



NATIONAL ASSOCIATION
OF STATE HEAD INJURY
ADMINISTRATORS

Webinar: Respite for Family Caregivers of Individuals with Brain Injury

EXPLORING NEW PARTNERSHIPS

APRIL 14, 2021 | 2:00 PM EDT



Presenters

Susan Vaughn, Director of Public Policy, National Association of State Head Injury Administrators

Rebecca Wolfkiel, Executive Director, National Association of State Head Injury Administrators

Jill Kagan, Director, ARCH National Respite Network and Resource Center

Dana Allard-Webb, FCSP Program Manager, Home & Community Services, Aging & Long-Term Support Administration, Washington State Department of Social and Health Services

Geene Delaplane, Kinship Care and Lifespan Respite Program Manager, Home and Community Services, Aging & Long-Term Support Administration, Washington State Department of Social and Health Services

Presentation Overview

- ❑ What is respite and why is it important?
- ❑ Respite and Caregiving Needs of Individuals with Brain Injury and their Family Caregivers
- ❑ Resources from the Brain Injury Network
- ❑ Partnering with the Lifespan Respite Care Program
- ❑ Lifespan Respite Washington and TBI Partnerships





Respite is...

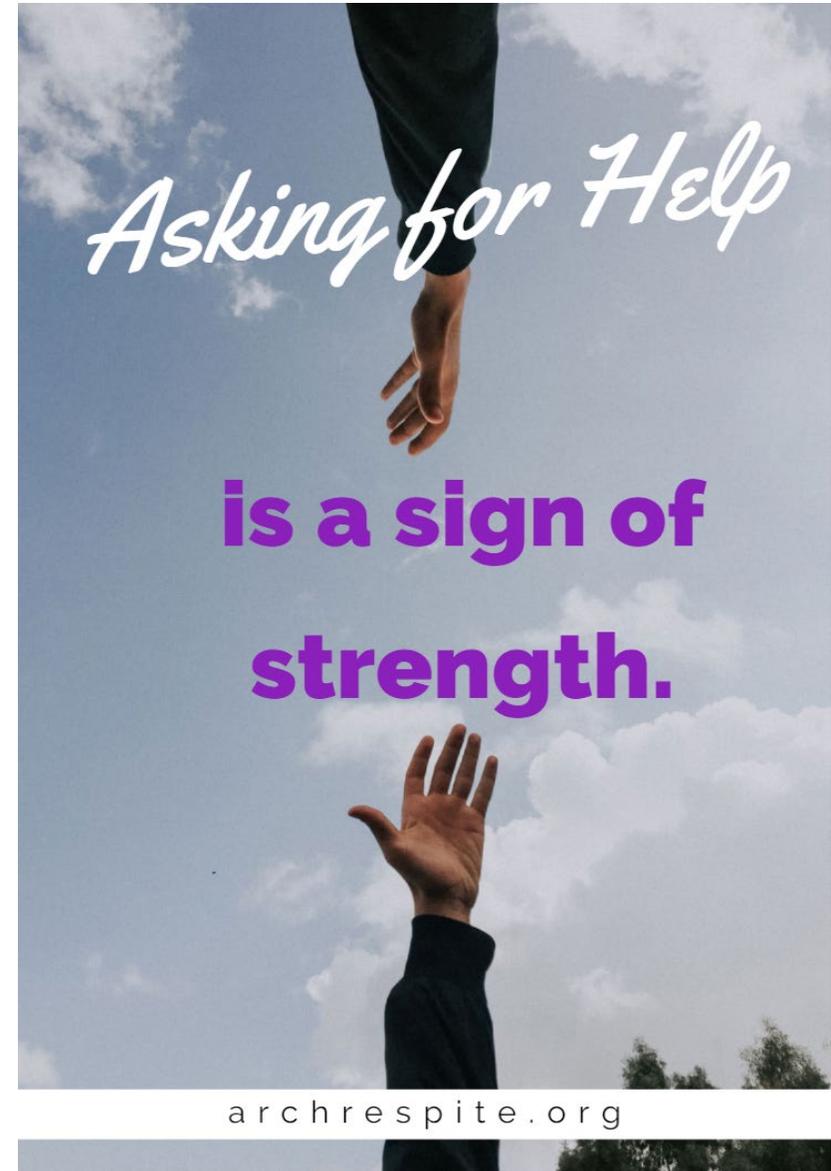
Planned or emergency care provided to a child or adult with special needs in order to provide temporary relief to family caregivers who are caring for that child or adult.

***Lifespan Respite Care Act
PL 109-442***

Everyone Needs Respite!

Benefits of Respite

- ❑ Reduces Stress
- ❑ Improves physical and emotional health
- ❑ Enhances relationships and reduces social isolation
- ❑ Care recipients benefit, too!





Respite: Too Little, Too Late

- ❑ Just 14 percent of family caregivers report having used respite, though 38 percent feel it would be helpful (*2020 Caregiving in the US, NAC/AARP*).
- ❑ Of those who do, they often receive too little, too late.

Respite for Family Caregivers of Individuals with Brain Injury – *Exploring New Partnerships*

