

Transition Toolkit

*Transition Milestones Assessments and
Supporting Skills, Tips and Tools*



**SPECIALIZED CARE
FOR CHILDREN**

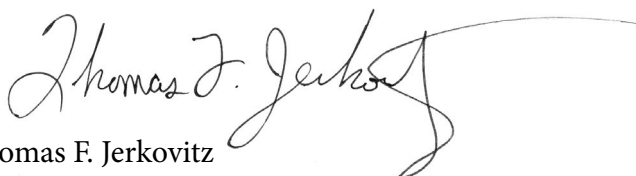
DSCC Transition Toolkit

The transition to adulthood is a significant and exciting time in a person's life. For youth with special healthcare needs and their families, this journey is no less rewarding, but requires careful planning and knowledge of valuable resources to assist in the transition. The University of Illinois at Chicago's Division of Specialized Care for Children (DSCC) is here to provide this support and help youth and their families prepare for what lies ahead.

We have developed a set of checklists and materials to help both youth and their families learn and practice new skills and gain greater confidence and independence as they navigate changes and choose the path that is right for them. They are compiled here in one convenient packet for your ease of reference and organized by planning areas such as health care, education and employment. These handouts and more are also available electronically in the Transition Tools section of our website at <https://dscc.uic.edu/browse-resources/transition-resources/>.

Our Care Coordinators are also experts at working with families to put together a transition plan that identifies clear goals for adulthood and the strategies, services and resources necessary to achieve them. If you would like more information, call us toll-free at (800) 322-3722 or email dscc@uic.edu. We are eager to partner with you to make the journey to adulthood as successful as possible.

Sincerely,



Thomas F. Jerkovitz
Executive Director

Name: _____ Age: _____ Date: _____

The activities listed will help youth gain the skills and abilities needed to reach their highest level of independence and ability. Some of these activities may not apply to everyone.

HEALTH CARE Skills and Abilities:	YES	NO	N/A	Need More Info
1. Can you describe your own health condition/disability?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Can you describe how your health condition/disability affects your daily life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Do you wear or carry a medical alert (list of allergies, medical conditions, etc.)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Do you tell the doctor or nurse how you feel and what you think you need?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Do you answer questions that are asked by the doctor or nurse?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Do you ask questions of the doctor or nurse?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Do you call the doctor about unusual changes in your health (allergic reaction)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Do you take part in making health care decisions with your parents and doctor?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Do you see your doctor without your family/parents in the room?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Do you call the doctor's office to make an appointment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Do you make a list of questions before the doctor's visit?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Do you sign consent forms for your medical treatment (surgery, tests, etc.)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Do you fill out the medical history form and list your allergies?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Do you have a guardian or power of attorney for health care, if needed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Do you know when to call 9-1-1 or seek urgent medical care?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Do you know your rights to control how your health information is used?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Do you keep a calendar or list of your appointments on your own?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Do you follow up on any referral for tests, checkups or labs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Do you arrange for your ride to medical appointments?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Have you found an adult doctor?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Have you made your first appointment with an adult doctor?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
MEDICATIONS/TREATMENTS Skills and Abilities:	YES	NO	N/A	Need More Info
22. Do you take part in your medical treatments?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Do you know the names of your medicines?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Do you know why you take each of your medicines?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. Do you know the side effects or bad reactions of each medicine?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

MEDICATIONS/TREATMENTS Skills and Abilities: (continued)	YES	NO	N/A	Need More Info
26. Do you take your own medicines, with reminder?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. Do you direct (know the steps and tell another how to do it) your treatments?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. Are you able to do your own treatments?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. Do you know what can happen if you skip your treatments or medicine?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. Do you take your medicines correctly and on your own?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. Do you use and take care of medical equipment and supplies?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. Do you call the company when there is a problem with your equipment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. Do you reorder medicines and/or supplies before they run out?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. Do you fill a prescription if you need to?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
INSURANCE Skills and Abilities:	YES	NO	N/A	Need More Info
35. Do you understand what health insurance is for?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36. Do you carry a health insurance card?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. Do you show your health insurance card at your medical appointments?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. Do you know what your health insurance covers - co-pays, deductibles, referrals, etc.?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. Do you apply for health insurance when you lose your current coverage?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

TIPS FOR USING THIS SKILLS LIST:

Think about the skills you want to work on. Make notes of your needs and concerns. Then you can talk about the next steps to take with the people that are helping you prepare for your future.

Notes to Myself: For each “Need More Info” item you checked, list questions you have or what you would like to know more about.

Next Steps – Goals: List what you need to work on to help you learn how to take care of yourself in the future. You can ask the people who are helping you plan for your future to work on this with you.

I would like more information about: ☐ Insurance ☐ Medicaid ☐ Managing My Own Health Care
☐ Other _____

We’re here to help. To learn more about UIC-Specialized Care for Children’s programs and services, check out our website at:

dscc.uic.edu

or like us on



facebook.com/dscc.uic.edu

Health Care Transition

What is Health Care Transition?



Health care transition means moving from pediatric (child) to adult health care. A good transition takes planning. You will need to:

- Learn to take care of your own health
- Find new doctors
- Keep your health insurance coverage or find new insurance
- Get the services you need so you can lead the kind of life you want to have

Who Should Help with Health Care Transition Planning?

The following people can help you and your family plan for transition:

- Your doctors
- Your family and friends
- Social worker, nurse, care coordinator, therapist, case manager, and others involved with your care
- School IEP team



What Can I Do?


- Use resources like the Transition Timeline to learn what steps you need to take
- Use your support network (friends, advocates, personal assistant, co-workers) to help you plan and find resources
- Work with your doctor to create a portable medical summary
- Complete the health care skills checklist each year
- Set goals for skills you'd like to work on
- Practice skills at home and in real life settings. Ask your doctor for skill sheets to help with:
 - Finding adult health care providers
 - Managing medications
 - Getting a prescription
 - Responding to a medical emergency
 - Understanding health insurance
 - Working with your doctor

Materials supported through a grant from the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, D70MC12840. Developed by the UIC - Division of Specialized Care for Children and the Illinois Chapter, American Academy of Pediatrics.


Differences in Care

When you become an adult, your experience at the doctor's office and the hospital might be different from what you are used to. This fact sheet explains some of the changes you might notice.

Comfort & Familiarity

Pediatric	Adult	Tips
<ul style="list-style-type: none">• You have known your doctors for a long time.• You feel comfortable during your visits.• You know what to expect during the exam. 	<ul style="list-style-type: none">• You won't know much about your new doctors and the staff.• You will need to explain more about yourself and your condition.• You might feel nervous about talking with the doctor.• The exam might be different.	<ul style="list-style-type: none">• Set up a “meet-the-doctor” visit with your new doctors.• Be patient as your doctors get to know you.• Ask your pediatric doctor to send records or a portable medical summary to your new adult doctor.• Tell the doctor and someone you trust how you feel.• Ask the doctor to explain what will happen during the examination.

Responsibility

Pediatric	Adult	Tips
<ul style="list-style-type: none">• Parents often stay with you during your doctor visits.• Parents help answer questions from the doctor for you.• Parents help make decisions about your treatment.• Parents arrange follow-up and check on test results.• Parents help you follow your treatment plan.	<ul style="list-style-type: none">• You will decide if someone (friend, parent, caregiver) stays with you during your doctor visits.• You will explain things about your treatment and condition on your own.• You will decide about treatment.• You will follow-up on tests and appointments on your own.• You will take more responsibility for your medical care.	<ul style="list-style-type: none">• Don't be afraid to ask questions.• Practice to be ready to take care of your own health.• Ask your doctor for help to build your skills.• If you want, someone you trust can stay with you.• Some may need help with adult expectations, and guardianship or alternatives may need to be explored. 

Services

Pediatric

- You might be seen by a team of doctors and other health providers at the same visit.
- You might have a number of support services to help you.
- Your doctors focus on your present and future possibilities.
- Your parent is told about your health information and medical care.



Adult

- You might have to see doctors and other providers at different locations and on different days.
- You might not qualify for the services you received before you turned 18.
- Your adult doctors might focus on what you can do in the present.
- Your health information will be kept private and can only be shared with your consent.
- If you have a guardian, he/she will be told about your health information.

Tips

- **Find an adult primary care doctor** who will help you **coordinate care** with specialists and other providers.
- **Talk** to a social worker about **adult services you may need and be eligible for** (personal assistant, home services, financial help, etc.).
- Ask your doctor to help you think about how **work choices may affect your health** and explore accommodations available.
- Be sure to **sign a consent** to share your health information with whom you choose.

Insurance and Payment

Pediatric

- Parents help you with your insurance benefits (referral process, co-pays, in-network providers).
- Parents pay for your medical care.
- You may have insurance coverage available only to dependents (parent's policy) or children through age 18.

Adult

- You will be more responsible for knowing and using your adult insurance benefits.
- You will need to pay for your own medical care.
- You may need to find new insurance to cover you as an adult (employer benefits, Health Benefits for Workers with Disabilities, etc.).

Tips

- Learn ways to **maximize your benefits**.
- Learn about adult **insurance options**.
- Find out when your current **coverage will end**.



Materials supported through a grant from the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, D70MC12840. Developed by the UIC - Division of Specialized Care for Children and the Illinois Chapter, American Academy of Pediatrics.

Regular Check-Ups!!!



