

Parent Outreach District 34

11/6/2024

Goal to Connect to Resources

- Eligibility for services for Dept of Human Services/Div of Dev Disabilities (DHS/DDD)
- PUNS (Prioritization of Need for Services)

Options Available w DHS/DDD Medicaid Waiver

- Home Based Services
- CILA (Community Integrated Living Arrangement)

Final Thoughts



Transition Outreach Specialist

Provide Support, Linkage, and Resources

Provide Information and Assistance (during Transition starting at age 14 ½ - 25 yrs)

- Linkage to Independent Service Coord (ISC) agency for PUNS
- Home and Community Based Waiver Programs
- Residential Options (CILA, ICF/DD, Supportive Housing)
- Adult Community Day Services
- Department of Rehabilitation Services (DRS)

Provide Information Regarding Legal/Financial Considerations

• Delegation of Rights, Supported Decision-Making, Guardianship

Assist with Applications for SSI and Adult Medicaid

Provide Outreach/Training Support

- Attend IEP Meetings
- Parents
- School Professionals
- Self-Advocates



The Goal of Transition

To identify and develop sustainable activities/routines that will move the young adult from his/her 22nd birthday to help him/her lead a satisfying life*.

(*adapted from IL Autism Training and Technical Assistance Project IATTAP, Resource Fair handout)

A seamless transition is one where following the exit from school, scheduled activities commence that may include: paid job, volunteer work, day services, vocational training, memberships at health or fitness center, or exercise classes, social clubs, household chores/responsibilities, maintain and develop new friendships/relationships, participate in recreation/entertainment, leisure, religious/spiritual, financial assistance, medical services, residential services and supports are identified.





Definition of Developmental Disability The Federal Developmental Assistance and Bill of Rights Act of 200 (Public Law 106-402)

A Developmental Disability is a severe, chronic disability that:

- Is attributable to a mental or physical impairment or a combination of mental or physical impairment;
- Is manifested before the person attains the age of 22
- Is likely to continue indefinitely

Results in the substantial functional limitations in 3 or more of the following areas of major life activities:

- Self-Care
- Receptive and Expressive Language Skills
- Learning
- Mobility
- Self-Direction
- Capacity for Independent Living and Economic Self-Sufficiency



Determination of Disability

A. Intellectual Disability

Significant sub average intellectual functioning (IQ 70 or below)

Existing with deficits in Adaptive Behavior

Manifest before the age of 18

B. Related Condition (severe and chronic disability that meets the following)

Attributed to cerebral palsy or epilepsy

Any condition other than mental illness found to be closely related to intellectual disability be cause it results in the impairment of general intellectual functioning, or adaptive behavior similar to that of a person with intellectual disability and requires treatment or services similar to those required for these persons (eg autism spectrum disorders, Prader Willi Syndrome)

Fetal Alcohol Syndrome and disorders due to nerves or muscles are not related conditions



Assessments Required by Disability

ICAP (Inventory for Client and Agency Planning) administered by QIDP (Qualified Intellectual Disability Professional)

Psychological (if intellectual disability) to include: cognitive, adaptive, developmental history, educational history, multi-axial diagnosis and recommendations

- Completed by licensed psychologist within 5 yrs for mild-moderate range; for severe-profound range can be more than 5 yrs
- Child standardized instruments include: Stanford-Binet, WISC, WPPSI, MCSCA, K-ABC, Woodcock-Johnson Part 1, original Slossen, Leiter
- Adult standardized instruments include: Stanford-Binet, WAIS-R or WAIS-III, Woodcock-Johnson Part 1, Slossen, Leiter
- Assessment of Adaptive Functioning: AAIDD Adaptive Behavior Scales, Vineland Adaptive Behavior Scale, ABIC, Scales of Independent Behavior

Medical Reviews

- Medical history
- Medical Review
- Physical Exam

For persons with autism who do not have Intellectual disability, must also have

- Psychiatric evaluation
- Psychosocial evaluation

For more detailed information: https://www.dhs.state.il.us/page.aspx?item=53021





Department of Human Services (DHS)

Secretary – Dulce M. Quintero 9/2023



Program Divisions

- Division of Developmental Disabilities (DDD) Tonya Piephoff 6/16/23
- Division of Early Childhood Kirstin Chernawsky, Director





- Division of Mental Health (DMH) David Albert, Director
- o Division of Rehabilitation Services (DRS) Rahnee Patrick, Director
- Division of Substance Use Prevention and Recovery Laura Garcia, Director







Independent Service Coordination Agencies (ISC)

- Geographical catchment area
- Entry point for services for individuals with intellectual/developmental disabilities to be listed on Prioritization of Urgency of Need for Services (PUNS) list https://www.dhs.state.il.us/page.aspx?item=47620 English, Spanish, Tagalog, Korean, Hindi, Chinese
- The role of Pre-Admission Screening (PAS)/ISC agency is to educate individuals of all ages and families that present themselves by informing them of and explaining all the services and support options available.