Rebecca Wolfkiel, MPP

Executive Director

rwolfkiel@nashia.org

Susan L. Vaughn, MEd

Director of Public Policy

svaughn@nashia.org

April 14, 2021



About NASHIA

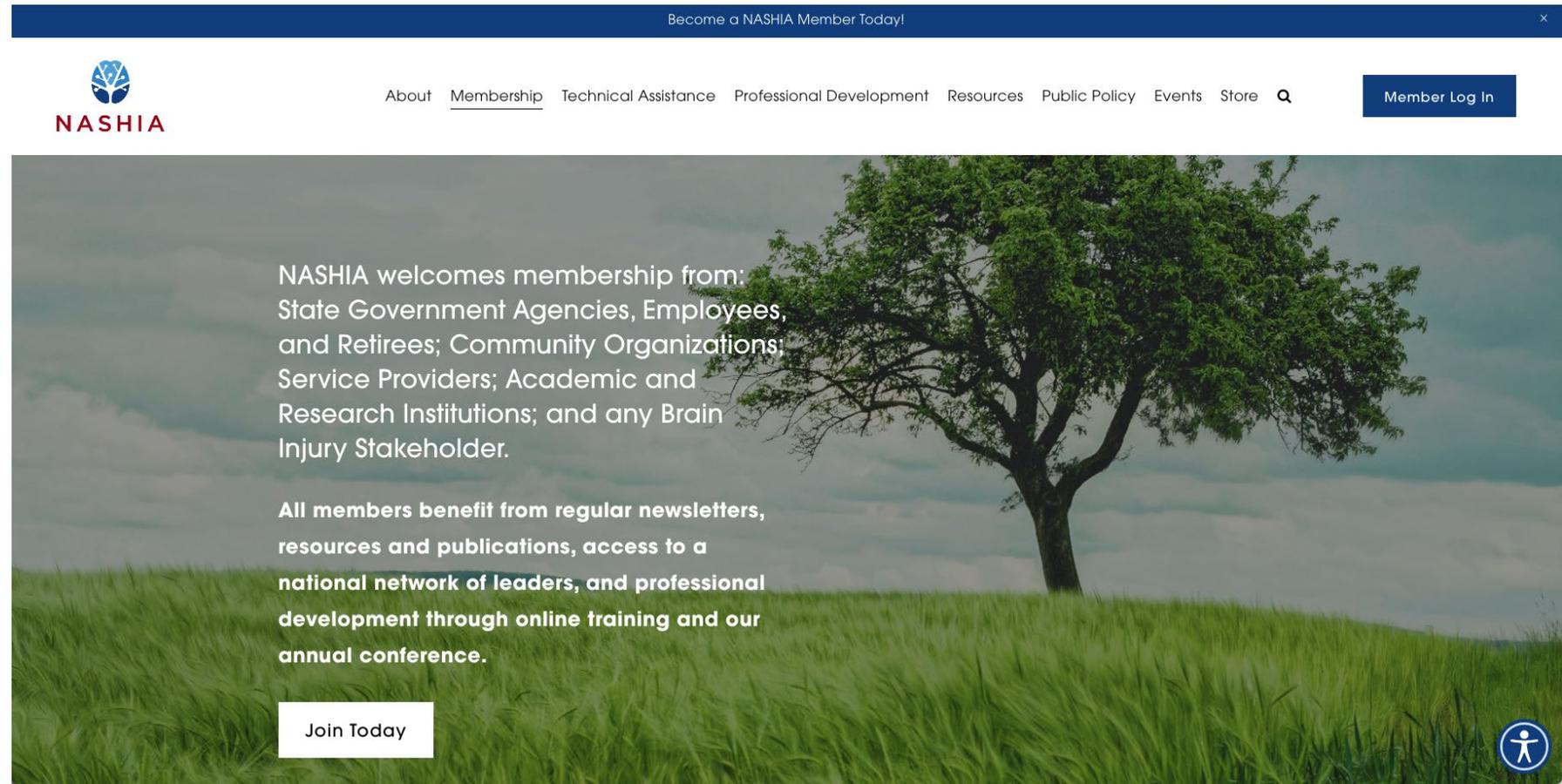
NASHIA is a nonprofit organization created to assist State government in promoting partnerships and building systems to meet the needs of individuals with brain injury and their families.



NASHIA

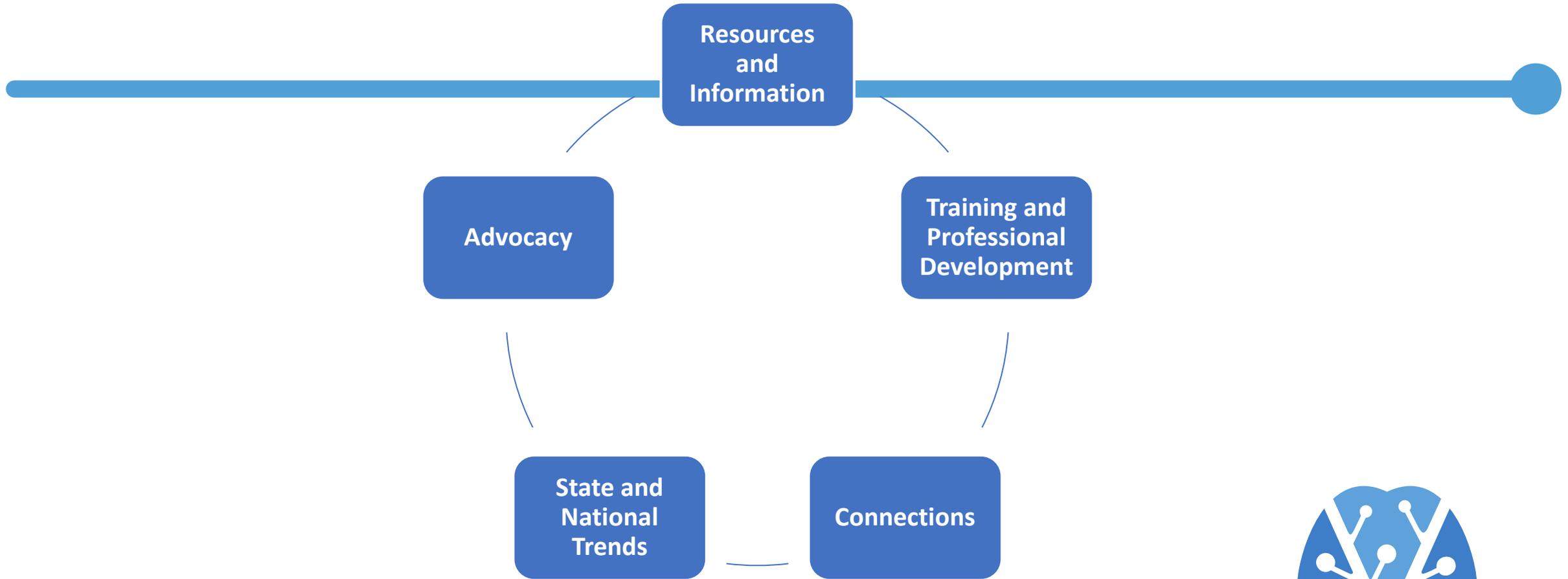
About NASHIA

- Group and individual memberships
- More information about membership at nashia.org



The screenshot shows the NASHIA website homepage. At the top, a dark blue banner contains the text "Become a NASHIA Member Today!" with a close button (X) on the right. Below the banner is the NASHIA logo, which consists of a blue circular icon with a white brain-like shape inside, and the word "NASHIA" in red capital letters below it. To the right of the logo is a navigation menu with the following items: "About", "Membership" (underlined), "Technical Assistance", "Professional Development", "Resources", "Public Policy", "Events", "Store", and a search icon (Q). On the far right of the navigation menu is a dark blue button labeled "Member Log In". The main content area features a large background image of a green field with a single large tree under a cloudy sky. Overlaid on this image is the following text: "NASHIA welcomes membership from: State Government Agencies, Employees, and Retirees; Community Organizations; Service Providers; Academic and Research Institutions; and any Brain Injury Stakeholder." Below this text is another paragraph: "All members benefit from regular newsletters, resources and publications, access to a national network of leaders, and professional development through online training and our annual conference." At the bottom center of the main content area is a white button with the text "Join Today". In the bottom right corner of the website, there is a small circular icon with a white figure inside a blue circle.