They're a Part of Every One's Life

1. An annual routine health visit (yearly physical) is important, even when you feel fine.
2. Early treatment may help to keep health problems from becoming serious.
3. Check-ups help to identify your health needs and make sure you are getting all of the care that is required.
4. Annual health guidance can promote a better understanding of your physical growth, social and sexual development, and the importance of becoming actively involved in decisions regarding your health care.
5. Your doctor should talk to you about eating, including the benefits of a healthy diet, ways to achieve a healthy diet, and safe weight management.
6. Your doctor should tell you about the benefits of exercise and encourage you to engage in safe exercise on a regular basis.
7. Your doctor will discuss reasons you should avoid using tobacco, alcohol and other abusive substances.
8. You need to be screened annually for high blood pressure. You may also need to be screened to determine your risk of developing adult coronary heart disease.
9. Your doctor will need to ask about behaviors or emotions and, if needed, refer you to resources to help keep you healthy.
10. You might need to get a vaccine to prevent you from getting sick.
11. It is also important to see your dentist every 6 months for a dental check-up and to have your teeth cleaned.

We're here to help. To learn more about UIC-Specialized Care for Children's programs and services, check out our website at:

dscc.uic.edu or like us on  facebook.com/dscc.uic.edu

Do You Understand Insurance?

Learn Your Insurance Benefits

- Use providers who are in your network to be sure your insurance benefits will cover as much of the cost as possible.
- Begin to learn more about what services are covered by your insurance. Know your plan's deductible(s) and co-payments. This will be in your policy book.
- Always carry your own copy of your current insurance card.
- Find out if you need a referral from your primary care physician before you go to a new doctor or specialist.
- Find out if your insurance company will pay for your equipment to be fixed and/or replaced if necessary.
- Read about the appeal process in your policy book and use it when you think services have been denied in error.
- Before turning 18 years old, check what age your current plan coverage will end and apply for adult health insurance before your coverage ends.

When Contacting Your Insurance Company, Be Ready to Provide:

- ✓ Your name
- ✓ Date of birth
- ✓ Identification number (on your insurance card or social security number/policy holder social security number)
- ✓ Relationship to the policyholder (self, child, parent, etc.)
- ✓ Policyholder's date of birth, address and phone number
- ✓ Date of service
- ✓ Reason you are calling
- ✓ If available, a reference number (on the EOB or letter from insurance)

Keep Track of Insurance Information

- Keep track of phone calls with your insurance company. Write down the date, the number you called, who you talked to, what you talked about and what is going to happen next.
- Follow up to make sure issues/problems are resolved.
- Keep all insurance information where you can easily find it (folder or large envelope marked insurance). Save information, such as *Explanation of Benefit* (EOB) forms, eligibility and denial letters, and notices regarding a change in covered or excluded services, deductibles, co-payments or out-of-pocket expenses.

(Turn over for adult health insurance options)



Explore Adult Insurance Options

Before turning 18 years old, check what age your current plan coverage will end and apply for adult health insurance before your coverage ends.

You can search to find which **public, private and community programs** meet your needs at:
<http://finder.healthcare.gov/>.

Employee Benefits - your own coverage: Set career goals for gainful employment with health insurance coverage offered through employment.

Employee Benefits - your parent's coverage: The *Illinois Insurance Facts on Young Adult Dependent Coverage* web site (http://insurance.illinois.gov/HealthInsurance/ya_dependent.pdf) can help you figure out how long you can stay on your parents' policy and what the cost of coverage would be. Most plans carry all young adults up to age 26. Adults who are dependent on their parents for lifetime care and supervision may be able to stay on their parents' plan for longer. You can also call the **Illinois Department of Insurance** at **(877) 527-9431** to ask questions about health care coverage.

The Affordable Care Act sets-up a new Health Insurance Marketplace:

Visit <http://getcovered.illinois.gov/en> to view plans to see if you can find the right plan for you.

Campus Health Plan: College students may qualify for their school's insurance plan.

Private Plan: You may be able to purchase an individual plan from a health insurance company.

Health Benefits for Workers with Disabilities: If you have a disability and are working, you may qualify for this program. Visit www.illinois.gov/hfs/MedicalPrograms/hbwd/pages/default.aspx or call **1-800-226-0768** or **1-866-675-8440 (TTY)**.

Medicaid: Illinois residents with disabilities and low income and assets may be eligible for insurance through Medicaid. Visit <http://www.hfs.illinois.gov/programs/> or call **1-800-843-6154**. To apply go to <http://abe.illinois.gov>.

Medicare: Individuals with certain disabilities who have received Social Security Disability Benefits for 24 months may be eligible for health insurance through Medicare. Call **1-800-MEDICARE (1-800-633-4227)** or go to www.medicare.gov.

Pre-Existing, Severe or Chronic Medical Conditions Insurance Option: Illinois residents who have been denied or would be denied coverage due to pre-existing conditions may qualify for the following programs:

Comprehensive Health Insurance Plan (CHIP): Visit www.chip.state.il.us
General Info - **1-800-962-8384**; Eligibility Info - **1-866-255-5437**.

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What is Your Health Condition?



1. Knowing your health condition/disability can help you in many ways:

- Makes it easier to talk with your doctor, family, friends, teachers and others.
- Increases your ability to speak up for yourself to get your needs met.
- As you get older you will want to be able to better understand your condition and what it takes to keep yourself healthy.
- Take responsibility for your own health care.
- Helps you stay healthy and makes it easier to do the things you enjoy.
- You'll know how your health condition/disability affects your daily activities so you can find the supports, devices or accommodations needed to help you become more independent.

2. You can learn more about your health by:

- Keeping a record of your medical history, including conditions, surgeries, treatments (dates, doctors, recommendations).
- Filling out medical forms at the doctor's office.
- Knowing your warning signs so that you get help as soon as it is needed.
- Knowing the names of your medications and what they do for you. If you are not able to remember the names or what your medicines do, you should ask somebody to write this down for you. Always carry it in your wallet to share with providers when needed.
- Asking your doctor, nurse or DSCC Care Coordinator to help you write a plan of care or a portable medical summary to use to share information with others that care for you, including the new doctor(s) that will care for you when you are an adult.
- Talking to others who have a similar disability/health condition.

3. You may find helpful information about staying healthy and/or specific information about your condition/disability at:

- <http://kidshealth.org/>
- National Dissemination Center for Children with Disabilities:
<http://www.nichcy.org/Disabilities/Pages/Default.aspx>
- Kids as Self Advocates: <http://fvkasa.org/index.php>

(Go to the next page for more tips on learning more about your health condition)

Knowing about Your Medical Condition/Disability

1. Go to www.npsf.org/askme3 to learn more about the three questions you need to ask at each doctor's visit:

- **What is my main problem?**
- **What do I need to do?**
- **Why is it important for me to do this?**

2. Know your diagnosis and treatment:

Diagnosis(es):

Treatment:

3. Record what medical symptoms are typical for your condition. Include affect, behavioral issues, physical symptoms, and frequency of occurring illnesses.

4. Symptoms to Watch for:

Action Plan:

1.

2.

3.

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facebook.com/dscc.uic.edu

What to Do In a Medical Emergency

Emergencies Can Happen at Any Time

- **Plan Ahead** so if ever there is an emergency, you can **Act Fast** and **Stay Calm**.
- **Learn symptoms** that need **urgent medical** help, for example:
 - Sudden dizziness or fainting
 - Increased weakness
 - Change in level of awareness/alertness (hard to wake up)
 - Seizure
 - Hard time breathing
 - Feeling like you will hurt yourself
 - Severe allergic reaction
 - Sudden change in eyesight
 - High fever
 - Severe vomiting or diarrhea
 - Coughing up blood
 - Loss of consciousness
 - Severe burns



Always Be Prepared for an Emergency

- Practice how you will tell others when you are having a medical emergency.
- Make sure you or somebody with you can explain ALL your health conditions and medicines.
- Be ready to **call 9-1-1** if you or someone else is badly hurt or in danger.
- Be sure to have an **In Case of Emergency (ICE)** name and number saved in your cell phone.
- Learn about symptoms that would need 9-1-1 and symptoms that could wait long enough to drive to the nearest emergency room.
- Talk with your doctor about wearing a medical alert bracelet if needed and ask your doctor or search the web to find a bracelet that fits your needs.
- Always carry identification, your insurance card, medication list, and your emergency care plan (if you have one).
- Know where the closest emergency room is to your home, job, and other places you spend time.

(Turn over for more practice tips and resources)



Practice Giving the Information Needed When Calling 9-1-1

What is the emergency: _____

Your name: _____

Phone number: _____

Where you are: _____

Emergency contact and phone number: _____
(parent, friend, roommate)

Who is with you: _____

Insurance information: _____

- When calling 9-1-1, stay on the phone until the operator says you can hang up.
- It might be helpful to write down your name, address, phone number, emergency contact phone number, and insurance information to keep near your home phone, in your wallet, or taped to your cell phone.



Emergency Resources

The following resources might be helpful with planning for emergencies:

- Making a Family Emergency Plan: <https://www.ready.gov/make-a-plan>
- Personal Preparedness Planning for People with Disabilities: https://www.disability.gov/emergency_preparedness/personal_preparedness (scroll down)
- Making a Disaster Kit: <https://www.ready.gov/build-a-kit>
- The Emergency Preparedness for Children with Special Health Care Needs Form: <http://www.acep.org/clinical---Practice-Management/Emergency-Information-Form-for-Children-with-Special-Health-Care-Needs/>

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Illinois Resources:

Depression Understood. An online support community for those suffering from depression and anxiety. The website contains information and links to different associations as well as a depression hotline within your community. It also contains a chat room and forum where you can express your feelings and concerns to those within the mental health community.

