

PATHWAYS FOR SUCCESS

Preparing for Life After High School

A Transition Resource Guide

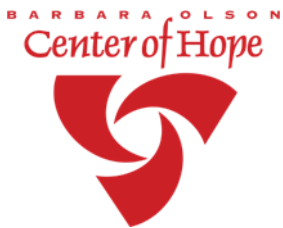
For Students with Developmental Disabilities & their Families.

This handbook was developed by the agencies of Intersect for Ability - Rockford, a collaborative group of organizations serving people with developmental disabilities in the Rockford, Illinois region. Funding for this resource guide was realized through a grant award from the Community Foundation of Northern Illinois.



MISSION: To build partnerships and agency capacity to **better serve** people with developmental disabilities.

Intersect for Ability – Rockford agencies participating in this project:



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Transition Planning – An Introduction

It's NEVER too early to start planning for adulthood!

This Transition Resource Guide was created for use by youth and adults with developmental disabilities and their families, educators, and community support teams. The purpose of this guide is to help youth with developmental disabilities and their families take the lead in planning for their adult lives. It is never too early to start planning for adulthood! Our vision is that this resource guide will be easy to use and accessible to every person who has a developmental disability or those who advocate for people with developmental disabilities.

When a child with developmental disabilities reaches age 14 ½ in the state of Illinois, the official process of Transition Planning may begin. Transition Planning is a coordinated set of activities for a child with a disability which is:

- a result-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from school to post-secondary education, vocational education, integrated employment(including supported employment), continuing and adult education, adult services, independent living, or community participation;
- based on the child's individual needs, taking into account the child's strengths, preferences, and interests.

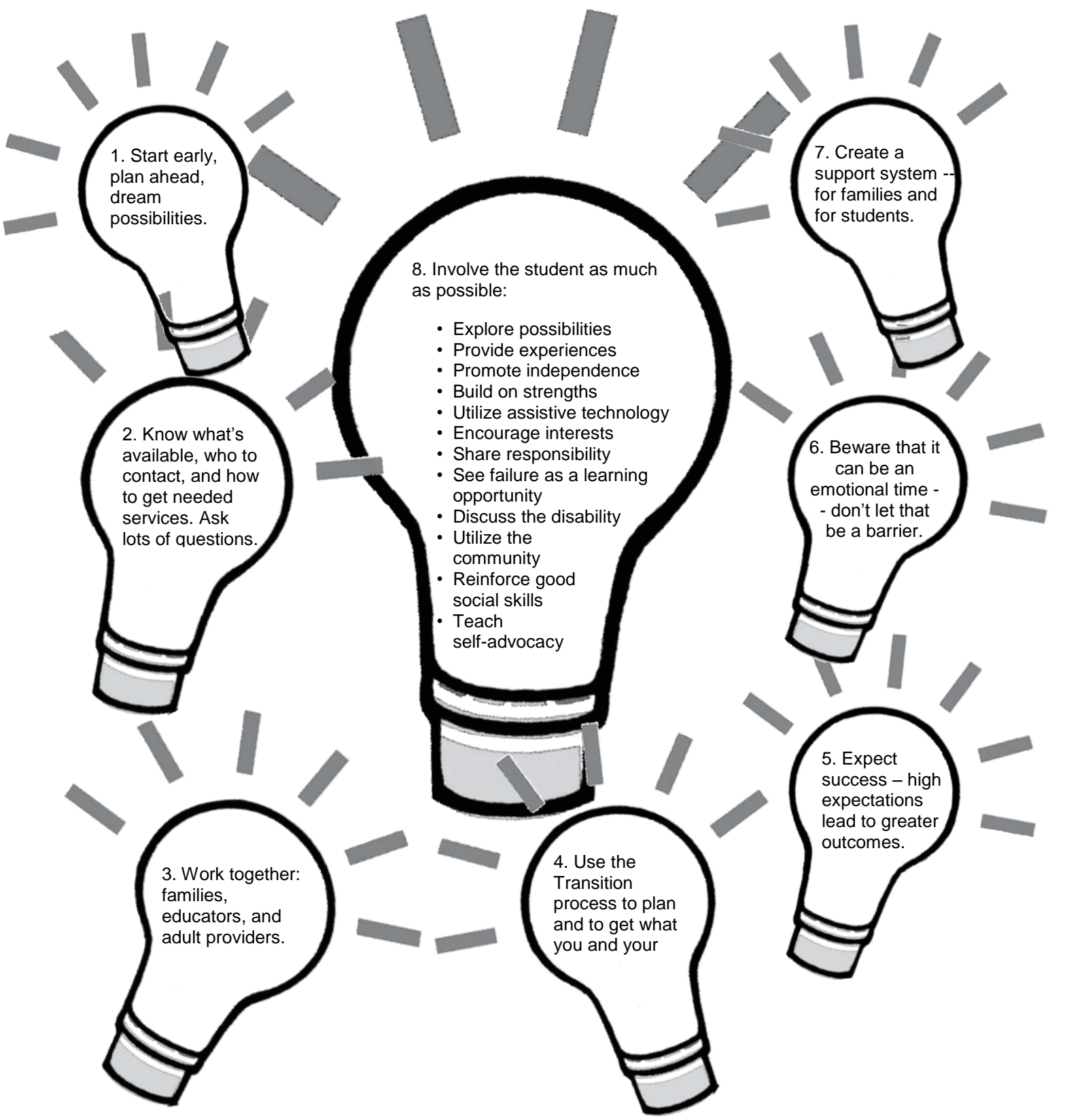
The Individuals with Disabilities Educational Improvement Act of 2007 (IDEA) requires that for students identified as having a disability, each annual meeting will include the discussion and written statement of transition service needs. Transition Services include “instruction, related services, community experiences, development of employment and other post-school adult living objectives; and if appropriate, acquisition of daily living skills and functional vocational evaluation. The statement of needed transition services must also include a statement of the interagency responsibility or any needed linkages.” (IDEA)

Other agency representatives who may be invited to the IEP meeting for the discussion of transition services include the following:

- Local service coordination agency (Access Services of Northern Illinois)
- Rehabilitation counselor (DRS-Vocational Services)
- Employment agency staff (Barbara Olson Center of Hope, Milestone Industries, Illinois Growth Enterprises, Goodwill Abilities Center)
- Center for Independent Living (RAMP)
- Residential Service Providers (Mosaic, Milestone, Goldie Floberg, RocVale, Stepping Stones)
- Post-secondary education staff (Rock Valley College, other community college or university staff)
- Persons knowledgeable about financial benefits such as Social/Supplemental Security Income and Medicaid/Medicare (Social Security Administration, Department of Healthcare and Family Services)
- Personal care or health care providers (DRS-Home Services)
- Community park and recreation staff (Local Park District, YMCA, ARC)
- Transportation agency (RMTD-Para Transit, Care-A-Van)
- Juvenile justice support team (when there are pending legal issues)

If an agency is not able to send a representative, written information should be sought along with the name of a contact person. Families should keep in mind that each agency may have different criteria for eligibility and may have a waiting list.

Tips for Helping Students Make Successful Transitions to Adulthood



1. Start early, plan ahead, dream possibilities.

2. Know what's available, who to contact, and how to get needed services. Ask lots of questions.

3. Work together: families, educators, and adult providers.

4. Use the Transition process to plan and to get what you and your

7. Create a support system -- for families and for students.

6. Beware that it can be an emotional time - - don't let that be a barrier.

5. Expect success – high expectations lead to greater outcomes.

8. Involve the student as much as possible:

- Explore possibilities
- Provide experiences
- Promote independence
- Build on strengths
- Utilize assistive technology
- Encourage interests
- Share responsibility
- See failure as a learning opportunity
- Discuss the disability
- Utilize the community
- Reinforce good social skills
- Teach self-advocacy

My Information Sheet

TRANSITION ASSISTANCE:

Contact Name: _____ Phone: _____

Notes: _____

PUNS (ACCESS SERVICES of NORTHERN ILLINOIS)

Service Coordinator: _____ Phone: _____

Notes: _____

GUARDIANSHIP

Agency/Lawyer: _____ Phone: _____

Notes: _____

SOCIAL SECURITY

Contact Name: _____ Phone: _____

Notes: _____

MEDICAID/LINK

Contact Name: _____ Phone: _____

Notes: _____

RESPITE ASSISTANCE

Contact Name: _____ Phone: _____

Notes: _____

OTHER (Name of Agency: _____)

Contact Name: _____ Phone: _____

Notes: _____

School Name: _____

Principal's Name: _____

Case Manager's Name: _____

Date of Next IEP: _____

School Psychologist: _____

IEP (Individualized Education Program)

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Transition Checklist



The following is a checklist of transition activities that you and your son or daughter may wish to consider when preparing transition plans with the IEP team. Your student's skills and interest will determine which items on the checklist are relevant. Use this checklist to ask yourself whether or not these transition issues should be addressed at IEP transition meetings. The checklist can also help identify who should be part of the IEP transition team. Responsibility for carrying out the specific transition activities should be determined at the IEP transition meeting.

4 - 5

Years Before Leaving the School District (or 8th Grade)

- Identify personal learning styles and the necessary accommodations to be a successful learner and worker.
- Identify career interests and skills, complete interest and career inventories, and identify additional education or training requirements.
- Explore options for post-secondary education and admission criteria.
- Identify interests and options for future living arrangements, including supports.
- Learn to communicate effectively your interests, preferences, and needs.
- Be able to explain your disability and the accommodations you need.
- Learn and practice informed decision making skills.
- Investigate assistive technology tools that can increase community involvement and employment opportunities.
- Broaden your experiences with community activities and expand your friendships.
- Pursue and use local transportation options outside of family.
- Investigate money management and identify necessary skills.
- Acquire identification card and the ability to communicate personal information.
- Identify and begin learning skills necessary for independent living.
- Learn and practice personal health care.

2 - 3

Years Before Leaving the School District (or 9-10th Grade)

- Identify community support services and programs (Vocational Rehab, County Services, Centers for Independent Living, etc.)
- Invite adult service providers, peers, and others to the IEP transition meeting.
- Match career interests and skills with vocational course work and community work experiences.
- Gather more information on post-secondary programs and the support services offered; and make arrangements for accommodations to take college entrance exams.
- Identify health care providers and become informed about sexuality and family planning issues.
- Determine the need for financial support (Supplemental Security Income, state financial supplemental programs, Medicare, Medicaid).
- Learn and practice appropriate interpersonal, communication, and social skills for different settings (employment, school, recreation, with peers, etc.).
- Explore legal status with regards to decision making prior to age of majority.
- Begin a resume and update it as needed.
- Practice independent living skills, e.g., budgeting, shopping, cooking, and housekeeping.
- Identify needed personal assistant services, and if appropriate, learn to direct and manage these services.

