

# The Arc of Illinois

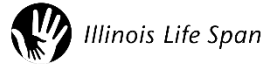
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## The Arc Fact Sheet Book

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**Disclaimer:** The information listed in this booklet is current as of May 1, 2024.





## 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!**



[www.thearcofil.org](http://www.thearcofil.org)  
[info@thearcofil.org](mailto:info@thearcofil.org)  
815.464.1832



**The Arc**  
Illinois

[www.thearcofil.org](http://www.thearcofil.org) | [info@thearcofil.org](mailto: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/illinoislifespanspan](http://www.thearcofil.org/illinoislifespanspan)  
[illinoislifespanspan@thearcofil.org](mailto:illinoislifespanspan@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/familytofamilyfamilytofamily@thearcofil.org](http://www.thearcofil.org/familytofamilyfamilytofamily@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.



### 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.



## September 2023 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 on the PUNS.

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

Through Medicaid, a person with DD is entitled to access institutional services (Intermediate Care Facilities). These facilities are not accessed through funding from the Adults with DD Waiver. 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 Adult 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.

*The Independent Service Coordination Agency is the “doorway” to PUNS and funding for services.*

Some of the services funded by the DHS -Division of Disabilities Medicaid Home and Community Based waivers 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 getting on the PUNS and to DD Waiver services. Questions about the individual and his/her needs are part of the PUNS enrollment 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.

There are 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](http://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 no later than 5 years.

**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.

<https://www.dhs.state.il.us/page.aspx?item=68933>

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](mailto: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.

**Crisis**

Children and adults on the PUNS experiencing a crisis (homelessness, abuse or neglect) can call their ISC to request consideration of a crisis application for waiver funding.

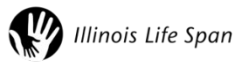
## **Children and PUNS**

PUNS selections for children have resumed after a period of about 12 years when few children were funded for services except in crisis situations. 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 a likelihood of developmental disabilities.

**For more information:** For Spanish: 708-218-1958

- Family to Family Health Information Center  
[www.familyvoicesillinois.org](http://www.familyvoicesillinois.org)  
866-931-1110
- Illinois Life Span Program  
[www.illinoislifespan.org](http://www.illinoislifespan.org)  
1-800-588-7002
- The Ligas Family Advocates Program\_  
[www.ligasfamilyadvocateprogram.org](http://www.ligasfamilyadvocateprogram.org)  
708-331-7370
- Family Support Network\_  
[www.familysupportnetwork.org](http://www.familysupportnetwork.org)  
708-331-7370
- The Arc Spanish Helpline - Línea de Información en Español





## 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](http://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](http://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>

**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](http://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](mailto: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](https://www.isbe.net/Documents/lay_advocate_guideline.pdf)







# Supplemental Security Income (SSI)

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

## Planning for SSI

For many individuals with intellectual/developmental disabilities (IDD), Supplemental Security Income (SSI) is a very valuable source of funding. Even though most people don't qualify on their own financial record for SSI until they reach age 18, families need to understand the various SSI restrictions long before that. Parents can learn early in their child's life by attending trainings on these issues shared by legal and benefits experts, hosted by The Arc of Illinois and others.

Simply being diagnosed with an intellectual or developmental disability (IDD) 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 IDD. This includes but is not limited to medical reports, medication lists, psychological evaluations, psychiatric evaluations/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 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. 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.

## 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/>

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-](https://www.ssa.gov/pubs/EN-05-11005.pdf)

[11005.pdf](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](https://www.ssa.gov/disability/disability_starter_kits.htm)

SSI denials based on disability status can be appealed, but if you are ineligible for SSI for financial reasons you cannot appeal. If you need a psychiatric evaluation as part of your SSI application, but cannot find one, you should submit your application anyhow and SSI will find a psychiatrist for the evaluation. 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/LAP2022-23.pdf> Additional helpful information:

