

Assisting families and professionals in transitioning students with developmental disabilities to the world of adult services.

Acknowledgement

A project of this measure has one main objective; to assist students and families of students with developmental disabilities through the often intimidating process of transitioning out of high school and into the world of adult services. Life is challenging enough and facing the unknown is a fear we all have in the back of our minds. Well all need a helping hand at times in our lives, particularly as we approach crossroads.

Now your student is ready to leave to school. What's next? Suddenly you are traveling down a winding road faced with deadlines and paths of direction requiring many decisions to be made. You need to know what your options are. There is no reason anyone should have to take this road blindly.

Building Bridges to the Future was seeded by a call for help. Intersect for Ability, a newly formed network comprised of ten human service agencies heard that call and through the network along with financial support of the Coleman Foundation we have hit the ground running to form a committee of dedicated, passionate professionals and masters of their field. It is from this collaborative effort that we are able to bring the concept of Building Bridges to the Future into fruition. This program is not only providing our families a map to navigate, but taking a hands on, face to face approach to being your liaison and friend as we take your hand and lead you through your family's period of transition.

Introduction

The "Nuts and Bolts"

Clearbrook, Elim Christian Services, Helping Hand Center, PACTT Learning Center, Park Lawn Services and Seguin Services have come together to form an innovative and exciting program for students with Developmental Disabilities called

"Building Bridges to the Future"

Together, our agencies are able to reach students and families who live in all four cardinal points of the greater Chicagoland area. From the North to the South, East and West we are here for you!

This program supports and coaches families of special needs students. Our goal is to help in the transition process from the school system to adult services. We understand how challenging it is to leave school and learn to navigate the system of adult services. Our program assists with entry into the adult Developmental Disabilities programs, obtaining financial and medical benefits and provides assistance with linkages to legal resources. We are here to make things less intimidating while guiding you through the important steps of the timeline during the process of your transition.

Table of Contents

5 – 26	The Timeline
9 – 20	PUNS
28 – 31	PAS Agencies
32 – 36	Day Services
39 – 41	Rehabilitation Services
42 – 50	Residential Services
53 – 58	Transportation Services
61 – 67	Recreational Programs
70 – 85	Financial Assistance
88 – 92	Legal
95	Definitions and Abbreviations

Finding your way down the road of transition...



...A Step By Step Walk Through the Timeline of Your Family's Transition

- Elementary School Age
- Middle School Age
- PUNS
- 14 years old
- 15 years old

- 16 years old
- 17 years old
- 18 years old
- -19 through 22 years old

The Timeline

A Journey of Exploration, Growth and Education

The transition into adult services is a process with critical steps that need to be taken throughout your child's life to ensure eligibility and help open doors for your family. The following section has suggestions and resources broken down by categories of ages to consider these steps. Each featured stop down the road of transition will be accompanied by examples of things we are suggesting, and will direct you to the place in the manual where you may find more resources.

Take your time exploring these steps and revisit them often! The timeline is a grid; put in place to support the structure of your family's plan. Do not hesitate to call the agencies/organizations listed through out this handbook with questions you may have along the way, it's why they are here. We have also provided pages for you to take notes along the way to help keep important reminders and information as you read each section; all intended as a means for you to keep your information organized and at your fingertips each time you open the manual.

Elementary School Age

- Introduce the concept of work into everyday activities.
- Students become familiar with all types of careers.
- Develop self-care and daily living skills and routines.
- Focus on human relationships and good social skills at home and school.
- Explore vocational opportunities at the upper grade levels
- -Make your child a productive part of the household, introduce chores and allowance.
- Explore self-advocacy information and community advocacy organizations that are available. You will undoubtedly need some additional support at some point in time.
- Ensure that accessibility issues or adaptive equipment (i.e. communication, wheelchairs) needs are being addressed.
- Request information on Public Law 105-17, the Individuals with Disabilities Education Act (IDEA) of 1997 and the 1999 regulation updates. These are good resources.

Middle School Age

- Begin Career Exploration, watch movies, read books, go to work with adults
- Support teachers efforts to provide job training as part of the school program.
- Find out the types of education program options such as inclusion, vocational, combination etc.
- At home explore careers by chores around the house, volunteering in the community and participating in community services projects.

PUNS Priority Utilization of Needed Services

The State of Illinois has developed a database of unmet service needs. This is PUNS. PUNS is an acronym for Priority Utilization of Needed Services. The PUNS database is a listing of individuals with developmental disabilities and their service needs. The state would like to have all individuals with a need for services added to this database. This PUNS database will help the state with planning for the needs of individuals with developmental disabilities through requesting the appropriate funding necessary to provide these services.

It's important that you complete the PUNS questionnaire. This must be completed before any adult services can be offered to individuals with a Developmental Disability, including Full Scale IQ below 70, Cerebral Palsy and Autism. This can seem very overwhelming, but you are not alone. Your PAS agency will assist you with this.

For more information on PUNS, visit the Illinois Department of Human Services (DHS) website at **www.dhs.state.il.us**

To apply, you should go through your PAS agency. The following is an example of the PUNS questionnaire.

Illinois PUNS Illinois Prioritization of Urgency of Need for Services

	INDIVIDUAL DATA
Date Form Completed and	d Signed By All Parties (e.g., 9/09/2002)://
Name: First:	Middle Initial: Last:
Social Security Number:	
New Change of category Change of service n	lose PUNS
All info	rmation in this form is confidential. Please note that
	on in the database does not assume eligibility for services
or guar	antee the receipt of services.
Service Coordinator:	(Please Print Legibly)
_	(Signature)
Name of Agency:	Phone No
*Individual:	(Please Print Legibly)
	(Signature) Phone No
*Guardian:	(Please Print Legibly)
	(Signature) Phone No
Other:	(Please Print Legibly)
	(Signature) Phone No
Primary care giver, if appl	icable (not applicable if in residential placement)
Name:	Date of Birth (e.g., 07/04/1959)
Address:	City: State: Zip:
If there is a secondary car	re giver, list date of birth (e.g., 07/14/1959):
If person is in school or h the past 5 years, enter da	as graduated in te of graduation (e.g., 06/2001)
*Guardian must sign. I	f no guardian is appointed, individual must sign. (Both may sign).

DHS Community Reporting System CLIENT CASE REGISTRATION INFORMATION

Agency Name:	Agency F	EIN:	
Staff completing this form:	Date con	npleted:	Time:
Staff entering data from this form:	Date con	npleted:	Time:
**** CLIENT DEMO	GRAPHIC INFORMA	TION ****	
CLIENT ID:			te Code:
First Name: MI:			
Mother's Maiden Last Name:	SSN:		
Birth Date: / /	Sex:	Male / Female	
Race: White	Black/African Ameri	ican	Asian
American Indian/Alaskan Native	Native Hawaiian or	Other Pacific Island	er Unknown
Recipient ID (RIN):	State Operated F	Facility ID:	
Primary Language:			
Hispanic Origin: Area of	Residence - County:	Tw	p/CA:
Medicaid Site ID:	DHS Case ID:		
Client Address - Street:			
City:		ode:	
	Status:		
SSI/SSDI Eligibility: DFI/CFI Er			Citizenship:
Military Status: Court/Forensic Treatr		preter Services I	Needed:
Optional Data A:	B:	C:	
1 Guardian Type: MI:			
City:			
Date of Appointment as Guar	dian://		
2 Guardian Type:			
First Name: MI:	Last Name:		
Address:			
	ST: Z	W	

DHS Community Reporting System CLIENT DEVELOPMENTAL DISABILITIES (DD) INFORMATION

	Agency Name:			_FEIN:	
	Staff completing this form:				
	Staff entering data from this fo	orm:		Date completed:	Time:
_		GISTRATION		ON ****	
	Registration Date:/			viduals in Setting:	
	Residential Arrangement:			rioddis iii Sctorigi	_
	Area of Origin - County:		Zip Co	ode:	
	_	CLINICAL IN			
	Diagnosis Type:			Principal Diagnosis	::
	A. Axis I #1:	B. Axis I	#2:	C. Axis I	#3:
	D. Axis II #1: E.	Axis II #2:		F. Axis II #3:	
	Axis III #1:				
	Age at Onset:			_	
	ICAP/SIB - Service Score:	Behavioral S	Score:	Score Type	:
	Mobility:	CLOSING IN	ODMATION	****	
	Closing Date://_			viduals in Setting:	
	Disposition:			idential Arrangement:	

(Specify:_

For the following items indicate the reason for need by checking all that apply.

	ne	rgency Need (Person needs in-nome or day supports immediately)
_	1.	Individual needs immediate support to stay in their own home/family home (short term – 90 days or less); e.g., hospitalization of care giver or temporary illness of an individual living in their own home.
_	2.	Individual needs immediate support to stay in their own home/family home or maintain their employment situation (long term); e.g., the person can no longer live alone due to health or behavioral issues; or the person's health or behavior has deteriorated significantly, and the family needs immediate enhanced supports.
_	3.	Care giver needs immediate support to keep their family member at home (short term – 90 days or less); e.g., family member recuperating from illness and needs short term enhanced supports.
—	4.	Care giver needs immediate support to keep their family member at home (long term); e.g., care giver is permanently disabled or is terminally ill and needs long term enhanced supports immediately to keep their family member at home.
Er	ne	rgency Need (Person needs out-of-home supports immediately)
_	1.	Care giver is unable or unwilling to continue providing care (e.g., person has been abandoned).
_	2.	Death of the care giver with no other supports available.
_	3.	Person has been committed by the court or is at risk of incarceration.
_	4.	Person is living in a setting where there is suspicion of abuse or neglect.
_	5.	Person is in an exceedingly expensive or inappropriate placement and immediately needs a new place to live (for example, an acute care hospital, a mental health placement, a homeless shelter, etc.).
	6	Other crisis

