



RCAW
Respite Care Association
of Wisconsin

2021 Respite Summit Activity & Feedback

The 2021 Wisconsin Respite Summit was held over two days in July. Attendees from various counties across the state gathered for the sake of respite care in Wisconsin, networking, understanding services, sharing ideas amongst peers, and providing valuable feedback to RCAW.

Participants at the summit represented family caregivers, care receivers, respite professionals, and experts who serve families across the lifespan; those who serve caregivers and people living with disabilities came together to learn, share, network, and build meaningful relationships.



July 28 & 20, 2021

Stevens Point, WI

Summary - Day 1

I. Partner Sharing/Mapping – What activities are you aware of or involved with?

Workforce—Recruitment & Retention

- CORE Collaboration with ADRCs (replicating RCAW / BRW)
- Oconto County is looking for ideas
- Independent Consultant – building/use of registry
- Dane County – CLTS has funds & needs providers
- Pierce County – Looking to get into respite
- GT Caregiver Link
- St. Ann Center MKE County
- Supplemental Insurance
- Instagram advertising for respite workers
- Investigate why caregivers/respite workers quit

Workforce—Training & Development

- CORE Collaboration with ADRCs (replicating RCAW / BRW)
- Trualta
- Multigenerational Care Training
- SDS
- NWTC Gerontology Advisory Board

Equity & Diversity Initiatives

- Marathon County – Self-Study / Books / Info Search
- Mindworks – Fox Valley Memory Project (Calumet, Outagamie, Winnebago)
- Community Groups – Grandparents as Caregivers (Brown County)
- Community-Based Volunteer Programs – Fox Valley Area
- Intergenerational Care – St. Ann's
- DAWG
- Relationship with community groups and agencies
- Rec Departments
- Rotary Clubs
- AmVets

On the first day of the summit, attendees introduced themselves and gave a high-level overview of their roles in the community, gave feedback on respite, and shared their goals in attending the summit. RCAW staff recorded things that participants said that fit into the topics of Partner Sharing & Mapping.



Policy & Advocacy

- Disability Advocacy Day – Rusk County

Research and Evaluation

- Individual Consultant – Students – SE Wisconsin (Concordia)

Other

- NFCSP/AFCSP
- Increase respite awareness & identify as respite. People provide respite services but don't call it respite
- Memory Cafés
- Isolation in rural communities
- PPE Kits – Statewide GT Independence
- Caregiver connection groups & associations
- Involve families and siblings
- Rings of Care (Respite, Housekeeping, Companionship)
- Mental health communities

Employer Connections

- CLTS – Rusk County



II. Wisconsin Respite Summit 2021: Feedback on Lifespan Fed Grant Activities

- Outreach
 - Discharge planners at hospitals
 - In-person or zoom to staff meetings
 - County Human Services Boards
 - Faith-based groups
 - Students
 - Parades
 - Job Centers
 - LTC
 - CLTS
 - AARP
- Hard (Printed) copy of the registry
- Map of physical respite locations
- Increase pay
- Offer mileage reimbursement
- Awareness campaign
- Bulk up registry
- Allow content on the website to be easily shareable

Summary - Day 2

I. Mapping the Respite Care System in Wisconsin

Where do caregivers learn about respite

- Physicians/Health Care Providers
- Friends & Family
- Day Centers
- Faith-Based Communities
- Service Providers (non-traditional sources, i.e., beauticians, bartenders, etc.)
- Public Awareness Campaigns
- Non-Digital Resources (flyers, brochures, etc.)
- Discharge Planners
- Social Media
- Children and Youth with Special Health Care Needs Regional Centers

Where do you go to find out about respite?

- Coffee Shops
- Friends/Family
- Counties
- CYSHCN Regional Centers
- Counties
- ADRCs
- RCAW

Which formal & informal respite opportunities are available?

Both forms of caregiving involve a spectrum of tasks, but informal caregivers seldom receive enough training for these tasks. Formal caregivers are trained in the field, but the depth of their training varies.