- ✓ *Understanding Supplemental Security Income* <https://www.ssa.gov/ssi/text-understanding-ssi.htm>
- ✓ The 'Red Book' can be found at SSA.gov and this resource has detailed information regarding SSI: <https://www.ssa.gov/redbook/newfor2023.htm>
- ✓ *What You Need to Know When You Get SSI* - <https://www.ssa.gov/pubs/EN-05-11011.pdf>
- ✓ *Working While Disabled: How We Can Help* - <https://www.ssa.gov/pubs/EN-05-10095.pdf>
- ✓ *How You Earn Credits* - <https://www.ssa.gov/pubs/EN-05-10072.pdf>
- ✓ *Who Receives the full monthly maximum by paying pro rata share toward monthly operating expenses? (\$914.00 in 2023):* <https://www.ssa.gov/ssi/spotlights/spot-one-third-reduction.htm>

*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.*

Resources from 2022 (reflecting SSI amount from 2022) from The Arc of Northern Virginia:

<https://thearcofnova.org/programs-services/library/#social-security>

**Rental Agreement**

[Calculating Rent for Social Security Recipients in the Family Home](#) – This handout gives information and ideas for setting up a rental agreement and charging rent for adult children receiving Social Security benefits while still living in their family home.

[Sample Rental Agreement for SSA](#)

**Representative Payees**

[Representative Payees with Social Security](#)

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**Comparison of Adult 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 Adult Waiver Home-Services Program for Persons with Disabilities/ Persons with Brain Injuries(TBI) must make a choice whether to remain with the DRS waiver or begin the application for services through the Adults with DD Waiver. Please note two key differences: The DRS waiver offers funding that can increase as the complexity of the disability increases. DRS Home Services are mostly offered in one's home. Whereas, DDD home-based services can be offered outside of the home and are based upon a fixed funding award of 3 x SSI monthly program allotment.

**DRS Medicaid Waiver**  
[www.illinois.gov/hts/MedicalClients/HCBS/Pages/disabilities.aspx](http://www.illinois.gov/hts/MedicalClients/HCBS/Pages/disabilities.aspx)

**DDD Medicaid Waiver – HBS**  
[www.dhs.state.il.us/page.aspx?item=52665](http://www.dhs.state.il.us/page.aspx?item=52665)

**DDD Medicaid Waiver – CILA**  
[www.dhs.state.il.us/page.aspx?item=52665](http://www.dhs.state.il.us/page.aspx?item=52665)