Critical Need (Person needs support within one year)

—	1.	Individual or care giver will need support within the next year in order for the individual to continue living in their current situation.
_	2.	Person has a care giver (age 60+) and will need supports within the next year.
_	3.	Person has an ill care giver who will be unable to continue providing care within the next year.
_	4.	Person has behavior(s) that warrant additional supports to live in their own home or family home.
_	5.	Individual personal care needs cannot be met by current care givers or the person's health has deteriorated.
_	6.	There has been a death or other family crisis, requiring additional supports.
_	7.	Person has a care giver who would be unable to work if services are not provided.
	8.	Person or care giver need an alternative living arrangement.
_	9.	Person has graduated or left school in the past 10 years, or will be graduating in the next 3 years.
_	10	Person is living in an inappropriate place, awaiting a proper place (can manage for the short term; e.g., persons aging out of children's residential services).
_	11	Person moved from another state where they were receiving residential, day and/or in-home supports.
_	12	The state has plans to assist the person in moving within the next year (from a state-operated or private Intermediate Care Facility for People with Developmental Disabilities, nursing home or state hospital).
_	13	Person is losing eligibility for Department of Children and Family Services supports in the next year.
_	14	Person is losing eligibility for Early Periodic Screening, Diagnosis and Treatment supports in the next year.

_	 Person is losing eligibility for Intermediate Care Facility for People with Developmental Disabilities supports in the next year.
_	 Person is losing eligibility for Medically Fragile/Technology Dependent Children's Waiver supports in the next year.
_	17. Person is residing in an out-of-home residential setting and is losing funding from the public school system.
_	18. Person is losing eligibility for Individual Care Grants supports through the mental health system in the next year.
_	19. Person is leaving jail, prison or other criminal justice setting in the next
	year.
_	20. Person wants to leave current setting within the next year.
_	21. Person needs services within the next year for some other reason. (Specify:)
	Planning for Need (Person's need for service is more than a year away but less than 5 years away, or the care giver is older than 60 years)
_	 Person is not currently in need of services, but will need service if something happens to the care giver.
_	Person lives in a large setting, and person/family has expressed a desire to move (or the state plans to move the person).
_	 Person is dissatisfied with current residential services and wishes to move to a different residential setting.
	4. Person wishes to move to a different geographic location in Illinois.
_	Person currently lives in out-of-home residential setting and wishes to live in own home.
_	Person currently lives in out-of-home residential setting and wishes to return to parents' home <u>and</u> parents concur.
_	 Person is receiving supports for vocational or other structured activities and wants and needs increased supports to retire.
	Person or care giver needs increased supports.

_	
_	Person is losing eligibility for Department of Children and Family Services supports within 1-5 years.
_	 Person is losing eligibility for Early Periodic Screening, Diagnosis and Treatment support within 1-5 years.
—	 Person is losing eligibility for Technology Dependent Children's Waiver support within 1-5 years.
—	 Person is losing eligibility for Individual Care Grants supports through the mental health system within 1-5 years.
—	 Person is residing in an out-of-home residential setting and is losing funding from the public school system within 1-5 years.
_	14. Other (Explain:

Existing Supports and Services

Check the supports that are currently in place specifying whether the supports are funded by the Division of Developmental Disabilities or are Other Supports (Other Supports include Education, Early Periodic Screening, Diagnosis and Treatment, Generic, etc.).

Individual Supports	DD Funded	Other Supports
Respite Supports (24 hour)		
Respite Supports (<24 hours)		
Behavioral supports (includes behavioral intervention, therapy and counseling)		
Physical Therapy		
Occupational Therapy		
Speech Therapy		
Education		
Assistive Technology		
Homemaker/Chore Services		
Adaptations to Home or Vehicle		
Personal Support under a Home-Based Support Program, Which Could Be Funded By Developmental Disabilities, Division of Rehabilitation Services or Department on Aging (can include habilitation, personal care, respite, retirement supports, budgeting, etc.)		
Medical Equipment/Supplies		
Nursing Services in the Home, Provided Intermittently		
Other Individual Supports		

Transportation	DD Funded	Other Supports
Transportation (include trip/mileage reimbursement)		
Other Transportation Service		

Vocational or Other Structured Activities	DD Funded	Other Supports
Senior Adult Day Services		
Developmental Training		
"Regular Work"/Sheltered Employment		
Supported Employment		
Vocational and Educational Programs Funded By the Division of Rehabilitation Services		
Other Day Supports (e.g. volunteering, community experience)		

Residential Supports	DD Funded	Other Supports
Community Integrated Living Arrangement (CILA)/Family	runded	Саррона
Community Integrated Living Arrangement (CILA)/Intermittent		
Community Integrated Living Arrangement (CILA)/Host Family		
Community Integrated Living Arrangement (CILA)/24 Hour		
Intermediate Care Facilities for People with Developmental Disabilities (ICF/DD) 16 or Fewer People		
Intermediate Care Facilities for People with Developmental Disabilities (ICF/DD) 17 or More People		
Skilled Nursing Facility/Pediatrics (SNF/PED)		
State Operated Developmental Center (SODC)		
State Operated Mental Health Hospital (SOMHH)		
Supported Living Arrangement		
Community Living Facility		
Shelter Care/Board Home		
Nursing Home		
Assisted Living Facility		
Children's Residential Services		
Child Care Institutions (including Residential Schools)		

Children's Foster Care	
Other Residential Support (including homeless shelters)	

Supports Needed

For the following items indicate if new or additional support is needed by placing a checkmark in the last column. Leave blank if the support is not needed.

Individual Supports (If this section is applicable, check all that apply)

Individual Supports	
Personal Support (includes habilitation, personal care and intermittent respite services)	
Respite Supports (24 hours or greater)	
Behavioral Supports (includes behavioral intervention, therapy and counseling)	
Physical Therapy	
Occupational Therapy	
Speech Therapy	
Assistive Technology	
Adaptations to Home or Vehicle	
Nursing Services in the Home, Provided Intermittently	
Other Individual Supports	

Transportation (If this section is applicable, check all that apply)

Transportation	
Transportation (include trip/mileage reimbursement)	
Other Transportation Service	

Vocational or Other Structured Activities (If this section is applicable, check all that apply)

Vocational or Other Structured Activities	
Support to work at home (e.g., self-employment or earning at home)	
Support to work in the community	
Support to engage in work/activities in a disability setting	
Attendance at activity center for seniors	

Residential Supports (If this section is applicable, check the one that applies)

Residential Supports	
Out-of-home residential services with less than 24-hour supports	
Out-of-home residential services with 24-hour supports	

- Complete informal questionnaire on transition needs
- Explore recreation and leisure interests
- Discuss medical needs and therapies
- Develop independent living skills
- □ Begin early career exploration
- Explore summer employment options
- Increase self advocacy skills
- Write transition goals in the Individualized Education Program (IEP)

- Attend Career events for students with special needs
- Discuss supplemental Social Security (SSI) and Social Security Work Incentives (SSWI) See our section on Social Security
- Discuss home services and assistive technology
- Discuss and visit residential programs.
 See our section on Residential Services
- Determine transportation needs/mobility training
 See our section on Transportation
- Explore case management regarding residential programs/waiting lists
- Consider placement on residential waiting lists
- Consider referral to a school work program
- Write transition goals in the Individualized Education Program (IEP)

- Consideration of vocational interest survey for parents and students.
- □ Discuss Supported Employment (SEP) and job coaching.
- Access career counseling and job shadowing
- Consider school based and community work experience programs.
- Obtain a state ID card
- Explore legal representation; guardianship, wills and trusts.
 See our section on Special Needs Trusts
- □ Write transition goals in Individualized Education Program (IEP)

- Enroll in vocational education classes
- Discuss taxes and medical insurance
- Investigate financial aid
- Consider vocational evaluation
- Discuss mental health services
- Establish graduation date
- Visit campuses and post-secondary training programs.
- Revisit residential programs
- Explore SSI and medical benefits
 See our Section on Financial Assistance
- Consider waiting lists for services from adult agencies.
- Write transition goals on Individualized Education Program (IEP)

- Apply for post-secondary vocational services (colleges/trade schools) and contact special needs coordinator.
- Explore apprenticeship programs
- Access therapy/counseling
- Refer to adult service providers and include in transition planning meetings.
- Confirm adult legal status of student for self representation.
- Discuss the need for assistive technology
- Apply for income support (SSI), public aid (Medicaid) and general assistance.

See our section on Financial Assistance

- Implement guardianship, power of attorney, wills and trusts.
- -Register both to vote and males register for selective service.
- Secure high school records for planning/services

19 through 22 Year Olds

- Continued Parental/guardians advocacy for student/graduate needs.
- Pursue recreation/leisure options
- Active participation in post secondary vocational services (college/trade schools) and/or employment.
- Encourage active participation with adult service providers (for students remaining in high school)
- Follow up with referrals for service provision from adult services providers.

