The Arc of Illinois

The Arc Fact Sheet Book

Produced by The Arc of IL

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The Arc
Illinois

June 2022

On behalf of The Arc of Illinois, we are happy to provide you with a copy of our most requested Fact Sheets in booklet form. This collaborative effort was made possible by both retired and current staff members from the IL Life Span program, Ligas Family Advocates, and Family to Family Health Information Center.

We hope you find this useful and encourage you to reach out to The Arc to provide feedback. Additional copies can be found on our website.

Sincerely,
Amie Lulinski, PhD, FAAIDD
Executive Director

Rocio Perez
Director of Illinois Life Span

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Disclaimer: The information listed in this booklet is current as of May 16, 2022.

Advocacy | Family Support | Training | Resources

Happy lives with full participation in community. That has been the vision of families for their loved ones with intellectual and developmental disabilities, since they created The Arc of Illinois. The Arc of Illinois is a non-profit that has grown into the largest statewide advocacy organization of people with disabilities, their families and community agencies that support them.

We bring together advocates, connect people and families, train and educate, and provide resources and support. Learn about our programs and public policy work, which are still led by individuals and families, who are changing systems and living the lives they choose.

We invite you to be a part of our vision. Join us today!

The Arc®
Illinois

www.thearcofil.org
info@thearcofil.org
815.464.1832

The Arc Illinois

www.thearcofil.org | info@thearcofil.org | 815.464.1832

Illinois Life Span

Information & resources across the life span

The Illinois Life Span Program provides information and resources on advocacy, supports and services for individuals with intellectual and developmental disabilities of all ages, their family members, and other stakeholders across the state via website and toll-free help line.

www.thearcofil.org/illinoislifespan
illinoislifespan@thearcofil.org
Toll Free: 1.800.588.7002 / 815.464.1832 x1028
Español: 708.218.1958

Family to Family Health Information Center

Information & resources for families of children under 22

The Family to Family Health Information Center, the Illinois affiliate of Family Voices of Illinois, provides information and resources specifically for families of children and youth with any disability, special needs and/or chronic illness. We focus especially on healthcare and benefits issues.

www.thearcofil.org/familytofamily
familytofamily@thearcofil.org
Toll Free: 866.931.1110 / 815.464.1832 x1029
708.218.1958 (Español)

Family Support Network of Illinois

Support for individual & family advocacy

The Family Support Network supports individuals and families advocating for individual funding, services and community resources that meet individual needs and are key for independent living.

Ligas Family Advocate Program

Information & support for the PUNS waiting list

The Ligas Family Advocate Program works with the State of Illinois Independent Service Coordination agencies and providers to ensure that information about all available options for services reaches consumers over 18 years of age and their families.

Family Transition Project

Support in transitioning to community living

The Family Transition Project supports individuals and families who want to explore the possibilities of community living, for those currently living in large institutions.

Consumer Stipend Program

Stipends to attend conferences

The Consumer and Family Stipend Program provides financial assistance so that individuals or their family members can attend a conference of their choice – provided the conference is related to intellectual and developmental disability issues.

Assistive Technology Fund

Assistive technology access

The Assistive Technology Fund purchases assistive technology devices for individuals with intellectual and developmental disabilities who have an evaluation from a qualified provider and do not qualify for AT through Medicaid, Medicare or private insurance.

Training Department

Training in advocacy

The Training Program offers educational conferences and trainings for self-advocates, family members, and professionals.

The Arc of Illinois is grateful for program support from the Illinois Department of Human Service and the Illinois Council on Developmental Disabilities

April 2021 Update
PUNS, The Basics

What is PUNS and why is it important?
PUNS is the name for the list of the people in Illinois with developmental disabilities who want or need services, but do not yet have funding. Individuals who need help from the government to pay for needed Division of Developmental Disabilities Waiver services now, or in the future, should register for PUNS.

To get on the PUNS list, one must have a developmental disability (DD). The Independent Service Coordination Agency (ISC) will determine eligibility.

The Independent Service Coordination Agency is the "doorway" to PUNS and funding for services.

Through Medicaid, a person with DD is entitled to access institutional services (Intermediate Care Facilities), not DD Waiver services. Individuals with DD do not need to be on the PUNS to access an Intermediate Care Facility (ICF/DD). In Illinois, there is a wait for DD Waiver services and one must join the PUNS list unless in crisis (homeless, abused, or neglected). If the consumer is in crisis, speak directly to the ISC. Crisis situations are addressed outside of the PUNS waiting list.

