

Quality Care for Down Syndrome and Dementia

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Abstract

This article will give both examples and methods to use when providing services to individuals with a dual diagnosis of Down syndrome and Dementia. This is a prevalent issue that most care facilities are facing as the population with Down syndrome age. Staff training, schedule adjustments, living space adjustments and a new thought process regarding active treatment are essential for successful, quality care to take place.

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Intermediate Care Facilities for the Mentally Retarded (ICF/MR) are facing the aging of the individuals whom they serve. This aging has led to many of the residents with Down syndrome being diagnosed with dementia. This growth in dementia can be dramatic and overwhelming for both the person with the diagnosis as well as the caregiver and family members. Lott (2008) reported: “more than 25% of persons with Down syndrome over the age of thirty five will develop symptoms of Alzheimer’s type-dementia where as in the general population Alzheimer-like indications do not usually develop before the age of fifty”. Individuals with Down’s syndrome (DS) often survive long enough to develop dementia, and their increasing life expectation has major social and health service implications. “Knowledge of the natural history of DS in late middle age is essential for planning the provision of adequate family and community care for this population. Clinical signs of the disease have been found to develop during the fifth decade of life, associated with poor memory and deterioration in living skills” (Holland)

The difficulties involved in providing quality care for these individuals has led to new and innovative ways to help staff learn how to provide the care needed by these persons. In order for these persons to receive the care they need, the caregivers and families need to learn how to become advocates. This will be essential if there is to be any change in policy or law dealing with Dementia. “Caregiver advocates must lead the fight for policy changes that expand in-home and community based options for adult day programs; protect access to quality intermediate care options for those who need it; and provide some type of compensation or credit for the effective training of direct care staff in all settings.” (Riggs 2003-2004)

One of the most difficult areas to make sense of when dealing with this population is getting an accurate diagnosis of dementia. “ It is difficult to distinguish between cognitive deterioration and the various degrees of pre-existing intellectual disability. “ (D.Kay,2003) “ The current neuropsychological batteries are unsuitable for testing up to one-third of people with DS because the difficulty in assessment of those with profound ID. (Haxby 1989; Crayton et al. 1998; Hon et al. 1999) The Prudhoe Cognitive Function Test (PCFT), provides a reliable quantitative measure of cognitive function in individuals

with Down syndrome. This testing instrument is used to develop a baseline of intellectual functioning in individuals. Using a behavioral scale could help determine whether any skills in everyday activities might be a more sensitive indicator of the onset of dementia than the direct measurement of cognitive change. Observing a client in their daily living and self help skills, is a much easier way to begin to chart the declines seen in an individual who is on a dementia watch list. This information comes almost exclusively from the persons who care for these individuals. Thus most of the scales used to help with the diagnosis of Dementia are completed by the people who provide the care for dementia patients.

Many individuals with a diagnosis of Down syndrome reside in either an ICF/MR facility or a group home operated by the facility. This living arrangement is great for the individuals as it allows them to be in the community where they work, participate in activities and develop relationships with others. The difficulty arises when signs of dementia begin to come to the fore front. “ This is particularly true for younger age adults with intellectual disabilities where they are able to age in place. Aging in place is defined as remaining in the same residence where one has spent his or her earlier years.” (Cohen & Day,1993) “Group homes, typically community homes with a small number of residents, have been identified as an alternative housing option for all people with dementia, but many are not equipped to maintain an individual in the later stages of the disease” (Coons & Mace, 1996).

Quality of life is another issue that must be considered with individuals with a diagnosis of Down syndrome. A decision has to be made by the staff and guardians about what living situation is best for the quality of life of someone with dementia. Tough decisions must be made due to the medical complications that often accompany a diagnosis of dementia. Most community and group homes are not equipped to deal with the numerous medical issues that arise. Staff training and education are essential factors in contributing to the quality of life for individuals with dementia. “There is a need to support caregivers in coping with cognitive and behavioral change associated with dementia and Down syndrome. If interventions are to be implemented they need to be put in place via caregivers as the knowledge and skills of the caregiver are essential to ensuring good quality of life and care for the person with intellectual disabilities and dementia (Wilkinson et al. 2005). Interventions in the form of training are likely to be helpful in supporting caregivers and improving the life experiences of the individuals for whom they care.” (S. Kalsy*, R. Heath*, D. Adams & C. Oliver p. 65)

Along with quality of life issues, there are also issues of providing active treatment to individuals with dementia who live in ICF/MR community homes. Active treatment is a process of offering continual learning opportunities to promote development of new skills. This is difficult if not impossible with individuals with dementia. “Included in this conflict with the philosophy of care management, there may also be difficulties with compliance of mandated documentation of services such as the writing of goals and objectives for the person’s individual support or service plan. A possible approach is to use the principle of habilitation. This is described as an approach that is based upon maintenance of skills and enhancement of well-being by creating a positive environment

through the promotion of personal worth, basic trust and security in the environment and others.” (Koenig-Coste & Raia, 1996).

One method that will help staff program for persons with dementia is using person centered planning. Person centered planning allows staff to program based on each individual they serve. It allows for personalization of the program. Things that are important to that individual are given the most emphasis in the programming. “Person-centered planning is a process of discovery, a way of supporting a person and his or her family to identify what is important to them in their lives while identifying what is necessary to achieve it (Mount and Zwernick 2000, Department of Health (DH) 2001, O'Brien and O'Brien 2001, National Disability Authority 2005, Kilbane and McLean 2008).” Using person centered planning allows the staff, family, and the individual to establish a plan that will address all of the issues that are important. A person with the diagnosis of dementia, this can include things that are familiar and provide emotional stability for them. Attention can be given to things such as fingernail polish, favorite television shows, particular clothing, etc. that contributes to the feeling of familiarity needed.

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