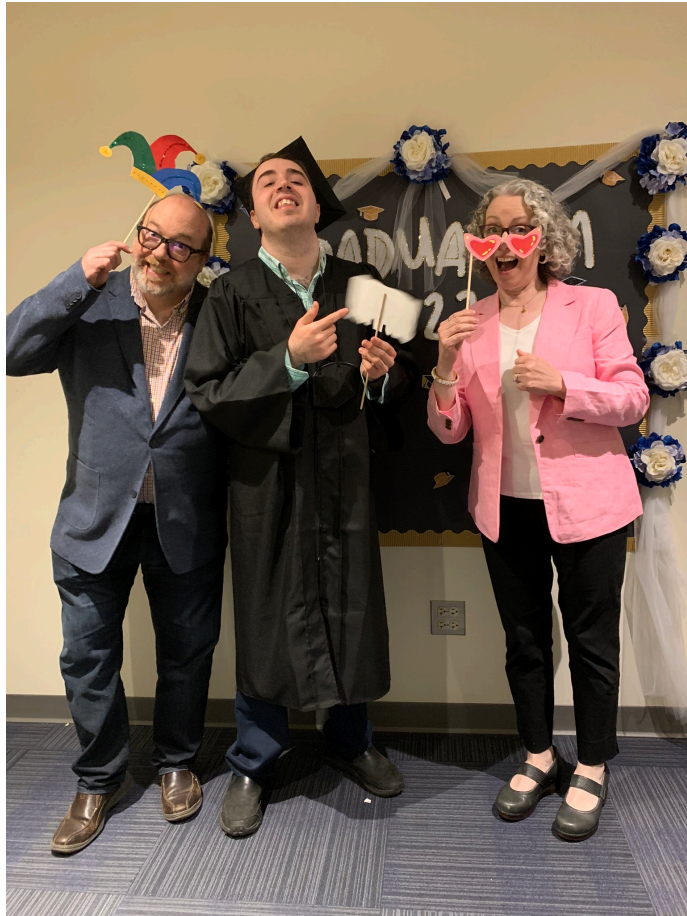


Knowledge is Power: Preparing for your child's Transition to Adulthood

Suzanne Aaron

**Information & Outreach Specialist, The Arc of Illinois Life Span
Program
Mom to Thomas**

My “why”:



- Proud mom of a fantastic human being
- Career change after diagnosis
- Motivated to help others never feel as alone and overwhelmed as we did

About The Arc:

Largest National Community-Based Organization

Advocating for and serving people with intellectual and developmental disabilities and their families throughout the entire life span.

650 Chapters Nationwide

Advocating on the front lines to ensure that people with IDD and their families have the support and services they need to be fully engaged in their communities.

Vision and Mission

The Vision:

Happy lives with full participation in the community.

The Mission:

Empowering persons with disabilities to achieve full participation in their community life through informed choices.

Our Advocacy Includes:

Providing key information on legislative and policy issues.

Empowering individuals to stand up for important policies impacting people with ID/DD.

Making information and resources accessible through our programs, webinars, and events.



Programs of The Arc:



Illinois Life Span



*Family to Family Health
Information Center*



*Family Support
Network of Illinois*



*Assistive Technology
Program*



*Ligas Family
Advocate Program*

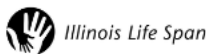


Family Transition Project




Training Department

*And..Going Home Coalition
& Project Welcome Home!*



A large orange circle on the left side of the slide, partially cut off by the edge.

Today's purpose: Empower.

- Transition to Adulthood is a multi-year process
 - Truly individualized
 - No “one correct path”
 - THE CLIFF (so let's avoid it)
 - Professional and personal perspective
- 
- A series of yellow dashed line segments in the bottom right corner, curving upwards and to the right.

Believe.

**Educated parents become empowered parents.
Empowered parents can create beautiful lives
with and for their child.**

FAMILY-TO-FAMILY GUIDANCE

“Get educated early”

“Go to parent trainings provided by a variety of agencies”

“Start early asking for transition plans and services! Document everything.”

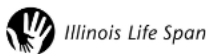
“Be realistic with the post transition goals. It is a process of adjustment and it takes some trial and error to get it right.”

“Get on the PUNS list ASAP.”

“You have to ask a lot of questions and do a lot of research on your own”

“Use whatever social and community connections you have to develop meaningful activities.”

