



RESPITE PROGRAM

GUIDELINES

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CONTACTS

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PROGRAM DESCRIPTION

In recognition that families who have sons and daughters with developmental disabilities often have more extensive caretaking responsibilities than families of typically developing children, the Respite program is meant to provide parents or caregivers with short-term relief and time away from their child/adult family member with a disability. Family members decide for themselves how to use their “break” from caretaking.

The Illinois Department of Human Services Division of Developmental Disabilities (DHS-DDD) provides funding to Community Support Systems for the provision of respite services for families who have children and adults with developmental disabilities residing in their homes. Parents, foster parents, and guardians who live in the Illinois counties of Clay, Crawford, Cumberland, Edwards, Effingham, Fayette, Jasper, Lawrence, Richland, Wayne and Wabash may be eligible for DHS respite services through CSS. Persons who are enrolled in DDD funded residential services are not eligible to receive respite services. Persons who receive Home Based Support Services are not eligible to receive in-home (including provider home and community) respite.

Respite care is provided either in the consumer’s home, in the home of the respite provider, or in the community. The family selects providers they determine are qualified to take care of their family member with a disability and then provide individualized training on their family member’s care needs. The family will then report the hours of care to CSS and will be reimbursed for the cost of that care. The number of families eligible for the Respite program is limited only by the availability of funds.

CSS accepts enrollment requests from families seeking respite services, determines eligibility, determines the level of care (with the input of the family), allocates the number of hours of care families will receive and processes all the enrollment and payment forms needed to reimburse families for the respite care that is provided. Families provide records that document their family member’s developmental disability. These may be medical records, educational records, or psychological assessments.

Each family enrolled in the Respite program will be notified of their monthly allocation of hours that can be used through arrangements made between families and providers. Typically the beginning allotment will be 15 hours per month per family. **If a family does not use the entire allotted amount of hours for the month, the remaining hours cannot be “saved”.** If a family has extenuating circumstances or an emergency and needs additional hours during the month, they may contact the coordinator to discuss availability of additional emergency hours. Respite use will be analyzed throughout the year and allotments of hours will be increased or decreased accordingly.

CSS does not receive additional funding when the number of eligible families increases, so when new families enroll in the program the available hours may need adjusted for all participants. The actual number of hours available is dependent upon the amount of funding received and the number of participants enrolled.

The Respite Coordinator will complete the enrollment process for families, will notify families of the hours available to them, will collect the reimbursement forms verifying the hours of care that were used, and will submit the payment information to the CSS business office so that families will be reimbursed to pay their providers.

The Respite program does not provide direct social services, educational services, vocational services, medical services or special therapies. Respite providers are available to provide parents a break. Families will make their own arrangements with their providers for suggested activities, instructions, and expectations for each respite event.

RESPIRE PROGRAM ELIGIBILITY

Services are provided to adults and children age twelve and older who need care because of their developmental disability, and children ages 11 and younger whose developmental disability **requires care by a worker with special skills or training beyond the skills and training required of any worker qualified to care for non-disabled children.**

Determination of a developmental disability is based on the existence of an intellectual disability OR related condition AND the need for active treatment.

Intellectual disability refers to:

- Significantly sub average general intellectual functioning
- existing concurrently with deficits in adaptive behavior and
- manifested before the age of 18 years.

A Related Condition is a severe, chronic disability that meets all of the following conditions:

- is attributable to
 - Cerebral palsy or epilepsy
 - Any condition other than mental illness found to be closely related to an intellectual disability and requires treatment or services similar to those required for those with an intellectual disability
- is manifested before the individual reaches age 22
- is likely to continue indefinitely
- results in substantial limitations in 3 or more of the following areas of major life activity: self-care, language, learning, mobility, self-direction, capacity for independent living

There is no maximum or minimum age limit for consumers but the consumer must not be receiving DHS-DDD residential services. Families must provide proof of disability (i.e. copies of evaluations, IEPs or IFSPs), must provide copies of guardianship papers if they are the legal guardian for the consumer (for program recipients over age 18 or those who have legally appointed guardians) and must provide the needed information for DHS registration to enroll in the Respite program.

