

Mississippi Lifespan Respite Summit Notes

Questions for Facilitated Breakout Discussions

MORNING SESSION

Current State of Respite – Needs, Gaps and Opportunities

Please share your connection to respite services.

1. Do you offer respite services in your area or are you a family caregiver who uses respite?

- Connection to Respite:
- MIND Center-refer to respite
- DAAS –flow-thru funding/Grant Title B
- Personal/caregiving- what's available rurally
- Adult day care provider (our time)
- Alzheimer's Association refer to respite
- MAC Center – resource database
- Area Agencies
- Non-profits
- Social Services for county
- St. Joseph Hospice
- Jaquith Nursing Home
- Professor at MSU in gerontology
- Community Links
- Nursing Homes
- Merit Hospitals
- DMH
- Area Agency on Aging
- Care Nurses
- Hospital/Greenwood
- MS Dept. of Rehab
- B2I-Bridge to Independence-Division of Medicaid (person must be Medicaid eligible)
- Medicaid Waivers (low income to qualify)
- Disability Rights, MS Referral
- Home Health –Medicaid Waivers (preventative service. Keep person at home)

2. What systems or help already exists to assist families in accessing respite?

- Mississippi online Resource Directory
- MDOT Public Transit Division

- The MIND Center (research and diagnosis for Alzheimer's and other dementias)
- CMPDD -- Dr. Chelsea Crittle
- MAC Centers (2)
- Website
- Sitter Services (Cost Prohibitive)
- Church Programs / Day Care throughout state (see Alzheimer's Assn purple book for list)
- In Home Hospice (Hospice volunteer respite)
 - Respite for those homebound & on hospice
- Area Aging Agencies
- Medicaid Wavier
- Family Members
- Adult Day Care Services/Centers (2)
- Mississippi Department of Mental Health (Respite Services / Children & Youth Vouchers)
- IDD Wavier
- Intellectual (?) – Developmental Disability
- Dependable Source – Division of Medicaid
- Silver Lining Carthage _____(?)
- Harmony Court (short & long term)
- Bridge to Independence (B 2 I) Division of Medicaid Program. P.A. required
Plan of care needed
- Senior Centers
- MS Family as Allies in Jackson – Dr. Joy Hall (raising funds to provide more respite services)
- St Catherine's Village
Provides respite /Alzheimer's and assisted living
Private Pay (short or long term)
- Community Eldercare Services (Pleasant Hills)
- Adult Day Care, Rehab, A.L., LTC, outpatient rehab
- Medicare, Medicaid, Private

3. What tools are currently missing that would improve the ability of Mississippi Family caregivers to have increased access to respite care? Please list any additional challenges, barriers, and unmet needs.

- Needs Assessment For Person-Driven Care
- Different Levels of Respite Care
- Community Involvement (2)

- Financial Needs (2)
- Annual Report-to-Show Success
- Professional & Lay Caregivers (Need to educate lay public of resources)
- Agency on Aging – great resource
- “Middle Class” how to pay for services
- Sitters expensive
- Developmental Disabilities who are aging (what services are available)
- Insurance is expensive – where can we find insurance?
- Rural Areas Services Lacking (2)
- Information Given at Discharge at hospital & Other Providers
- Do Not Qualify for Services (2)
- Using Our Voice
- Advocacy
- Family Support / Connectedness
- Mobility
- Better Advertising/Publicity/Public Awareness
- Website(s) With Search Engine Functions (2)
- Funding For Outreach
- Support Groups
- Funding for Respite (2)
- More Care/Respite Professionals With MH Expertise
- Transportation (Can’t Cross County Lines) (2)
- More Services for Children
- Enough Advocacy
- More Information of Resources Available
- Need Easier System to Negotiate
- Resources for Those Who Aren’t on Medicaid or Enough Money for Private Pay
- Available Services in All Counties/Neighboring Counties
- Tele-health Options/Technology
- Quality Home Based Assistance (2)
- Information That Is Simple and Clear
- Faith Based Groups
- Peer-to-Peer Registry
- One Resource Directory
- Services Not Available When Needed
- Qualified Providers for Respite
- Respite Services on Weekends And After Hours

- Reliable Help/Trustworthy Help
- Training
- Screening Process
- Employer Education
- Legislators – Educated – Funding
- Integrated Systems
- Medical Home Platform
- Education b/w healthcare providers
- Continuity (some transportation provided -- not from others)
- Short-Term “facilities” Where are they?
- M.W. pays for A.L – There is a waiting list
- A.L for children with disabilities – may face

AFTERNOON SESSION

Strategies and Solutions Respite Needs for– Collaboration to Build Programs

Designing and Building the Mississippi Lifespan Respite Care Program (Lifespan Respite is defined as a coordinated system of community-based respite for all family caregivers.)