- Formal care usually refers to paid care services provided by:
 - Individuals
 - Facility-Based Respite Providers
 - HCBS Providers
- Informal care generally refers to unpaid care provided by:
 - Family
 - Relatives
 - Friends
 - Neighbors
 - Volunteers

How are eligibility and funding determined?

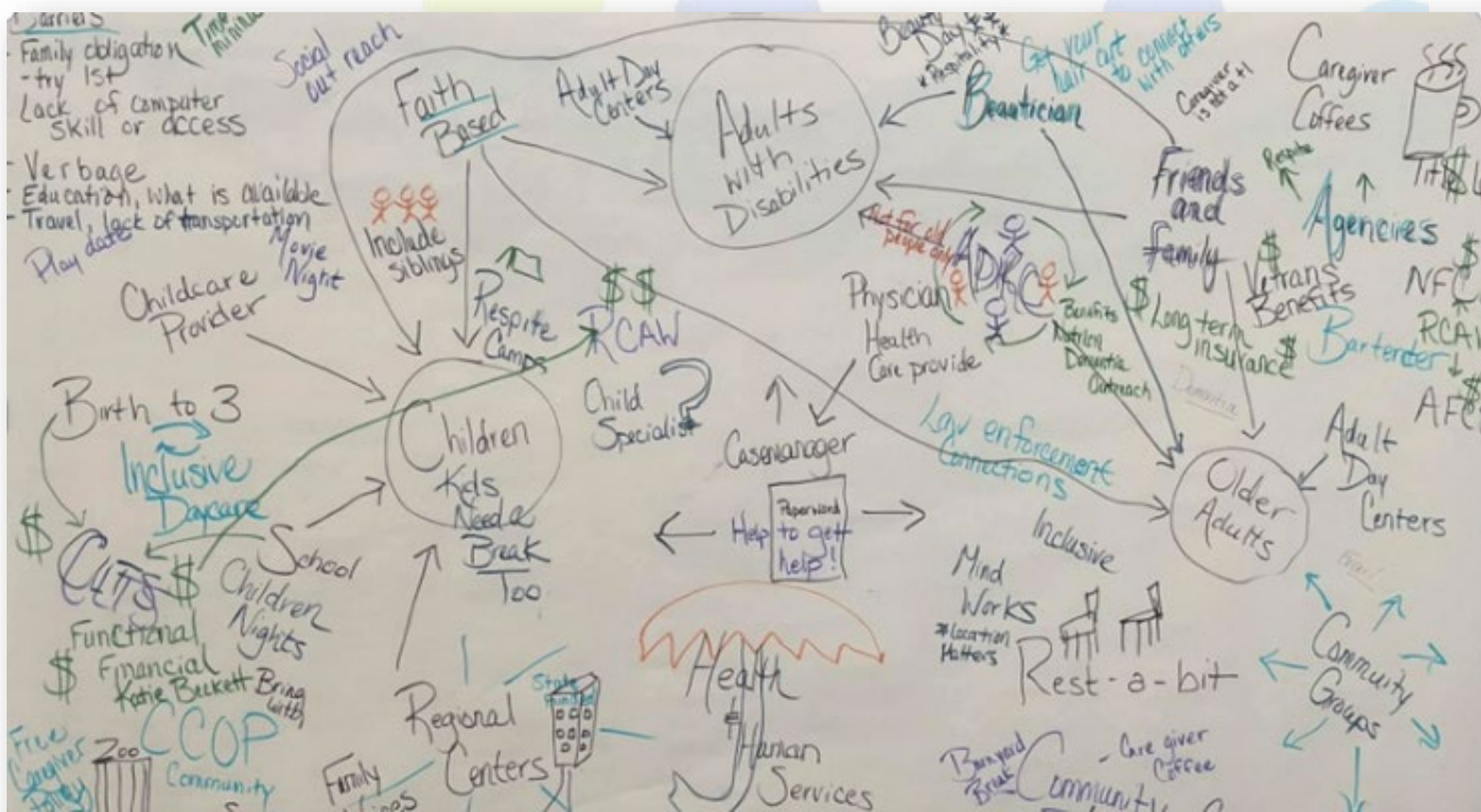
- Counties
 - Birth to 3
 - Katie Becket
 - CLTS
 - CCOP
- ADRCs
 - AFCSP
 - NFCSP
 - Family Care
 - IRIS
- VNA