“Connect the Dots in Transition Fact Sheet”, The Arc of Illinois
[Connect the Dots Tool.indd \(illinoislifespans.org\)](http://illinoislifespans.org)



Educate yourself. Become a sponge. Prepare to make informed choices.

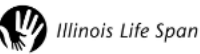
- On Facebook? Join IPADDU. Illinois Parents of Adults with Developmental Disabilities. [IPADDUnite | Facebook](#)
- Take every tour you can offered by :
 - Your school district
 - Nearby school districts too!
 - Local support groups
 - For example: Connect to Community [Connect to Community \(connecttocommunityinc.org\)](http://connecttocommunityinc.org), based in Palatine
- Tour and learn about:
 - Social programming providers (Special Recreation Associations, agencies, etc)
 - Day programs
 - CILAs (these are typically scheduled by a school district or other advocacy organization)

Your continuing roles:

Service Coordinator
And
Case Manager

The big shift:

from Entitlement to Eligibility



It's not what you know,
but who you know

SOCIAL CAPITAL



Where do we even start?

- Take a deep breath.
 - Tired?
 - Overwhelmed?
 - Unsure?
 - Avoiding?
- Clean the slate mentally. Forget about what's typically done. Now...



**What does
your child
like to do?**

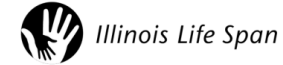
- Preferences?
- Strengths?
- Talents?



Having trouble?

- What do YOU like to do?
- How do you fill your day? Your week? For example...
 - Hobbies?
 - Classes? City/county recreation association, library, community college, craft stores, Illinois extension, university classes
 - House of worship? Services, small group meetings, outreach or community events
 - Civic engagement? Boards, council meetings, elections
 - Recreation? Exercise, travel, festivals
 - Entertainment? Movies, plays, concerts

Weekly Calendar

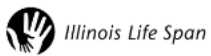


(815) 464-1832

www.thearcofil.org

Day Planning for the Week of: _____

	Monday	Tuesday	Wednesday	Thursday	Friday
Morning					
Mid-Morning					
Noon					
Afternoon					



Decisions to be made

- **Social**

- Recreation
- Day programming

- **Employment**

- Do you need Vocational Rehabilitation (“Voc Rehab” or VR)?
- Which agency that provides Voc Rehab/job training will you hire?
- If not, using your own connections & social capital?

- **Residential**

- Where will your young adult live, now and in the future?

Social

Will you need an agency for:

- Day programming
- Recreation
- Special events
- Weekend programs

Do they have space? Is there a waiting list?

Can they meet your young person's physical and medical needs?

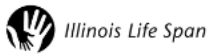
Employment

Vocational Rehabilitation services needed? [IDHS: Vocational Rehabilitation \(state.il.us\)](https://www.idhs.state.il.us/VocationalRehabilitation)

- Will you need an agency for:
 - Employment exploration for a good fit?
 - Job coaching?
 - Job placement?
- Do they have space? Is there a waiting list?
- Can they meet your young person's physical and medical needs?

But my kid can't work...

www.intelligentlives.org



Housing/residential

DDD PUNS waitlist/database (not available through DRS)

- CILA through Adults with DD Waiver:
 - 24-hour - group home
 - 24-hour - host family
 - Less than 24-hour: Intermittent CILA
 - Community Living Facility
- ICF-DD Intermediate Care Facility for individuals with Developmental Disabilities
- MCDD Medically Complex for Developmentally Disabled
- SODC State Operated Developmental Center
- [Residential-Options-for-Adults-with-IDD-in-IL-Sept-2023.pdf](#)
[\(illinoislifespan.org\)](#)

Post-secondary options: college bound?

- Think College is dedicated to developing, expanding and improving research and practice in higher education for students with intellectual disability.
 - [Home | Think College](#)
 - [College Search | Think College](#): information on over 300 postsecondary education programs for students with an intellectual disability
- PACER's National Parent Center on Transition and Employment
 - Inclusive Postsecondary Education for Students with Intellectual Disabilities
 - [Inclusive Postsecondary Opportunities for Students with Intellectual Disabilities - PACER's National Parent Center on Transition and Employment](#)

But my kid can't go to college...