<http://www.depression-understood.org/>.

Illinois Department of Human Services-Division of Mental Health (DMH). DMH provides services at all levels for adults and children throughout the state. <http://www.dhs.state.il.us/page.aspx?item=2935>.

Fact Sheet:

Depression facts, causes, symptoms and treatments.

http://www.pbs.org/wgbh/takeonestep/depression/pdf/dep_facts.pdf

Video:

PBS presents: Depression: *Out of the Shadows*

http://www.pbs.org/wgbh/takeonestep/depression/video-ch_01.html

(adult/adolescent/postpartum/treatments)

<http://www.youtube.com/watch?v=cMJbn1-apcU>

You tube video on how to parent a depressed child.

National Organizations:

National Alliance on Mental Illness (NAMI). NAMI's mission is grassroots and the sharing of information with people with mental illness, their families, friends, mental health professionals, and the general public. NAMI strives to offer hope, reform and health our American community through support, education, and advocacy efforts. Find your local NAMI at:

<http://www.nami.org/Find-Your-Local-NAMI>.

Finding Adult Providers

It is important to find your adult doctors early. You should begin seeing an adult doctor around age 18 to 21. If possible, have your first appointments and send your records to your new doctors while you are still being seen by your old doctors in case there are questions about your condition or treatment.



How to Find Adult Providers

- Ask your current doctor for a referral
- Consider your parents' doctor
- Call your insurance company
- Check with your local support groups
- Call large medical and specialty rehab hospitals and ask for referral line
- Ask your Care Coordinator or Case Manager for suggestions
- Ask friends for suggestions
- Check the *Illinois Provider Directory*

Questions to Ask

It is important to find a doctor who makes you feel comfortable and can meet your needs. Before you choose your new doctor, call his/her office and ask to speak with a staff member who has time to answer your questions, or make an appointment to meet the doctor and staff in person.

Ask the office:

- ☐ Does the doctor accept your insurance coverage? Is he/she taking new patients?
- ☐ Is the office accessible (easy to reach and easy to get around inside the building or clinic area)?
- ☐ What are the office hours? How can the doctor be reached after hours?
- ☐ How will the doctor exchange information with your specialists?
- ☐ Will the office be flexible to meet your health needs (allow service dog, schedule visits so you will not miss a meal, or schedule at quiet times if you are sensitive to noise)?

Ask the doctor:

- ☐ Is the doctor willing to discuss your health history and special needs with your pediatric doctor?
- ☐ Does the doctor currently see patients with health conditions similar to yours?
- ☐ At what hospital does the doctor schedule procedures?
- ☐ Where did the doctor get his/her medical school and specialty training? Is he/she board certified?
- ☐ Does the doctor have any special interests or more advanced training?

Ask yourself:

- ☐ Does the doctor listen to your questions or is he/she constantly interrupting you?
- ☐ Can the doctor explain information so that you can understand it?
- ☐ Does he/she take enough time to answer your questions?
- ☐ Does the doctor treat you with respect?



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For More Information Visit:
<http://illinoisAAP.org/projects/transition/>

03/14



Make Each Doctor's Appointment Work for You...



1. Before your appointment, write down your questions and concerns. If it's a long list, ask for longer appointment.
2. Bring your list of health concerns to tell your doctor or nurse.
3. Begin making your own appointments:
 - watch your parent make an appointment;
 - practice with your parent what you will say;
 - have a calendar ready and know what appointment dates will work with your school schedule and other activities you are involved in;
 - talk to the receptionist to schedule your appointment.
4. Keep track of your appointments (on a calendar, on your phone, in a notebook, appointment card in your wallet).
5. Try asking the following three questions at each appointment:
 - What is my main problem?
 - What do I need to do?
 - Why is it important for me to do this?
6. Help your health providers out by knowing your own medical history and what your needs are.
7. If you see specialists, ask them to send their reports to your primary care physician and/or your other specialist.
8. Bring a list of the medicines that you take regularly.
9. Bring your insurance card.
10. Ask lots of questions. Make sure you understand what you need and why certain medication, therapy, or equipment is being used.
11. Have parent(s) remain in the waiting room while you spend time with your healthcare provider on your own.

(Next page provides tips for making your own appointments)

How to Make an Appointment:

- Be prepared. Fill in as much of the following as you can before you call. Get help and practice some before doing this by yourself.
- Have your calendar ready to be sure you make the appointment where it fits best with your school schedule or work schedule.
- When you call, be sure to ask to be put in touch with Dr. _____
(fill in your doctor's or nurse practitioner's name) appointment desk.
- Know your date of birth.
- Know the name of your insurance provider.
- Know the reason you need the appointment.
- If you need assistance to get onto the exam table or need an interpreter, be sure to mention it when you call.

Sample Script:

"Hello, my name is _____"
(Use your first and last name)

"I need an appointment to see _____"

"Because _____"
(Example: "I need a check up, I'm having headaches, I'm having ear pain.")

"How soon can I get in? _____"
(Write date and time here)
If the date and time is okay, just say, "Thank you, that will be fine."
If not, just say, "That won't work for me, can you look for something else?"

"How long is the appointment? _____"
If you think you will need more time, just say, "I think I will need more time."

If you will need extra help or equipment, just say so:

"I will need _____"
(Example: a lift to get onto the exam table)

Before you end the phone call, repeat the date and time of your appointment:

"Okay, I will be there on _____ at _____"
(Date) (Time)

Follow-up steps: _____

(Put the appointment on the calendar so you won't forget it. Prepare questions for your doctor. Bring a list of your medications)

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dscc.uic.edu

or like us on



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Take Medications As Directed

Things to Know About Your Medicine



- Make sure you know the exact name of the medicine(s) you take (brand and generic).
- Some medications have brand and generic forms. Ask your doctor if it is alright to substitute with generic form.
- Learn why you need to take each medicine (how it treats your condition).
- Take your medicine at the same time every day. Taking your medicine at a specific time such as 10:00 p.m. might be better than bedtime if your bedtime changes. Work with your doctor to set a schedule that works for you.
- Ask your doctor or pharmacist if you have questions about taking your medicine.
- Let your doctor know if you have trouble taking your medicines (hard to swallow, forget to take, upset stomach, other problems).
- Side effects can be bothersome and dangerous - make sure you know what to look for.
- Don't take too much or too little medication. Know how much to take, when you can take more, and which medicines can be taken together.
- Whenever you go to a doctor or to the hospital, always bring your medications or a list of your medications, including non-prescription medications.
- Keep track of when you need to refill your medicines and call the pharmacy for your refills.
- Keep your list of medicines with you.

Find a Way to Remember to Take Your Medicines

You may want to use medication reminders:

- Take at the same time you do another daily routine (with breakfast, brush your teeth, watch a daily TV show).
- Set up a text message or cell phone alarm.
- Use an alarm-vibrating pillbox, pill organizer, automatic pill dispenser, time watch, or alarm pocket watch. To find the right system for you:
 - ✓ Ask your pharmacist.
 - ✓ Check with your local medical supply stores.
 - ✓ Search the web using search words such as pill alarms, automated medication dispenser, e-pill, or pill timer.

(Turn page over to begin your medication list)

Medication List

(Please use pencil to complete this form.)

Name: _____

- Ask your physician or pharmacist to help you complete this list.
- Read the label on each medicine for directions on how to take and for possible side effects/ danger signs/interactions. For more information see drug sheets.
- Whenever you see the doctor, including your primary care physician and any specialists, review and update this medication list.
- After hospitalizations, always review your medication list with your doctor.

Medicine	Dosage (how many you take)	Time (when you take it)	Why You Take It	What Happens If You Skip It	Possible Side Effects

Materials supported through a grant from the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, D70MC12840. Developed by the UIC - Division of Specialized Care for Children and the Illinois Chapter, American Academy of Pediatrics.

Guardianship and Alternatives

Who Will Make Decisions for Your Adult Child?

- At age 18, your child will gain the right to make his or her own decisions unless you take legal action. This includes the right to vote, marry, obtain a credit card, consent to medical treatments, make living arrangements, and sign contracts.
- Shifting rights to young adults who cannot make informed decisions or take responsibility for their choices carries many risks.
- You may need to take legal action to protect your child if he or she cannot:
 - Recognize when a decision needs to be made
 - Think about possible options
 - Understand the consequences of decisions
 - Express his or her needs
- Explore guardianship or another form of support to protect adults who cannot make decisions on their own.



- **Alternatives to Guardianship** - For some individuals with disabilities, less restrictive options to legal guardianship may provide the protections needed. Examples include a joint bank account to help with spending, Durable Power of Attorney for Healthcare, Living Will, or Advance Medical Directive.
- **Estate Planning** - This means looking ahead and deciding who will care for your youth, where he/she will live, and the financial needs he/she will have (includes writing wills and setting up special needs trusts).