General eligibility criteria include:

- Age
- Disability
- Household Income
- Location

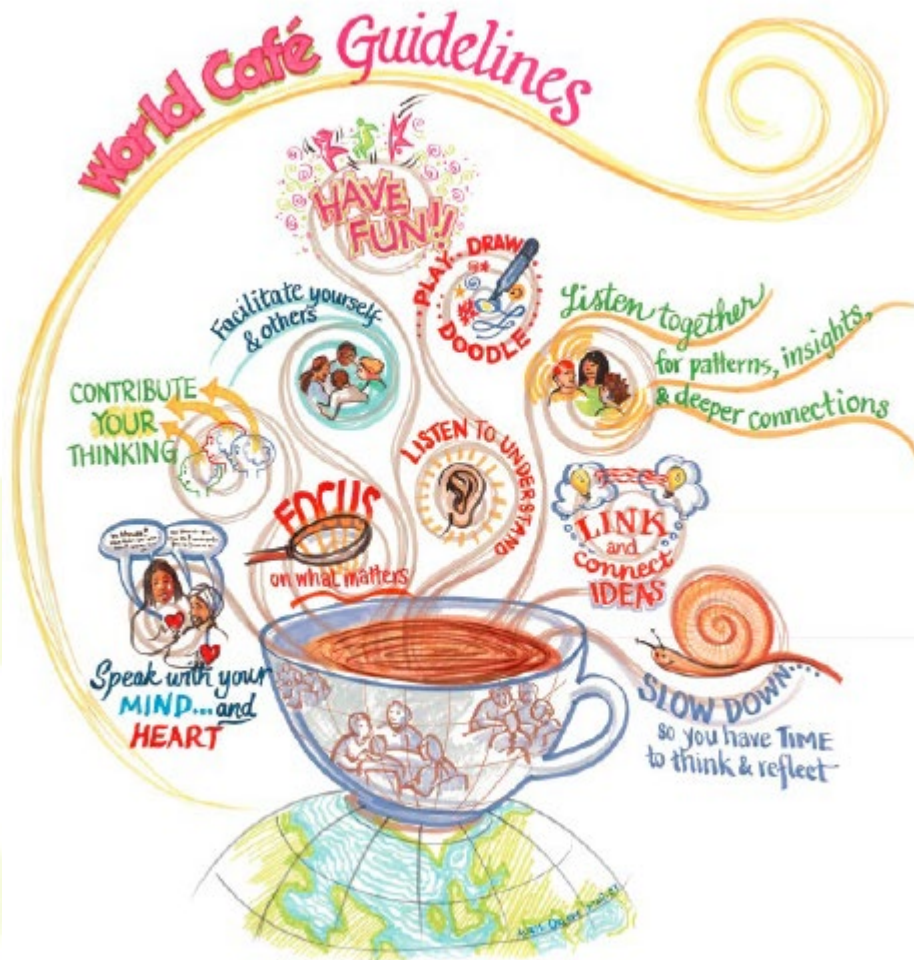
Additional shared thoughts...

- Use the term 'programs' for persons with a disability as a guide for family caregivers to get respite, i.e., Barnyard Breaks, Bistro 65, Memory Café's, etc.
- Be aware of friends or families who are caring for someone and social isolation. Be proactive – ask them to partake in group activities. Don't let the fact that someone is caring for someone with a disability be a reason not to invite them to activities.
- Please think of the whole family (siblings too) when it comes to respite.
- Provide a list of attractions or activities with free caregiving activities.
- Have a respite number like 811 (much like United Way's 211)



WI Respite Summit 2021 World Café Results

What is the current state of respite?

