

TRANSITION TO ADULT CARE

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Transition Planning: A Guidebook for Young Adults and Family





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Introduction

Why Transition?

When you hear the word transition, many things may come to your mind. You will make many transitions in your life. This workbook will look specifically at the transition into adulthood. There are a lot of things to consider for anyone, but for someone with special health care needs there may be some extra steps to take. This includes, finding the right providers for you as an adult, finding new health insurance once you've aged off a family plan, and making the steps to the most independent life possible. This workbook will be the beginning steps in the planning process for this transition and may help you organize this daunting task!

How to Use This Workbook...

This workbook is divided into different sections. Each section describes an area that you might want to start planning for as an adult. Some sections might be more useful to you than others. This is your workbook so move around and use the information and tips that are the most helpful to you. Each section will have background information on the topic. Each section will also offer tips, tools, and strategies to help you in your planning. There will also be room in the back for you to make notes.

While this workbook can be used on your own, it might be helpful for you to discuss certain areas with professionals such as doctors, nurses, and social workers that may help coordinate your care. It is a great tool to begin communication on the topic of transition.



Health Care Transition

Health Care Financing

How you are going to pay for your care as you get older is a very important thing to think about. Sometimes your health insurance changes as you get older. You should know if or when that change happens. You should know what you may do if it does change. Some things to consider:

If you are currently on your Family's Health Plan:

- How long are you eligible to be covered under this plan as you get older?
- Can you stay on the family health plan if you are student? What are the requirements?
- Can you stay on a family plan as a disabled adult?
- What will you do when you are no longer eligible to be covered under a family plan?

If you are currently on a Government-Funded Program:

- How long are you eligible for this program? (Don't assume anything, often times there are different guidelines for people over 18.)
- Will you still be eligible for this program as you get older?
- What will you do when you are no longer eligible for this program?

Adult Providers

As you get older you should have a conversation with your doctors to find out how long they will continue to see you. Some doctors, such as pediatricians, will stop seeing patients when they reach a certain age. You want to be prepared for this change. Ask your current doctors if they will see you as an adult. If they will not see you as an adult they may be able to



Health Care Transition

help you find a new doctor. It is best to have a plan for this transition between providers. Here are a few questions to ask your doctors:

- At what age will you stop seeing me?
- How will you refer me to a new doctor?
- Do you know of any doctors you could refer me to?
- Will you help me put together a portable medical summary?
- Will you communicate with my new doctor during this transition time?

Health Care Skills

As you become more independent as an adult you might need to learn some new skills, especially health care skills, if you have special health care needs. These include things that may have been taken care of for you in the past. These can include getting prescriptions refilled, making doctor's appointments, or setting an alarm to remind you to take medications. Use the health care skills checklist to find out what you may need to learn or what you already know.



Parent Tips

- Let your child meet privately with providers at appointments.
- Start planning health care transition early.
- Research the options available on your family health plan.



Youth Tips

- Meet privately with your provider at appointments.
- Take more control of your health care activities.

Health Care Skills Checklist (Check items you can do)

- I can describe my chronic illness or disability
- I am responsible for taking my own medications
- I know how to call the doctor's office to make an appointment
- I know about my medical insurance coverage
- I prepare questions to ask my doctors, nurses, and therapists



Educational Transition

Transition and Special Education

If you receive special education services in school you will also start transition planning at school. You will probably even have a special transition IEP. IEP stands for Individualized Education Program. You will only have one of these if you receive special education. If you do not receive special education, but still need some assistance when you are done with high school skip to "Beyond High School".

What will a transition IEP include?

The Transition IEP should focus on any supports you may have to help you carry out a course of study. It should also include any needs for post-school activities such as work experiences, college or trade schools, daily living skills, and many other things for post high school living. Emphasis should be on life planning. The IEP should be an ongoing planning process. In order for transition planning to be successful it should be meaningful to your vision and goals.

Beyond High School

You should think about your future after high school. If you have special health care needs there may be some extra steps you need to take. The most important thing to your future is staying healthy. You can't work or go to school if you are not healthy. That is why it is important to remember your health care as you think about your future plans. If you are attending school away from home you should consider how you will continue to receive the care that you need. Some family health insurance plans will let you stay on the plan as long as you are a full time student. You should know these rules ahead of time. Sit down with your family to talk about these issues.



Educational Transition

If you are heading off to college

- Identify local providers in the area where you will be living
- Contact the schools disability office for needed accommodations
- Prepare a portable medical summary in case of an emergency.
- Understand how your health insurance works and what doctors you are allowed to see.

Employment Assistance

Finding a job is not always easy. That is why it is important to plan for employment and get training through school. In high school you may have opportunities like job shadowing or volunteering. In college you might have an internship to help you get ready for work. All of these activities can help you prepare for finding employment as you get older. For those with special health needs you might need some extra support to get ready for work. If you receive special education and have a transition IEP, make sure you let them know what special supports you need.

In Michigan you may also be eligible for employment assistance through agencies such as Michigan Rehab Services or Michigan Works!. You can find contact information for these agencies in the last section of this workbook titled "Community Agencies".