An Introduction to Programs and Services...

- PAS Agencies
- Day Programs
- Rehabilitation
- Residential Programs Legal
- Transportation
- Recreation
- Financial Assistance



You are about to enter the world of Adult Programming. There are more services available than you know, but there are things that must be done along the way to ensure your child's eligibility for these incredibly beneficial services. Throughout the manual we will take you through the necessary steps and help you make very important decisions along the way.

First Things First

The first step in obtaining any form of adult programming is to be connected with a PAS agency, which is determined by what county you reside in. The PAS agency will assign a case manager who will be your liaison and assist you to explore options and obtain services.

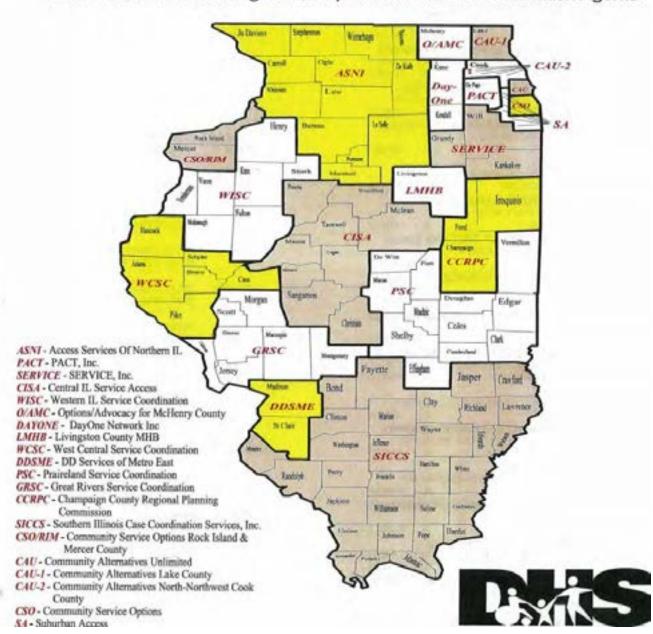
Your PAS agent, or Independent Service Coordination Agent, is truly your key to services in every sense imaginable. They are your friend, your advocate and your voice when it comes to securing funding, insurance, and access to services and programs. The PAS agent must be your first step. While you read this manual we will remind you to refer to your PAS agent on almost everything included in this manual. They will be the ones to guide your through proper documents, procedures and advise you when it comes to making decisions to best fit your specific situation.



The following chart lists PAS agencies in the state of Illinois.

Pre-Admission Screening and Independent Service Coordination Agents





Agents at a Glance

As you can see, there are many *Pre-Admission Screening and Independent Service Coordination Agents*. Their caring and knowledgeable staff are a compassionate link to services necessary to meet the needs of an individual with disabilities. They are sounding boards and friends during difficult times, advocates for those who desire to live independent, fulfilled lives, and a resource assisting individuals and families through the maze of providers and issues related to their needs. Below is a brief summary of three agents supporting the immediate chicagoland and surrounding areas.

PACT

PACT, Inc. is committed to assisting individuals with disabilities live engaged and meaningful lives through independent service coordination.

They achieve their mission through programs that help link people to the service and supports they choose and assist in their ongoing satisfaction with those services and supports.

They are here to assist in pre-admission screening, community case coordination, individual service coordination, individual service and support advocacy and PUNS. For more information on these services, and others provided by PACT, Inc. visit their website at www.pactinc.net

Agents at a Glance

Suburban Access

Suburban Access, Inc., is a nonprofit corporation that offers case management and service coordination to individuals with developmental disabilities in eighteen townships of the South Suburbs and West Suburbs of Cook County, Illinois. The Mission of Suburban Access, Inc., is to improve the quality of life for individuals with developmental and other disabilities through activities of individual service coordination, case management, and community education. For more information on Suburban Access, visit their website at www.subacc.org

Community Alternatives Unlimited

Case management is a service. This direct service provides assistance to people with developmental disabilities and people with mental disabilities. The goal of case management is to link a consumer with the services he or she needs. Case management aims to minimize the feeling that he or she is being shuffled around, waiting in the wrong line, or being caught in "red tape." Case management exists with a wide variety of organizations. Fundamentally, it is a collaborative process that attempts to achieve multiple outcomes, including quality care, cost containment and consumer empowerment. To learn more about Community Alternatives Unlimited, visit their website at www.cau.org



Day Services

Day Service Programs help participants acquire new skills and refine existing skills in the areas of daily living, communication, decision-making and socialization. Areas of vocational training or Recreation and Leisure activities are provided to serve a number of different interests while addressing the needs of individuals in a safe and friendly environment.

The Gamut of Day Services

The variety of Day Services is vast. These breakthrough programs are structured to cultivate skills and inspire learning, exploration and fun in the daily lives of the individuals they serve. Providers are innovative in the framework of their programs and are constantly implementing growth to apply a system of "best practices" in every area, ensuring the goals of each participant in the programs are met.

Below are some examples of programming available in your area. Again, your PAS agent will help determine what types of services best suit your special interests and guide you to a provider in your area.

Developmental Training Programs

These are full day programs emphasizing independence in the areas of daily living, communication, social skills enhancement, functional life and survival skills. Community exploration is frequently an important component of these programs as well as health promotion and wellness.

Sheltered Workshops

These programs frequently combine vocational skills training with furthering independence in life skills. Individuals are provided opportunities to complete work in house under the supervision of agency staff and receive pay for their finished work. All sheltered workshops must be approved by both the Illinois Department of Labor as well as the Federal Department of Labor and adhere to their guidelines. Individuals are generously paid a "piece rate" wage, determined by the percentage of work they are able to complete per hour. Rates are determined by time study data. Routine jobs found in these environments include: collation, mailings, shredding, assembly, sorting, order fulfillment and janitorial skills. Continued training may occur in the areas of: social skills, money management, independent living, reading and writing and communication

The Gamut of Day Services

Supported Employment

In this program, organizations seek employment opportunities in the local community for the individuals they serve. A job match is conducted to pair the right job with the right individual. Full and part time employment opportunities are developed and the individual is provided training and support by a job coach hired by the organization.

Competitive Employment

This program focuses on long term, independent employment for individuals with disabilities. Job search assistance is provided and some job coaching may be provided for a short period of time. The Department of Rehabilitation Services gears their service provision to those individuals who would likely be successful in this type of short term service category.

Senior Day Programs

Many organizations are now offering specialized programs geared to the specific needs of aging adults with disabilities and those who have been diagnosed with dementia. Communication skills, memory, service to peers, wellness and recreation and leisure pursuits are hallmarks of these programs. The focus of these senior programs is to continue to afford the opportunity for individuals to lead full, happy and meaningful lives in a less stimulating environment.



Commonly Asked Questions About Day Services

What are Day Services?

Day services are directed toward acquiring, retaining, and improving skills necessary for an individual to participate in the community. Services can be provided in the community or in a specific location.

What is day treatment?

A planned combination of diagnostic, treatment, and rehabilitative services provided at a specific location.

What is day training?

Vocational services are designed to assist people with acquiring skills and competencies to improve their vocational functioning. Day training can range from a workshop setting to an enclave to competitive employment.

Can there be a flexible schedule to meet the needs of the individual with disabilities?

Each service is unique depending on the agency providing the service and the service recipient. Some day services are designed around the individual with many creative alternatives

Day Service Providers in Your Area

Barbara Olson Center of Hope 3206 North Central Avenue Rockford, IL 61101 815-964-9275 www.b-olsoncenterofhope.org

Clearbrook 1835 West Central Road Arlington Heights, IL 60005 847-385-5300 www.clearbrook.org

Elim Christian Services 13020 South Central Avenue Palos Heights, IL 60463 708-293-3673 www.elimcs.org

Easter Seals of Metro Chicago 1939 West 13th Street Suite 300 Chicago, IL 60608 www.chicago.easterseals.com

Helping Hand Center 9649 West 55th Street Countryside, IL 60525 www.hhcenter.org

Little Friends, Inc. 140 North Wright St Naperville, IL 60540 630-355-6533 www.littlefriendsinc.com

Little Friends Center for Autism 1001 East Chicago Avenue Naperville, IL60540 630-305-4196 www.littlefriendsinc.com/lfca.asp

Misericordia Heart of Mercy 6300 North Ridge Chicago, IL 60660 773-973-6300 www.misericordia.com

PACTT (Parents Allied with Children and Teachers for Tomorrow)
7101 North Greenview Avenue Chicago, IL 60626 773-338-9102 www.pactt.org

Park Lawn Association 10833 South LaPorte Oak Lawn, IL 60453 708-425-3344 www.parklawn.com

Seguin Services 3100 South Central Cicero, IL 60804 708-863-3803 www.seguin.org



Rehabilitation Services

Another major player in Illinois in providing services to people with developmental disabilities is a division of the Department of Human Services, "the Division of Rehabilitation Services."