NASHIA Provides



NASHIA

Training and Professional Development

- Annual State of the States Meeting
- Webinars
- Co-sponsor Training Other National Partners
 - Mid-America Addition Technology Transfer Center and Rocky Mountain
- Leading Practices Academy



NASHIA

Resources and Materials

- Webpage: www.nashia.org
 - ✓ Resource Library
 - ✓ State Program Contacts
 - ✓ Latest News
- Special Publications, e.g., National Family Caregivers Month



NASHIA

Federal and National Partnerships

- ACL Technical Assistance and Resource Center
 - ✓ TA and Training
- AoD Disability Employment TA Center
- National Center on Advancing Person Centered Practices and Systems (NCAPPS) www.ncapps.acl.gov
 - ✓ Brain Injury Learning Collaborative
 - ✓ Targeted Technical Assistance



NASHIA

NASHIA State TA and Consultative Services

- **State Planning**
- **Advisory Board Development and Training**
- **Improve and Expand Service Delivery and Funding**
- **National Trends and Best Practices**
- **Facilitation of Workshops and Summits**



NASHIA

State Brain Injury Programs and Services

- **State appropriations**
- **Trust fund programs**
- **Medicaid HCBS waivers; State Plan HCBS**
- **Multiple funding sources**



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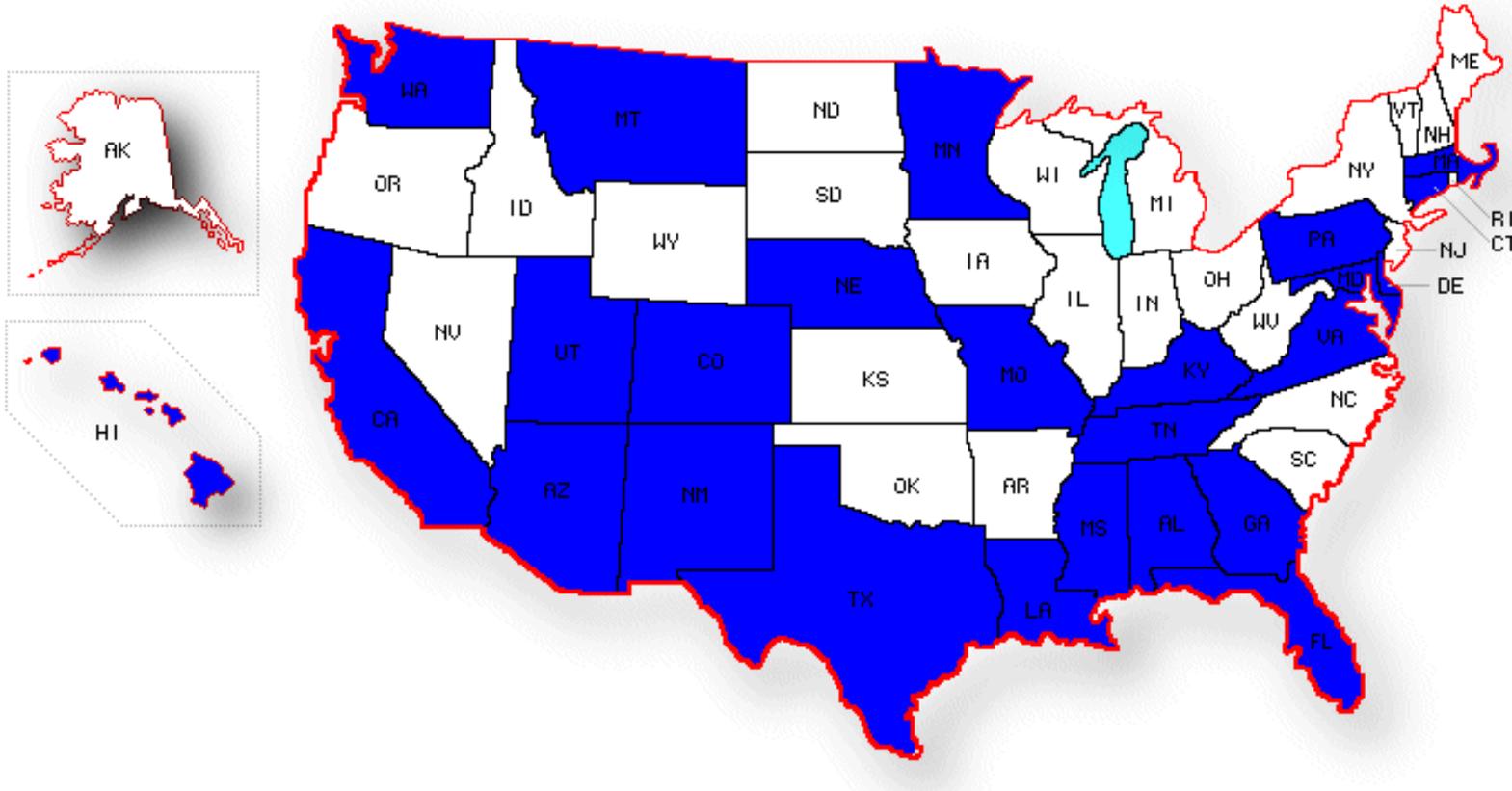
Brain Injury Trust Fund Programs and Services

- Revenue generator, usually traffic fines; a few states do not have one
- Advisory boards/councils or task forces
- Purposes – vary:
 - research, public information, prevention administration, services and supports
 - thru contracts, grants, provider agreements or direct program staff (e.g., care coordinators)



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State Trust Fund Programs



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1915(c) Medicaid Brain Injury HCBS Waivers

- Colorado
- Connecticut (2)
- Florida
- Illinois
- Indiana
- Iowa
- Kansas
- Kentucky (2)
- Maine
- Massachusetts (3)
- Minnesota
- Mississippi
- Missouri
- Nebraska
- New Hampshire
- New York
- North Carolina
- South Carolina
- Utah
- West Virginia
- Wyoming



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Medicaid Brain Injury HCBS Services

Section 1115 Waiver

- New Jersey
- Pennsylvania
- Vermont

1915(i)

- North Dakota

1915(k)

- Oregon



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Where are These Programs Located?