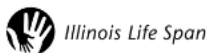
[LikeRightNow Films](#) | [My Disability Roadmap](#) | [Films](#) |



DISABILITY UNSCRIPTED 2020:



SAMUEL HABIB INTERVIEWS
NH GENERAL ELECTION
CANDIDATES



- 
- And now, the tangible. Tasks!
- 

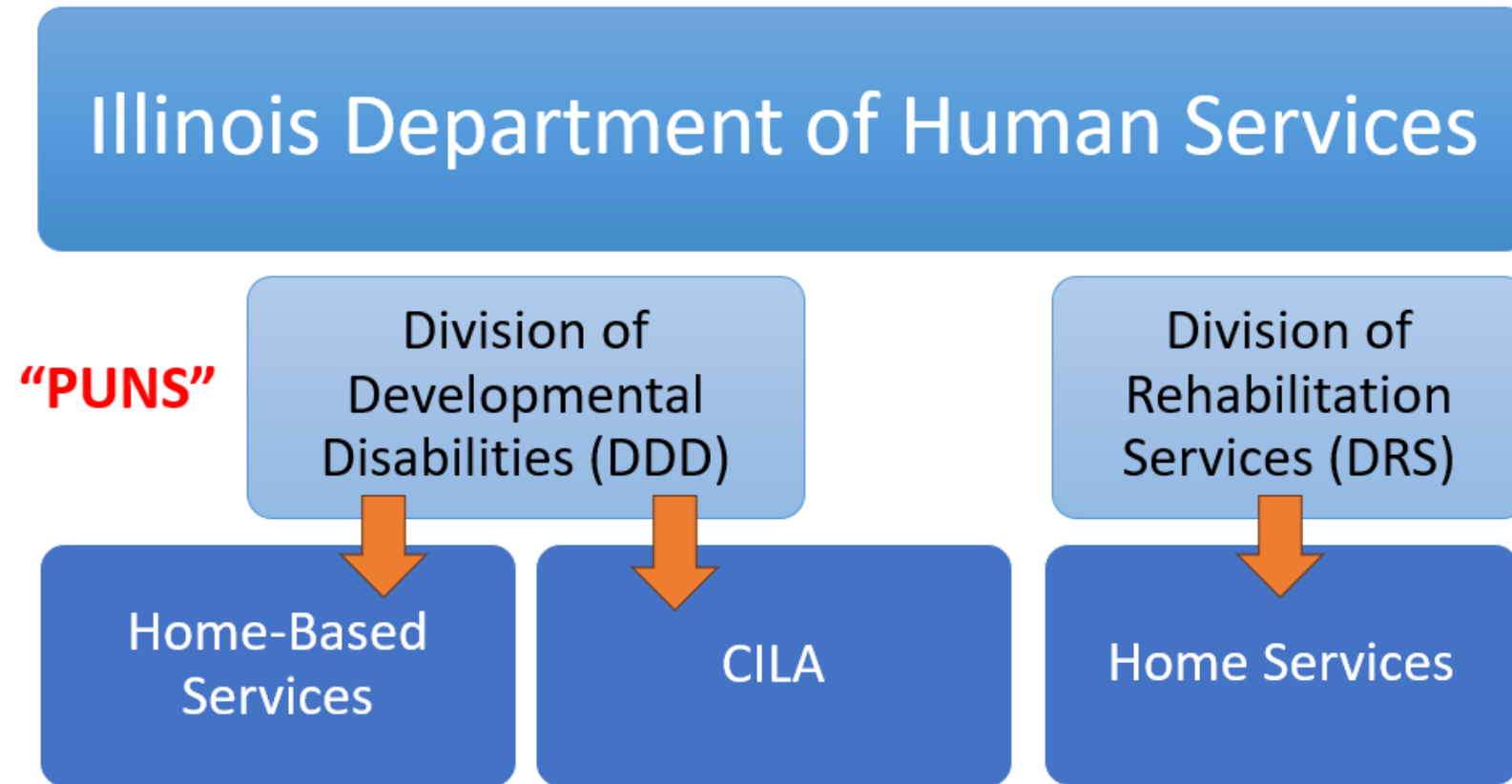
To-Do List

- Get an Illinois State ID!
- Selective Service: all male US citizens and male immigrants age 18-25 are required to register
- PUNS? DRS Home Services?
- Apply for SSI once 18yo
- Apply for Medicaid once 18yo
- Legal support options
 - Supported Decision-Making?
 - Guardianship? What level of guardianship?
 - Power of Attorney?
- Gather and save paperwork
 - IEPs & Summary of Performance

