

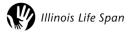
The Programs of The Arc: How Can We Support You?
Wednesday, May 1, 2024 – 1:30-2:30

Rocio Perez, Shirley Perez, Greg Walkington, Susan Agrawal

Goals for this morning

- Identify the programs of The Arc of Illinois
- Discuss the role of each program within the state
- Explore populations served by each program
- Discover how to connect with resources offered within each program





Illinois Life Span Team

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- Provides information and resources related to developmental disability services and supports statewide, for all ages.
- Monthly webinars designed with families in mind to share information of interest statewide and for all ages

Information provided by **toll-free helpline** at **1-800-588-7002**www.illinoislifespan.org







intellectual and developmental disabilities

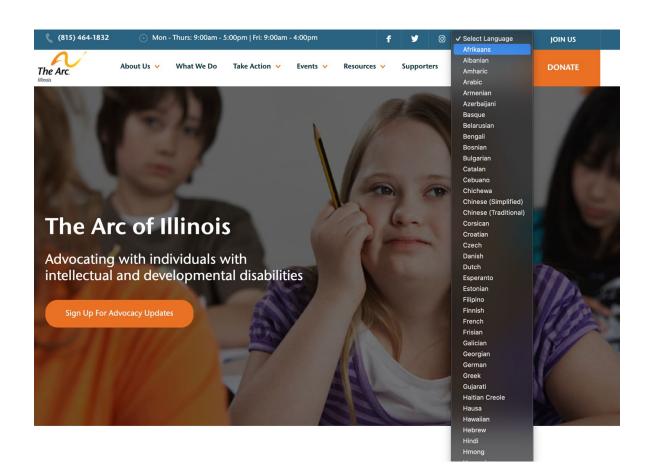
Important website locations

Sign Up For Advocacy Updates



Website Language Accessibility

To view web pages in other languages, go to right corner of main page select the language of your choice. Embedded documents do not auto translate





We can help direct people to the resources that best fit their needs!

1-800-588-7002

www.illinoislifespan.org

Search for Resources

The search buttons below will take you to frequently requested resources in your County and Statewide. If you can't find what you need or just want additional help, please call us at 1-800-588-7002.



www.illinoislifespan.org



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Illinois Life Span Program

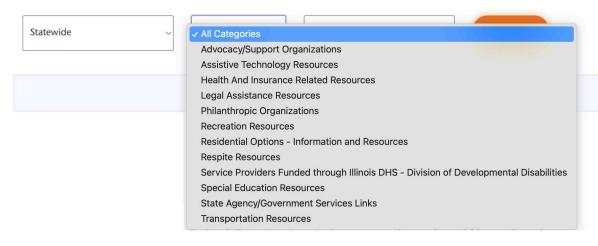
Statewide Resources and Information, Focused on Developmental Disability Services and Supports

Illinois Life Span (ILS) is a program of The Arc of Illinois – a statewide advocacy organization committed to empowering people with disabilities to achieve full participation in community life through informed choices.



Search for Resources

The search buttons below will take you to frequently requested resources in your county and Statewide. If you can't find what you need or just want additional help, please call us at 1-800-588-7002.



A "Statewide" search results in a lengthy list, organized by broad, general category. Categories include:

- Advocacy/Support Organizations
- Assistive Technology Resources
- Health and Insurance Related Resources
- Legal Assistance Resources
- Philanthropic Organizations
- Recreation Resources
- Respite Resources
- Service Providers IL DHS DDD
- Special Education Resources
- State Agency/Government Services Links
- Transportation Resources

A "County" search will yield a brief list of the most requested resources in a specific county.

Categories available are:

- Center for Independent Living
- Child & Family Connections Office
- Equip for Equality
- IL DHS DRS
- IGAC/HRA
- Independent Service Coordination Agency
- PTIC
- Support Groups





Find the Information You Need



Resource Toolbox

Advocacy information specific to available disability services and supports in Illinois, arranged by topic.

View Resource Toolbox >



Related Links

An extensive list of links to helpful resources, organized by category.