1a. What should a “Dream” Lifespan Respite Care Program look like in Mississippi?

- No waiting list
- Eligibility criteria covering all ages, disabilities, etc.
- Dependability
- Well-skilled care providers
- Adequate hours to meet needs
- Person-driven care- individualized
- Structure that provides oversight to make sure care giver and client are getting what is needed
- Computer resources information shared in one place
- Medical records sharing electronically through the state
- Also, agencies , service centralized
- Someone to manage/ update with technical expertise
- Format that is easily searchable, quick , good info
- Would include community resources, churches, volunteer groups
- Peer to peer respite

- Service for volunteer (maybe through AARP)
- Funds available for needed respite and someone to manage grants/applications
- Community groups could match funds
- State lead agency will manage
- Respite workers at home
- Transportation
- Training for home respite workers (Criteria for workers)
Specifically focused on the type of respite care they will provide.
- Research – PDDS/NFL and other states—what do they do?
- Ability to individualize respite based on their needs-person-centered, and
Region-centered, each person has different needs
- Transport across counties
- Financial Backing
- User Friendly Apps
- Assistance in navigating the system
- Call for services all over the state, free of charge and for emergency and continuing care
- Let the calls go to the MAC Center
- Support (Humana)
- Tele-health
- Education and training (caregivers, professionals , community research workers)
- Discharging planning
- In-home assistance

1b. What type of Infrastructure would be needed to establish the Mississippi Lifespan Respite Care Program and help to ensure sustainability?

- Embed LRCP into MAC Center
- How do approach whole state?
- Physical Access to care
 - *transportation
 - *location within a county, etc.
 - *coordination/continuity among regions (region to region)
 - *telemedicine
- Collaboration with results
 - *Stakeholders with caregivers
 - *Workforce- knowledgeable

To ensure sustainability:

- Create policy for insurer to include respite as a benefit
- Lobbying
- Have other funding sources, “ Medicare, etc.”
- Lottery
- Information should be distributed to the medical community to be given to the family immediately
- Website
- Educate the medical community on the program
- Make information simple and clear
- Allow respite workers to do more than currently allowed
- To sustain the work, use the MAC Center to assist PTS navigate the system **Respite
- Showing outcome data
- The first point of contact equipped with knowledge to assist PTS
- Involve the community:
 - *Civic Clubs *Auxiliaries *Student Nursing * Social Workers
 - * Churches *Fraternities *Sororities
- Advertising & Marketing

Strategies and Solutions

- Coordinated Care Manager
 - *education, *mental health
- Advocate (voice)
- Overnight, 3-5 day respite
- Day Service for youth and Adults
- In home respite
- Emergency respite
- No gap in service provision
- Community based organization-(contracted out)
- One Stop Shop for current resources
- Resource Specialist
- Respite Mentors
- Each health care provider have resource information
- Outreach workers
- Education for healthcare providers to better assist PTS

- Fund respite services for those who don't fit the regular Medicaid Insurance guidelines, etc.

Building Collaboration – As we build a statewide Family Caregiver Coalition to support a statewide Lifespan Respite Care Program:

2a. Who needs to be part of the Mississippi Family Caregiver Coalition?