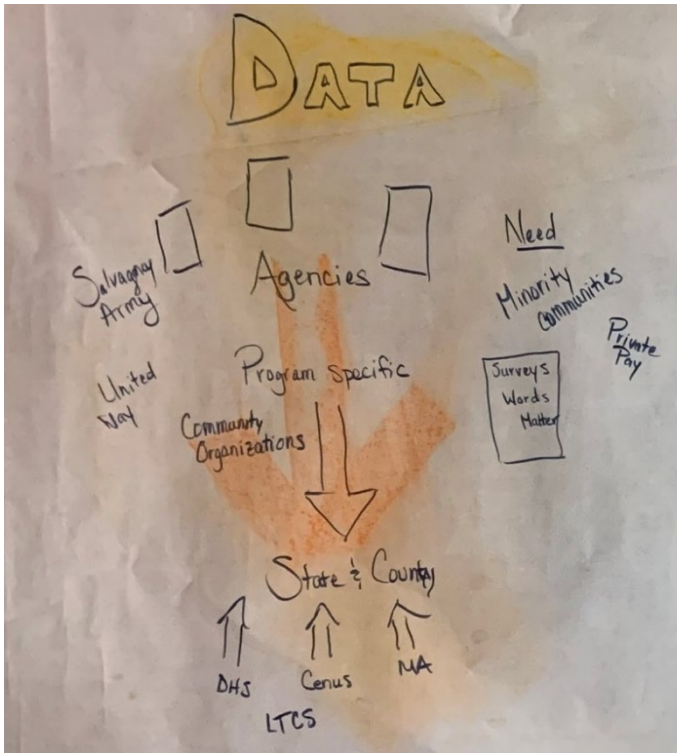


On the second day of the Respite Summit, the group participated in a World Café interactive exercise to help RCAW develop and disseminate a comprehensive statewide survey to better understand the current state of respite in Wisconsin. Four "Courses" of Conversation included

- 1.) Existing Data Sources.
- 2.) Key Stakeholders.
- 3.) Survey Questions.
- 4.) Survey Distribution Methods.



What data do we already collect?



General Demographics (Census, program level)

- Age
- Location
- Disability
- Gender
- Race
- Veteran Status

Program Data (individual agencies/programs)

- Client numbers
 - Gain & Loss – looking at COVID as well
- Days/ hours of client attendance
- Care Level/ Disability
- Food/ meals
- Transportation logs
- Engagement (activity) logs
- Staff Info
 - Hours
 - Wages
 - Education

- Turnover
- Referral (How did you hear about us?)

Caregiver data (collected at funding source or program?)

- Relationship to the care recipient
- Location
- Income
- Household size
- Impact on health
 - Mental
 - Emotional
 - Physical
 - Stress/ burnout

