the organization
- Energetic - Positive - Self-Driven - Mature - Competitive - Take Charge Individual

These things are what almost every employer is looking for. They are usually listed on job ads using the same or similar words.

Why does an employer care what my personality is like?

“Quality” requirements are actually a hint about what the job itself is like. For example, a job description might say you need to have:

- a “fun and positive attitude”
- a “passion for customer service”, or
- “superior interpersonal skills”

You might be thinking—who has a “passion for customer service?” Well, probably very few people. So why do they list it as a requirement?

Because job “quality” requirements don’t really mean this is what you actually need to be like all the time!

It means that an employer has expectations about the way employees should socially interact, **and this is part of performing the tasks of the job.**

For example, these might be qualities needed for a barista. A barista is a person who makes coffee. A barista would be dealing with customers.

In addition to having their orders processed quickly and correctly, these customers will also expect to be greeted with a cheery, light-hearted barista. Your customers might be rude to you, but you would be expected to keep calm and be polite regardless.

Remember, you are representing a company. Companies want to have a reputation for having happy, friendly employees.

Job “quality” requirements are actually a hint about what the job itself is like.

This is especially true for jobs that you can get without specialized training. For example:

- waiters
- cashiers
- ushers at movie theatres

There is less pressure to be this way in jobs that are less centered around customer service and social interaction. Or, jobs that are not a part of big corporations. For example, you might apply to be a computer system administrator or a bus driver. These jobs would not require putting as much energy into being friendly or seeming happy all the time.

This is related to workplace culture. We will talk more about workplace culture later.

Where should I look for a job?

Online job boards are the most popular way to find job openings. Major job boards include Monster.com, Indeed.com, and Careerbuilder.com. These sites are so popular that you might get lost in the crowd.

You might want to try doing a search on specific job boards, for example:

- Snagajob.com - Best for searching for hourly work
- FlexJobs.com - For jobs with more flexibility
- DiversityWorking.com: People with disabilities
- OneDayOneJob.com - Good for finding entry-level positions
- AllRetailJobs.com

Gathering information about jobs

You will need to have some idea of the required skills or qualities for the job you want to have.

To research this, you can look up listings for that job to see what the employers are looking for. Most jobs have industry-wide standards and expectations that do not vary that much between listings.

Save and print a few different listings. Four or five is a good amount. Compare the listings—look at the similarities between them. Pick out the things it's likely you'll need to learn how to do or have a qualification in.

This will help you decide what to do next to get the job you want. This can be a part of your transition plan.

Build experience

Education

Some jobs have certain requirements.

You might need a college degree.

You might need to have completed vocational school training.

You might need a particular skill or skill set.

- ▶ You may need to prove that you have this skill. This can mean passing some sort of test, or showing past experience with that skill.

If you already know what field you're interested in working in, take a look at the job requirements. Usually, there will be similar requirements. Then, you can make a plan to learn the required skills, or get the required training or qualification.

See Chapter 7: Post-Secondary Education for more information about training and qualifications.

Internships

Some career paths are easier to start with an internship. Internships provide real-world job experience to people, usually young people. Internships are usually brief.

The focus of an internship is job training; an internship is like an introductory job. Interns work part-time, no more than 20 or 25 hours a week, giving them free time to go to school or college. The work might be less demanding than what full-time employees would be expected to do. At the end of the internship, interns are sometimes hired as full-time employees.

An internship is different from a traditional job. Besides being part-time, **internships are often unpaid**. The employer will not pay you for your services. The reason people accept unpaid internships is because they want to build up experience in their preferred field. You can list this experience on your résumé. This experience can make you more noticeable to potential employers.

The main advantage of an unpaid internship is work experience. But, people who don't have the money to work a volunteer job won't be able to work an unpaid internship. Also, paid interns may be more likely to find a job.

Many students take on part-time work while they are interns. Other students get financial help from their parents while they work their way through an unpaid internship.

If you are a low-income student, there are some companies offering subsidized internships. The U.S. Department of Labor has an extensive list of companies that offer internships. [You can search this list here.](#)

Applying for jobs

Résumés & CVs

What is a résumé?

A **résumé** is a brief summary of your work experience and is what you send with a job application. It is no longer than two pages. A résumé includes your:

- education
- most recent and relevant work experience
- special skills and certifications, and
- a couple references.

Each résumé you have should cater to the specific job you are applying for. In other words, your résumé will be different for each job you apply for.

résumé

a one-page summary of your education, work experience and any other credentials or accomplishments

What is a CV?

A **curriculum vitae**, or CV, is a longer, more general document. It contains the information in a résumé, as well as awards, publications, honors, affiliations, etc. Having an updated version of both can help make your job search experience much easier.

curriculum vitae

a longer, more detailed summary including education, work experience, awards, honors, and publications

What should I include?

In your résumé and CV, make sure to showcase the things that would make you an asset to a company. Do you know another language (including ASL)? Are you familiar with Augmentative and Alternative Communication, or AAC? Do you have relevant computer skills? Do you have any certifications? Any of these, as well as other relevant interests, skills, accomplishments, and experiences, can help you to stand out as an applicant.

Also, many websites, such as visualcv.com, allow you to host your résumé or CV online for free. Putting a URL to an online CV can allow an employer to learn more about you as an employee, further helping you to stick out as an applicant. There are many online platforms like about.me which act as the website version of a business card.

You can find links to sample résumés and CVs in the Chapter 8 Resources starting on page 366.

Being proactive

When applying for a job, keep in mind that for each open position, there are many different applicants competing with you for that opportunity. So, it is important to be proactive in your application process.

Seek out the companies you wish to work for. Send in résumés and applications for them to keep on file, even if there aren't any openings at that time. This way, employers will know that they can already contact you if something becomes available.

What should I do after I send my application?

Once you have sent in your application, you should get a confirmation that the company received it. After this, the best thing to do is **wait for them** to contact you.

What if I haven't gotten a confirmation?

If you have not gotten a confirmation after several weeks, it is okay to contact the company **once** to ask if they got your application. Contacting the company more than that will make you seem annoying. It will hurt your chances of getting an interview.

What if they got my résumé, but I don't hear anything back from them?

If In the vast majority of cases, they have not forgotten. If they are interested, they will contact you. If they are not interested, you might not hear back from them. It's a good idea to apply to several companies at once. That way, you have a better chance of finding a company that is interested.

Interviews

How do I prepare for an interview?

The most important thing to remember is that the company is looking to fulfill **their** needs as a company. You should tailor your interview answers to the company. Your answers should show why you are the best person to fulfill the company's needs.

Here are three things you should absolutely do during your interview preparation:

- 1. Research the company.** What are their values? What is their company culture like? [Glassdoor](#) has reviews of companies by actual employees.
- 2. Practice answering common interview questions.** You can get a friend or family member to pretend to be the interviewer.
- 3. Memorize a few success stories that show your skills.** [This article from The Interview Guys](#) goes more in-depth about how to use success stories during an interview.

Common interview questions

- ▶ Why should we hire you?
- ▶ What are your strengths?
- ▶ What are your weaknesses?
- ▶ Where do you see yourself in five years?
- ▶ Why do you want to work for us?
- ▶ What do you know about the company?
- ▶ How would your coworkers describe you?
- ▶ How do you deal with pressure?
- ▶ How do you manage your time?
- ▶ Why did you leave your last job?
- ▶ What are your goals?
- ▶ How do you make decisions?
- ▶ Why is there a gap in your résumé?
- ▶ How do you handle difficult customers?
- ▶ Do you have any questions for me?

What should I wear?

It's a good idea to ask the person setting up the interview what you'll be expected to wear. Generally speaking, you'll be expected to dress professionally.

Here are some tips for dressing professionally:

- Avoid jeans, shorts, and flip-flops

- Interview suits should be simple and dark colors

- Wear clothes that fit you well (you may need to get a suit tailored)

- Avoid bright/flashy/distracting jewelry, neckties, makeup, and nail polish

- Shoes should be in good condition, not scuffed

- Clothing should be clean, neat, and ironed

- When in doubt, dress conservatively. It's much better to be more dressed up than too casual.

After the interview

Ideally, plan ahead for what to do after the interview by asking an employer their timeline and when you can expect to be contacted. Do this during the interview.

- That way, you can contact them at times that fit with their plans.

- You are more likely to get a helpful response, and run less risk of coming across as badgering or nagging.

If you haven't asked the employer about time limits, at least two weeks is a good amount of time to wait before getting in touch after an interview.

Asking if you got the job can be too forward, but just asking how the job search is going won't really get you the information you need, and is too vague a question. Instead, you can ask what the timeline is for the next steps for them hiring someone.

- Keep it short and informal, but don't use exclamation marks or tell jokes.
- Always thank the person for the interview in your follow-up response.

Script

You could send an email saying something like, "Hi Chandler, thanks for interviewing me a few weeks ago. I wanted to get an update about the Data Processor position. I'm really interested in the job. Do you have an approximate timeline for the hiring process?"

Workplace culture

What is it?

We have already touched on workplace culture a little. Workplace culture includes the expectations about how you:

talk

act

dress

There are many differences in the way you behave at work and how you behave at home. But customs also vary among workplaces.

Workplace culture is complex and varies from place to place. All the different aspects of it could fit in a whole separate book!

There are resources in the appendix of this book if you want to better understand workplace culture.

Dress code

Some workplaces might not have a dress code, but you are still expected to look professional. Other places are more casual. Pay attention to how other people are dressed and follow suit.

Schedule

Time is kept differently among workplaces. Many places operate a strict 9 to 5 schedule and everyone leaves at 5pm. Other times, employees might stay behind later, or come in early. There may be flexibility on when you can take a lunch break and how long that break is. Then again, there may not.

Communication

Sometimes employees communicate with each other in a casual, friendly way. But there are some jobs where you're expected to be more formal in your communication - maybe you need to ask if you can speak to someone before starting a conversation with them, or shake hands when greeting, or avoid using slang.

Workplace communication: Justin's story

Justin has just started a new job at a fast food restaurant. He's not sure what the norms are for communicating with his co-workers. For the first few days, he doesn't start conversations with anybody. He pays attention to how his co-workers interact with each other.

Justin figures out that his co-workers like to make lighthearted conversation about pop culture or current events. He learns that it's okay to make conversation when the store isn't busy. But, when there are lots of customers, it's not appropriate to have conversations with his co-workers.

Interaction with customers

As mentioned above, the way you interact with customers also varies—even among similar workplaces. In some workplaces, like if you worked at a fancy restaurant, you would be expected to be calm, formal and polite. In others, like at cafés, you may be expected to be upbeat, friendly and much less formal in your speech.

Employment and the law

Wage laws

FLSA Section 14(c)

Section 14(c) of the Fair Labor Standards Act says that people with disabilities can be paid less than minimum wage. For a company to be able to do this, they have to get a special certificate from the U.S. Department of Labor. These wages are called “Special Minimum Wages”.

Special Minimum Wages are usually used in **sheltered workshops**.

sheltered workshop

a place where people with disabilities are employed in a segregated setting, and are often paid less than the minimum wage

Minimum wage

Minimum wage is also covered by the Fair Labor Standards Act. The idea behind minimum wage is that a worker should be able to work a standard work week and make enough money to cover the basic needs of themselves and their families. It protects workers from unfairly low compensation.

minimum wage

the lowest possible wage you can be paid according to the law

Receiving minimum wage depends on many factors. Certain employees don't qualify for minimum wage. This includes:

- independent contractors

- workers who earn tips or commissions

- farm workers

- employees who are under 20 years old, and

- student workers.

With employees who earn commissions or tips, their tips are supposed to make up the difference. There are laws in place to protect workers who do not make the minimum wage from their commissions or tips so that in the end they at least make the minimum wage.

The federal minimum wage is currently set at \$7.25 an hour. A state or city can choose to pay more than the federal minimum wage. But, a state or city cannot pay less than the federal minimum wage.

Overtime

Wage and hour laws vary from state to state. The average laws say that if an employee works more than 40 hours in a week, they are to be paid time and a half. Time and a half means 50% of your normal hourly pay + your normal hourly pay for that time.

For example: Someone who is paid \$10.00 an hour works 41 hours. For that week, they will be paid \$10.00 for their 40 hours, and they will be paid \$15.00 for that one hour of over time.

Not all employees can get overtime pay. We encourage you to research the Wage and Hour Laws of your state to make sure that you are making a fair wage

You can learn more about your state's Wage and Hour Laws here:
<http://www.nolo.com/legal-encyclopedia/wage-hour-laws-state>

Breaks

Meal and rest breaks are not required by federal law, but many states have their own laws in regards to breaks. What federal law **does** require is that if an employer allows for break time any breaks that are 5 to 20 minutes long must be paid.

A meal break is considered a break in which an employee is relieved of all duties for a specified amount of time. This is usually 30 minutes. During that time an employer is not required to pay their employee. But, if an employee works through their lunch break, they must be paid.

Workers' compensation

If you are injured while at work, or become ill due to your work, you may be able to receive **workers' compensation**. This is often shortened to “workers' comp.” Workers' comp can help with medical bills. It may give an employee partial wages while they can't work.

After an injury or illness, you must file a workers' comp claim to be considered. You will have to get an independent medical examination to verify any claims that you have made. At that point the claim will be gone over and either approved or denied.

There are many other things that workers' compensation deals with. This includes permanent disability due to injury or illness. If you are denied workers' comp, you may want to get a lawyer to help fight for your case.

Each state has its own laws about what kinds of injuries are covered by workers' comp.

workers' compensation

a form of insurance for workers who have gotten injured or sick due to their work

The Chapter 8 Resources section starting on page 366 has links to help you find your state's office and laws dealing with worker's comp.

Unions

A union is an organized group of workers. They voice concerns about their workplace as a group. A single employee may not have the ability to change the unfair practices of an employer. But, a union has more power. A union may be able to change wages, hours worked, benefits, safety on the job, and many other issues.

Federal law allows employees to join or form unions to act together to improve their job conditions. The National Labor Relations Act (NLRA) specifies what an employer can and can't do in regards to a labor union.

At-will employment

Being employed 'at-will' means that an employer can let an employee go at any point. This means that an employer **does not have to have good cause** to end your position. All employees are considered at-will, unless you have a contract that says you are not employed at-will. You can rely on those contracts to fight your termination if it does happen without good cause. It would be considered a breach of contract.

What at-will employment **does not** allow is illegal **discrimination**. Employers are still subject to federal and state laws about equal opportunity employment. Your employer cannot fire you for your race, religion, age, sexuality, or gender.

Also, employers must follow all laws set forth by the ADA. This means you cannot be discriminated against due to disability.

You also cannot be fired because you have made a complaint about:

- harassment
- illegal activities, or
- health and safety violations.

discrimination

treating a person less favorably because of bias against their race, gender, sexual orientation, or disability

Sexual harassment

Sexual harassment is any unwelcome sexual advance or conduct while you are on the job. **You are not required to work in an intimidating, hostile, or offensive atmosphere.** Sexual harassment doesn't have to be blatant. Blatant sexual harassment includes groping or threatening to fire a person if they don't perform sexual favors. Sexual harassment can also be subtle, such as sexual jokes. No matter your gender or sexuality, if you feel that you have been subjected to sexual harassment, you have the right to report it.

Both state and federal laws protect workers from sexual harassment on the job.

There are many things that you can do to stop the harassment. Of course, if you feel strong enough, you can tell the harasser to stop. Another thing that you can do is take your complaint to your supervisors, or the people who are above them. You must first use your company's internal complaint procedures and allow them to try to fix things before you can take your case to court.

Document all claims of sexual harassment as thoroughly as possible. This way, there is no question about when, where, or how you were sexually harassed.

If your employer doesn't help with the sexual harassment, the next step is to take your complaint to the Equal Employment Opportunity Commission (EEOC).

NOLO has [a guide on the next steps to take](#) when making a sexual harassment complaint.

Americans with Disabilities Act (ADA)

a federal civil rights law that protects people with disabilities from discrimination

reasonable accommodations

changes made to a work environment, living space, or other building to make it accessible to people with disabilities

The Americans with Disabilities Act

Under the **Americans with Disabilities Act**, you have the right to reasonable accommodations in your workplace.

Reasonable accommodations are changes or adjustments to a job or work environment. These changes would allow a qualified applicant or employee with a disability to:

- Take part in the job application process
- perform the essential functions of a job
- enjoy benefits and privileges of employment equal to those enjoyed by employees without disabilities

Employers can choose not to hire you if your disability completely prevents you from being able to do the job in question. They can also choose to not hire you for any reason they would use if you did not have a disability. This can include hiring a better-qualified candidate for the job. But, they do not have the right not to hire you just because you have a disability. You have the right to not face job discrimination.

How does this fit into my transition plan?

Employment goals are something you will write into your transition plan.

Deciding on your employment will require going through the Strengths and Interests parts of your plan. Find an option that includes one or more of your strengths and interests. That way, you can find something that might be a little easier for you to do - and even if you find it difficult, the fact that you enjoy it and find it interesting will motivate you to get better and work harder.

You need to decide on the things you'll need related to your employment, such as

- the kind of education you'll need for a position you want, or

- what skills you need to learn (budgeting? driving? social skills?)

These will be in the Needs section of your transition plan.

Some goals for employment might be:

- Learn what to expect in an interview, like what questions you will be asked, and what questions you will be expected to ask.

- Learn your rights by reading about employment laws.

- Ask your team for tips and job leads.

If you get stuck with knowing what you need to do, or how to set clear goals for yourself, refer back to Chapter 4: Making Your Transition Plan to help you.

Summary

- ▶ To achieve independence, happiness and stability in life, it is likely you will need to find a job.
- ▶ Everyone has a different set of strengths and weaknesses. There are jobs available for all types of people with many different skill sets.
- ▶ You can self-advocate as an employee or potential employee.
- ▶ Self-advocating in employment is how you get a job you enjoy and are able to do.
- ▶ To self-advocate at work, you must learn your rights, your goals and your accommodation needs.
- ▶ There are laws that protect you at work. For example, the Americans with Disabilities Act.
- ▶ Before you apply for a job, you will need to figure out what skills are required, and what kind of things you'll be expected to do.
 - These might be qualifications or previous experience.
 - But, some things may not always be listed in a job description - they might be unspoken aspects of workplace culture.

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9

Housing and Independent Living



Image: A miniature person riding a bicycle through a city without using their hands.

“Independent living is not doing things by yourself. It is being in control of how things are done.

—Judy Heumann

What you'll learn in this chapter

- ▶ What independent living is
- ▶ What options you have for housing
- ▶ What supports you have available
- ▶ How to choose where to live
- ▶ How to pack and prepare for a move
- ▶ What laws protect you when you rent

Key terms

- ▶ independent living
- ▶ self-determination
- ▶ self-advocacy
- ▶ natural supports
- ▶ supported housing
- ▶ Personal Care Assistant (PCA)
- ▶ reasonable accommodations
- ▶ disclosure
- ▶ Fair Housing Act
- ▶ Americans with Disabilities Act

Outline

- ▶ Overview
- ▶ During transition
- ▶ Self-determination and self-advocacy
- ▶ Housing options
- ▶ Choosing where to live
- ▶ Making the move
- ▶ Hidden costs
- ▶ Legal protections
- ▶ How does this fit into my transition plan?
- ▶ Summary

Overview

You have many choices about where to live.

You may want to live alone and take care of all your needs yourself.

You may want to live alone and be on your own with some occasional help from friends or family. For example, your sister may help you balance your checkbook once a month. Or your neighbor may take you along for grocery shopping weekly.

You may decide to live with roommates. This will be different in each situation because every roommate has their own personality, strengths, and weaknesses. You and your roommates might share responsibilities, or your roommates might help you with some things.

You may choose supported living with part-time or full-time paid staff. This could range from as little help as having someone cook dinner for you and pay your bills once a week to as much help as having someone with you all the time. There is major cost associated with having paid staff, but they can usually be paid for through **Medicaid** (if you qualify).