1

Year Before Leaving the School District (or 10th grade and beyond)

- At age 18, apply for financial support programs (Supplemental Security Income, Independent Living Services, Vocational Rehabilitation, and Personal Assistant Services).
- Identify the post-secondary school you plan to attend and arrange for accommodations.
- Practice effective communication by developing interview skills, asking for help, and identifying necessary accommodations at post-secondary and work environments.
- Specify desired job and obtain paid employment with supports as needed.
- Take responsibility for arriving on time to work, appointments, and social activities.
- Assume responsibility for health care needs (making appointments, filling and taking prescriptions, etc.).
- Register to vote and for selective service (if a male).
- Match career interests and skills with vocational course work and community work experiences.

Using the IEP Process to Enhance Transition Outcomes

Successful transition to adulthood takes families, educators and students working together.



Parents, you can have a discussion with your child and together come up with your dreams and expectations in the areas of living, learning and working. Ask them what they see themselves doing when they get out of school. Follow that with, “If for some reason, you couldn’t do that, what other things would you want to do?” Remember, it is normal if you and your child have differences of opinion.

Allow for those differences to be discussed.

The Transition IEP should be built around your child’s strengths, interests and preferences. Get their input; let them know what you see them good at; point out where they have been successful; talk about pursuing interests they may not yet have explored. Remind your child that they can change their minds as they explore, eliminate, and change what they hope to do with their lives.

Transition planning is driven by each student’s Individualized Education Program (IEP).

The IEP must:

1. Begin transition planning at age 14 ½ and focus on life after school.
2. Be individualized and include the student and family members as decision makers.
3. Be reviewed and updated every year.
4. Should be coordinated by the school, and have the involvement of a variety of school staff.
5. Include a statement of the student’s transition needs and focus on the student’s course of study.
6. Include a statement of needed transition services for the student.
7. Include a statement of connections between various agencies.
8. Be a cooperative effort between the student, family, employers, and community agencies.

The “Parents’ concerns for enhancing their child’s education” section of the IEP is where you can address your child’s needs. Maybe you aren’t sure your child has the skills to match what they desire to do. Perhaps you are wondering what supports will be available to help them explore interests. The list could go on, and that’s okay – write down all of your concerns and share them with the team.



The Transition Goals should reflect the strengths, concerns, and the transition assessment information completed in the areas of living, learning, and working. The information gathered should answer questions like:

- What information has been gathered from my child's transition assessments?
- What skills will my child need to be **successful living** as independently as possible where they want to live? How will they learn those skills?
- What **work experiences** should be built into my child's program to explore jobs in which they have expressed an interest?
- What **program of studies** will be important for my child to have if they plan to attend a post-secondary educational program?
- What **work skills** should my child work on or develop that will help them be a good employee?
- What is being done to help my child **learn to be an independent** and responsible adult?
- How will my child be helped to **understand her/his disability** and become a strong self-advocate for her/his needs?
- In what ways can we help my child **develop leisure skills** that will contribute to a meaningful adulthood?
- **How much time** in my child's day will go toward addressing their transition goals?



You will be kept informed about how your child is doing with the IEP goals. You should receive that information as often as other students receive progress reports; i.e., midterm and grading times. Don't hesitate to request that your child's teacher "show you" how they know what your child's progress has been. Schools regularly collect and chart data on student progress so they will have that information for you.

IEP Meeting Attendees: Families and students can request whom they would like to have in attendance at the IEP Meeting. Adult Service Providers are often very willing and wanting to get involved early.

"Start early" and "Use the IEP Process" are two good rules of thumb for transition planning.

Learning to Make Decisions: Students and Their IEPs



When you think about your child's future do you see them being able to make decisions and take at least partial responsibility for choices in their life? Does your child have the communication skills, the confidence and the desire to have a voice in the decision process?

Being involved in their own IEP meetings **can be a great learning experience for the student to practice making decisions.** Their thoughts and wishes should be central to the team's planning for her future.

Student involvement can yield several results:

- Taking over responsibility for some of the direction setting about the future.
- Preparation for assuming age-of-majority rights by age 18.
- Coming to a better understanding of the disability and its implications for life after school.
- Learning to interact with professionals who will share responsibility for the student's receiving services.
- Having to learn how to resolve differences when teachers and/or parents want something different from what the student wants.

A student should **not** be expected to walk into a meeting “cold” and effectively participate.

Before The IEP Meeting:



- Teachers can help students understand the IEP Process and the student's role in it.
- Parents can talk with their son/daughter about the kind of input he or she may want to offer to help the IEP team plan for transitional programming.
- Students can be given responsibility for a specific part of the meeting – reporting goal progress since the last meeting, sharing perspectives on how their disability impacts their lives, or covering the Strengths and Concerns parts of the IEP with their interests, desires and worries.

During the IEP meeting:



- Students should be encouraged to share; have them identify their strengths from their point of view; they should have input into every decision made.
- Someone who has helped them prepare should assist and prompt students through the process.
- Periodically checking with students for understanding will help clarify their input.
- All team members should work to affirm effort and help students feel successful.

After the IEP meeting:



- Goal progress should be reviewed with the student on a regular basis.
- Parents should have on-going discussions about decisions made and the student's satisfaction with the direction those decisions are taking him/her.
- Where there is failure, parents and teachers need to help the student learn from the experience.
- Planning for the next IEP meeting should be a continuous process.

Does Your Child Have Good Self-Advocacy & Self-Determination Skills?



Choice making, problem solving and goal setting are **all a part of being a strong self-advocate**. Helping children become self-determining adults begins when they are very young and is **certainly a critical part of transition planning**. Do your child's transition goals address self-advocacy and self-determination?

Becoming a confident person willing to speak up for one's self, express needs and seek assistance **begins with an understanding of one's disability**. Yet so often we avoid that topic with our youth with disabilities, not wanting to point out differences, offend or make them feel badly. We will talk with them about what they can and can't do yet we don't discuss what's behind some of what they can't do. If our children with disabilities are going to feel good about themselves, **they must first feel okay about being a person with a disability**.

So, parents:

- Don't talk *around* the disability. Naming or describing the disability can demystify and disarm the power that makes some afraid and anxious about it.
- Let's raise our children with disabilities to be knowledgeable, comfortable, accepting of themselves, articulate and assertive.
- Equip them to speak frankly about their strengths, needs, wants, and feelings.
- Give them tools (information and skills) they will need to gain and keep as much control over their lives as possible.
- Consider them a part of the planning team for their IEPs and teach them to collaborate with those providing care/services.
- Give them gifts we want all children to receive – courage, self-determination, knowledge of themselves, self-acceptance and self-sufficiency.

REMINDER QUESTION: How do we as parents, teachers, and community service providers empower students to make choices, solve problems, and set

Ten Areas of Transition Need

When planning for a student's transition from high school to the adult world of work or further education, think of these 10 categories of life skills and how IEP teams can include them in the student's high school program.

	LIFE SKILL	EXAMPLES
1	SELF DETERMINATION	Explaining your needs and strengths in the workplace or school. Requesting your needed accommodations. Getting advocacy or legal support when needed. Learning about Assistive Technology (AT), Personal Assistance Services (PAS), Disability Pride.
2	ACADEMIC/LIFE-LONG LEARNING	Taking classes at a university or community college. Going to community workshops such as gardening, parenting classes, home repair. Using community resources such as the library.
3	DAILY LIVING	Cooking meals, using home or commercial washers & dryers, using home cleaning equipment, painting walls.
4	HEALTH/PHYSICAL CARE	Personal cleanliness such as bathing, washing hair, using deodorant. Dental care, making doctor appointments, learning CPR. Sex education. Mental health screenings.
5	LEISURE ACTIVITIES	Joining a bowling league, pursuing a hobby, making dates for movies with friends, going out to eat, biking, and attending community events.
6	MOBILITY	Getting a driver's license, how to ride the city bus/para transit system, using the city maps, calling a cab, sharing the cost in a car pool.
7	MONEY MANAGEMENT	How to open and manage a checking account, what credit cards mean, how to get a bank loan, how to budget.
8	SOCIAL SKILLS	Speaking and greeting others, appropriate behavior at work/school/ friends. Good manners in restaurants, going out on a date, relationships with the opposite sex.
9	WORKPLACE READINESS	Managing workplace stresses, dealing with authority, going to a job interview, time management.
10	OCCUPATIONAL SPECIFIC SKILLS	Learning the functions of the tools needed for the job, finding a mentor, practice job skills after work such as computer skills, cooking skills.



Planning Tools to Prepare for the IEP Meeting



The following pages offer four different planning formats to use as you and your student prepare for your IEP meeting. Each of these tools looks at things differently. Choose the one that best suits you and your child's planning style, needs, and interest.

Think planning, think transition, think future!

WHAT?

The educational activities in the IEP are based on student's needs, preferences and interests as well as on the parent concerns, and the strengths of the student. IEP Transition goals are based on this information, as well as, results from any transition assessments.

FOR WHOM?

Students turning 14 ½ years old (and older), and their families.

WHY?

Thinking about the future can seem fuzzy and distant. Families lead busy lives with many immediate concerns. Take time to reflect about the future. A little time now will pay off in big ways by easing your family into the next step of life.

Answering specific questions can help parents, students, and teachers see transition in a concrete manner.

WHEN?

Engage in the process before each IEP meeting. Completing the grid (see next page) annually allows reconsideration as needs and goals change with new experiences. Schools in Illinois will be required to initiate the transition planning process with students who are age 14 ½ and older. Age 14 ½ is not too early to start transition planning.



HOW?

Complete the grid that works best for you on the next pages at home and bring it to the IEP meeting. Have your child complete one as well with or without your assistance.

Allow ample time for explanation and discussion. This is a time for dreaming of possibilities.

Transition Planning Grid for Students and Parents

Transition Areas (ideas to consider)	What does your child do now?	What goals do you and your child have for his/her future?	Is support needed to participate?	What agencies or support services are you using now?
Home Living (live alone, with a room- mate, with support, with family or relatives, or in a group home)				
Community Participation (drive car; use bus, taxi, paratransit - SEATS, LIFTS, or ECICOG; shopping; make dental or medical appointments; bank; vote; participate in religious or community events)				
Recreation and Leisure (participate in sports, hobbies, group activities, fitness activities, family events, clubs, make or maintain friendships, volunteering)				
Careers or Job Preparation (full, part-time, supported or sheltered employment; on-the-job training, volunteer work)				
Post-Secondary Education (community college, community and adult basic education, on-the-job training, military service)				

A Useful Tool for Meetings

Child Study Team (CST) Meetings, Individual Education Program (IEP) Meetings, or Parent-Teacher Conferences

Exchange of information is essential in understanding and making decisions about children and how they learn best. For sure, listing a child's strengths and needs for all team members to see and keep fresh in mind is one effective way to help the team make good decisions. Having parents list options which they would like to see in place to help their child be successful in school can serve as a springboard for discussion and a point from which to negotiate. Also helpful is having the parent(s) list questions, fears and concerns about their child and/or situations the child may be in. Once people state or hear these issues, they can better understand all perspectives and take them into account when planning for the child.