- Health
- Medicaid
- Aging and Disabilities
- Behavioral Health/Mental Health
- I/DD Agency
- Vocational Rehabilitation
- Human or Social Services



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Traumatic Brain Injury (TBI) Program Reauthorization Act of 2018

- Authorizes grants to States or American Indian Consortium to improve access to rehabilitation and other services
- Requires Advisory Board
- Requires State Match
- Designates Administration for Community Living



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Traumatic Brain Injury (TBI) Program Reauthorization Act of 2018

(A) To develop, change, or enhance community-based service delivery systems that include timely access to comprehensive appropriate services and supports.

(B) To focus on outreach to underserved and inappropriately served individuals, such as individuals in institutional settings, individuals with low socioeconomic resources, individuals in rural communities, and individuals in culturally and linguistically diverse communities.



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Traumatic Brain Injury (TBI) Program Reauthorization Act of 2018

(C) To award contracts to nonprofit entities for consumer or family service access training, consumer support, peer mentoring, and parent to parent programs.

(D) To develop individual and family service coordination or case management systems.

(E) To support other needs identified by the advisory board under subsection



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ACL TBI State Partnership Program

- **TBI Technical Assistance and Resource Center (TARC)**
- **27 States awarded Mentor or Partner Grants; ending 2021;**
- **28 to be awarded (5 yr.); \$170,000 – \$260,000**
 - **Due Date May 27, 2021**



NASHIA

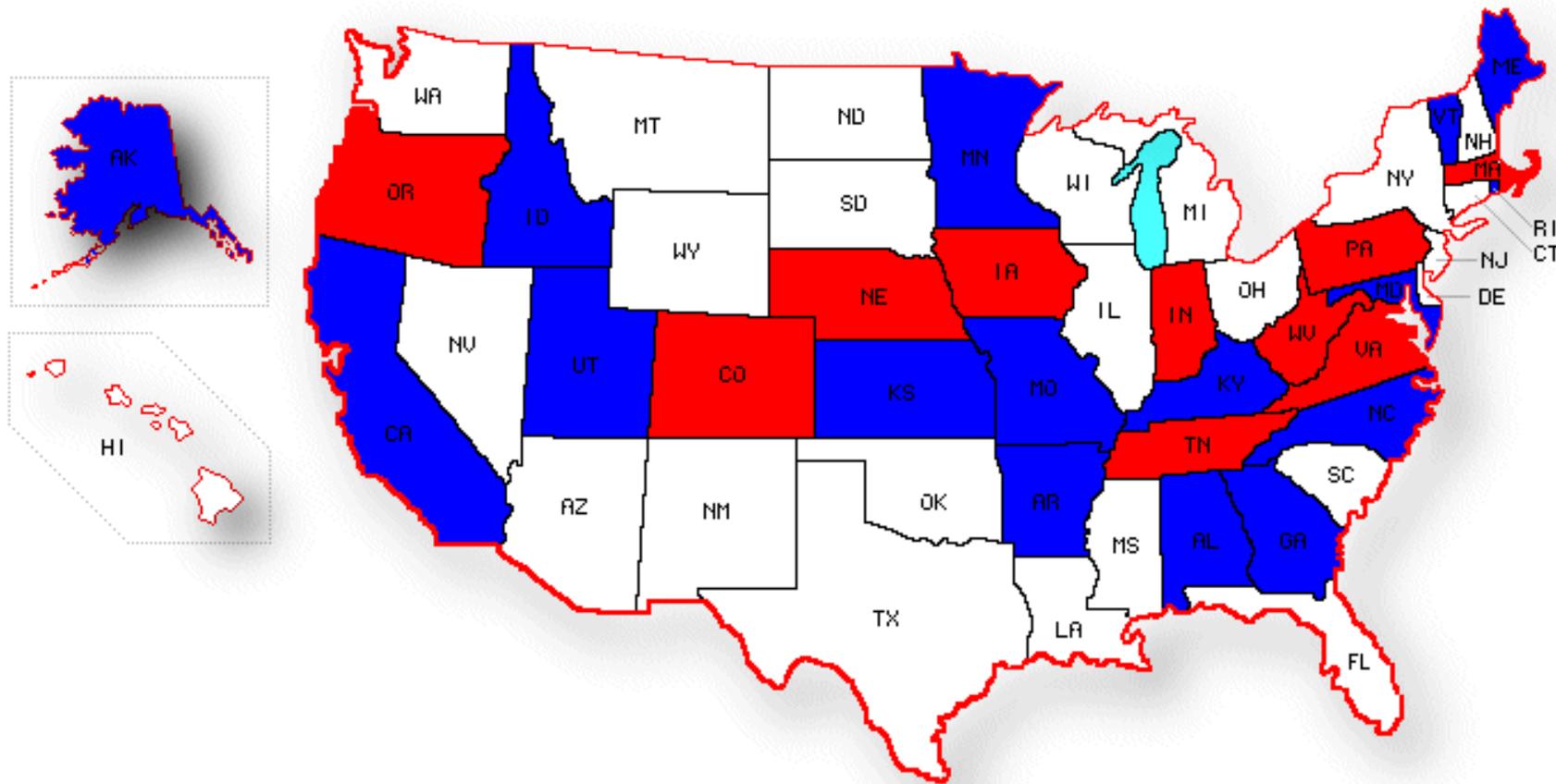
ACL TBI State Partnership Program

“To increase collaboration and coordination of state level activities across systems and supports and to ensure all people with TBI, including those from diverse and underserved populations, and other stakeholders are provided ample opportunity to contribute meaningfully to needs assessments and state plans that will drive improvement of TBI services and supports.”



