

# 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](mailto: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 may 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?

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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?

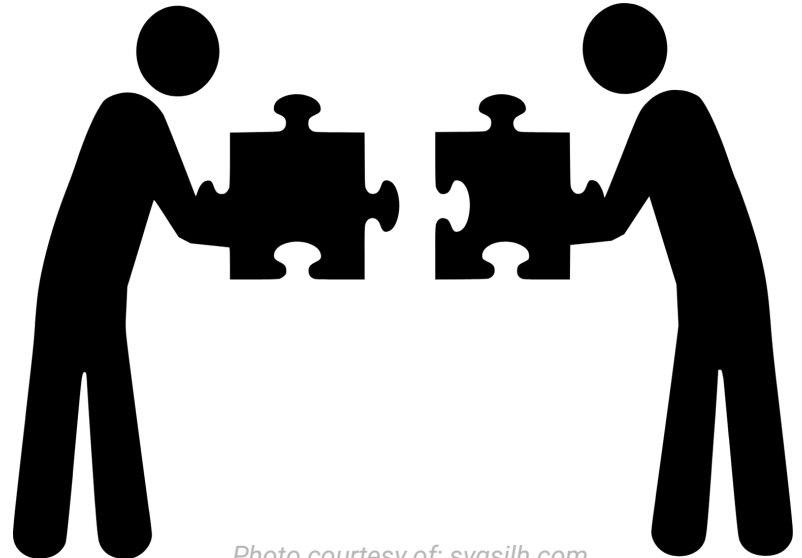
- Applications also differ depending on the program/ provider
- Since services for individuals with disabilities is spread throughout various Illinois governmental agencies, the application process will look different
- However, most agencies provide support and guidance in filling out their applications

# 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



*Photo courtesy of: [svgsilh.com](http://svgsilh.com)*

# 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>

# Home and Community Based Services (HCBS) Waiver

- 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>



Photo taken from IDHS website: <https://www.dhs.state.il.us/page.aspx?item=27893>

# 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://dsccl.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>

# Special Rec / Parks and Rec Options



# Special Rec and Parks and Rec Options

- Special Recreation Association Network of Illinois
  - <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)



# ERC → How to Apply

pt.1

- **Contact Us!**

- Phone: 866-455-7377 ext. 101
- Email: [irc.statecoordinator@gmail.com](mailto: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

# ERC → How to Apply

pt.2

## ● 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/>



# Contact Information



Tina Yurik

Executive Director, Illinois Respite Coalition  
Services Statewide

(630)207-8479

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866-ILL-RESP

866-455-7377

ext. 103 for Spanish-speaking callers

[ilrespitcoalition@gmail.com](mailto:ilrespitcoalition@gmail.com)

[www.illinoisrespitcoalition.org](http://www.illinoisrespitcoalition.org)