You could live with your family or another family. Family living providers are paid to share their lives with people with disabilities.

Before you decide what kind of living arrangement you want to have, it's important to first think about:

- what your support needs are, and
- how you will get the support that you need.

This is important no matter where you end up living.

Medicaid

government-funded insurance for low-income people

Your ideal living arrangement might mean moving house. The moving process can be difficult. In this chapter, there are some useful tips on managing the tricky aspects of moving, like packing and protecting your belongings and transporting all of your possessions to a new place.

This chapter also tells you what you need to know about signing leases and the legal protections a lease gives you. It also lists the possible hidden costs you may have to pay upon signing a new lease.

During transition

Overview

Transition means the major changes that youth with disabilities go through as we become adults. These changes can include:

- continuing education

- finding a job

- finding a place to live

This chapter is about the transition from living dependently with carers to living independently, and finding a housing option that works for you.

transition

the process of changing from one way of life to another way of life

Independent living

Independent living means that we live in the community and not in institutions. It means that we choose and control our own supports and direct our own lives. Independent living means that we are free to make decisions about our own lives instead of somebody else making decisions for us.

It doesn't mean living alone or not having help.

independent living

living in the community and having control of your life, including your support services

Rights

Fair Housing Act

a federal law that protects people buying or renting property from discrimination

Americans with Disabilities Act (ADA)

a federal civil rights law that protects people with disabilities from discrimination

The **Fair Housing Act** protects you. It is illegal for a landlord or seller to refuse to rent or sell a home to you based on your disability.

The **Americans with Disabilities Act** is also supportive. With these laws in place, a guide dog must be allowed to live in a home that normally wouldn't allow pets. Wheelchair access has to be made available. New buildings with four or more apartments must be built so someone in a wheelchair could safely and comfortably use the space.

You can file a Fair Housing complaint if:

- ▶ a landlord or seller won't agree to rent or sell to you due to your disability, or
- ▶ they won't make adjustments to the living space to meet your needs

You can file a complaint by:

- ▶ calling 1-800-669-9777, or
- ▶ TTY 1-800-927-9275.

Responsibilities

It is your responsibility to find your own individual housing needs. Do you prefer a quiet environment or do you prefer to have noise? Do you desire a short commute to work or school? Do you prefer to live alone or with others? Do you have a budget and can you afford to live in the place you desire? Do you require adjustments to a living space in order to be mobile?

It is your right to live comfortably and safely as you desire, and it is your responsibility to seek out the opportunities that work best for you and your needs.

Goals

Your goals are the things you are aiming to do, or be able to do, as part of your transition to adulthood. You need to figure out what your goals are, and write them in your transition plan. You have to make sure you also write down how you plan to achieve them.

It is important to have goals when preparing to make your own personal housing transition.

Reaching those goals can make your transition smooth, empowering, and even fun!

Your individual needs will certainly differ from others. List a few goals that will help assure your individual needs are met, and step-by-step, you can reach them.

Some examples of goals might be:

Find a home close to my school or work

Find a home in a safe neighborhood

Find a home that is walking distance from town or public transportation

Learn how to create a budget

Find a roommate with shared interests

Find a wheelchair accessible apartment

Connect with my new community's Freecycle program to help furnish my home

Find any supports or doctors you may need

Self-determination & self-advocacy

self-determination

the idea that each person has the right to decide how to live their life

self-advocacy

the act of speaking up for what you need and want

What are self-determination and self-advocacy?

“**Self-determination**” and “**self-advocacy**” mean people with disabilities have control over their lives. Self-determination is the power to decide what you need and want. Self-advocacy is the action of making your needs and wants known.

Autistic people may need help from outside sources. Nonetheless, we get to decide what that help may be and who we wish to get it from. This is self-advocating.

Self-advocacy in housing and independent living

Here are some examples of self-advocacy in housing and independent living:

- Talking to your roommates about your sensory sensitivities
- Calling the landlord to fix a broken appliance
- Requesting reasonable accommodations in housing
- Reporting an instance of housing discrimination
- Asking a friend to go with you to the grocery store

Housing options

Overview

This section will help you decide which housing option works best for you.

Your options are:

- Independent living on your own
- Independent living with informal supports
- Living with roommates
- Supported housing
- Independent/supported living with (part- or full-time) paid staff
- Shared living
- Living with your family or another family

Independent living on your own

Living on your own after living with your family can be one of the biggest changes during transition. It can also be a very exciting time!

Being on your own means that nobody will tell you what to do or when to do it. This can be an awesome new level of freedom you've never had before! However, it could also mean that you forget to do things because other people used to remind you to do them.

You can ask family and friends for advice. They might have helpful insight that you wouldn't have thought of otherwise.

Living alone can be good if you have a lot of specific sensory needs.

For example, if you need a lot of light, you can buy your own bright white lightbulbs to put in all of your light fixtures without having to worry about your roommates' preferences.

One thing to keep in mind is that even if you are living by yourself, if you are living in an apartment complex there will still be other people in the building with you.

You still need to respect other people in the building. This could mean:

- if you live on a floor above other people, be careful not to stomp or jump too much - your floor is somebody else's ceiling!
- not blasting music too loudly because it could disturb other people in the building
- not leaving trash in the hallway

Living alone might be a good choice for you if you don't have support needs that require having support staff living with you, or if you'll only need to call a friend once in a while to help you out with something.

Independent living with natural supports

You may live independently with unpaid, informal supports. These are **natural supports**. Some examples of informal supports might be any of the following:

A friend helps you balance your checkbook once per month.

You go along with your neighbor every week when he goes grocery shopping to do your own shopping.

Someone from your church brings you a casserole every Saturday and spends dinnertime with you.

You walk a neighbor's dog every day. In return, she gives you rides to your doctor appointments.

A friend drives you to the movies and watches them with you once a week.

You have a cat or dog to keep you company all the time.

natural supports

unpaid, informal support that you get from friends, family, and community members

Living with roommates

Living with roommates can be a wonderful option for many autistic youth in transition. Living with roommates is an excellent option for people who would like some more supports, but do not want to feel as though the people they are living with are their "supervisors."

For example, because roommates are often close to the same age, living with roommates could allow for more freedom than living with your parents.

Roommates would be able help each other out in their living space. But, one roommate wouldn't feel as though their role was to "take care of" the other.

In “shared living,” roommates DO have a support role. We will talk about shared living that at the end of this section.

Living with roommates can be a problem for people who would like more security. While many roommates do become close friends, that is not what always happens.

You might want to live with people that you know you will have a close, personal relationship with. In that case, living with your family or close friends might be best for you.

Living with roommates requires a lot of thought and consideration.

Here are a couple factors you may want to consider if you decide living with a roommate is best for you:

Financial situations

People who live together as roommates must be able to trust each other to pay their share of the rent, bills, and groceries on time.

Before signing a lease, make sure that living with roommates is something you can easily afford. It’s also important to make sure you only live with roommates who can afford to live with you too.

Personal situations

While it may not be necessary to become good friends with your roommates, it is really important that you choose to live with people who are easy for you to get along with.

Take the time to get to know a little bit about potential roommates before signing a lease.

You may want to ask prospective roommates some questions like these:

Do you usually stay up late, or do you like to go to bed early?

Do you usually have a lot of people over to visit? At what times? Should I expect or be prepared for overnight visitors?

Do you have any sensory needs I should know about?

Your prospective roommates might also want to take the time to get to know you as well. While it is always up to you to decide if you want to tell others that you are autistic, it might be helpful for other roommates to know that you are autistic.

This could be especially helpful if you choose to live with people who are not autistic and might not be familiar with autism already. But, that decision is always up to you.

Roommate agreement contracts

If you decide to live with roommates, it might be a good idea to create a roommate agreement contract.

Many colleges have roommates living in a dorm room fill out a roommate contract to decide together what rules they will have for living together.

Some questions a roommate agreement contract might have are:

- What time of day do you prefer to shower?
- How will we divide chores?
- How will we share refrigerator space?
- What is our policy for guests/visitors?
- How will we handle conflicts be?

Your roommate agreement contract might include specific accessibility-related requests.

Some examples are:

- asking that they not spray scented perfumes in shared living areas, or
- that they not re-arrange items or furniture without telling you first.

You should fill out your contract together and discuss every item on it to make sure that everybody understands what is being decided.

After the contract is filled out, it might be a good idea to give a copy to every roommate and post one copy in a common area so that you can reference it later.

In the Chapter 9 Resources starting on page 369, there is a section with links to sample roommate agreement contracts that you can use as a starting point.

Supported housing

Supported housing is government-funded, permanent housing for people with disabilities.

People receiving supported housing live on their own in their own apartments. We get a lot of supports and services to help us to live in our homes and take part in the community. Residents control the services. All services are community-integrated. Services focus on promoting independence. They also help people with disabilities to live in our communities.

Some services that may be available to you in a supported housing setting:

- | | |
|--------------------|-----------------------|
| Social programming | Emergency call system |
| Laundry | Medication oversight |
| Housekeeping | 24-hour security |
| Nursing services | |

supported housing
a government-funded program that combines housing with support services

Independent/supported living with paid staff, part- or full-time

You can choose to live in your own home with a paid **Personal Care Assistant (PCA)** to help you with things like cooking and cleaning or even bathing. A PCA might provide transportation around the community. You may also have other help like a speech therapist.

A PCA can help people with important daily tasks and chores. A PCA can help a person with a disability with day-to-day tasks such bathing and dressing, preparing a meal, or managing household chores.

Personal Care Assistant
a kind of support staff that you can hire to help you with non-medical care tasks, like meal preparation or chores

Medicaid

government-funded
insurance for low-income
people

They can also support you in accessing the community or anything else that is a part of your day-to-day life.

PCAs are trained staff, usually hired through **Medicaid**. The laws stating who is acceptable may vary by state.

Some ways that support staff could help you include:

- bathing
- toileting
- grooming
- dressing
- extension of therapies
- meal preparation
- assistance with eating
- household cleaning
- laundry
- shopping
- banking
- budgeting
- using public transportation
- social interaction
- recreation
- productivity and inclusion in the community.

Shared living

Roommates can also provide support in a “shared living” or “home sharing” arrangement.

Shared living programs can be a more secure choice than other roommate options. Many shared living programs have staff who do background checks on the people you would be living with.

In a shared living arrangement, the people who are your roommates would also provide you with an agreed-upon level of support. A shared living arrangement can offer many things to autistic youth in transition, including:

- companionship
- affordable housing
- security
- mutual support, and
- much more!

Besides giving you supports you may have otherwise gotten from hiring staff, the people you live with can help you:

- Connect with your community
- Learn important independent living skills
- Make friends

Different states have different shared living programs. You can find out more by searching the Internet for “shared living” or “home sharing” and the name of the state you live in or are planning on living in.

Living with your family or another family

Living with your family is another option. There are many benefits to living with your family during this time in your life.

Some benefits include:

Cost

Living with your family does not usually cost any extra money. Even if your family asks you to contribute some money to the household, it will almost always be much less than what you would pay living with roommates or on your own.

Living on your own requires you to spend money on:

- rent
- utilities (like the water or power bills), and
- groceries.

Familiarity

It is much easier to live with people that you already know well, especially people that you have lived with before. Also, your family already knows what to expect from you. This makes adjustments easier for both you and your family.

Security

Living with your family can provide you with a sense of security. You might not get the same security living on your own or with roommates.

For example, if you are living with your family and become ill, your family will be able to help take care of you and help you recover from your illness. If you live on your own, there won't be anyone there to help you. Also, if you choose to live with roommates, they unfortunately might not feel as big of a commitment to helping to take care of you as your family would.

All these benefits are mainly associated with living with your own family. But, you can also find many of these benefits if you choose to live with another family. If you do decide to live with a family other than your own, that family will often treat you as just another family member.

There are a few possible drawbacks to living with a family, whether it's your own or another family.

These drawbacks can include:

Lack of independence

Many families have certain rules that people in them must follow. There may still be some "house rules," or rules everyone living together must follow if you live with roommates. But, these rules are usually more relaxed and less strict than those you would find in a family.

For example, if you live at home with your parents, they might insist on only allowing overnight visitors when they approve of it. But, if you live with roommates, you won't need to get permission as long as you are respectful of the shared living spaces when you have company over.

Hard to establish connections

Often, people who live at home can have a hard time making new friends. This is because you don't have the exposure to different people that you might have if you lived with roommates.

People who live on their own often spend a lot of time out of the house as well. This makes it easier to meet new people than if you lived with your family. But, if you are currently happy with your social life and the number of friends you already have, making new friends might not be important right now.

Choosing where to live

Accessibility & accommodations

reasonable accommodations

changes made to a work environment, living space, or other building to make it accessible to people with disabilities

Fair Housing Act

a federal law that protects people buying or renting property from discrimination

Under Title II of the Americans With Disabilities Act, all housing must provide **reasonable accommodations** to people with disabilities. The **Fair Housing Act** also makes sure that nobody can refuse to rent to people on the basis of their disability. But, there are many other things to consider as well. For example:

- Do you need access to public transportation?
- Are there grocery stores nearby?
- What other kinds of places would you need to be able to access?
- Is noise an issue?

It is important to take these factors into consideration when choosing housing. Where you live and how you live can have a major impact on your independence.

Public transportation could come in the form of buses and carpooling. If you live in a major metropolitan area such as New York, Boston, or Chicago, subway and other train systems can also get you where you need to go. Having grocery stores near where you live can be a plus as it can allow easy access to your living essentials.

If you need access to wheelchair ramps or similar forms of living help, be sure to make this known and housing and transportation providers are required by law to provide these accommodations to you. If noise is a major problem, it can negatively affect your living experience. Housing can come in many forms and it's very important to know your needs and preferences when choosing a place to live.

Reasonable accommodations

A reasonable accommodation is a change made so that people with disabilities can use a house or common space. This could be a change in:

- rules
- policies
- practices, or
- services

For example, even buildings with no-pet rules have to let people keep service animals. Also, a landlord would have to let someone put in grab bars for the bathtub.

How to research

Choosing a place to live is a big decision. Where you live and who you live with can affect every part of your life. Because of this, it is important that you—and any supporters helping you—do a lot of research before applying to any kind of housing.

Here are some tips for researching potential housing:

- Ask friends and family if they know of any places that are available, or if they know anybody who is looking for a roommate
- Keep a record of all of the housing options you're considering. This could be a physical folder with newspaper clippings or a bookmarks folder on your computer.

It is important that you—and any supporters helping you—do a lot of research before applying to any kind of housing.

disclosure

the act of telling
somebody else that you
have a disability

- There are a lot of websites for finding and comparing housing options. The Appendix at the end of this tipsheet has some state-by-state links. For general apartment searches, a few websites you can use are:
 - [Padmapper](#)
 - [Apartments.com](#)
 - [RentJungle](#)
 - [ForRent.com](#)
 - [Apartment List](#)
 - [My Apartment Map](#)
 - [Move.com](#)
- When you find a place that you like, you should also check how close it is to other places you might need to access (such as grocery stores). WalkScore (www.walkscore.com) is a website that gives ratings based on how easy it is to get from your housing to other important places.
- Find out what public transportation is available in the area and if the routes are accessible to you.
- If you have a service animal, find out whether or not the place you're looking at is animal-friendly. If it isn't, the landlord might still make an exception—but this will require **disclosure** of your disability. Disclosure is discussed more at the end of this chapter.

Making the move

Overview

Moving to a new place is challenging for anybody. There's a lot of preparation work to do before you even start packing.

Once you start packing, you have to make sure you're not going to leave anything important behind or accidentally break things when you pack them. Maybe you have way too much stuff to pack, or some of it is very heavy!

Finally, you have to find a way to get all of the things you've packed to your new place.

Tackling your first big move can seem scary. You might be worried that you'll forget to do an important step, or that you'll end up paying hidden fees for moving without realizing it.

There are a lot of steps to moving, and it's perfectly natural to be nervous! With the right tools and planning, you can be confident in your move.

The next few sections will give you some basic tips and guidelines to help make your packing and moving process less stressful. You'll also find links to more resources in the appendix at the end of this handbook.

Preparation

Updating your information

You'll need to make sure that all the services you were getting before continue after you move. You'll want to update your information and address with:

- Banks
- Insurance providers
- Credit card companies
- Magazine subscriptions
- Doctors
- Lawyers or other professional services
- The Postal Service

Try to do this at least two weeks before your move. That way, there's enough time to make sure that there won't be any issues with receiving your mail or other services.

Making the move easier

There are things you can do ahead of time to make move-in day easier on yourself.

Be sure to confirm your move-in date. It wouldn't be good to go through all the effort to pack and move all of your stuff just to show up and find out you can't move in yet!

There are many tips and tricks to make moving easier, like:

- Make your last grocery trip two weeks before moving, so that you don't waste any food that you can't transport

- Pick up anything that was being cleaned, repaired, or stored (including at a gym locker)

- Return anything you've borrowed from friends

- Take a picture of how your electronics are hooked up so that re-assembly is easy when you move in

- Plan ahead, and consider travel arrangements for your pet/pets.

- Make copies of birth certificates, medical records, etc. You'll find more resources in the Appendix of this handbook.

Deciding what to bring

You probably won't be able to bring everything with you to your new place, even if you really want to. This can also be a really good opportunity to get rid of things that have been taking up a lot of space!

How do I decide?

Here are a few things you can try to help you decide what will come with you to your new place.

Work in reverse. This exercise will help you figure out what items are the most important.

First, go somewhere away from your home where you can think carefully, like a coffee shop or library. Then ask yourself: "If my house burned down and I lost everything, what would I replace first?"

It's important that you do this exercise away from home, because you might be tempted to just look around and write things down.

You want to go through every room in your home and decide what's coming with you and what isn't. You'll have to make decisions about many things.

It may be tempting to think that everything that you own is essential.

Here are some questions you can ask to help you decide if an item is worth bringing:

- What does this item do for me that nothing else does?
- When was the last time I used this item? Does it still work?
- When was the last time I wore this clothing item? Does it still fit?

Especially when it comes to furniture, asking “will this fit in my new place?” is a good question to ask. Of course, if you’re moving out of your parents’ place, you might not be taking any furniture with you at all.

It’s also a good idea to talk to your supporters about what they think is important and what lessons they learned from the times that they have moved.

What do I do with the things I’m not bringing?

Donate or recycle as much as you can. A yard sale might seem like a good idea, but you’ll end up spending money to advertise it and you might not even get rid of all the things you want to get rid of!

If you have friends help you with packing and moving, you might consider letting them have first choice of things you were otherwise going to give away.

Packing and protecting your belongings

Materials

Boxes are the number one thing you'll need when you're packing. But it is also important to have some of these other items on hand:

- Labels or different colored tape
- Ziploc bags for small items
- Zip ties for securing cables
- Tape gun for quickly sealing boxes
- Permanent markers for writing on boxes

Free boxes

There's plenty of places to buy packing boxes from, but there are also lots of ways you can get free boxes! Many stores receive shipments in boxes that they end up recycling or throwing away, but will gladly give to someone who will make use of them.

- Call or check out these places to see if you can get some boxes for free:
- Local grocery stores
- Local liquor stores - they might even have boxes with dividers for storing glassware
- Hospitals/pharmacies often have heavily reinforced boxes good for storing fragile things
- Bookstores
- Craigslist.com
- Freecycle.org

Packing tips

There are many more tips and tricks in the resources listed in the Appendix, but here are a few for starters:

Label EVERYTHING.

Try to organize boxes by what room they're for (a box for kitchen items, bathroom items, etc)

Use a color coding system for boxes (i.e. red tape for "unpack first")

Label boxes by weight (light, medium, heavy) as well as contents

Put drinking glasses in clean socks for extra padding

Leave clothes on hangers and place them all in a large garbage bag to make unpacking easier later

Number your boxes to make sure you don't lose any

Use rolling suitcases for heavy items

Place disposable foam plates between plates to prevent them from breaking

To keep containers filled with liquid from spilling, take off the cap, put plastic wrap across the top, and then put the cap back on

Pack some "comfortable" clothes, such as sweats, pajamas, or something else, and two changes of clothes for the first few days after shortly moving in.