(Turn over for Next Steps)



Next Steps

- ✓ Start exploring guardianship or alternatives around your child's 17th birthday. The guardianship process takes time. Be ready to file the paperwork on your child's 18th birthday.
- ✓ Read the Illinois Guardianship and Advocacy Commission's "Guide to Adult Guardianship in Illinois" and "Guardianship Fact Sheet" online at <http://gac.state.il.us/osg>. Or, you can call (866) 274-8023 and request to have copies mailed to you.
- ✓ For help, contact an attorney with experience in setting up special needs trusts or guardianship for young people with disabilities.
 - Check the Illinois Attorney General website to find free legal help:
<http://illinoisattorneygeneral.gov/about/probono.html>
- ✓ Forms and petitions for guardianship are filed through each county's Circuit Court Clerk. Visit <http://www.state.il.us/court/default.asp> to find your Circuit Court Clerk's contact information. Guardianship forms are often available on the Circuit Court's website under the Probate Division.
- ✓ Talk to your child's doctor about guardianship. You will need the doctor to fill out a medical report within 3 months prior to filing for guardianship. Remember to schedule the annual check up with this in mind.



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For More Information Visit:
<http://illinoisAAP.org/projects/transition/>

Name: _____ Age: _____ Date: _____

The activities listed will help youth gain the skills and abilities needed to reach their highest level of independence and ability. Some of these activities may not apply to everyone.

I plan on: ☐ **getting a job** ☐ **tech school or job training** ☐ **going to college** ☐ **other** _____

EDUCATION Skills and Abilities:	YES	NO	N/A	Need More Info
1. Are you in an education program (Special Education, Gifted Program, College, etc.)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Are you happy with your school program (class work, grade level, life skills)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Do you have worries about your school attendance?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Do you need reminders to start your homework?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Do you finish your homework without someone helping you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Do you go to your IEP or 504 meetings at school?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Do you take an active part in your school IEP, 504, transition meetings?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Do you take part in any activities at school (clubs, sports, attend school games)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Are you taking classes to help with independent living (foods, money management)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Are you in work experience (for example, STEP) classes through your high school?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Do you plan ways to meet your health needs with school staff?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Do you feel you are understood when you express yourself to friends, neighbors and grown-ups (teacher, boss, principal)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Do you need assistive technology at school (communication device, adaptive equipment, keyboard)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Do you ask and get the accommodations and supports you need (at school, work, community, home)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Do you know what to do if your needs are not being met at school?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Do you know your rights under the Individuals with Disabilities Education Act (IDEA)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Do you take lessons outside of school to learn more about something you enjoy? (swimming, sewing, art class, scrapbooking, dancing and others)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Do you use a computer to surf the web, type papers or letters, email or use other software?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Do you have post-high school plans (i.e. college, trade school, job, etc.)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Do you know which classes to take to learn more about your planned career or job?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Are you exploring colleges and funding for college?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

TIPS FOR USING THIS SKILLS LIST:

Think about the skills you want to work on. Make notes of your needs and concerns. Then you can talk about the next steps to take with the people that are helping you prepare for your future.

Notes to Myself: For each “Need More Info” item you checked, list questions you have or what you would like to know more about.

Example: #19 - I want to know more about what I can do after high school so that I can get a job.

Next Steps – Goals: List what you need to work on to help you learn how to take care of yourself in the future. You can ask the people who are helping you plan for your future to work on this with you.

I want more information about: ☐ College Disability Support Services ☐ Special Education Rights

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dsc.uic.edu

or like us on



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Planning Your Education and Transition for Life after High School



1. **If you receive special education services while you are still in high school**, by the time you are 14 ½ years old:
 - You will be asked to come to your IEP (Individualized Educational Program) meetings to discuss your goals for life after high school.
 - You can request several **IEP/Transition Planning meetings** during the school year.
 - Be sure to include health goals on your IEP. For more, go to the recorded webinar, *Health and Transition to Adulthood: Building the Foundation for Success*, at <http://illinoisap.org/projects/medical-home/transition/resources-for-families/>
2. These meetings are very important to you and **YOU** are the most important team member. Be sure to attend and be an active participant.
3. Your job is to **speak up** about your interests, strengths and skills, and let them know what you want to do to get ready for:
 - Your future job
 - Going to college
 - Living out on your own
4. **Special Education laws** state legal requirements for transition services to support your goals of employment in the community or for further education. There are still several things you need to do to prepare for life after high school:
 - You may find the guide helpful from the Illinois State Board of Education, *Educational Rights and Responsibilities*, at: <https://www.isbe.net/Pages/Special-Education-Parent-Rights.aspx>.
 - The school should assist with your therapy and health care needs during the school day.
 - If you have any problems, request an IEP meeting to discuss your concerns. Remember to keep written records of everything you do (meetings, chats, etc.).
 - If you still disagree with your school, either ask for mediation in writing or locate an advocate to assist you. For assistance locating an advocate, call **Equip for Equality in Illinois** at **1-800-537-2632**.
 - You have the right to invite people from other agencies, such as your DSCC Care Coordinator, your Division of Rehabilitation Services Vocational Specialist, your Service Coordinator from Division of Developmental Disabilities, and others to your IEP meeting.
 - If the IEP Team, which includes you and your parents, determine that your transition needs can be met by participating in transition programs on college campuses or in community-based settings, these services should be included in your IEP.
5. **You may find the *Transition Planning Checklist* on the next page helpful.**

Transition Planning Checklist

- ☐ **Confirm the date you will graduate.** Illinois law states that you are eligible for special education until the day before your 22nd birthday.
- ☐ Find out if you will receive a regular high school diploma or a certificate of attendance.
- ☐ Find out if you will be able to take part in the graduation ceremony.

- ☐ **If you are planning on going to college:**
 - Take your ACT or SAT in your junior year of high school.
 - Decide which college or university you want to go to.
 - Find out about financial aid to help with your tuition and educational expenses.
 - Talk with a disability counselor on the college campus.
 - Plan with your doctors, school nurse, IEP team, and UIC-Specialized Care for Children Care Coordinator about meeting your health needs while at college.

- ☐ **If you are planning to go to work:**
 - Find out what local agencies provide job coaching. Contacting adult providers before you graduate or “age out” will help to ensure services will continue after graduation. This may also prevent you from being placed on a long waiting list for adult services.
 - Find out if you are eligible for vocational services by going to your local Department of Human Services/Division of Rehabilitation Services/ Division of Developmental Disabilities/ Division of Mental Health office and file the necessary paperwork.
 - Decide on a career.
 - Find opportunities to job shadow (watching someone already doing the type of job you want to do).
 - Request information about post-high school training programs at local vocational schools, community colleges, business schools and other training schools.
 - Plan for any health accommodations you may need in the workplace. For more information, visit the Job Accommodation Network online, <http://askjan.org>.

- ☐ **Start planning if you are going to move out on your own:**
 - Where are you going to live and how will you pay for it.
 - What furniture and house wares will you need.
 - Contact the local **Center for Independent Living** for help with planning and building skills for living on your own: <http://www.incil.org/locate/> or call toll-free **1-800-587-1227**.
 - Plan for what you will need and practice skills to care for your own health.

- ☐ Discuss your transportation needs. If you will need assistance, request and fill out applications for public transportation services.

- ☐ Request information about social/recreational opportunities for young adults with disabilities in your community. Ask for contact information.

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Planning for Accommodations at College

1. **Planning for college will take time, so start early.**
2. **Decide if you want to go** to a vocational school, career school, post-secondary transition school, community college or university.
3. **Start by contacting the school** and asking about services for students with disabilities. You can call on the phone, visit the campus, or even review their website to learn about services.
4. You may want to ask some of the following common questions students have for the Campus Office of Disabilities:
 - What are the name, phone number, and hours of operation for the Office of Disabilities?
 - How far in advance should I contact the Office of Disabilities?
 - What is the process for accessing the services of the Office of Disabilities and is there a deadline?
 - What documentation must I provide to identify myself as a student with a disability to get reasonable accommodations?
 - Who decides if I qualify for academic accommodations?
 - What types of accommodations are considered reasonable?
 - Is tutoring available and is there a cost?
 - Is there a support group on campus for students with disabilities?
 - Do professors have regular office hours?
 - Is there any other information I should know?



Typical Types of Accommodations*

Instruction:

- Adaptive aids
- Adaptive furniture (desk)
- Assistive technology
- Enlarged text
- Extra time on assignments
- Reader (talking tapes or person reading)
- Selective seating
- Sign language interpreter
- Someone to take notes
- Tape record information
- Tutor
- Typist

Testing:

- Assistive technology
- Computer-read test
- Contrasts in ink and paper
- Enlarged text
- Essay test vs. multiple choice test
- Extended time
- Misspellings not graded
- Printed copy of oral instructions
- Someone to read the test
- Scribe (one to write down answers)
- Tape-recorded lectures, tests
- Quiet environment, no distractions

**accommodations vary and you should check with your individual institution to learn what is available.*

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Planning and Going to College



1. **Start planning early** while still in high school (beginning your freshman year). Make sure you take the high school classes that will enable you to get into college.
2. **Set goals** to help you get ready for college.
3. **Get to know your strengths, interests and learning style.** The *Going to College* website, <http://going-to-college.org/>, may be a helpful resource.
4. **Think about who your support system will be** when you are away from home.
5. Once you have registered, if you are 18 or older, your parents will no longer have access to things such as your grades, course selection, and so on. It will be up to you.
6. You, as a college student, will need to ask for accommodations and provide documentation. Once you are a college student this responsibility shifts to you and you will need to communicate your needs.
7. **Choosing a college will take time.** Attend college fairs, explore on the internet, talk to friends, family and others to learn more about colleges. Schedule a campus visit with the colleges you're interested in.