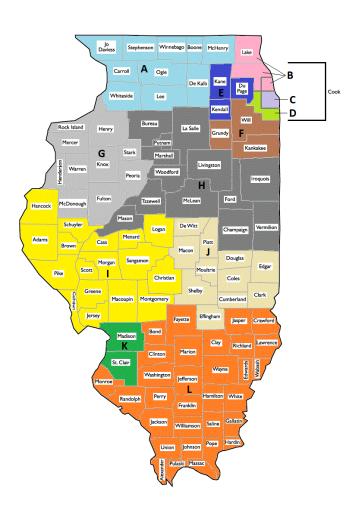
https://www.dhs.state.il.us/page.aspx?item=47629



IL Department of Human Services Division of Developmental Disas. (DHS)

Illinois Department of Human Services Division of Developmental Disabilities

Area	ISC Agency	
Area A	Service Inc. of Illinois	
Area B	Community Alternatives	
	Unlimited	
Area C	Community Service Options	
Area D	Suburban Access Inc.	
Area E	Service Inc. of Illinois	
Area F	Service Inc. of Illinois	
Area G	Prairieland Service	
	Coordination Inc.	
Area H	Champaign County	
	Regional Planning Commission	
Area I	Central Illinois	
	Service Access	
Area J	Prairieland Service	
	Coordination Inc.	
Area K	DD Services of Metro East	
Area L	Southern Illinois	
	Case Coordination Services	





Independent Service Coordination Agencies (ISC)

Community Alternatives Unlimited

Northern Cook, Chicago Northside, Lake 8765 W. Higgins Suite 300 Chicago, IL 60631 (773)867-4000 www.cau.org



When Do I Contact ISC?

- As soon as you are aware there is a Developmental Disability after age 3
- Get on the PUNS list and update annually. Get referral for Respite Services
- Update if your situation changes, you move, or phone number changes
- Contact ISC if you receive an Award Letter from DHS
- Check status on PUNS: send email to <u>DHS.DDD.PUNS@Illinois.gov</u> with name, address, DOB and name of ISC





4 Reasons To Get on PUNS List

- 1. You don't have a crystal ball and cannot predict the future. One step in the process is already completed, if you need the services sooner than you expected.
- 2. State funding is allocated based on the anticipated need for services: Seeking= now or within the next 5 years or Planning= for services anticipate needing in the future.
- 3. At age 18 you will be contemplating adult transitions such as guardianship, eligibility for Supplemental Security Income and Medicaid. Each is a time-consuming process. Having your child on the PUNS list is one thing you can "cross of your list".
- 4. Funding was available for 500 children on the list in FY '24 and FY'25. Only those on the list were eligible to receive services.



Respite Services Michelle Bosco mbosco@clearbrook.org (847)385-5335

- Voucher Program provides annual stipend for reimbursement to purchase direct care support for individual with I/DD or to participate in special recreation program.
- In-Home Program awards a monthly allowance for respite care to an individual with I/DD.
- Group Respite Program provides individuals 18 years and older with social interaction and community experiences two Saturdays/month (locations, Clearbrook CHOICE in Crystal Lake, Palatine).



What Services Are Available Through Department of Human Services (DHS) From the PUNS List? 2 Medicaid Waiver Options

Home Based Services (HBS)

Child/Adult Home Based Services (CHBS/AHBS)

- Personal 1:1 Support in home/community
- AHBS DHS Licensed Community Day Services (CDS)
- Active Treatment, speech, PT, OT
- Vocational and skill training
- Supported or Competitive Employment
- Supportive Housing

Community Integrated Living Arrangement (Adult CILA)

Licensed Community Day Services/Employment Services

- iCILA
 - Family Home
 - Agency Intermittent Support
- Host Family CILA
- 24 Group Home support
 - 1-8 individuals
 - · Shift staff on-site



Home Based Services

Monthly allotment of services based off the current SSI (Supplemental Security Income) maximum allotment. It is not a check, but the amount available in billable services.

2024 maximum SSI allotment is \$943/month; (2025 maximum SSI=\$967/month)

- Children 2x SSI amount (\$1886/month w flexible spending option) 2024
- Adults (out of school) 3x SSI amount (\$2829/month, no flexible spending 2024)

2 Models of service delivery

- Self-Directed
- Agency Based

One time Funding \$15,000 over 5 years for Assistive Technology, Home/Vehicle Modification



Home-Based Services

• This program provides active treatmentbased services to children and adult family members with intellectual/developmental disabilities.

Home-Based Responsibilities

- Provides support in the comfort and familiarity of a home, educational setting, and/or community environment.
- Provides services to promote skill development and community integrations.
- Coordinates with other programs in which family members may participate.
- Serves more than 1600 families in 16 Illinois counties.





