

Background

Caregivers in the United States Are valuable to society, there is a growing demand for them, and they need support!

- 46 million >65 now, there will be 98 million >65 by 2060
- Caregivers provide an equivalent to \$470 million/year of care, this is more than what the U.S. spends on Medicaid
- Dementia caregivers make up over half of caregivers
- Dementia caregivers experience more caregiver burden than other caregivers
- Resources help mitigate caregiver burden, save money, and support the caregiver to provide care longer
- Utilization of resources remains very low 2-11%

Method

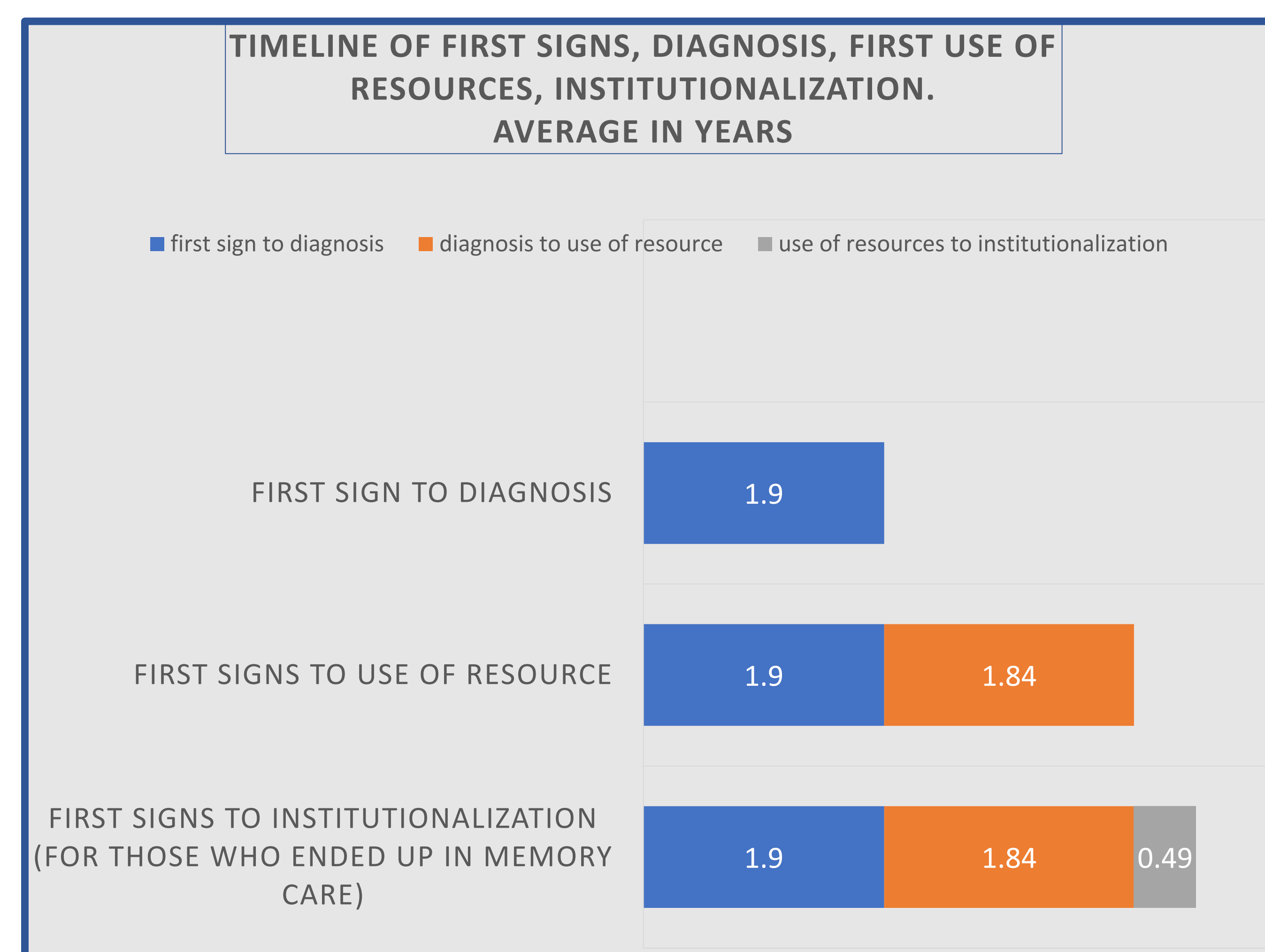
What are the barriers to accessing resources?

This study sought to answer this question by using semi-structured interviews of caregivers of persons with dementia who have used caregiver resources. Questions addressed three main topics: early signs of dementia observed and the diagnostic process, caregiving duties performed, and utilization of resources, including the timeline of these experiences.