Think College provides information for persons with intellectual disabilities. The information is for transition-aged students as well as adults attending or planning for college. It provides resources and tools for students, families, and professionals. <http://www.thinkcollege.net/>.

8. To be successful at college you may want to **access assistance through the campus' Office of Disability Services**. Start by asking the school about services for students with disabilities. You can call on the phone, visit the campus, or even review their website to learn about services.
9. **If you use assistive devices** such as a wheelchair or a hearing aid you will need to check on repair services available near the campus just in case something goes wrong while you are away at college.
10. If you have special health care needs you should plan where you will go for health services, medications and supplies.
11. **Become aware of the laws that protect students with disabilities** at colleges, universities and community colleges.
 - *Fact Sheet on Disabilities in Higher Education: Your Legal Rights*
 - *Students with Disabilities Preparing for Post Secondary Education: Know Your Rights and Responsibilities* has information about admissions, accommodations, academic adjustments, documentation, and discrimination under Section 504 Rehabilitation Act at: <http://www.ed.gov/about/offices/list/ocr/transition.html>
12. Talk to your family, friends, and guidance counselor at school about your plans.

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College Navigator online tool to help students and parents get information on post-secondary institution throughout the U.S. <https://nces.ed.gov/collegenavigator/>

College or Training Programs: How to Decide: PACER Center tip-sheet for youth deciding on a path after high school. <http://www.pacer.org/transition/resource-library/publications/NPC-26.pdf>

Disabilities, Opportunities, Internetworking, and Technology - University Of Washington website promotes use of computer and networking technologies to increase independence, productivity, and participation in education and employment. <http://www.washington.edu/doit>

Education Quest is a website to assist with college planning. They have developed a free guide, "College Planning for Student with Disabilities," which you may order or view their condensed version online. Finding a college that meets your needs will require research, campus visits and asking the right questions. You will also find a hyperlink to the booklet entitled **Guided Tour for High School Students and Parents** for helpful steps to follow. <https://www.educationquest.org/11th-12th-grade-students/information-for-students-with-disabilities/>.

Going to College is a website containing information about living college life with a disability. It is designed for high school students and provides video clips, activities and additional resources that can help you get a head start in planning for college. <http://going-to-college.org>

Heath Resource Center from George Washington University's website is an online clearinghouse on postsecondary education for individuals with disabilities. This website has information for students with disabilities on educational disability support services, policies, procedures, adaptations, accessing college or university campuses, career-technical schools, and other postsecondary training entities. <http://www.heath.gwu.edu>

Mapping Your Future is a free resource for career, college, financial aid, and money management information. Their goal is to help individuals achieve life-long success by empowering students, families, and schools with free, web-based information and services. <http://mappingyourfuture.org/>

The National Technical Assistance Center on Transition website is a tremendous resource for individuals planning to go to college. There are videos and inventory surveys to assist you with exploring your strengths and interests, accepting your disability and how to advocate for yourself. Information is presented on what campus life is like and planning for going to college. <https://transitionta.org>

Shirley Ryan AbilityLab life center website provides information specific to people with physical disabilities, disability organizations, government agencies, support groups, and health information on key areas of life including books, videos, magazines and multimedia learning resources. <http://lifecenter.ric.org/>

Students with Disabilities Preparing for Post Secondary Education: Know Your Rights and Responsibilities is for students who plan to continue their education after high school; includes questions and answers about admissions, accommodations & academic adjustments, documentation, evaluations, and discrimination under Section 504 of the Rehabilitation Act. <http://www.ed.gov/about/offices/list/ocr/transition.html>

Think College provides information for persons with intellectual disabilities. The information is for transition aged students as well as adults attending or planning for college. It provides resources and tools for students, families, and professionals. <http://www.thinkcollege.net/>

Name: _____ Age: _____ Date: _____

The activities listed will help youth gain the skills and abilities needed to reach their highest level of independence and ability. Some of these activities may not apply to everyone.

I plan on living: ☐ with my parents ☐ on my own ☐ group home ☐ other _____

NUTRITION Skills and Abilities:	YES	NO	N/A	Need More Info
1. Do you eat a variety of foods (or take tube feedings well)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Are you able to feed yourself (or do tube feedings), once your food is set on the table?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Can you fix a meal without help?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Do you know about the need for good nutrition?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Are you happy with your weight?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
PERSONAL CARE Skills and Abilities:	YES	NO	N/A	Need More Info
6. Do you brush and floss your own teeth?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Do you dress yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Do you bathe yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Do you brush/fix your own hair?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Do you have regular sleep times?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Do you know how much sleep you need each day?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Do you put yourself to bed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Do you wake up on your own (with the alarm clock)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Do you feel you get plenty of rest?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
PERSONAL HYGIENE Skills and Abilities:	YES	NO	N/A	Need More Info
15. Can you tell when you need to go to the bathroom?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Do you go to the bathroom on your own?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Do you handle your clothing, wipe yourself and flush the toilet?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Do you need a personal assistant to help you with activities of daily living?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
MOBILITY/EXERCISE Skills and Abilities:	YES	NO	N/A	Need More Info
19. Can you get out of bed, or the tub or shower, on your own?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Do you exercise on a regular basis (walk, lift weights, stretching exercises, swim, etc.)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

INDEPENDENCE Skills and Abilities:	YES	NO	N/A	Need More Info
21. Do you do your share of family chores (clean up after yourself, set the table, etc.)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Are you learning to do things around the house (laundry, fixing meals, etc.)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Do you keep home and/or room clean or clean up after meals?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Do you use nearby stores and services (know what to buy, where to find things, and how to pay for groceries)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. Do you help plan or fix meals or food?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. Have you spent nights away from your family (camp, sleepover with friends, school trips)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. Are you happy with how you are able to get around (home to school or work)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. Do you call and use community services (accessible transportation) and advocacy services (legal services) when you need them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. Do you have a plan for where you will live when you leave your family home?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. Do you know how to go places on your own (bus, follow directions or maps)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. Do you have a state identification (ID) card or driver's license?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. Do you manage your own money (make change, use debit or checks, balance checkbook, follow a budget)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33. Have you found housing that meets your health and safety needs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34. Do you know your fair housing rights that are listed in the Fair Housing Act?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. Do you have a plan for housekeeping help, if needed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36. Do you know how to locate disability support and counseling services?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. Do you need help making major decisions with living or health care?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. Do you have a legal guardian or power of attorney, if needed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. Do you know about the Americans with Disabilities Act?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

TIPS FOR USING THIS SKILLS LIST:

Think about the skills you want to work on. Make notes of your needs and concerns. Then you can talk about the next steps to take with the people that are helping you prepare for your future.

Notes to Myself: For each "Need More Info" item you checked, list questions you have or what you would like to know more about.

Next Steps – Goals: List what you need to work on to help you learn how to take care of yourself in the future. You can ask the people who are helping you plan for your future to work on this with you.

I would like more information about: ☐ Independent Living ☐ Transportation ☐ Other _____

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**We make decisions every day,
big and little.**



1. **Learning to make good decisions is a skill that will help you** grow up to be an independent, responsible, and happy adult.
2. **Build your decision making skills.** This will require time, patience and practice.
3. **Study which decisions get you more of what you want** (more fun, more independence, more time with friends, more control over your daily life) **and which decisions result in more of what you do not want** (arguments with parents, conflicts with peers, social drama, loss of privileges and adults telling you what to do) to help you learn to make good decisions.
4. **Learn from mistakes.** Choices always have consequences, not all are harsh. Mistakes play a very important role in life. Any mistake is an opportunity to learn how to handle a situation better the next time. It is not an opportunity for an adult to criticize. **Allow parents to stay involved in the process and model appropriate actions.**
5. **Work through the steps in decision making and make more of your own decisions.** Using the SODAS model (below) may help you remember some of these steps:
 - S** = Situation
 - O** = Options
 - D** = Disadvantages
 - A** = Advantages
 - S** = Solution
6. **Keep a decision journal** to write down and review all the decisions made during the day. This can help you evaluate how well you handled decisions and begin to learn how to do better.
7. **For more information** on building good decision making skills, go to:
 - *Decision Making (SODAS Method) 5 steps that will help your child make better decisions in any situation*, <http://www.smarterparenting.com/lesson/view/decision-making-sodas-method>.
 - Fact Sheet: *Decision Making/Problem Solving with Teens*, <http://ohioline.osu.edu/hyg-fact/5000/pdf/5301.pdf>

(Turn page over to begin steps to decision making and problem solving.)

Steps to decision making and problem solving



1. What is the problem that needs to be solved? (or state the problem)

2. Why is this a problem?

3. What are my desired results? (What do I want to see happen?)

4. **List 3 possible solutions.** (What can I do to get my desired results?) As you look at these, ask yourself:
a.) How will you feel afterwards? b.) How will others you value feel about you after this decision?
c.) Would you suggest the same solution to a friend?

1. _____
2. _____
3. _____

Look at your first solution. List what may happen if you go with #1.

Look at your second solution. List what may happen if you go with #2.

Look at your third solution. List what may happen if you go with #3.

Pick from #1, #2, or #3. Which one works best for solving the problem?

