

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: 866-455-7377 ext. 101 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 statewide except for Cook county and voucher respite in 69 counties in central and southern Illinois and one northern county, Lake county.
 - 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?

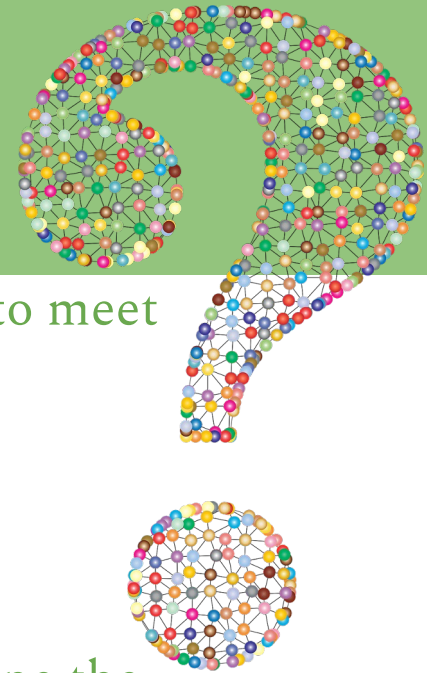
- Respite is a short time of rest or relief, it is a break for the caregiver
 - The caregiver has downtime while the person with special needs receives care from qualified individuals
- An individual can receive respite care:
 - At home, through a community organization or residential care center
 - 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 more than 65 million people provide care for a chronically ill, disabled, or aged family member or friend during any given year



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

Why use Respite 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:
 - Their loved one is receiving appropriate care from someone the caregiver trusts
- Offers the care recipient - an opportunity to interact with others, spend time in a safe environment and participate in activities that match their abilities

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)



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>

Home and Community Based Services (HCBS) Waiver

- Once an individual, seeking DD waiver services is pulled from the PUNS list they are eligible to apply for waiver funding.
- 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>

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 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: tfoster@illinoisrespitecoalition.org (Tammy Foster)
- **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

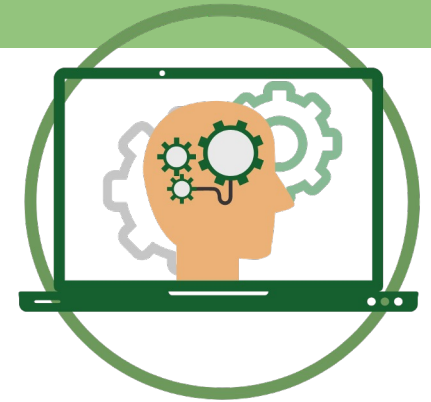
ERC → How to Apply

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

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
- <http://www.illinoisrespitecoalition.org/training.html>



Contact Information



Illinois Respite Coalition
Services Statewide
ilrespitcoalition@gmail.com

866-ILL-RESP

866-455-7377 ext. 101

ext. 103 for Spanish-speaking callers

www.illinoisrespitecoalition

The Most Difficult Part of Being a Caregiver

We gave options and allowed caregivers to select all that applied. Nearly every caregiver selected more than one option, and many selected every option.

The options were as follows:

1. Meeting personal needs
2. Personal finances
3. Balancing family, work, and caregiver duties
4. Spending time with other loved ones
5. Completing daily chores/tasks
6. Managing personal health/mental health
7. Knowing what other resources are available

Impact on Employment

“It is difficult to work on little to no sleep. I enjoy working but often get overwhelmed at the needs of loved ones and the need to earn enough to support our family. Paperwork required to advocate for our loved one can be time consuming.”

“My husband and I have been fortunate enough to find flexible mostly work from home jobs and we are self-employed. It would be very difficult to maintain employment outside the home.”

“Lower wages, hourly job due to needing to be available to son, sick days are used up every year and usually have to take unpaid time off, can't work in my chosen profession because work hours would not coincide with caregiving needs.”

“What employment? This is the hardest job I've ever had. In my pre-mom life, I worked as an RN on the floor of a local hospital – before that, 8 years in skilled nursing facilities . . . Well, the day I had my daughter, I clocked in for a shift that has never ended.”

Impacts on Friends and Family

“Not many friends left; they just quit coming around.”

We cannot always do events or social commitments on the account of caregiving – if we do we pick wisely and when do, it often ends up being a blow-out of a situation, which leaves us wondering why we decided to try to participate. We have to forfeit plans last minute, wasting money and impacting our relationships. Things that other families enjoy (like going to the pool in the summer) can be extra stressful and challenging for us to participate in. I have had to take mental breaks before going to work, after caregiving, because of how challenging/stressful the moments leading into work are/were. We cannot travel on planes, and we hesitate to travel by car, so the ability to take trips and visit friends is very limiting with our child, but then it's equally as challenging to travel without our child because we must find someone to care for him while we are gone and to have someone equipped to do that for overnights is near impossible. Our child is still in diapers and the world is not equipped to deal with a larger child in diapers, so that limits our ability to run errands and go to social events (where are we supposed to change him if he needs a diaper change?)”

“Most of my family is out of state or in later age to take care of him. I stopped asking some people because it feels like a burden to them, I don't have many friends because I can't go out when they can.”

What Would you Like us to Know About Caring for a Loved One?

“It’s extremely hard on our bodies in every area. We also worry more than most people. Respite is vital to the longevity of our lives.”

“It is one of the most rewarding and heart wrenching experiences I’ve ever had. It’s a lifelong commitment for an entire family to support their special needs person. For the parents but also for the siblings. I’m trying to get by day by day but also planning for the day I am gone if my brother doesn’t have the weight of the world on him to care for her. Having funds to help her live her life now is so important to us. The small amount of respite care we do get means a lot to our family.”

“It is a great and loving honor that we have, and that we know we will face for the rest of our lives, unlike other parents whose children will eventually fly the nest and have their own lives. Even as we hope and plan for a CILA placement, we also know that our son does not advocate for himself and is the perfect potential victim. This is a heartbreaking reality.”

“Very stressful on the family. Cannot do anything together like going to dinner, movies, sports events, etc. Someone always must be home with my son. I’ve missed out on my other children’s sports events for years.”

Positive Impacts of Caregiving

“She has taught me a lot; she had made me understand our world better. She helps us slow down and enjoy the small things, she teaches us to not complain so much.”

“Fulfilling a promise to my late mother. Helping my dad.”

“My son is so full of joy. It has made me prioritize what’s important. I have confidence in how to take care of him. I can help others who are in similar situation. I’ve learned so much about Down Syndrome.”

“Hugs, smiles, cherish time together, enjoy exploring together, seeing their growth, observing how they try new experiences, perceive life’s experiences, problem solve, etc. Watching them flow when enjoying activities, they like, and they are beaming when [they are] around peers enjoying [the] same thing. New things they think of and new stages and phases.”

“Sharing his joy of life. Our son loves his job. He is very active in Special Olympics. He has friends who are delightful. He is loving of his extended family. He cares for the poor and homeless. He is accepting of everyone”