Pack an "Open First" box, which has important items. For example, scissors, plastic silverware, bottle openers, a pot and pan, and some pens.

Most importantly, keep an inventory of everything you're packing.

natural supports

unpaid, informal support that you get from friends, family, and community members

Moving

Now that you've got all of your boxes packed and ready to go, it's time to get to your new place.

You've got two main options: hiring a moving company or reaching out to your natural supports to help you. You can always use a moving company for some things and your **natural supports** for others.

Here are some things to consider for each option.

Moving trucks

- Better for longer moves
- Wide range of options
- <http://www.twomenandatruck.com/moving-tips> has a list of suggested questions to ask a moving company
- Always look at reviews and recommendations
- There may be less physical work for you, but it may be more expensive
- May have hidden fees
- Need to reserve as far in advance as possible - summer and the weekends are the most packed times
- Estimate what size moving truck you'll need, and reserve it. Here's a website to help you look for the right truck: <http://www.pensketruckrental.com/truck-wizard.html>

Help from family and friends (natural supports)

Can help with packing and unpacking

Costs less financially - but you'll still want to show your appreciation somehow

Not professionals

Better for short moves – within the same city or town

May require many separate trips between locations

Always have a game plan and direct instructions for how each person is to help

Hidden costs

If you plan to move, it is best to ask family and friends what help or advice they are able to give. Their experience will help you be better prepared for some of the problems you may run into while moving.

One big problem that first-time movers don't think about is the hidden costs that come with some services. With good planning, you can reduce or avoid some of these hidden costs.

Moving

- ▶ Charges for extra stops
- ▶ Charges for handling bulky items
- ▶ Storage fees
- ▶ Moving insurance
- ▶ Long carry and elevator fees
- ▶ Cancellation fee
- ▶ Packing labor and packing supplies

Signing a new lease

- ▶ Security deposits
- ▶ Having to pay the first and last months' rent up front
- ▶ Extra deposit fee for having a pet (even if it's a service animal)
- ▶ Extra fees in small print in your contract

It's always a good idea to have one or more trusted supporters read over any contracts that you have to sign to help make sure that you understand what you're agreeing to.

Legal protections

Overview

Autistic people have the same rights as anybody else when it comes to looking for a place to live. Whether you own a home or rent an apartment, you are legally protected from discrimination. The laws that prevent discrimination are the Fair Housing Act and the Americans with Disabilities Act.

The Fair Housing Act

The **Fair Housing Act** (FHA) forbids housing discrimination. Discrimination against a tenant who is able to pay their rent or mortgage is illegal if the discrimination is because of their:

- race
- color
- religion
- sex
- disability, or
- parenting status.

The FHA does not currently forbid discrimination because of sexual orientation. But, some states have laws prohibiting discrimination in housing based on sexual orientation.

Fair Housing Act

a federal law that protects people buying or renting property from discrimination

For a Fair Housing Act violation:

- ▶ contact the Office of Compliance and Disability Rights Division
- ▶ www.hud.gov/offices/fheo
- ▶ (800) 669-9777

Americans with Disabilities Act (ADA)

a federal civil rights law that protects people with disabilities from discrimination

The Americans with Disabilities Act

Title II of the **Americans with Disabilities Act (ADA)** applies to all programs, services, and activities provided by public entities. This includes Public Housing Agencies.

You should document any time you feel that you've been discriminated against because of your disability. If you feel that a housing provider is discriminating against you, you have the right to file a complaint. Having documentation will make filing these complaints easier.

For an ADA violation:

- ▶ contact the U.S Department of Justice's Civil Rights division
- ▶ (800) 514-0301

Disclosure

disclosure

the act of telling somebody else that you have a disability

Disclosure is the act of telling someone else that you have a disability. A disability can be disclosed if you need an accommodation. Disclosure of your disability is necessary because a disability creates the need for accommodations.

You are not required to disclose any disability; it's your choice whether you tell someone, anyone, or no one. Other people won't know you need an accommodation if you don't disclose your need.

reasonable accommodations

changes made to a work environment, living space, or other building to make it accessible to people with disabilities

The Americans with Disabilities Act (ADA) states that people with disabilities have a right to **reasonable accommodations**. An accommodation is reasonable if it allows you to carry out your responsibilities, but doesn't place an excessive burden on the person (such as your employer) or institution granting the accommodation.

Pros:

You can access to accommodations that you may need for living

Communicating with your landlord by email instead of by phone

Getting rid of strobing lights on fire alarms

Might be able to get exception to bring your service animal with you

Cons:

Some landlords may try to take advantage of you!

They might change the terms in your contract or try to overcharge you for bills

They may try to find an unfair reason to evict you or not renew your list

How does this fit into my transition plan?

Becoming independent is the last step to being an adult. It is a complicated process. Fortunately, people with disabilities have many resources to use when making this big transition. The three main problems adults have to deal with are:

housing

finances, and

keeping track of legal agreements.

Most of the work is easy once you are used to it, but doing it for the first time is hard. States supply a lot of resources when it comes to young adults.

Supported decision making and in home staff can help someone who wouldn't otherwise be able to live independently have a home of their own. Talk with the people helping you with your transition plan to decide whether you need in home staff.

Transitioning to a new living situation is often a stressful chore. It helps to break it down into sections and set yourself goals.

You might need to learn independent living skills so you can cook, clean, or do laundry.

If you're moving house:

You will need to apply for and secure a rental, or another type of living arrangement.

You need to transport all your things from your old home to the new one.

You need to figure out if you'll need to learn how to budget, or use public transit.

You may need to develop self-advocacy skills, so you can make your needs known to your roommates or landlord, for example.

Maybe you need to set a transition goal like taking a basic cooking class, or figuring out how you'll build your support network.

Summary

If you are moving house:

- ▶ Think about what kind of living situation would be the most suitable for someone in your position.
- ▶ This might include things that are to do with the area nearby. What is the public transport like? Does the area feel safe? Is it busy, or is it quiet?
- ▶ Do your research about suitable places. Ask around, and use the websites listed above.
- ▶ Pack your belongings in a way that ensures you won't break or forget anything important.
- ▶ Make sure you read all the small print before signing a lease. Find out about any hidden costs.

If you are planning on sharing with others:

Think about issues that might arise from sharing a living space and good ways to resolve them. Can you come to a compromise on noise levels, or come up with a rota for cleaning?

No matter where you end up living:

- ▶ You need to know what your support needs are.
- ▶ It is a good idea to learn your rights and legal protections when it comes to your living situation. Read the Rights section in this chapter, and Chapter 3: Know Your Rights.
- ▶ Decide if you need to work on any independent living skills, like being able to do laundry, shop or cook for yourself.

10

Health Care

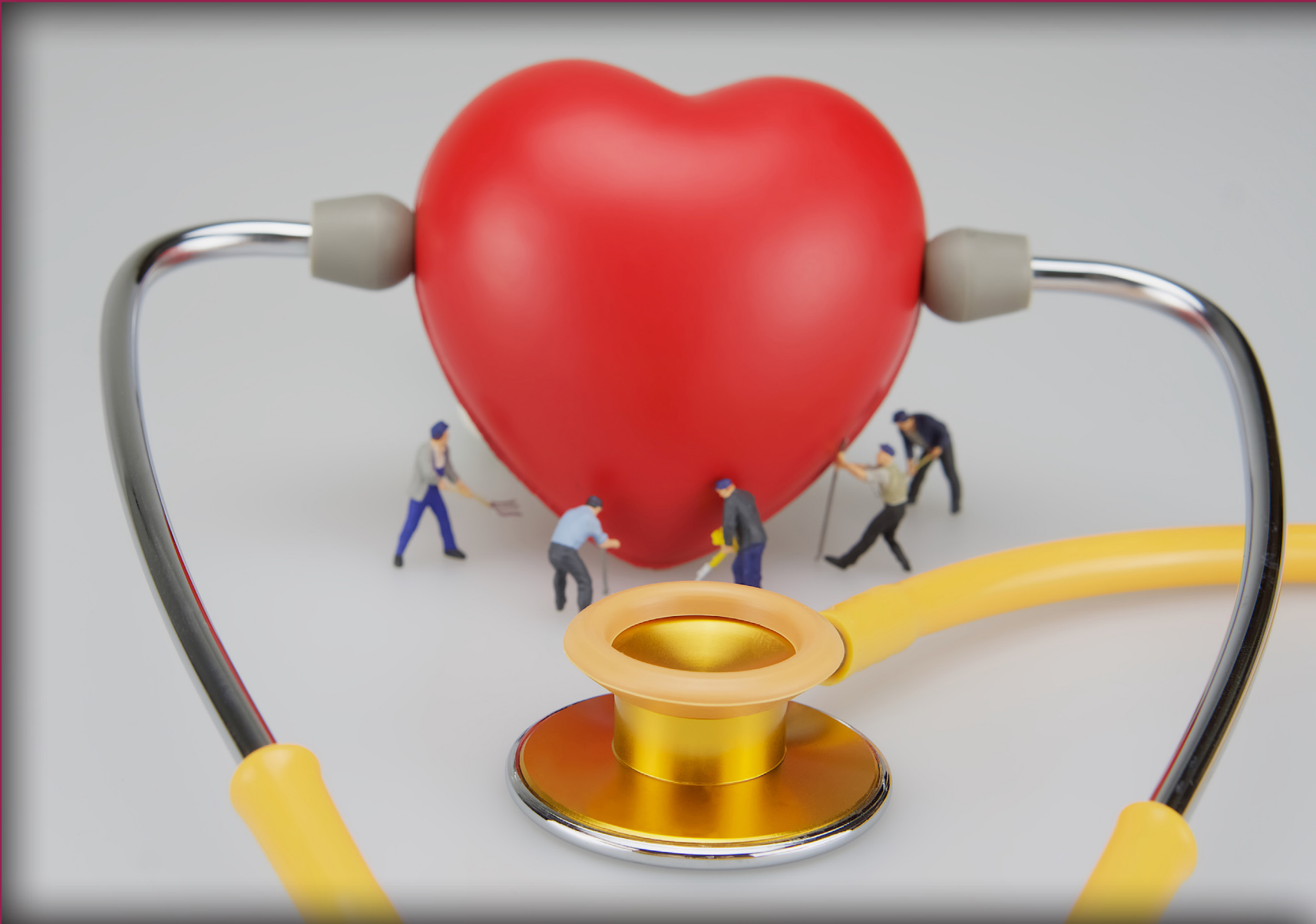


Image: A plastic heart with a stethoscope. Miniature people are cleaning and taking care of the heart.

“The key to making healthy decisions is to respect your future self.

—A.J. Jacobs

What you'll learn in this chapter

- ▶ What a medical home is
- ▶ How insurance works
- ▶ How to work with health care providers
- ▶ How to manage your own health
- ▶ Important laws about health care

Key terms

- ▶ Affordable Care Act
- ▶ pre-existing condition
- ▶ medical home
- ▶ health insurance
- ▶ insurance ID card
- ▶ copay
- ▶ coinsurance
- ▶ deductible
- ▶ insurance claim
- ▶ explanation of benefits (EOB)
- ▶ provider network
- ▶ Medicaid
- ▶ primary care physician
- ▶ preventive care
- ▶ mental health

Outline

- ▶ Overview
- ▶ During transition
- ▶ Self-determination & self-advocacy
- ▶ Building your medical home
- ▶ Understanding insurance
- ▶ Health care providers
- ▶ Managing your health
- ▶ Health care and the law
- ▶ How does this fit into my transition plan?
- ▶ Summary

Overview

This section is about accessing health care. Health care isn't just about going to the doctor. It also means how you take care of yourself, both physically and mentally.

First, we will talk about what will change about your health care setup when you transition into adulthood.

Your rights and responsibilities about your health will change as you become an adult.

You may want to set goals for the things you find difficult during your transition. Maybe you need to learn how to schedule appointments, or learn which things your insurance covers. Maybe you need to set reminders to take medicines or vitamins every day. There are lots of resources on how to do all these things.

A large part of this chapter is about helping you to understand and get health insurance. There are many different types of insurance. We will explain these. There is also a glossary of common words used when talking about insurance programs.

Next, we will talk about why you need health insurance, and help you to choose insurance based on your circumstances.

There are different types of health care providers. There are primary care physicians, therapists and specialists. We will talk about the different roles of these people.

Primary care physicians are usually the people you see first. They will refer you to a specialist if you have a condition that they can't treat themselves, or if it requires long-term specialized care.

The last section in this chapter is about keeping yourself healthy. There are lots of different things involved in keeping healthy.

There are things to do with your day-to-day health, like:

- eating a balanced diet
- drinking enough water, and
- finding exercise you enjoy.

This includes your mental health, like coping with stress or sadness.

Then there are things involving other people, like:

- keeping appointments
- knowing when to call your doctor
- talking to your doctor and taking their advice, and
- maintaining your medical records.

Finally, we will cover some of the important laws about health care that you should know.

During transition

Overview

transition

the process of changing from one way of life to another way of life

Transition means the major changes that youth with disabilities go through as we become adults. These changes can include:

- continuing education
- finding a job
- finding a place to live

This chapter is about the transition from children's health care to adult health care. This includes transitioning from having health care decisions made for you. As an adult, you gain more control over your health care.

Rights

You have the right to have all the equipment at your health care provider's office be accessible.

Some examples of accessibility:

Exam tables and weight scales should be physically reachable and useable by you.

The office should not be so loud or overwhelming that it prevents you from being there.

In some cases, you may have to ask that your access needs be met. But, you have the right to have this request be honored. You also have the right to extra time on visits if you need that time, and to bring in your service animal.

You have the right to get the health care services you need. You have the right to not be discriminated against in getting those services.

You have the right to have your concerns taken seriously.

You have the right to accurate information from your doctor.

The **Affordable Care Act** gives you some new rights:

- You have the right to stay on the same insurance plan for life
- You have the right to get affordable insurance even if you have a **pre-existing condition**
- You have the right to get some kinds of health care, like shots or screening tests, for free
- You have the right to have your insurance plan explained to you in plain language

Find out more about the Affordable Care Act here:
<http://www.hhs.gov/healthcare/>

Affordable Care Act

a federal law which made health care more affordable, accessible, and high quality

pre-existing condition

a medical condition that you already had before you got health insurance

Responsibilities

Under the Affordable Care Act, you must have **health insurance**. You have to pay a fine every month if you don't have insurance.

It is your responsibility to make sure that you have insurance.

It is your responsibility to tell doctors about any symptoms that you are concerned about.

You are responsible for making sure you go to your doctor's appointments.

You also have post-appointment responsibilities.

If your doctor schedules a lab appointment for you, or refers you to a specialist, you need to make sure to go to those appointments. If you need a follow-up

health insurance

an arrangement where a company, or the state, pays for certain health care services.

appointment, make sure to also schedule that.

You need to make sure you take any medications that are prescribed to you.

You are responsible for following the instructions that come with your medication. All medicine bottles, whether they are for pills, syrups, or syringes, will have instructions on how to take your medication.

If you are confused, make sure to clarify the directions with your health provider.

Goals

Your goals are the things you are aiming to do, or be able to do, as part of your transition to adulthood. You need to figure out what your goals are, and write them in your transition plan, making sure you also write down how you plan to achieve them.

Here are some health care goals you might set:

- Find a new doctor
- Create a regular bedtime routine
- Start taking a multivitamin every day
- Learn about your insurance and how to find out what it covers
- Exercise for 30 minutes every day
- Drink at least 64oz of water every day

Self-determination & self-advocacy

What are self-determination and self-advocacy?

“**Self-determination**” and “**self-advocacy**” mean people with disabilities have control over their lives. Self-determination is the power to decide what you need and want. Self-advocacy is the action of making your needs and wants known.

Autistic people may need help from outside sources. Nonetheless, we get to decide what that help may be and who we wish to get it from. This is self-advocating.

self-determination

The idea that each person has the right to decide how to live their life

self-advocacy

The act of speaking up for what you need and want

Self-advocacy in healthcare

To get what we need from health care providers and to be responsible for our wellbeing, we need to self-advocate. Here are some examples of self-advocacy in health care:

Going to a doctor about a health concern and asking for advice

Asking for a second opinion if you think a doctor has misdiagnosed you or not given you the correct advice.

Finding a new provider if you are unhappy with a health care provider or therapist

Filing a complaint if you think your health care provider has not given you the treatment you need, or has discriminated against you.

Building your medical home

medical home

a way of delivering health care that is patient-centered, coordinated, supportive, and appropriate for the patient's culture

medical home care team

the health care providers who work together to deliver patient-centered care, including primary care physicians, specialists, and therapists.

What is a medical home?

A **medical home** is not a physical place. It's a way of getting health care that is:

- High-quality
- Patient-centered
- Coordinated
- Community-based
- Accessible
- Compassionate
- Respectful of your culture

Patient-centered care

A medical home creates a team of people. This is your **medical home care team**. Your medical home care team are the people who coordinate and provide care.

A medical home is **patient-centered**. That means you are always at the center of this team. Other people in the team can include:

- Your primary care physician
- Family members
- Health educators
- Specialized doctors
- Therapists
- Care coordinators
- Personal care assistants
- Social workers
- Staff at school or work
- Other supporters

This team works together. By working together, everybody is on the same page. Your team helps you:

- Manage your long-term health
- Work with your insurance
- Consistently get the accommodations you need
- Understand and take control of your health care
- Access the services you need
- Make appointments
- Build a relationship with health care providers
- Make a plan for your care

What your care team should do

Learn about you

Your care team should take time to learn:

- Your preferred way of communicating
- Your accommodation/support needs
- Your values
- Your preferences
- Your current life situation

Your care team should remember these details. That way, you can get health care treatments that make sense for you.

Treat you as a full team member

Your medical home care team should never make decisions without you. Your team can help you understand the choices you have. But, you get to make the final decision.

Communicate with you

Your care team should give you time to ask questions. They should answer in a way that you can understand. You have the right to have your health care explained to you.

Your care team should also ask for your feedback. They should ask you how you feel about the way you're getting your health care.

Support your transition to independence

Your care team should help you set health care goals. They should work with you step-by-step to meet those goals.

Your team should make sure that you know what to do after you go to a doctor's appointment.

They should help you find programs in your community that support the goals you've set.

Use technology to coordinate your care

The medical home model means your care providers will use new technology to improve care. This can include:

- Sharing electronic medical records between providers
- Sending electronic prescriptions directly to your preferred pharmacy
- Online portals where you can see your medical records
- Being able to make appointments online
- Sending you texts to remind you of upcoming appointments
- Scheduling medication refills and delivery through a mobile app

Technology makes it easier for every member of your team to have accurate, up-to-date information.

What you should do

Take an active role

You're the center of your medical home. Tell your team about other care providers you're seeing so they can coordinate your care.

You should understand your health situation. Ask your team questions about your care to help you understand.

Follow your care plans

You should follow the plan that you and your team make. This can include:

- Taking medications as prescribed
- Going to scheduled appointments
- Making follow-up doctor's visits
- Other changes to improve your health

Communicate with your team

You should talk openly with your care team. Tell care providers when you don't understand something they've said. Or, ask them to explain another way. Remember, your medical home care providers will respect your communication preferences.

Bring a list of questions and current medications to all appointments. Let care providers know about changes to your health.

Be open with your team about your care plan. If you're having trouble following your plan, let your team know. Together you can make changes if needed.

Understanding insurance

Do I need health insurance?

Yes.

health insurance

an arrangement where a company, or the state, pays for certain health care services.

It is illegal to not have **health insurance**. You get fined for every month you don't have insurance. If you don't have insurance for a whole year, you might have to pay up to \$695.

It is much more expensive to get a medication or go to the doctor without health insurance.

Without insurance, it can cost you between \$100-200 for one doctor's appointment. With insurance, it would be closer to \$10-\$20.