Some of the services funded by the Medicaid waiver programs that may be needed are:

- In-Home Supports
- Job Coaches
- Community Day Services
- Residential Services
- Therapy Services
- And many others

How to get on the PUNS list

To get someone on the PUNS list, a date for a PUNS interview needs to be arranged with the local Independent Service Coordination Agency (ISC). The ISC is the "doorway" to PUNS and funding for DD Waiver services. Questions about the individual and his/her needs are part of the PUNS enrolment process.

The PUNS list is a waiting list for Medicaid waiver funding to pay for services, provided through the IL DHS Division of Developmental Disabilities (DDD).

Don't forget to update the PUNS form every year. Only those who have completed the PUNS - and keep it updated - have a chance to be "selected" to receive services. Watch the U.S. Mail for a letter alerting the consumer that a PUNS annual update is due. If the consumer does not get a letter, call the ISC to schedule an update appointment.

How to find the ISC

To find the ISC for the individual seeking services, call any of The Arc Programs listed on the final page of this document. Contact the DHS Customer Help Line at (800) 843-6154 or go to the Illinois DHS Office Locator and choose "Developmental Disability Services" as the Office Type, along with your county. DHS Office Locator: https://www.dhs.state.il.us/page.aspx?module=12

The PUNS list is a wait list

PUNS is a database, or list, of individuals who want or need Developmental Disability waiver services funded by the Illinois Department of Human Services/Division of Developmental Disabilities. Individuals are selected from the PUNS waiting list and invited to apply for DD Waiver services.

From the Ligas Implementation Plan, 5/3/19. *"Effective August 2017, PUNS categories were revised to "Seeking Services" (for those who want supports now) and "Planning for Services (for those who do not currently want or need supports but may in the future)." Future PUNS selections will be based*

on the length of time an individual has spent in the Seeking Services category since the age of 18."

There are now two PUNS categories. The two categories are **Seeking Services**, for people who currently need or desire supports, and **Planning for Services**, for people who do not currently want or need supports but may in the future.

PUNS selections are based on a person's cumulative length of time in the Seeking Services Category since the age of 18. *Note: If you are not in the Seeking Services Category and you are currently in need of supports, you must request that your (Independent Service Coordination (ISC) Agency move you to the Seeking Services category.*
www.dhs.state.il.us/page.aspx?item=41131

Thanks to the ongoing Ligas Consent Decree, the Division of Developmental Disabilities plans that by 2025, a person age 18 or older in the Seeking Service Category will be selected from the PUNS in 60 months or 5 years. This means that by 2025, a person in the Seeking Services category at age 18 would receive a PUNS selection at age 23, and by 2025 a person who moves to Seeking Services at age 26 will receive a PUNS selection at age 31, etc. Time on the PUNS in the Planning for Services category does not count toward a PUNS selection.

ISCs will enroll individuals in the Seeking Services category who are in any of these situations:

- Persons whose caregiver is clearly progressing toward being unable to provide care for any number of reasons (age of the caregiver, physical/psychological/health condition of caregiver, health or other situation of the individual). The individual and/or family are coping for now but supports are needed.
- The individual him/herself has a deteriorating situation, which requires formal supports.
- Cases where, although the caregiver and person with developmental disabilities have not been directly affected, a death in the family (especially of a care giver's spouse or other family member who may have assisted in

providing care) or other circumstance has affected their situation requiring a need for additional support.

- Situations where the caregiver(s) must work to provide income to pay the rent, etc. If services are not provided, the caregiver(s) would have to remain at home to provide support, and effectively be unable to continue working.
- Persons who have (or will shortly) graduate from school and will need day supports (i.e., there are no other employment or other day support options available/planned).
- Person is dissatisfied with current setting and would like to have DD residential services.
- Person prefers to live in his/her own home rather than in a funded residential setting but would need supports to do so.
- Person currently lives in out-of-home residential setting that is not funded by the Division of DD and wishes to return to their family home (and family concurs). The family is capable of providing care but would like support to return this person to the home.