View Related Links >



Statewide Event Calendar

Discover upcoming programming, conferences, and trainings.

View Statewide Event Calendar >



Fact Sheets from The Arc of Illinois

Documents and information created by The Arc of Illinois and Programs of The Arc of Illinois

View Fact Sheets from The Arc >

View Fact Sheets from The Arc in Spanish >



Monthly Webinars

Where to go to find information about recorded Monthly Webinars

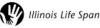
View Webinars >

View Webinars in Spanish ➤

All the information you need in one user-friendly location at:

www.illinoislifespan.org





Website Links

Camp Directories/Recreation Resources

Day Care and Early Childhood

Educational Information and Resources

Emergency Preparedness Information

Employment Related Links

Faith-Based Organizations and Information

Federal Government

Financial Assistance Resources

Group Specific Advocacy

Health and Human Services

Health Care Coverage and Access

Illinois Government / Program Resources

Information in Spanish

Laws and Information: Health Insurance

Manuals

Media Resources

Mental Health Resources

National Advocacy Organizations / Resources

Oral Health/Dental Care

Products and Services – ILS

Regional Resources for Illinois

Special Education: Conflict Resolution Resources

State Advocacy Organizations

State of the States in Developmental Disabilities

Transition Resources

Travel/Transport Resources

Related Links

Additional resources that are available on the *Illinois Life Span* website include an extensive list of Website Links that cover the following categories:



Ligas Family Advocate Program – Know Your Options

Join us to learn about options available following a PUNS selection or Early Notification of an upcoming PUNS selection. We will discuss the Medicaid Home and Community Based Waiver, support services, residential options, and key preparatory steps. We will review both Home-Based and CILA options and discuss how families have utilized funding to support their... Read more »

WED

May 8 @ 12:00 pm - 1:00 pm

Programa de Abogacía Ligas – Conoce Tus Opciones LFA

¿Recibió recientemente una carta de notificación anticipada o una carta de selección PUNS? Únase a nosotros para conocer sus opciones bajo la exención de Medicaid basada en el hogar y la comunidad para adultos con discapacidades del desarrollo en Illinois. Discutiremos las opciones de servicio y soporte, exploraremos el rol de su ISC, revise los... Read more »

TUE **14**

May 14 @ 12:00 pm - 1:00 pm

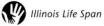
ILS & F2F Webinar Series: IL Assistive Technology Program

Presenters: Steve Daniels, Smart Home Manager Elizabeth Wright, Chef Instructor Jacqueline Gunther OTD, OTR/L, CAPS Join Illinois Assistive Technology Program (IATP) staff to learn about the wide variety of services available to all people with disabilities in the state of Illinois at IATP, and in particular two new programs, Smart Home and the Tech Kitchen.... Read more »

Statewide Events Calendar

Trainings/conferences sponsored or hosted by organizations across the State of Illinois. Arc of IL events including our webinars are also posted here.





The Arc of Illinois Fact Sheets

Fact Sheets in Alphabetical Order

Fact Sheets Books

Government Benefits

- Adults with Disabilities Living Options
- ▲ Adults with Disabilities Living Options Spanish
- **▶** Becoming A Dual Medicare-Medicaid Eligible Recipient
- ▶ Becoming A Dual Medicare-Medicaid Eligible Recipient Spanish
- DDD v DRS Comparison
- ▶ DDD v DRS Comparison in Spanish
- Diaper Fact Sheet
- Diaper Fact Sheet Spanish
- **▶** Family Guide to Medicaid Managed Care Appeals
- ► Family Guide to Medicaid Managed Care Appeals Spanish
- ▲ General Medicaid Questions
- **▲** General Medicaid Questions Spanish
- **▲ Illinois Health Benefits for Immigrants**
- ▶ Illinois Health Benefits for Immigrants Spanish
- SSI Supplemental Security Income
- SSI Supplemental Security Income in Spanish
- Understanding SSDI & Medicare
- Understanding SSDI & Medicare Spanish
- ▶ What is a Spenddown and Why Do I Have One?
- ▶ What is a Spenddown and Why Do I Have One?- Spanish

Adults on the DD Medicaid Waiver/PUNS

- ▲ Connect the Dots Transition Tool
- Connect the Dots Transition Tool Spanish

Fact Sheets

Developed by ILS and F2F to provide a list of easy-to-navigate resources based on the questions that are frequently asked.