NASHIA

Current ACL TBI State Grantees



Partner States
Mentor States



NASHIA

ACL TBI State Partnership Program

- **Designated Lead Agency**
- **Needs and Resources Assessment**
- **State Plan**
- **Topical Workgroups**



NASHIA

Advisory Boards/Councils

2017 Missouri Traumatic Brain Injury Needs Assessment Report

Report on the TBI Survivor / Family Needs Assessment Survey and the Professional Service Provider Needs Assessment Survey

January 7, 2018

Submitted to:



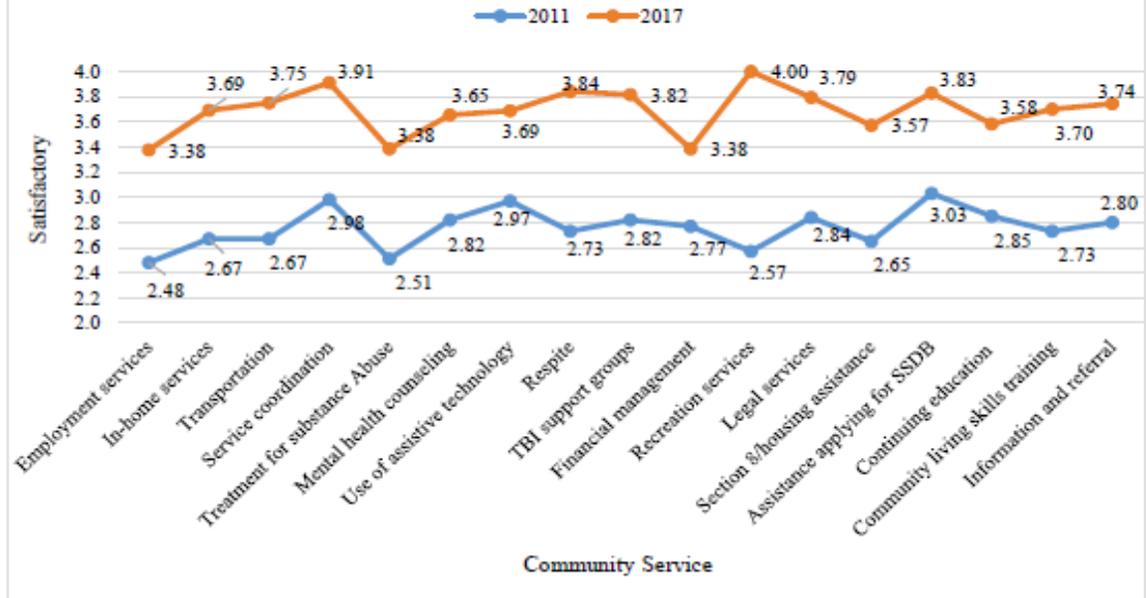
The Missouri Department of Health and Senior Services
Brain Injury Unit
PO Box 570, 920 Wildwood Drive
Jefferson City, MO 65102

Submitted by:



George S. Gotto, Ph.D., Associate Director, Research
Kelli N. Barton, Ph.D., Senior Research Associate
Danielle F. Chiang, A.B.D., Senior Research Assistant
Manuel L. Clark, B.A., Research Assistant

Figure 1.16. Community Service Satisfactory Level across Years



NASHIA

Summary

- ✓ **NASHIA is a resource for State program contacts, information and training.**
- ✓ **States may have resources to provide or could provide respite services, training and other caregiver supports.**
- ✓ **State Advisory Boards/Councils may be useful in assessing respite care needs.**
- ✓ **ACL FOAs for TBI State Grant and Respite Care Coalitions may provide avenue to foster collaboration.**
- ✓ **For more information visit: www.nashia.org**



NASHIA

Lifespan Respite and Opportunities for Collaboration

Jill Kagan, MPH

Respite for Family Caregivers of Individuals with Brain Injury

Exploring New Partnerships

April 14, 2021





Respite Barriers

- ❑ Limited government funding
- ❑ Cost
- ❑ Shortage of qualified, well trained providers
- ❑ Limited respite options, appropriate or preferred services
- ❑ Reluctance to use respite, ask for help, or self-identify as caregiver
- ❑ Access issues
 - Transportation
 - Multiple funding streams with confusing and restrictive eligibility
 - Lack of information

Ways to Pay for Respite

- Medicaid Waivers
- Family Caregiver Support Program
- Veterans Programs
- Disability or Aging organizations
- Self-pay or long-term care insurance
- Lifespan Respite Care Program

Lifespan Respite ... a system of services

Lifespan Respite Definition:

Coordinated **SYSTEMS** of accessible, community-based respite services for all family caregivers regardless of age or special need.





Federal Lifespan Respite Care Program

U.S. Administration for Community Living administers competitive state grants for required uses of funds:

- ❑ Development or enhancement of State and local Lifespan Respite systems
- ❑ Planned or emergency respite for all ages
- ❑ Training and recruitment of providers/volunteers
- ❑ Provision of information to caregivers about respite services, and assistance in gaining access

Lifespan Respite Grant Activities

Statewide Respite
Registries

Connecting
families to respite

Consumer-
directed Respite
Voucher Programs

Volunteer and
Faith-based
Respite

Recruiting and
Training Respite
Providers

How to Connect with Lifespan Respite

- ❑ State Respite Coalitions
archrespite.org/state-respite-coalitions
- ❑ State Lifespan Respite
Program Grantees
<https://archrespite.org/lifespan-programs>