How does health insurance work?

The basics

You might already have an idea about how insurance works. Having insurance means you don't have to pay the full cost of your treatment. But, insurance doesn't make the actual health care cheaper. It just changes who's actually responsible for paying for it.

Here's how it works:

1. You go to your doctor's office and check-in with the receptionist.
2. They take your insurance card and look up how much you have to pay right then.
 - It's not the full cost of the treatment.
 - The doctor's office pays for the rest of it.
3. You have your appointment.

4. The doctor's office writes up a list of what they had to pay for and sends it to your insurance company.
 - This is an insurance claim. We'll talk about that more in the next section.
5. The insurance company looks the list over and pays the doctor's office back for anything that's "covered" under your insurance.
6. You get a bill from the doctor's office for whatever amount is left over after the insurance company pays their share.

That's the basic outline. In the next few sections, we'll explain in more detail how this process works.

insurance ID card

card that gives your personal information and information about the insurance plan you have to a health care provider

The insurance claim process

When you go to the doctor's office, you will need to present your **insurance ID card**.

You may be asked to pay:

- a **copay**
- **coinsurance**, or
- part of your **deductible**,

depending on the type of plan you have.

Read the section below titled "Types of insurance plans" for more information about choosing an insurance plan.

copay

a fixed amount that you pay every doctor's visit

coinsurance

the percentage of the cost of health care services that you have to pay

deductible

the total amount you have to pay for your health care before your insurance starts to cover part of the cost

Learn more about copays, coinsurance, and deductibles here:

<http://www.bcbsm.com/index/health-insurance-help/faqs/topics/how-health-insurance-works/deductibles-coinsurance-copays.html>

insurance claim

a request made to your insurance company asking them to pay for a health care service that was provided

explanation of benefits

a letter from your insurance company explaining how much money you owe for recent health care

provider network

a list of the doctors, other health care providers, and hospitals that an insurance plan has a contract with to provide medical care to its members

in-network provider

a health care provider whose services are covered by your care plan

out-of-network provider

a health care provider whose services are not covered by your insurance and will cost more

Once you have seen the doctor, the doctor's notes are translated into insurance codes that represent the kind of care you received from them. These codes are then sent to your insurance company. This is called an **insurance claim**.

The company uses these codes to figure out how much of your bill they have agreed to pay you. Once they have determined this, they will send the doctor a statement. The statement will show how much they owe the doctor as insurers, and how much you owe as a patient. They will also pay your doctor at this stage.

You will get a letter from your insurance company, explaining how much money you owe the doctor, and how this was worked out. This letter is called an **explanation of benefits (EOB)**.

Then, if you're responsible for paying any money for your treatment, your doctor will bill you for that amount.

Types of insurance plans

Insurance companies want you to use the doctors and hospitals in their **provider network**. Insurance companies make contracts with certain health care providers. These providers are "**in-network**." You will pay less if you see in-network providers.

Not all health care providers will have contracts with your insurance company. These are **out-of-network providers**.

Your plan might not help you with the cost of visits to out-of-network providers. It depends on your insurance plan.

There are no industry-wide definitions of these plan types, and state standards vary. So, different insurers can market similar plans under different names, which can be confusing.

You can use the following as a rough guideline on what your insurance plan will cover:

Health maintenance organizations (HMOs)

Health maintenance organizations (HMOs) only cover doctors and hospitals inside their network. HMO members usually need a **referral** from their primary care physician to see a specialist.

Preferred provider organizations (PPOs)

Preferred provider organizations (PPOs) cover both in-network and out-of-network care. But, you usually pay a higher percentage of the cost of care outside the provider network. One PPO may offer very different out-of-network coverage than another.

Exclusive provider organizations (EPOs)

Exclusive provider organizations (EPOs) are a lot like HMOs. They usually won't cover care outside the plan's provider network. But, if you're a member, you may not need a referral to see a specialist.

Point of Service (POS)

Point of Service (POS) plans vary, but they're often a mix between HMOs and PPOs. Members may need a referral to see a specialist, but they may also have coverage for out-of-network care. You would still need to pay a higher percentage of the cost of out-of-network care.

You should always try to see a doctor that is on your insurance plan.

Doctors who are a part of your insurance plan's network have promised to bill certain services at a discount. So, you will end up paying much less money when you see these doctors.

The law says that insurance companies have to provide plan coverage summaries. It is important to read the details of an insurance plan's coverage carefully.

Health insurance paperwork

Benefits and coverage summaries

Legally, all private insurers must provide a list of what benefits are included in your plan, and the details of their coverage. The summary must use plain language that is easy to understand. A sample plan is provided in the resources section in the appendix.

Why do I need to read the benefits and coverage summary?

You should keep your summary of benefits and coverage somewhere safe. That way, when you need to access health care, you will be able to know ahead of time:

- What kinds of doctor's visits are covered
- How much you will need to pay up front at the doctor
- How much more you might end up paying for the bill

The summary also includes information on:

- Your rights if you have a complaint about your insurance, and more about the complaints procedure.
- Definitions of the financial terms used.
- Whether the plan meets the federal requirements for insurance.
- Whether you are exempt from any tax penalty for not having insurance.
- Instructions for how to get information in other languages.

Summary of benefits and coverage checklist

The summary should include:

Your deductible

Your cost-sharing amounts - the part of the treatment that is your responsibility to pay for

Your **out-of-pocket limit**

Whether the plan has a network of providers you must use

The difference in cost-sharing if you use an out-of-network provider

Whether you need a referral to see a specialist

Any services or treatments the plan doesn't cover

Coverage of common medical events, like visits to primary care providers, lab tests, and hospital stays

out-of-pocket limit

the limit on how much you pay for health care services yourself during a year—after you hit your limit your insurance plan covers 100% of any other costs

EOBs

After you see the doctor, they send an insurance claim to your insurance company. After your insurance company gets this, they will send you an **explanation of benefits (EOB)**. In this context, “benefits” means the financial benefit of having one of their insurance plans.

The EOB describes:

the treatment you got from the health care provider

a breakdown of the costs of the treatment

how much of the cost was covered by the insurance company

how much you will be responsible for paying

explanation of benefits

a letter from your insurance company explaining how much money you owe for recent health care

Why is an EOB important?

It lets you review the money that's being paid for your health care. By checking your EOB, you can track how much your health care costs. You also can look for errors. EOBs give you the chance to question any payment if it seems incorrect.

What information should be on an EOB?

- Your name and address
- Your policy number
- The name of the doctor who provided the care
- The date of the service
- How much you were charged for treatment
- How much your insurance paid
- How much you owe after your insurance paid.

Your EOB should also mention the type of care you got. If part of the care was not covered by your insurance, the EOB should explain why.

Make sure to check carefully for these things:

- If the name and date on the letter is correct
- Whether you got the services the provider claims to have given
- Whether you are being billed more than once for the same service
- Whether you have to pay any or all of the bill
- If the insurance company rejected any of the claim, and the reason why.

Bills

A bill is a request for payment from your health care provider. It will show how much you owe for your medical care after your insurance has paid its share.

What information is on a bill?

It should include:

The name and address of the medical provider	A description of the medical service that was given
The date of the bill	How much you were charged overall,
Your name, address, and account number	The portion that your insurance paid
The date you got the treatment	The remaining amount that you owe.
The patient's name (if it's not you)	

Before you pay your bill, always **check to see if you got an EOB first**. Sometimes, doctors might send you a bill for your treatment before your insurance company has paid it.

The bills you get before your insurance pays their share would end up being a lot more expensive. You don't have to pay these early bills, but it is easy to make the mistake of doing so.

If you did get an EOB from your insurance company, compare it side-by-side with the doctor's bill, and see that the following things match:

- The dates of the treatment
- The service you got
- The amount the insurance paid
- The amount you owe.

Asking a question about your doctor's bill

- Call your health care provider if you have questions about the care itself. For example, the dates you had appointments or what care you got.
- Call your insurance company if you have questions about payment.

Fighting a bill

Sometimes your bill will be higher than you expected. You might have been charged for something you thought would be covered by your insurance.

You have the right to challenge any decision made by your health insurance company. This is appealing the decision.

There are two types of appeals:

- Internal appeals
- External reviews

Affordable Care Act
a federal law which made health care more affordable, accessible, and high quality

The **Affordable Care Act** states that health plans must provide an internal appeals process. The insurance company will do another review of your bill. You can also find out why a claim was rejected.

In an external review, your appeal gets looked at by a third party. The insurance company doesn't get the final say about your bill when you do an external review.

Some states have consumer assistance programs within the state insurance office. You can go to the [National Association of Insurance Commissioners](#) to find out what help is available in your state.

You also can get information and assistance about fighting a medical bill from:

- U.S. Department of Health & Human Services: 877-549-8152
- Patient Advocate Foundation: 800-532-5274
- Cancer Legal Resource Center (CLRC): 866-843-2572

How can I get health insurance?

Coverage through a parent's insurance plan

You might be covered through a parent's health insurance plan. You can continue to be covered under that insurance plan until the age of 26. This option can be useful when:

- Your parent can afford to keep you on their health plan
- Your parent's health plan covers all the health care that you need
- You aren't eligible for **Medicaid** or other public health insurance programs
- You need a source of health coverage while waiting to be enrolled in another source of coverage, like Medicaid.

Medicaid
government-funded
insurance for low-income
people

It may not be the best option when:

- Your parent is unwilling or unable to afford to maintain coverage for you
- You're approaching the age of 26
- You need long-term supports and services that the health plan doesn't cover
- You have other health needs not covered by the plan – such as maternity benefits in some cases
- You have access to better or more cost-effective coverage through:
 - ▶ an employer
 - ▶ the health care exchange, or
 - ▶ Medicare/Medicaid.

Coverage through an employer

You may be able to get health insurance through an employer. Not all employers offer health insurance. Many employers offer insurance only to people who work full-time. Unless you already have a job that offers health insurance, it is best to plan ahead to make sure that you have alternative insurance options.

These options could be:

- A parent's insurance plan
- individual health insurance marketplaces, or
- Medicaid.

Buying individual coverage

You can buy insurance through statewide **health insurance marketplaces** for:

Yourself

Your spouse

Your children

This insurance is available to everyone who is a United States citizen. It is also available to other qualified residents. You can get insurance even if you have a pre-existing medical condition or disability.

All insurance plans have to cover a range of services. These services include mental health treatment and occupational therapy. Some plans can charge high co-pays and deductibles on top of the monthly insurance **premium**. But, preventative care is free. Preventative care includes annual check-ups and vaccines.

Some people can get tax credits to help pay for insurance. These are the conditions you have to meet:

You have to earn between 133% and 400% of the federal poverty level. In 2016, that means between \$15,800 and \$47,520.

You don't have another insurance plan.

You don't have another affordable source of insurance. This can include Medicaid or insurance through your job.

These tax credits are available even to people who don't usually earn enough to pay federal income taxes.

health insurance marketplace

a state website, also known as an "exchange," where you can compare and buy different kinds of health insurance plans

premium

the amount you pay each month to be able to have a certain insurance plan

Medicaid

government-funded
insurance for low-income
people

You can apply these tax credits directly to monthly insurance premiums. This means that you do not have to pay the full cost up front and then wait to be reimbursed.

The application for health insurance through the statewide marketplaces is available at www.healthcare.gov.

Filling out these applications is also a good way to find out whether you are eligible for **Medicaid**. You might be eligible for Medicaid because of:

- low income
- pregnancy
- parental status

You may need to fill out a separate application to see if you qualify for disability-based Medicaid coverage.

Applying for individual coverage is a good idea when:

- It is no longer possible to stay on your parent's plan, or your parent's plan is no longer affordable
- You are not eligible for Medicaid
- You want to apply for Medicaid and individual insurance at the same time, and
- You work but can't get health insurance through an employer.

People who want to buy individual coverage can only do so at specific times, so it is important to plan ahead.

You may apply for coverage:

- During the “open enrollment” period, which is between November 15 and February 15, OR
- Within 60 days of when you:
 - ▶ Lose a previous source of insurance.
This can happen when you:
 - Age out of Medicaid
 - Lose your job, or
 - Lose coverage through a parent’s health insurance plan
 - ▶ Get married, divorced, or have a child
 - ▶ Move to a new state
 - ▶ Start filing individual tax returns instead of being included on your parent’s tax return
 - ▶ Have a major change of income that affects your eligibility for tax credits or Medicaid

Medicaid expansion

Some states have expanded their Medicaid programs to cover all people with household incomes below a certain level. Others haven’t.

Whether you qualify for Medicaid coverage depends partly on whether your state has expanded its program.

To find out more about how Medicaid expansion affects you, visit
<https://www.healthcare.gov/medicaid-chip/medicaid-expansion-and-you/>

Health care providers

Overview

This section is about:

- different health care providers
- what they do
- how to find a provider that is suitable for you
- how to communicate with them about your needs.

Why do I have to change doctors?

As you get older, you'll begin to have health needs that you didn't have as a child. It's important to have a doctor who knows how to keep you healthy as an adult. Pediatricians are trained to care for babies, children and teens. They aren't trained to treat the medical conditions that you might have as you get older.

Having a different provider as a young adult just makes sense. As we get older, our needs change. So do the people who help us meet those needs. For example, you wouldn't have the same math teacher in 11th grade as you did in 2nd grade.

Health and health care is a very personal experience. So, as you become an adult, part of your transition includes finding a new health provider. An adult health care provider can respond and relate to you during this phase of your life.

Primary Care Physicians

A **primary care physician** is a general doctor. They are the first point of contact when you seek help for an undiagnosed health problem.

Primary care physicians can:

- treat
- give advice on, and
- prescribe medicines for many common complaints.

Primary care physicians perform check-up health exams and screenings to make sure you don't have any undetected health problems. They also help to manage a variety of long-term medical conditions and illnesses.

Sometimes, with certain health conditions, you might need follow-up appointments with a specialist doctor. In this situation, your primary care physician might be the one to refer you to that specialist. They might also help oversee the care you get from the specialist.

Specializations

Some doctors focus on a specific body part or subject area. These doctors are **specialists**. Depending on your needs, you might include specialists as part of your care team.

Here are some examples:

- Cardiologist** - heart.
- Dermatologist** - skin, including some skin cancers.
- Gastroenterologist** - stomach.
- Endocrinologist** - hormone balance.

primary care physician
a general doctor who is the main point of contact for a person's overall medical care

specialist
a health care provider who works with treating specific conditions, or a certain area of the body

Mental health therapists

Health care goes beyond just your physical health. Your mental and emotional health are very important too. You might choose to see a therapist. There are a lot of ways a therapist could help you. For example:

You may need accommodations to help with communication, organization, or sensory sensitivities. Mental health therapists may be able to offer:

- specific strategies
- scripts (things you can memorize and say in specific social situations), or
- other ideas to help with these.

You can get therapy to identify behaviors you wish to change and find ways to change them.

For example, to help you:

- stop smoking
- change rituals that are interfering with your life
- overcome a phobia

Therapy can help you to find ways to understand and respond to negative emotions, or to help prevent meltdowns.

Some mental health therapists teach people ways to understand and manage social situations.

Different mental health therapists have different approaches to therapy. They might use different resources or tools available to help address their clients' specific needs.

It's important to find a mental health therapist whose ideas about therapy fit well with your own goals and beliefs.

Finding a health care provider

To find a health care provider, you might need to:

- Ask people or organizations you know and trust (for example, friends and family, other professionals, autism groups, or hospitals).
- Look through listings provided by your health insurance provider (if you have insurance).
- Search for safety-net or self-pay clinics (if you do not have insurance).
- Search on the Internet.
- Search through Yellow Pages, contact organizations offline, or look around physically for a provider or clinic in your neighborhood.

You need to know if you are able to see a health care provider. You need to make sure of the following:

- That the provider takes your type of insurance (if you have insurance), and that you can pay for the in-network or out-of-network service.
- That the provider takes on self-pay patients (if you don't have insurance).
- That you can afford to pay for the service.
- That the provider is taking new patients.
- That you can get to the provider when you need to.

self-advocate

somebody who speaks up for their own wants and needs

Communicating with providers

Communicating is a two-way street—giving and receiving information. If you are going to take care of yourself and be a **self-advocate**, you must be able to communicate in both directions.

A starting place for communicating with your health care provider is to take all your medications or a list of all your medications to every appointment.

If you have more than one or two simple things you want to discuss with your doctor, it helps to make a list. If you can be specific about what is bothering you, you will give your doctor the best possible chance of making the correct diagnosis and treatment decisions.

- What is bothering you? (sharp pain, crampy pain, nausea, etc.?)
- How long have you been noticing the discomfort? (two hours, a day, a month?)
- How long does the discomfort last? (seconds, hours, all the time?)
- Does anything make you feel better or worse? (eating, lying down, exercising?)
- How bad is the discomfort?

Using the numbers 0 through 10, where 0 is feeling fine and 10 is the worst you've ever felt, can help your provider know how best to help you.

When the provider tells you what is wrong and what to do about it, ask any questions you have about what the diagnosis means and what you'll be expected to do about it. For example, "Can I take this medicine with food?" or "How long will it be before I feel better?"

Is my provider a good choice?

Some ways to figure out if a provider is a good fit for you are:

Find out information about the provider by:

- ▶ looking them up on the Internet
- ▶ asking people you trust for their opinions
- ▶ contacting the provider's office.

Schedule a “getting to know you” visit with the new provider.

See the provider a few more times, and think about how the visits went.

Use [this list of “Questions to Consider”](#) as a guide to some things that might be important to think about in figuring out if a health care provider is a good match for you.

If after a few visits you don't feel comfortable with a particular health care provider, it's absolutely okay to see a different provider.

Managing your health

Preventive care

preventive care

health care actions you take while you're healthy to prevent getting sick

Preventive care is the action taken to prevent a major health problem, or to detect a potential health problem when it is still minor and easier to treat.

Preventive care involves the following:

- Checking your blood pressure, cholesterol levels, and weight. These things are done at any regular doctor's check-up.
- Testing for cancers, such as cervical, breast, colon, prostate, and skin cancer. Preventive care related to cancer also involves you regularly checking for irregular lumps on your own, and knowing how to find them.
- Testing for lots of diseases, like diabetes, osteoporosis, thyroid disease, or HIV. Most doctors will ask for a urine sample when you register with them, usually so they can check for diabetes.
- Sexual health checks, like getting cervical smear tests. Preventive care in this area can include using condoms when you have sex to prevent sexually transmitted infections.
- Screening for mental health issues, such as depression or anxiety. A primary care physician can often diagnose these. But for more specific mental health issues, like OCD, you may be referred to a specialist.

Screening for substance abuse, and monitoring your current use of any substances.

Helping someone out of serious life situations that affect health, such as domestic violence.

Getting vaccinations to prevent conditions such as tetanus, the flu, or cervical cancer. Some of these need to be done once a year, and sometimes you can go a decade or longer without needing a repeat vaccination.

Having eye exams, dental exams, and dental cleanings

Getting advice about exercise, diet, or other things you can do to stay healthy, and following that advice.

First Aid Kit

It's important to have a well-stocked first aid kit in your home. This will enable you to deal with minor injuries. Keep your first aid kit in a cool, dry place that is easy to access and in a place you'll remember.

Here are some things you should keep in a first aid kit.

- **Band-aids.** You should have different sizes in case you get a bigger cut or burn.
- **Neosporin.** This is an antibiotic for minor cuts and scrapes. Put this on before you apply a band-aid.
- **The phone number for the poison control center:**
1-800-222-1222
- **Gauze squares.** These are used to clean wounds.
- **Hydrogen peroxide** for cleaning wounds.
- **Individually wrapped wound dressings.**
- **Over-the-counter painkillers** like Advil, Ibuprofen, or Tylenol
- **A thermometer** (preferably digital). Useful for checking to see if someone has a fever.
- **Tweezers** for removing small objects.
- **Sterile eye dressings** and saline solution for cleaning eyes.
- **A reflective emergency blanket** to keep someone warm.
- **A pack of ace bandages.** These elasticated bandages are useful for sprains. They create localized pressure that supports your joints and muscles. They don't need any additional fastening tools.