Results

The Barriers

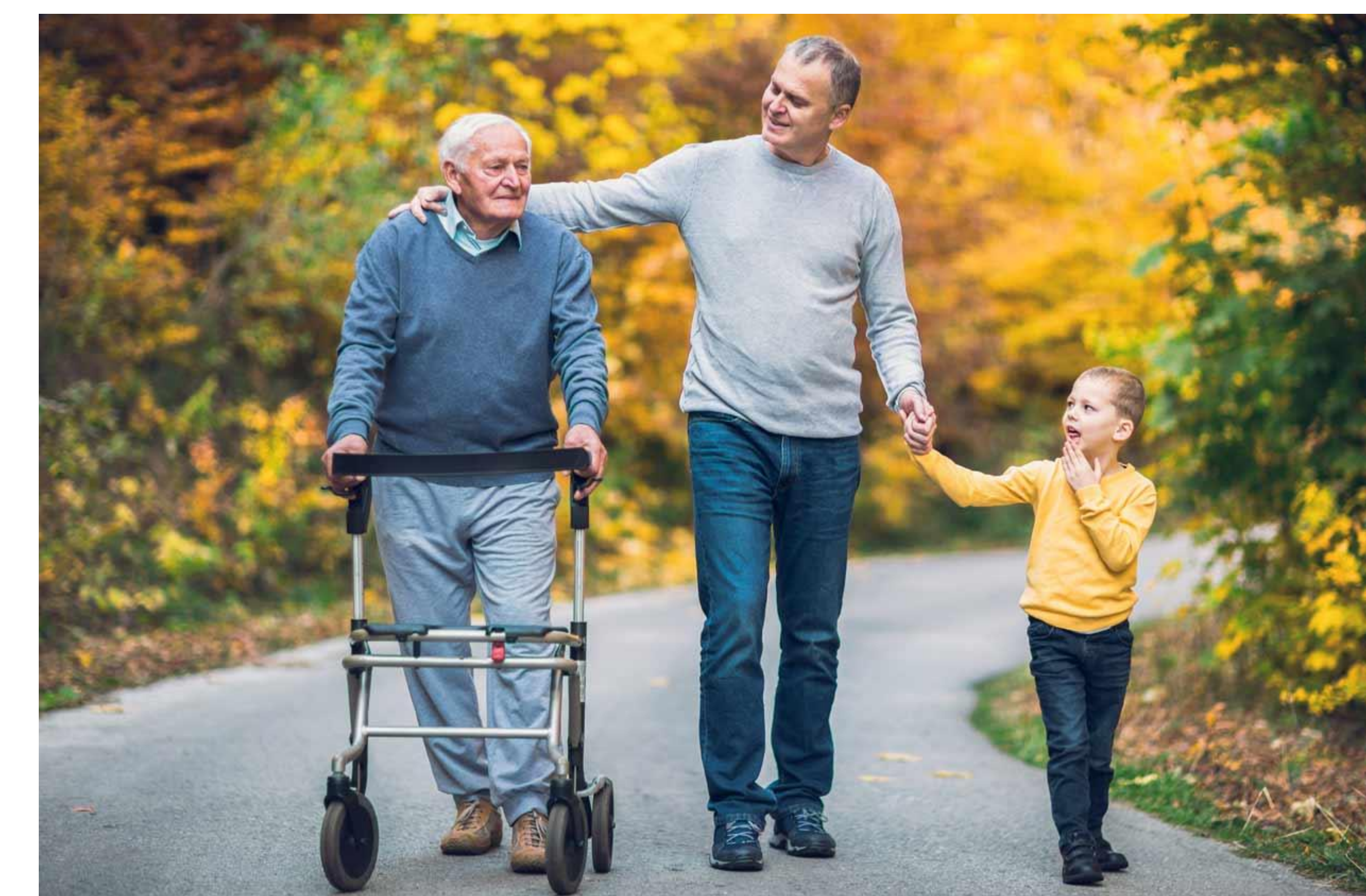
- Omission of referrals in the diagnostic process
- Person with dementia is resistant
- Unaware of the resource
- Not available
- Not useful
- Inconvenient timing
- Did not meet needs
- Cost was prohibitive



THE HEALTHCARE STRUCTURE IS A BARRIER TO RESOURCES.

By not referring patients and caregivers to resources the healthcare structure prolongs or prevents use of resources.

- The diagnostic process includes comprehensive testing but rarely involves referral to services. Average time from diagnosis to use of resources was 1.84 years.
- There is a common barrier of not being aware of resources.
- Those who did use resources were prompted by learning about them.
- The advice from caregivers in hindsight is to start using resources earlier.



What's Next

Get help earlier so you can love them longer." - caregiver

"get help a lot sooner!" - caregiver

"start with support group, from there you will quickly discover from others what it is you need." - caregiver

"Support groups saved my life. It is a terrible feeling to be out there alone" - caregiver

Tie resources to the diagnosis process

On average, caregivers wait nearly 2 years before seeking medical services. Furthermore, most caregivers did not find support services until 2 years after the diagnosis was made. During this time, family caregivers observe declines in their loved one and experience significant stress. When caregivers finally seek answers, they are often simply given a diagnosis and prescription meds. Although most are satisfied with the diagnostic process, there is often a missed opportunity to connect families to valuable support services. Connection with services could be done in many ways such as a follow-up meeting with a social worker or nurse after a diagnosis is made or as a referral to a partnering agency.