(Available in English & Spanish)





Children's Services

Children's Services and PUNS Services for children with developmental disabilities are accessed primarily through the special education services provided by local school districts.

Special Education Services

Special Education Services are available to students with disabilities from age 3 until they graduate or until the day before their 22nd birthday, as long as the need for services is indicated in the Individualized Education Plan or IEP.

Transition

Before a family looks into any pre-designed program of transition for their child, it is important to have a vision of the child's future.

Government Benefits Program

Government Benefit Programs are an integral part of the service system for people with disabilities. Although they can be complicated, it is important to understand how to access and utilize these benefits.

Early Intervention

Early Intervention services are available in Illinois for children from birth to age three who demonstrate a developmental delay or who are diagnosed with a developmental disability.

Early Childhood Special Education

Early Childhood Special Education serves children ages three to five who have developmental delays or disabilities. These programs are part of the special education continuum operated by the public schools of Illinois.

Adult Services

Services for adults with developmental disabilities are accessed through Independent Service Coordination (ISC) agencies.

Advocacy Groups

Advocacy is a very broad category that includes organizations that support people with disabilities and their families in a variety of different ways.

Resource Toolbox

Provides an introductory overview of several important advocacy topics.



2024 Webinars



Adult Guardianship and Other Decision-Making Options

February 14, 2024

Presented by Sarah Hess, JD, Legal Council for Health Justice

Recording: Adult Guardianship and Other Decision-Making Options

Powerpoint presentation: Adult Guardianship and Other Decision-Making Options Slides



Supporting Survivors with Disabilities: Sexual Health and Abuse Prevention

January 9, 2024

Presented by Guardian Angel Community Services: Emily Morrisette and Breann Fisher

Recording: Supporting Survivors with Disabilities

Powerpoint presentation: Supporting Survivors with Disabilities Powerpoint

Monthly Webinars

Monthly webinars provide timely and relevant information on disability-related topics

Held on the second Tuesday of each month from Noon – 1:00 PM. Webinar recordings posted to "Monthly Webinars" page afterward





Programación (Webinars) en Español

Programación (Webinar) en Español – The Arc of IL

26 de marzo 2024, Disciplina y La Ley IDEA

Presentado por Maria Castillo Entrenadora Bilingue, Family Resource Center on Disabilities

Grabación de la presentación: Disciplina y IDEA Dispositivo de la presentación: Disciplina y IDEA

15 de marzo 2024, Programa de Participación del Consumidor – The Arc of IL

Presentado por Ruth Aguilar y Rocio Perez

Grabación del la presentación: Programa de Participación del Consumidor Dispositivo de la presentación: Programa de Participacion del Consumidor

23 de octubre 2023 – Opciones para La Toma de Decisiones

Presentado por Consuelo Puente abogada jubilada

Grabación de la presentación: Opciones para La Toma de Decisiones Dispositivo de la presentación: Opciones para La Toma de Decisiones

Material Suplementario:

Delegación de Derechos Escolares – español: Delegación – espanol

Delegación de Derechos Escolares – ingles: Delegacion- ingles

Formularios para completar el proceso de la Tutela para el Condado de Cook en el estado de Illinois: Formularios para el Condado de Cook

3 de octubre 2023 – Seguro de Salud para Ninos y Familiares Inmigrantes

Presentado por Daniela Velez-Clucas JD

Grabación de la presentación: Seguro de Salud para Ninos y Familiares Inmigrantes Dispositivo de la presentación: Seguro de Salud para Ninos y Familiares Inmigrantes

Webinars in Spanish

Webinars hosted by Spanish-speaking professionals focused on disability-related topics for our Spanish-speaking friends in the community.

Sign up for our newsletter to receive updates on our webinars hosted in Spanish.





102

Counties

6500+

Advocates

25k

People informed, supported and trained

Where to start?

