

Improving Services for Older Individuals with Intellectual and Developmental Disabilities and Those Experiencing Dementia and Alzheimer's Disease

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Brief Description:

To address the needs associated with the aging of our service population, the agency's new "Aging Committee" (in 2008) addressed facility needs such as accessibility in the residential homes and day programs, caregiver supports, nutrition and other health related needs. We develop programs and services that could assist our consumers as they aged in the residences and community and facilitated a process to track and enhance services for individuals presenting dementia symptom.

This submission was selected as part of a national challenge issued to leaders in all communities seeking new "best practices" and "best possibilities" for the future of nutrition and aging.

Alzheimer's disease (AD) is the most common cause of dementia, among older people. This decline in cognition is not a normal part of aging. In most people with AD symptoms first appear after age sixty (1). People with Down syndrome (DS) develop a clinical syndrome of dementia similar to that of individuals without DS. The main clinical difference is the early age of onset of AD in individuals with DS, with symptoms present in their late 40s or early 50s. Studies show that there may be differences unique to persons with DS (2).

Organization's Activities

To address the needs associated with the aging of our service population, the Schenectady ARC had convened a committee of clinicians, support staff and others in early 2008. The agency's "Aging Committee" addressed facility needs such as accessibility in the residential homes and day programs, caregiver supports, nutrition and other health related needs. Through various surveys (for consumers, their families, and program staff) we found that we needed to develop programs and services that could assist our consumers as they aged. For this project in particular, those individuals experiencing symptoms of dementia and its progression. We identified a lack of

communication between all disciplines; medical, speech, psychiatry, social work, occupational and physical therapy and nutrition. There was also a clear need for training of all agency staff on aging processes and dementia.

The Aging Committee pulled together clinicians to develop protocol to address the needs of individuals showing signs of dementia, the “Dementia Data Committee.” Although most of our consumers in this project had DS, it was not exclusive to individuals with DS. This project was to:

1. identify symptoms and needs earlier,
2. anticipate needs so we can be proactive versus reactive,
3. be prepared with quality/effective services that make a difference,
4. identify patterns of decline,
5. provide more staff education,
6. provide care in a consistent and responsible way throughout the agency, and
7. ultimately identify what, when, and where supports benefit our consumers most.

Each discipline was responsible for developing a measurement tool using existing models, research, reports, and observations. Common measurement scales were developed in order to compare data across disciplines. Scales were similar in that the higher numbers (0 – 4) reflected worsening symptoms or a higher frequency that a particular symptom was observed. Measures were descriptive, not diagnostic. Such information was collected quarterly for each consumer in the project and the data was input into a customized database.

Discipline assessments with rating scales addressed the following symptoms and/or functions: Psychology looked at self-care, cognitive functioning, socializing/isolation, emotional self-regulation and behavioral self-regulation. Physical Therapy included posture, muscle tone, functional mobility, perceptual/spatial skills, and abilities such as sitting, transferring, ambulation and wheelchair use. Occupational Therapy assessed dining skills, dressing, showering, toileting, fine motor coordination and changes in perceptual/spatial deficits. Speech Language Pathology noted changes in expressive language, receptive language, pragmatics, memory, attentiveness, and swallowing/dining. Nutrition assessed changes in food preferences, appetite, eating patterns, and memory around food and hunger. The rating scale used information from the National Institute on Aging, the Alzheimer’s’ Association and other sources (1, 3, 4, 5, 6, 7).

Effects of dementia and AD

Appetite and food desires can be affected by psychological and behavioral factors such as depression, social withdrawal, agitation, wandering, paranoia, confusion, and/or irritability (usually negatively). The individual may not be aware of being hungry, may forget to eat or needs encouragement to eat. They may not be aware that their stomach is full and overeats or wants to eat all the time and may forget what they liked or didn't like to eat.

A number of these symptoms, traits and/or changes may be the result of a change in the person's life or their care and treatment. Medications and their side-effects (dry mouth, taste, hunger or anorexia, GI distress, level of alertness) can affect food intake. A food consistency change can alter how foods are perceived or recognized and affect intake. Sores in the mouth, poor-fitting dentures, gum disease or dry mouth may make eating difficult. The individual may need special utensils and dinner ware and/or other table set ups. Problems with constipation, swallowing or dysphasia, and/or congestive obstructive pulmonary disease, to name a few, can limit the desire to eat or eat adequately (4, 8).

Organization and Project Outcomes

Beginning in 2008, staff worked with our regional Alzheimer's Association to create classrooms in one of our day program facilities to address the needs of our consumers who are aging and experiencing the onset of dementia. Called "Spring Hill," the three classrooms had color contrasting walls and other visual and functional features and offers specialized activities. A caregiver support training program was developed and groups met on various topics. In addition, the agency established a training program to all staff that work with consumers. It included the Virtual Dementia Training™ purchased program. This was a simulated program allowing one to experience the effects of dementia and to try to complete assigned task. After the brief "exposure" there was a personal review of the experience with trained staff. Nutrition guidance has been reviewed during in service training to all group homes and day programs. The deployment of altered feeding schedules, use of nutrient dense foods and supplements, appetite-enhancing scents, and general diet flexibility have been relatively successful in curtailing nutrition degradation and undesired weight loss.

More detailed analysis, including linkages with changes reported from the other disciplines has not been done as yet. This would provide a more complete picture of the

individual, their disease progression and the assistance provided. This is an evolving project with changes expected along the way to improve the coordination of care and the individual's quality of life.

Additional Background information: A recent published report *'My Thinker's Not Working': A National Strategy for Enabling Adults with Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports*, provides a summary of the challenges facing the nation as we observe an increasing rate of dementia found in older people with intellectual disabilities. The Report offers recommendations for the various stakeholders in the field of IDD, many of which are being addressed by our organization.

- Primary care and supports for adults with IDD affected by dementia can be primarily provided within the community and appropriate services can preclude institutionalization.
- Providers are beginning to adapt small group homes for specialized community care and supports for persons with IDD affected by dementia.
- There is a lack of background knowledge and training in late life problems of adults with IDD among primary care health providers in community practice.
- Specialized assessment and diagnostic resources are needed to help more effectively identify adults with IDD and dementia.
- Creating a national program of trainings using workshops, webinars, and other teaching methods, would advance the knowledge and skills among workers and clinicians working with adults with IDD affected by dementia.
- Creating a national information and education program for adults with IDD and family members would improve their understanding of dementia and potentially lead to earlier identification and acquisition of timely supportive services.

From the National Task Group on Intellectual Disabilities and Dementia Practice. (2012). Executive Summary: 'My Thinker's Not Working': A National Strategy for Enabling Adults with Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports. January 2012

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