<p><b>Home Services Program</b>                  Union membership that offers health care for personal assistant (PA); union sets PA hourly wage</p>	<p><b>Home-based services from monthly allotment of 3 X SSI (Adult)</b>                  Employer and personal support worker (PSW) negotiate an hourly rate for the PSW to be paid.</p>	<p><b>Community Integrated Living Arrangement</b>                  Group or Host Family (24/7 care) or Intermittent/Family CILA (&lt;24/7); DDD sets amount of individualized award</p>
<p><b>Eligibility:</b> Under age 60 with severe disability lasting at least 12 months or life, imminent risk of health facility placement</p> <p><b>Services include:</b> PA/In-home Service -PA hours based on determination of need (DON) score.</p> <ul style="list-style-type: none"> <li>- Electronic Home</li> <li>- Response System</li> <li>- Home-Delivered Meals</li> <li>- Adult Day Care (ADC)</li> <li>- Assistive Equipment</li> <li>- Environmental Modification</li> <li>- Respite</li> <li>- Homemaker</li> <li>- Nursing/Intermittent</li> <li>- Nursing</li> <li>- Therapies (PT/OT/ Speech)</li> <li>- Home Health Aide</li> <li>- Specialized Medical Equipment</li> <li>- Supported Employment (SEP)*</li> </ul> <p><i>NOTE: No Community Day Services Programming and or residential services</i></p>	<p><b>Eligibility:</b> 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); PUNS waiting list</p> <p><b>Services include:</b></p> <ul style="list-style-type: none"> <li>- Individualized Service and Support Advocacy</li> <li>- Support Services Team</li> <li>- PT/OT/Speech Therapy* - Adaptive Equipment*</li> <li>- Assistive Technology*</li> <li>- Home Accessibility &amp; Vehicle Modifications*</li> <li>- Self-Direction Assistance</li> <li>- Personal Support</li> <li>- Temporary Assistance</li> </ul> <p>(** when unpaid caregiver is unable to provide support due to a temporary absence.)</p> <p>The SSI monthly allotment is determined by Social Security. This amount is generally updated in January of each year.</p>	<p><b>Eligibility:</b> 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); PUNS waiting list</p> <p><b>Services include:</b></p> <ul style="list-style-type: none"> <li>- Individualized Service and Support advocacy</li> <li>- Residential Habilitation</li> <li>- Community Day Service (CDS) program</li> <li>- Temporary Intensive Staffing*</li> <li>- Supported Employment (SEP)*</li> <li>- Adult Day Care*</li> <li>- Other Day Program (formerly sheltered workshop)*</li> <li>- PT/OT/Speech Therapy*</li> <li>- Behavior Counseling (Individual and Group</li> <li>- Behavior Intervention and Treatment</li> <li>- Psychotherapy - Adaptive Equipment*</li> <li>- Assistive Technology*</li> <li>- Home Accessibility Modifications*</li> </ul>
<p><b>Non-Waiver Specialized services:</b> 12 week Vocational Training (Blind/ Visually Impaired) • Employment Assistance (Deaf/Hard of Hearing) • Bilingual Staff Assistance (Hispanic/Latino)</p>	<p><b>*Services that require both authorization and prior approval are marked with an asterisk. *See DHS DDD comparison chart offered at <a href="https://www.dhs.state.il.us/page.aspx?item=101181">https://www.dhs.state.il.us/page.aspx?item=101181</a></b></p>	

# Questions to Consider:

## What services does my adult child need to funding for?

- ☐ (ie. Personal Support, Community Day Services, Residential Services, etc)

## Where will the majority of services take place?

- ☐ In the home and the community
- ☐ At a residential setting
- ☐ Must take place in Illinois; waiver funding is non-transferable to another state

## How does each waiver provide my adult child with an amount of service?

- ☐ DRS assigns each individual a fixed number of personal care service
- ☐ DDD provides a fixed monthly amount to be allocated for personal support and other services

## Location of services:

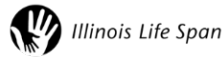
- ☐ A Personal Assistant (PA) paid through DRS Home Services Program enrolled in the persons with disabilities waiver provides some services exclusively within the home, which can include some community hours.
- ☐ A Personal Support Worker (PSW) paid through DDD can provide services in the home, in the community, and in an agency setting. (Note: if a person is being supported by a CDS provider, they're not allowed to receive and bill for PSW services during that time.)

**The Family Advocate Program**  
**The Arc of Illinois**  
**9980 190th Street, Suite C**  
**Mokena, IL 60448**

*Disclaimer- This is a broad explanation. More specific information can be provided by DDD or DRS.*

**815.464.1832 ext 1032**  
**[www.thearcofil.org](http://www.thearcofil.org)**





# 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=2.157448248.347981663.162992244-88651520.1484748314](https://futureplanning.thearc.org/?_ga=2.157448248.347981663.162992244-88651520.1484748314)

*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.*

## **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>

## **Letter of Intent – Rubin Law**

A sample Letter of Intent Form

<https://www.rubinlaw.com/resources/letter-of-intent-sample-form/>

## **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. Illinois list:

<https://www.specialneedsalliance.org/find-an-attorney/illinois/>

### **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/Legal-Assistance-Referrals/index>

*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](http://www.illinoislifespan.org).*



*Committed to empowering persons with disabilities to achieve full participation in community life through informed choices.*



9980 190<sup>th</sup> St, Suite C, Mokena, IL 60448  
815.464.1832 815.464.5292 (F)

[www.thearcofil.org](http://www.thearcofil.org)  
[info@thearcofil.org](mailto:info@thearcofil.org)