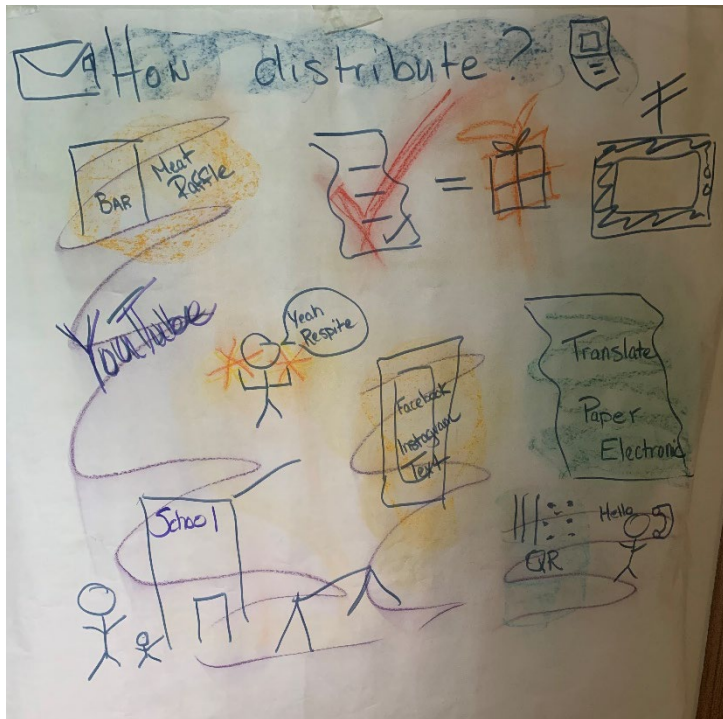
Potential Places to gather data

- DHS
- CPS/APS
- Birth to Three
- GWAAR
- United Way
- Salvation Army
- AFCSP/NFCSP
- Specialized Clinics
- Annual Reports of Disability Agencies
- School Districts (IEP)
- ADRCs
- BADR: Bureau of Aging and Disability Resources
- Non-traditional respite: daycare, adult day, home health, companionship, church programs, etc.
- Private pay will not be in any of these data sources, unsure how to gather this info

Cultural Considerations

- Groups not in human service programs
- Build trust, use their terms and language
- Define what respite is

How Should We Distribute the Survey?



Who:

- WIC
- National Alliance on Mental Illness (NAMI)
- YMCA
- Daycare – Child & Adult
- Community Centers
- Support Groups
- Doctors
- ADRCs / TADRS
- Case Managers
- HHS – Board Members & Directors
- Skilled Nursing Facilities (SNF) / Community Based Residential Facilities (CBRF) / Residential Care Apartment Complex (RCAC)
- Children's Long Term Supports (CLTS) / Children's Community Options Program (CCOP)
- ARC
- Dementia Care Specialists (DCS)
- Managed Care Organizations (MCO's) / IRIS Consulting Agencies (ICA's) / Fiscal Employment Agencies (FEA's)
- Relatives As Parents Program (RAPP)
- Children's Protective Services (CPS)
- Faith-based organizations
- Lutheran Social Services (LSS) & Catholic Charities
- Homeless Shelters
- Respite Agencies
- Youth Centers
- WI Dept. of Health Services
- Families
- Specialty Clinics
- Disability Rights
- Teacher's Conferences
- Law Enforcement / Emergency Medical Staff (EMS)
- Salvation Army
- Universities, Tech Schools
- Boy & Girls Scouts / 4-H
- Retirement 101
- Elder Benefit Specialists
- Home Health Agencies

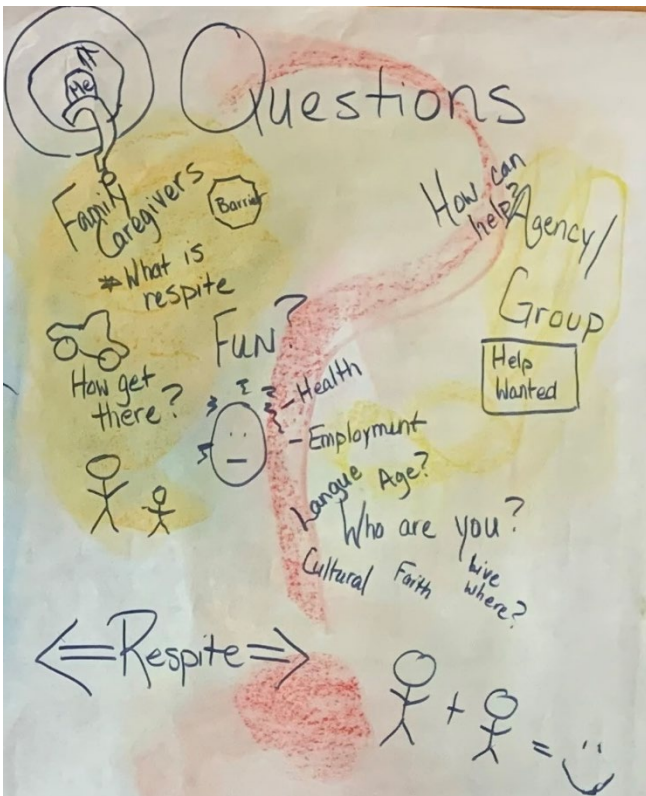
How:

- Email
- Paper—USPS & enclose with a stamp
- Newsletter
- Social Media: Facebook, IG, Twitter, LinkedIn
- YouTube Video for sharing
- Translate into Hmong, Spanish, and Somalian
- "Ready to Go" tablets at various locations with the survey
- Attend conferences, fairs, farm markets, flea markets, festivals, bars, beauty salons
- Flyers
- Send in Meals on Wheels
- Find respite champions to disseminate
- Town Halls
- GOV-D emails
- Attend staff meetings (in person and Zoom)
- Include an incentive for people to complete the survey (gift cards, etc.)
- Text to Apply
- QR Code

How Should We Distribute the Survey Cont'd?

