



Wisconsin Lifespan Respite Summit 6/13/18 – Summary



Who Is Missing?

- Veterans
- Persons who need or receive respite
- Pastors
- AARP
- Legislators
- CMO's
- County Directors
- ADRC
- Large Employers
- Legislators
- DWD
- People with disabilities
- Life Navigators
- Actuaries
- Easter Seals of Northeast Wisconsin
- Respite care recipients
- People with Disabilities
- Dept. of Veteran's Affairs
- Millennials
- Non-Baby Boomers
- Cultures
- Tribes
- Hispanic
- Color
- Dept. of Children and Families

Key Issues & Needs:

- Need navigators who are culturally competent across the lifespan
- Increase awareness of respite
- Access barriers
- Education about respite and value to caregiver/provider
- Increase accessibility to providers
- Engage civic organizations (churches)
- Increase training for mental health caregivers
- Provider-specific training awareness and matching
- Transitions between counties and across the lifespan
- Increase qualified providers
- Increase awareness of respite and how to access
- Parent responsibility to educate providers about child needs
- Increase trust in providers
- Sustain providers (increase workforce supports) i.e. health insurance,
- Parent led training/sharing & knowledge
- Need to market respite as 'life saving'

Infrastructure:

- One stop shop
- Make respite a priority
- Lifespan respite coordinator in each region of state
- Families who get respite get it in a timely manner
- Leverage federal funds
- Finding quality, trained providers
- One coordinated system
- Have a resource center, or a Lifespan Resource Center
- Eliminate age restrictions
- Respite is universal
- Children’s services should also have a no wrong door service
- Learn from other cultures about how they provide care for family
- Be part of a culture that uplifts caregivers
- Tax credits for caregivers

Barriers to Access:

- Too proud to accept help
- Reframe how respite is presented (as benefit to care-recipient)
- Need to train case managers on how to talk about respite
- Bureaucracy/paperwork is overwhelming and then no one is available to provide care
- Low pay for providers – zero travel reimbursement, zero insurance
- Lack of funding
- Assessing needs incorrectly
- Low wages
- Timeline from ‘approval’ to getting a provider
- Lack of setting expectations and reality of timeline to match
- Need transparency/honesty
- Providers quit before they start
- Stigma of working for county
- Caregiver/provider burnout (“stuck”)
- Past trauma experiences
- Underfunded for community based care and family caregivers
- Lack of self-awareness of
- Lack of providers
- Need universal forms
- County to County consistency

Sustainability:

- Advocacy – engage employers as partners
- Educate legislators
- Lobbying
- Sharing stories
- Use data we already have
- Leveraging
- Sharing with statewide advocacy
- Day at the Capital
- Need permanent, paid staff
- Identify the stakeholders who should be lobbied
- Promote respite so it is as well-known as hospice
- Legalize marijuana and fund respite with tax proceeds
- Medicaid
- Caregiver awareness month - join with the alliance to educate
- Time banking
- Flex dollars for respite

Solutions to improve access:

- Global review of successful countries
- Learn from other cultures
- Remove income; and eligibility requirements
- Help families to understand the benefits of respite
- Community respite events to engage the population
- Lifespan resource center

- Turn caregivers into navigators
- Culturally and linguistically appropriate resources
- Dr.'s screen for respite needs
- Medical, teachers, clubs, churches – they can be advocates for respite – share info on respite

| Rank | One Big Idea (Higher the rank – more votes for the Big Idea) |
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| 25 | To have Wisconsin adopt a minimum wage for all employees of at least \$15.00 per hour. |
| 23 | Caregiver support specialist in every county |
| 22.75 | Respite is incorporated into employee benefit packages |
| 22 | Value human beings and quality of life for all. Less value on entertainment-entertainers/athletes, etc. |
| 22 | Societal change - to make respite care a right. To be used when needed rather than a service that carries stigma and great difficulty to even get. |
| 22 | Tax-free respite savings accounts. If you don't use it for respite it will be there for when you need care. |
| 21 | One resource center in every county that covers all ages and is familiar with all programs and resources (informal & formal) in the community that also does outreach to employers, schools, hospitals, churches, etc. to educate on need |
| 20.75 | Caregiver wages must be higher and agencies that pay caregivers need proper margins. |
| 20.5 | Each county has a centralized resource center to help find providers access. Providers find link to funding help with advocacy provider receive resources and tools they need |
| 20 | Lifespan Resource Center (ADRC) |
| 20 | Cultivate a culture of caring for one another - "It Takes a Village" concept |
| 19 | College credit for providing respite or reduction of tuition at UW for service, i.e. min# of hours |
| 19 | Customize hourly care rate based on child's need and caregiver's skill set vs fitting into a pre-valued category |
| 19 | Fed and state tax credits for caregivers (deducted directly from their taxes) |
| 19 | Film a commercial to show benefits of respite, how to access in your community, etc. (Hire Ryan Gosling to do it?) |
| 19 | The state funds and supports a family navigator system where an experienced family member can walk alongside a family caregiver - help them identify needs and connect to resources, including respite (it is culturally competent, cost effective and increases access) |
| 18.5 | Support family navigators across the lifespan |
| 18 | Caregiver tax credit with stipulated use for respite care |
| 18 | Promote community-wide inclusive volunteer efforts that covers schools, churches, business and government agencies "Points of light for caregivers" |
| 17 | Community/civic group involvement to create a volunteer system to support underlying paid respite position deficiencies. Groups could include: Knights of Columbus, Lions Club, Elks Club, Veteran Posts, |
| 17 | Community Involvement |
| 16 | Legalize and decriminalize cannabis and use tax dollars for respite |
| 16 | Do a respite telethon on local channels asking for respite money or qualified respite worker volunteer some hours over the year making this an annual event. |
| 14 | Idea for getting respite to every caregiver: every other person (50%) gets their own 'time of the month' when they must take a day-long break and trustworthy care or worthwhile activities will be provided by the other 50% |
| 12 | Adopt/implement other countries respite structure |
| 12 | Ongoing respite workgroup and networking workers, including providers, caregivers, state reps., etc. |
| 11 | What we can do is to ensure that this issue about respite care is address as individuals are running to become the new governor of Wisconsin |