

Family Caregiver Support

Illinois Respite Coalition



What is the Illinois Respite Coalition?



Our Mission:

- The IRC is also dedicated to increasing awareness of the importance of “Lifespan Respite” and promoting education and training for families and providers of respite services
- The Illinois Respite Coalition was founded in 1998 as part of a grassroots organization led by caregivers and providers.

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What is the Illinois Respite Coalition?



What We Do:

- The Illinois Respite Coalition (IRC) is a non profit organization that provides respite care, information and referral services, and advocacy in Illinois
 - Through the Illinois Department of Human Services, Division of Developmental Disability we provide in-home support to over 27 counties in Central and Southern Illinois
 - Through the Administration for Community Living, with IDHS, DDD as our lead agency, the IRC provides Emergency Respite Care funding across the state for eligible caregivers of a loved one of any age or disability in an emergency situation

Types of Caregiver Support at a Glance

- Services through the Illinois Department of Human Services (IDHS)
 - Respite (In-home, Voucher, Group, Residential Respite Beds)
 - Rehabilitation Services
 - Home Based Waiver when pulled from PUNS List
- Division of Specialized Care for Children
- Crisis Nurseries
- Services through the Illinois Department on Aging
 - Care Coordination Units/ Area Agency on Aging
 - Grandparents Raising Grandchildren
- Emergency Respite Care Program (ERC Program)



Illinois Department of Human Services

- IDHS offers funding for respite programs
 - Respite programs include: In-Home, Voucher, Group, Residential Respite Beds
- Respite is a short time of rest or relief, it is a break for the caregiver
- Respite is a relatively new service
 - Although there were some programs in the 1960s, it wasn't until the 1980s that respite began to flourish
- To date, there are still a shortage of both respite programs and respite workers and other personal support workers across the nation



IDHS Respite Programs



- **In-Home Respite Program**

- Provides a bank of respite hours per year to eligible caregivers of a loved one diagnosed with an intellectual or developmental disability
 - Agency hires and trains the worker

- **Voucher**

- Provides a stipend/ reimbursement to eligible caregivers of a loved one with a an intellectual or developmental disability
- Voucher amounts vary but can be used in a variety of ways (pay for programs, to pay a worker, etc)

IDHS Respite Programs

- **Group**
 - Provides respite to individuals with a developmental disability in a group setting for a portion of the day (Ex: days programs before/ after school care)
- **Residential**
 - Residential Respite program provides short-term stays for individuals in a residential setting that is licensed, certified or approved and is appropriate for their needs.
 - Supervision and care for children and adults.



Rehabilitation Services

- The Department of Rehabilitation Services (DoRS) is the lead agency serving individuals with disabilities
- Helps individuals with disabilities and their families make informed decisions
 - Works to achieve full community participation
 - Through employment, education and independent living opportunities

Website:

<https://www.dhs.state.il.us/page.aspx?item=29736>

Photo: taken from DHS website <https://www.dhs.state.il.us/page.aspx?item=51120>



PUNS List/ Home-Based Waiver



- PUNS is a database that registers individuals who want or need Developmental Disability Waiver services
 - (i.e. Community Integrated Living Arrangements, Home Based Supports, Child Group Homes)
- PUNS has 2 categories
 - **Seeking Services:** category for people who currently need or desire supports
 - **Planning for Services:** category 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.

Website:

<https://www.dhs.state.il.us/page.aspx?item=41131>

Home and Community Based Services (HCBS) Waiver

- Once an individual is pulled from the PUNS list they are eligible for waiver programming - each waiver has different eligibility requirements
- Currently there are 9 different waivers
 - Children and Young Adults with a Developmental Disability- Support Waiver
 - Children and Young Adults with a Developmental Disability- Residential Waiver
 - People who are medically fragile, Technology Dependent
 - Persons with Disabilities
 - Persons with Brain Injuries (BI)
 - Adults with Developmental Disabilities
 - Persons who are elderly
 - Persons with HIV or AIDS
 - Supportive Living Program