ISCs will enroll in the Planning for Services category individuals who are:

- Not currently seeking services but will be seeking if something happens to the caregiver (e.g. caregiver becomes ill or passes away) or other family circumstances change.
- Currently receive funding or services through entities other than DD, and whose eligibility will be terminating primarily due to the age of the individual. This person is not in crisis and does not have a current need or desire for DD services. This might include, but is not limited to, persons who are funded through:
    - Early, Periodic Screening, Diagnosis and Treatment (EPSDT) program
    - Medically Fragile/Technology Dependent Children's Waiver
    - Individual Care Grant supports through the mental health system
    - Illinois State Board of Education or public school system. www.dhs.state.il.us/page.aspx?item=68933

From the Independent Service Coordination Manual, posted July 2019.
"PUNS selections for Waiver services will occur as funding is available. Selections will be based on a person's cumulative length of time in the Seeking Services Category after age 18. Selections will not be made from the Planning for Services category. If the individual enrolled in PUNS before turning age 18, the length of time begins calculating on the individual's 18th birthday provided that they are in the Seeking service category. In order to move from one category to the other, individuals and/or guardian must notify their ISC. Movement from one category to the other is not automatic."

The waiting time on the PUNS list has been lengthy. It is possible to find out when one is likely to be selected by sending an email with name of the individual, address, birthdate, and the name of the ISC to the following address. DHS.DDD.PUNS@illinois.gov.

Please keep in mind that many factors influence the PUNS list and it changes frequently. There is a possibility that a selection may occur slightly earlier or later than estimated. All estimates of selection and funding availability are subject to appropriation by the Illinois Legislature.

From the Ligas Implementation Plan, Exhibit A, 5/3/19.
"PUNS selections will be tailored such that by the FY2025 selection, no individual will wait on PUNS for over 60 months. For individuals who are added to the PUNS list before their 18th birthday, the 60-month period will begin when the individual turns 18." *Please note that the individual must also be in the "Seeking Services" category.

Crisis
Children and adults on the PUNS experiencing a crisis (homelessness, abuse or neglect –see https://www.dhs.state.il.us/page.aspx?item131772 can call their ISC to request consideration of a crisis application for waiver funding.

Children and PUNS

Although very few children have been funded for services except in crisis situations in recent years, there are still Medicaid waiver programs in place for children and youth. Those with current or anticipated future needs are encouraged to complete the PUNS process to get on the PUNS waiting list. A PUNS interview can be requested for children age 2.5 years and older with developmental disabilities.

For more information . . .

If you want more information about PUNS or DD Waiver services, the following Programs of The Arc of Illinois may be helpful:

- Family to Family Health Information Center
  www.familyvoicesillinois.org
  866-931-1110
- Illinois Life Span Program
  www.illinoislifespan.org
  1-800-588-7002
- The Ligas Family Advocates Program
  www.ligasfamilyadvocateprogram.org
  708-331-7370
- Family Support Network
  www.familysupportnetwork.org
  708-331-7370
- The Arc Spanish Helpline - Linea de Información en Español
  708-218-1958

Arc of Illinois staff members are also available to talk about other possible options, programs and services for your family member with a developmental disability.

Resources for Special Education Assistance

There are two **Parent Training & Information Centers** in Illinois. These PTICs can:

- Assist parents of children with disabilities to be informed participants in the special education process.
- Assist students with disabilities to understand their rights and responsibilities.
- Supply information to teachers and other professionals who provide special education and related services to children with disabilities.

1) **Family Resource Center on Disabilities** (FRCD) is the Parent Training & Information Center for the Chicago and collar county area. You can find more about their work and their contact information at www.frcd.org. For Spanish: https://frcd.org/category/recursos-en-espanol/

2) **Family Matters Parent Training & Information Center** (FMPTIC) is the resource available for all other Illinois counties. You can learn more about FMPTIC at www.fmptic.org.

Equip for Equality is the Protection and Advocacy Agency for people with disabilities in Illinois. They provide help with special education rights and responsibilities through the information available on their website, trainings, and a Special Education Help Line. You will find their website at https://www.equipforequality.org/issues/special-education/

The Illinois State Board of Education (ISBE) has a **Facilitated IEP Program** that is free and available to families. You can learn more about this service at https://www.isbe.net/pages/iep-facilitation-system.aspx

The **Parent Rights Handbook** from the Illinois State Board of Education (ISBE) is a must-have resource for families of children receiving special education services. Available at the following link in both English and Spanish. https://www.isbe.net/Pages/Special-Education-Parents-of-Students-with-Disabilities.aspx

Susy Woods is an Educational Advocate who works for the Illinois Assistive Technology Program. You can reach Susy by email at swoods@iltech.org or via phone at 217.638.8411.