Clearbrook Community Day Services

Getz

Clearbrook's Getz program helps participants acquire new skills and refine existing ones in the areas of daily living, communication, decision-making, and socialization. The program places individuals into different ratios based on level of need.

PAL

The PAL (Partners in Adult Learning) Program presents an array of experiences to young adults with intellectual/developmental disabilities and significant physical challenges in the areas of continued learning and community involvement.

CHOICE

The primary goal of the CHOICE program is full community integration for participants, empowering them to live their fullest lives possible. Whether through independent or supported employment, engaging in volunteer opportunities, or participating socially— the individuals are given the freedom to choose their activities day-to-day.

Techny

This program is modeled after the CHOICE Program. Clearbrook partners with community organizations, allowing our individuals the opportunity to help others as volunteers, learn job skills, participate in leisure activities, and to socialize with peers.

PURSUIT

PURSUIT is a collaborative program between Clearbrook and the Northwest Special Recreation Association (NWSRA), providing services that offer a variety of recreational and leisure activities, and experiences in a structured setting.



SUPPORTIVE HOUSING

The Supportive Housing Coordinator assists individuals and their families with exploring affordable and supportive housing options.

ASSISTANCE CONTACTING **STATEWIDE** HUD WITH LOCAL PUBLIC **SKILLS PHONE** REFERRAL **RESOURCE FINDING** HOUSING CONSULTATIONS **ASSESSMENT NETWORK** LOCATOR UTILITY **AUTHORITIES RESOURCES**



Community Integrated Living Arrangements (CILA)

Clearbrook has 50+ locations throughout the North and Northwest Chicagoland suburbs.

Brookmeade



Bosworth



- 24 hour awake support
- 24 hour awake/sleep support
- Intermittent support

Evergreen



Elaine Circle





Community Integrated Living Arrangements (CILA)





EMPLOYMENT AND TRAINING SERVICES

A full spectrum of work services are offered that help people with intellectual/developmental disabilities learn skills, gain experience, and find meaningful employment that matches their interests and skills.

COMMUNITY
EMPLOYMENT
SERVICES (CES)

SUPPORTED
COMMUNITY
EMPLOYMENT

JOB
TRAINING



SUPPORTED COMMUNITY **EMPLOYMENT**

- Participants receive onsite training and support from a Job Coach who helps them focus on achieving success at their community-based job.
- Coaches assist individuals in a variety of ways, including their orientation to the work environment, duties, integration into the employment site, appropriate work behavior, and more!

Our current partners include:

- Culver's
- Olive Garden
 Cozzini
- WalmartFedEx
- McDonald's
- Home Depot
- Jewel

- Gap
- Mariano's
 Sedgebrook Senior Living
 - Schaumburg Boomers
 - RTC Industries
 - Lowe's

and more!



SUPPORT SERVICES IN YOUR COMMUNITY

INFORMATION ABOUT AUTISM AND **RELATED ISSUES**



PROFESSIONAL **AUTISM** ORGANIZATIONS, GROUPS, AND

SERVICES

PHYSICIAN AND **THERAPIST INFORMATION**

PRE-MADE VISUAL FAMILY AND COMMUNITY **AUTISM RESOURCE** SPECIALIST (FCARS)

- Provides autism resources that include consultation, visual communication systems, and a vast library of resources at no cost
- Provides information to the community at large by serving and supporting individuals and their families
- Assists in finding programs, services and available supports

For more information contact:

Tracy Hellner

(847)707-0655

Thellner@clearbook.org

https://www.clearbrook.org/programs-and-services/for-children/fcars/



COMMUNITY MENTAL HEALTH CENTER (CMHC)

Serves residents in the area that have a mental illness diagnosis

Provides additional support to individuals
Clearbrook serves

Individuals do not need to be a part of Clearbrook prior to service



There are two locations: Rolling Meadows and Crystal Lake

Department of Rehabilitation (DRS) Employment Services/Home Supports Program

DRS Vocational Services:

job development job placement job coaching

May also receive HBS simultaneously

DRS Home Support Program

based on DON score (Determination of Need) to remain in home.

Cannot receive HBS with DRS Home Support Program. Sometimes DRS provides more hours of service. However, DRS Home Supports will not pay for Community Day Services.

http://www.dhs.state.il.us/page.aspx?item=29737



What Can I Do While Waiting To Be Selected From PUNS?