Who to refer people to?

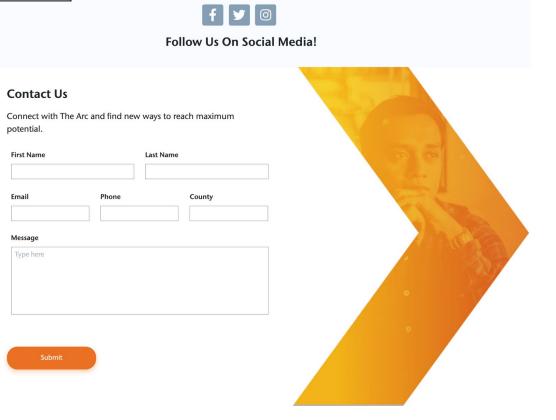




An email inquiry/request can be made via website.

It is located at the bottom of the home page.

Please complete the boxes and provide as much information as possible in the message section.



Top 5 Questions We Address:

- My child was recently diagnosed with IDD, what do I do now?
- I heard about PUNS, What is this? & How to I get on the PUNS list?
- I need help with my child's IEP. Where do I go for help?
- Public Benefits: I need help with Medicaid, SSI/SSDI, etc.
- Where can I learn more about guardianship options for my child?







The Ligas Family Advocate Program & The Family Support Network

The Ligas Family Advocate Program is generously funded by a grant from the Illinois Department of Human Services

The Arc.

Contact the LFA Program

- When an individual receives an Early Notification letter/PUNS selection
- When a family is seeking a connection to their ISC, Independent Service Coordination Agency
- When you are working with a family that needs education regarding the PUNS list and core components for the Adult Development Service System
- If you have a family seeking help in understanding options available to them under the Medicaid Home and Community Based Waiver



Who is a Ligas Class Member?

- You must be an adult (18 years or older) in Illinois, have an intellectual or other developmental disability and qualify for Medicaid Waiver services.
 Also...
 - Reside in ICFs-DD with 9 or more residents or in a family home
 - The state must have a current record of your request for community-based services or community-based living

*IF YOU HAVE QUESTIONS ABOUT THE CONSENT DECREE, SERVICES UNDER THE DECREE, OR HOW TO BECOME A MEMBER OF THE CLASS, PLEASE CONTACT LAURA MILLER (312) 895-7316.



Common Questions for LFA:



My child just received an Early Notification letter. What do we do next?



Does my adult child need to be on Medicaid to receive waiver services after a PUNS selection?



How do we find services in our area?



What should we consider when we are pursuing housing options?



How can a Self Direction Assistant help us with Home-based services?



Key Resources for Families

- Find you Independent Service Coordination Agency: http://www.dhs.state.il.us/page.aspx?module=12
- Illinois Consumer Handbook on Home-based Services: http://www.dhs.state.il.us/page.aspx?item=101181
- System Navigation Map for Families: PUNS Pathway <u>https://www.illinoislifespan.org/wpcontent/uploads/202</u> <u>0/02/PUNSFlowchart-for-print.pdf</u>
- CILAS vs Home-based at a Glance: <u>CILA-v-HBS-Support-Program-Infographic.pdf</u>
 (arcofil.wpenginepowered.com)
- Check out our webpage:

Ligas Family Advocate Program | The Arc of Illinois

*CILAS vs Home-Base Link-Please note that the monthly budget is 3xs the SSI amount, which as of 2024 is \$943.





Visit the LFAP Online:

Key Resources

Family advocates work to empower individuals and their families with the information they need to make informed choices. We understand the system can be confusing, which is why we provide the necessary tools and connections to ensure you and your family get the support you deserve.