- Hospice
- Birth-3 / Head Start
- Health Fairs
- Tribal Government
- Survival Coalition
- ARCH
- Wisconsin Family and Caregiver Support Alliance (WFACSA)
- Wisconsin Personal Support Alliance (WPSA)
- The Break Exchange
- WI Long Term Workforce Alliance
- NWADWA

Possible Questions for Survey to Assess the Current State of Respite in Wisconsin



Questions for Caregivers

1. What does respite mean to you?
2. Are you receiving respite currently or in the recent past?
3. If yes, who is providing respite for you?
4. If not, what is keeping you from receiving respite?
5. If you are a caregiver, are you caring for a child, adult, or older adult?
6. Do you know where to look for respite in your community?
7. What time of day would you prefer to have respite services provided?
8. Is culture a barrier to respite for you?
9. Is language a barrier to respite for you?
10. Is technology a barrier to respite for you?
11. Are finances a barrier to respite for you?
12. Is a lack of care providers a barrier to respite?
13. Do you have access to a computer/smartphone?
14. Do you have a trusted source for information about respite? If so, who is it?
15. How would you spend time during a break from caregiving?
16. Are you comfortable having care providers in your home?
17. Do you live in a rural or urban setting?
18. Is transportation an issue to finding respite?
19. Is transportation an issue in providing respite?
20. Do you live in a multi-generational home?
21. Do you have time to arrange for respite?
22. As a caregiver, what services would your care recipient feel comfortable receiving? (Rings of Care)
23. Are you aware of financial/services supports in your community?
24. What is the most stressful part of arranging respite for you?

25. Is there a shortage of respite providers in your community?
26. How do you handle your stress?
27. Did you have hobbies/social networks before becoming a caregiver that you do not have time for now?
28. Are you able to find consistent respite providers?
29. What concerns do you have when searching for a respite provider?
30. Do you encounter caregivers in your community?
31. What is respite to you?
32. How do you identify respite?
33. Do you feel like you need a break?
34. What might you do if you get a break?
35. Do you experience guilt while contemplating respite care?
36. What is a good match between care provider and care recipient?
37. How to expand the use of respite?
38. What is the cost of ongoing respite care?
39. How can respite care be funded?
40. How can we expand the Wisconsin Respite Care Registry to be more diverse?
41. How may you find cultural resources for respite care?
42. Is respite care financially sustainable?
43. How are you addressing the respite needs of your family?
44. Who supports you?
45. What barriers do you come across while trying to access respite care?
46. Can providing respite care be a career?
47. What is your biggest worry concerning caregiving?
48. What training do you feel you may want/need to become a respite care provider?
49. Does caregiver stress impact our healthcare system?
50. If you have a job outside of being a primary caregiver, do you have flexibility in that job?
51. How do I learn to care for myself as a primary caregiver?
52. How can we help identify the needs of primary caregivers?
53. Do you feel there is a stigma that goes along with receiving respite care?
54. What do you feel are the benefits or outcomes of respite?
55. Do you think you live in an inclusive community?
56. Are there needs that need to be addressed before receiving respite care?
57. How is the caregiver shortage impacting respite care?
58. What is keeping you from receiving respite care?
59. How can we create an environment where true respite is received?
60. What expectations do you have going into respite?
61. What type of respite attracts you?

Questions for Care Providers/Organizations

1. Employers – what benefits/services do you provide to employees who are caregivers?
2. Agencies – how do you recruit care providers in your community?
3. Agencies – can you quantify the shortage of care providers in your community?
4. Care Providers – does your career as a care provider allow you to be financially secure?
5. Care Providers – do you have sufficient clients to sustain your career?
6. Potential providers – what would attract you to becoming a care provider?