5. Is this the best time to make this decision?

6. What resources do you need to carry out your choice?

7. Try out your chosen idea, test it. Did it solve the problem?

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Living On Your Own



and Knowing When to Ask for Help

1. **The key to independence is learning to make the most of your abilities and working around your limitations.**
2. **One way to help you become more independent is to start setting your own goals and making your own decisions.**
3. **Learn about adaptive equipment that can make your every day life easier.** Ask your health care providers and educators for more information.
4. **The Illinois Assistive Technology Program (IATP) promotes the availability of assistive technology services and programs for people with disabilities throughout Illinois.** IATP offers device loans, a demonstration center and much more. To learn more, go online to: <https://www.iltech.org/> or call toll-free **(800) 852-5110** (v/tty).
5. **Illinois has a new loan program for people with disabilities. The ILoan Program,** Illinois Loans for Independent Living, makes loans to purchase assistive technology for daily living. The ILoan Program also makes loans for other equipment, for self-employment and home-based employment. To learn more, go to: <https://www.iltech.org/repository/financialloans> or call toll-free **(800) 852-5110** (v/tty).
6. **Knowing what you need help with and setting up ways to get that help are important.** For example, you may need an attendant to help you in the mornings and evenings with your personal care.
7. **Everyone has some limitations.** People who become independent have figured out when and how to get the help they need.
8. **To help you look at what skills you have and what skills are still needed,** go to the Adolescent Autonomy Checklist at: http://www.spannj.org/Family2Family/adolescent_autonomy_checklist.htm.

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Housing Options

Explore your options so you and your family/guardian can choose programs and services that best suit your needs, help meet your transition goals, and allow you to live as independently as possible in the community of your choice.

You should plan early. Getting into adult service programs may take months. Accessing adult services will be much different than getting services through the school.

The process will take time, many phone calls, lots of follow-up and appeals. Try not to get discouraged. Don't give up!

You will need to plan how to fund your future services, trainings, supports and your living arrangements.

Adult service options and funding sources are much different than child-focused services and funding. Some differences are:

- Government-funded programs for adults are very limited;
- You must meet the program's eligibility guidelines in order to get services;
- There are waiting lists, applications, disability determinations and other processes required.

Residential Living for People with Disabilities. Options include a range of settings that enable individuals with disabilities to live with their own families, or in their own homes or apartments with supportive services from community-based supported living service providers.

- **Independent living** - you live on your own.
- **Semi-independent living** - you need minimal levels of help to live and work in the community. Some hire a personal assistant, roommates share responsibilities, and family members may take turns to help out.
- **Community-Integrated Living Arrangements (CILA) or Group Homes** - residential options that provide 24-hour care in a variety of settings. Most are home-like settings located in communities where individuals have support staff available as needed, supervision and assistance in the activities of daily living, and access to local stores, libraries, restaurants.
- **Nursing Home or Intermediate Care Facilities for the Developmentally Disabled (ICF/DD)** - health care facilities for people who need ongoing developmental services and intermittent skilled nursing care.
- **State institutions** - for individuals with the most severe disabilities who require intensive services.

(Next page provides a list of resources)



Find Supported Living Arrangements:

- Find and ask about **unique group arrangements** funded by the residents' families. Such families pool their resources to provide supportive living arrangements in single-family homes for their family members with disabilities who need help with daily living skills.
- **Illinois Association of Microboards and Cooperatives** can help individuals with disabilities live the lives they *want* to live, with the support of family, friends, community and public resources. Together with trained volunteers (PATH guides) and their closest friends and family members, individuals identify concrete goals that are positive and possible. Then the group enrolls themselves and others to carry out the concrete action steps needed to move forward. For more information: <http://www.iambc.org/>
- Contact your area's **Center for Independent Living (CIL)** for a wide array of independent living services. For more information online: <http://www.incil.org/>, or call **1-800-587-1227**.
- **Know your rights for fair housing.** Go online to the U.S. Department of Housing & Urban Development: https://www.hud.gov/program_offices/fair_housing_equal_opp/disabilities.
- **In-Home Support Options.** You may want to apply for one of nine Home- and Community-Based Services (HCBS) waiver programs to get services to help you live more independently in your family's home or on your own. For additional information about the HCBS waiver programs: <https://www.illinois.gov/hfs/MedicalClients/HCBS/Pages/default.aspx>.

Other Resources:

- **Statewide Independent Living Council of Illinois** - supports independent living services across Illinois. For more information, call **1-217-744-7777** (V/TTY) or go online at <http://silcofillinois.org/>.
- The **Housing Assistance** web site contains resources about rental and homeownership assistance, housing accessibility and other programs that help with locating and securing housing for people with disabilities: https://www.disability.gov/housing/housing_assistance.
- **Habitat for Humanity** may be able to help you identify accessible and affordable housing. Go online to <http://www.habitat.org/getinv/apply.aspx> to find Habitat services in your local area; use the [Habitat online search tool](#), or call them at **1-800-422-4828**.
- The **Illinois Assistive Technology Program** - promotes availability of assistive technology services such as the **ILoan Program**, which provides loans to buy assistive technology for daily living, self-employment and home-based employment. Call **1-800-852-5110** or go online: <http://www.iltech.org/repository/financialloans>.

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Home-based Supports and Day Programs

Explore your options so you and your family/guardian can choose programs and services that best suit your needs, help meet your transition goals, and allow you to live as independently as possible in the community of your choice.

You should plan early. Getting into adult service programs may take months. Accessing adult services will be much different than getting services through the school.

The process will take time, many phone calls, lots of follow-up and appeals. Try not to get discouraged. Don't give up!

You will need to plan how to fund your future services, trainings, supports and your living arrangements.

Adult service options and funding sources are much different than child-focused services and funding. Some differences are:

- Government-funded programs for adults are very limited;
- You must meet the program's eligibility guidelines in order to get services;
- There are waiting lists, applications, disability determinations and other processes required.

In-Home Support Options. You may want to apply for one of nine Home- and Community-Based Services (HCBS) waiver programs to get services to help you live more independently in your family's home or with living on your own. For additional information about the HCBS waiver programs, refer to the "Get Financial Help" section on the next page. **Some in-home supports provided are:**

- Homemaker
- Assistance with nursing or personal care
- Respite care
- A personal case manager
- Non-medical transportation
- Emergency home response
- Environmental accessibility adaptations
- Specialized medical equipment and supplies
- Home delivered meals
- **Day Programs** include activities to foster skill building, appropriate behavior, greater independence and personal choice, and may include daily living skills instruction, community outings, vocational training, employment opportunities and recreation.

(Next page provides a list of resources)



Get Financial Help for Needed Supports

Home- and Community-Based Services Waivers

- **Persons with Developmental Disabilities • Home- and Community-Based Services Waiver** - register for the Prioritization of Urgency of Need for Services (PUNS) through the Department of Human Services Division of Developmental Disabilities (DDD). Call your area's Independent Service Coordination (ISC) agency at 1-888-DDPLANS (1-888-337-5267) or 1-866-376-8446 (TTY). You can also check online at www.dhs.state.il.us or the Governor's Developmental Disabilities web site at www.dd.illinois.gov.
- **Persons with Disabilities • Division of Rehabilitation Services (DRS) Home Services Program** - this waiver serves individuals with severe physical disabilities. A fact sheet on the Home- and Community-Based Services Waiver / Home Services Program is available online at <https://www.illinois.gov/hfs/MedicalClients/HCBS/Pages/default.aspx>. For more information contact the Division of Rehabilitation Services at 1-800-843-6154, 1-800-447-6404 (TTY), and online at <http://www.dhs.state.il.us/page.aspx?item=29738>.
- **Persons with Brain Injuries • Division of Rehabilitation Services (DRS) Home Services Program** - a fact sheet on the Home- and Community-Based Services Waiver / Home Services Program is available online at <https://www.illinois.gov/hfs/MedicalClients/HCBS/Pages/default.aspx>. For more information contact the Division of Rehabilitation Services at 1-800-843-6154, 1-800-447-6404 (TTY), and online at <http://www.dhs.state.il.us/page.aspx?item=29738>.

Other Resources

- **The Illinois Assistive Technology Program** - promotes availability of assistive technology services such as the **ILoan Program**, which provides loans to buy assistive technology for daily living, self-employment and home-based employment. Call 1-800-852-5110 or go online: <http://www.iltech.org/repository/financialloans>.
- **Supported Living Facilities • Illinois Supported Living Program** - offers housing with support services to persons with physical disabilities (22 and older), depending on the population served by the facility. This is a Department of Healthcare and Family Services waiver program that allows for supported living services that include personal care, homemaking, laundry, medication supervision, social activities, recreation and 24-hour staff. **The resident is responsible for paying the cost of room and board at the facility.** For more information, see the online fact sheet at <https://www.illinois.gov/hfs/MedicalClients/HCBS/Pages/slf.aspx> or call 1-217-782-0545.
- **Statewide Independent Living Council of Illinois** - supports independent living services across Illinois. For more information, call 1-217-744-7777 (V/TTY) or go online at <http://silcofillinois.org/>.

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Name: _____ Age: _____ Date: _____

The activities listed will help youth gain the skills and abilities needed to reach their highest level of independence and ability. Some of these activities may not apply to everyone.