A pack of crepe rolled bandages. These bandages are breathable and do not obstruct your muscle or joint flexibility. They are useful for insulation and support of certain injuries.

Scissors for cutting tape, band-aids and bandages.

Safety pins or claw grips, for securing bandages.

A triangular bandage. Used for making a sling.

Disposable gloves. These will reduce the risk of infection being passed on, for example, through blood.

If you drive, consider keeping a first aid kit in your car for emergencies. Sometimes, basic first aid can stop a person's injury getting a lot worse.

You can keep something distracting or soothing, like a stim toy, in or near your first aid kit, in case you begin to panic after or during an accident.

In case of emergency

It's a good idea to carry some medical information about yourself, especially about:

any allergies or health conditions you have

what your medications are and where they are kept, and

who you'd like to be contacted in an emergency.

You can create your own medical ID card here for free:

<http://www.medids.com/free-id.php>

Keep your emergency medical information on you, perhaps in your wallet, or on a keychain. This way, if someone finds you injured or unconscious, they can locate your details, and have a clearer idea of what might have happened and how best to help you.

You may need to know what to do in a specific medical emergency. Check the resources list in the back of the book.

Maintaining your personal medical records

Maybe you're thinking of getting a new doctor. Maybe you just want to remember if your check-ups are up-to-date. Having a file folder with your important medical records can come in handy.

Here's how to gather your medical records to create a file:

1. Write a list of the doctors and other health providers you've seen recently.

This could include your regular pediatrician and any specialists you see, for example:

- neurologist
- cardiologist
- gynecologist or urologist
- dentist
- psychiatrist
- endocrinologist
- dermatologist
- occupational therapist, etc.

It may help to ask for help from your parent or any other person who helped schedule doctor's appointments for you.

2. Contact each doctor and request your records.

You have a right to these records under federal law. The one exception is psychotherapy notes. But, you still have a right to your therapist's records about other details. These details include information about appointments and medications you've taken. You may have to sign a form to get a copy of your health records.

3. Take a look at the records when you receive them to make sure that they are correct and complete.

You may need help understanding the records or remembering whether the information in them is correct. A trusted friend, family member, or service provider can help you.

If your records are wrong, you can request an appointment to get your medical records fixed.

4. Put the records away in a safe place.

Keep your records together. You may need help keeping your records organized. A trusted friend, family member, or service provider can help you.

It is best to not write on your records or give your only copy of your records to anyone – not even a doctor! If a doctor wants a copy of a record that you brought with you, ask if you can use their copier. If you do not have the copy with you, offer to sign a form that allows your doctor to request a copy from the other doctor's office.

Keeping appointments

As an adult, it is your responsibility to organize your own medical appointments. If you need help with doing that, make sure to ask a friend, family member, or someone else you trust.

In some cases, you will have to make your appointments by yourself, unless you have signed a waiver that allows another to schedule your appointments for you. You should know where your appointment is located, and what time you need to be there. Try to arrive at least 20 minutes early, so that you have time to fill out any paperwork that they give you.

If you know that it is difficult for you to find where you need to go, or if you get lost easily, go to where your appointment is a few days in advance, so that you can easily find the place later.

This will also help you to familiarize yourself with the new surroundings so that it isn't a surprise at your appointment.

Having everything you need for an appointment is also important. If your doctor has asked you to bring anything, make sure to do so. Always have your health insurance information, and a way to pay for your copay if you have one.

If it is your first appointment, you need to give your new doctor a list of:

- all medications you are taking,
- any conditions you have,
- past surgeries or hospital visits.

An easy way to accomplish this is to have your medical information forwarded from your old doctor to your new doctor. This does require filling out a form. This is so that your new doctor can legally request the information from your old doctor.

Your time in the doctor's waiting room might be long and boring. Make sure to bring something quiet to keep yourself occupied. A book, knitting, a phone, or a handheld video game system are a few suggestions.

Also remember that doctor's offices typically use fluorescent lighting and may play music or have televisions in the lobby, or be crowded.

If any of these things bother you, prepare by bringing items that will help like sunglasses, headphones, earplugs, etc., but don't forget to listen out for when the doctor calls you into their office.

Check out the Chapter 10 Resources starting on page 371 for worksheets you can use before, during, and after a doctor's visit.

Managing medicines

If you are prescribed a medication, read the description inside the box. Learn about any possible side effects you might get from it, so that you're prepared if they happen.

Make sure you keep your medicine in a safe place and do not move it from that area. A cabinet in your bathroom is a good idea, or, if it's easier to remember, a drawer right next to your bed.

If you need to carry an emergency medicine with you, like an EpiPen or an inhaler, don't take it out of your bag. It's wise to keep it in an inside pocket of a bag, so it's easy for you or someone else to locate quickly.

[This flowsheet](#) will help you to manage your regular medicines. You can print this, and then fill out the sections to plan and remind yourself. Record what things you need to take, what time of day to take them, and how long your course of medication is.

Editor's tip: Besides being autistic, I also have ADHD. I often forget whether I've taken my medications in the morning. I got a 7-day pill container. It has compartments for my morning and bedtime medications for each day. That way, when I take my meds, I can see that the compartment is empty.

For medications that don't fit in a pill container, try setting an alarm on your phone. You can give it a name like "Time to take gummy vitamins!"

Paying attention to your body

This section is about taking care of your physical and psychological needs from day to day. This should be a big life priority for everyone. It is the starting point to being able to do other things. You can't do much if you're tired, hungry, dehydrated, or stressed out. You must take care of these basic things before attempting to do anything else.

When you're fatigued, or lightheaded, or have a headache, ask yourself:

- Am I drinking enough water today?
- When did I last eat?
- Have I been out in the sun for too long?

Your body can't lie to you, it can only react in ways that try to keep itself alive. When you have been in the heat, you can get nauseous and lightheaded until you cool off by sweating. You need to drink water for this to be efficient. When you haven't had enough food, you will feel drained of energy, and your stomach will growl and feel empty, telling you it's time to eat.

Pay attention to how you feel and what you need. Check in with your body every now and then during the day. If you find this hard, set reminders or alarms.

Eating

Food is one of the most important things about staying healthy and feeling good. Not getting enough food or nutrients can cause lots of health problems depending on what you are deficient on. Your mood, energy and ability to process information all rely heavily on your food intake.

Pay attention to your hunger. Assess how hungry you are, but don't obsess over it. If you feel hungry, eat. When you feel full, stop. Don't feel guilty for the amount you need to eat. Don't make yourself eat less or more than you need out of guilt or obligation. Your body needs fuel in the form of food. It is that simple.

For your brain and organs to work properly, your body needs vitamins and minerals. Different vitamins and minerals come from different foods. Generally, fruit, vegetables, nuts, and seeds are good.

If you are often low on energy, or often find it difficult to sleep, adding more vitamins and nutrients to your diet could change that.

Check the Chapter 110 Resources starting on page 371 to learn more about what vitamins and minerals are and how they improve your health.

Try to eat healthy. But, if you find that hard or impossible, don't feel bad or ashamed for eating foods that:

- are available to you

- you enjoy, or

- you can tolerate from a sensory perspective.

If you find it hard to change your diet, try making small changes to the food you already eat. For example:

- Adding a little protein powder to a milkshake or smoothie

- Eating whole-grain bread instead of white bread

- Getting 100% fruit juice instead of the ones with additives.

If you find it hard to cook meals or get groceries, then this is something you should address in your transition plan. Go through your everyday needs in your transition plan with someone you trust. This will help you figure out if you can get support when shopping, or find ways to work on your cooking skills.

Check the Chapter 10 Resources starting on page 371 for advice on making cheap, easy meals. Chapter 4 has more information on making your transition plan.

Staying hydrated

Water is essential for life. It makes up 50-70% of your body weight. Your body loses water through breathing, sweat, urine and feces. When you don't have enough water in your body, your mood and energy levels deteriorate fast.

Research has shown that even when humans are dehydrated by just 1%, it negatively affects our:

- mood
- attention, and even
- motor coordination.

Most of the time we don't even realize that we're dehydrated. By the time we actually feel thirsty, our ability to perform well has already dropped a lot.

Try to drink a glass of water every hour. You could keep a big bottle with you and take a sip every few minutes. Buying a colorful water bottle that you like can help encourage you.

You need to drink more fluids when:

- you are ill

- it's hot outside

- you've been exercising

Try to cut back on drinks with lots of sugar and caffeine. These drinks can actually dehydrate you. Water is always the best liquid for staying hydrated.

Getting enough sleep

The amount of sleep that you need is different for everyone. You should try to aim for around 8 to 10 hours a night. Getting enough sleep is essential. Getting enough sleep helps you do lots of things. For example, being well-rested helps you:

- Process information

- Make decisions

- Prevent and recover from illnesses

- Heal wounds

- Regulate your mood

Practice good **sleep hygiene**. Sleep hygiene means the habits and patterns you form that affect your sleep.

sleep hygiene

the habits and patterns you form that affect your sleep

Some examples of good sleep hygiene include:

- **Having a regular bedtime.**
- **Doing things that relax you before bedtime.** Have a routine of one or two relaxing and non-challenging things. For example, reading a lighthearted book, or playing with silly putty. Don't do, or think about, stressful things. Put these things away until the daytime.
- **Reserving your bed as a place for sleep.** Don't use your bed for watching TV, eating, using the Internet, or studying. Your body needs to learn that getting into bed means it's time to relax and become sleepy.
- **Getting enough natural light during the day.** This helps to give your brain a healthy sleep-wake cycle. Keep your curtains open when the sun is up. Spend some time outside every day.
- **Exercising in the morning or afternoon.** Read the next section about exercise for help with this.
- **Not using stimulants like caffeine during the evening.**
- **Limiting your use of your laptop, TV and phone close to your bedtime.** These devices give off a blue-tinted light. This tricks your body into thinking it's still daytime. It keeps you awake. It stops your body from producing melatonin. Melatonin is the hormone that makes you sleepy.

If you want to use something with a bright screen at night, try downloading **f.lux**. It makes your screen color warmer as the sun goes down. It's free, and you can use it for laptops and some other devices.

Go to <http://justgetflux.com>.

Some modern smartphones have their own built-in ways to adjust screen temperature. Check your phone's settings.

Autistic people often have sensory needs when relaxing and going to sleep. Some sensory stimuli can make sleep hard or impossible, while other things can be soothing.

Make sure your room is the right temperature for you, and that your bed is as comfortable as it can be. If you know you need them to sleep, get eye masks and earplugs, and keep them on or under your pillow.

If you need background noise to sleep:

- The **Sleep With Me Podcast** is a regular podcast where you can listen to a boring, rambling story that sends you to sleep.
- **A Soft Murmur** is a webpage with different background noises. You choose from white noise, waves, thunder, wind, crackling fire, rain and other noises. You can create your own background noises by combining the different sounds and adjusting the individual volumes.
- **YouTube** has many videos of white noise, machine sounds, traffic noise or other relaxing continuous background sounds. Some of the videos are 10 hours long. YouTube also now gives you the option to loop videos.

Some people, especially autistic people, need weights or pressure to sleep well.

You can search online for weighted blankets. www.sensorydirect.com sells these.

There is a link in the resources section of this book which explains how you can make your own weighted blankets.

If you find that weighted blankets are too expensive, try buying padded ankle or wrist weights. You can get these by searching online or in fitness stores. They can be helpful if you suffer from restless legs or arms in the night.

Exercising

Exercise counts as anything that makes your heart beat faster than normal, your skin sweat, and your joints and muscles get used. This could be:

- playing a sport
- taking a walk around your neighborhood
- dancing to your favorite songs in your bedroom
- yoga
- pilates and stretching
- riding a bike
- going swimming.

Exercise helps you in many ways. Here are some benefits of exercise:

- It helps you feel more alert
- It makes you stronger
- It makes your heart healthier
- It helps you sleep better
- It improves your mental health.

As a guideline, it's easier to do short bursts of exercise regularly and get into a routine, than it is to do more intensive exercise less often. When you don't exercise regularly:

- it gets harder to convince yourself to do it
- you're more likely to injure yourself, and
- your body takes a longer time to recover.

Here are some things to consider when deciding which exercise is right for you:

- Am I physically able to do this?

- Can I afford to do this?

- Is it easy to take part in this? For example, is there a place to do this nearby, like a running track or gym?

- Do I find this fun? Make sure you pick something you enjoy, so you're motivated to do it. If you love music, for example, try dancing, either on your own, out with friends or in a class.

Some people just really don't enjoy most exercise, or can't do it for other reasons, like a physical disability or difficulty leaving the house. It is still good to try and get a little exercise. Here are some examples of home exercise:

- Doing some stretches in the morning to help you wake up

- If there is a flight of stairs in your home, go up and down one extra time whenever you use them

- Flex your shoulders while watching TV

- Do calf-raises while you wash the dishes

mental health

the quality of your mood and thoughts from day to day

Mental health

Young adults going through their transition have a higher incidence of **mental health** issues. Mental health issues negatively affect the way you think and feel. They can get in the way of you enjoying your life. Mental health issues can be situational or clinical.

Situational: This means the issues happen because of your external life circumstances.

Clinical: This means that your body is causing the issues. For example, a chemical imbalance in your brain.

Many mental health issues are a mix of these things. Medication is often helpful regardless. If a mental health issue is situational, then therapy is helpful. You can get therapy on its own, or alongside medication.

While this is a time of excitement for many young adults, it's also a time of uncertainty. All the big changes can be overwhelming for autistic people. It's important to learn tactics for managing:

- stress
- anxiety
- low self esteem
- other mental health issues

Preventive care to stop any negative feelings from persisting or interrupting your life is also important.

Here are some tips:

Keep in touch with your friends. Having someone to vent to about frustrating things, but also have fun and relax with, is great for your mental health, and theirs too

Comparing yourself to other people is a sure-fire way to reduce your self-confidence. Often, we only see other people's successes, popularity and good news. This is because so many people go to a lot of effort to hide what they see as failures and flaws. It is easy to think that you are less exciting, attractive, or lucky than everyone else, and feel isolated as a result. Try to keep in mind that many other people going through the same thing as you feel similar to you. You are doing fine.

Alcohol and drugs might become more accessible.

Do not take anything you don't want to, or if you don't know what it will do to you. There are resources about drugs and help with addiction at the back of this book.

It's normal for people going through this stage to experience sadness, homesickness, or feeling directionless. If these feelings don't go away, or they interfere with your ability to work or study or relax, you can seek help. Refer to the section about finding a healthcare provider.

If you slip up or something goes wrong, you can restart your day at any time. You don't have to wait until tomorrow to try again. Just sit down, breathe deeply for a few minutes, and start things over.

- **If you're having a rough night**, put on your favorite TV show, light some candles, or play some good music. Cuddle up under some blankets.
- **Experiment until you find things that de-stress you effectively.** Then you can create a personalized emergency toolkit of de-stressing things that work for you.
- **If you struggle with intrusive thoughts**, especially at night, here are a few things you can tell yourself:
 - ▶ That thought isn't helpful right now.
 - ▶ Now is not the time to think about it. I can think about it later.
 - ▶ This feels urgent, but it really isn't.
 - ▶ It's good practice to let go of this worry. I want to practice.
- **It's okay to ask for reassurance and compliments.** You can say to someone you trust, "I don't know if I'm doing okay. Can you reassure me?" or, "Can you tell me a few things to boost my confidence?"
- **Make the effort** to take part in things that lift your mood or give you a new experience. Here are a few ideas:
 - ▶ Try and create something new. Sketch a picture, or an interesting pattern, or go out and take some photographs of things you like. Or you could make a poem with word magnets, write a short humorous tune, or sculpt something out of clay. Don't be afraid to make mistakes. Enjoy the process rather than worrying about the end result.

- ▶ Connect with nature. If you are able, try climbing a hill, and take in the view when you reach the top. Explore a forest, or stroll along a beach. If you can't do this, sit in a nearby park and read a book instead of at home.
- ▶ Change your appearance. Dye your hair a fun color, try a new clothing style, experiment with makeup. If you find a new look you like, take selfies and show your friends.

Don't get bogged down with worrying about your life and purpose. You don't need to have it all figured out. Many people don't develop a sense of life direction until their mid to late 20s, or later. You aren't a failure for not having that yet. Focus on your happiness and enjoyment from day to day.

Make sure you have small, easy to achieve goals alongside your bigger life goals.

It's easy to focus on the negatives when you have a slip-up. But try to put it in perspective. Focus on how far you have come. Be proud of yourself for making decisions, even if they don't seem to be immediately paying off.

Managing your physical health in all the ways listed above will also improve your mental health.

Health care and the law

Americans with Disabilities Act

What is it?

Americans with Disabilities Act (ADA)
a federal civil rights law that protects people with disabilities from discrimination

The **Americans with Disabilities Act (ADA)** is a law which makes discrimination against people with disabilities illegal in:

- jobs
- transportation
- schools, and
- all public and most private spaces (except homes and some other places)

How does it apply to health care?

Health care facilities are a “private space” under the ADA.

Anyone with a disability must be able to take part in an **integrated setting**. Sometimes a building can’t be modified to make it accessible. In that case, the business must find alternative ways of providing its service.

Health care facilities could make their buildings accessible to autistic people by:

- providing sensory-friendly waiting or examination areas,
- providing maps or help with finding your way around the building,
- making sure mobility devices can access the building.

integrated setting
places where people with disabilities are equal and included with people without disabilities, rather than being in a separate place

Health care facilities must make an effort to enable effective communication between all patients and health care providers. This might mean providing things like:

- interpreters
- note takers
- transcription services or real-time captioning
- written materials and exchange of written notes
- Braille materials
- screen readers
- large print materials

When it comes to autistic people, this might mean:

- allowing a service animal or supporter/advocate to be with you in the appointment,
- providing an alternative to using the phone for you to make an appointment,
- allowing you extra time for communication,
- preparing a schedule of your appointment in advance and letting you know of any changes,
- using direct, specific language when talking to you.

Affordable Care Act

a federal law which made health care more affordable, accessible, and high quality

pre-existing condition

a medical condition that you already had before you got health insurance

preventive care

actions taken while you're healthy to prevent illness

health insurance marketplace

a state website, also known as an "exchange," where you can compare and buy different kinds of health insurance plans

The Affordable Care Act

What is it?

The **Affordable Care Act (ACA)** was written into law by President Barack Obama on March 23, 2010. It is sometimes known as "Obamacare."

What does it do?

The ACA helps to make health care more accessible and affordable, especially for young people.

It gives you more power over your health care, rather than insurance companies and employers making decisions for you.

It requires insurance plans to cover people with **pre-existing health conditions** without charging more.

It makes free **preventive care** a legal requirement.

It gives young adults more coverage options.

It makes it illegal for health insurance companies to cancel your health insurance just because you get sick.

It gives you the right to buy a **marketplace** plan rather than the one your employer offers you.

It gives you the right to appeal a health plan decision.

Additionally, the ACA means that you must be able to access:

- Breastfeeding equipment and support
- Birth control methods and counseling
- Mental health and substance abuse services.

COBRA

What is it?

COBRA stands for Consolidated Omnibus Budget Reconciliation Act. It applies to insurance you get through an employer.

It gives you temporary health care coverage, if you lose your health benefits due to things like:

- losing your job
- changing between jobs
- getting a divorce
- someone dying
- your work hours being reduced.

COBRA

law that helps you get temporary health care coverage if you lose benefits in some circumstances

HIPAA

What is it?

HIPAA stands for Health Insurance Portability and Accountability Act. HIPAA protects your right to keep your medical records private.

HIPAA

law that protects your right to keep your medical records private

Who does HIPAA apply to?

- ▶ HMOs
- ▶ Pharmacies
- ▶ Hospitals
- ▶ Doctors and nurses
- ▶ Anyone else who works in a health care profession.