STRENGTHS	NEEDS	OPTIONS	QUESTIONS, FEARS, & CONCERNS

For Families and Students



Transition Planning Worksheet

Now is the time! It's not too early; it's not too late! It's time to look ahead, difficult though that may be, and think about LIFE AFTER GRADUATION. That's because the choices you and your daughter or son make now are important to success after high school. Use this worksheet every year as a guide.

Strengths that will be useful in life after graduation:

Needs that will affect life after graduation:

Ideas for after Graduation

As you look ahead what can you see as possibilities in the areas of:

1) Ongoing learning or training _____

2) Living _____

3) Working _____

Next Steps: Use the checklist on page 7 to determine what your next steps will be during the coming year. Consider the following areas:

- Information from transition assessments
- Curriculum considerations to think about now
- Goals to be included in the IEP
- Agency contacts to make and gather information about possible programs for after graduation – post-secondary programs, community support services, personal assistance, etc.
- Skill needs areas to be working on during the coming year both at home and through the IEP – be sure to include self-advocacy skills
- Interest areas to explore for possible career/job opportunities

What needs to happen yet this year? Together, make a list:

What do we yet need to know?

Who do we need to talk to?

What do we need to do?

What Do I Want My Life to Look Like After High School?

Answer the question, “What is my day going to look like after high school?”

The following pages list questions for you to answer. Your answers will help you plan what your days may look like after high school. You can write your answers in the spaces provided or there is a page following each set of questions for either drawing pictures or pasting pictures cut out of magazines that show your answers.

Education/Training

Would you like to attend college? If so, why? What would you like to learn? Would you like to participate in a degree program, audit classes, or take classes that are of a particular interest to you?

Would you like to learn a trade such as construction? Welding? Auto mechanics? Cooking or food preparation?

What about an apprenticeship program where you work alongside someone who knows how to do the things you want to learn and they teach you as you help them? What types of things might you like to learn through an apprenticeship program?

If you think on-the-job training might be a good way to learn a new job, have you thought about supported employment services? With supported employment, a person called a job coach helps you find and learn a job in the community. Once you learn the job and you and your employer feel comfortable that you can do the job on your own, the job coach won't be with you at the job anymore.

Education/Training

If it is helpful, use the space below to draw or paste pictures that show what additional education or training you want after graduation.



(example picture)

Work/Employment

Do you plan to work after graduation?

What type of work will you do?

How many hours a day do you want to work?

What type of help might you need to find a job? Do you think you will need help to apply for a job? What kind of help do you think you might need to learn and do the job? Do you think you will need help to keep the job?

Do you want to own your own business?

Work/Employment

If it is helpful, use the space below to draw or paste pictures that show what kind of job you want after graduation.



(example picture)

Home

Where will you live after you graduate from high school?

Will you live with your family? Friends? Or do you plan to live alone?

Do you want to live in town where you are close to stores and neighbors or do you want to live out in the country with more space?

What type of help might you need to live in the community?

Will you rent an apartment or a house? Own a house or condo?

Home

If it is helpful, use the space below to draw or paste pictures that show where you want to live after graduation.



(example picture)

Community

Make a list of places in the community that you might like to go and a list of things you would like to do in your community?

What would help you do more of these activities and get to these places?

How will you get around? Is there a bus system where you live? Will you drive, ride your bike, carpool with friends, or walk to where you want to go?

Where will you go for fun?

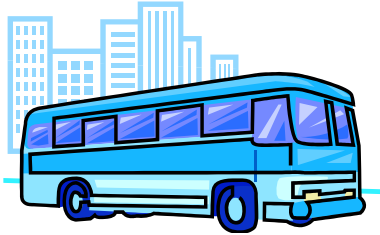
Will you want to go to grocery stores, go places just to have fun, eat out at restaurants, go to doctor's offices and banks?

Will you want to have a volunteer position or help out in your community?

Will you vote?

Community

If it is helpful, use the space below to draw or paste pictures that show what things you want to do in your community and how you will get to the places you want to go after graduation.



(example pictures)

Parent Survey to Prepare for IEP Conference

Junior or Senior High School Years

1. Please list the positive attributes (strengths) of your child.

2. Please list your child's interests. What does he/she enjoy doing or learning about?

3. Name the career interests your child has indicated:

4. List jobs your child does at home (on his/her own by request):

5. Looking ahead – list the things you would expect your child to be doing at school and at home in three years (for example: improved behavior, more integration into regular class activities, more responsible to complete jobs at home, etc.):

6. Do you have any concerns at this time? yes no

If yes, what are they? _____

7. What is your hope for your child?

Parent Survey to Prepare for IEP Conference (Continued)

8. What goals do you have for your son/daughter?

Short term: _____

Long term: _____

9. From the list below check what you think your child will do following graduation from high school with regard to education, employment, and living arrangements. (Check all that apply)

Education	Employment	Living Arrangements
<input type="checkbox"/> Two-year college	<input type="checkbox"/> Full-time	<input type="checkbox"/> With parent
<input type="checkbox"/> Four-year college	<input type="checkbox"/> Part-time	<input type="checkbox"/> With friend
<input type="checkbox"/> Trade/technical school	<input type="checkbox"/> Military	<input type="checkbox"/> Own house or apartment
<input type="checkbox"/> No additional education	<input type="checkbox"/> At home	<input type="checkbox"/> With relative
<input type="checkbox"/> Apprenticeship program		<input type="checkbox"/> Dormitory
<input type="checkbox"/> Other: _____ _____ _____		<input type="checkbox"/> Other: _____ _____ _____

Our goal is to help students learn to become effective citizens, informed consumers, lifelong learners, responsible family members, and productive workers.

10. Check **all** the skills below that you feel would help your son/daughter to reach these outcomes.

- Responsibility
- Self-control
- Flexibility
- Motivation
- Initiative
- Problem-solving
- Decision-making
- Collaboration
- Self-determination
- Sociability
- Creativity
- Communication

11. What else does the student need to reach these outcomes?
 Check **all** that apply.

- More instruction in the regular class setting
- More small group instructions in special education setting
- Participation in the work-experience program
- Take part in leisure & community activities
- Develop more friendships
- Receive extra help in other area(s):

 Other: _____

Student Survey to Prepare for IEP Conference

IEP Conference Date: _____

Student Name: _____

Date of Birth: _____

Will turn 18 on: _____

Persons Present at IEP Conference:

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____

Strengths:

Areas of Improvement:

Graduation Plans:

- Living arrangements:
- With parent
- With friend
- Own apartment or house
- With relative
- Dormitory
- Other (describe) _____

Career goals:

Do you want to go to college? yes no

If yes, where: _____

Are you currently employed? yes no

If yes, where? _____

Where would you like to work? _____

What are your learning strengths? How do you learn best? Check all that apply to you.

- By hearing information
- By seeing things
- By doing things hands-on
- By reading information

What are your Extra Curricular Activities?

Leisure time activities/interests/things you enjoy?

What do you like to do during summer?

What are your chores/responsibilities?

Need a transition plan (age 14 1/2)? yes no

Taken Computer Applications? yes no

Taken Driver's Education? yes no

Mediations (please list): _____

What classes/courses still need to be taken?

LIFE PLANNING

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Helping Children & Youth Make Career Plans

Parental Responsibility



Career decision making is a process, not a single event that occurs at a given time. Your child's future career will be influenced by events that occur in the preschool years and continue through adult life. Your child's career choices will certainly affect your future as well as your child's; thus, you have a right, as well as a responsibility, to be active in helping your child make career plans. What can you do at home and in your community to help your child?

In the Community:



- Visit offices, shops, factories, and other places of employment to help your child acquire a realistic view of a variety of jobs.
- Introduce your child to individuals with similar disabilities who are working/ participating in the community. Find out where you might meet some people, individually or in groups, by calling a resource agency. (See pages 57-60)
- Point out workers to your child when you go out in the community. Discuss what the worker is doing and encourage your child to think about what jobs he or she might like.
- Talk about the skills and education it may have taken for those individuals working in your child's fields of interest.
- Help your child explore hobbies and other leisure time activities that are productive and meaningful. Contact your local recreational center, i.e. YMCA, RPD, and Community Centers.

In Your Home:



- Encourage your child to ask and think about the question, "What will I be when I grow up?" Try to help your child think about alternate choices with the question, "If for some reason you couldn't do this, what other things would you want to do?"
- Teach decision making, self-advocacy and responsibility by giving your child choices about which movie to go to, where the family will eat out, or making small purchases at the grocery store.
- Plan with your child chores and jobs around the house (when and how they will be done), remembering that you might have to teach your child the necessary steps to complete the job. Then hold your child accountable with rewards (allowance) and consequences (lost privileges).
- Encourage an awareness of the value of money using allowances and savings accounts, and having your child shop with you.
- Encourage your child to engage in part-time or volunteer work - individually or with you. Help your child fill in applications and locate a job. It will help your child explore career interests and discover the sense of accomplishment and self-pride that can come from work.

Are You Accessing Your *Natural Supports*?

What is a *natural support*?

A natural support is something that you or your family can access for fun, for encouragement, or for assistance because it has already been established by natural relationships or typical routines. This support is available to you, regardless of any “disability” issue, just like it is available to others!

Natural supports are already there! They might not be especially “helpful” at this moment. They might not be especially “attractive” at this moment, but nevertheless, they are there for you just like they are there for other people in this world.

You WILL have to put more energy into their development than others do. You may have to be patient, persistent, and maybe even insistent on your right to access.

Natural support refers to the support and assistance that naturally flows from the associations and relationships typically developed in natural environments such as the family and community. These relationships and the support and assistance they offer, maintain and enhance the quality and security of life for people with disabilities.

WHY?

Using natural supports promote feelings of belonging and participation in LIFE! They draw on people’s natural inclination to care for others and form relationships that last. They do NOT contribute to artificial relationships, but rather people are together because they desire to be together. They have longer staying power!

Developing and using natural supports makes more sense for your long-term sanity! They are not dependent upon “funding” or “eligibility”. They do depend upon YOU though and your persistence to find them and make them fit into your life.

Think of the long-term benefits for your child to have the opportunity to participate and for you and your family to HAVE A LIFE!

If you see that you are not accessing many natural supports, check out these HINTS:

Don’t limit Your Options to Specialized Programs

Explore a variety of resources and programs in your community. Options need not be limited to specialized or segregated programs for individuals with disabilities. While participation in special programs is at times beneficial, regular programs offer a wider range of opportunities and are offered at more locations.

Move Toward Inclusion

If special programs are chosen, consider transitioning at some point into a program of similar nature where skills can be carried over. For example, participation in Special Olympics swim training can lead to taking a swim class at the local community center.

Tell others WHY this is Important for Your Child

Remind others that your child wants to participate in his community just like all of his friends and other children. Let them know how important this is for his self-confidence and self-esteem.