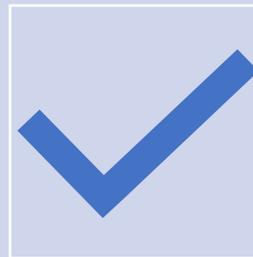
Respite During the Pandemic



In-home services/Voucher
Respite



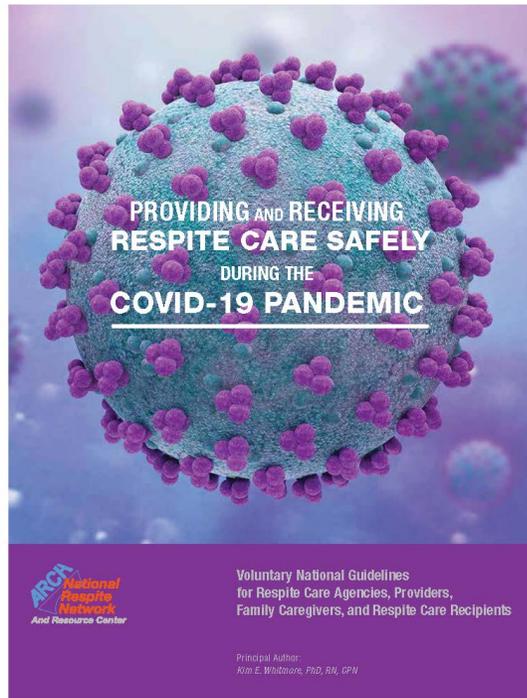
Community-based
Respite Services



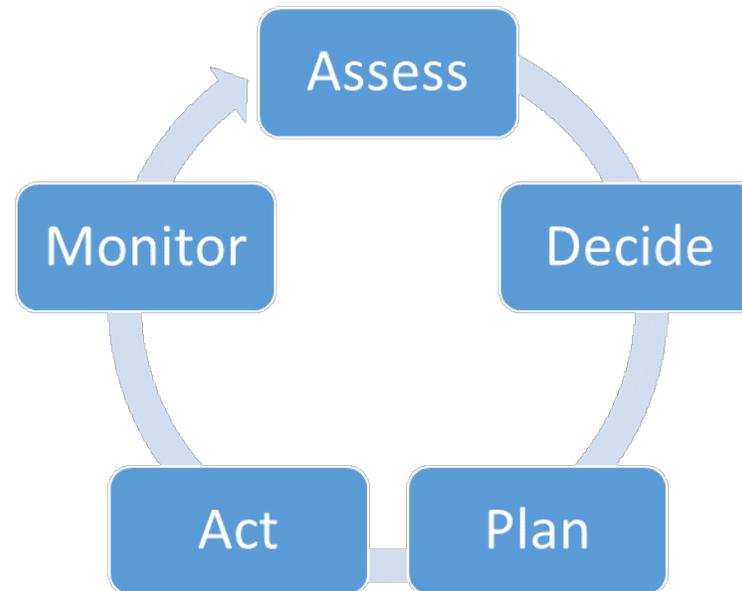
Alternative Respite

National Voluntary Guidelines for Providing and Using Respite Safely During the Pandemic

Guidelines



Decision Guides



Case Studies



New Jersey Family Resource Network

Program Description

The Family Resource Network (FRN) provides direct support services to children and adults with intellectual and developmental disabilities and their family caregivers statewide in New Jersey. Originally known as the Epilepsy Foundation of New Jersey, the Family Resource Network is in its 50th year of operation and includes Epilepsy Services of NJ, Autism Family Services of NJ, and Caregivers of NJ.

The FRN roughly serves 1,800 children and adults with disabilities monthly. Services are funded by the Department of Human Services. Children's services are coordinated through the NJ Department of Children and Families, and adult services are coordinated through the Division of Developmental Disabilities (DD).

The FRN provides respite services through their voucher program, in-home services, and various out-of-home community-based options, such as an afterschool program, summer camp, and community inclusion activities and events.

Due to the COVID-19 pandemic all community-based respite services were closed March 12 at the time of the statewide shutdown. For voucher and in-home services, a phased-in approach was used to reopen due to different state agency oversight guidance and requirements for child vs. adult services. Direct Support Professionals (DSPs) were determined to be essential workers by the Governor, which allowed FRN to continue to offer voucher and in-home respite services. During the shutdown, the voucher service for children was able to continue, and in-home respite continued where possible, available, and agreed upon. Though significantly reduced, services were maintained. This occurred within 30 days of the shutdown.

Planning and Guidance for Reopening Respite Services

The Family Resource Network immediately began planning to explore pandemic resources and information, address staff financial support, and determine feasible strategies for addressing reopening in-home respite services safely for staff and families.

- Researched information and resources through the Centers for Disease Control and Prevention (CDC), NJ Department of Children and Families, Division of Developmental Disabilities (DD), NJ Academy of Pediatrics, FRN Health and Innovations Department (internal public health experts), and Governor Orders/Guidance.
- To gain clarity on how to proceed, communicated on a regular basis with the NJ Department of Human Services, Department of Children and Families and Division of DD.
- Applied for and received a Paycheck Protection Program (PPP) loan from the federal government to continue to maintain DSP staff salaries and benefits.
- Applied for free Personal Protective Equipment (PPE) with NJ organizations such as the NJ Association for Community Providers.
- Immediately contacted all DSP staff to discuss options for continuing to work as PPP loan provided option to retain staff. Some staff did not continue to work. Others were repurposed and used in other services or administrative tasks.
- Conducted extensive outreach to families including weekly emails, social media posts, and individual phone calls to each family.
- Identified regional Respite Coordinators in each area of the state to assist with planning, PPE purchase and dissemination, family outreach, and service reopening protocols.
- Developed the FRN Guide for Use of PPE² to instruct DSPs around using masks and gloves, including how to decontaminate masks, and provided specific guidance on hand washing techniques. Also addressed other ways to stop the spread of the coronavirus, including proper sneezing and coughing etiquette, social distancing, cleaning surfaces, and when to seek medical care.
- Identified best options for purchasing PPE, delivering or shipping to Regional Coordinators, and disseminating to DSPs.
- Developed COVID health screening procedures for both families and DSPs to be conducted 24 hours prior

Access Resources here: <https://archrespite.org/national-respite-guidelines-for-covid-19>

For More Information



Jill Kagan
Program Director
703.256.2084

jkagan@archrespite.org

ARCH National Respite Network
and Resource Center

<http://www.archrespite.org>

Lifespan Respite Technical Assistance and Resource Center



This project was supported, in part by grant number 90LRLT0001, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy.

Lifespan Respite Washington and Partnership with TBI

Dana Allard-Webb FCSP Program Manager Lifespan Respite Director

dana.allard-webb@dshs.wa.gov

Geene Delaplane Kinship and Lifespan Respite Program Manager

Geene.Delaplane@dshs.wa.gov

Agenda

- General description of Lifespan Respite in Washington State
- Partnership with TBI
- Hey Peers Platform – virtual support groups

What is Lifespan Respite Washington (LRW) respite care?

- Short-term intermittent care to provide relief for unpaid caregivers*



FIND RESPITE

Accessing Respite

www.lifespanrespitewa.org



Voucher Program and more.....

Call Us: 253-442-3214 HOME DONATE CONTACT Q aA ☀



FIND RESPITE

- ABOUT US
- VOUCHER PROGRAM
- FOR SERVICE PROVIDERS
- RESPITE CARE
- RESOURCES
- NEWS & EVENTS

About Us

Who We Are

Lifespan Respite Washington (LRW) began in 2002 as a statewide coalition known as the Respite & Crisis Care Coalition of Washington (RCCCWA). In 2010, RCCCWA received its first federal Lifespan Respite Grant to expand the program and to pursue sustainability. The RCCCWA coalition was renamed in 2012 to Lifespan Respite Washington (LRW). In September 2017, LRW was awarded its fifth grant funding for three years through the U.S. Administration on Aging, Administration for Community Living.



