

# Emergency Respite Care

Creating a safety net for Caregivers in  
Crisis

Illinois Respite Coalition

# Purpose of the program

- Lifespan Emergency Respite Program offered funding and resources to support caregivers of children and adults with special needs.
- Have an urgent need for respite care in the absence of any other funding source.
- The Lifespan Emergency Respite Program supports the caregiver's decision to request emergency respite care and determine where the care will be delivered and by whom.

## DEFINITIONS

Definitions were critical as the program progressed so that agencies and caregivers had a clear understanding of the process.

**Care Recipient:** An adult with special needs or child with special needs who requires care or supervision to meet the person's basic needs; prevent physical self-injury or injury to others; or avoid placement in an institutional facility.

**Emergency Respite Care:** means the placement of an in-home respite care worker during an unplanned or planned event, or the temporary placement of the care recipient outside the home, to substitute for the caregiver. Emergency respite care may be provided on one or more occasions.

An **emergency** is:

an unplanned event that results in the unavoidable absence of the primary caregiver or back up caregiver from the home.

**Primary Caregiver:** shall mean an unpaid family member or other adult or foster parent who provides in-home monitoring, management, supervision or treatment of a child or adult with special needs. Such caregiver may, but need not, reside in the same household as the care recipient.

**Provider:** a non-profit, for-profit organization or an individual which provides respite care services (ex):

- Home based and consumer-directed services
- Long term care facilities and Hospitals
- Respite centered-based model
- Crisis nurseries and foster home settings
- Camps
- Adult day care

**Respite Care:** the planned or unplanned provision of intermittent and temporary substitute care or supervision of a child or adult with special needs on behalf of and in the absence of the primary caregiver for the purpose of providing temporary relief from the stress or responsibilities of providing constant care, so as to enable the caregiver to continue the provision of care in the home.

**Unplanned events that threatens:**

The health and safety of the care recipient or the caregiver thereby placing the care recipient in danger.

## **EMERGENCY RESPITE PROGRAM:**

Services may include, but not be limited to the following circumstances:

- Caregiver illness (physical, mental or emotional)
- Caregiver hospitalization or doctor appointment
- Illness of a loved one
- Funeral/Wake
- Reduction of stress level
- Drug/ Alcohol Abuse counseling/support
- Care recipient transitions (living arrangements)
- Loss of employment/Work related situations

**\*Not for child or adult day care on a routine basis**

## **ELIGIBILITY**

Caregivers caring for a child with special needs or adult with special needs.

## **PRIORITY FOR SERVICE**

- Caregivers with the greatest emotional, medical, or economic need (targeting low income caregivers).
- Caregivers of a child or adult with special needs that cannot be cared for by other individuals or other organizations within the community (due to the complexity of their special needs).



## **CONFIRMING THE NEED FOR EMERGENCY RESPITE SERVICES:**

The Interviewer should review community resources to determine that all other funding possibilities have been explored. (ex)

- Access the ARCH Respite Resource Network for a respite provider that will agree to provide respite care services.
- Access the Illinois Respite Coalition (IRC) website to locate respite providers.

- Contact the appropriate Area Agency on Aging (AAA) if the care recipient is an adult 60 years of age or older with special needs.
- Search for funds through civic groups, local churches, community case management agencies and other sources.
- Investigate volunteer respite resources to enhance or supplement paid respite.

# APPROVAL PROCESS

- The request for emergency respite will be reviewed by the Lifespan Respite Care Program Director or designee who will determine the greatest need based on specific criteria.
- After receiving approval to release funds the Program Director or designee will contact the interviewer or caregiver with the results of the decision within 48 hours.

## **SPECIAL INSTRUCTIONS FOR RESPITE CARE**

- The caregiver and/or the care recipient will choose the location where respite services will be provided.
- If the family does not have a respite provider, a list from the Lifespan Respite Program will be provided.
- The Director approves the respite request, the caregiver arranges the respite services with the provider.
- The respite provider bills the Lifespan Respite Program directly.

## **FOLLOW UP REQUIREMENTS**

- After emergency respite services have occurred, the Lifespan Respite Program staff will follow up with the caregiver to determine if the caregiver received the services and their needs were met.
- A caregiver evaluation survey as well as other outcome tools will be used to measure the success or failure of the emergency respite program.