Council of Parent Attorneys & Advocates (COPAA) is a national organization with a Directory of Parent Attorneys/Advocates that includes Illinois. Look for the Directory tab at the top of the Home Page on their website at https://www.copaa.org/

Local **Centers for Independent Living** (CILs) sometimes have special education or IEP support available but this differs from CIL to CIL. You can find the CIL that serves your area at www.incil.org.

The Arc@School – Through The Arc@School, The Arc provides training, and resources to help families and other stakeholders navigate the special education system. https://thearcatschool.org In Spanish at https://thearcatschool.org/en-espanol/

Loyola University Law School provides **Stand Up For Each Other (SUFEO) Chicago** - a student-run organization that provides **free** information and services for K-12 students facing suspension, bullying, or exclusion from school. SUFEO law students operate a **helpline,** supervised by attorneys in the *Civitas* Child Law Clinic. After a brief intake, SUFEO can provide information, referrals, advice, and, in some cases, representation for K-12 students in school-based meetings, on issues such as:

- Suspension appeals
- Bullying complaints and investigations
- Safety planning meetings
- Individualized Education Program (IEP) meetings
- Manifestation Determination Reviews (MDRs)
- Records appeals

Contact: 773-800-0338 (phone) sufeo-chicago@luc.edu (email)

Finally, it is very important to thoughtfully consider your advocacy choices. See the following for advice on **How to Choose a Lay Advocate in Special Education**. https://www.isbe.net/Documents/lay_advocate_guideline.pdf

Supplemental Security Income (SSI)

Information to help families and individuals with intellectual/developmental disabilities understand and plan for SSI.

Planning for SSI

For many individuals with intellectual/developmental disabilities (ID/DD), Supplemental Security Income (SSI) is a very valuable source of funding. Families want to make informed decisions about future planning for their loved one with ID/DD and it is a complex process. Even though most people don't qualify on their own financial record until they reach age 18, families need to understand the various SSI restrictions long before that. Parents/caregivers can begin to educate themselves in the early years of their child's life by attending trainings on these issues shared by legal and benefits experts, hosted by The Arc of Illinois and others. Cautious use of the internet can also provide helpful information.

Simply being diagnosed with an ID/DD or having had an Individual Education Plan in school does not qualify an individual for SSI. It is important for parents of children with a diagnosis of ID/DD to keep information that provides proof and creates a paper trail proving that the child has an ID/DD. This includes but is not limited to medical reports, medication lists, psychological evaluations, psychiatric evaluations or hospitalizations, school evaluations, reports from therapists, and copies of Individual Education Plans (IEPs).

Rules and policies pertaining to SSI are determined at the Federal level. Families must update their knowledge on SSI frequently to assure compliance.

When considering assets, SSI currently has a three year look back. Because of this look back period, a professional should be consulted when moving or cashing in assets.

Assets and SSI

There is an asset test or a maximum amount allowable in assets to qualify for SSI. Assets are things that you own. Assets include: cash, checking and savings accounts, stocks, bonds, savings bonds, money market, cash value of life insurance, non-homestead property, vehicles and anything else of value that you own. If the individual applying is under 18 years of age, parental assets are used in the determination. Assets that parents may hold in a foreign country (i.e. house/land) are also counted.

Often parental assets exceed the maximum, disallowing the child from SSI. Unless parental assets fall below the allowable limits, which are based on a percentage of the poverty level, the child will not qualify as a minor. The application process is less complicated after the child's 18 birthday as parental assets are no longer counted. In order for parental income and assets to NOT count for a child, apply for SSI AFTER the child has turned 18. The child must be 18 on the first of the month

that you apply. Example**:** Zach turned 18 on December 11. December 1st he was 17 so his parent's income and assets will count if they apply in December. The first time Zach could apply for SSI where parental income and assets would NOT count would be January because he was 18 on the first of January.

How to Apply

An application for SSI can be filed in person or online, but not everyone is eligible to apply online. Children's SSI and some adult applications are not available online. Learn more about the exceptions here: https://www.ssa.gov/benefits/ssi/

Call 1-800-772-1213 to schedule your appointment. This is helpful especially if you need a bilingual Social Security staff. You can also schedule an appointment online.