APPLICATION INFO

If you are seeking respite :

[Application if you are seeking respite](#)

[List of current registered providers](#)

Information for Respite Provider Agencies (RPA):

[RPA Applications](#)

[Policies and Procedures](#)

[Interagency Agreement](#)

Washington's Caregiver Training

- By Washington law for all paid respite caregivers
- Training Partnership through SEIU union
- 70 hours of training
- Background checks
- Yearly continuing education credits



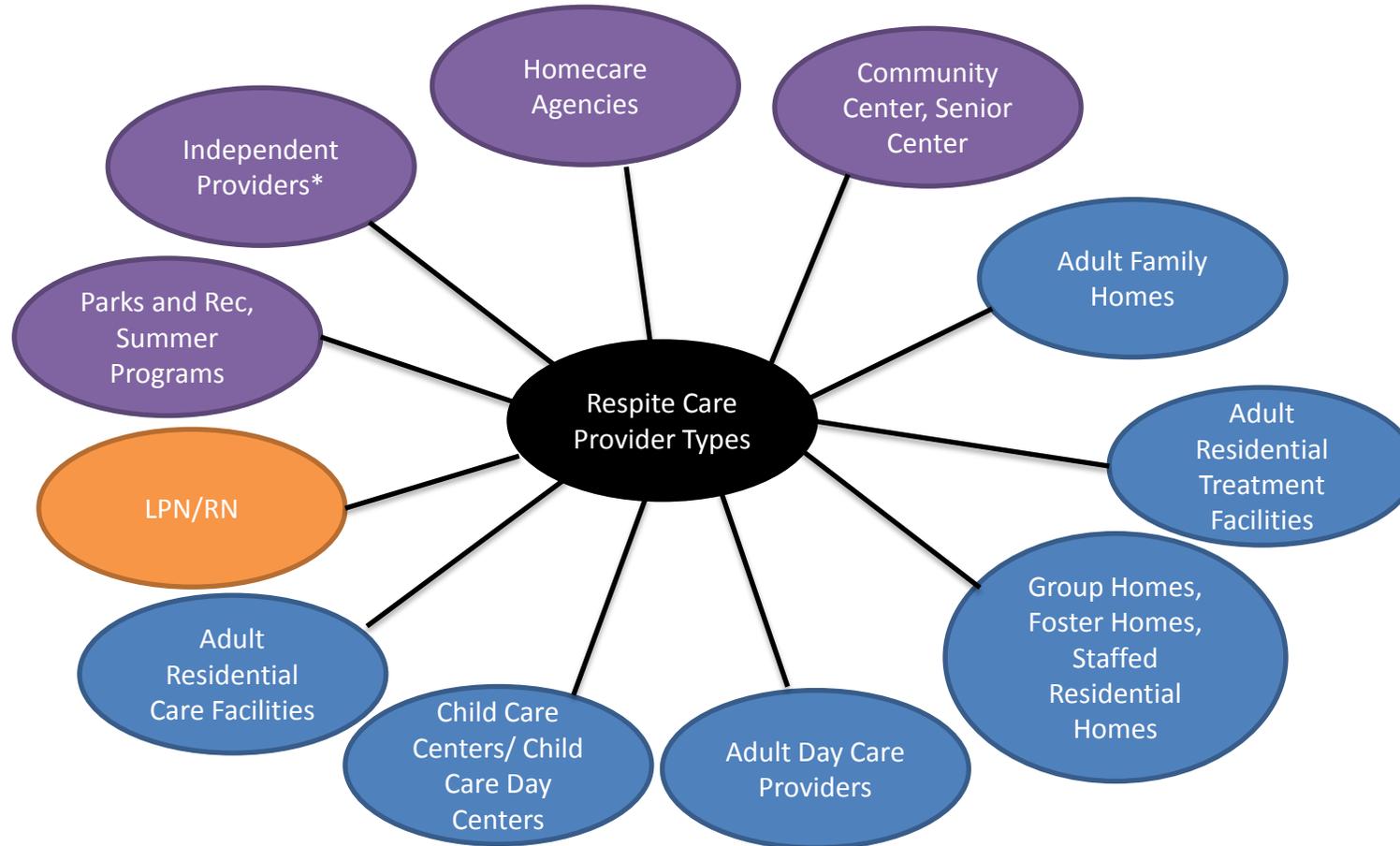
[FIND RESPITE](#)



Washington's Caregiver Training

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Who can provide respite care?

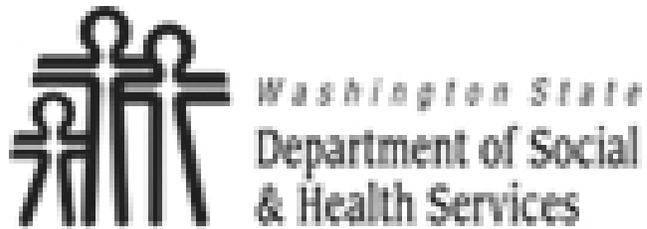


Where can respite be provided?





FAMILY CAREGIVER SUPPORT PROGRAMS



Transforming lives



TBI Caregivers

Tried

Offered Respite Vouchers to caregivers of people with TBI through two TBI focused organizations that provide resources and some case management.

Outcome

Caregivers didn't trust that paid caregivers are equipped to handle issues and behaviors of people with TBI.

TBI Caregivers

Tried

Developed and offered TBI care training in CE credits for all paid caregivers in WA.

Presented the importance of respite for caregivers.

Outcome

Caregivers of people with TBI still didn't use many vouchers over two years



TBI Caregivers

Trying Currently

Family caregiver support Groups
Online in a virtual platform

Outcome

Currently in Pilot process

TBI Caregivers Support Groups – “Hey Peers” Platform

- TBI Virtual Support Groups: Virtual Education and Social Support
- Virtual Support Groups are being offered on the “[Hey Peers](#)” platform



Washington State Department of Social & Health Services
ALISA Aging and Long-Term Support Administration

Traumatic Brain Injury
TBI Council of Washington

Brain Injury Support Groups: Virtual Education and Social Support

Our virtual support groups are focused on developing long-term knowledge and generic problem-solving skills to aid those that have sustained a brain injury in overcoming obstacles that may interfere with a fulfilling life. We welcome people from all walks of life, including caregivers and veterans.

People living in a rural area can access the internet through Washington State Drive-In Hotspots. Locations can be found on the website, www.driveinwifi.wa.gov.