Families must reside in Clay, Crawford, Cumberland, Edwards, Effingham, Fayette, Jasper, Lawrence, Richland, Wabash, or Wayne counties or reside in a school district of those counties to be eligible for the DHS Respite program through CSS.

RESPITE PROVIDERS

A respite provider is employed by the individual family who enrolls in the DHS Respite program. The respite provider is not an employee of CSS. Respite providers are selected and paid by each family and must be someone who is **18 or over** and does **not live in the consumer's home**. They must be qualified to provide the level of care needed and have received individualized training specific to the consumer by the parents/guardians/caregivers. Many families prefer to use extended family members such as grandparents, cousins, aunts, uncles, grown siblings or other individuals who know the consumer and can meet their needs.

Families utilizing the DHS Respite program will conduct their own screening of potential providers, will evaluate their own satisfaction with the quality of their providers, and will set their own expectations for the providers' performance after providing adequate individualized training.

Families will provide specific information and instruction to their providers about the individual needs of their sons and daughters. They also will provide schedules of routines and express their expectations for the respite caregiver so that the provider will understand how to care for the consumer.

Families who do not have a provider in mind or readily available to care for their family member and need assistance in locating a provider, may contact the Respite Coordinator for a list of providers used by other families or for ideas on how to recruit a new provider.

Families may request assistance from the Respite Coordinator at CSS for resources to use in training a respite provider. The Respite Coordinator will help locate appropriate materials for training providers including printed materials and videos with disability specific educational information.

DURING AND AFTER THE RESPITE SESSION

After families have selected a provider, they will make arrangements for the dates and times at which respite care will occur. The Department of Human Services limits respite to a **10 hour maximum per day**. Families will be responsible for keeping records of the dates and times that respite care took place and then for submitting those records to CSS for reimbursement which will be used to pay their providers. Each reimbursement sheet must be signed by both the provider and the family member to verify that respite care took place on those dates and times and that the family was satisfied with the services. One time sheet will be completed for each provider who worked with the consumer during the month. These forms are in triplicate so that a copy can be kept by the family, a copy can be given to the provider, and the original can be given to CSS. They may be submitted by mail, fax or email.

Completed reimbursement forms for the month containing the necessary signatures should be submitted to the Respite Coordinator by the first day of the next month (may be submitted earlier). This will result in reimbursement checks being written by the 10th day of the month that follows the month of respite use.

REIMBURSEMENT RATES

To determine the level of care needed for each consumer the Respite Coordinators will discuss with families the consumers' needs in the following areas:

- Self help Skills (ability to toilet, eat, dress, groom, etc. at age appropriate level)
- Mobility Skills (ability to move around the environment at age appropriate level)
- Communication Skills (ability to speak and understand language at age appropriate level)
- Behavioral/Emotional Issues (ability to interact, respond, and engage with others or environment at age appropriate level)
- Medical Issues (presence of seizures, G-tube, breathing treatments, oxygen, feeding assistance, etc.)

Level 1 – more than two areas are **significantly** affected

Level 2 – two areas are **significantly** affected (may have other areas that are mildly affected)

Level 3 – only one area is **significantly** affected, or multiple areas are mildly affected.

Reimbursement to families for respite care will be at the rate of \$13.20 per hour for Level 1 care; \$10.61 per hour for Level 2 care; and \$9.57 per hour for Level 3 care.

SATISFACTION

Parents and adult consumers will receive surveys quarterly to report their level of satisfaction with the respite program. Please complete the surveys to let CSS know how the program is working for families. Between the surveys, families are welcome to contact the Respite Coordinator for any assistance or to express concerns. Families can also contact the Director of Family Support at the number listed in the front of this handbook to resolve any problems.