Resistance to Participation

Sometimes others don't understand why you would want to participate and will direct you to programs with special supports. You may have to spend more time explaining why it is so important to your child and family that you participate. As the question, "What will it take?" You may have to assist with "modifications", give suggestions, or even be willing to model assisting your child to participate.

Ask your support program to help you!

When you do access special support services (therapies, special education, etc.) ask for goals that will directly work toward community participation. If family and friends are not comfortable around your child, ask for your services to include them, so that more folks know about your child than just you! If you are not able to go out in your community, ask for your therapist to go with you and give suggestions for participation.

Fight the Isolation

Too many families become isolated when they have a child with a disability. It is a progression in our culture that you must FIGHT! You are not doing your child any favors to isolate him. While you may feel that it is a temporary solution due to overwhelming environments, you CANNOT make isolation be your long-term solution. That is no solution and will only create new problems.

Get Emotional Support

Find somebody (possibly another parent in a similar situation) that can give you moral and emotional support when you reach out and get bit! There is a lot to be said for talking to somebody that has been there or is experiencing similar feelings. It is natural to need emotional support when life throws you curve balls.

Think Long-term

What you do every day is your child's "program". LIFE is your program! Get out, get about, and get on with your life! Don't let today's problems keep you and your children from experiencing life and all it holds. Make sure you have developed a set of supporters that care about your child like you do, so that he will have lots of opportunities in the future.

Be Patient

None of this happens overnight. You will have setbacks. Some people will never understand, don't let them get you down. Keep your eye on the goal. Cut yourself a break now and then.



Natural Activities Worksheet

by Dee Blose

The following are ideas for opportunities to participate in natural activities within your community. Check ideas that appeal to you and your family, but that you are NOT currently accessing.

- Community centers
- Parks and recreation programs
- Churches, synagogues, and temples
- Private health and fitness clubs
- Gyms and aerobics programs
- T-Ball, baseball, basketball, football (playing or watching)
- Dance studios (gymnastics, ballet, tap, jazz, ballroom, cheerleading)
- Karate schools
- Bowling alleys
- Museums and zoos
- Libraries
- Community service organizations
- After-school and summer camp programs
- Local daycare or childcare
- YMCA
- Arts Center
- Pottery classes
- Arts Council
- Theater
- Gardeners group
- Bridge club
- Public park facilities
- Orchestra
- Senior centers
- Sports events
- Stables/Riding Academy/Trail rides
- Camping
- Fishing
- Playground
- Picnic
- Marina
- Putters golf
- Arcade (pool tables, video games, air hockey)
- Swimming
- Personal training
- Nutrition
- Tai Chi
- Kickboxing
- Line dancing
- Flower potting
- Jewelry making
- Walking trails
- Girl and Boy Scouts
- Birthday parties
- Hayride
- Community Development Corporation
- Cooperative Extension Service – 4-H
- Rotary club
- Community Fundraisers
- Other:

Also included in natural supports are “generic” agencies and supports, those that are offered to all who need assistance within a community. Some of these supports are medical services, educational services through the local school district, community service organizations, commercial businesses, non-profit agencies, and similar entities.

**What supports
will you need to
make it happen?**

Age of Majority:

Transfer of Rights to Your Eighteen Year Old Student with Special Needs



The age of majority is when your child obtains the rights of any Illinois citizen and is legally responsible for his or her own decisions, including educational decisions. **In Illinois, your child reaches the age of majority when he or she turns 18, gets married, or is incarcerated into the adult legal system.** Federal and state law requires school to transfer educational rights to students with Individualized Education Program (IEP) when they reach the age of majority.

Does this transfer of rights mean parents no longer have a voice in their child's educational planning? Not necessarily. It does, however, change the parental role. **That's why it is important to be informed!**

Your high school has information about this transfer of rights. At your child's first IEP meeting when he or she is 14 ½, ask the team about Age of Majority and Transfer of Rights. **It is never too soon to plan** for the time when your child with a disability will become an adult.

Some parents may want and need to obtain legal representation for their adult child. (Definitions for these are given on page 36) It is recommended that discussion about pursuing these legal procedures should take place before the child turns 18. Call your lawyer, or ARC of Winnebago, Boone & Ogle Counties for additional information.



Planning For The Future:

Who Makes Decisions When My Child Becomes an Adult?



Parents of children with intellectual/developmental disabilities have to prepare for their child becoming an adult *before* the child turns 18!

Questions families must consider are:

- Can my child take responsibility for their own personal safety?
- Can my child take responsibility for providing the necessities of food, clothing, and shelter, on their own?
- Can my child manage their money independently?
- Is my child's decision-making ability and judgment so impaired that being completely independent would be a threat to their welfare?

Parents should consider, **BEFORE** their child turns 18, visiting with a lawyer and/or a financial planner to help prepare the whole family for when the child with a disability becomes an adult and what supports that **ADULT** child will now need.

Two basic types of guardianship:

Guardianship of the Person: A “guardian of person” is appointed by the court when a disabled individual cannot make or communicate responsible decision regarding his personal care. This guardian will make decisions about medical treatment, residential placement, social services and other needs.

Guardianship of the Estate: The court appoints the “guardian of the estate” when a disabled person is unable to make or communicate responsible decisions regarding the management of his estate or finances. The guardian will, subject to court supervision, make decisions about the ward's funds and the safeguarding of the ward's income or other asset's.

The Illinois Probate Court gives the court the flexibility to tailor guardianship to meet the needs and capabilities of disabled persons. This includes:

Limited Guardian: Person granted the power to make only those decisions about personal care and/or personal finances that the court specifies.

Plenary Guardian: Person has power to make all decisions about the personal care and/or finances for the disable person.

Temporary Guardian: Person appointed by the court for the period between the filing of a petition for guardianship and the conclusion of the court hearing where the need for guardianship is decided.

Who can be a guardian?

- Any person 18 years of age and older who has not been convicted of a serious crime
- Any person who is of sound mind
- Must be a legal resident of the United States
- Public and private not-for-profit agencies are also eligible, however...
- Agencies providing residential services to disabled persons residing in their facilities can NOT serve as guardians



Initiating the Legal Guardianship Process



1. A petition must be filed in the court by an “interested person.”
2. A report must also be filed which includes a physician’s description of the person’s physical and mental capacity along with their relevant evaluations which would enable the Judge to determine the kind of guardianship needed.
3. The alleged disabled person, or Respondent, must be served with a summons and a copy of the petition.
4. Where appropriate, the court will appoint an attorney or lay person to serve as the “guardian ad litem”.
5. The guardian ad litem acts as the “eyes and ears of the court, and advocates for the best interest of the Respondent.
6. At the hearing, evidence about the Respondent’s health, mental faculties, finances, housing, and life style is presented. The court reviews all the information presented, and either enters limited or plenary guardianship order or finds that no guardianship is warranted.

What happens once guardianship is granted?

- An appointed guardian is responsible for overseeing a program intended to maximize the ward’s self-reliance and independence.
- A personal guardian may be required to submit an annual report to the court concerning the services provided to the ward and the status of the ward’s personal care.
- Estate guardians must file inventories of the ward’s assets and periodic accounting of estate receipts and disbursements. All estate expenditures are subject to court review, and the guardian may be held accountable for estate assets improperly managed.

What Costs are Associated with this Process?



- Fees for filing
- Sheriff fees for the service of the summons on the Respondent
- Attorney’s fees if applicable
- In some cases, the petitioner may pay fees for the services of the guardian ad litem or physician who prepares the medical report.

When to Consider Alternatives to Guardianship



Because guardianship can be a serious intrusion into a person's affairs, the law requires that alternatives to guardianship be explored. The law says that a guardianship is to be used only if it is necessary to achieve **all** of the following:

- Promoting the well-being of a person with a disability;
- Protecting against neglect, exploitation, or abuse; **and**
- Encouraging maximum development of self-reliance and independence

Also, guardianship is proper only to the extent required by the person's actual mental, physical and adaptive limitations. In other words, **a guardianship should be entered only if a person's needs cannot be met by some other means.** If they can be met by some other means, alternatives to guardianship should be considered.

What are the Alternatives to Guardianship?

There are several possible alternatives to obtaining a guardianship. Some may enable a person to assist in handling financial matters. Others may enable a person to assist in handling personal matters such as health care, living arrangements and other personal matters. The various alternatives are discussed below.

Guardianship Alternatives for Personal Decision-Making

I. Power of Attorney for Health Care

A Power of Attorney for Health Care (POA) is a written document in which someone names a person who is given the right to make health care and personal care decisions on his or her behalf. The person to whom this authority is given is called the "agent" or "attorney in fact". The person granting this authority is called the "principal". Despite the use of the word "attorney" in the title of the document, the person appointed as agent usually is not a lawyer. It is usually a spouse, a parent, or other close relative or friend.



A Power of Attorney can be used to grant the agent the authority to make any health care and personal care decision that is necessary. This may include the power to:

- Consent to medical treatment
- Refuse or withdraw medical treatment, even if doing so will result in death, if this is what the principal wants
- Give consent to admit the principal to (or discharge from) any hospital, institution, home, residential/nursing facility, treatment center or any other health care institution
- Contract for any type of health care service or facility
- Examine and copy the principal's medical records, and to consent to their disclosure

The agent can also make decisions such as where the principal will reside, and the types of non-medical services to be received by the principal. **Thus, a valid Power of Attorney for Health Care may eliminate the need for a guardianship of the person.**

Within the Power of Attorney document, the principal may designate the person who he or she would want to be appointed as his or her guardian in the event that a guardianship was to become necessary. However, in a guardianship proceeding, a judge is not absolutely required to appoint the person designated in the Power of Attorney document. Instead, the judge will select the person who the judge believes is best able to perform the duties of the guardian. In making this determination, the judge will certainly take into consideration the ward's wishes expressed in the Power of Attorney document.

When determining how to make a decision on behalf of the principal, **the agent is required to consider the best interests of the principal.** The agent should try to act in accordance with what he or she believes the principal's wishes would be under the circumstances. The agent does not have the right to perform actions which are contrary to the principal's express wishes.

An important consideration is whether the person with a disability has the "legal capacity" to execute a Power of Attorney. At a minimum, in order to validly execute a Power of Attorney, a person must:

- Understand the fact that he or she needs assistance in making decisions and handling his or her affairs
- Have a basic understanding of the principles involved in the Power of Attorney, i.e., that he or she is appointing an agent to make and carry out decisions and handle his or her affairs; **and**
- Be free from coercion or undue interference in deciding whether to execute the Power of Attorney.

Even a person with significant mental impairments may possess the legal capacity to execute a Power of Attorney. **However, in some cases, a Power of Attorney and a Guardianship are mutually exclusive options.** A person who lacks a basic understanding of the nature of the decisions that must be made, or who cannot make or communicate their wishes about whom they want to make those decisions, clearly lacks the capacity to execute a Power of Attorney. In questionable cases, it would be wise to consult with the physician of the person with a disability or other specialist to obtain a professional opinion concerning the capacity of the person with a disability.