# CAREGIVER RESPITE SERVICES REIMBURSEMENT

- The request for payment must be made within 60 days from the first day of service.
- Providers will be reimbursed within 30 days from the date the Request for Emergency Respite reimbursement is received.

# CAREGIVER RESPITE FUNDING

- The Lifespan Respite Program will approve and track each emergency respite care request.
- Unused funds for the request will remain in the Emergency Respite fund for initial or revised requests.
- Within 60 days of the service reimbursement request must be submitted to insure payment.
- Providers can contest non-payment of funds and may be paid if funds are available.

## Funding Caps per Family

- \$500.00 per family per fiscal year
- Upon prior approval up to an additional \$500.00 may be authorized.
- Including special approval, families may not exceed \$1,000.00 per fiscal year.
- Exceptions may be allowed contingent upon availability of funds.



## CANCELLATION OF EMERGENCY RESPITE

- The caregiver's circumstances change and the service is no longer needed.
- Interviewer or person requesting services can cancel an approved service, by writing "CANCEL" over the approved Emergency Respite Authorization Form.
- Faxes and or scans it to the Lifespan Respite Program Director.

# LIFESPAN RESPITE PROGRAM REQUIRED FORMS FOR EMERGENCY RESPITE CARE

- Emergency Respite Care Authorization Form
- Emergency Respite Voucher Form
- Emergency Respite Reimbursement Form
- Receipt of payment for respite services (if required)
- Caregiver Survey Form

# **Illinois Lifespan Respite Emergency Respite Care Authorization**

## **SECTION A – AGENCY/PROVIDER INFORMATION**

Only needed if an agency is applying on behalf of the caregiver.

## **SECTION B – CAREGIVER INFORMATION**

Race

Age

County

Relationship to Care Recipient

Time spent caregiving each week

Caregiver Income

## **SECTION C – CARE RECIPIENT INFORMATION:**

Age

Diagnosis

Sex

Race

Primary Language Spoken

Are they receiving any type of funding from the state (ex. waivers)

## **SECTION D – ADDITIONAL RESOURCES**

**To be completed by the Interviewer**

List of additional resources/services that the care recipient is receiving

## **SECTION E – EMERGENCY RESPITE CARE SERVICES (use additional pages if needed)**

- Reason for emergency respite services.
- How will the services benefit the caregiver?
- Does the caregiver typically receive respite?
- Other Respite funding sources not available.
- Would the care recipient be “at risk” if the caregiver didn’t receive ER services?

## **Without emergency respite care, what alternate choices would the caregiver have for services?**

- None
- Hospital
- Long Term Care Facility
- Use Alternate Caregiver (when possible)

## **Location where respite care will be provided:**

- In Home of Caregiver
- In Home of Care Recipient
- Adult Day Center / Child Day Care
- Adult Nursing Home
- Pediatric LTC Facility

## **Amount of Respite Care Needed:**

- Hours/Days
- Dates of Service
- Time of service

## **Respite Care Rates Requested:**

- Hourly Rate
- Daily Rate

## **Service Provider:**

- Person to provide respite care (SSN required)
- Agency to provide respite care (Tax ID # required)

## **SECTION F – CRITERIA FOR EMERGENCY RESPITE FUNDS**

### **Care Recipient Must:**

- Be living in the community
- Be identified as health and safety risk
- Require a trained worker.
- Not be able to be cared for by a neighbor, friend, or family member and cannot be left alone.
- Be able to receive respite care safely.
- Be a child or adult with special needs



## **SECTION F – CRITERIA FOR EMERGENCY RESPITE FUNDS**

### **Caregiver Must:**

- Have an illness (physical, mental, emotional)
- Need hospitalization / Go on an appointment.
- Need to attend a Funeral or Wake.
- Need to reduce stress level.
- Need Drug/Alcohol abuse counseling/support .
- Have employment or work related issues
- Have a family emergency or need.

