

Home and Community-Based Services
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Are community based services “dementia friendly”?

- Keep in mind that all providers are not created equal. In our area, we do know who the quality providers are that have a good knowledge and understanding of dementia and how it impacts both the patient and the caregiver. This varies County by County in both the public and private sector.

Is dementia specific training included as part of training for staff providing community-based services?

- The quality training usually happens with larger providers. They tend to value training for their staff more. However, many providers do not consistently include dementia specific training.

What services/resources are available?

- Special Assistance In Home Services (SAIH)
- Home & Community Care Block Grant (HCCBG)-we already have a mechanism in place to prioritize needs in each community as it relates to funding core services.
- Program of All-Inclusive Care for the Elderly (PACE)
- Community Alternatives Program (CAP)
- Adult Day Health & Day Care Centers
- Information & Options Counseling
- Alzheimer’s Association
- Family Caregiver Support Program
- Multiple Secure Units in adult care homes & nursing homes
- AHEC, Alzheimer’s Association, & AARP sponsored trainings (good for caregivers as well as professionals)

What really works?

- When training is systemic, ongoing, and recurring.
- Communities that include citizens, consumers, and providers must have continuing opportunities for training and education to reach a “tipping point”.
- A continuum for which consumers can move up or down in depending on their needs.
- Person centered services that are tailored to the individual and their family as each one is uniquely different.
- One source/hub for Information and Referral.
- We already have a strong foundation in NC, so we do not have to reinvent much. Our core issue is really capacity to keep up with demand, and fragmentation of services.

What factors influence the availability and utilization of services/resources?

- NC is ranked 9th among states who have the highest population of over age 60.
- By 2018, NC will have more people 60+ than ages 0-17.
- In 2013, 60 NC counties had more 60+ population than 0-17. In 2025, that number is projected to be 90 Counties.
- Eligibility requirements that make no sense, or are based on old ways of doing business with little flexibility.
- Citizens who cannot afford private pay, but aren't eligible for Medicaid either.
- Waiting lists for services, or a limited number of capitated slots for the particular service.
- Approximately 25% of North Carolina's 1.4 million older adults over the age of 65 have two or more physical or mental conditions that make it difficult to do activities required to remain independent.
- Cuts to the Home and Community Care Block Grant-below are only the state dollars in the Home and Community Care Block Grant that the General Assembly allocates:
 - 2009: Decrease of \$500,000 (Non-Recurring) in 09-10 and 10-11.
 - 2011: Decrease of \$200,000 (Recurring).
 - 2014: Decrease of \$969,549 (Recurring=1,500 persons impacted who would not receive needed services.

Where are the gaps?

- Collective Community Impact Models focused on outcomes specific to local issues and needs.
- Coordinated effort to easily link resources via a single point of contact for information and referral for citizens with the disease or their caregivers.
- Affordable services for Non-Medicaid eligible families.
- Funding for programs that currently have large wait lists (CAP, SAIH, In Home Aide, Adult Day Care/Health, Caregiver Programs, Meals on Wheels, Congregate Sites, Housing and Home Repair, Senior Centers, Transportation, etc.):
 - The waiting List for HCCBG In Home Aide Services excessive with little hope of getting onto programs.
 - As of February 2015, NC had 8459 seniors on the wait list for HCCBG services, many of whom will pass away before ever being served. Approximately 80% of those currently on the wait list are waiting for In-Home Aide Services or Home Delivered Meals.
- Needed services are not available across the state. More options exist in urbanized areas.
- Need support groups for people diagnosed with Alzheimer's and Dementia, especially those recently diagnosed. Support groups tend to focus on the caregiver and not the individual.
- Poor Supports for Caregivers.
- Citizens who desperately need services, but are just over the poverty or eligibility limits, who cannot pay privately. There is nothing for many of these people.

- Transportation is critical for access to services especially for people living in rural areas.
- Less informal support available due to many adult children working longer and/or moving to other areas:
 - The caregiver support ratio (the number of potential caregivers age 45-64 for each person 80 or older) will decline from 8.0 in 2010 to 3.9 in 2030.

What suggestions do you have for how to address gaps and move forward in better serving those with dementia and their family members?

- Just 1 Call (Mecklenburg County)-Resource line for citizens, consumers, and caregivers.
- Decrease waiting lists and/or increase slots for needed services.
- Affordable services for those that often “fall through the cracks”. Assess changes in eligibility requirements allowing individuals to meet a deductible and still be eligible for services.
- More assistance for caregivers:
 - More than 60% of all family caregivers work.
 - Expand Project Care to more Counties than just a handful.
 - Subsidized payments or tax breaks for caregivers who are unable to work as a result of their caregiving responsibilities.
 - Allow caregivers to use existing sick leave benefits for caregiving purposes.
 - Allow caregivers to take short increments of unpaid leave for a family member’s illness, injury, or medical appointment.
 - Increase the availability of respite care services, which provide short periods of relief for family members from their on-going caregiving tasks.
- More funding for community based services (much cheaper):
 - According to a 2014 industry survey, an average nursing home costs \$73,913 annually.
- Begin awareness campaigns among younger people about aging (sensitivity to functional, physical and cognitive limitations) to help with future stigma associated with the disease. California’s plan did this.
- Early/accurate diagnosis is critical
- Continue to stress the importance of advance planning and provide caregiver coping strategies. Hawaii’s plan addressed some of these efforts.
- Educate/engage the public about Alzheimer’s and Dementia through an education/public awareness campaign to reduce stigma, promote early/accurate diagnosis, risk factors, 10 warning signs, brain health, difficult behaviors, and the importance of advance planning and caregiver coping strategies.
- A more coordinated response among governmental agencies, medical associations, medical providers, health and community support providers and insurers to identify and/or create improved detection tools for dementia and coordination of medical care and referral for community support and services. Maine’s plan spoke about this.
- Adding dementia assessments into part of the annual physical leading to early detection/diagnosis. We would not be re-inventing the wheel or creating something totally new or different that would require extensive funding.