- Consider Respite Services <u>mbosco@clearbrook.org</u> (847)385-5335 or contact your ISC
- Review other future planning needs, such as Special Needs Trust, guardianship, ABLE Accounts
- Join advocacy groups and be engaged in voting/legislation that impacts services (IPADDunite.org; CityofSupport.org; FB, North Suburban Parents of Kids with Special Needs)
- Learn about providers in your area, schedule activities, including ADLs, exercise/fitness, social/leisure, recreation, community involvement, future employment/volunteer activities, CDS
- At age 18, email <u>DHS.DDD.PUNS@Illinois.gov</u> with name, DOB, address and ISC to find out approximate date of PUNS selection.
- Apply for Supplemental Security Income (SSI) if eligible at age 18; Apply for Adult Medicaid if at least 19 years of age



Advocacy and Laws Create Change

Since 1865, large congregate settings dominated the country for over a century

1972 Wyatt vs Stickney judge ruled for "least restrictive environment"

1975 Public Education (PL 94-142 aka IDEA)

1985 CILA(Community Integrated Living Arrangement)open

1990 ADA (Americans with Disabilities Act)passed

1991 Olmstead Act (moved individuals out of segregated settings)

2006 HCBS (Home and Community Based Services)

2011 Ligas Lawsuit (ability to live in a community setting)

2014 WIOA (Workforce Innovation and Opportunity Act)

2016 ABLE Act (A Better Life Experience)

2021 PA 102- 0172/0173 Extends Special Ed services end of school year of 22nd bday



DDD Update

PUNS list has been cleaned up to reflect the number of people Seeking vs Planning for services.

- FY '18 reflected a little more than 19,000 on the PUNS list
- As of 9/30/24 there were 16, 306 with 6,271 Adults and 4,790 Children Seeking Services
- Waiting time for adults to be selected is less than 60 months from the 18th birthday, in the *Seeking* category.

https://www.dhs.state.il.us/page.aspx?item=141313



PUNS 18+ Seeking Services Time Waiting

Time waiting	total adults	percentage
60 or more months	12	0%
48 to 59.99 months	250	4%
36 to 47.99 months	1173	19%
24 to 35.99 months	1379	22%
12 to 23.99 months	1609	26%
0 to 11.99 months	1848	29%
Total	6271	



Stay Informed Advocate Vote

State budgetary constraints
Allocation of resources
Types of services available
Regulatory considerations

Visit your representatives

Sign up for Action Alert e-mails:

Legislative Alerts/Policy Priorities/Take Action https://advocacy.clearbrook.org/

Join Support/Advocacy Groups

The Arc of IL thearcofil.org

IPADDUnite.org (Transition age)

Cityofsupport.org (children)

North Suburban Parents of Kids with Special Needs FB (children)





1955

Five Families in a Church's Basement

1960s

Vocational Services 1970s

Residential Services & CHILD Program

1980s

Expansion of Residential Services

1990s

Clearbrook Clinic, Respite, CILA, & CFC 2000s

Plaza Opens, Home-Based Services Expand TODAY

Largest Provider of Home-Based Services Home to over 8,000

Resources

Benefits

Medicaid Application

http://www.dhs.state.il.us/page.aspx?item=56772

Supplemental Security Income http://www.ssa.gov

SSA Red Book https://www.ssa.gov/redbook/

SSA Policies https://secure.ssa.gov/apps10/poms.nsf/lnx/0501130740

Employment/WIOA http://www.leadcenter.org; WIPA https://iltech.org/services/work-incentives-planning-and-assistance/

Financial

- ABLE Accounts https://savewithable.com/il/home.htm
- Special Needs Trusts https://www.rubinlaw.com/blog/special-needs-trusts-and-how-to-fund-them/

Housing

- Corporation for Supportive Housing https://www.csh.org/supportive-housing-101/
- Center for Independent Futures https://independentfutures.com/blog/housing-solutions/

Legal

- Special Needs Alliance https://www.specialneedsalliance.org/
- Supported Decision Making http://www.supporteddecisionmaking.org
- IL Guardianship & Advocacy Commission https://www2.illinois.gov/sites/gac/Pages/default.aspx
- National Center on Secondary Education and Transition __www.ncset.org/publications/printresource.asp?id=318

Recreation/Leisure

- Special Olympics www.soill.org
- Special Recreation <u>www.specialrecreation.org</u>

Transition Planning

• Transition Module https://equipforequality.org/tm/transition-plan/index EFE02 Transitions.php; Pacer's National Parent Center on Transition and Employment https://www.pacer.org/transition/

Transportation www.rtachicago.com www.pacebus.com



Resources IL DHS/DDD https://www.dhs.state.il.us/page.aspx?item=29749

The Arc Of US on Voting

https://thearc.org/vote/?utm_source=cc&utm_medium=email&utm_campaign=vote

The Arc Of US on Future Planning

https://futureplanning.thearc.org/pages/learn/future-planning-101

The Arc of IL on Residential Options https://www.illinoislifespan.org/wp-content/uploads/2020/02/ResidentialOptionsFinalAug2019.pdf





It's not what you look at that matters. It's what you see.

Henry David Thoreau





Thank You!

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