State ID: do this before applying for Medicaid

- [Driver's License/State ID Card \(ilsos.gov\)](https://ilsos.gov)
- Free State ID cards valid for 10 years are available for persons with disabilities. To obtain a state ID card, please visit a [Secretary of State facility](#). The applicant must provide an [Application for an Illinois Person with a Disability Identification Card](#) completed by his/her doctor.
- Acceptable identification documents: [Applying for an Illinois Driver's License or ID Card \(ilsos.gov\)](#)
- Article from Illinois Legal Aid Online: [ID cards for people with disabilities | Illinois Legal Aid Online](#)

Adult Home and Community Based Services (HCBS) in Illinois



How to apply

DDD

- Call your Independent Service Coordination office
 - [IDHS: Office Locator \(state.il.us\)](https://state.il.us)
 - Choose “Developmental Disability Services” from dropdown
- Ask to apply for PUNS list for Adults with DD Medicaid Waiver

DRS

- Contact local Division of Rehabilitation Services office
 - [IDHS: Office Locator \(state.il.us\)](https://state.il.us)
 - Choose “Rehabilitation Services” from dropdown
 - Or use Rehabilitation Services Web Referral [DHS: Rehabilitation Services: Apply Online \(illinois.gov\)](https://illinois.gov)

SSI: Supplemental Security Income

- SSI makes monthly payments to people who have low income and few resources, and who meet one of the following criteria:
 - They are age 65 or older.
 - Blind.
 - They have a medical condition that keeps them from working, which is expected to last one year or result in death
- Income/Resource limits
- Medical eligibility
- [Understanding SSI - If You Are Disabled or Blind \(ssa.gov\)](#)
- [Get Started to Apply for SSI | SSA](#)

Medicaid

- Healthcare coverage for low-income individuals
- Why apply if our child is on our private insurance?
 - Medicaid is payor of last resort always
 - Once pulled from PUNS, the Adults with Developmental Disabilities waiver is paid for by Medicaid
- ABE.Illinois.gov
- Arc of Illinois Fact Sheet on Medicaid General Questions
 - [F2F-Medicaid-general-questions-fact-sheet-Oct-2023-update-with-info-about-Child-DD-PUNS-selections-Nov1.pdf \(illinoislifespan.org\)](#)

Guardianship

- At age 18, an individual becomes an adult and is legally able to make all their own decisions. In other words, parents can no longer make any decisions (medical, educational, employment, financial, personal, etc) for their child.
- Will your young adult need help when making these decisions?
- Options:
 - Do nothing (not recommended, but Health Care Surrogate Act comes into play)
 - Power of Attorney (least restrictive, multiple would be needed)
 - Supported Decision-Making
 - Guardianship (Limited, Person or Estate, or Plenary)

Guardianship continued

- [Self-Determination/ Guardianship - Equip for Equality](#)
- [ITEM-5-REQUEST-FORM-Guardianship-and-Alternatives.pdf \(rubinlaw.com\)](#)
- [Office of State Guardian \(illinois.gov\)](#)
- [IGAC Supported Decision Making bro 5-4-22 \(illinois.gov\)](#)

Gather and save paperwork

- IEPs, especially the most recent
- Summary of Performance (SOP): the document that is provided by the school when your young adult exits school services
- Educational Evaluations
- Psychological Evaluations (especially IQ test if possible)
- Diagnostics
 - Anything that proves the disability, especially that proves diagnosis prior to age 22

ILLINOIS STATEWIDE TRANSITION CONFERENCE ON NOVEMBER 7 & 8, 2024

Stepping Stones of Transition

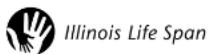
~ SAVE THE DATE FOR THE 2024 CONFERENCE ~

Crowne Plaza Springfield Convention Center
3000 South Dirksen Parkway
Springfield, Illinois 62703

The 19th Annual Illinois Statewide Transition Conference for transition-aged youth and young adults with disabilities, their family members and teachers, vocational professionals, caregivers, health care professionals, college students pursuing careers in special education, and community advocates will be held on November 7 – 8, 2024.

The conference will focus on best practices in promoting effective, person-centered transition planning that addresses all aspects of adult life for youth with disabilities.

illinoistransitionconference.org





The Arc of Illinois' Annual Convention is in the spring each year. Held in Bloomington-Normal in 2024 in response to requests to have conferences outside Chicagoland! Stay tuned for 2025's location and dates.