Children who received SSI must reapply as adults. More information is available in the SSA publication "*What You Need to Know About Your SSI When You Turn 18",* available at: https://www.ssa.gov/pubs/EN-05-11005.pdf

SSA has free Disability Starter Kits (one for children up to age 17, and one for adults age 18 and over) with all of the details, forms and directions to help you get ready to apply: https://www.ssa.gov/disability/disability_starter_kits.htm

In Illinois, a separate application has to be filed for Medicaid. The application for SSI typically is completed first, because eligibility for SSI verifies disability status. It's a good idea to attach a copy of your approval letter for SSI to your Medicaid application. **Keep copies of all documents!**

Communication Access and More Information

Regarding communication access, SSA provides all services in English and in Spanish. Additional translated materials and interpreter support are available in another 18 languages at: https://www.ssa.gov/site/languages/en/ For more information see the SSA Language Access Plan: https://www.ssa.gov/pubs/LAP2018-19.pdf

Helpful information from the Social Security Administration:

1. *Understanding Supplemental Security Income How Someone Can Help You With Your SSI* -- 2019 Edition - https://www.ssa.gov/ssi/text-help-ussi.htm
2. The '*Red Book*" can be found at SSA.gov and this resource has detailed information regarding SSI - https://www.ssa.gov/redbook/
3. *What You Need to Know When You Get SSI* - https://www.ssa.gov/pubs/EN-05-11011.pdf
4. *Working While Disabled: How We Can Help* -https://www.ssa.gov/pubs/EN-05-10095.pdf
5. *How You Earn Credits* - https://www.ssa.gov/pubs/EN-05-10072.pdf
6. *What You Need to Know about Your SSI When You Turn 18* - https://www.ssa.gov/pubs/EN-05-11005.pdf
7. Get started to apply for SSI: Get Started to Apply for SSI | SSA

DRS & DDD ADULT IDD WAIVER PROGRAMS: COMPARISON OF ELIGIBILITY AND SERVICES

IL Division of Rehabilitation Services (DRS) Medicaid waiver Home Services Program or the IL Division of Developmental Disabilities (DDD) Home-Based Services Program/Community Integrated Living Arrangement (CILA)

Individuals with disabilities can receive funding for services through only one Medicaid waiver. Some people with I/DD selected from the PUNS have been receiving services through the DRS Home-Services Program and must make a choice whether to stick with the DRS waiver or begin the application for services through the Adults with DD Waiver. This chart offers a comparison of the differences between the DRS and Adults with DD Medicaid waivers that must be considered when making this choice.

DRS Medicaid Waiver
www.illinois.gov/hfs/MedicalClients/HCBS/Pages/disabilities.aspx

Home Services Program
Union membership that offers health care for personal assistant (PA); union sets PA hourly wage

Eligibility: Under age 60 with severe disability lasting at least 12 months or life, imminent risk of health facility placement

Services include: PA/In-home Service -PA hours based on determination of need (DON) score.

- Electronic Home Response System
- Home-Delivered Meals
- Adult Day Care (ADC)
- Assistive Equipment
- Environmental Modification
- Respite
- Homemaker
- Nursing/Intermittent Nursing
- Therapies (PT/OT/Speech)
- Home Health Aide
- Specialized Medical Equipment
- Supported Employment (SEP)*

NOTE: No Community Day Services Programming

Specialized services: 12 week Vocational Training (Blind/Visually Impaired) • Employment Assistance (Deaf/Hard of Hearing) • Bilingual Staff Assistance (Hispanic/Latino) • 2-4 year Illinois state college financial assistance

For example, in 2019 (remember that hours awarded are based on NEED and will vary from individual to individual) 120 hours month awarded at $13.00 an hour comes to about $1560.00 per month.

