



## Summary of Themes

### CARF International Standards Advisory Committee Dementia Care Standards for Individuals with Intellectual or Developmental Disabilities

In January 2013, CARF International met with leaders of the National Task Group for Individuals with Intellectual and Developmental Disabilities and Dementia as well as CARF leaders and persons served.

Topics were identified as priorities for standards that can be implemented by community-based organizations providing services and supports to the ID/DD population. This document provides the top themes that were identified along with specific points related to each theme.

Throughout the summer of 2013, further input will be obtained by CARF to ensure that accreditation standards adequately address the themes. A public field review of draft standards will be part of this effort. This work will be conducted so that selected 2014 CARF standards manuals will include dementia care standards appropriate for ID/DD populations.

Feedback and questions regarding this information may be directed to Susanne Matthiesen, Managing Director of Aging Services, 1-866-888-1122, ext. 5006 or [smatthiesen@carf.org](mailto:smatthiesen@carf.org).

#### **Support for the family and support system of individuals with intellectual and developmental disabilities and dementia.**

The following practices can be implemented by organizations to demonstrate this concept:

- Information should be provided to caregivers using methods and resources that are understandable to them.
- To demonstrate a provider's focus on the individual person served, that individual should be included in service planning discussions early in the diagnosis of dementia in order to develop a written "life plan" reflecting individual choice. This life plan should be tracked, reviewed and updated according to changing preferences, and shared with caregivers in order to support person-centered care when the individual becomes unable to articulate their wishes due to the progression of dementia or other factors.
- Alternate decision-makers should be identified and tracked by providers.
- Provider organizations should demonstrate how they communicate information regarding the expected progression of dementia and the impact on the individual to the family and support system.
- Providers should provide opportunities for expression of grief to the individual and their family and support system.
- Communication regarding person-centered planning, changes in care needs and health status, as well as other information necessary to support quality of care and quality of life should be conducted in ways that are accessible to families and support system so they can be part of the service delivery team. Methods could include meetings, phone calls, emails, and other systems that are available at times that are convenient for the family/support system.
- In order to provide effective services, the provider organization should obtain a history of the individual and their family/support system in order to support care delivery.
- Provider should implement cultural competence in service delivery as well as interactions with family/support systems.

- Education regarding dementia care practices and health promotion is made available for family/support systems as well as personnel of provider organizations.
- Family/support system representatives are involved in legal processes related to care and services for the individual with dementia.

**Personnel education should address topics important for dementia-specific care to individuals with ID/DD and Dementia.**

The following practices can be implemented by organizations to demonstrate this concept:

- All direct care personnel should receive education regarding providing services to individuals w/ ID/DD and dementia.
- Dementia-specific education should be geared differently toward direct care staff vs. management and/or administration as each may require different areas of knowledge.
- Typical age-related changes should be included in education regarding dementia and its impact on individuals with ID/DD.
- Education should be accessible, linguistically appropriate and culturally appropriate to meet the needs of personnel in caring for a diverse population.
- Administrator education should sensitize management to issues specific to provision of quality services to individuals w/ ID/DD and dementia.
- Initial and ongoing personnel education should address topics including, but not limited to:
  - Co-occurring conditions typical in the ID/DD population.
  - Appropriate recognition and expression of grief regarding decline of individual receiving services.
  - Observation and documentation in service delivery process including understanding the meaning of body language of the individual.
  - Communication approaches to promote rights of individual with ID/DD and dementia.
  - Dementia risk factors, approaches to measuring health outcomes, preparation for healthcare visits.
  - Observation protocols: frequency and specificity of observations to identify needs of persons served.
- Transportation providers receive education regarding safety practices necessary when transporting individuals with ID/DD and dementia.
- Interdisciplinary communication skills for personnel are incorporated into program design.

**Information regarding aspects of and progression of dementia are necessary for effective service provision.**

The following practices can be implemented by organizations to demonstrate this concept:

- Families and support systems of individuals receiving services are offered information to enhance their knowledge of dementia in the ID/DD population.
- Education should be provided regarding sensory deficits and change with age should be made available.

- Systems for tracking observations of individuals from personnel on all shifts should be implemented to provide clarity to personnel regarding the most important observations related to identifying major changes in the individual.
- Providers should be aware of the increased need for creation of “calming environments” for individuals as the progression of dementia may cause various types of behavioral communication.
- Collaboration should occur with researchers regarding science of “psychoneuro immunology”

**Approaches for maintaining community living environments for individuals should support rights of the individual while also promoting safety and security.**

The following practices can be implemented by organizations to demonstrate this concept:

- Environments should promote a culture that is proactive and productive for individuals with dementia.
- Individuals with dementia need to be in physical environments that are conducive, compatible, accessible and supportive and that can change and evolve as the disease progresses.
- Environmental design or modifications to promote safety of the physical space should be evaluated as individuals with dementia may exhibit signs of agitation, confusion, and/or wandering.
- Features in the physical environment should be based on evidence related to bio-ecology and enviro-psychosocial stressors.
- Multi-sensory environments should be integrated into environmental design in order to support “sensory diets”.
- Cornell checklist for safety may be a useful resource for providers that serve dementia-affected persons.
- Consistency amongst caregivers can provide natural means for maximizing safety while also helping to maintain function.
- Practices for service delivery should consider other individuals who may be living in the person’s environment.
- Transition criteria should consider the needs and preferences of individuals as well as others in the program.
- In order to address “anticipatory grief” (will this happen to me?) of individuals as they see the progression of dementia with other residents, providers should have communication and education regarding dementia for all individuals as necessary.
- The interdisciplinary team and clinical supports should evolve to reflect the changing needs of the persons served.
- Service delivery settings should be supported with current assistive and information technology.
- Transitions in living environments, even if they are temporary in nature, should foster stability. Personnel assist with such transitions by passing on information about the individual including personal preferences, rhythm of the day, along with essential clinical information.

