Let’s Talk Respite

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.
- We are dedicated to providing support and advocacy to individuals across the age and disability spectrum in Illinois.

Phone: 630-207-8479   Email: ilrespitecoalition@gmail.com
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
What is respite?
What is Respite Care?

- Respite is a short time of rest or relief, it is a break for the caregiver
  - The caregiver has downtime while the person with special needs receives care from qualified individuals
- An individual can receive respite care:
  - At home, a community organization or residential care center
  - From paid staff, volunteers, family or friends
  - For part of the day, evening or overnight
  - Occasionally or on a regular basis
- Respite is important because approximately 43.5 million Adults in the US are family caregivers of an adult or child with a disability or chronic condition
Why use Respite Care Services?

● Respite can give a caregiver the time and assistance required to meet personal needs
  ○ Errands: shopping, exercising, doctors visits
  ○ Sleep
  ○ Socialize

● Respite provides comfort and peace of mind to the caregiver knowing:
  ○ Their loved one is spending time with another caring individual, receiving appropriate care, and following family preferences

● The care recipient might need changes in routine and social interactions due to their own changes and challenges
  ○ With respite, they can interact with others, spend time in a safe environment and participate in activities that match their abilities
Who is eligible for respite?

How to apply for respite?
Who is eligible for respite?

- In Illinois, respite eligibility largely depends on the kind of program and other services the individual may be receiving.

- Generally speaking, Illinois has services for a wide variety of disabilities across the age and disability spectrum:
  - Programs for the aging community
  - Programs for mental illness
  - Programs for developmental disabilities
  - Programs for physical disabilities

- Illinois also offers emergency respite, which is a stipend given to caregivers to cover expenses while they are in an emergency situation:
  - This funding is available to caregivers of persons of any age with any disability as long as they are not receiving state or waiver funding.
How to apply for respite?

- Applications also differ depending on the program/provider.
- Since services for individuals with disabilities is spread throughout various Illinois governmental agencies, the application process will look different.
- However, most agencies provide support and guidance in filling out their applications.
What are different types of respite in IL?
What are different Kinds of Respite?

- There’s a number of ways that respite can be provided, but there are five common types (dependent on eligibility):
  - In-home respite care
  - Day centers & Recreational centers
  - Informal Respite Care
  - Residential Respite Care
  - Respite for emergency situations
- The varying types of respite are essential so families can have the respite that fits their schedule and needs.
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)
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

Photo taken from IDHS website: https://www.dhs.state.il.us/page.aspx?item=27893
Once an individual seeking DD waiver is pulled from the PUNS list they are eligible to apply 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
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

Website: [https://www.dhs.state.il.us/page.aspx?item=55909](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://dscc.uic.edu/](https://dscc.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](https://www2.illinois.gov/aging/programs/caregiver/Pages/grg.aspx))

Website: [https://www2.illinois.gov/aging/Pages/default.aspx](https://www2.illinois.gov/aging/Pages/default.aspx)
Special Rec / Parks and Rec Options
Special Rec and Parks and Rec Options

- Special Recreation Association Network of Illinois
  - [https://www.specialrecreation.org/](https://www.specialrecreation.org/)
- The link above has a list of the special recreation associations in Illinois
- Special rec’s have a variety of programs
  - Day programs
  - Group programs
  - Year-Round Programs
  - Special Olympics
  - Summer Camps
Emergency Respite Care Program (ERC)

● **What is it?**
  ○ The ERC Program is a one-time-only 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
    ■ After services have been used, the IRC provides information and referral to other services, if available

● **Eligibility?**
  ○ Caregivers receiving no other services, any age or disability is accepted (cancer, mental illness, physical disability, etc)
Contact Us!
- Phone: 866-455-7377 ext. 101
- Email: irc.statecoordinator@gmail.com

Referrals
- You can contact us directly, or you can be referred to us by other providers/ agencies

Eligibility Screening
- Staff conducts a 5-minute call to verify information essential for program eligibility
  - Ex: you are not receiving other state services, monthly stipends, or waiver services
  - Ex: Your spouse/partner is not the desired respite worker, because you both are considered caregivers
  - Ex: The person providing respite is over 18 years old
  - Ex: Care recipient was diagnosed with a disability (intellectual, developmental, chronic illness, cancer, dementia, alzheimer's, parkinsons, MS, etc)
  - Ex: The hours will be utilized within one month after official approval
Application + Contract
- Once the screening process has been completed, a fillable PDF application and contract is sent to the caregiver
  - The application is ~5 pages, it will request caregiver and recipient information as well as social security numbers for the caregiver, care recipient and respite worker
    - Tax ID if the respite provider is an agency
  - The contract is an agreement between you and your respite provider (whether it is a person or a program)
    - This sets the rate, the number of hours and the total amount requested
      - The amount CANNOT exceed $500

Post-Approval Process
- If approved, the Statewide Coordinator will send an email confirming the rate and number of hours, typically within 24-48 hours
- In the email a timesheet, reimbursement check request form, and survey will be attached
  - All need to be filled out and submitted as soon as respite hours have been used
How to Identify a Respite Worker?
How to identify a respite worker?

- PAS Agency
- Hiding in plain sight
  - High schools / colleges
  - Religious groups
  - Neighbors/ friends
  - Posting at community groups
- Relying on respite agencies
Illinois Respite Coalition Lifespan Respite Training

- Free virtual training opportunity for any individual in Illinois
- Certificate of Completion when the training is finished
- Modules can be completed on your own time
- Opportunity to opt in to be included in the respite care worker registry
- If you are looking for a worker and want to make sure they are trained, this training is a great way to get foundational knowledge on respite
- [https://illinois-respitecarewi.talentlms.com/](https://illinois-respitecarewi.talentlms.com/)
Contact Information

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