Throughout this manual you will see references to the Department of Human Services (DHS). They are the regulatory and funding agency for the state of Illinois. In a nutshell, this means they set the standards for and fund many of the programs outlined in this manual. DHS's *Division of Rehabilitation Services* is the state's lead agency serving individuals with disabilities. *DRS* works in partnership with people with disabilities and their families to assist them in making informed choices to achieve full community participation through employment, education, and independent living opportunities.

How do I get aid for a person with disabilities?

The Office of Rehabilitation Services supervises the State of Illinois' Disability Determination Services Program. This program determines which Illinois citizens are eligible for benefits through Social Security's disability programs. To apply for benefits or for more information, contact your local Social Security office or call 800-772-1213.

How do I find out about centers and schools for disabled persons?

The State of Illinois offers three residential education programs for Illinois children with disabilities. For detailed information about these programs visit their site or call 800-843-6154.

How do I get help finding a job that will accommodate my disabilities?

The Office of Rehabilitation Services offers a Vocational Rehabilitation Program that helps individuals find and keep quality jobs. Services are provided in 51 offices located throughout Illinois.

How do I sign up for an independent living program?

The State of Illinois' Independent Living Program offers Centers for Independent Living in more than 20 communities throughout Illinois. The centers provide counseling, housing services, job training, living skills training, and much more. Check out the <u>Independent Living Program</u> for more detailed information or call 800-843-6454 to find the nearest center.

Vocational Rehabilitation Services

What is the purpose of this service?

DHS helps people with disabilities find and keep jobs. Their goal is to help our customers find quality employment that pays a living wage and offers a chance for advancement.

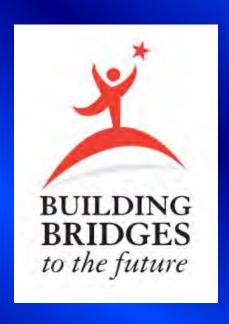
What services are offered?

Our staff talk to people about their employment needs and help them find a job or get ready to go to work. They also make sure that people have the supports they need to stay on the job.

DHS helps high school students who have disabilities plan for their futures after high school graduation through our Transition and STEP programs.

The Work Incentive Planning and Assistance Program helps people who receive SSDI/SSI benefits understand how working will affect their benefits.

Their Supported Employment Program (SEP) serves eligible people with significant disabilities who want to go to work and need on-going support services to succeed on the job.



Residential Services

Social Service Agencies have implemented a myriad of residential programs for people with disabilities. Many of these programs have been in place for over fifty years. Over that time, programs have evolved, tailoring each to provide something for everyone.

The following section serves as your guide to available residential services and can assist you in making a decision on a living situation that best suits your special needs.

There are several types of residential options available for individuals with a developmental disability. Whether you are looking for minimal support in your own home, or require around the clock specialized care there is a variety of programming in place within your area to provide every element of a successful adult life in a residential setting. While you continue to explore this section of the manual, you will learn about different types of residential living arrangements and hopefully gain perspective to guide you as you begin to work with your PAS agent.









While you go through these programs, keep in mind some factors that you would like to see in an ideal

Situation for your family member. Do not hesitate to discuss these factors with your PAS agent, or to contact different services providers to keep yourself updated on growth in agencies and programs. As you correspond with your PAS agent and other service providers, keep a log of notes in the pages provided after each section of this manual.

The following pages list different types of residential programs available in your area.

CILA

Community Integrated Living Arrangements (CILA) provides a family living environment. These programs offer people with developmental disabilities the opportunity to live in a homelike setting while receiving the individualized care they need in a warm, consistent and supportive environment. Some CILA programs are licensed 24-hour residential programs operated under CILA guidelines set forth by the Department of Human Services. CILA programs fluctuate depending on eligibility and specific needs of the consumer.

24 Hr. CILA

The CILA model offers the greatest freedom for people with disabilities to live, work and socialize as others do. They become more and more self-sufficient as they take part in community activities along with their neighbors.

The house is typically owned and operated by an agency that is in charge of providing services to the residents of the home. Agencies also maintain the home by ensuring all bills are paid and the property is kept to agency, state and federal standards. The number of people that live in a CILA home varies depending upon the needs of the residents, or *program participants*, as well as the size and lay out of the home. A CILA cannot ever accommodate more than eight residents. Staff to participant ratios and supervision is determined by the needs of the participants living in the home. Additionally, when an individual resides in a CILA they are expected by DHS to either maintain employment or attend a day program on a regular basis. In order to reside in a CILA a person needs to be funded through the Department of Human Services and be accepted by the agency that runs the CILA. The funding for a CILA is attached to the individual and follows the individual as long as there is an opening and he or she is accepted into the program and continues to meet eligibility requirements. Similar to all CILA funding, Day Services and Case Management are covered.

Intermittent CILA

Another CILA model is Intermittent CILA. Although similar to 24 hr. CILA in the sense that funding covers case management and day services, Intermittent CILA residential services provide a minimum of 15 hours of respite care weekly usually either at community residences of individuals who live independently and require minimal support, or in the family homes of individuals.

Family CILA

Similar to Intermittent CILA in terms of receiving a minimum of 15 hours of respite care weekly depending on the needs of the participant, Family CILA also funds day program and case. The resident or participant generally resides in their family home. With Family CILA, the agency providing services does not own the home, nor does the participant have to obtain their own apartment for residence. For many, it is best to support the participant in maintaining their independence in the community while residing in the family home.

Home Based Services

Home Based Services seems to be the trend the state is moving towards. This is designed for people on the PUNS waiting list. When funds become available, the guardian is awarded an allowance to pay for services. It can go towards day services, respite services, transportation services and case management to name a few. Under the Home Based Services plan, you can tailor your services, within the means awarded to you from the state, that best suit your individual needs. Just like CILA this is a waiver program; all waiver programs require being eligible for Medicaid. Your PAS agent will better guide you through the different services, eligibility and how to go about the process of securing funding and obtaining appropriate services.

CSLA

Community Supported Living Arrangements (CSLA) offer adults with developmental disabilities services and supports in their own homes. Many agencies tailor services to meet their needs and the needs of their families.

The CSLA initiative reinforces existing social networks and enables many individuals to live successfully in a house or apartment in a community with or near their families and friends. Some other services offered through CSLA include in-home rehabilitation, personal assistance, 24-hour emergency assistance, case coordination and service facilitation. The main difference between CSLA and Intermittent CILA is that CSLA does not fund day services.

ICF-DD

ICF stands for Intermediate Care Facility for Developmental Disabilities which is a facility for individuals who generally have more skilled nursing needs, daily living skills, or self care skills. In an ICF setting, nursing staff is generally available on-site 24 hours every day.

Additionally, ICF-DD facilities are monitored by the Department of Public Health. There is staff on-site 24 hours each day. ICF-DD's also have a medical director who is a doctor and operates as the primary care physician for the residents of the ICF-DD.

If an individual is in need of living in an ICF-DD, they still need to contact their local PAS agency to set up services and determine which level of care is needed. The funding for an ICF-DD is different from the funding for a CILA because an ICF-DD is funded for the bed not the individual. The funding does not stay with the individual it stays with the bed.

Commonly asked questions about residential and supported living situations

How many people are in the homes?

- This depends on the type of residential arrangement. Some will be a dorm like setting while others could be small homes on campus, an apartment building, individual apartments or individual homes. A good follow up question to this could be, "How many people share a bedroom?"

Is there a maximum time of stay for the facility?

-The majority of arrangements are permanent; some arrangements have goals to assist people to move to a more independent environments. Other residential arrangements may be strictly for respite care.

What is the wait list to get in?

-First, there is the wait list to be assigned a PAS Individual Services Coordinator. Second, there are the lists that each residential service provider maintains. These lists can be years long. This is why you should apply early and tour several facilities. If you are in the system early and know what you want, you will be ahead of the game!

What is the staff to resident ratio? When are staff available?

-Each Program provides for a different staffing pattern. The staff ratio will differ depending on the arrangement and the time of day. Some can base availability on individual needs.

Other questions to ask:

- •What type of wait list does the agency have?
- •What expenses is the client responsible for?
- •Who is responsible for making doctors appointments?
- •How long can the client go on vacation?
- •Can the client go home for the weekends?
- •What kind of activities will the client participate in the community with?