Other Transition events

- Check with your school district or Special Education District about any info fairs or trainings they may host.
- Transition Planning Committees may host trainings as well.
- State legislators
- Sign up for newsletters
- Attend Lunchtime Webinars!

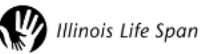
Centers for Independent Living (CILs)

- “...provide community-based, non-residential support for people with disabilities so they may achieve independence in every aspect of their lives, including home, work and school.”
 - [Home – INCIL](#) “Creating Barrier-Free Lives for People with Disabilities”
 - [Find a CIL - INCIL](#)
 - CILs are run by and for the people they serve, with at least 51% of each CIL’s staff and Board of Directors comprised of individuals with disabilities.
- Independent Living Movement
 - **“People with disabilities are entitled to civil rights, options, and control over choices in their own lives”**
 - [Independent Living History - Access Living](#)

Speaking of the Independent Living Movement...



[Crip Camp | A Disability Revolution](#)



How does Illinois compare to other states?

Illinois Services for People with Intellectual and Developmental Disabilities by the Numbers 2023

- 7 = Number of Illinois state institutions
- 17 = Number of states with no state institutions
- 1,645 = Number of people living in Illinois state institutions
- 16 = Number of states with fewer than 200 people living in state institutions (1)
- 49 = Number of states with fewer people living in state institutions than Illinois (1)
- \$347,375/Yr. = FY22 Interim average annual Medicaid claiming rate for all Illinois state institutions (2)
- \$405,150/Yr. = FY22 Interim average annual Medicaid claiming rate for most expensive Illinois IDD state institution (2)
- \$90,728/Yr. = 2022 average topline CILA reimbursement for people receiving 24-hour care (3)



What to do, then?

- Join The Arc of Illinois advocacy listserv
 - [Arc of Illinois Advocacy Information | Disability Assistance & Support \(thearcofil.org\)](https://thearcofil.org)
- Identify your local Illinois legislators
 - [Find My Elected Officials \(il.gov\)](https://il.gov)
 - Email them, call them, attend their events, tell your story
- Voice your support or opposition to legislation by submitting Witness Slips
 - [\(1\) How to file a witness slip in the state of Illinois – YouTube](#)
 - Many times, you will be sent a link directly to the bill by an advocacy organization
- Attend the Legislative Advocacy Series
 - [Legislative Advocacy Webinar Series - The Arc of Illinois](#)

The Arc of Illinois Transition information

- [Connect the Dots Tool.indd \(illinoislifespan.org\)](#)
- [PUNS-The-Basics-with-Categories-Sept.-2023-1.pdf \(illinoislifespan.org\)](#)
- [Residential-Options-for-Adults-with-IDD-in-IL-Sept-2023.pdf \(illinoislifespan.org\)](#)
- [The Arc of Illinois Fact Sheets - Illinois Life Span Program](#)

Transition Toolkits

- University of Illinois – Chicago, Division of Specialized Care for Children (UIC – DSCC)
 - [0520-TRANSITION-TOOLKIT-WEB-4.pdf \(uic.edu\)](#)
 - [Preparing for transition - UIC Specialized Care for Children](#)
 - [Transition Tools - UIC Specialized Care for Children](#)
- Got Transition?
 - [Got Transition® - Parents & Caregivers](#)
 - Focuses on the medical side of the Transition to Adulthood
- University of Illinois – Urbana Champaign: Illinois Center for Transition and Work
 - [Illinois Center for Transition and Work \(ICTW\) | Illinois Center on Transition and Work | UIUC](#)
 - [School-to-Work Transition Guide | Illinois Center on Transition and Work | UIUC](#)

Other helpful websites

- PACER's National Parent Center on Transition and Employment
 - [National Parent Center on Transition and Employment \(pacer.org\)](http://pacer.org)
- Disability Benefits 101 – Illinois
 - [DB101 Illinois – Home](#)
- Dan Habib: Vimeo library
 - [Dan Habib \(vimeo.com\)](https://vimeo.com/danhabib)

Parting words of advice:

Never take the first no as the
last answer.

Questions?



Thank you for attending today!

Suzanne Aaron

Information & Outreach Specialist, The Life Span Program

The Arc of Illinois

suzanne@thearcofil.org

(800) 588-7002 x1020



Illinois Life Span