7. Potential providers – what are barriers to becoming a care provider?
8. Employers, churches, clubs (Kiwanis, etc.) – does your organization sponsor or host respite for members?
9. Employers, churches, clubs (Kiwanis, etc.) – could your organization encourage and foster volunteers to provide respite in your community?
10. Employers, churches, clubs (Kiwanis, etc.) – are you aware of members who are family caregivers?
11. Is there funding for activities while providing respite care? i.e.,
 - a. Tickets for movies
 - b. Admission for zoos

Demographic Questions

1. Age
2. Gender Identification
3. Location
4. Race
5. Ethnicity
6. Primary Language
7. Education Level
8. Income
9. Faith
10. Primary Caregiver/Paid Caregiver/Care Recipient/Volunteer/Student

Who Are the Key Stakeholders?



City/Community/State

- City Councils
- Legislators
- County Boards (Human Services)
- WI Dept. of Health Services (DHS)
- Tribal Governments
- Colleges
- Schools/Education/Teachers
- Library/Staff/Programs
- Community Centers
- Faith Communities
- Radio/TV/All Media
- Rotaries
- Health & Human Services Board
- Mayors
- Federal Government - \$\$\$
- Law Enforcement
- Emergency Response Teams
- Fire Depts
- Park & Rec Depts.
- Farmer's Market



- Chamber of Commerce
- Meals on Wheels
- Senior Centers
- Nutrition Programs
- Airports
- Kinship Program - Senators
- Shelters - Domestic; Sexual Abuse
- Veterans (hospitals/mental health centers)
- State Visitor Center
- Dept of Aging
- ADRC

Healthcare

- Mental Health Professionals
- Discharge Planners
- Healthcare Professionals
- Dentists
- Primary Care
- Medical Facilities
- Occupational & Physical Therapists
- Social Workers
- Hospice Agencies
- Speech Therapy
- Electronic Medical Records (EPIC)
- Emergency Medical Technicians
- Emergency Room
- Medical Home Care

Businesses

- Providers: Technology/Assistive Equipment
- Local diners/bars (waitresses/bartenders)
- Small business owners
- Corporations and EAP (Employee Assistance Program)
- Fast food hangouts (men's coffee time)
- Grocery Stores (local connections)
- Employment Agencies
- Dept. of Workforce Development (DWD) / Dept. of Vocational Recreation (DCVR)
- Hairdressers
- Home Care Agencies
- YMCA

- Advertising/Marketing
- Independent Living Centers
- Fiscal Services
- Workforce Resources
- FoodShare Employment and Training (FSET)
- Northwest Wisconsin Concentrated Employment Program (NWCEP)
- Private funding - through community
- Cell Phone Providers
- Box stores (Walmart/Target)
- Insurance (Long-term Care)
- The ARC Wisconsin
- Bureau Aging Disability Resources (BADR) - State level

Organizations/Groups/Alliances

- 2-1-1 in counties (resource)
- Create a # like 2-1-1 for respite
- Caregiver Support Groups
- Foster Homes
- United Way
- Communities Connecting on Transition (CCOT)
- Adaptive Sports Programs
- Volunteer Agencies
- Respite Organizations
- Muscular Dystrophy Association (MDA)
- United Cerebral Palsy (UCP)
- Autism Society
- All Disability Groups
- Support Groups
- Play Groups
- Neighborhood Organizations
- National Alliance on Mental Illness (NAMI)
- Alzheimer's Association
- American Heart Association
- 4-H/UW Extensions
- USD
- Center for Deaf & Blind

Cultures/People

- Families
- Recipient of Care
- Potential Caregivers/Respite Workers
- Hmong (Hmong Centers: Wausau/La Crosse)
- Tribes
- Somalian Refuge (Jenny-O-Turkey Store)
- Hispanic (Lincoln Co. - CommuNiDad Hispana)
- Italian Community Center - Milwaukee
- Polish Newspaper
- Cultural Events
- LGBTQ
- Interpreters/Translators
- Fairs/Festivals
- Interfaith Organizations