What information is protected under HIPAA?

- ▶ Any part of your medical records
- ▶ Your medical billing information
- ▶ Information about you in your health insurance company's computer system
- ▶ Most other medical information about you held by any health care professional.

HIPAA releases

Sometimes you'll need a health care provider to be able to share your medical records.

For example, you might want to share your records with a new doctor. Or, a trusted supporter.

If you want the provider to be able to share your records, you will have to sign a form called a **HIPAA release**. This form lets the doctor release your records to a specific person or organization.

You have to sign a new HIPAA release anytime you want to share your records with another person or organization.

HIPAA release

a form you can sign that lets your doctor share your medical information with somebody else

The Mental Health Parity & Addiction Equity Act

What is mental health parity?

“Parity” means something is equal. Before this law passed, insurance plans usually would have very low levels of coverage for health care related to:

- mental health, or
- substance use disorders

What does the law do?

This law makes it illegal for many insurance plans to set different limits on the care you can get.

For example, let’s say you have an insurance plan that lets you have unlimited doctor’s visits for a long-term condition like diabetes. Your insurance plan would also have to let you have unlimited doctor’s visits for long-term mental health conditions, like depression.

Most insurance plans have to follow this law.

How does this fit into my transition plan?

- ▶ Your rights and responsibilities about your health will change as you become an adult. For example, you'll need a new doctor.
 - You need to make sure you can book and attend appointments and communicate with a doctor about your health care needs.
- ▶ You need health insurance, so it's worth learning about the different kinds, how to get them, and which services they cover.
- ▶ You may need to learn about your rights when accessing health care. This includes any accommodations and supports you need and how to get them.
- ▶ You need to take care of yourself. This includes making sure you
 - Drink enough water
 - Eat healthy
 - Get enough sleep
 - Exercise
 - Manage your stress levels

- ▶ Sometimes emergencies happen, so you need to be prepared.
 - You should know who to call in an emergency.
 - Be sure to carry any emergency medicines you need on your person.
 - Keep a well-stocked first aid kit. Part of your transition plan will be to do with making sure you are able to manage your health care needs.
 - As a young adult, you need to ensure you have an age-appropriate doctor.
 - You need to make sure you know how to make an appointment, and how to get there.
 - You will need to know some information about your insurance and what it covers.
 - ▶ You could plan what you would do if you needed something your insurance doesn't cover.

In addition to being able to attend a doctor and access health care services, you'll need to take care of yourself.

- Will you need supports for keeping healthy? For instance, a gym buddy or someone to cook you healthy meals?
- How will you remember to take medication?
- What are the best things for your mental health?
- What would you need in a first aid kit?

Summary

- ▶ Your rights and responsibilities about your health will change as you become an adult. For example, you'll need a new doctor.
- ▶ You need to make sure you can book and attend appointments and communicate with a doctor about your health care needs.
- ▶ You need health insurance, so it's worth learning about the different kinds, how to get them, and which services they cover.
- ▶ You may need to learn about your rights when accessing health care.
 - This includes any accommodations and supports you need and how to get them.
- ▶ You need to take care of yourself. This includes making sure you
 - Drink enough water
 - Eat healthy
 - Get enough sleep
 - Exercise
 - Manage your stress levels
- ▶ Sometimes emergencies happen, so you need to be prepared.
 - You should know who to call in an emergency.
 - Be sure to carry any emergency medicines you need on your person.
 - Keep a well-stocked first aid kit.

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11 Appendix

What is this?

The appendix is the last part of this book. It is where you can find more resources and information. The appendix is organized into:

- Glossary of Terms
- Resources by Chapter
- National Resources
- Resources by State

There are different kinds of resources, including:

- websites
- printable worksheets
- mobile apps
- blog articles
- search engines and calculators

Glossary of Terms

We have tried to make this book as easy to read as we can. But, sometimes there are more complex phrases or words that we can't avoid using. Sometimes, even when you Google a term such as “durable power of attorney”, it's hard to find an easy to read definition. The Glossary of Terms section lists these phrases and gives a brief explanation.

Any time you come across an unfamiliar phrase, you can check to see if it is in the glossary. Words that are **pink and bold** in the text of a chapter can be found in the glossary.

Resources by Chapter

This section has more resources to go along with each chapter.

There are a lot of links for each chapter. Some links are to specific pages of a website. But, that doesn't mean that the authors of this book agree with everything on the site.

Some resources are on websites that are targeted at people outside of the United States. But, the rest of the website might have information that doesn't apply to you. We've made sure to label these resources.

You will see some resources more than once. That's because they are relevant to more than one section of the book.

National Resources

National Resources are resources that anyone in the United States can use, regardless of their state. The section has different government and nonprofit organizations.

Resources by State

In the Resources by State section, you can look up your state and find out if there are local programs and organizations that can support you. The states are listed alphabetically. For each state, we've linked to the state's:

Official website

List of departments and agencies

Centers for Independent Living

Vocational Rehabilitation program

Chapter of The Arc, if there is one

The Arc works to protect people with intellectual and developmental disabilities. It does this by working with public policy and legal advocacy. They also offer training and employment programs.

If you can't find a state resource, you could try searching online for:

"[state] disability services"

"[state] department of disability"

"[state] health and human services"

Glossary of Terms

504 plan

A plan for how a student with a disability will get the accommodations they need for a general education in school.

activities of daily living (ADLs)

Basic skills such as housekeeping, meal planning and preparation, money management, arranging social activities, use of public transportation and self-medication.

advocate

To defend something or to argue for a certain thing to happen. Or, a person who does these things.

Affordable Care Act

A federal law which made health care more affordable, accessible, and high quality.

Americans with Disabilities Act

A federal civil rights law that protects people with disabilities from discrimination.

augmentative and alternative communication (AAC)

Any way of communicating that doesn't involve speaking out loud.

COBRA

The Consolidated Omnibus Budget Reconciliation Act. This law helps you get temporary health care coverage in certain circumstances. Applies to insurance you get through an employer.

coinsurance

The amount your insurance company requires you to pay for a medical claim, apart from any copayments or deductible.

competitive employment

Employment where people with disabilities are paid at least the minimum wage.

copay

A fixed amount that you pay to see your doctor. Your insurance might have a set copay amount that you pay to see the doctor, regardless of how much the doctor's office charges. The insurance company will pay the rest of the cost.

curriculum vitae (CV)

A type of document you might send to potential employers. It contains academic and career-related information about you, including achievements, awards, and publications. A CV is much more detailed and lengthy than a résumé.

deductible

The amount of money you're charged on your medical bill before your insurance kicks in.

disclosure

The act of telling somebody else that you have a disability.

discrimination

Treating a person less favorably because of bias against their race, gender, sexual orientation, or disability status.

durable power of attorney

A legal agreement where you give decision-making power to someone else. This power lasts even if you can't make decisions for yourself anymore.

Employment First

A government program which helps people with disabilities find and keep integrated employment.

essential job functions

The core tasks someone must be able to do in order to do their job. The term is used in the ADA to identify the rights of employees with disabilities.

Exclusive provider organization (EPO)

A managed care plan where services are covered only if you go to doctors, specialists, or hospitals in the plan's network (except in an emergency).

explanation of benefits (EOB)

A letter your insurance company sends you after you have received medical treatment. It tells you how much money you owe the doctor, if any, and how this was worked out.

Fair Housing Act

A federal law that protects people buying or renting property from discrimination.

Fair Labor Standards Act (FLSA)

Federal law that established the minimum wage and other rules about employment.

The Family Education Rights and Privacy Act (FERPA)

A federal law that protects the privacy of student education records.

GED

GED stands for General Educational Development. The GED is a test you can take if you didn't graduate high school. Passing the test is the equivalent to having a high school diploma.

guardianship

A legal arrangement where you are given a "guardian" who can make decisions for you.

health insurance

An arrangement where a company, or the state, pays for certain health care services.

Health maintenance organization (HMO)

A type of health plan where you choose a Primary Care Physician, and then that physician refers you to in-network specialists or hospitals when necessary.

HIPAA

The Health Insurance Portability and Accountability Act. This is a law that protects your right to keep your medical records private.

HIPAA release

A form you can sign that lets your doctor share your medical information with somebody else.

independent living

A living situation where you are free to make your own day-to-day choices.

Individualized Education Program (IEP)

A plan for how a student with a disability will get the services and supports they need in school, including specialized education.

Individuals with Disabilities Education Act (IDEA)

A federal law that makes sure students with disabilities get a free public education that includes the supports they need.

in-network provider

A health care provider whose services are covered by your care plan.

institutions

Places where people with disabilities live but don't have control over our own lives.

instrumental activities of daily living (IADLs)

Tasks that help you live independently but are not essential for basic functioning

insurance claim

A request made to your insurance company asking them to pay for a health care service that was provided.

insurance ID card

A card that gives your personal information and information about the insurance plan you have to a health care provider.

integrated employment

Employment where people with disabilities work alongside people without disabilities.

integrated setting

A place which is accessed by both people with disabilities and people without disabilities.

joint bank account

A bank account you set up with another person. You might do this with a supporter. Many married couples have a joint bank account. The money in a joint account belongs to both of you, usually equally.

Medicaid

Government-funded insurance for low-income people.

Medicaid expansion

Part of the Affordable Care Act which makes more people eligible to get Medicaid, if their state chooses to be part of expansion. In states that choose not to expand Medicaid, the old requirements still apply.

medical home

A way of delivering health care that is patient-centered, coordinated, supportive, and appropriate for the patient's culture.

medical home care team

The health care providers who work together to deliver patient-centered care, including primary care physicians, specialists, and therapists.

mental health

The quality of your mood and thoughts from day to day.

natural supports

Unpaid, informal support that you get from friends, family, and community members.

out-of-network provider

A health provider who does not have a contract with your health insurance company. It is more expensive to get care from an out-of-network provider.

Olmstead vs. L.C.

A Supreme Court case that decided it is discrimination to force people with disabilities to live in institutions rather than in their communities.

Personal Care Assistant (PCA)

A kind of support staff that you can hire to help you with non-medical care tasks, like meal preparation or chores.

Point of Service (POS)

A type of health insurance plan. You usually get lower medical costs in exchange for more limited choice.

pre-existing condition

Any medical condition you already have before your health insurance takes effect.

Preferred provider organization (PPO)

A health care plan where a network of doctors, nurses and other health care providers have agreed with an insurer to offer their services at a reduced rate.

preventive care

Actions that keep you as healthy as possible and prevent illnesses from happening or getting worse. This could be things like getting tested for diseases, getting vaccinations, or getting a good night's sleep.

primary care physician

A general doctor who is the main point of contact for a person's overall medical care.

Protection & Advocacy (P&A) agencies

State-level organizations that protect the rights of people with disabilities.

provider network

A provider network is a list of the doctors, other health care providers, and hospitals that an insurance plan has a contract with to provide medical care to its members.

reasonable accommodations

Changes made to a work environment, living space, or other building to make it accessible to people with disabilities.

regular power of attorney

A legal agreement where you give decision-making power to someone else. It lasts until either 1) you take the power away or 2) you can't make decisions for yourself anymore.

representative payee

A person who gets your disability benefit money and manages it for you.

résumé

A document you send to an employer. It is a summary of your education, work experience and any other academic or work-related credentials or accomplishments. Résumés are usually not more than a page long.

Schedule A

A hiring process that gives people with disabilities an advantage when applying for government jobs. Government agencies pull applicants with disabilities into their own applicant line.

Section 14(c)

A section of the Fair Labor Standards Act that says people with disabilities can be paid less than minimum wage. A company has to get a special certificate from the government to be able to do this.

Section 504 of the Rehabilitation Act

Section 504 makes it illegal for organizations that get money from the federal government to discriminate against anyone based on disability.

segregation

Being set apart from the general population.

self-advocacy

The act of speaking up for what you need and want.

self-advocate

The action of speaking up for your own wants and needs. Or, somebody who does this.

self-determination

The idea that each person has the right to decide how to live their life.

sheltered workshop

A place where people with disabilities are employed in a segregated setting, and are often paid less than the minimum wage.

sleep hygiene

The behavior patterns that influence your ability to sleep.

specialist

A health care provider who works with treating specific conditions, or with a certain area of the body.

spoons

The amount of energy people with disabilities have to complete tasks each day. Comes from Christine Miserandino's essay called "The Spoon Theory."

supports

The help you get to accomplish everyday tasks.

support team

A network of people who help guide you in your decision-making.

supported housing

A government-funded program that combines housing with support services.

transition

The process of changing from one way of life to another way of life.

transition plan

A plan you make to help you transition to adulthood. It helps you figure out what you want out of your life, and what you need to do to get there.

transition planning

The process of making a transition plan. This is done with the help of your support team.

transition services

Activities that help you develop the skills you'll need to live independently.

tuition

How much you pay to take a class, separate from the costs of course materials.

vocational rehabilitation

A process that helps people with disabilities overcome barriers to finding and keeping jobs.

workers' compensation

A form of insurance for workers who have gotten injured or sick due to their work.

Resources by chapter

Chapter 2: Self-Determination & Self-Advocacy

Self-determination

- ▶ [What is Self-Determination?](#) - National Gateway to Self Determination
- ▶ [The Arc's Self-Determination Scale](#) (PDF worksheet)
- ▶ [Checklist for Enhancing the Participation and Input of People with Disabilities](#)
- ▶ [PACER Center – Self Determination](#)

Self-advocacy

- ▶ [Self-Advocacy Resources for Youth](#)
- ▶ [Be Your Own Best Advocate](#) (PDF)
- ▶ [Sample Self Advocacy Plan](#) (worksheet)
- ▶ [Your IEP Meeting: A Great Place to Practice Self-Advocacy Skills](#) (PDF)

Mentorship

- ▶ [The Scoop: What's a Mentor and How Do I Get One?](#) - BigFuture by the College Board
- ▶ [Dropout Prevention and Youth with Disabilities: The Role of Mentors](#)
- ▶ [KASA: Kids As Self Advocates](#) is a grassroots project helping kids, teens and young adults to self-advocate and make decisions. They also speak to policy makers at public events and hearings.

Augmentative and Alternative Communication

- ▶ [An FAQ on Augmentative and Alternative Communication](#)
- ▶ [Different types of Augmentative and Alternative Communication](#) and how to use them (PDF)

Olmstead

- ▶ [History of the *Olmstead* decision](#) and the effect it has had on people with disabilities
- ▶ [The *Olmstead* supreme court decision in a nutshell](#). The page also has a 34-minute informative video about the case.
- ▶ [Olmstead v. L.C. Decision Q&A](#) - NDRN

The Fair Housing Act

- ▶ [Fair Housing Act FAQ](#), including information about reasonable accommodations
- ▶ [More basic information about the Fair Housing Act](#) - includes what to do if your rights have been violated

Protection & Advocacy Services

- ▶ [PADD - Protection and Advocacy for Individuals with Developmental Disabilities.](#)
- ▶ [CAP - Client Assistance Program.](#)
- ▶ [PAIMI - Protection and Advocacy for Individuals with Mental Illness.](#)
- ▶ [PAIR - Protection and Advocacy for Individual Rights.](#)
- ▶ [PAAT - Protection and Advocacy for Assistive Technology.](#)
- ▶ [PABSS - Protection and Advocacy for Beneficiaries of Social Security.](#)
- ▶ [PATBI - Protection and Advocacy for Individuals with Traumatic Brain Injury.](#)
- ▶ [PAVA - Protection and Advocacy for Voting Accessibility.](#)

Chapter 3: Know Your Rights

- ▶ [Know Your Rights](#) - American Civil Liberties Union

Individuals with Disabilities Education Act (IDEA)

- ▶ [What is the Individuals with Disabilities Education Act?](#)
- ▶ [The IDEA's official website](#)
- ▶ [Links to copies of the full text](#) of the IDEA.
- ▶ [At a Glance: Free and Appropriate Public Education \(FAPE\)](#)
- ▶ [Least Restrictive Environment \(LRE\): What You Need to Know](#)

Family Educational Rights and Privacy Act (FERPA)

- ▶ [FERPA for Students](#) - U.S. Department of Education
- ▶ [FERPA Primer: The Basics and Beyond](#) - Nace
- ▶ [FERPA Sherpa](#)

The Americans with Disabilities Act

- ▶ An [introduction to the ADA](#) is on the ADA's official government website.
 - On that same page, there are links to the ADA's text in full, and a page explaining how to file a complaint under the Act.
- ▶ [Understanding the Americans with Disabilities Act](#) (PDF) - United Spinal Association
- ▶ [ADA Q&A - Back to School](#) - PACER Center

Section 504

- ▶ [Section 504: What Does It Mean](#) - Kids Legal
- ▶ [Rehabilitation Act of 1973](#) - Disability.gov
- ▶ [Understanding 504 Plans](#) - Understood.org
- ▶ [Section 504](#) - U.S. Dept. of Housing & Urban Development

Chapter 4: Making Your Transition Plan

- ▶ [Opening Doors: A guide to adult services \(PDF\)](#)
- ▶ [Youth In Transition: Moving Into Adulthood Resource Center](#)
- ▶ [List of State Transition Websites](#)
- ▶ [Transition QuickGuide: Take Charge of Planning and Managing Your Own Health and Career Goals \(PDF\)](#)

Transition assessments

- ▶ MyPerfectResume.com has a [list of different types of self-assessment](#), including links to several popular career and personality tests.
- ▶ MyNextMove.org has a [free test](#) to help you figure out what kind of work you would be good at and enjoy.
- ▶ [What is my learning style?](#) Learn about different learning styles and find out which ones suit you best.
- ▶ [Seattle University's list of transition assessments](#) can be found here. There are career assessments, preference surveys, independent living assessments and assessments for self-determination and self-advocacy.
- ▶ [JobShadow.com](#) is a site where you can read real interviews from people talking about their careers and what their jobs entail.

Goal writing

- ▶ [IEP Goal Bank by Category](#) - TheGoalBank.com
- ▶ [IEP Goal Bank](#) - The School Psych Toolbox
- ▶ [IEP Annual Goals](#) - Center for Parent Information and Resources

Organizing your transition plan

- ▶ The Dummies website has a great, simple [list of tips for organizing paperwork](#)
- ▶ [Transition Plan Samples - Waukegan Public School District 60](#)

Chapter 5: Getting the Supports You Need

Figuring out your support needs

[This printable PDF worksheet is all about assessing your transition skills](#). It has 4 distinct types of assessment. It focuses mainly on independent living skills, but also assesses your ability to work, study and plan.

Support networks

- ▶ [Building a Support Network](#) - BigFuture's guide on building your support network, by the College Board.
- ▶ [Build support networks](#) - Students Against Depression. Site focuses on people with depression, but this has good general information

Activities of Daily Living

- ▶ [Assistive Technology for Activities for Daily Living](#) (PDF)
- ▶ [Disability Secrets – What Are Activities of Daily Living for Social Security Disability?](#)
- ▶ [PBS – Checklist of Activities of Daily Living](#)

Government-funded programs

- ▶ [Accessing HCBS: A Guide for Self-Advocates](#) (PDF) can help you to access home and community-based services.
- ▶ [Community Resources and Partners - Who is Able to Help?](#) (PDF)
- ▶ [Medicaid.gov - Learn How To Apply](#)
- ▶ [Supplemental Security Income \(SSI\) Benefits](#)
- ▶ [Disability Starter Kits](#) - Social Security Administration
- ▶ [Disability-Benefits-Help.org](#)

Chapter 6: Supported Decision-Making

Guardianship and supported decision-making

- ▶ [Easy-read PDF guide](#) to the differences between guardianship and supported decision-making.
- ▶ SupportedDecisionMaking.org has lots more information about [the right to make choices for people with disabilities](#).

Supports

Powers of attorney

- ▶ [Power of attorney FAQ](#) from CT Law Help.
- ▶ [Free power of attorney forms here](#).