FINANCIAL Skills and Abilities:	YES	NO	N/A	Need More Info
1. Do you know the value of money (coins and bills)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Do you receive an allowance?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Are you able to count change?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Do you pay for items at the store?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Do you pay or arrange payments for your medications?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Do you have a bank account?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Do you need a joint bank account and someone to help you oversee your money?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Do you know how to write a check and/or use a debit card?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Are you able to balance a checkbook?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Do you know how to gain credit (apply for a credit card, line of credit, loan, etc...)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Do you know what a budget is?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Do you know your strengths and interests?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Do you know people or agencies that can help you find a job?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Do you know what taxes are?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Do you manage your money and budget household expenses? (housing, food, heat, phone, insurance, etc...)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Do you know how your living expenses will be paid when you become an adult?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Do you know about special programs to help pay for job training or college?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Do you get financial help with school or work?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Do you plan to work to support yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Are you able to fill out an application?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Do you know about government programs for income support? (Supplemental Security Income, Social Security Disability Income)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Have you applied for government income support (SSI), if needed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Do you have a representative payee, guardian of the estate or power of attorney, if needed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Do you have a Special Needs Trust set up to protect your finances and program benefits, if needed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. Do you have a will?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. Do you know the civil rights of persons with disabilities?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>


TIPS FOR USING THIS SKILLS LIST:

Think about the skills you want to work on. Make notes of your needs and concerns. Then you can talk about the next steps to take with the people that are helping you prepare for your future.

Notes to Myself: For each “Need More Info” item you checked, list questions you have or what you would like to know more about.

Next Steps – Goals: List what you need to work on to help you learn how to take care of yourself in the future. You can ask the people who are helping you plan for your future to work on this with you.

I want more information about: ☐ Insurance ☐ HFS Health Benefits for Persons with a Disability
 ☐ SSI ☐ Other _____

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Managing Money, Budgeting & Setting Up Credit



1. **Begin to manage (co-manage) your own money.**
2. **Start a checking account** (or a joint account). Regular deposits show responsibility. Learning how to balance your checkbook – and balancing it every month when your bank statement arrives – is among the best money management habits you can keep. You may find this online tool helpful: <http://mappingyourfuture.org/money/checkbook.cfm>.
3. You will need to begin [establishing good credit](#) to make it easier in your future to obtain financial assistance of any kind, such as an auto loan or a credit card. An absence of prior credit history can lead to the same set of problems as a bad credit history.
 - **Establish a Joint Account.** Your parents can add you to their account; the credit history is reflected on both your account and your parents'.
 - **Start a Savings Account.** Regular deposits with limited withdrawals can create a line of credit.
 - Check with your local bank or department store if they report the credits to the credit bureau. **Consider applying for a small loan at the bank or a credit card from the local department store.** A co-signer will be needed if younger than 18. It is better to opt for a loan with terms that can be satisfied without undue financial strain.
4. Creating a budget may not sound like the most exciting thing in the world to do, but it is vital in keeping your finances in order. Budgets are the only practical way to get a grip on your spending - and to make sure your money is being used the way you want it to be used.
5. **Creating a budget** generally requires three steps. You may find this tool helpful: <http://mappingyourfuture.org/money/budgetcalculator.cfm>.
 - Identify how you're spending money now.
 - Evaluate your current spending and set long-term financial goals.
 - Track your spending.
6. You can get help with applying for benefits and making a budget at your local **Center for Independent Living**. To find a center, go to <http://www.incil.org/locate/>. Call toll-free **1-800-587-1227**.
7. **Explore your career options early and while in high school.** To successfully transition to adult life, finding gainful employment is the ultimate outcome. Unemployment results in poverty, lower health status and dependency on government programs.
8. **When you begin earning your own income, you will need to file income taxes.** Your Center for Independent Living may know of a free resource in your community to help you complete and file taxes.

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What a Good Idea!...

Use SSI to Get Ready for your Future!

1. **Supplemental Security Income (SSI)** helps to pay for your food, clothing and shelter needs. It also helps you maintain your medical benefits.
2. **Apply or reapply for SSI when you become an adult** (around age 18).
3. **Your eligibility is re-evaluated on a regular basis** based on your income and resources.
4. **Some ways SSI can get you one step closer to working:**
 - It can help you get money every month for your food, clothing and shelter needs.
 - Less than half of the money you earn from work is counted against your SSI check.
 - When you work, you can keep your Healthcare and Family Services' healthcare coverage.
 - Using a **Plan for Achieving Self Support (PASS)** will allow you to set aside money to help you achieve an occupational goal and become independent.
 - You can deduct your work-related expenses from your earnings.
5. **Work incentives** are a great way to get people working. Wouldn't it be nice to make more money than what comes from Social Security every month?
6. **You can learn more** online at the SSI Work Site, <http://www.socialsecurity.gov/work/index.html>, or by calling toll-free **1-800-772-1213**.
7. **Applying for SSI involves many steps.** If you are interested, you can get more information by calling toll-free **1-800-772-1213**.
8. If you are already getting SSI and want to learn more about work incentives, call your **Work Incentive Planning and Assistance Program**.
 - Mayor's Office for People with Disabilities (City of Chicago): **1-312-746-5743 (Voice)** **1-312-746-5739 (TTY)**.
 - Illinois Assistive Technology Program (North and West Suburbs and Other Parts of Illinois): **1-800-852-5110 (Voice/TTY, IL only)** **1-217-522-9966 (TTY)**.
9. **If you have already applied for benefits in the past and were denied, don't give up!** In fact, most people are initially denied when they apply on their own. You can still reapply or appeal the denial with the help of a qualified social security disability advocate or attorney. You can contact Protection and Advocacy for Beneficiaries of Social Security, Equip for Equality, Inc. at 1-800-537-2632 (Voice) 1-800-610-2779 (TTY).

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Paying For College



1. You should **contact the higher education institutions** (by phone or their internet website) where you are interested in enrolling and ask about the following:
 - The cost of attendance, including the breakdown of tuition and fees, room and board, travel, books and supplies, and personal and miscellaneous expenses.
 - The types of financial assistance available.
 - The procedures and timeframes for submitting applications for assistance.
 - The criteria institutions use to award financial aid.
 - The interest rates on various student loans, the total amount you must repay, the length of time to repay, when to start repaying, and what cancellations (deferments) apply.
 - Other conditions that affect financial assistance.
2. ***Mapping Your Future*** is a free resource for career, college, financial aid, and money management information. Their goal is to help individuals achieve life-long success by empowering students, families, and schools with free, web-based information and services. <http://mappingyourfuture.org/>
3. **Complete the *Free Application for Federal Student Aid (FAFSA)*** at: <http://www.fafsa.ed.gov/>
4. **Explore additional funding sources** to help pay for college.

Go to the next page for ideas and scholarship information.

Financial Resources for Post-Secondary Education

Scholarship	Website	Description
Federal Student Aid	http://studentaid.ed.gov/sa/fafsa	Financial help for students enrolled in eligible programs at participating schools. Includes tuition and fees, room and board, books and supplies, and transportation. Most federal aid is need-based. The three most common types of aid are grants, loans, and work-study.
HEATH Resource Center	http://www.heath.gwu.edu/graduate-school-disability-and-financial-aid	A comprehensive resource on financial aid with a list of scholarship opportunities for people with disabilities.
FinAid	http://www.finaid.org/	Free scholarship search including one for financial aid for students with disabilities.
College Scholarships	http://www.collegescholarships.com	Large database of scholarships available.
College Illinois	http://www.collegeillinois.com/PlansAndPricing/Comparing529Plans.htm	A 529 Prepaid tuition program offering tax incentives. Compare different types of 529 plans.
Illinois Board of Higher Education	http://www.ibhe.state.il.us/consumerInfo/finance.htm	Information on grants, scholarships and loans.
General Scholarships for Students with Disabilities	http://collegescholarships.org/financial-aid Keyword Search: disabilities	Comprehensive listing of scholarships for wide variety of individuals with disabilities.
College Funding Strategies for Students with Disabilities	http://www.washington.edu/doit/Brochures/Academics/financial-aid.html	Has loads of information on different types of financial assistance for higher education.
Illinois Department of Human Services (DHS) and the Division of Rehabilitation Services (DRS)	Learn more about our customer success and apply online: www.drs.illinois.gov/success Contract us directly: 1-877-761-9780 (Voice), 1-866-264-2149 (TTY), 1-312-957-4881 (VP)	DHS's Division of Rehabilitation Services is the state's lead agency serving individuals with disabilities. DRS works in partnership with people with disabilities and their families to assist them in making informed choices to achieve full community participation through employment, education, and independent living opportunities. Are you an individual with a disability who's interested in furthering your education beyond high school? If so, then DRS may be able to help defray the costs of your education and help you achieve a successful career.

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**Point of Entry to Services in Illinois for
Individuals with Developmental Disabilities**

Register for PUNS!



PUNS stands for Prioritization of Urgency of Need for Services

- ❖ The **Illinois Division of Developmental Disabilities** uses the PUNS database to identify who needs services and what services they need.
- ❖ Persons are **chosen based on urgency of needs** as governmental funding becomes available. At age 18 individuals will be reassessed by the **Independent Service Coordination Agency**.
- ❖ People are selected from this database to get help with:
 - ✓ In-home supports for independent living
 - ✓ Respite care to provide temporary relief to caregivers
 - ✓ Entry into Day Services, sheltered workshops or supported employment
 - ✓ Training Programs to teach life and work skills
 - ✓ Job coaches to help with training and success in the workplace
 - ✓ Emergency or long-term placement in residential living facilities
 - ✓ Adaptive equipment to promote independence
 - ✓ Other supports to improve quality of life

To fill out the PUNS form:

- ❖ Contact the local **Independent Service Coordination Agency** (ISC) and ask for an appointment to register for PUNS. To find your local ISC Agency:
 - ✓ Call DHS at: 1-888-DD-PLANS
 - ✓ Visit online: www.dd.illinois.gov
 - ✓ Call Illinois Life Span at: 1-800-588-7002
 - ✓ View DD PUNS Brochure at:
 - Services: <http://www.dhs.state.il.us/OneNetLibrary/27897/documents/Brochures/4309.pdf>
 - PUNS: <http://www.dhs.state.il.us/OneNetLibrary/27897/documents/Brochures/4313.pdf>
- ❖ Arrange a time to meet with a Pre-Admission Screener. He/she will ask questions about individual and family needs. Needs are divided into:
 - ✓ **Seeking Services** – needed within the year
 - ✓ **Planning for Services** – person doesn't need services for at least a year or caregiver is older than 60 years
- ❖ The PUNS should be **updated yearly** or anytime needs change.