Current Monthly Group Schedule (PST)

- 1st Tuesday (5:00 - 6:00 PM)
- 1st Thursday (5:00 - 6:00 PM) - Caregiver Focus
- 2nd Wednesday (3:00 - 4:00 PM and 6:00 - 7:00 PM)
- 3rd Monday (6:00 - 7:00 PM) - Veteran Focus
- 3rd Friday (5:00 - 6:00 PM)
- 4th Monday (5:00 - 6:00 PM)
- 4th Thursday (4:00 - 5:00 PM)

Group discussion topics can vary, but many will include a focus on Personal Development, Self-Care, Communication, and Interpersonal Dynamics.

Funding and oversight of this program is provided by the Washington State Traumatic Brain Injury Council through the Department of Social and Health Services (DSHS).

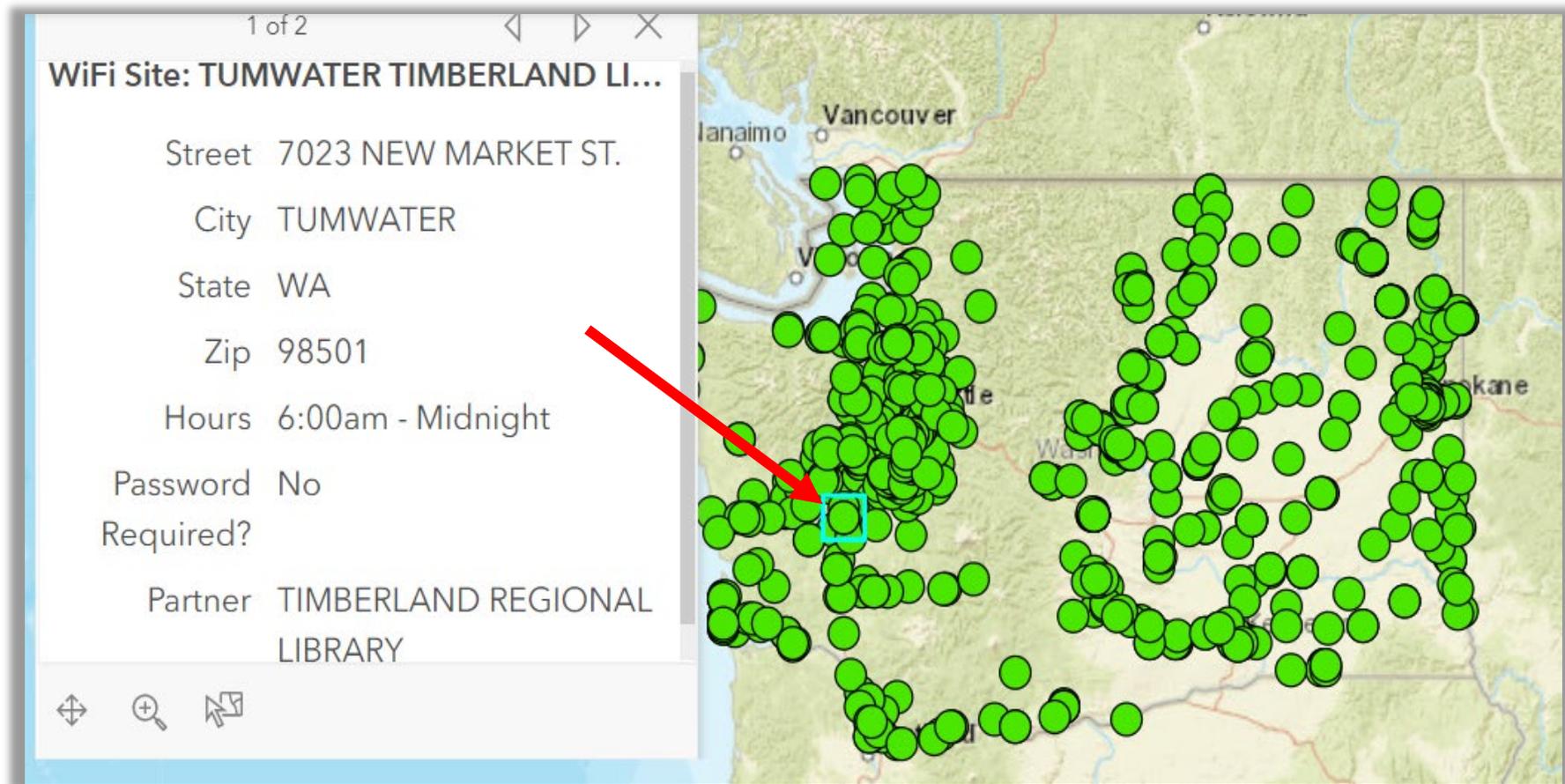
i
These educational support groups will be hosted 100% online through the Hey Peers platform by certified support group facilitators.

Hey Peers!
These monthly meetings can be accessed through the website below:
heypeers.com/meetings

Questions? Email us at tbihelp@outlook.com

Wi-Fi Hot Spots in Washington

<https://www.commerce.wa.gov/building-infrastructure/washington-state-drive-in-wifi-hotspots-location-finder/>



1 of 2

WiFi Site: TUMWATER TIMBERLAND LI...

Street 7023 NEW MARKET ST.

City TUMWATER

State WA

Zip 98501

Hours 6:00am - Midnight

Password No

Required?

Partner TIMBERLAND REGIONAL LIBRARY

The image shows a map of Washington state with numerous green circular markers representing Wi-Fi hot spots. A red arrow points to a specific hot spot in the Tumwater area, which is highlighted with a blue square. The sidebar on the left displays details for this hot spot.

Family Caregiver Virtual Support Groups – “HeyPeers” Platform

Session One – Self-Care Caregiver Health and Respite

March 4, 2021

6:00 PM

Session Two – Caregiver Burnout Managing Personal Stress

April 1, 2021

6:00 PM

Session Three – Family Caregiver Communications Constructive Communication

May 6, 2021

6:00 PM

Session Four – Social Isolation Finding Joyful Moments in Caregiving

June 3, 2021

6:00 PM



Please join the Unpaid Family Caregiver Support Group Pilot

- Attendees will sign up for meetings in the Hey Peers portal.
- Participating Caregivers will be sent instructions for attending support group meetings.
- Attendees may attend any or all of the sessions, from March through June.
- We will ask attendees to answer pre and post survey questions to understand caregiver support group needs and opinions.

Questions?



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dana.allard-webb@dshs.wa.gov

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