Once a Power of Attorney is validly executed, it will remain in effect even if the principal later loses legal capacity. **A Power of Attorney will remain in effect until the date or event stated in the document.** Most often, the document states that it will remain in effect until the principal's death. However, a Power of Attorney can be revoked or amended by the principal at any time. The principal may do this by destroying the document, or by preparing a formal written revocation. A revocation can also occur if the principal tells the agent or to any other person relying on the Power of Attorney document of his or her intention to revoke it.

2. Health Care Surrogate Act



The Health Care Surrogate Act provides another means by which medical care decisions can be made without resort to legal process, i.e., without having to seek a guardianship. This law provides a legal means for family or friends of a person with a disability to make decisions concerning medical treatment. This can include decisions whether to withhold or withdraw life support. The Health Care Surrogate Act may be used only if the following conditions are met:

- The person lacks the ability to make and communicate an informed decision about his or her health care, as determined by the person's treating doctor; **and**
- The person does not have a valid Living Will, Health Care Power of Attorney, **or**
- Mental Health Treatment Preference Declaration in place or one is in place but it does not apply to the person's condition or it is invalid for some reason.

In addition to routine medical care decisions, the Health Care Surrogate Act also permits others to make the decision whether to withhold or withdraw life support. However, this may be done only if the patient is terminally ill, permanently unconscious, or has an incurable or irreversible severe medical condition which will ultimately result in death, as determined by two doctors.

If the person meets these conditions, the Health Care Surrogate Act authorizes the person's spouse, family, or close friends to make health care decisions on behalf of the person with a disability. The following order of priority is used in determining who will serve as the surrogate decision maker:

- The patient's legally appointed "guardian of the person"
- The patient's spouse
- Any adult son or daughter of the patient
- Either parent of the patient
- Any adult brother or sister of the patient
- Any grandchild of the patient
- A close friend of the patient
- The patient's legally appointed "guardian of the estate"

When there is more than one person at the same priority level, they are required to try to reach an agreement about the decision to be made. If they cannot reach an agreement, the doctor will honor the decision made by the majority of the persons in the priority level, unless the minority initiates a court case to resolve the issue.

In making decisions on behalf of the patient, the surrogate decision maker should try to do what the patient would have wanted done under the circumstances, taking into consideration the patient's personal, religious, and moral values. If this cannot be determined, the decision should simply be made in accordance with the patient's best interest.

Guardianship Alternatives for Financial Decision-Making

1. Power of Attorney for Property



A Power of Attorney for Property may eliminate the need for a guardianship of the estate. A Power of Attorney is a written document in which someone names a person who is given the right to make certain decisions on his or her behalf. The Power of Attorney for Property can be used to grant the agent the authority to make any financial or property decision that is necessary. This includes the authority to handle the principal's income and all other financial affairs.

The agent's powers can include the ability to:

- Make real estate or personal property transactions;
- Control all bank (or other financial institution) transactions or accounts;
- Buy and sell all types of stocks and securities;
- Open and control safe deposit boxes;
- Deal with any type of insurance or annuity policy or transaction;
- Contribute to or withdraw from any retirement plans;
- Handle all tax matters;
- Bring, defend or settle all claims and lawsuits;
- Conduct all business operations;
- Borrow money or mortgage property;
- Handle all legacies, bequests, or other estate transactions.

As stated above, the agent is required to act in the principal's best interests, and cannot take actions which are contrary to the principal's express wishes. As with the Power of Attorney for Health Care, a Power of Attorney for Property can be validly made only if the principal has a basic understanding of the nature of the decisions that must be made and can make and communicate his or her choice of agent.

2. Representative Payeeship

If a person with a developmental disability is entitled to certain types of public benefits, those funds may be paid to a third person, called a "representative payee". These types of benefits include Social Security, Supplemental Security Income (SSI), and pension benefits. The representative payee is legally bound to use the money for the benefit of the person with a disability. The payee may be required to file periodic reports with the government agency showing how the funds have been used. If the person with a disability has little or no income or assets other than the monthly public benefits, a representative payeeship may eliminate the need for a guardianship of the estate.



3. Trusts

A "trust" is a legal process by which money, property, or other assets are placed in the control of another, called a "trustee". The trustee is then required to manage the property in a responsible manner on behalf of the person(s) who is entitled to receive the benefit of the money. A trust established for the benefit of a person with a disability may be sufficient to ensure that his or her funds are adequately supervised. It is very important to consult with an attorney in deciding whether to establish a trust because a trust may affect the person's eligibility for Medicaid or other public benefits, and may involve significant expenses or tax liability.

4. Limited Guardianship

In many cases, a person with a disability may not need a guardian for all of his or her affairs. It may be that the person with a disability is able to personally handle some matters himself or herself. In other cases, it may be that some matters can be sufficiently addressed using one or more of the guardianship alternatives outlined above. In these cases, a “limited guardianship” may be appropriate. A limited guardianship grants a guardian the authority to handle only certain specified matters.

5. Living Will

A Living Will is a document by which a person indicates a choice not to receive life-sustaining treatment if he or she is terminally ill. It authorizes the person’s doctor to withhold or withdraw most forms of medical treatment in the event of a terminal condition. A Living Will may be made by any person of “sound mind”. This means that at the time the document is signed the person must have a basic understanding of meaning and effect of the Living Will. The Living Will remains in effect even if the person later lacks capacity to make decisions about his or her health care.

Estate Planning

The Will



Most parents find it difficult to even contemplate their death, and as a result, do not plan for the future. However, you must have a legal will drafted to ensure that your assets go to people you designate and to name a guardian for a minor or adult child with a disability who needs guardianship. If you die without a will, the state determines how your assets are distributed and the probate court determines who shall serve as a guardian of that child, even when there is one surviving parent. The probate court’s decision on a guardian may or may not be the same person you have chosen and your assets may not be distributed in the way you desired. You should contact a qualified attorney to assist you with will preparation.

Special Needs Trusts

Special needs trusts are used for advanced planning and are critical. Even though many people believe they are for rich people, the truth is that Trusts are for everybody.



A trust is nothing more than a written set of instructions for managing money and other belongings (assets). There are several types of trusts, but a Special Needs Trust is specifically designed to work for the benefit of a person with a disability. It provides a set of instructions for managing money set aside to help a disabled person.

The U.S. Congress has created a special Federal law permitting the use of Special Needs Trusts. Special Needs Trusts are valid throughout the country. Nobody can legally question the validity on a Special Needs Trust as long as it meets the requirements written into the law.

Special Needs Trusts are created for supplemental care (not the basic support) of the person with a disability. The Special Needs Trust must:

- Provide specific examples, unique to each person and their disability, of what is meant by "supplemental care"
- Be created and managed by a person other than the disabled Beneficiary.
- Be irrevocable -- once created and funded its instructions cannot be changed
- Contain specific instructions allowing a payback to Medicaid (under certain circumstances)

Special Needs Trusts allow an unlimited amount of money to be held for the benefit of a disabled person **without disqualifying him from benefits such as SSI and Medicaid! Failing to create a Special Needs Trust** means that any money given or left to the disabled person is counted as their asset, and **will disqualify the person from benefits.**



A Special Needs Trust means there is a pool of funds available for the needs of a disabled person. This pool of funds is not counted as an asset. This pool of funds can be added to at any time by anyone **and is tax deductible!** It can be funded by insurance or by a personal injury settlement, by family members, or by the Beneficiary himself (with certain limitations.)

The Trust can own a house or car, or other items which would otherwise disqualify a person from governmental benefits. The disabled beneficiary can enjoy a comfortable life **and still qualify for needed governmental benefits.**

The United States Congress has recognized that people with disabilities are entitled to Life, Liberty, and the Pursuit of Happiness, just as any other citizen. Although the rules about governmental benefits limit the amount of money a recipient may have (less than \$2000 a month), Special Needs Trusts were specially created by Congress to sidestep these rules and provide to people with disabilities an equal chance to enjoy the inalienable rights with which everyone is endowed.

Disbursements the Trust can make on behalf of beneficiary:



- Medical, dental or podiatry services not covered by government benefits
- Clothing, computer, or furniture
- Utilities and transportation
- Companion care and caregiver expenses not covered by government benefits
- Educational and vocational training
- Psychological therapy
- Hobbies or recreational activities

Is there anything the trust cannot pay for?

- Disbursements directly to the Beneficiary
- An account bearing the Beneficiary's name or Social Security number, including a patient trust fund at a nursing home
- Reimbursement of an individual who has given the Beneficiary cash or has deposited funds into an account bearing the Beneficiary's name
- A gift or donation to others

Additionally, disbursements for food or shelter may reduce the beneficiary's SSI benefit dollar-for-dollar up to 1/3 of the total benefit amount, so are generally discouraged.

Registration and Voting Q&A



Who can register to vote?

Any person who is a U.S. citizen, 18 years of age at the time of election, and a resident of the state for 30 days immediately prior to an election day.

When can a person register?

Registration is open year round at the office of election authority except during the 28 days preceding an election and during the 2 days after an election.

Where can a person register?

- Board of Elections (in some areas the County Clerk)
- Precinct committeemen
- Office of Municipal or Township Clerk
- Any deputy registrar duly appointed by the county clerk or board of elections (i.e. League of Women Voters)
- A person can register by mail, but will need to send in a copy of their photo ID.
- A person can also register to vote at the driver's license facility when obtaining a license or I.D. card

Does a person ever have to re-register?

Not unless a person:

- Changes address
- Changes name
- Fails to vote over a 4 year period

2 forms of identification, one showing your current address, are needed to register to vote. An individual can be assisted in the voting process by bringing someone of their choice with or two election officials (one Democrat, one Republican) will enter the booth with the individual.

A person can vote by absentee ballot for a variety of reasons. Some of the reasons are as follows:

- A registered voter expects to be absent from the county of residence on election day;
- A registered voter is unable to present at the poll because of a physical incapacity;
- A registered voter is observing a religious holiday and unable to be present at the polls because of the tenets of their religion.

(There are many other criteria allowing for absentee ballot voting. Please contact your local election authority for further information.)

An absentee ballot can be obtained:

- By mail - not more than 40 days nor less than 5 days prior to the election.
- In person -not more than 40 days nor less than 1 day prior to the election.

A registered voter can apply for a Disabled Voter's 5 year identification card that would mail absentee voter ballots automatically during that time frame by contacting the appropriate election authority for a form. The application may have to include a physician's affidavit.

***Please contact the appropriate election office in your community for clarification or questions regarding the above information.