## **SECTION G – AUTHORIZATION FOR EMERGENCY RESPITE SERVICES**

- Identifies numbers of hours approved
- Discussion notes (summary of caregivers need)
- Approved
- Denied
- Date and Signature of Lifespan Respite Program Director

# Emergency Respite Care Voucher Form

- Respite Services Approved
- Name of caregiver
- Name of care recipient
- Name of respite provider
- Dates of Services Approved
- Rate Approved

# **Emergency Respite Program Challenges:**

## **Application and Evaluation Process:**

- People who got the applications off of the website did not refer to the instruction sheet therefore many errors occurred and delayed the approval process.
- Sometimes people had to fill out the application several times.

## **Solution:**

- We assisted people over the phone to complete the forms.
- Caregivers emailed the information to complete the application process.

## **Challenges continued:**

### **Caregiver Surveys:**

- Evaluations on how the program and process worked were not returned on a regular basis.

### **Solution:**

- We tried to reach people by phone.
- In the future we would send the reimbursement form with the survey
- Require that the survey be returned in order for the payment to be processed.

## **Challenges Continued:**

### **Limited Families Served:**

- The program description and forms only available in the English language.

### **Solution:**

- Social workers and case managers assisted the caregivers to fill out the forms.
- In the future we would make the forms available in Spanish at a minimum.
- We will change the word provider to respite provider on all of the forms. Often the caregivers would sign on the provider line.

## Challenges:

### Reimbursement Process:

- Half way thru the project vouchers for approved hours were dispersed.
- The vouchers secured the agreement between the IRC and the caregivers.
- Reimbursement forms were at times not submitted in a timely manner.
- Reimbursement forms not available on the website.
- Forms had to be individually sent out with vouchers.

## **Reimbursement Solution:**

- Need the respite workers address on the Respite application.
- Prefill out the reimbursement form to prevent confusion.
- Allows for an easy verification process of information and signatures to confirm that the service was done.

## **DATABASE:**

- Time consuming to maintain.
- Provided tracking information.
- Needed to be modified to complete various reports.



## **SUSTAINABILITY FOR FUNDING AND MANAGEMENT OF THE PROGRAM:**

- DCFS continues to provide a grant to the IRC on an annual basis to provide the salary of one Statewide Respite Coordinator.
- IDOA has provided support for the Lifespan Respite Program.
- Plan to work with IDHS to continue the emergency respite program in Illinois.
- Currently there is no funding available for this program thru any state or private partners.

## **Impact and Project Activities to be sustained:**

- Many caregivers throughout the state were able to get a break for a variety of reasons.
- The process was easy and quick which allowed anyone with a worker in their own personal network to be served.
- People were able to get services regardless of their income.
- Respite awareness and access to services was improved.

- Statewide respite database is more robust and user friendly:
  - Divided by county
  - Available on the IRC website
  - Caregivers can click on a state map divided by county and find respite providers
- Networks of state agencies, private providers and caregivers are developed.
- An Emergency Respite program has been set up for the state of IL and can easily be utilized as soon as funding is available.

- The Illinois Respite Coalition became the “one stop shop” and is a resource for caregivers.
- The IRC continues to provide trainings and resources for the state through the DCFS grant.
- The IRC continues to provide activities to increase support for caregivers and agencies that provide respite.

## **LESSONS LEARNED:**

- There is a great need for Respite and caregivers tend to rely on crisis services in the absence of a comprehensive respite support system.
- A wide range of disabilities, and healthcare conditions are present throughout the state.
- Hard to find respite services in rural areas.
- There are more resources listed in database for seniors than children.
- Gaps in services were identified for those with Mental Illnesses – lack of routine respite services forces caregivers to rely solely on emergency funding to get a break.

- LTC agencies charged exceeded the cap set at the beginning of the project.
- Private partners are needed as sustainability.
- Communication of the ER program was difficult phone conferences, emails, and training sessions throughout the state were conducted.
- It took approximately one year before many people were aware of the program and started to apply for emergency respite services.

**Responses received from caregivers were separated into 4 categories:**

The Emergency Respite Application process was easy to use:

- 75% strongly agreed

- 25% agreed

Requests for emergency respite services was handled properly:

- 85% strongly agreed

- 10% agreed

- 5% were neutral

The IRC website was helpful in assisting me to identify/locate respite providers:

60% strongly agreed

30% agreed

10% were neutral

I would refer the Lifespan Emergency Respite Program to others in need of emergency respite services:

90% strongly agreed

5% agreed

5% were neutral