Website:

<https://www2.illinois.gov/hfs/MedicalClients/HCBS/Pages/default.aspx>



Crisis Nurseries

- The Department of Human Service partners with crisis nurseries service providers to meet the needs of families who experience short-term crisis
- The goal of the crisis nursery program is to reduce parental stress, parenting skills, and reduce the risk of child abuse or neglect.
- There are currently six crisis nurseries that currently provide respite and short-term care
 - **Crisis Nursery of Urbana**, 1309 W. Hill Street, Urbana, Illinois 61801, Telephone (217) 337-2730
 - **Mini O'Beirne Crisis Nursery**, 1011 North 7th Street, Springfield, IL 62702, Telephone (217) 585-6800
 - **Children's Home and Aid Society of Illinois/MotherHouse**, Rockford, 910 2nd Ave. Rockford, Illinois 61104, Telephone (815) 962-4858
 - **Children's Home and Aid Society of Illinois/Children's Foundation**, Bloomington, 403 South State Street Bloomington, IL 61701, Telephone (309) 827-0374
 - **Maryville Academy**, 4015 N. Oak Park Avenue, Building B Chicago, IL 60634, Telephone (773) 205-3637
 - **Crittenton Centers**, Peoria, 442 W. John Gwynn Jr. Avenue Peoria, Illinois 61605, Telephone (309) 674-0105

Website: <https://www.dhs.state.il.us/page.aspx?item=55909>

Division of Specialized Care for Children (DSCC)

- DSCC serves families across all Illinois counties with children and youth with special health care needs, and assists them in access services and resources
- Some of their supports include:
 - Accessing diagnostic tests
 - Finding specialized medical care
 - Developing a care coordination plan
 - Finding resources & information
 - Preparing for transition
 - Paying for certain medical expenses
 - Communicating with doctors, specialists and schools



Website: <https://dsc.uic.edu/>

Illinois Department on Aging



- Care Coordination Units (CCU)
 - **Care Coordination Services** provided by "care coordinators" help older adults and caregivers determine what their specific needs are and what services are available to meet those needs.
 - The care coordinator can discuss community-based services that are funded by the state and federal government and those that an individual can purchase with his or her own resources.
- Area Agencies on Aging (AAA)
 - Area Agencies on Aging(AAAs) have the primary task of planning and coordinating services and programs for older people in their respective areas.
 - The AAAs contract with local agencies which provide services to the older people who live in the same community. Services are based on available funding.
- Grandparents Raising Grandchildren Program (IL Family Caregiver Support Program)
 - Typically can provide: respite, caregiver counseling, assistance in gaining access to services (<https://www2.illinois.gov/aging/programs/caregiver/Pages/grg.aspx>)

Website: <https://www2.illinois.gov/aging/Pages/default.aspx>

Emergency Respite Care Program (ERC)

- **What is it?**

- The ERC Program is a voucher program intended to help caregivers of individuals across the lifespan with any disability
- Through funding from the Administration for Community Living through their lifespan respite care program state program enhancement grant, the IRC is able to offer funding to support caregivers in a planned or unplanned emergency.
- In a crisis or emergency situation (ex. Caregiver illness or hospitalization, other family emergency or need, extreme stress)
- The ERC Program reimburses the cost of supervision for the caregiver's loved one

- **Eligibility?**

- Caregivers receiving no other services, any age or disability is accepted (cancer, mental illness, physical disability, etc)



IDHS Funding Update



- The Illinois General Assembly and Governor Pritzker approved a budget for Fiscal Year 2022 that includes a \$2.056 billion budget for the Division of Developmental Disabilities and provides \$170M in new funding towards I/DD services
 - This is a historic, highest-ever investment in the DD system in Illinois
- Temporary Increases to stabilize the System
 - Increases to adult CILA, CDS hourly rate, and children's group home
- Guidehouse Rate Study Priorities
 - Provide permanent rate increases effective 1/1/2022 for waiver funded services, pending formal waiver amendment approval

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