Parent Tips

- Let your child lead any meetings you might have about education and employment
- Encourage your child to pursue volunteer opportunities



Youth Tips

- Don't be afraid to ask for the supports you need in school and at work
- Take advantage of volunteer opportunities and part-time employment



Adult Living

Independent Living Skills

Whether you plan to live by yourself, with your family, or with roommates when you get older you will need to learn some things that will make you more independent. Some of these things include:

Daily Living Skills: These skills include cooking, cleaning, self care, and household safety. Most likely you already know some or most of these skills through chores or helping out around the house.

Decision Making: Many decisions must be made by adults on a daily basis. Some decisions are more serious than others. Begin to plan for what decisions you will make on your own or what decisions you might want to rely on a trusted person to help you make.

Transportation: Getting from one place to another is an important part of daily life. Whether you are living by yourself or with family you should begin to plan for your transportation needs. That may include learning to drive and getting a drivers license. It may also include learning how to ride the bus or calling a friend for a ride. It's also important to plan ahead if you have a wheelchair or other assistive devices.

Housing

As you begin to plan for your transition to adult life one of the most important things, and sometimes exciting, is the prospect of where you will live. Some people may remain at home with their family. Other people may want to live on their own or with roommates in an apartment or even someday own their own home. This is a decision you will have to make. Here are some things to think about:



Adult Living

- Identify interests and options for future living arrangements, including supports if needed.
- Investigate assistive technology tools that can increase independent living and community involvement
- Pursue and use local transportation options available outside of your family

Managing Money

Paying bills and managing money are important skills that adults need to learn. You should learn money management skills such as balancing a checkbook, or paying utility bills. While you are learning these skills you also want to consider how you plan to earn an income. For many people income will come from employment. For others income may come from Social Security benefits. Consider the following:

- Determine your need for financial support
- Investigate money management and identify necessary skills
- Apply for any financial support programs that may be needed

Guardianship and Alternatives:

At age 18, you become your own guardian. Some people are unable to do this because of their disability. If so, you and your family may face some choices. Questions for you and your family to ask are:

- What are my main concerns for my future? Are they financial, medical, or emotional concerns?
- What decisions will I be able to make on my own?
- What decisions will I need assistance making?



Adult Living

Think about what you would like to secure for your future. Below is a list of choices you and your family may consider if you need this kind of help. The list does not include all options. Other choices may be best for your family.

- ❑ **Full Guardianship** provides full decision making rights to an appointed guardian.
- ❑ **Partial Guardianship** provides rights in certain areas of decision making to an appointed guardian.
- ❑ **Durable Power of Attorney** allows health care decisions by an appointed guardian. Power of Attorney can cover other decisions too.
- ❑ **A Patient Advocate** acts for the individual receiving care. Most hospitals and providers have information on this choice. The appointed individual might be a family member or friend.
- ❑ In a **Conservatorship** an appointed individual manages a person's finances.
- ❑ A **Representative Payee** manages the finances of a person with SSI or SSDI benefits. Applications and help are available at local Social Security Administration offices.

Many of these actions must be done through the court system. Start exploring them when you turn 17. There may be legal and court fees for each. Seek qualified legal counsel if needed.



Bringing it all Together

Transition Plan of Care

Once you have thought about all or some of the areas discussed in the previous sections it is a good idea to start putting a plan in place. A Transition Plan of Care will help to keep things organized. It might also help you remember different things you need to do to get ready for the transition to adulthood. A Transition Plan of Care can be on paper or it can be done on a computer. However you want to keep it is fine. If someone is helping you put a plan together be sure to tell them how you would like to keep it.

What should a Transition Plan of Care include?

A Transition Plan of Care may look different for everyone. It will typically include goals that you have for yourself as you get older. For each goal you might find activities listed that need to be completed in order to reach your goals. For each activity you can create a list of who will be responsible to do these things. The person responsible can be you, your parent, family member, nurse or care manager you're working with. Whoever is helping you put the plan together might have different ways of doing it. Be sure you are comfortable with everything that is included in your plan.



Youth Tips

- Now is the time to speak up! Make sure you are heard and your personal goals are included.

Who can help me put a Transition Plan of Care together?

A transition plan of care can be put together with your help by someone at your doctor's office, or any other person/program that is helping you get ready for the transition to adult life.



Community Agencies: Navigating the Maze

This workbook has looked at health care, education, and independent living. Putting all these different topics together in a plan of care can help keep you organized. When you need assistance to reach some of your future goals you might find yourself working with different organizations and agencies, even programs at the state and federal level. So who do you go to? And what do you ask for? This section should give you some guidance on navigating your way to find help. It is also a place to keep notes and find contact information for some helpful resources.

Making the Call...

Don't know what to ask when you call? Consider this first. What information/support do you really want from this agency? Be sure you are specific and only ask about services they provide. Once you clear that up use this very simple script:

Sample Script for calling community agencies:

"Hello my name is _____. I have questions about _____. Can you please connect me with someone who can help?"



If you will be contacting many community agencies here is a tip. Keep a notebook with dates, names of who you spoke with, the action to be taken and expected date of completion.



Use the notes section to keep contact information handy.