Residential Service Providers In Your Area

- **Abraham Lincoln Centre** 3858 South Cottage Grove Ave. Chicago, IL 60653-2096 (773) 285-1390 (773) 373-6602-Fax info@abrahamlincolncentre.org
- Camp Ramah Rose Sharon 65 E. Wacker, Chicago, IL 60601312-606-9316 rsharon@ramahwisconsin.com www.ramahwisconsin.com
- **Clearbrook** The Wright Home 2500 Commonwealth Ave. North Chicago, IL 60064 Telephone (847) 473-2891 Contact Steven St. Louis www.clearbrook.org Email: sstlouis@clearbrook.org
- Clearbrook 1835 West Central Rd., Arlington Heights, IL 60005 847-385-5354 847-385-5300 Contact: Gina Genovesi Genovesi Clearbrook.org www.clearbrook.org
- CONCEPTS PLUS 2017 N. Pine Waukegan, IL 60087 Telephone 847-662-6444 or (847) 473-3309 Contact Desiree Matthews Website www.Ddhomes.net
- GLENKIRK 3504 Commercial Ave. Northbrook, IL 60062 Telephone (847) 272-5111 Contact: Colette Stone & Shayna Green Email cstone@glenkirk.org Website www.glenkirk.org
- Housing Options for the Mentally III in Evanston1132 Lawrence Ave. Evanston, IL 60202 Telephone (847) 866-6144 Contact: Melba Swoyer Email mswoyer@housingopt.org Website www.housingopt.org
- **Lamb's Farm** 14245 W. Rockland Road P.O. Box 520 Libertyville, IL 60048 Telephone: (847) 362-4636 Contact: Marie Nelson Email: mnelson@lambsfarm.org www.lambsfarm.org

Residential Service Providers In Your Area

- **Mount. St. Joseph** 24955 N. US HWY 12 Lake Zurich, IL 60047 Telephone (847) 438-5050 Contact: Sister Mary Walker www.mtstjosephhome.com
- **Orchard Village** 7670 Mamora Manor Skokie, IL 60077-2680 Telephone (847) 967-1800 Contact Kristin Westby or Tim Bobrowski www.orchardvillage.org
- Rimland 1265 Hartrey Ave. Evanston, IL 60202 Telephone (847) 328-4090 Contact Crizelda Naviamos Email cnaviamos@rimland.org www.rimland.org
- **Riverside Foundation-ICF/DD** Contact Paula Wiznerowicz 14588 W. Highway 22 Lincolnshire, IL 60069 Telephone (847) 634-3973 Website www.riversidefoundation.org
- Seguin Services 3100 S. Central Ave. Cicero, IL 60804 Contact Tina Golas 708-222-4815 tgolas@seguin.org website www.seguin.org
- **Shelters for Healthy Environments, Inc.** Canterbury Place Apartments 615 Meadow Creek Dr. Dekalb, IL 60115 Telephone (815) 748-4433 Contact Sue Larson Email s.larson@tbcnet.com
- Shepherds Ministries, Inc. 1805 15th Ave. Union Grove, WI 53182 Telephone (262) 878-5620 ext. 257

 Contact: Jane Slye Email jslye@shepherdsministries.org www.shepherdsministries.org

 Trilogy 1400 West Greenleaf Chicago, IL 60626 Telephone (773) 508-6100 Contact: Janet Hieshetter www.trilogybehc.org
- PACTT (Parents Allied with Children and Teachers for Tomorrow)
 7101 North Greenview Avenue Chicago, IL 60626 773-338-9102 www.pactt.org
- Park Lawn Association 10833 South LaPorte Oak Lawn, IL 60453 708-425-3344 www.parklawn.com

Residential Service Providers In Your Area

Elim Christian Services 13020 South Central Avenue Palos Heights, IL 60463 708-293-3673 www.elimcs.org

Helping Hand Center 9649 West 55th Street Countryside, IL 60525 www.hhcenter.org

Little Friends, Inc. 140 North Wright St Naperville, IL 60540 630-355-6533 www.littlefriendsinc.com

Meadows 3250 S. Plum Grove Rd. Rolling Meadows, IL 60008 Telephone (847) 397-0055 Contact: Byrn Witt/Robin Witt Klee meadows@comcast.net

Misericordia Home North 6300 N. Ridge Chicago, IL 60660 Telephone (773) 973-6300 Contact Gail Wojceichowski Email gailw@miseracordia.com www.misericordia.com



Transportation Services

Surrounding counties have several transportation resources for individuals with disabilities. Accessing and utilizing these services have traditionally been quite challenging. However, being prepared with appropriate questions and a good base of information can make the process much simpler.

PACE

WHAT'S PACE?

Pace is the Suburban Bus Division of the Regional Transportation Authority (RTA). We've been operating paratransit services and accessible fixed route public transportation for more than twenty years.

Pace is the 13th largest public transit provider in the country, and one of the largest providers of paratransit and vanpool services. Our agency is a leader in the use of technology, above peers in efficiency standards and we work with a network of partners to provide innovative services to nearly 140 million people a year.

We're committed to creating a premier transit system for all residents of the six counties of northeastern Illinois. Pace serves People. We believe that improving public transportation for persons with disabilities improves service for everyone and enhances the quality of life in our communities.

PROGRAMS

WHAT CAN PACE DO FOR YOU?

PACE has a family of services to make sure that people have a ride when they need one. We have a fully accessible fleet of over 1200 vehicles. Pace was the first carrier in the state of Illinois to be fully accessible. To learn more about Pace services, call the RTA Travel Information Center at 836-7000, TTY number 312-836-4949 or visit our website at www.pacebus.com.

PACE

PARATRANSIT

Fare Info

Pre-arranged curb-to-curb service for persons with disabilities whose eligibility has been determined by the regional certification process. Pace's ADA Paratransit Services operate in all suburban areas that are within 3/4 mile of Pace's regular fixed routes and during the same days and hours as the regular fixed route service.

ADA Paratransit Service Directory

Pace Dial-a-Ride

Non-fixed route (paratransit) service utilizing vans and small buses to provide pre-arranged trips to and from specific locations within the Diala-Ride service area to individuals deemed eligible based on local requirements, usually elderly and/or disabled.

Dial-a-Ride Service Directory

Accessible Fixed Route Bus Service

All Pace routes are accessible for persons who use mobility aids.

Please contact Pace <u>Customer Services</u> for more information on Pace ADA Paratransit Services or visit the PACE website <u>www.pacebus.com</u>

Regional Transportation Authority

WHAT'S THE RTA?

The Regional Transportation Authority (RTA) gets you where you're going with our three transit operators: the Chicago Transit Authority (CTA) bus and rail system, Metra commuter rail, and Pace suburban bus service.

As the second largest public transportation system in North America, you'll have a safe and comfortable ride around Chicago and all over northeastern Illinois.

PROGRAMS

There are many ways to save money while using transit services from the RTA. Explore our various fare programs and see if you're eligible for a reduced fare or even a free ride.

Reduced Fare Program

Are you eligible for our Reduced Fare Program? If you meet our qualifications, you could reduce your fare by half while still enjoying all of the convenience of public transportation.

People With Disabilities Ride Free Program

Disabled individuals who qualify through the Illinois Circuit Breaker program can now ride transit for free. We make it easy to register and ride.

Regional Transportation Authority

ACCESSABILITY

The RTA has always been committed to ensuring that everyone is able to ride our transit services. The Americans with Disabilities Act of 1990 (ADA) gives people with disabilities broader rights and protections, including access to public transportation. In accordance with the ADA, the RTA has taken specific steps to offer services for people with disabilities.

Accessible Transit

Travel on CTA and Pace fixed route buses, the CTA "L" trains and Metra commuter rail service is safe and easy for people with disabilities. Find out more about the accessibility of fixed route buses and trains, and commuter rail and why it is a good choice for travel throughout the RTA region.

ADA Paratransit Overview

To support the need for equal access to public transit services, ADA Paratransit was created. This is shared-ride, origin-to-destination transportation provided in the RTA region by Pace (the suburban bus division). Find out more about the eligibility criteria and the steps you need to take to apply for this service.

Travel Training

If you are eligible for ADA Paratransit, find out how you can participate in travel training to learn how to travel on CTA or Pace fixed route transportation, or on Metra commuter rail service.

For more information on the RTA and their programs, visit the RTA website

www.rtachicago.com

Some key considerations to address when choosing a transportation provider

- What accommodations are available for people with disabilities?
- What times and/or days are the transportation services available?
- Are there any residential or mileage boundaries for services?
- Are there other people in the vehicles?
- Is there a necessary qualifying process to receive the transportation service?
- What is dial a ride service and is it available to us?
- What are the fees and are there special rates?
- What is the targeted age group or population served?



Recreation Programs

The Chicagoland area has several providers of social/recreational activities. These services are offered to individuals of all ages with special needs including learning disabilities, physical disabilities, hearing or visual limitations along with cognitive disabilities. In addition to agencies that provide services, you may also want to consider local park districts who provide recreational opportunities with necessary supports when exploring your options to best suit your individual situation.

Recreation

Special needs recreation providers typically welcome participants of all ages and ability levels into their programs. Preschoolers, children, teens, adults and senior adults can realize the benefits of involvement in recreation activities. Programs are generally designed with a close staff-to-participant ratio to assist people with disabilities in achieving their greatest success. Program adaptations to accommodate a physical limitation are common in most adapted sports and fitness programs. Many programs for people with developmental disabilities enhance socialization and foster independence. Activities for youth-at-risk promote cooperation and social skills in a therapeutic and challenging setting. In keeping with the goals of each program, the #1 objective is to have fun!

What goes on in Recreation programs?

Most programs reflect the mood and the activities of the changing seasons. Often times, age-appropriate recreation opportunities are designed to meet the individual needs of each participant. Some examples offered through a majority of local recreation service providers are:

Arts and Culture

Athletics

Dance

Games

Social Clubs

Toy Lending (Lekotek)

Bowling

Day Camps/Away

Camps Music Special Olympics Community Trips

Fitness

Skill Development

Swim Trips

Your local park district is a fantastic resource for special needs recreation programs.

Recreation



SPECIAL OLYMPICS!

Along with the extensive menu of recreation activities and the benefits of those there is also the Special Olympics which offer a myriad of events to meet every interest and skill level.

The focus in Special Olympics is the abilities of each athlete. Like everyone, Special Olympics athletes like to win, but more importantly - they strive to do their best. The sportsmanship that is demonstrated on the court, in the field, or on the track serves as an inspiration to all.