- **▶ Self Direction Assistance Guidelines UPDATED 12.28.22**
- ▶ New! 11.22.22 LFA Special Topics: EP!C Home Host Webinar Webinar Recording
- ▶ New! PUNS Bilingual Webinar, 10.25.22 Passcode: PUNS10/25
- New! 7.27.22 LFA Special Topics: Home-Based Back-up Plans with Derek Hedges of the IL Division of Developmental Disabilities Webinar Recording, PowerPoint, and Responses to questions received during the presentation
- 10th Annual Informational Seminar Recording and Materials
- New Costs to You Rate − Effective January 1 2022
- SA Guide
- **► IL Acces**\$ Service Authorization Form
- ▶ Crisis and Waiver Service Transition Information Bulletin
- ▶ 9th Annual Informational Seminar Recording and Materials
- ▲ Assistive Technology and the Waiver 02/25/21
- ▲ Assistive Technology and the Waiver Q & A Document
- ▲ Ligas Family Advocate Program Brochure
- Cost to You Pay Rate for Personal Support Workers
- ▶ DDD Memo − Increases in the Home-Based Support Services Program (HBS)



"Thank you, LFA so very much for taking time to share a wealth of information with me. I am just so happy that this process looks so very positive.

I can't tell you how refreshing it is to know that there are individuals such as yourself that are very tenacious and have seen this project come to fruition. I am excited and am so looking forward to this opportunity opening up for my son."



Family Support Network (FSN)

- Partner with families and self-advocates to navigate challenging and complex barriers in the developmental disability system
- Search out resources, funding, and connections to assist individuals to live as independently as they wish in the community of their choosing
- Provide group education on key topics of interest in the developmental disability community
- Past topics have included: Supported Housing, Home-Based Services, Transportation, College programs for individuals with I/DD



Contact the Family Support Network

- Working with a family who needs additional resources to obtain the supports and services needed
- Identify that a family is experiencing difficulty entering or navigating the developmental disability support system
- Learn that a family is running into significant barriers in attempting to find the supports that they need
- Have a question or concern about the I/DD system and would like to assist a family who is experiencing difficulty





Common Questions for FSN:

- I'm in services but my funding suddenly stopped, and I have been unable to resolve. Can you help?
- My adult son is being suddenly discharged from his CILA. We do not know what to do. Can you help?
- We are moving to another area of the state, and have not been able to find the same type of services that we have now. Who should we contact?
- My son has been living at home and we have not been able to get support services that are in line with what we need. Can you assist us?



Program Impact Jan – Mar 2024



1,338 Letters of Introduction sent to Early Notification families



Over 250 1:1 LFAP consultations preparing families after an Early Notification from IDHS



150 Family-to-Family support calls through FSN



Webinars in English and Spanish focused on system navigation and service options monthly



Know Your Options: English May 9, 2024 Webinar Registration -Zoom



Know Your Options: Spanish May 8, 2024 Webinar Registration -Zoom



Contact us!

- Shirley Perez, Program Director Ligas Family Advocate Program and Family Support Network, <u>Shirley@thearcofil.org</u>
- Ruth Aguilar, Senior Ligas Family Advocate, QIDP, Ruth@thearcofil.org
- Annie Bruno, Ligas Family Advocate, LCSW, QIDP, Annie@thearcofil.org
- Shakari Asbury, FSN Liasion, Ligas Family Advocate, <u>Shakari@thearcofil.org</u>
- Troy Market, FSN Family Advocate, Troy@thearcofil.org





The Family Transition Project

Gregory Walkington, Director

- At our heart is hope. We encourage individuals living in large institutions to explore the possibilities of community living.
- We listen.
- We share stories of success.
- We advocate for individuals and their families.
- We have firsthand experience in making transitions to the community and have interacted with hundreds of individuals and families.

The Arc of IL Mentors – Sharing their Stories of Community Life

- The Arc of IL mentors have lived in large institutions and share their lived experience in many different venues.
- They are advocates for the empowering benefits of community life.



The Arc.

Illinois









- Ongoing support for individuals and families via phone, email, text, in-person, virtual meetings about where they are in the process and what to expect from a family perspective
- Advocacy for families who request our presence at transition related meetings
- Connections for individuals and families, if helpful, to our transition mentors and/or other families with lived transition experience
- Problem solving with Division staff and families around barriers to community living
- Operation Welcome Webinar Series



Mentors

- Worked on their personal story to share during public speaking.
- Working with them on their Zoom presence.
- Scheduling meetings with government officials to share their personal stories about living in a State Operated Developmental Center (SODC) vs living in the community.
- Advocate for issues: Increase pay for DSP's, Housing, Advocating for community services including meeting with the Resident Council and family members at the SODC's.