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Name: _____ Age: _____ Date: _____

The activities listed will help youth gain the skills and abilities needed to reach their highest level of independence and ability. Some of these activities may not apply to everyone.

I plan to: ☐ **get a job** ☐ **go to tech school or job training** ☐ **go to college**

EMPLOYMENT Skills and Abilities:	YES	NO	N/A	Need More Info
1. Do you know how to use time properly, keep your work space neat, respect other people's property and care for tools and supplies?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. When you are asked to do two or more things, can you do this on your own? (such as "get the envelope and put it in the mailbox")	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Do you have chores or tasks that you must do at home?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Do your chores or tasks match your abilities?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Do you use a computer to surf the web, type papers or letters, send email or other software?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Can you speak up to make your needs known? (At school, work, community, or home)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Do you do volunteer work?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Do you talk about what job or career you would like to do when you are older?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Do you know which clothes to wear based on where you are going (work, play, etc.)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Do you know how to stay safe when away from home (such as finding the right streets, getting on or off the bus at the right place, using a phone)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Do you tell your friends and grown-ups (teacher, boss, principal) what you think?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Do you know your strengths and interests?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Do you know people or agencies that can help you find a job?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Have you written a job resume?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Can you fill out a job application?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Do you apply for a job or work or vocational services?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Do you know how to get along with others at school and work?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Do you have a plan for work or job training or college?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Have you visited job sites or done job shadowing?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Do you know what accommodations you can get at work to help you do your job?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. Do you have a part-time or a full-time job for pay?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Do you know your workplace rights under the Americans with Disabilities Act (ADA)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

TIPS FOR USING THIS SKILLS LIST:

Think about the skills you want to work on. Make notes of your needs and concerns. Then you can talk about the next steps to take with the people that are helping you prepare for your future.

Notes to Myself: For each “Need More Info” item you checked, list questions you have or what you would like to know more about.

Next Steps – Goals: List what you need to work on to help you learn how to take care of yourself in the future. You can ask the people who are helping you plan for your future to work on this with you.

I want more information about: ☐ Vocational Rehab ☐ Job Resources ☐ Other _____

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What Are YOU Going To Be?



1. **It is never too early to start deciding what kind of job you want to do after you finish school -** you can always change your mind later.
2. **There are programs out there that can help you** in planning for your future while you are still in high school.
3. Contact the **Division of Rehabilitation Services (DRS)** toll-free at **800-843-6154** (or TTY **800- 447-6404**). DRS can help guide you in many ways as you prepare for work or college:
 - Career planning and counseling
 - Job training (job coaches)
 - Funding for college when it leads to employment
 - On-site support, including transportation
 - Funding for a personal assistant
4. **STEP is a program that your school district might have if you have an IEP.** This program can help you to learn job skills and get job training in your home town.
5. **If you are interested in vocational training** you may find these resources helpful:
 - Vocational and career training programs through your high school
 - Vocational Schools Database: http://www.rwm.org/rwm/tf_ill.html
6. **Illinois WorkNet Centers**, www.illinoisworknet.com, can help you with:
7. Writing resumes, learning to interview, job search, and disability resources
8. Ask your school counselor, health care provider, DRS high school liaison, your DSCC Care Coordination Team, friends and others for help finding and accessing vocational opportunities in your community.

On the other side of the page is a list of important steps to think about before leaving high school.

Before Leaving High School - Important Steps in Planning for Transition

- **Figure out what your learning style is and what helps you learn best.** Do you learn best by seeing, hearing or hands-on?
- **Know your strengths and weaknesses.**
- **Explore career interests and skills.**
- **Take classes to learn more about your areas of interest and that match your career interests.** This could include vocational classes and training.
- **Attend your transition IEP (Individualized Educational Program) and be ready to answer these questions:**
 - Would you like to go to college or tech school?
 - What would you like to study?
 - If you don't want to go on to college, what do you plan to do after high school?
 - Where do you want to work? Do you have the skills it will take to work there?
 - Where will you live after high school?
 - What do you like to do for fun when you are not in school?
- **Be able to explain your disability or health condition and know what supports you may need to live and work in a place of your choice.**
- **Check out assistive technology tools that could help you** on your job, or to do things in the community.
- **Develop interview skills.**



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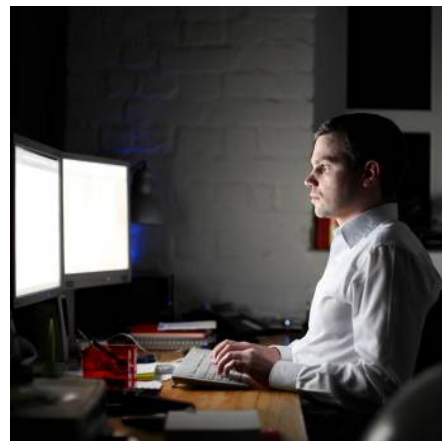


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What Job Do You Do?

You may already have job experience: Do you...

- Baby-sit younger kids?
- Help your family around the house?
- Do yard work for your neighbors?
- Care for a pet?
- Help your grandmother in her garden?
- Volunteer to help your teachers?
- Work a part-time job in the summer or during the school year?



Work is a great way to learn basic skills:

- Cooperating with others
- Increased responsibilities
- Value of money
- Job skills
- Time management skills
- Self-confidence

Remember, although it is nice to get paid for what you do, **volunteer work is a good way to get experience** when you are not sure what you want to do or how much time you will have to do it.

Getting work experience when you're young will help you learn how to keep your future jobs and can help you to save money to buy the things you want to have.

You may find the following resources helpful:

- **Illinois Worknet Center:** <https://www.illinoisworknet.com/>
- **Department of Human Services Disability and Rehabilitation Services:** <http://www.dhs.state.il.us/page.aspx?item=29727>
- **Illinois Career Resource Network:** <http://ilcis.intocareers.org/materials/portal/home.html>
- **Job Accommodation Network:** <http://www.jan.wvu.edu> or 800-526-7234
- **Illinois Employment & Training Center:** <http://www.ides.state.il.us> or 888-367-4382

Some skills you may need for interacting well with your boss and co-workers are listed on the backside of this page.

Skills for Interacting with Co-Workers



- Know how to greet others, shake hands say hello.
- Use good eye contact when talking to or listening to others.
- Know how to introduce yourself, such as stating your first and last name.
- Respect personal body space of others.
- Use an assistive device to talk to others.
- Smile and talk to others during breaks.
- Indicate what you need to be able to do your job.
- Ask and answer questions.
- Get along with others.
- Show likes/dislikes in workplace.
- Keep your emotions within limits.



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It's Time to Get a Job?



Volunteer and Paid Work Will Help Your Future Career

1. Work is a great way to learn basic skills:

- Getting along with others
- Job skills
- New responsibilities
- Value of money
- Time management skills
- Self-confidence

2. Volunteer work is a good way to get experience when you are not sure what you want to do or how much time you will have to do it.

3. Having a job when you are young will help you to find and keep a job when you are older.

4. If you would rather not work during the school year, consider working only during the summer.

5. Wouldn't it be nice to **have work benefits and make more money** than what comes from Social Security every month? Did you know, with SSI work incentives, you can go to work and not lose your medical/Medicaid card or your SSI?

6. Ways to gain work experience:

- Volunteer for community work or school projects.
- Work around the house or for neighbors or friends.
- Spend time watching (job shadowing) someone already doing the type of job you want to do.
- Participate in "Take Our Son/Daughter to Work " programs in the spring.
- Work a part-time job for experience and establish a good work record.
- Work a job within the community during the school year as part of the school-work program.

7. On the other side of the page is a list of activities to think about doing.

Employment Activities: Learning Job Skills



- ☐ Demonstrates the meaning of “yes” or “no”.
- ☐ Listens to instructions.
- ☐ Gets and puts items away when asked.
- ☐ Sweeps, mops, vacuums or dusts.
- ☐ Folds paper.
- ☐ Uses scissors, stapler, paperclips.
- ☐ Looks for an opportunity to job shadow (watch somebody do their job to learn more about that type of work).
- ☐ Arrives at work on time.
- ☐ Repeats tasks after modeling.
- ☐ Follows instructions requiring an action and an object.
- ☐ Uses basic tools in the workplace.
- ☐ Uses the telephone.
- ☐ Makes copies.
- ☐ Prints, writes or dictates messages.
- ☐ Delivers a simple message.
- ☐ Uses assistive technology in the workplace.
- ☐ Allows a personal attendant to assist in the workplace.
- ☐ Lets supervisor know if you will be late.
- ☐ Lets supervisor know when absent due to illness or appointment.
- ☐ Obeys time limits for breaks and lunch.

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