Representative payee services

- ▶ [CrissCross representative payee services](#)
- ▶ [Frequently asked questions about representative payees](#).
- ▶ [When A Representative Payee Manages Your Money](#) is a PDF leaflet explaining what a representative payee is and what is expected of them, and what to do if you have a problem with your representative payee.
- ▶ [How to Change Your Social Security Disability Payee](#)

Supported decision-making agreements

- ▶ [Here is a sample supported decision making agreement](#) that you can print off and use (PDF).

Prepaid cards

- ▶ [Prepaid Debit Cards: What You Should Know](#) - NerdWallet
- ▶ [Best Prepaid Debit Cards of 2016](#) - NerdWallet

Credit Card/Bank Alerts

- ▶ [Consumer Watchdog: Setting Up Credit Card Transaction Text Message Alerts](#)
- ▶ [3 mobile banking alerts everyone should activate](#) - Bankrate

Joint Bank Accounts

- ▶ [When to Consider a Joint Bank Account](#) - NerdWallet
- ▶ [Joint Bank Accounts: How They Work & How To Open One](#) - WalletHub

Augmentative and Alternative Communication

- ▶ [An FAQ on Augmentative and Alternative Communication](#)
- ▶ [Different types of Augmentative and Alternative Communication](#) and how to use them (PDF)

Protection & Advocacy/Adult Protective Services

- ▶ [Finding your state's P&A services](#)
- ▶ [Printable version of P&A/CAP contact list](#) (PDF)
- ▶ [Get Help](#) - National Adult Protective Services Association

Chapter 7: Post-Secondary Education

Succeeding in College and Work: Students with Disabilities Tell Their Story videos

Listen to several students tell their stories: [Santara](#) (a college student with spina bifida, explaining the process of negotiating classroom accommodations); [Valeska](#) (who has learning disabilities); [Alexander](#) (now an engineer at Mathworks); and Danielle (a pediatric nurse who's missing her right hand). More disability-related videos can be found at the main video page, at newenglandada.org/videos.

Preparing in high school

- ▶ [Make a Plan - Create a Road Map for College Planning](#) - BigFuture
- ▶ [Get College Ready Now](#) - a page about why it's important to start getting ready for college while you're still in high school and avoiding remedial courses

College search

- ▶ [College Search - Find colleges and universities by major, location, type, and more.](#)
- ▶ [College Search Step-by-Step](#) - a guide that can help you decide what kind of college is right for you

Applying to college

- ▶ [Applying 101](#) - This page is essentially another list of resources with lots of links to guides to the different aspects of college application, such as how to approach an interview, an application checklist and FAQs about applying to college.
- ▶ [Quick Guide: The Anatomy of the College Application](#) - Goes through every different aspect of applying to college separately and explains how they work. Included subjects are auditions and portfolios, letters of recommendation and your high school transcript.
- ▶ [College Interviews](#) - Everything you need to know about college interviews - practice questions and strategies, what to do before and after your college interview, and what the person interviewing you really wants to know.

Paying for college

- ▶ [College Cost Calculator](#) - You can use this calculator to see how much college will cost by the time you enroll.
- ▶ [Financial Aid 101](#) - Everything about financial aid, including how to complete the FAFSA, taking steps to make sure you're eligible for financial aid, plus helpful videos and checklists.
- ▶ [Financial Aid Awards - Understand the types of Financial Aid](#)
- ▶ [Compare Your Aid Awards](#) - Comparison tool to help you compare financial aid awards.
- ▶ [An overview of college grants and scholarships](#)
- ▶ [Student Loans - Pay for College](#) - Lots of information about taking out a college loan, guides to picking a loan, and advice if you feel nervous about taking out a loan
- ▶ [Student Loan Calculator](#) - This calculator will help you understand your student loan repayments in relation to your possible starting salary.
- ▶ [Student Loan Comparison Calculator Private/Alternative Loans](#) - A loan calculator for people who want to take out a private loan or other type of loan.

Scholarships

Here are several different search engines from different websites to help you find a scholarship:

- ▶ [College Scholarship Search](#) - Peterson's
- ▶ [Scholarship Search Engine](#) - Scholarship Monkey
- ▶ [Scholarship Search](#) - Scholarships.com
- ▶ [Scholarship Search](#) - BigFuture
- ▶ [Mach25 Scholarship Search](#) - CollegeNET
- ▶ [Find College Scholarships](#) - Fastweb
- ▶ [Finding and Applying for Scholarships](#) - advice on scholarships from Federal Student Aid, U.S. Department of Education

Community college

- ▶ [Why Community College? - Finding Colleges That Fit](#) - Some useful information and statistics about community college
- ▶ [Advantages of Attending a Community College](#)
- ▶ [7 Reasons Why Community College Is Awesome](#) - Listicle from the Huffington Post about the advantages of community college
- ▶ [Community College: FAQs](#)
- ▶ [4 Reasons to Consider Community College](#) - Article from The Princeton Review about community college

Trade schools

- ▶ [Trade Schools, Colleges & Universities](#) - Find a trade school in what you want to do. There are lots of different categories to search in. You can search by program or by location.
- ▶ [Learn More About Vocational Schools and Technical Careers](#)
- ▶ [Vocational Training: A Guide to Non-Degree Education](#) - Find out some facts about vocational training, where you can get it and the pros and cons of vocational training.
- ▶ [Trade School Might Be a Better Choice Than College. Here's Why](#) - Lifehacker
- ▶ [Schools for the Trades by State](#) - Explore different trade schools in your state

Online courses

- ▶ [Ten Advantages of Online Courses](#) - Montgomery College

Course providers

- ▶ [Khan Academy](#) - especially good for learning math & science fundamentals
- ▶ [Coursera](#)
- ▶ [edX](#)
- ▶ [FutureLearn](#) - UK-based

TPSIDs

- ▶ [Information on TPSIDs](#) from the US Department of Education site.
- ▶ [Think College! College Options for People with Intellectual Disabilities](#)

Accommodations

- ▶ [Getting Accommodations](#) - Going-To-College.org
- ▶ [Reasonable Accommodations & College Students with Disabilities](#) - Disability.gov
- ▶ [Help Your Young Adult Learn About Accessing Accommodations After High School - PACER Center](#) - some information about accommodations. This PDF is addressed to parents, but it could still be helpful to you.

Legal protections

Americans with Disabilities Act & Section 504

- ▶ [What are a public or private college-university's responsibilities to students with disabilities?](#)
- ▶ [Questions and Answers on Disability Discrimination under Section 504 and Title II](#)
- ▶ [ADA Q&A: Section 504 & Postsecondary Education](#)

Family Educational Rights and Privacy Act (FERPA)

- ▶ [FERPA for Students](#) - U.S. Department of Education
- ▶ [FERPA Primer: The Basics and Beyond](#) - Nace
- ▶ [FERPA Sherpa](#)

Majors

- ▶ [Explore Careers - Choose an interest or college major](#) - BigFuture by the College Board
- ▶ [CollegeMajors101.com](#)
- ▶ [Find a Major](#) - The Princeton Review
- ▶ [“What’s My Major?” Quiz](#) - Loyola University Chicago

Budgeting

- ▶ [Creating Your Budget](#) - a guide from Federal Student Aid
- ▶ [How To Make A Budget: A Primer For College Students](#)

Budgeting apps

- ▶ [Mint](#) (Web, iOS and Android)
- ▶ [Toshl Finance](#) (iOS and Android)
- ▶ [Debt Payoff Planner](#) (free on Android)
- ▶ [SmartyPig](#) (Web, iOS and Android)

Making a decision

- ▶ [Compare Colleges Tool](#) - BigFuture
- ▶ [College or Training Programs: How to Decide Tips for Youth](#) (PDF)

What to do if you're not accepted

- ▶ [No Acceptance Letters? You Still Have Options](#) - BigFuture
- ▶ [What to Do if You Don't Get a College Acceptance](#) - Peterson's
- ▶ [Complete list of colleges with rolling admissions](#) - PrepScholar

Chapter 8: Employment

Disclosure

- ▶ [Disclosure](#) - Advice about whether or not to disclose having a disability to your employer, from Autism Now
- ▶ [Disclosure Decisions: To Get the Job Fact Sheet](#) - VCU WorkSupport

Schedule A

- ▶ [The ABC's of Schedule A for applicants with disabilities](#) - U.S. Department of Labor
- ▶ [Example Schedule A letter](#) - U.S. Department of Labor
- ▶ [The ADA: Your Employment Rights as an Individual With a Disability](#) - Equal Employment Opportunity Commission

Job interviews

- ▶ [Dressing for Interviews](#) - MSU Career Services Network's guide to dressing for interviews
- ▶ [What to Wear to an Interview](#) - The Interview Guys' piece on dressing for interviews
- ▶ [Job Interview 101](#) - Dos and don'ts for job interviews from Women For Hire, how to prepare, what to bring, what to say.
- ▶ [4 Job Interview Errors and How to Correct Them](#)

Finding a job

- ▶ [Find a Job Using These 26 "Under The Radar" Job Search Engines](#) - The Interview Guys
- ▶ [Disability Employment: Getting a Job](#) - U.S. Office of Personnel Management
- ▶ [The Top 10 Job Board Sites for Job-Seekers](#) - LiveCareer
- ▶ [7 Job Boards To Find Your Dream Job](#) - Mashable

Researching a company

- ▶ [Search Company Reviews](#) - Glassdoor
- ▶ [7 Things to Research Before Any Job Interview](#) - Glassdoor Blog
- ▶ [Step-by-Step Guide to Researching Companies: How to Conduct Job-Search Research](#) - LiveCareer
- ▶ [The Ultimate Guide to Researching a Company Pre-Interview](#) - The Muse

Resumes & CVs

- ▶ [Category: Perfect Your Resume](#) - The Interview Guys
- ▶ [Cover letter & resume sample by industry](#) - Monster
- ▶ [Free Resume Builder](#) - LiveCareer
- ▶ [Building a Resume: Tips for Youth with Disabilities](#) (PDF)
- ▶ [Starting with Me: A Guide to Person-Centered Planning for Job Seekers](#) - Community Inclusion

Supports

Accommodations

- ▶ [Accommodations Categories Chart \(PDF\)](#)- PACER Center
- ▶ [Help Your Young Adult Learn About Accessing Accommodations After High School](#) (PDF) - PACER Center

Vocational rehabilitation

- ▶ Refer to the state resources section below to find out about VR in your state.
- ▶ [What is vocational rehabilitation?](#) An FAQ from rehabworks.org.

Workplace culture

- ▶ [Understanding workplace culture](#) - Professionals Australia
- ▶ [Office Politics: Must You Play? A Handbook For Survival/Success](#) - Forbes
- ▶ [What Is Organizational Culture?](#) - Harvard Business Publishing
- ▶ [Developing Workplace Skills for Young Adults with Autism Spectrum](#) - book by Michelle Rigler, Amy Rutherford, and Emily Quinn. Contains exercises to help you think about what to do in certain workplace situations.

Employment laws

- ▶ [WorkplaceFairness.org](#)
- ▶ [Employee Rights](#) - U.S. Dept. of Labor
- ▶ [The ADA: Your Employment Rights as an Individual With a Disability](#)
- ▶ [Handy Reference Guide to the Fair Labor Standards Act](#) - U.S. Dept. of Labor
- ▶ [Facts About Sexual Harassment](#) - U.S. Equal Employment Opportunity Commission
- ▶ [Subminimum Wage Employment for Workers with Disabilities](#) - U.S. Dept. of Labor
- ▶ [Minimum Wage Laws in the States](#) - U.S. Dept. of Labor

Chapter 9: Housing & Independent Living

Roommates

- ▶ [Finding and Living With Roomies: Your Roommate Survival Guide](#) - Rent.com
- ▶ [Roommate Agreement Checklist - First Apartment Guide](#)
- ▶ [24 Rules for Living with Roommates](#) - My First Apartment

Personal Care Assistant

- ▶ [Find, Choose, and Keep Great Direct Support Professionals Toolkit](#)
- ▶ [Making the Move to Managing Your Own Personal Assistance Services \(PAS\): A Toolkit for Youth with Disabilities Transitioning to Adulthood](#)
- ▶ [PAS Center for Personal Assistance Services](#)
- ▶ [PASS User's Guide: A Comprehensive Guide to Assist Individuals in Self-Direction](#)
- ▶ [You Are the Employer: A Guide to Hiring and Managing Direct Support Staff](#)
- ▶ [Personal Care Assistance \(PCA\) Program: Consumer Guide Book](#)

Apartment hunting

These sites can help you search for an apartment:

- | | |
|----------------------------------|------------------------------------|
| ▶ Padmapper | ▶ Apartment List |
| ▶ Apartments.com | ▶ My Apartment Map |
| ▶ Rent Jungle | ▶ Move.com |
| ▶ ForRent | |

Packing & moving

- ▶ [33 Moving Tips That Will Make Your Life So Much Easier](#) - BuzzFeed
- ▶ [41 Easy Moving And Packing Tips That Will Make Your Move Dead Simple](#) - MakeSpace
- ▶ [Room by Room Packing Guide](#)
- ▶ [MovingScam.com](#): This site lists reputable movers in your area

Signing a lease

- ▶ [10 Things You Should Do Before Signing a Lease](#) - Rent.com
- ▶ [11 Things to Know Before Signing Your First Lease](#) - Huffington Post Blog
- ▶ [Rights of Tenants: Tips Before You Rent](#)
- ▶ [Renting with Disabilities](#) - Tenant Resource Center

Fair Housing Act

- ▶ [HUD.gov: Fair Housing - It's Your Right](#)
- ▶ [Common Questions about Section 8 Housing](#)

Chapter 10: Health care

Accessing health care services

- ▶ [Five Tips For Choosing A New Primary Care Physician](#) - BlueCross BlueShield
- ▶ [How to prepare for and make a doctor's appointment](#)
- ▶ [Things to bring with you to a doctor's appointment](#) - Oprah.com

Insurance

- ▶ [Understanding the basics of health insurance](#)
- ▶ [Things to know before picking an insurance plan](#)
- ▶ A [step-by-step guide](#) on choosing an insurance plan
- ▶ [Healthy Young America](#) has answers to frequently asked questions about insurance

Medical homes

- ▶ [Building Your Medical Home Tool Kit](#) - American Academy of Pediatrics
- ▶ [Brochure explaining the patient-centered medical home](#) (PDF)
- ▶ [This page](#) explains medical homes. It also contains lots of extra resources to help with discussing medical home model with clinicians, families, and policy makers.
- ▶ A list of [principles and guidelines](#) for patient-centered and family-centered care.

In case of a health emergency

Contacting emergency services for people with disabilities

If you have great difficulty speaking over the phone, you may qualify to get a teletypewriter, also known as a TTY. [Here is some information about how to get a TTY.](#)

[Text-to-911 information](#)

[Areas where you can use Text-to-911](#)

There are disability indicator programs for 911 callers with disabilities. This enables a special code to appear on the 911 call taker's screen. The code alerts the 911 call taker that someone living at that address may require special assistance during an emergency. Search for the disability indicator form for your state.

- ▶ [Free custom medical ID cards](#) - useful for others to quickly find out your allergies or medical conditions in an emergency.

Specific emergencies

- ▶ [How to put someone in the recovery position](#)
- ▶ [How and when to perform the Heimlich maneuver](#) (stop someone choking). You can also perform this on yourself, if you are choking!
- ▶ [What to do when someone is having a seizure](#)
- ▶ [What to do if someone is having a stroke](#), and how to know.
- ▶ [Here is a guide to basic hands-only CPR.](#) If someone is having a heart attack, hands-only CPR can more than double their chances of survival.

Keeping healthy

General

- ▶ [AASPIRE's health care toolkit](#), which covers all of the basics of keeping healthy (PDF)
- ▶ [A guide to taking care of yourself when you're sick](#) from Parade.com.

Preventive care

- ▶ [Preventive health services](#) - HealthCare.gov
- ▶ [What Is Preventive Healthcare?](#) - Medical Mutual
- ▶ [Preventive Care Schedule](#) - PublicHealth.org

Eating & drinking

Nutrition and healthy eating

- ▶ [How to have a balanced diet](#)
- ▶ [Basic info about the main food groups](#)
- ▶ [Guide to getting vitamins and minerals](#) (with recipes)
- ▶ Some easy-to-read charts with all of the vitamins and minerals you need, and why you need them:
 - [Vitamin chart](#)
 - [Mineral chart](#)
- ▶ [NutritionData.com](#) has information about what nutrients are in which foods, and what your daily nutritional needs are.

Accessible and affordable food

- ▶ [Supercook](#) is a website that helps you make a meal with the ingredients you already have in your house.
- ▶ Cooksmarts can help you [fill your kitchen with essential food basics](#). With a stock of essentials, you will always be able to make a simple, healthy meal with the ingredients in your cupboard.
 - They have a specific section that helps you [buy cheaper ingredients, and store them correctly](#) so they last longer without going bad.
- ▶ Here's a guide to [setting up your kitchen with the right utensils](#) to help you prepare food.
- ▶ [No More Ramen](#) is a blog with low-cost, low-spoons recipes.

Staying hydrated

- ▶ [Importance of hydration FAQs](#) - Natural Hydration Council (UK)
- ▶ [Article: Here's what happens to your body when you're dehydrated](#)
- ▶ [Waterlogged](#) is a free iOS app that encourages you to drink more water. It uses charts, reminders and positive reinforcement, and lets you record the amount of water you drink every day.
 - A similar app for Android users, called [Water Drink Reminder](#), can be found on Google Play.

Sleep

Sleep hygiene

[Sleep Hygiene](#) - National Sleep Foundation

[Twelve Simple Tips to Improve Your Sleep](#) - Harvard Healthy Sleep

Background noises

- ▶ [Sleep With Me Podcast](#)
- ▶ [A Soft Murmur](#)
- ▶ [Noisli](#)
- ▶ [Long list of ambient noise websites](#)

Weighted blankets

- ▶ [How to make a weighted blanket on WikiHow](#) (with pictures)
- ▶ Or, you can buy your own weighted blankets from [SensoryDirect.com](#)

Exercise

- ▶ [20 creative ways to get exercise](#)
- ▶ [NerdFitness Free Resources](#) - this is a huge list of resources on staying fit and healthy for absolute beginners. Includes how to warm up, how to do a push up, how to start eating vegetables and even resources to help you think differently about exercise.
- ▶ [4 Workouts for People with Limited Mobility](#)
- ▶ [Hate to Exercise? Try These Ideas!](#) - a collection of quotes from people who found their own ways to make exercising easy and enjoyable.
- ▶ [Disability Exercises: Exercising for Persons with Disabilities](#)
- ▶ [Fitness Blender Full-Length Workout Videos](#) **[Video]**
- ▶ [30 Workouts Under 30 Minutes You Can Do Anywhere](#) **[Video]**

Apps for exercise

- ▶ [Fitocracy](#) (free, iOS/Android) is a fitness tracker that motivates you by using a system of 'leveling up' when you work out. It is also community-based - you can interact and follow others using the app to get advice and motivation.
- ▶ [Zombies, Run!](#) (free, iOS/Android) is a survival game that relies on you running in order to advance. In the app, you have to run from 'zombies'. Running means you pick up supplies to help you defeat zombies, like medicine and ammo. Note that this game has horror elements to it and is designed to be scary. It may not be suitable for everyone!
- ▶ [Superhero Workout](#) (\$2.99, iOS/Android) is another game, but it's based on workout exercises like push ups and squats rather than running. In the game, you have to defend Earth against aliens. Your workout exercises become battle moves and gun blasts.
- ▶ [Wokamon](#) (free, iOS) is an app that lets you raise virtual pets. When you walk, the steps you take are transferred into 'energy' that causes the pets to grow. It also earns you game currency that you can spend on backgrounds, accessories and collecting more virtual pets. Unlike some virtual pet games, Wokamon's virtual pets don't get 'hungry' or 'lonely' if you don't use the app

Mental health

- ▶ [MentalHealth.gov](https://www.mentalhealth.gov)
- ▶ [NAMI: National Alliance on Mental Illness](https://www.nami.org)
- ▶ [Factsheet about depression in autistic adults](#)
- ▶ [A list of ways to reduce stress](#) - Mayo Clinic
- ▶ [How I Chose My Therapist: 9 Patient-Approved Tips](#) - Everyday Health
- ▶ [81 Awesome Mental Health Resources When You Can't Afford a Therapist](#) - Greatist

Apps for mental health

- ▶ [Habitica](#) (free, browser/iOS/Android) - an app that lets you role-play as a magical character, and gives you in-game rewards for checking off your to-do list and doing your daily activities.
- ▶ [Vent](#) (free, iOS/Android) - a community based app where you can post about your feelings and the community gives you support.
- ▶ [SuperBetter](#) (browser/iOS/Android) - an app based on scientific research that helps you to build mental, emotional, and social resilience through different small quests. You create a SuperBetter “alter ego” and complete small quests to work towards a goal you set for yourself.
- ▶ [Happier](#) (free, iOS/Android) community-based app where you can post positive things, and read other people’s positive updates. The app also reminds you of happy posts you’ve made in the past, and encourages you to write down positive things about yourself, to look at when your confidence is low.
- ▶ [BoosterBuddy](#) (free, iOS/Android) an app with a virtual sidekick who checks in with you about how you’re feeling every day, and helps you follow self-care routines and use coping skills. The app also has a calendar and reminders so you can keep track of medications and appointments.