Lobbying and Working with Your Legislators

- Learn the names of your State Representative and State Senator
- Address them as Representative or Senator
- Reintroduce yourself each time
- In all correspondence - letters, faxes, e-mail, telephones, etc. - always be concise and polite
- Make appointments - don't just drop in
- Ask where they would like their correspondence sent
- If time sensitive be sure to include the date and reason
- Don't threaten
- Don't use form letters
- Don't assume the Legislator knows all about the bill/issue
- If you want him/her to introduce legislation, begin discussing the issue with the Legislator in August
- Send group letters together -vs- mass mailing individual letters
- Correspond with Chair or Minority Spokesperson
- Develop a relationship with your Legislator



List of Legislators serving Our Region (2014)

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ADULT LIFE

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Questions to Ask

When Gathering Information about Adult Service Providers & Support



After graduation, a school district no longer has a legal responsibility to provide services. However, there are sources of help available in the community for people with intellectual/developmental disabilities. Please don't make the assumption, however, that your student will be eligible for certain programs. Instead, make plans to learn about the programs that seem to match your child's needs, visit them and learn how or if one becomes eligible for them. **Eligibility is the key to whether your child receives such services or not.** **Freshman year in high school is not too early to begin making these contacts.**

When looking for an agency or service provider to assist you, it is important to get answers to some key questions. **Shop around** and **ask questions** so that you select the services that will best accommodate your child's needs.

It is important to **talk with your child** to understand, the best you can, what s/he wants. Allow your child opportunities to self-advocate by stating his or her likes, dislikes, hopes, preferences in IEP meetings and meetings with agencies. **Self-determination is another key word to understand.** Make sure self-determination skills are included in the IEP so your child can work on them during his high school years.

The following page has suggested questions to get you started as you gather information from adult providers.



Questions to ask When Considering Service Providers



Selecting someone to provide adult supports and services to your family member is an important decision. Here are some suggested questions to guide you in your search and help you and your family make decisions about who will provide supports and services to your family member. In selecting a provider you should be comfortable with them and you should feel that your questions are welcome.

- What are the provider's mission, vision and core values?
- Is the provider certified, accredited or licensed and by whom?
- How does the agency make sure people are treated with respect?
- Can friends and family visit anytime? How much notice to they have to give before a visit?
- How does the agency actively assist people to make choices?
- Does the agency encourage and support people to be active with self-advocacy groups? How?
- How much say-so do people receiving services have in deciding and selecting the staff that work for them? How much say-so do they have in deciding where they live and with whom?
- Do people have keys to their own home or apartment?
- How does the agency provide for privacy for the person?
- How many people with developmental disabilities and family members are on the board of directors?
- How do you routinely report to families? How often?
- How does the agency handle a person's finances?
- How much experience does the provider have in working with individuals with intellectual/developmental disabilities?
- How does the agency help transition the individual from his own home to the new residential setting? The new day services setting? What do they do to smooth the process?
- What kind of training does the staff receive? How many staff are on duty in the home or day setting?
- What is the staff turnover rate?
- How does the staff deal with health emergencies and behavioral issues?
- How structured is the schedule? What does a typical day look like?
- What activities take place in the home? In the community? How often do activities take place? Is there interaction with other members of the community?
- How does the agency help people to learn to be part of their community?
- How will we be involved in planning for services? How involved will our family member be involved in planning for services? Can I talk with other families who you serve?
- How can families reach staff in an emergency after normal office hours?
- What are the policies regarding medication and its administration?
- How are services individualized to meet individual needs?
- How many people were discharged from the agency last year? Why were they discharged?
- How many people discharged moved to less supervised settings?
- How does the agency respond to life changes such as dating, marriage, complications of aging, medical issues, etc.?

Adapted from Service Coordination, The ARC of Frederick County, Inc.; Signs of Quality by People On The Go of Maryland; and the ARC of Maryland.

How to Access State Funded Supports and Services



A number of state agencies provide funding for supports and services for persons with intellectual/developmental disabilities. Eligibility requirements may vary by the state agency and types of supports and services provided. This information describes various supports and services funded by state agencies and how to access those supports and services.

Illinois Department of Human Services – Division of Developmental Disabilities (DHS- DDD)

DHS-DDD provides funding for a variety of supports and services to people with intellectual/developmental disabilities over the age of three. Those supports and services include:

- Adult Residential Services – Medicaid Waiver program
- Adult Residential Services – ICF/DD not a waiver program
- Children’s Residential Services – Medicaid Waiver program
- Adult Home Based Services – Medicaid Waiver program
- Children’s Home Based Services- Medicaid Waiver program
- Adult Day Services – Medicaid Waiver program
- In-home Respite, Residential Respite, Group Respite – Grant program

To access Medicaid Waiver supports and services funded by DHS-DDD, individuals must work with **Access Services of Northern Illinois** which is the designated Individual Service Coordination/Pre-Admission Screening agency for Winnebago County. Access Services of Northern Illinois can also assist in accessing respite programs which are grant funded.



In order obtain funding for Medicaid Waiver supports and services, an individual must be enrolled in Medicaid, have an intellectual/developmental disability or related condition, have a need for active treatment and be enrolled in the statewide waiting list called PUNS (Prioritization of Urgency of Need for Services). Access Services of Northern Illinois assists individuals and their families in the process to obtain funding for services.

Currently individuals seeking funding for Medicaid Waiver programs administered by the Division of Developmental Disabilities are randomly drawn from the PUNS database or are considered to have an emergency need for services (homeless, loss of a caregiver, or victim of abuse or neglect). Services for ICF/DD placement (facilities with generally 9 residents or more) are considered entitlements so funding is made available provided the individual meets functional eligibility requirements and is enrolled in Medicaid.

Illinois Department of Human Services – Division of Developmental Disabilities (DHS- DDD) (continued)



To begin the process of obtaining Medicaid Waiver services the individual or their guardian should **call Access Services of Northern Illinois at 815-282-8824 and ask for the Service Coordinator of the Day**. That person will ask for information such as date of birth, contact information, Medicaid number, Social Security number, diagnoses, prior services, etc. in order to complete an intake. Once an intake is completed and there is a reasonable belief that the person has an intellectual/developmental disability or related condition, a Service Coordinator will be assigned to assist the person. An appointment will be scheduled to meet with the person and interested parties to explain our services and to complete a PUNS. That Service Coordinator will be available to the person and their family as long as the person desires. The PUNS is updated annually until such time as the person has been selected for funding and receiving services.

If someone has been selected for funding for programs administered by the DD Division, the Service Coordinator will then complete eligibility determination, and if eligible, will assist the person in securing organizations that will provide them with services.

The PUNS should only be completed if someone is seeking services funded by the DD Division within five years and there is a reasonable belief that the person has an intellectual/developmental disability or related condition.

Illinois Department of Human Services – Division of Rehabilitation Services (DHS-DRS)



The Division of Rehabilitation Services provides funding for services for persons with disabilities, including individuals with intellectual/developmental disabilities provided they meet specific eligibility requirements for those programs. Those services/programs include:

- Vocational Rehabilitation – evaluation, guidance and counseling, obtaining and maintaining competitive employment, education, training, assistive technology, job development, job placement and post-employment services.
- Home Services – Services and supports to assist an individual with significant disabilities to remain in their home and live as independently as possible.
- Centers for Independent Living – agencies who provide services to assist individuals to live in the community. **RAMP is the local Center for Independent Living. Their phone number is 815-968-7467 (voice/TTY)**

To access services and programs offered by DHS-DRS, contact the local DRS office located at **107 N. Third Street, Rockford, IL 61107. Their phone number is 815-987-4964.**

Illinois Department of Human Services – Division of Mental Health (DHS-DMH)

The Division of Mental Health provides funding for a many services and programs for persons with mental health issues. The entry point for local mental health services is **Rosecrance Ware Center (adults) or the Rosecrance Berry Center (children and adolescents)**. Call (815) 391-1000 or visit www.rosecrance.org/mental-health/.

To learn more about services and programs administered by the Illinois Department of Human Services visit their website at www.dhs.il.us.

Public Benefits: Medicaid and Social Security

Medicaid



Medicaid is a partnership program offered by the federal government and the State of Illinois. In Illinois Medicaid provides comprehensive medical benefits to eligible residents and also pays for certain residential and day services for persons with developmental disabilities. In order to receive state funded residential and day services individuals must be enrolled with the Medicaid program. The Illinois Department of Healthcare and Family Services administers the Medicaid program in Illinois.

Children under 18 can receive health insurance and coverage for special services like speech or physical therapy through the All Kids program. Eligibility for All Kids requires that they reside in Illinois and meet established income limits. **You can learn more about the All Kids program or apply online at www.allkids.com or you can actually work with an All Kids application agent. To find an application agent near you can call 1-866-255-5437 or find them on line at www.allkids.com.**

Individuals over 18 may receive medical assistance provided they have an eligible disability and meet certain financial eligibility requirements. You can apply for Medicaid by going to your nearest **Illinois Department of Human Services (DHS) office located at 1111 N. Avon, Rockford, IL 61101, call 1-800-843-6154** or online at <https://abe.illinois.gov/abe/access/> or www.hfs.illinois.gov. In addition to medical assistance/services the Medicaid program will pay for certain residential and day services administered by the Illinois Department of Human Services – Division of Developmental Disabilities. To initiate the process of accessing state funded residential and day services, individuals will need to contact Access Services of Northern Illinois at 815-282-8824.

Social Security

People with disabilities may receive income benefits through the Social Security Administration (SSA). There are two disability income benefits programs available through SSA, Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). When applying for either SSI or SSDI you should have a copy of the person's Social Security card, birth certificate, records of income and assets (checkbooks, banks savings books, etc.), contact information for doctors and other health care providers, documents that may indicate the type of disability the person has (psychological assessment or IEP) and proof of U.S. citizenship.