Special Olympics provides year-round sports training and competition in a variety of Olympic-type sports for children and adults with intellectual disabilities by giving them continuing opportunities to develop physical fitness, demonstrate courage, experience joy, and participate in a sharing of gifts, skills and friendship with their families, other Special Olympics athletes and the community.



"Let me win. But if I cannot win, let me be brave in the attempt."

Keep in mind when seeking recreation programs...

- What is the target age group?
- What is the targeted population, meaning level of disability?
- Does the program offer transportation services? If so, do I need to pay?
- Does the program offer integration programs?
- What are the fees? What do they cover? Is financial assistance available?
- How much supervision is provided?
- Typically, how many participants attend events?
- What times of the day/year are programs offered?
- Are there residential boundaries for participants?
- Are there newsletters, or bulletins from the organization regarding incoming events?

Who Provides Recreational Services In Our Area?

Many programs can be found through your local park district and your PAS agent will provide information on Special Recreation Programs in your area.

Some providers in the surrounding Chicagoland area:

AYSO Region 372 P.O. Box 783 Mundelein, IL 60060 847-949-6320 www.ayso372.org

Camp Red Leaf 26710 W. Nippersink Ingleside, IL 60041 Telephone: 847-740-5010 Website: www.jcys.org/redleaf

THE CENTER For Enriched Living 280 Saunders Road Riverwoods, IL. 60015 847-948-7001 Website: www.centerforenrichedliving.org

GREAT LAKES ADAPTIVE SPORTS ASSOCIATION 400 E. Illinois St. Lake Forest, IL 60045 Telephone (847) 283-0908 Website www.glasa.org

Jewish Council for Youth Services P.O. Box 297 Ingleside, IL 60041 Telephone (847) 740-5010 Website www.jcys.org

Northern Illinois Special Recreation Association (NISRA) 820 E. Terra Cotta Ave. Suite 125 Crystal Lake, IL 60014 Telephone (815) 459-0737 website www.nisra.org

Northern Suburban Special Recreation Association (NSSRA) 3105 MacArthur Blvd Northbrook, IL 60062 Telephone (847) 509-9400 website www.nssra.org

Special Olympics of Illinois 103 Shelter Road Suite 21 Lincolnshire, IL 60069 Telephone (847) 478-0935 website www.soill.org

Misericordia Heart of Mercy 6300 North Ridge Chicago, IL 60660 773-973-6300 www.misericordia.com

Who Provides Recreational Services In Our Area?

Providers Continued

Special Recreation Services of Northern Lake County Upton Park, Douglas House 732 North Genesee Street Waukegan, IL 60085 847-360-4760

Special Recreation Assoc. of Central Lake County (SRACLC) 290 Oakwood Dr. Vernon Hills, IL 60061 Telephone (847) 816-4866 website www.sraclc.org

Warren Special Recreation Association 17801 W. Washington St. Gurnee, IL 60031 Telephone (847) 244-6619

West Suburban Special Recreation Association 2915 Maple Street Franklin Park, Illinois 60131 **Phone:** (847) 455-2100 website www.wssra.org

SWSRA: South West Special Recreation Association 12521 South Kostner Avenue, Alsip, Illinois 60803 (708)-389-9423

Orland Park Special Recreation Association 14650 South Ravinia Avenue, Orland Park, Illinois 60462 (708) 403-7275

Oak Lawn Park District Special Recreation Programs at Oakview Recreation Center 4625 West 110th Street, Oak Lawn, Illinois 60453 (708) 857-2200 www.olparks.com

South Suburban Special Recreation Association

19910 80th Avenue, Tinley Park, Illinois 60487 (815) 806-0384

Tri-County Special Recreation Association

201 Normantown Road Suite LL East, Romeoville, Illinois 60446 (815) 407-1819

Helping Hand Center 9649 West 55th Street Countryside, IL 60525 www.hhcenter.org

Who Provides Recreational Services In Our Area?

Providers Continued

Gateway Special Recreation Association

15W431 59th Street, Burr Ridge, Illinois 60527 (630) 325-3857

Special Recreation Services (SRS)

16931b South Park Avenue, South Holland, Illinois 60473 (708) 825-9417 www.newhopecenterinc.com

Special Recreation of Joliet and Channahon (SRJC)

3000 West Jefferson Street, Joliet, Illinois 60435 (815) 741-7275 x169

Joliet-Bolingbrook Special Recreation Association (JBSRA)

230 East Briarcliff, Bolingbrook, Illinois 60440 (630) 739-1124 www.bolingbrookparks.org

Lincolnway Special Recreation Association (LWSRA)

P.O. Box 547 Frankfort, Illinois 60423 (815) 464-2811 www.lwsra.org

Chicago Park District: Mount Greenwood

3721 West 111th Street, Chicago, Illinois 60655 (312) 747-6564

Chicago Park District: Marquette Park

6734 S. Kedzie Avenue, Chicago, Illinois 60629 (312)747-6469

Easter Seals of Metro Chicago 1939 West 13th Street Suite 300

Chicago, IL 60608 www.chicago.easterseals.com



Financial Assistance

Many people with disabilities are eligible to receive some form of financial assistance. The following section breaks down some examples of benefits that may suit your family's individual situation while helping to plan for your child's future. Like everything else we highlight in this manual, the key to success is planning ahead in order to see your next move before you come to each crossroad.

Many students with severe disabilities will eventually be eligible for the income and health programs under the Social Security Administration (SSI, SSDI, Medicaid and/or Medicare). Specific eligibility criteria should be discussed with your PAS agent or agency you are working with. Let's take a look at some benefits and what they mean for you.

SSI Supplemental Security Income

SSI is short for Supplemental Security Income. It pays monthly cash benefits to people who are age 65 or older but also to those who are 18 years of age (or older) and meet the criteria of having a disability. It also pays benefits to those who are blind or those who have a disability and who do not have much in terms of assets or considered low-income. **SSI** is not just for adults. Monthly benefits may go to disabled and blind children too. There are two main factors the state considers in determining your child's eligibility:

✓ Your child must meet the Social Security Administrations definition of being disabled.

✓ Your child must have less than \$2,000.00 in assets.

It is key to apply prior to your child's 18th birthday

Because of ongoing systematic changes, we encourage you to direct your attention to the websites of each agency you are considering for financial assistance to get the most current information available.

SSDI Social Security Disability Insurance

Social Security Disability Insurance or SSDI is a payroll tax funded, federal insurance program. SSDI, managed by the Social Security Administration, is designed to provide income to people who are unable to work because of a disability. SSDI is not necessarily a long-term income solution. It is intended to provide income until an individual's condition improves. The Social Security Administration regularly requests proof of disability through an auditing process. As long as the disability is proven each time Social Security requests such as SSDI will guarantee long-term income. Under this program there are three main factors the state considers in determining your child's eligibility:

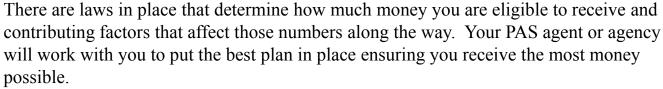
- ✓ Your child must meet the Social Security Administrations definition of having a disability
- ✓ Your child must have paid into social security over their lifetime.
- ✓ The parents of a disabled child paid into social security and are deceased, retired or have a disability of their own.

What's the difference between SSI and SSDI?

SSDI and SSI are two of the disability programs administered by the Social Security Administration. You qualify for SSDI, or Disability if you meet SSA's definition of disability, and have enough credits from past work to meet the earnings requirements set out in Social Security law. When you were working you paid FICA (Social Security) taxes and contributed to the Social Security system.

Questions to ask sources of financial assistance:

- -What proof of my financial situation or disabling condition is required?
- -What happens to the financial/medical benefits if I get a job?
- -How often is my eligibility for benefits reviewed?
- -How are benefits affected if I live at home with my parents?
- -What do I need to do to continue receiving the financial benefits?
- -What records need to be turned in regularly?
- What changes in my situation need to be reported?



For example, if your child or family member living with you assists with rent, they may be eligible for a larger monthly benefit. This money can be reinvested by placing it in a Special Needs Trust, which will help to secure ongoing supports for the future once you are no longer able to provide care. By establishing them as "self-sufficient" there is a plan in place. It is all about planning for the future.



Medicaid and Medicare

Medicaid is a health care program for people with low incomes and limited resources. In most states, children who get SSI payments qualify for Medicaid. In many states, Medicaid comes automatically with SSI eligibility. In other states, you must sign up for it. Some children can get Medicaid coverage even if they do not qualify for SSI. Check with your local Social Security office, your state Medicaid agency, or your state or county social services office for more information.

Some people may not feel comfortable being on "public aid" but even if you have a primary health coverage provider (private insurance), Medicaid will not only fund services, but serve as a supplemental insurance provider; picking up what your other insurance would not cover.

Like other services mentioned in this manual, we strongly urge you to work with your PAS agent or agency you wish to receive services from to make sure you are taking the proper steps to secure funding, benefits and services.

Here's the shift; while Medicaid is commonly associated with health insurance, it is required of any state funded services including Day, Residential, Respite, and case management to name a few. Medicaid is not just insurance, It provides funding for services and could be considered the "payer of last resort" When approaching service providers, one of the first requirements you are going to face is whether or not your child has Medicaid or is eligible for Medicaid.