**Personnel Support Systems are implemented to reduce worker stress, enhance knowledge, and promote quality in service delivery.**

The following practices can be implemented by organizations to demonstrate this concept:

- To manage personnel stress and burnout; resources such as emotional support groups, as well as approaches for grief and loss support could be provided.

- Personnel resources should recognize that the most intensive care delivery needs emerge at the mid-level stages of decline and plan accordingly.
- Front-line caregivers should be provided with strategies for effective service delivery as well as flexibility to make decisions based on their knowledge of the person served.
- All care giving personnel should have the opportunity to provide input into the care practices to be followed and objectives to be met for the individual.
- Personnel should receive education on aging, risk factors, and health care advocacy on behalf of adults with IDD.
- Leadership of the organization should have systems for tracking, disseminating information and educating personnel on trends and findings in the field of dementia care.
- Resources should be Cochrane database approved.

### **Screening & assessment, diagnosis, and monitoring of individuals.**

The following practices can be implemented by organizations to demonstrate this concept:

- Since dementia can manifest differently, personnel should be knowledgeable about the signs of dementia and steps to proper diagnosis.
- Assessments may have to be conducted more frequently when there is a rapid patient decline.
- Identify how to measure outcomes appropriately for this population.
- Personnel should work as part of an interdisciplinary team for effective assessment and monitoring.
- Co-occurring conditions should be identified and monitored along with dementia.
- A process should be implemented to enhance personnel knowledge of the criteria, data, and frequency of assessments to prompt service delivery.
- Annual wellness visits should be implemented for persons served.
- Ensure that assessments consider changing lifespan issues.
- Annual or biannual assessment of functioning should be implemented to determine if services are helping to maintain functioning and placement (home, job, day program) of the individual.
- Communication strategies for personnel should emphasize what data means in terms of an individual's health and well-being.
- Use data to understand changing function and inform therapeutic strategies.
- Engage in education of health professionals including physicians and associations focused on dementia in order to advocate on behalf of the needs of persons served

### **Effective communication.**

The following practices can be implemented by organizations to demonstrate this concept:

- Leadership should define how to determine effective communication between individual team members both within an agency and between systems.
- Procedures are in place for an individual with dementia to have someone accompany them to medical appointments and record necessary diagnostic and treatment information.

- Systems for communication between shifts are in place.
- Systems for inter-agency communication as well as communication with other services such as transportation are implemented.
- The frequency of communication is determined individually based on person's current functioning.
- Personnel demonstrate respect, dignity, and sensitivity in their communications with individuals.
- Ethical practices address discussions with individuals and/or their support systems related to decision-making.
- The frequency of team meetings w/ all care providers and care coordinators present is appropriate to the needs of the population and can increase as necessary.
- Providers demonstrate ongoing communication methods between the care facility and the other part of the healthcare system.
- Service delivery planning for the individual includes specific treatments in place pre-dementia diagnosis and determines where changes should be made; ex., behavior modifications, reviews of anti-psychotic/psychotropic medications.
- Communication should be linked to current technology platforms.

### **Person-centered care planning.**

The following practices can be implemented by organizations to demonstrate this concept:

- Person-centered planning considers disease progression and anticipates the needs of the individual.
- Families and support systems are involved in integrated health planning as it relates to establishing and attaining short-term and long-term goals for the individual.
- The person who has legal responsibility for the individual is identified and receives regular updates.
- The person w/ dementia is involved respectfully, creatively, & meaningfully in any decision making and implementation or provision of care. This process for doing so shifts with the changes in the person's functioning.
- Advance directives and end of life plans are integrated into person-centered plans and primary care physicians follow this information.
- Dignity of individuals are recognized and honored throughout service delivery.
- Providers should implement ongoing processes for breaking down systems barriers related to providing quality care.
- The provider clarifies the components of the care delivery system including the components that may exist outside of the home/care facility.
- Flexible supports accommodate changing abilities (important to look at context of family/system approach)
- Ongoing modifications & adaptations to environments demonstrating awareness of sensory needs, look at the environment first – not last.
- Emphasis should be placed on “age-appropriate” exchange; i.e., verbal and non-verbal.
- Use “pathographies” written by staff as aid to understanding perceptions and care delivery.
- Develop life profiles for all individuals identifying their unique preferences, needs, and effective approaches for service delivery.
- Tools such as scrapbooks and videos are shared to help personnel know personal histories and other important life details of each individual.
- Information regarding the individual with dementia should be shared with providers such as physicians, dentists, hospitals, and other healthcare providers.

- Goals or targets for effective care should be identified for individuals.
- Data collected is essential to determine the quality of services, but make sure to focus on the individual receiving services.
- Person-centered planning should address topics such as: life-long learning; maintaining skills/reasonable expectations of function; health promotion
- Identify appropriate goals for the individual: i.e., age in place, slow the loss of function based on typical data
- Outcomes can't be followed; goals need to be set that are individualized and then plans need to be followed to reach the goals.
- Support provider culture that embraces stellar care which should include some process for sharing new data from field/research across all dimensions from therapeutic, supportive, administrative, maintenance, culinary, security, etc.
- Providers should demonstrate an understanding of available community resources to support service delivery; ex., hospice

**Addressing funding, regulatory, and licensing systems.**

The following practices can be implemented by organizations to demonstrate this concept:

- Providers should explore ways to involve resource coordinators so their advocacy for funding can be effective on behalf of persons served.
- Providers should understand methods to access funding across agencies for individuals in congregate residential settings as well as those living at home and accessing services such as respite, adult day services, home health care and home care.
- Markers to trigger contact with funding agencies should be identified in order to access additional resources to support service delivery.