Supplemental Security Income (SSI)

SSI makes monthly payments to people who have low income and few assets that are age 65 or older, or blind, or disabled. Children with disabilities may also be eligible to receive SSI. SSI is a needs-based program that considers one's income, assets, and level of impairment. **To apply for SSI for yourself or your child you can visit a local Social Security office, call 1-800-772-1213 or online at www.socialsecurity.gov.**

Social Security Disability Insurance (SSDI)

Adults with disabilities may receive SSDI monthly payments if the disability occurred before their 22nd birthday and at least one of their parents is receiving Social Security retirement or disability benefits, or if at least one parent has died and worked long enough under Social Security to have received benefits. **To apply for SSDI you can visit the local Social Security office, call 1-800-772-1213 or online at www.socialsecurity.gov.**

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Agencies and Services Directory

ADVOCACY PROGRAMS

The Arc of Winnebago, Boone and Ogle Counties

1222 E. State Street
Rockford, IL 61104
Phone: (815) 965-3455
Fax: (815) 965-3673 www.arcwbo.org

La Voz Latina

4990 E. State St
Rockford, IL 61108
(815) 968-9681 <https://www.ywcanwil.org/la-voz-latina/>

RAMP

202 Market St
Rockford, IL 61107
Phone/TTY: (815) 968-7467 <http://rampcil.org/>

ALTERNATIVE SERVICES

Illinois Association of Microboards and Cooperatives

104 Woodcreek Ct
Mahomet, IL 61853
(217) 778-5388 <http://www.iambc.org/>

ANIMAL ASSISTANCE

Bravehearts Therapeutic Riding & Educational Center

7319 Maxon Rd
Harvard, IL 60033
(815) 943-8226

AND

4950 Route 173
Poplar Grove, IL 61065
(815) 765-2113

www.braveheartsridding.org

Canine Companions for Independence

P.O. Box 446
Santa Rosa, CA 95402-0446
1-800-572-BARK
www.cci.org

AUTISM

The Autism Program – Easterseals

1601 Parkview Ave
Rockford, IL 61107
(815) 395-5566 <http://www.easterseals.com/chicago/our-programs/autism-asd-services/TAP-Rockford.html>

Barbara Olson Center of Hope

3206 N. Central Ave
Rockford, IL 61101
(815) 964-9275 www.b-olsoncenterofhope.org

The Arc

1222 E. State St.
Rockford, IL
(815) 965-3455 www.arcwbo.org

Autism Home Support Services

85 Revere Dr., Suite AA
Northbrook, IL 60062
(815) 790-1361 <http://autismhomesupport.com/>

Easterseals Family Support

650 N. Main St
Rockford, IL 61103
(815) 965-5069 <http://www.easterseals.com/chicago/our-programs/childrens-services/Family-Support.html>

Illinois Autism Partnership

1939 W. 13th Street
Chicago, IL 60608
312-491-4116
<http://www.easterseals.com/chicago/our-programs/autism-asd-services/illinois-autism-partnership.html>

CHILDREN'S ASSISTANCE

UIC – Specialized Care for Children

4302 N. Main St.
Room 106
Rockford, IL 61103
(815) 987-7571 www.dscc.uic.edu

DAY SCHOOLS

Easter Seals Academy

615 South 5th Street
Rockford, IL 61104
(815) 965-6745 <http://www.easterseals.com/chicago/our-programs/autism-asd-services/rockford-campus.html>

DAY SERVICES

Milestone

4060 McFarland Road
Rockford, Illinois 61111
(815) 639-2970 <http://www.milestone-inc.org/DayTraining.php>

Bridgeway

7200 Clinton Rd
Loves Park, IL 61111
(815) 962-8333 bway.org

New Horizons Belvidere Park District

1006 W. Lincoln Ave
Belvidere, Illinois 61008
815-547-5711 <http://belviderepark.org/nasr/programs-services/new-horizons/>

Barbara Olson Center Of Hope

3206 N. Central Ave
Rockford, Illinois 61101
815-964-9275 www.b-olsoncenterofhope.org

Malcolm Eaton

570 W. Lamm Rd
Freeport, Illinois 61032
815-235-7181 www.malcolmeaton.org

DENTAL CLINIC FOR PEOPLE WITH DISABILITIES

Milestone Dental Clinic

275 N. Phelps Ave
Rockford, Illinois 61108
(815) 484-8678 <http://www.milestone-inc.org/DentalInfo.php>

DEVELOPMENTAL TRAINING

Barbara Olson Center of Hope

3206 North Central Ave
Rockford, IL 61101
(815) 964-9275 www.b-olsoncenterofhope.org

Malcolm Eaton

570 W. Lamm Rd
Freeport, Illinois 61032
815-235-7181 www.malcolmeaton.org

Milestone

4060 McFarland Rd
Rockford, Illinois 61111
815654-6100 <http://www.milestone-inc-il.org/index.php>

DOWNS SYNDROME

GiGi's Playhouse

Down Syndrome Awareness Centers
8801 North 2nd St Ste 2
Machesney Park, IL 61115
(815) 654-7529 <http://gigisplayhouse.org>

DEPARTMENT OF HUMAN SERVICES (MEDICAID/FOODSTAMPS)

Family Community Resource Center (Winnebago and Boone Counties)

171 Executive Pkwy
Rockford, IL 61107
Phone: (815) 987-7620
TTY: (866) 322-2681

Family and Community Resource Center (Ogle County)

106 North 2nd St
Oregon, IL 61061
Phone: (815) 732-2166
TTY: (866) 323-4144

EARLY INTERVENTION

Child and Family Connections

1752 Windsor Road Ste 102
Loves Park, IL 61111
Phone: (815) 654-6170
Toll Free: (800) 921-0094
<http://www.accessni.com/programs/child-and-family-connections>

HEARING AND VISION

Center for Sight and Hearing

8038 MacIntosh Ln
Rockford, IL 61107
(815) 332-6800 www.centerforsighthearing.org

DHS Division of Rehabilitative Services Bureau of Blind Services

(815) 967-3723 <http://www.dhs.state.il.us>

HOME BASED SERVICES

DHS Division of Rehabilitative Services – Home Services

171 Executive Pkwy
Suite 103
Rockford, IL 61107
(815) 967-3725 <http://www.dhs.state.il.us>

Access Services of Northern Illinois

7399 Forest Hills Rd
Loves Park, IL 61111 (815) 282-8824
<http://www.accessni.com/>

HIGHER EDUCATION (POST-SECONDARY)

Rock Valley College

3301 N Mulford Rd
Rockford, IL 61114
(815) 921-2371 www.rockvalleycollege.edu/disabilityservices

For more information visit:
www.thinkcollege.net and
www.thinkcollegeillinois.org

Rockford Career College

1130 S. Alpine Rd
Rockford, IL 61108
(815) 965-8616 www.rockfordcareercollege.edu/

Rockford University

5050 E State St
Rockford, Illinois 61108
815-226-4000 <http://www.rockford.edu/>

INDEPENDENT LIVING SKILLS TRAINING

RAMP

202 Market St
Rockford, IL 61107
Phone/TTY: (815) 968-7467 <http://rampcil.org/>

JOB ASSISTANCE

Illinois Department of Human Services (Division of Rehabilitative Services)

171 Executive Pkwy
Suite 103
Rockford, IL 61107
(815) 967-3725 <https://www.dhs.state.il.us>

Bridgeway

7200 Clinton Rd
Loves Park, IL 61111
(815) 962-8333
www.bway.org

Goodwill Industries of Northern Illinois

850 N Church St
Rockford, IL 61103
(815) 965-3795 www.goodwillni.org

RAMP

202 Market St
Rockford, IL 61107
Phone/TTY: (815) 968-7467 <http://rampcil.org/>

Goodwill Industries of Northern Illinois

850 N Church St
Rockford, IL 61103
(815) 965-3795 www.goodwillni.org

LEGAL SERVICES

Prairie State Legal Services

303 North Main St, Suite 600
Rockford, IL 61101
(815) 965-2902 <https://www.pslegal.org/>

The Arc

1222 E. State St.
Rockford, IL
(815) 965-3455 www.arcwbo.org

MENTAL HEALTH

Rosecrance Ware Center

2704 N Main St
Rockford, IL 61103
(815) 391-1000 <http://www.rosecrance.org/mental-health/>

Stepping Stones

706 N. Main St
Rockford, IL 61103
(815) 963-0683 <http://ssrinc.org/>

NAMI

815-963-2470 <https://naminorthernillinois.org/history/>

INDEPENDENT SERVICE COORDINATION

Access Services of Northern Illinois

7399 Forest Hills Rd
Loves Park, IL 61111 (815) 282-8824 <http://www.accessni.com/>

PEER SUPPORT

RAMP

202 Market St
Rockford, IL 61107
Phone/TTY: (815) 968-7467 <http://rampcil.org/>

RECREATIONAL SERVICES

Rockford Park District – Therapeutic Recreation

401 S. Main St
Rockford, IL 61101
(815) 987-8800 www.rockfordparkdistrict.org/TR

BraveHearts

7319 Maxon Rd
Harvard, IL 60033
(815) 943-8426 www.braveheartsridding.org

NASR

1006 W. Lincoln Ave
Belvidere, Illinois 61008
815-547-5711 <http://belviderepark.org/nasr/>

Catch the Wave

1917 Blackhawk Blvd.
South Beloit, IL 61080
(815) 713-4481 www.catchthewaveswim.com

YMCA

200 Y Blvd
Rockford, IL 61107
(815) 489-1252 www.ymca.org

REFERRAL SERVICE FOR INDIVIDUALS WITH DISABILITIES

Illinois Life Span

c/o The Arc of Illinois
18207-A Dixie Highway
Homewood, IL 60430
800-588-7002 www.illinoislifespans.org

RAMP

202 Market St
Rockford, IL 61107
Phone/TTY: (815) 968-7467 <http://rampcil.org/>

RESIDENTIAL SERVICE PROVIDERS

Goldie B. Floberg Center

58 W. Rockton Rd
Rockton, IL 61072
(815) 624-8431 <http://www.goldiefloberg.org/>

DD Homes

235 N West St
Jacksonville, IL 62650
866-363-7909 <https://ddhomes.net/index.htm>

Mosaic

1111 S. Alpine Rd.,
Ste 401
Rockford, IL 61103-2116
Phone: (815) 387-8390
Fax: (815) 387-9055 www.mosaicinfo.org/rockford

Milestone

4060 McFarland Road
Rockford, Illinois 61111
(815) 639-2970 <http://www.milestone-inc.org>

Roc Vale Children's Home

4450 N. Rockton Ave
Rockford, IL 61103
(815) 654-3050 <http://www.milestone-inc-il.org/Residential.php>

Stepping Stones

706 N. Main St
Rockford, IL 61103
(815) 963-0683 <http://ssrinc.org/>

Walter Lawson Childrens Home

1820 Walter Lawson Dr
Loves Park, Illinois 61111
815-633-6636 <http://www.wlch.org/>

SOCIAL SECURITY

Social Security Office

502 E. Jefferson St
Rockford, IL 61107
(877) 628-6570 www.socialsecurity.gov

TRANSPORTATION SERVICES

Rockford Mass Transit District (Para transit)

520 Mulberry
Rockford, IL 611
(815) 961-9000 <http://www.rmtd.org/>

Stateline Mass Transit

110 E. Main St
Rockton, Illinois 61072
815-624-7788 <http://www.smtd.biz/how-it-works>

Links to Regulations, Legal Issues, and More

The following are links to sources of regulations, legal issues and other useful information and resources.

A Guide to Disability Rights Laws

U.S. Department of Justice, Civil Rights Division, Disability Rights Section. www.ada.gov/cguide.htm.

ADA

Americans with Disabilities Act. www.ada.gov

Fact Sheet - Your Rights under Section 504 of the Rehabilitation Act.

www.hhs.gov/ocr/civilrights/resources.factsheets/504.pdf

Illinois Department of Human Services

www.dhs.state.il.

Illinois Department of Healthcare and Family Services

Medicaid and other assistance programs. www.hfs.illinois.gov.

Health and Disability Advocates Resource Library

<http://hdadvocates.org/library/index.asp>.

U.S. Department of Health & Human Services (HHS), Centers for Medicare & Medicaid Services (CMS)

Medicare and Medicaid programs. www.cms.hhs.gov.

Wrights Law

Educational Rights information. www.wrightslaw.com.

