Resources for Respite

What is Respite?

Respite is a break for parents or other caregivers. Caregiving day after day can be hard, and having an occasional break can make a big difference in preventing caregiver burnout. Respite helps you be better a parent or caregiver.

To learn more about respite, you can always contact the **Illinois Respite Coalition** at 866 455-7377.

Who is Eligible?

- Any individual with a disability or chronic medical condition who is cared for by a parent or other family caregiver.

How Do I Get Respite?

There are several ways to get respite in Illinois:

1) Through state grant programs
2) Through a Medicaid Waiver Program like the Medically Fragile Technology Dependent Waiver or any of the DRS Home Services Program Waivers
3) Through specialized programs

If I Don't Have a Waiver or I am on the PUNS List, How Do I Get Respite?

There are several programs you may be eligible for:

1) Emergency Respite Care Program
2) In-Home, Group, and Residential Respite Programs
3) Voucher Respite Program
4) Special programs

As of the current date, **The Emergency Respite Care Program** provides a $500 voucher to help pay for respite in unexpected or emergency situations. Contact the **Illinois Respite Coalition** at 866-455-7377 for assistance.

The In-Home, Group, and Residential Respite Programs provide support in various settings for those of any age with an intellectual or developmental disability. Respite hours and ages served may vary based on the agency's program. You cannot receive these services if you are in a waiver. You can find **providers through the Illinois Department of Human Services**. Contact the provider directly to apply.

The Voucher Respite Program is a voucher-based program for those with intellectual or developmental disabilities in certain parts of the state. You hire your own provider and receive a voucher to pay the provider. You can also use your voucher to pay for an eligible service, such as a special recreation camp. Voucher amounts may vary. Caregivers should discuss the reimbursement process with the agency. You can find providers through the **Illinois Department of Human Services**. Contact the provider directly to apply.

Sometimes, **special programs** can provide respite. These may include:

- **Family and Caregiver Services through the Department of Aging**
- **Grandparents Raising Grandchildren Program**
- **The Community Care Program**
- **Pathways to Success Medicaid Respite for Children with Severe Emotional Disturbance**
- Some cities or areas like **Chicago** have their own respite programs
- In the future, the Pediatric Palliative Care Medicaid Program will also provide respite care

If I Have a Waiver, How Do I Get Respite?

- **Medically Fragile Technology Dependent Waiver**. You can get respite in your home by asking your Nursing Agency to arrange for a nurse. Most individuals get 336 respite hours per year. You can also get respite in a specialized facility for up to two weeks per year. These are listed in the section below. Contact your care coordinator at the **Division of Specialized Care for Children** for more help.
- **DRS Home Services Program (DRS Waiver)**. You can ask your case manager if you qualify for respite services. If so, you can receive your respite from a provider of your choice at home, who may be a nurse, aide, or other individual. You can get up

to 240 hours per year. Contact your case manager at the **Division of Rehabilitation Services** for more help.
- **Developmental Disability Home-Based Waivers for Adults or Children**. There is no traditional respite benefit in these waivers, but Temporary Assistance is available in emergency or crisis situations. Ask your case manager at your **Independent Service Coordination Agency** for assistance.

Community Respite Facilities for Children

Illinois has 5 houses that are approved to provide respite for children under 21 with medical needs or disabilities. Not all children will be eligible, as it depends on the type of support needed. The cost of this care may be covered by the Medically Fragile Technology Dependent Waiver, insurance, Medicaid, or can be paid for directly. These facilities include:

- **Almost Home Kids** (three facilities in Naperville, Chicago, and Peoria)
- **Maryville Children's Healthcare Center**
- **Ventracare**

Children under age six may also use a **Crisis Nursery** for respite care.

What If I Cannot Find Respite or Have a Caregiving Emergency?

- We always recommend making an emergency plan in advance for your loved one.
- Contact the **Illinois Respite Coalition** to see if you can get an Emergency Voucher.
- Contact your case manager through your waiver program for help, as extra services may be available.
    - Medically Fragile Technology Dependent Waiver – contact the **Division of Specialized Care for Children**
    - Developmental Disability Waivers – contact your **Independent Service Coordination Agency**
    - Home Services Program Waivers – contact the **Division of Rehabilitation Services**
- As a last resort, go to the Emergency Room or arrange hospital admission.