DDD Medicaid Waiver — HBS
www.dhs.state.il.us/page.aspx?item=52665

Home-based services from monthly allotment of 3 X SSI

Eligibility: IQ of 70 or below before age 18 OR related condition before age 22 with significant life skill deficits in 3 of 6 major life areas (self-care, language, learning, mobility, self-direction, capacity for independent living)

Services include:

- Individualized Service and Support Advocacy
- Supported employment (SEP)*
- Behavior Counseling (Individual and Group)
- Behavior Intervention and Treatment
- Psychotherapy
- Support Services Team
- PT/OT/Speech Therapy*
- Adaptive Equipment*
- Assistive Technology*
- Home Accessibility & Vehicle Modifications*
- Self-Direction Assistance
- Personal Support
- Temporary Assistance (if personal support worker unavailable)*
- Nursing
- Emergency Home Response Services
- Transportation (non-medical)
- Training and Counseling for Unpaid Caregivers
- Out of home respite
- Adult Day Care*
- Community Day Service (CDS) program
- Temporary Intensive Staffing (in CDS program only)*
- Other Day Program (formerly sheltered workshop)*

For example, in 2019 (remember that the amount is not variable and will be the same for every individual) =$2313/00 per month (3 X SSI per month) to use for approved services

DDD Medicaid Waiver — CILA
www.dhs.state.il.us/page.aspx?item=52665

Community Integrated Living Arrangement
Group or Host Home (24/7 care) or Intermittent/Family CILA (<24/7)

Eligibility: IQ of 70 or below before age 18 OR related condition before age 22 with significant life skill deficits in 3 of 6 major life areas (self-care, language, learning, mobility, self-direction, capacity for independent living)

Services include:

- Individualized Service and Support advocacy
- Residential Habilitation
- Community Day Service (CDS) program
- Temporary Intensive Staffing*
- Supported Employment (SEP)*
- Adult Day Care*
- Other Day Program (formerly sheltered workshop)*
- PT/OT/Speech Therapy*
- Behavior Counseling (Individual and Group
- Behavior Intervention and Treatment
- Psychotherapy
- Adaptive Equipment*
- Assistive Technology*
- Home Accessibility Modifications*
- Vehicle Modification (as part of the transportation component of the residential rate)*

*Services that require both authorization and prior approval are marked with an asterisk. *See DHS DDD comparison chart offered at www.dhs.state.il.us/page.aspx?item=52665

The Arc Illinois
Ligas Family Advocate Program, The Arc of Illinois | 9980 190th Street, Suite C Mokena, IL 60448 | 815.464.1832 ext 1032 | www.thearcofil.org

DRS MEDICAID WAIVER OR DDD MEDICAID WAIVER? YOU CAN ONLY HAVE ONE

Questions to Consider:

What type of support services do you need during the day?

- Think about managing your money, shopping, cleaning, laundry, meal planning, cooking, transportation, medical needs – how could support in these areas help you be more independent?
- How do you get to where you would like to go? What transportation options are available?
- How many hours a week of Personal Support do you need? Are you able to safely be alone for several hours at a time, or do you need someone available for assistance all or most of each day?

Do you have physical support needs that may increase (or decrease) over time? Is nursing support an important piece of your daily life?

- If you currently have the DRS Waiver Home-Services Program your personal support hours can increase based on your needs whereas personal support in the DDD Waiver Home-based Services Program is limited to a monthly allotment of 3 X SSI/mo.

Do you prefer to manage your supports or that a provider do so?

- If you want to manage your services, you may opt for the DDD Home-based Services Program.
- If you want a provider to manage your services, you may prefer one of the 4 CILA options in the DDD waiver (two are 24/7 support and 2 are less than 24/7 support: group or host home/intermittent or family CILA)

Do you work now or are you seeking employment? If so, what supports do you need to help you be most successful?

Do you prefer to live alone, with your family, or with others?

- You can opt for services through the DRS waiver or DDD waiver no matter where you live
- You might want to explore permanent supportive housing — an affordable apartment with your own lease and supports that help you maximize your independence. If so you should discuss with your ISC about their getting you on the Statewide Referral Network.

The Arc of Illinois, Ligas Family Advocates

9980 190th Street, Suite C

Mokena, IL 60448

Program Director – Shirley Perez: shirley@thearcofil.org
(Northern IL) Mary Dixon: mary@thearcofil.org
(Central/Southern IL) Megan Mutti: megan@thearcofil.org

815.464.1832 ext 1032
www.thearcofil.org

The Arc Illinois

Planning For The Future

Resources to help guide families through the process of planning for the future.

Where to start?

The Arc is a great place to start, providing a variety of tools to help each step of the way.