ARC of Illinois

www.thearcofil.org

Disability is Natural

Kathie Snow's website on community living. www.disabilityisnatural.com

Equip for Equality

Illinois' statewide protective advocacy organization. www.equipforequality.org

Family Support Network

Advocacy organization for families in Illinois. www.familysupportnetwork.org

Illinois Legal Aid Online

Online information on legal issues affecting people with disabilities. www.illinoislegalaids.org

Social Security

Information on Social Security benefits. www.ssa.gov

Quality Mall

Information on person centered supports for persons with disabilities. www.qualitymall.org

Illinois Assistive Technology Project

Information on technology to assist people with disabilities. www.iltech.org



Online Transition Resources

Planning for Life after High School: A Guide for Students, School Counselors, Teachers, Parents (2003)

This handbook, developed by the Wisconsin Department of Public Instruction, is a resource for students, parents, and teachers on preparing and planning for the postsecondary experience. It includes checklists and information on what to expect and how to prepare and plan for postsecondary education. This publication is available in PDF (20 pages) at: <http://www.dpi.state.wi.us/dpi/dlsea/een/pdf/tranopndrs.pdf>



Parent/Professional Collaboration Topic on NCSET's Website

This topic explores how teachers, families, and schools can collaborate to help families become and stay involved in helping their children to succeed in school and make the transition to jobs or postsecondary education. Interested?

Go to: <http://ncset.org/topics/family/?topic=29>

Making a Difference:

Thinking about Decision-Making Support in the Transition Process

http://wcdd.org/Publications/pub_all_details.cfm?pubID=40

(scroll down to “WCDD Publication,” click on “Subject,” and then on “Guardianship”)

In this 18-page paper, the author talks to parents of children with developmental disabilities about what they need to consider about guardianship as their children transition to adulthood. The paper explores guardianship decisions from the perspective of self-determination principles. It describes an approach that results in decision-making support tailored to the individual’s capacities and needs. This paper is free, and available from the Wisconsin Council on Developmental Disabilities.

Oregon Department of Education Transition Resources: Family Role in Transition

http://www.hsd.k12.or.us/schools/specprograms/discover_idea-edv5/OSE/Transition/

Visit the Oregon Department of Education’s web page to access a number of transition resources that address person centered planning, self-determination, and student and family roles in transition.



DisabilityInfo.gov

www.disabilityinfo.gov/

Provides information on employment, education, housing, transportation, health, income support (“entitlement programs”), assistive technology, community life (includes accessibility, disaster preparedness, recreation & travel, disability culture, and centers for independent living), and civil rights.

Online Transition Resources (continued)



Center for Effective Collaboration & Practice: Help with Behavioral Problems

The Center for Effective Collaboration & Practice (CECP) has published a series of short information briefs on research-based intervention practices and programs for children with behavioral problems. Written for use by families, these briefs translate research on effective intervention practices into a format that is easy to understand and useful for family members and practitioners. While they may not relate specifically to transition, there are good strategies for use in the home that will surely have ripple effects in preparation for adulthood. Briefs on a variety of topics are available on the CECP site at: <http://cecp.air.org/familybriefs>

Post-ITT (Postsecondary-Innovative Transition Technologies Project)

www.postitt.org/text/index.htm

A collection of resources and activities established to aid students, parents, educators and Disability Services coordinators in the task of planning for a student's transition from secondary to postsecondary education.

Family Village Project

www.familyvillage.wisc.edu/sp/trans.html

This source lists a wealth of internet websites on transition information organized under such topic headings as General Information, Employment, The IEP Process, Independent Living, Career Interest Inventories, Health, Legal Information, etc.

Job Accommodation Network (JAN)

Provides information and technical assistance on accommodating employees with disabilities. 1-800-526-7234 (voice/TTY) www.jan.wvu.edu

American Association of People with Disabilities (AAPD)

www.aapd-dc.org/

www.aapd-dc.org/JFA/JFAabout.html

Provides membership benefits, mentoring & leadership opportunities, and systemic advocacy. AAPD also sponsors the Justice For All E-mail Network (JFA) – a free e-mail listserv for awareness of national advocacy efforts.

Glossary – Abbreviations

You Should Know



AAIDD – American Association on Intellectual and Developmental Disabilities

ADL- Activities of Daily Living

AMI - Alliance for Mentally Ill

ARC – Association for Retarded Citizens

AT – Active Treatment

CFC – Child and Family Connections

CILA – Community Integrated Living Arrangement

CLA – Community Living Arrangement

CLF – Community Living Facility

CMHC –Community Mental Health Center

CMI – Chronically Mentally Ill

CON- Certificate of Need

DHS – Department of Human Services

DOA – Illinois Department on Aging

DON – Determination of Need

DSCC – University of Illinois – Division of Specialized Care for Children

DCFS- Illinois Department of Children and Family Services

DT –Developmental Training

DT- Developmental Therapy (Early Intervention)

EI – Early Intervention

EPSDT – Early and Periodic Screening, Diagnosis, and Treatment

FAP – Family Assistance Program

FAPE – Free Appropriate Public Education

FOIA – Freedom of Information Act

GAC – Illinois Guardianship and Advocacy Commission

HBSS – Home Based Support Services

HCBS – Home and Community Based Services (Federal)

HFS – Illinois Department of Healthcare and Family Services

HHS – Health and Human Services (Federal)

HRA – Illinois Human Rights Authority

IACBHA – Illinois Association of Community Behavioral Health Agencies

IAISCA – Illinois Association of Independent Service Coordination Agencies

IARF – Illinois Association of Rehabilitation Facilities

IATP -Illinois Assistive Technology Project

ICAP –Inventory for Client and Agency Planning

ICF – Intermediate Care Facility

ICF/DD – ICF for People with Developmental Disability

ICF/MR – ICF for People with Mental Retardation

IDEA – Individuals with Disabilities Education Act

IDT – Interdisciplinary Team

IEP – Individual Education Plan

IFSP – Individualized Family Service Plan

IHDA – Illinois Housing Development Authority

IPP – Individual Program Plan

ISBE – Illinois State Board of Education

ISC – Individual Service Coordination

ISP – Individual Service Plan

ITP – Individual Treatment Plan

MH – Mental Health

MI – Mental Illness

MI/DD- Mental Illness and Developmental Disability

MI/MR -Mental Illness and Mental Retardation

MI/SA- Mental Illness and Substance Abuse

NAMI – National Alliance for Mentally Ill

NF – Nursing Facility (Nursing Home)

NIA – National Institute on Aging

NIMH – National Institute on Mental Health

OAG- Office of Auditor General (State)

OASA – Office of Alcoholism and Substance Abuse

ODD – Office of Developmental Disabilities

OIG – Office of Inspector General

OMH- Office of Mental Health

OSG – Office of State Guardian

OT – Occupational Therapy

P&A – Protection and Advocacy

PAS – Press Admission Screening

PDD – Persuasive Developmental Disorder

POS – Purchase of Service

PT -physical therapy

QA -quality assurance

QE -Quality enhancement

QHMP -Qualified Mental Health Professional

QMRP – Qualified Mental Retardation Professional

RSD – Residential Services Director

SASS -Screening, Assessment and Support Services

SEP -Supported Employment Program

SIB- Scale of Independent Behavior

SLA -Supported Living Arrangement

SLC -Specialized Living Center

SLOF -Specific Level of Functioning

SNF- Skilled Nursing Facility

SS – Specialized Services

SSA – Social Security Administration

SSDI- Social Security Disability Insurance (Federal)

SSI -Supplemental Security Income

STARNET -Support and Technical Assistance Regional Network

TANF -Temporary Assistance to Needy Families

TASH- The Association for the Severely Handicapped

TBI- Traumatic Brain Injury

TDD or TTY – Telecommunication Device for the Deaf

VR -Vocational Rehabilitation Services

WAIS – Wechsler Adult Intelligence Scale (psych eval.)

Glossary – Words You Should Know

ADA: Americans with Disabilities Act (Federal) Prohibits discrimination against people with disabilities

Assistive Technology Device: any item, piece of equipment, or product system that is used to increase, maintain, or improve the functional capabilities of a person with a disability.

Attendant Care: Services provided to individual with a physical disability that cannot perform daily living tasks themselves.

Autism: A developmental disability significantly affecting verbal and nonverbal communications and social interaction that adversely affect a child’s educational performance. (Generally evident before age 3). Characteristics: repetitive activities, stereotyped movements, resistance to environmental change or change in daily routines, unusual responses to sensory experiences.

CCD (Consortium of Citizens with Disabilities): Brings together all the major disability advocacy organizations in the U.S to influence legislation and administrative policy at the federal level.

CP (Cerebral Palsy): Umbrella like term used to describe a group of chronic disorders impairing control of movement that appear in the first few years of life and generally do not worsen in time.

DD (Developmental Disability): Severe, chronic disability of an individual that is attributable to a mental or physical impairment; manifested before the age of 22; is likely to continue indefinitely, results in substantial functional limitations in three or more areas of major life activity.

Family Support: Services provided to help families keep a family member with a disability at home.

Future Planning: To plan for the services/supports, financial and/or legal aspects for someone with mental retardation.

Job Coach: In supported employment, the job coach provides one-on-one training to an individual on the job until that individual is able to complete tasks to the employer’s satisfaction.

LD (Learning Disability): Specific Learning disability means a disorder in one or more of the basic psychological processes involved in understanding or in using language.



LRE (Least Restrictive Environment): One of the principals or normalization. It requires that people with disabilities receive services and supports in environments that do not limit their life activities unnecessarily.

MR (Mental Retardation): A Significantly sub-average general intellectual functions (IQ 70-75 or below), existing concurrently with deficits in adaptive behavior during the developmental period (18 years or less).

PWS (Prader Willi Syndrome): Complex genetic disorder that includes short stature, mental retardation or learning disabilities, incomplete sexual development, characteristic behavior problems, low muscle tone, an involuntary urge to eat constantly.

Provider: Person or agency who delivers services/supports to people with disabilities.

Respite Care: Temporary care of a person with a disability to give the regular caregiver a chance to take a vacation, cop with emergencies and get some rest from the demands of constant special care giving.

Self-advocate: Self-advocacy means that individually or in groups, people with mental retardation speak on behalf of themselves or others on behalf of issues that affect people with disabilities.

Service coordination: Service families may choose to use when they need help in obtaining needed supports for their family member.

Sheltered Workshop: Term that describes the form of day habilitation service for people with disabilities.

Supported employment: Paid employment in a community setting for persons with severe disabilities who need ongoing support to perform their work.

Waiver: Reference to the Home and Community Based Waiver program where a state can use Medicaid funds to assist and keep people with disabilities in the community.

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Why Use a Transition Resource Guide?

Successful transition to adulthood

for students with developmental disabilities takes families, educators, and students **working together**.

This Transition Resource Guide was created to help youth with developmental disabilities and their families **take the lead in planning for their adult lives**.

It is never too early to start planning for adulthood!



IEP (Individualized Education Program)



Life Planning



Adult Life



Resources