- MDOT
- Transportation Coalition (Jan Larson?)
- Other coalitions that have gathered state information
- Technical Experts (database, apps, websites, etc.)
- Department of Education – maybe special needs
- Public Policy/Legislature (3)
- Caregivers
- People Who Have Received Care
- Representatives (Parkinson's, MS, Huntington's, Diabetes, VHA, Nonprofits)
- Family
- Board of Nursing
- Insurance Companies (2)
- Medical Community
- Case Managers
- Area Agencies
- Providing Agencies
- Faith Based Groups (3)
- Advocacy Groups
- Hospitals
- M.H.
- D.V. Ability Works
- S.W. / DHS/ VR
- Make – A – Wish
- Health Department
- Media (2)
- Protective Services
- Policy Makers – local government
- Schools (2)
- Adult Day Care
- Lawyers (3)
- Transportation Agencies

- Financial Planners
- AMR (the caregivers across life span)
- H.H. / N.H. / A.L.
- Homeless Shelters/Stewpot
- Government Agencies
- Health Care Providers (2)
- Volunteer Groups
- IDD/DD Providers
- Colleges/Universities
- Direct Care Workers Trainers
- Direct Care Workers, Housing
- Authority Healthcare Associations
- Elder Law Attorneys
- Department of Aging
- Info updates to public about Medicaid - “taking house” people don’t “apply” for help

2b. How do we ensure that all stakeholders (caregivers) are served regardless of age, STAGE, or disability?

- Representatives from all agencies that provide care to caregivers and care receivers are involved
- Keep current list or resources
- Make sure the members of the caregiver Coalition are present, engaged and aware of new changes
- Faith based community is involved
- Must involve the caregivers (must hear their voices)
- Documentation / evidence that it’s working
- Demonstrate good use of funds -- positive and negative outcomes
- Fiscal responsibility

2c. What should the role of the Mississippi Family Caregiver Coalition be in the Lifespan Respite Care Program?

- To be a watchdog
- To be an ongoing advisory group to suggest changes as needed
- Advocate for the caregivers (2)

- Advocate – positive & negative -- Compliance Department”
- Education – Public and Private
- Fundraising Efforts
- Lobbying
- Workshops
- Media / Public Relations
- Financial
- Set up Support Groups
- Advisory
- Point of Information
- Outreach person (Comprehensive Care Center) knows about everything available
- Bringing it all together
- Use caregivers Respite Coalition members
- CC Center available for face to face managers
- Volunteers
- Financial Planning

2d. What type of workgroups do we need to accomplish our goals, face the identified challenges, barriers, and unmet needs and to ensure the quality of a sustainable program is maintained?

- Interdisciplinary
- Regional
- Educational (2)
- Liaison to Legislature
- Grant writing
- Public Relations and communications
- Evaluation Groups
- Organizations/Providers
- Public Awareness
- Resource / Data Information
- Care Coordination
- Allocation of Funding
- Respite focus groups across the state (to hear from all caregivers in the state)
- Continue Respite Conferences and Outreach

- Faith based churches
- Place to start to provide resources to lay people / neighborhood managers
- Train the trainers
- Word of Mouth
- Safe place to share & be heard
- Respite care can assist hospital/ H/H / NHs to address re-admissions

Post-Summit Questions

Question 1: What services should be included in the Mississippi Lifespan Respite Care Program to build on current strengths and overcome obstacles?

- PCAs and CNAs are not able to administer meds when they provide respite.
- Training for CNAs and PCAs would possibly alleviate the problem.
- We don't want the Board of Nursing to think we are training PCAs and CNAs to do the nurses' jobs.
- Develop training programs for caregivers to offer specific training for specific areas of need.
- Where can we find a database of respite services?
- Defined problem, evidence based solution, and political willingness.
- Many clients go out of state to other facilities so the family caregiver can get respite.
- Professional education briefing so that physicians, etc. are aware of available services.
- We need reviews, references and ratings from families who have used these services.
- We need a support group for caregivers, possibly virtual.
- 1-800-Respite for the professionals.
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Action Steps

- Contact Board of Nursing
 - Contact Hospital Association
 - State Medical Association
 - Contact Hospice
 - Community Centers
 - Assisted Living Homes
2. Continue to identify and discuss solutions to improve respite access within Mississippi.
- MAC Center has a web-site that lists over 6000 resources statewide.
MississippiAccessToCare.org.

Grant Writing Committee

- Becky Brookshire
- Ellen Jones (Spencer Blalock)
- Grant focus
 - Training
 - Information and referral