Contact information: Gregory Walkington, Director, Family Transition Project The Arc of Illinois gwalkington@thearcofil.org

Work Cell: 312.593.8459

https://www.thearcofil.org/about-us/programs/familytransition-project/

Family-to-Family Health Information Center

Susan Agrawal, Director



Who is Family-to-Family?

Federal Grant Program

Part of a National Network of Family-to-Family Programs

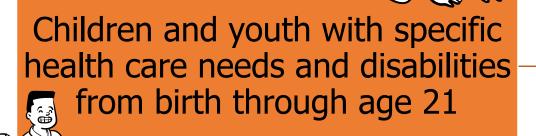
Program of The Arc of Illinois

Staffed by family members who are trained to help other families

State Affiliate of Family Voices, a national family-led organization of families and friends of children/youth with disabilities and chronic medical conditions



Who Does Family-to-Family Serve?



Their families



Professionals who care for them

Who Do We Serve?

Children with ANY specific health care need, disability, or chronic condition

- Physical disability
- Developmental delay or intellectual disability
- Behavioral condition or severe emotional disturbance
- Genetic or congenital condition
- Autism
- Technology dependent
- Chronic conditions like asthma, diabetes, sickle cell
- Deaf or blind



Some of the Things We Do













All regular services are free!



What We Do: Help Families Navigate the Healthcare System

Information to sign up for and understand insurance and Medicaid benefits

Find services for specific conditions such as autism or diabetes

Assist with finding services for behavioral health

Figure out what insurance/Medicaid covers and find ways to meet needs that aren't covered

Help families find healthcare services

Figure out how to respond to changes in state and federal policies



Find peer support and emotional support

Learn about Medicaid waivers, who is eligible, and how to apply Assist with special education questions, including Section 504 plans and IEPs

Learn about PUNS waiting list and how to get on it

Help families build their own leadership and advocacy skills Assist with questions about other benefits like SSI, Title V (DSCC), SNAP, WIC





Help find respite care

Assist with coordinating care providers



What We Do: Advocacy and Training



Advocate for programs to improve the lives of children with disabilities and chronic medical conditions

Increase awareness about disabilities

Work with professionals, legislators, and lawyers

Keep up-to-date on state and federal policies that affect children with disabilities

Partner with Title V (DSCC) and other agencies

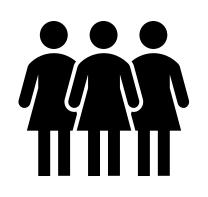
Outreach events at schools, for organizations, etc.

Webinars and conferences for families and professionals





What We Do: Helping Professionals



Provide information on topics outside their area of expertise

Assist with specific cases that require targeted help

Take referrals for cases from professionals

Provide new or recently updated/changed policy information

Provide trainings and webinars

Collaborate on advocacy or other projects

Professionals also teach us about their areas of expertise!





Common Questions

- How can I get an autism diagnostic screening for my child?
- Can you help me find a therapist (especially ABA)?
- How do I get diapers covered by Medicaid?
- What Medicaid Waiver(s) is my child eligible for?
- What is PUNS and how long is the waiting list?
- What resources are there for families who don't qualify for any waivers?
- What help can I get while I am on a waiting list?
- Can you help me appeal my cut in home nursing hours?
- What is SSI and how do I get it?
- Can I get paid to take care of my child with a disability?
- Can you help me get better school services for my child?



How to Reach Family-to-Family



779-254-9158 cell

815-464-1832 ext. 1017

866-931-1110

Spanish: 800-588-7002

Language Line for other languages



susan@thearcofil.org



https://www.familyvoicesillinois.org



https://www.facebook.com/ilfamilyvoices





Illinois Life Span — Ligas Family Advocate Program — Family Support Network Family-to-Family Health Information Center — Family Transition Project