Medicaid and Medicare

Medicare is our country's health insurance program for people age 65 or older. Certain people younger than age 65 can qualify for Medicare, too, including those who have disabilities and those who have permanent kidney failure or amyotrophic lateral sclerosis (Lou Gehrig's disease).

The program helps with the cost of health care, but it does not cover all medical expenses or the cost of most long-term care. Medicare is financed by a portion of the payroll taxes paid by workers and their employers. It also is financed in part by monthly premiums deducted from Social Security checks.

Medicare is broken into four separate sectors:

Part A	Hospital Insurance
Part B	Medical Insurance Note: If you're under 65 and disabled, you'll automatically get Part B after you get disability benefits from Social Security
Part C	Medicare Advantage Plans
Part D	Prescription Drug Coverage

HWBD Program

Health Benefits for Workers with Disabilities

All of us dream of seeing our children grow, be successful and live the most meaningful lives while maintaining some level of independence. This testament holds true for everyone, with or without a disability. With that in mind the HWBD program is in place to provide benefits to individuals who are able and wish to seek employment.

While these services are here to help you, the breakdown can be tricky so be sure to keep all of your records in order and continue to seek guidance from your PAS agent or agencies where you wish to receive services. It's critical that you make sure everything is kept in accordance with state requirements in order to maintain your eligibility for benefits.

- •The goal of this program is to help people with disabilities return to work with full Medicaid healthcare benefits.
- •HBWD encourages people to return to work or to increase the number of hours they are currently working.
- •Eligible Illinois residents between the ages of 16 and 64, who have a disability and who are employed can purchase HBWD.
- Income and assets can be higher than Medicaid normally allows

Health Benefits for Workers with Disabilities

(217) 558-6067 www.hbwdillinois.com

Working with Benefits

Trial Work Period

You are eligible to receive a total of 9 Trial Work Period (TWP) months over a rolling 60-month (five years) period. You are not required to use these 9 Trial Work Period months consecutively. In order to trigger a Trial Work Period month you must have gross monthly earnings at or above \$720 (2010 amount). Once you have used the first of these Trial Work Period Months, the rolling 60-months (five years) period begins. During the nine Trial Work Period months, you are entitled to keep your SSDI benefit check regardless of how much you earn.

You will continue to receive your SSDI benefits during your Trial Work Period months.

Working with Benefits

Extended Period of Eligibility

Once you complete your Trial Work Period, you enter what is known as the Extended Period of Eligibility, or EPE.

The Extended Period of Eligibility is a consecutive 36-month period immediately following the completion of the Trial Work Period.

During this stage, if you earn <u>less</u> than what Social Security considers SGA (\$1000 for 2010 for non-blind individuals and \$1640 for blind individuals) in any of the months within the EPE, you would be entitled to receive your full SSDI benefit check. If you earn more than what Social Security considers SGA (\$1000 for 2010 for non-blind individuals and \$1640 for blind individuals) in any of the months within the EPE, you would not be entitled to receive your SSDI benefit check. The first month following your EPE that you have gross monthly earnings at or above SGA, you will lose your eligibility for SSDI benefits.

If you have a child receiving SSDI benefits off your work record, anytime you are not eligible for an SSDI check your child will not receive their monthly benefits either. If your benefits are terminated your child's benefits will be terminated as well.

Working with Benefits

Grace Period

The Grace Period is triggered by the first month after the TWP in which you earn at or above what Social Security considers Substantial Gainful Activity, or SGA. For 2010 SGA is defined as \$1000.00 in gross earnings per month for a non-blind individual and \$1640 for a blind individual.

Like the TWP, the Grace Period is three months in which you will receive your benefits check regardless of your earned income. These months are consecutive, starting with the first month that you earn SGA following the completion of your TWP. It is possible to use your Grace Period either during OR after your Extended Period of Eligibility.

You will continue to receive your SSDI benefits during your Grace Period months.

If, at any time, you feel that you have received an SSDI check that you should not have received, report this to your SSA claims representative as soon as possible. This may avoid an overpayment of your SSDI benefits that you will be required to pay back to the SSA. The longer you wait to report, the more you will owe.

Deeming Income SSI

When the Social Security Administration (SSA) deems income or resources, it is saying that some of the income and/or resources of another are available to the <u>Supplemental Security Income (SSI)</u> recipient or applicant.

Deemed income or resources can cause an SSI applicant or recipient to be ineligible for SSI benefits.

Deemed income can reduce the SSI cash benefit of a recipient. SSI applicants or recipients who are under age 18 may have income and resources deemed from their parents

IMPORTANT NOTE: Deemed income or resources can be included in a <u>PASS</u> either for purposes of determining eligibility or raising the SSI cash benefit amount. If, for example, SSA deems that \$200 of parental income is available to an SSI recipient who is under age 18, then the recipient's SSI cash benefit will be reduced by \$180. If the parents set aside \$180 in a savings account and include that amount in a PASS (perhaps for the future purchase of Job Coach Services) then the SSI cash benefit amount will rise by \$180.

ALSO NOTE, HOWEVER: Individuals who are less than 15 years old are not considered by SSA to be likely candidates for a PASS.

Calculating earned income with benefits SSI

Supplemental Security Income (SSI) is a needs-based program; benefits are awarded to cover the basic needs (food, shelter, and clothing) of individuals. The maximum amount of SSI benefits a person is eligible for in 2010 is \$674 a month.

Any earnings over \$85.00 per month will reduce your SSI benefit check. The general rule to calculate SSI benefit check amount is that every \$2.00 you earn through employment, your SSI check is reduced by \$1.00 after the first \$85.00.

So let's calculate

SSI Calculations (Example) Calculation for Monthly Income

Full - Time	Part - Time
\$8.00 Hourly Wage	\$8.00
X 40 Hours per Week	X 20
\$320.00	\$160.0 0
\$320.00	\$160.00
X 4.33 Weeks per Month	X 4.33
\$1,385.60 Total Monthly Income	\$692.80

SSI Calculation

Full - Time Pa	art - Time
\$1,385.60 Monthly Earned Income	\$692.80
- \$65.00 Earned Income Exclusion	- \$65.00
\$1,320.60 Total	\$627.80
- \$20.00 General Income Exclusion	- \$20.00
\$1,300.60 Total	\$607.80
./. 2 Divided by 2	./. 2
\$650.30 Total Mo. Countable Earned Income	303.90
\$674.00 Federal Benefit Rate (2009)	\$674.00
\$650.30 Monthly Total Countable Income	- \$303.90
\$ 23.70 Adjusted SSI Benefit Check	\$370.10

Calculating earned income with benefits SSI

To Sum it up

Full-Time

- •If you were to work <u>full-time at 40 hours a week:</u>
- •40 hours a week at \$8.00 an hour you would still receive \$23.70 in SSI. This gives you a total monthly income of:
- -\$23.70(SSI) + \$1,385.60 (earnings) = \$1,409.30

Part-Time

- •If you work *part-time at 20 hours a week*:
- •20 hours a week at \$8.00 an hour you would still receive \$370.10 in SSI, This gives you a total monthly income of:
- •\$370.10 (SSI) + \$692.00 (wages) =**\$1062.10**

As you can see by the calculations above *your total income has increased by employment*. You can figure your own SSI amount by replacing the earnings amount in the calculation.

Make sure you report your earnings to your local SSA office so that they can adjust your SSI check to avoid an overpayment that you will be required to pay back to the SSA. The longer you wait, the more you will owe.

This can be very overwhelming to anyone, especially when you are first beginning to explore benefits. The more familiar you become with these services, the more comfortable you will be. You are not alone but be sure to keep checking the websites and speaking with your agent/organization to make sure you are up to date on all requirements.

Reporting Monthly Earnings

A "How To" Guide into Reporting Monthly Earnings to SSA

Things to tell SSA:

You need to notify SSA about the following things as they happen. Remember that you should always provide notification of changes in writing!

- 1) Start or stop working
- Increase or decrease your hours
- 3) Get married
- Leave school or go back to school
- 5) Move

What does Social Security consider to be earnings?

Earnings are wages and self-employment income that you get from working.

Why Report Monthly Earnings to Social Security?

 Reporting your monthly earnings to Social Security will decrease the risk of having overpayments.

How to Report Monthly Earning

What carnings information does Social Security need to sec?

- -Every pay stub, including pay stubs for overtime, vacations, and bonuses:
- -If self-employed, copies of your Federal Income Tax Forms, Schedule SE, Schedule C,
- Schedule C-EZ, or Schedule F: -Receipt for work expenses
- related to your disability

 If you are blind receipts for any
 work expenses.

For further clarification please feel free to contact me at:

Office: (630)495-0500 ext. 249 Toll Free: 800-807-6962 ext. 3 TTY: 866-444-8013 Email: Mhameria III.Tech.org Mariel Hameria III.Tech.org

- Take in pay stubs to local Social Security office in person.
- · Or, mail original pay stubs to local Social Security office
- Social Security also now offers a toll-free automated wage reporting telephone system for SSI recipients. Ask Social Security how you can report wages using the automated telephone system.
- Remember: It is very important that you get a receipt back from Social Security after reporting. That receipt is your proof of reporting each month.