National Resources

2-1-1

2-1-1 provides free and confidential information and referral. Call 2-1-1 for help with food, housing, employment, health care, counseling and more.

- <http://www.211.org/>
- <http://211us.org/>
- Dial 2-1-1

ADA.gov

ADA.gov provides resources and information to protect against discrimination against disabled people.

- <http://www.ada.gov/>

Administration for Community Living

ACL brings together the efforts and achievements of the Administration on Aging, the Administration on Intellectual and Developmental Disabilities, and the HHS Office on Disability to serve as the Federal agency responsible for increasing access to community supports, while focusing attention and resources on the unique needs of older Americans and people with disabilities across the lifespan.

- <http://www.acl.gov/Index.aspx>

American Disabled for Attendant Programs Today (ADAPT)

ADAPT are fighting so people with disabilities can live in the community with real supports instead of being locked away in nursing homes and other institutions.

- <http://www.adapt.org/>

American Public Transportation Association (APTA)

This organization represents large and small public transportation authorities and providers throughout the nation. Find a public transportation provider in your state.

<http://www.apta.com/Pages/default.aspx>

AssistantPages

Free directory for home caregiving that offers detailed information about caregivers and jobs for both private individuals and agencies.

<http://www.assistantpages.com/>

Association of University Centers on Disabilities

The Association of University Centers on Disabilities is a 501(c) non-profit organization that promotes and supports the national network of university centers on disabilities.

<http://www.aucd.org/>

Centers for Independent Living

The Centers for Independent Living provide counseling, classes, and programs to help people with disabilities build relationships, learn to self-advocate, and more.

<http://www.virtualcil.net/cils/>

Council on Quality and Leadership

The Council on Quality and Leadership is an international non-profit organization dedicated to advancing the quality of service.

<http://www.thecouncil.org/>

Disability.gov

Disability.gov includes links to thousands of resources for disability-related programs, laws, services, and policies.

- <https://www.disability.gov/>

Disability Secrets

Disability Secrets provides information about the U.S. federal disability system, including an overview of how the process works and answers to specific questions that are often asked by applicants and appellants.

- <http://www.disabilitysecrets.com>

Disabled Businesspersons Association

Assist enterprising individuals with disabilities maximize their potential in the business world, and work with vocational rehabilitation, government and business to encourage the participation and enhance the performance of the disabled in the work force.

- <http://www.disabledbusiness.org/>

disABLEDperson.com

disABLEDperson Inc. is a 501(c)(3) 509(a)(1) non-profit public charity whose mission is to help reduce the near 70% unemployment rate amongst disabled Americans.

- <http://www.disabledperson.com/>

Diversity World: Disability and Employment Resources

Disability and employment information from Diversity World. A source of articles, websites, books, videos and other resources on the topic of disability and employment.

- <http://www.diversityworld.com/>

Easter Seals

Easter Seals provides exceptional services, education, outreach, and advocacy so that autistic people and people with other disabilities can live, learn, work and play in our communities.

<http://www.easterseals.com/>

GLADNET—Global Applied Disability Research and Information Network on Employment and Training

To promote the mainstream employment of persons with disabilities through knowledge generation, collection and dissemination on an international level.

<http://www.gladnet.org>

HealthWrights

HealthWrights is a non-profit organization committed to advancing the health, basic rights, social equality, and self-determination of disadvantaged persons and groups.

<https://www.healthwrights.org>

Home Of Hope

Home of Hope gives to the developmentally disabled an opportunity to regain and maintain dignity, and a sense of self-worth.

<http://www.homeofhope.org/>

HousingPolicy.org

HousingPolicy.org is an online guide to state and local housing policy. The site includes easily accessible information on a broad range of state and local policy tools, as well as guidance on how to put them together to form a comprehensive and effective housing strategy.

<http://http://housingpolicy.org/>

Independent Living Institute

The Independent Living Institute creates training materials and solutions for people with disabilities. They have an online library of information on independent living and other topics.

- <http://www.independentliving.org/>

JobAccess

The goal of JobAccess is to enable people with disabilities to enhance their professional lives by providing a dedicated system for finding employment.

- <http://www.jobaccess.org/>

Meals on Wheels

Meals on Wheels provides home-delivered meals to seniors, the disabled, and people who are homebound and are unable to shop and cook for themselves.

- <http://www.mowaa.org/>

National Council on Independent Living

The National Council on Independent Living is the longest-running national cross-disability, grassroots organization run by and for people with disabilities.

- <http://www.ncil.org/>

National Disability Rights Network

NDRN is the nonprofit membership organization for the federally mandated Protection and Advocacy (P&A) Systems and Client Assistance Programs (CAP). Collectively, the P&A/CAP network is the largest provider of legally based advocacy services to people with disabilities in the United States.

- <http://www.ndrn.org/index.php>

SABE - Self Advocates Becoming Empowered

SABE protects the rights and equal treatment of people with disabilities.

- <http://www.sabeusa.org/>

Self-Advocacy Online

Self-advocacy online provides information to people with disabilities on topics such as relationships and being healthy. It also provides access to research and local self-advocacy groups.

- <http://www.selfadvocacyonline.org/>

Social Security's Representative Payment Program

Provides payee services for Social Security and SSI payments.

- <http://www.ssa.gov/payee/>
- 1-800-772-1213 (TTY 1-800-325-0778)

Society for Disability Studies

The Society for Disability Studies (SDS) is an organization devoted to a multidisciplinary analysis of disability. It is a multidisciplinary and international organization composed of social scientists, scholars in the humanities, disability rights advocates, providers, and agency personnel concerned with people with disabilities.

- <http://www.uic.edu/orgs/sds/>

Speaking For Ourselves

Speaking For Ourselves teach the public about the needs and wishes and potential of people with disabilities. They also speak out on important issues and support each other through sharing, leadership development, and helping and encouraging each other.

- <http://www.speaking.org/>

The Arc

The Arc promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.

- <http://www.thearc.org/>

The National Council on Disability

NCD is an independent federal agency charged with advising the President, Congress, and other federal agencies regarding policies, programs, practices, and procedures that affect people with disabilities

- <http://www.ncd.gov/>

The National Organization on Disabilities

The National Organization on Disability (NOD) is a private, non-profit organization that promotes the full participation and contributions of America's 56 million people with disabilities in all aspects of life.

- <http://nod.org/>

US Department of Education

The US Department of Education has several jobs. It researches issues in education and provides information on findings. It also creates and distributes funds for education. Finally, it makes sure everyone has equal access to education.

- <http://www.ed.gov/>

US Department of Housing & Urban Development (HUD)

The US Department of Housing and Urban Development provides resources for people with lower-income to find housing. It also provides resources to protect against housing discrimination.

<http://portal.hud.gov/hudportal/HUD>

US Equal Employment Opportunity Commission

The US Equal Employment Opportunity Commission enforces laws against workplace discrimination.

<http://www.eeoc.gov/>

WorkSupport.Com

Information on disability, rehabilitation and employment.

<http://www.worksupport.com/>

World Association of Persons with Disabilities (WAPD)

Advances the interests of persons with disabilities at national, state, local and home levels. They believe that all are entitled to high quality of life.

<http://www.wapd.org/>

World Congress & Exposition on Disabilities - WCD

Their mission is to provide support to children and adults with disabilities and their families.

<http://www.wcdexpo.com/>

Resources by State

Alabama

- ▶ Alabama.gov
- ▶ [The Arc of Alabama](#)
- ▶ [Alabama State Agencies](#)
- ▶ [Centers for Independent Living](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [Alabama Planning For Transition Handbook](#)
- ▶ [Transitioning to Adulthood - University of Alabama](#)

Alaska

- ▶ Alaska.gov
- ▶ [The Arc - Find a Chapter in Alaska](#)
- ▶ [Alaska State Agencies](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [Statewide Independent Living Council](#)

Arizona

- ▶ AZ.gov
- ▶ [Arizona State Agencies](#)
- ▶ [The Arc of Arizona](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [Statewide Independent Living Council](#)

Arkansas

- ▶ Arkansas.gov
- ▶ [Arkansas State Agencies](#)
- ▶ [Arkansas Independent Living Council](#)
- ▶ [The Arc of Arkansas](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [Arkansas Transition Services](#)

California

- ▶ [CA.gov](#)
- ▶ [California State Agencies](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [Statewide Independent Living Council](#)
- ▶ [California State Council on Developmental Disabilities](#)
- ▶ [Secondary Transition Planning](#)

Colorado

- ▶ [Colorado.gov](#)
- ▶ [The Arc of Colorado](#)
- ▶ [Colorado State Agencies](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [Secondary Transition - Colorado Dept. of Education](#)
- ▶ [Statewide Independent Living Council](#)

Connecticut

- ▶ [CT.gov](#)
- ▶ [The Arc of Connecticut](#)
- ▶ [Secondary Transition Resources - Connecticut Dept. of Education](#)
- ▶ [Connecticut Association of Centers for Independent Living](#)
- ▶ [Vocational Rehabilitation](#)

D.C.

- ▶ [DC.gov](#)
- ▶ [The Arc of D.C.](#)
- ▶ [D.C. Secondary Transition: Planning for Postsecondary Success](#)
- ▶ [D.C. Center for Independent Living](#)
- ▶ [D.C. Agencies](#)

Delaware

- ▶ Delaware.gov
- ▶ [The Arc of Delaware](#)
- ▶ [Delaware State Agencies](#)
- ▶ [Centers for Independent Living](#)
- ▶ [Vocational Rehabilitation](#)

Florida

- ▶ MyFlorida.com
- ▶ [Centers for Independent Living](#)
- ▶ [The Arc of Florida](#)
- ▶ [Florida Developmental Disabilities Council](#)
- ▶ [Vocational Rehabilitation](#)

Georgia

- ▶ Georgia.gov
- ▶ [The Arc of Georgia](#)
- ▶ [Georgia State Agencies](#)
- ▶ [Georgia Council on Developmental Disabilities](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [Statewide Independent Living Council](#)
- ▶ [Transition - Georgia Dept. of Education](#)

Hawaii

- ▶ Hawaii.gov
- ▶ [Hawaii State Agencies](#)
- ▶ [Vocational Rehabilitation - Hawaii.gov](#)
- ▶ [The Arc of Hawaii](#)
- ▶ [Transition Services: Moving from High School to Further Education and Work](#)
- ▶ [Statewide Independent Living Council](#)

Idaho

- ▶ Idaho.gov
- ▶ [The Arc of Idaho](#)
- ▶ [Vocational Rehabilitation - Idaho.gov](#)
- ▶ [Idaho State Agencies](#)
- ▶ [Idaho Centers for Independent Living](#)
- ▶ [Transition - Idaho Council on Developmental Disabilities](#)

Illinois

- ▶ [Illinois.gov](#)
- ▶ [The Arc of Illinois](#)
- ▶ [Centers for Independent Living](#)
- ▶ [Illinois State Agencies](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [Secondary Transition](#)

Indiana

- ▶ [IN.gov](#)
- ▶ [The Arc of Indiana](#)
- ▶ [Indiana Secondary Transition Resource Center](#)
- ▶ [Vocational Rehabilitation Services](#)
- ▶ [Indiana Centers for Independent Living](#)
- ▶ [Indiana State Agencies](#)

Iowa

- ▶ [Iowa.gov](#)
- ▶ [The Arc of Iowa](#)
- ▶ [Secondary Transition - Iowa Dept. of Education](#)
- ▶ [Statewide Independent Living Council of Iowa](#)
- ▶ [Vocational Rehabilitation Services](#)
- ▶ [Iowa State Agencies](#)

Kansas

- ▶ [KS.gov](#)
- ▶ [Kansas Association of Centers for Independent Living](#)
- ▶ [The Arc - Find a Chapter in Kansas](#)
- ▶ [Kansas State Agencies](#)
- ▶ [Vocational Rehabilitation](#)

Kentucky

- ▶ [KY.gov](#)
- ▶ [The Arc of Kentucky](#)
- ▶ [Statewide Independent Living Council](#)
- ▶ [Kentucky State Agencies](#)
- ▶ [Transition for Students](#)
- ▶ [Vocational Rehabilitation](#)

Louisiana

- ▶ [Louisiana.gov](#)
- ▶ [The Arc of Louisiana](#)
- ▶ [Centers for Independent Living in Louisiana](#)
- ▶ [Louisiana State Agencies](#)
- ▶ [Louisiana Transition Services](#)

Maine

- ▶ [Maine.gov](#)
- ▶ [The Arc - Find a Chapter in Maine](#)
- ▶ [Vocational Rehabilitation & Transition Services](#)
- ▶ [Maine State Agencies](#)
- ▶ [Centers for Independent Living in Maine](#)

Maryland

- ▶ [Maryland.gov](#)
- ▶ [The Arc of Maryland](#)
- ▶ [Maryland Statewide Independent Living Council](#)
- ▶ [Maryland State Agencies](#)
- ▶ [Vocational Rehabilitation](#)

Massachusetts

- ▶ [Mass.gov](#)
- ▶ [The Arc of Massachusetts](#)
- ▶ [Centers for Independent Living](#)
- ▶ [Massachusetts State Agencies](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [Transition from School to Adult Life](#)

Michigan

- ▶ [Michigan.gov](#)
- ▶ [The Arc of Michigan](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [Michigan State Agencies](#)
- ▶ [Statewide Independent Living Council](#)

Minnesota

- ▶ [MN.gov](#)
- ▶ [The Arc of Minnesota](#)
- ▶ [Minnesota State Agencies](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [Statewide Independent Living Council](#)

Mississippi

- ▶ [MS.gov](#)
- ▶ [The Arc of Mississippi](#)
- ▶ [Mississippi State Agencies](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [Statewide Independent Living Council](#)

Missouri

- ▶ [**MO.gov**](#)
- ▶ [The Arc of Missouri](#)
- ▶ [Missouri State Agencies](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [Statewide Independent Living Council](#)

Montana

- ▶ [**MT.gov**](#)
- ▶ [The Arc - Find a Chapter in Montana](#)
- ▶ [Montana State Agencies](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [Statewide Independent Living Council](#)

Nebraska

- ▶ [**Nebraska.gov**](#)
- ▶ [The Arc of Nebraska](#)
- ▶ [Nebraska State Agencies](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [Statewide Independent Living Council](#)

Nevada

- ▶ [**NV.gov**](#)
- ▶ [The Arc - Find a Chapter in Nevada](#)
- ▶ [Nevada State Agencies](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [Nevada Independent Living Centers](#)

New Hampshire

- ▶ [**NH.gov**](#)
- ▶ [The Arc - Find a Chapter in New Hampshire](#)
- ▶ [New Hampshire State Agencies](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [Statewide Independent Living Council](#)

New Jersey

- ▶ [**NJ.gov**](#)
- ▶ [The Arc of New Jersey](#)
- ▶ [New Jersey State Agencies](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [Statewide Independent Living Council](#)

New Mexico

- ▶ [NewMexico.gov](#)
- ▶ [The Arc of New Mexico](#)
- ▶ [New Mexico State Agencies](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [Statewide Independent Living Council](#)

New York

- ▶ [NY.gov](#)
- ▶ [The Arc - Find a Chapter in New York](#)
- ▶ [New York State Agencies](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [Statewide Independent Living Council](#)

North Carolina

- ▶ [NC.gov](#)
- ▶ [The Arc of North Carolina](#)
- ▶ [North Carolina State Agencies](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [Statewide Independent Living Council](#)

North Dakota

- ▶ [ND.gov](#)
- ▶ [The Arc - Find a Chapter in North Dakota](#)
- ▶ [North Dakota State Agencies](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [North Dakota Centers for Independent Living](#)

Ohio

- ▶ [Ohio.gov](#)
- ▶ [The Arc of Ohio](#)
- ▶ [Ohio State Agencies](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [Statewide Independent Living Council](#)

Oklahoma

- ▶ [OK.gov](#)
- ▶ [The Arc - Find a Chapter in Oklahoma](#)
- ▶ [Oklahoma State Agencies](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [Statewide Independent Living Council](#)

Oregon

- ▶ [Oregon.gov](#)
- ▶ [The Arc of Oregon](#)
- ▶ [Oregon State Agencies](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [Statewide Independent Living Council](#)

Pennsylvania

- ▶ [PA.gov](#)
- ▶ [The Arc of Pennsylvania](#)
- ▶ [Pennsylvania State Agencies](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [Statewide Independent Living Council](#)

Rhode Island

- ▶ [RI.gov](#)
- ▶ [The Arc - Find a Chapter in Rhode Island](#)
- ▶ [Rhode Island State Agencies](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [Statewide Independent Living Council](#)

South Carolina

- ▶ [SC.gov](#)
- ▶ [The Arc of South Carolina](#)
- ▶ [South Carolina State Agencies](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [Statewide Independent Living Council](#)

South Dakota

- ▶ [SD.gov](#)
- ▶ [The Arc - Find a Chapter in South Dakota](#)
- ▶ [South Dakota State Agencies](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [Statewide Independent Living Council](#)

Tennessee

- ▶ [TN.gov](#)
- ▶ [The Arc of Tennessee](#)
- ▶ [Tennessee State Agencies](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [Statewide Independent Living Council](#)

Texas

- ▶ [Texas.gov](#)
- ▶ [The Arc of Texas](#)
- ▶ [Texas State Agencies](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [Statewide Independent Living Council](#)

Utah

- ▶ [Utah.gov](#)
- ▶ [The Arc - Find a Chapter in Utah](#)
- ▶ [Utah State Agencies](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [Statewide Independent Living Council](#)

Vermont

- ▶ [Vermont.gov](#)
- ▶ [Vermont State Agencies](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [Statewide Independent Living Council](#)

Virginia

- ▶ [Virginia.gov](#)
- ▶ [The Arc of Virginia](#)
- ▶ [Virginia State Agencies](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [Statewide Independent Living Council](#)

Washington

- ▶ [WA.gov](#)
- ▶ [The Arc of Washington](#)
- ▶ [Washington State Agencies](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [Statewide Independent Living Council](#)

West Virginia

- ▶ [WV.gov](#)
- ▶ [The Arc of West Virginia](#)
- ▶ [West Virginia State Agencies](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [Statewide Independent Living Council](#)

Wisconsin

- ▶ [WI.gov](#)
- ▶ [The Arc of Wisconsin](#)
- ▶ [Wisconsin State Agencies](#)
- ▶ [Vocational Rehabilitation](#)
- ▶ [Statewide Independent Living Council](#)

Wyoming

- ▶ [Wyo.gov](#)
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