Future Planning from The Arc of US

The Arc's Center for Future Planning® has resources to help people with I/DD and their families create future plans.
https://thearc.org/our-initiatives/future-planning/

The Arc Center for Future Planning

Learn details about what future planning entails, guides to help build your future plan with resources to help, see examples of how others have planned, and find help for urgent needs.
https://futureplanning.thearc.org/?_ga=2.157448248.347981663.1629922244-88651520.1484748314

Videos on Special Needs Trusts and ABLE

https://www.youtube.com/user/thearcoftheus

This fact sheet was developed for parents and caregivers, to provide access to a variety of resources spanning multiple topics of importance in the future planning process. It is in no way meant to be a comprehensive guide – but a helpful tool to begin the process.

The Arc of Illinois Fact Sheet: Community Living Options for Older Adults with Disabilities

Concise information to assist in comparing and contrasting the differences between Medicaid Waiver Services for elderly individuals, Supportive Living Program for Persons with Medicaid managed care, Medicaid waiver services for adults with I/DD through DHS Division of Developmental Disabilities and Intermediate Care Facilities for Adults with Developmental Disabilities through IDPH.
https://www.thearcofil.org/wp-content/uploads/2020/07/Options-for-Older-Adults-with-Disabilities-1.pdf

Additional Guides & Workbooks:

A variety of resources that have been developed across the United States

Future Planning Workbook - Arizona Developmental Disabilities Planning Council

A "roadmap" workbook designed to be used by individuals with intellectual and developmental disabilities, family members, direct support professionals, and advocacy groups to guide the planning process.
https://addpc.az.gov/future-planning-workbook-roadmap-our-futures-our-wishes

Pacer Center Resources on Future Planning

General guide and strategies for creating a Person-Centered Plan.
https://www.pacer.org/publications/possibilities/planning-your-childs-future.asp

Sibling Leadership Network – Future Planning Guide

Informative guide for helping siblings of people with disabilities to better understand their role as they navigate planning for their sibling's future.
https://siblingleadership.org/wp-content/uploads/2021/01/Future-planning-for-siblings-of-people-with-disabilities.pdf

Helpful Articles & Documents:

Articles and documents focused on future planning that may be helpful along the way

Exceptional Parent – Financial Planning Resources Page
https://www.epmagazine.com/blog/category/financial-planning

November 2020 Financial Planning Issue (New Version released every November)
https://reader.mediawiremobile.com/epmagazine/issues/206518/viewer

November 2019 Financial Planning Issue
https://reader.mediawiremobile.com/epmagazine/issues/205494/viewer

Letter of Intent – Rubin Law
A sample Letter of Intent Form
https://www.rubinlaw.com/resources/letter-of-intent-sample-form/

Special Needs Alliance
A national alliance of attorneys for special needs planning provides a number of great resources for those who are preparing and navigating the future planning process.
https://www.specialneedsalliance.org/information-center/pressroom/

Free Trustee Handbook
https://www.specialneedsalliance.org/special-needs-101/free-trustee-handbook/

Where to Find Professional Help:

A variety of organizations that offer helpful information and listings for professionals providing future planning assistance

Special Needs Alliance
This national organization offers a searchable listing of attorneys who

are members of the organization.
https://www.specialneedsalliance.org/find-an-attorney/

Special Needs Answers

"The Academy of Special Needs Planners consists of special needs planning professionals such as attorneys, financial planners and trust officers who provide the highest quality service and advice to persons with special needs and to their families." A searchable list of Illinois future planning professionals is available here.
https://specialneedsanswers.com/about-us

National Academy of Elder Law Attorneys – IL Chapter (NAELA-IL)

"The National Academy of Elder Law Attorneys, Inc. (NAELA) was founded in 1987 as a professional association of attorneys who are dedicated to improving the quality of legal services provided to seniors and people with special needs. The NAELA membership is comprised of attorneys in the private and public sectors who deal with legal issues affecting seniors and people with disabilities."
The webpage for Illinois has a Directory for finding member professionals.
https://naela-il.org/

Illinois Attorney General Kwame Raoul Legal Assistance Referrals

Statewide resources for pro bono and other legal assistance options.
https://www.illinoisattorneygeneral.gov/about/probono.html

For further assistance, please contact the Illinois Life Span Program of The Arc of Illinois during regular business hours at 1.800.588.7002 or via their website at www.illinoislifespan.org.