Where to Report Monthly Earnings

 Report monthly earnings to your local Social Security Office.

Go online to the Social Security office Locater: https://secure.ssa.gov/apps6z/FOLO/fo001.jsp



Illinois Link Program

Welcome to the Illinois Link Program

Like other federal and state benefits, depending on your income, you maybe eligible for Link benefits, formerly called, "food stamps." Link benefits can only be used for food items. Like other benefits, if your earned income increases, your Link amount decreases.

The Illinois Link program lets you use the Illinois Link card, similar to a bankcard, to spend your benefits. You will select a secret Personal Identification Number (PIN) by calling the toll-free Help Line (1-800-678-LINK) or by going to the web site at www.Link.Illinois.gov.

Your Illinois Link card and PIN let you use your benefits that the Illinois Department of Human Services (DHS) deposits into an account - just for you. Once your benefits are deposited in your account and you have selected your PIN, you can begin using those benefits with your Link card.

Information you should know

- •You will receive your Illinois Link card through the mail at the address you gave to your local DHS office. Please allow seven (7) days for mail delivery.
- •You must have a PIN before you can use your benefits. You can call either the toll-free Help Line number or use a computer and go to the web site www.Link.Illinois.gov to select your PIN. The Help Line number and the web site are printed on the back of your Illinois Link card and in this pamphlet.
- •The first time you call to select your PIN, you will need the 19-digit number on the front of your Link card.
- •You must keep your card and PIN safe and private. If you think someone else has your Illinois Link card or PIN, you must call the Help Line or go to the web site to report your Illinois Link card as lost or stolen.

 84



Illinois Link Program

Information You Should Know Continued...

- •If you give your card and PIN to someone else and they use your benefits-your benefits will NOT be replaced. Remember: Never tell anyone your PIN. Do not write your PIN on your card. Do not carry it with you in your purse, wallet, or billfold or where someone could find it. Keep your card away from electronic equipment (like TVs, microwaves) and magnets. Keep your card out of direct sunlight, like a car dashboard
- •You are responsible for using your benefits and taking care of your Illinois Link card and PIN
- •You can use the toll-free number (1-800-678-LINK) or the web site at www.Link.Illinois.gov to get a history of your card use, check your benefit balances, select a PIN, report a lost, stolen or damaged Illinois Link card or request a replacement card by mail. Please allow seven (7) days for mail delivery.
- •You should keep this pamphlet with you because it contains important information that you can read again later if you need to.
- •If you would like to have your cash benefits deposited directly into your bank account instead of your Link card, contact your DHS office.

DO NOT THROW YOUR ILLINOIS LINK CARD AWAY. YOU WILL NOT RECEIVE A NEW CARD EACH MONTH.



-Guardianship

-Wills

-Power of Attorney

- Special Needs Trusts

Certainly one of the most intimidating factors of future planning are the legal procedures and steps that must be taken. These alone are enough to make anyone take pause. This section will explain the importance of four of the most critical legal elements of future planning and will provide resources necessary to utilize as you go through this process.

Guardianship Power of Attorney Wills and Trusts







Guardianship

A guardianship proceeding allows a court to give someone the authority to make decisions and manage the affairs of a person who, because of a disability, cannot manage his or her own affairs.

If your child is 18-years-old and needs help making decisions about finances and/or health care, it is imperative that you obtain **guardianship** so that you have the legal right to make decisions on behalf of the person with a disability. This must be done through the court system where a judge will determine if guardianship can and should be granted. You really need to get the courts to recognize your child's inability to make appropriate decisions in order for you to continue helping them along in these important steps to obtain adult services once they age out of the school system.

Do all people with disabilities need a guardian?

No Just because a person has a mental or physical disability does not mean that he/she must have a guardian. A good question to ask is -- can they manage their personal affairs by making decisions regarding money, understand and sign consents for medical treatment or medications and other critical factors. More often than not the answer is no which is why it's so important to establish guardianship and to do it before it's too late.

There are several steps involved when petitioning for legal guardianship. Your PAS agent will point you in the right direction..

89

Guardianship Power of Attorney Wills and Trusts







Power of Attorney

As a parent or primary caregiver of a child with developmental disabilities, it is imperative that you file for power of attorney before the child reaches their eighteenth birthday. This assures that the family retains control of the dependants' affairs.

A power of attorney is an authorization to act on someone else's behalf in a legal or business matter. Just as important as obtaining guardianship, your child will need guidance when making decisions and handling affairs.

How do we get Power of Attorney?

Start by finding an attorney in your area with experience in Disabilities law. Don't hesitate to call their offices and ask them what their experience is in getting power of attorney for special needs children. Make sure you have your child's paperwork in order such as their birth certificate and medical records including their letter of diagnosis and all medications your child is on. You can have your pharmacist print a list of all current medications. This will be critical in backing up your child's diagnosis.

Your lawyer will fill out the necessary paperwork and file you request for power of attorney with a local court. This can happen the same day or take several weeks depending on the courts case load. It is important to start the proceedings a few months prior to the child's eighteenth birthday!

Guardianship Power of Attorney Wills and Trusts







What is a Will?

A will or testament is a legal declaration by which a person names one or more persons to manage their estate and provides for the transfer of property at death.

In the strictest sense, a "will" has historically been limited to real property while "testament" applies only to dispositions of personal property thus giving rise to the popular title of the document as "Last Will and Testament", though this distinction is seldom observed today. A will may also create a testamentary trust that is effective only after the death of the person. Remember, any assets given to your son or daughter with a disability may disqualify them from any Social Security or state benefits. Any time there is a child with disabilities involved, it is even more important to take the time planning for the future of that child.

What is a Living Will?

Living Wills are instructions given by individuals specifying what actions should be taken for their health in the event that they are no longer able to make decisions due to illness or incapacity, and appoints a person to make such decisions on their behalf. A living will is one form of advance directive, leaving instructions for treatment. Another form authorizes a specific type of <u>power of attorney</u> where someone is appointed by the individual to make decisions on their behalf when they are incapacitated. People may also have a combination of both. It is often encouraged that people complete both documents to provide the most comprehensive guidance regarding their care

91

Guardianship



Wills and Trusts



Special Needs Trusts

Special Needs Trusts allow a disabled individual to receive lawsuit settlements, gifts and other funds while retaining eligibility for government programs such as Medicaid, Medicare, SSI and SSDI. They are designed not to provide basic support, but to pay for things like education, recreation, counseling and medical attention.

Special needs can include medical and dental expenses, special equipment (such as vans for the disabled), training and education, insurance, transportation, special dietary needs, spending money, electronic equipment, computers, vacations, movies and payments for a companion. While the term trust tends to imply great wealth, many special-needs trusts contain less than \$100,000. Because the trust does not belong to the disabled person but is used to supplement a lifestyle, it does not compromise government benefits.

Still, many parents are reluctant to start a trust because they fear making the wrong decision, do not want to face the idea that one day they will be unable to care for their child, or do not know how to establish one or whom to ask. In addition, they may not like the notion of putting their child on what is perceived to be welfare.

Some may believe they can avoid drawing up a trust by leaving the money to a trusted relative or friend. Specialists universally discourage that. Even people who intend to follow up on a moral obligation to care for the disabled child could lose the money in a divorce, bankruptcy, lawsuit, premature death or other unforeseen calamity, specialists say." For more answers to questions about Special Needs Trusts, contact a law firm that concentrates its practice in the area of Estate Planning Law

COMMON DEFINITIONS AND ABBREVIATIONS

ADA- American's with Disabilities Act.

CASE- Cooperative Association for Special Education.

CILA- Community Integrated Living Arrangement

CLF- Community Living Facility

COD- College of DuPage

CRA- Community Residential Alternative.

CSLA- Community Supported Living Arrangement.

DAVEA- DuPage Area Vocational Education Authority.

DD- Developmental Disabilities

DHS- Department of Human Services

DHS-ORS- Department of Human Services, Office of Rehabilitation Services (formerly DORS)

DMHDD- Department of Mental Health and Developmental Disabilities.

DPA- Department of Public Aid (now called DHS)

DRS- Department of Rehabilitation Services

DT- Developmental Training

ED- Emotionally Disturbed

EMH- Educable Mentally Handicapped

ICF- Intermediate Care Facility

IEP- Individual Education Plan

ISBE- Illinois State Board of Education

JTPA- Job Training Placement Act

LADSE- LaGrange Area Department of Education.

LD- Learning Disability

MI- Mentally Ill

MR- Mental Retardation

NDSEC- Northeast DuPage Special Education Association.

NEDSRA- Northeast DuPage Special Recreation Cooperative.

OT- Occupational therapy

PAS- Independent Service coordination Agent

PT- Physical Therapy

PUNS- Priority Utilization of Needed Services

RTA- Regional Transportation Authority

SASED- School Association for Special Education in DuPage County.

SEASPAR- Southeast Association for Special Parks and Recreation.

SEP- Supported Employment Program.

SGA- Substantial Gainful Activity

SLA- Supported Living Arrangement

SSDI- Social Security Disability Income.

SSI- Supplemental Security Income

TMH- Trainable Mentally Handicapped

TPC- Transition Planning Committee

TWP- Trial Work Period

WDSRA- Western DuPage Special Recreation Association.