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Encouraging Quality of Life for Aging Persons who have Developmental Disabilities

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Abstract

Studies indicate that people with developmental disabilities are aging at a similar rate to the mainstream. This has occurred from the time of deinstitutionalisation and the move into community based living. Community based programs and services have encouraged quality of life outcomes that address the need for improved medical, physical, and nutritional care. These factors have contributed to addressing psychological, social and spiritual needs, as well as generating opportunities for education and employment. This article discusses encouraging quality of life outcomes for those who are aging with developmental disabilities, and how social educators and caregivers need to attend to training programs that address the dual concerns of aging and disability services. This article gives an overview of the historical background of these issues and highlights the health concerns for those who are aging with developmental disabilities. [135 words]

Keywords: quality of life, aging, age, developmental disabilities, social educator, Caregivers, duty of care, person centred.

Introduction

First of all I would like to thank you for inviting me to partake in presenting a paper on aging persons who have developmental disabilities. I would like to acknowledge my ancestral Australian Aboriginal Culture and acknowledge the traditional custodians of this land Canada.

This article focuses on the issues related to encouraging quality of life for aging persons who have developmental disabilities. Griswold and Goldstein (1999) defined developmental disabilities as conditions which have occurred before age twenty-two that cause impairments in the following areas: independent living skills, self-care and receptive and expressive language. Overeynder (2004, p.1) also refers to a developmental disability which 'interferes with functioning in several life areas, such as learning, mobility, speech, caring for oneself, making life decisions and earning an income. The impairment should first occur prior to age 22.'

Since the change from large, overcrowded, understaffed, and under-funded institutions to community based living services for those with developmental disabilities, the main focus has been encouraging quality of life outcomes for these individuals and giving them the same rights and responsibilities as their able-bodied counterparts while still having supportive service provisions.

In view of the fact that these community based service providers in the past thirty years have developed services and programs which encourage quality of life outcomes through better medical technology, social services, physical activities, nutritional wellbeing, personal spiritual and educational endeavours, people with developmental disabilities are living longer.

This article focuses on encouraging quality of life outcomes for this client group and how organisations that care for these individuals are dealing with and meeting the needs of this aging population.

Historical Background

Prior to the middle of the 20th-century, people who had developmental disabilities were placed into institutions which were over-crowded, under-staffed, and under-funded (Overeynder, 2004). Since community based living programs and services came into existence and following the deinstitutionalisation of large service providers, programs and support systems have focused on giving people who have developmental disabilities the same quality of life opportunities as able bodied people. In the past thirty years community based living programs and services have had to become more innovative and resourceful as the population of people within these community-based organizations is aging. This is due to having improved medical treatments, better nutritional care, employment and educational opportunities, being in caring supportive relationships, living in their own home, supporting their spiritual and religious development, maintaining physical health through sports, recreation, rehabilitation and programs. Griswold and Goldstein (1999) also claim that people with developmental disabilities are living longer due to improved medical, health care and living conditions, which have contributed, to increased life expectancy.

In a US government study, it is claimed that people who have developmental disabilities are living longer due to better holistic care and lifestyle choices, for example, women without a developmental disability live to around 79, men to around 73, and the average

age for women who have a developmental disability to around 67 and for men to around 63 (Brown, 1999). Karp (1999) however suggests that survival statistics are now better than they used to be for those who have developmental disabilities, but in the 1940's people with a disability had a life expectancy of twenty plus and in the 1960s this improved to 30 years plus. Researchers believe that the survival rate for those with developmental disabilities will improve in the twenty first century due to medical advances and enhanced quality of life.

Social Educators, Caregivers, Programs and Services

Community based living programs and services provide assistance to people who have developmental disabilities by employing social educators and caregivers who provide ongoing support for quality of life outcomes. Social Educators and Caregivers are being assisted and educated through training programs to be aware of the impacts of aging for these people. Challenge Armidale (Australia) states in their employee handbook, that disability services are changing across Australia and staff within these organisations will need to gain nationally accredited certificates of competency. This is being achieved through nation wide service providers, such as, Directions Australia and Equalis, a team of Psychologists that ensures training and best practice standards and duty of care requirements are addressed. This training is an ongoing component of employment within these organisations, addressing issues, such as best possible medical treatments, physical care, daily living, functional problems in dressing, toileting and mobility. Other issues will be instrumental, such as change to their shopping, money management, transportation, working and recreation (Karp 1999). Social Educators and Caregivers will need to attend dual educational programs on developmental disabilities and aging. Griswold and Goldstein (1999) also support that there is an increasing awareness of the need for multidisciplinary approaches, improved training of professionals, and development of relevant models of care.

These community based living programs are now presenting special challenges as well as special opportunities for the organisations , which support people with developmental disabilities, the social educators and Caregivers as well as for these older persons themselves. Organisations, which provide generic services for the elderly, have had to adapt to this 'new' population of people living longer, by retraining its workers and designing innovative programs that promote integration between service providers for people who have developmental disabilities (Overeynder, 2004).

Studies also note that people with developmental disabilities have coexisting issues, such as language difficulties, impairment in mobility, hearing or visual losses which degenerate with age. These losses affect the person's communication skills. This in turn may isolate and alienate the person from the social educator and carer. The aging person with a developmental disability and significant behavioural disorders feels a progressive loss of control over the environment so that challenging behaviours will become evident (Griswold and Goldstein, 1999). Social educators and caregivers need to be aware of effective communication skills if they are to address quality of life issues and needs of the person who has a developmental disability.

Challenge Armidale employs a speech pathologist that supports people who have receptive language difficulties, expressive language difficulties, physical difficulties, and social language difficulties. These can be addressed through programs, such as, Augmentative and Alternative Communication (AAC) strategies, which support and enhance the communication of people who have limited oral language skills. People who use AAC systems are non-verbal, partially verbal, visual and hearing impaired, have learning disabilities, and intellectual disabilities. Unaided AAC systems are body, facial, eye-gaze movements, vocalisations, and challenging behaviours. AAC systems can be symbolic, for example, gestures, speech, and the use of signs. Aided AAC systems use objects, pictures, photographs, Braille, written words (Challenge Armidale). Augmentative and Alternative Communication is a form of therapeutic relationship between the social educator, caregivers, and the aging person who has a developmental disability. Carl Rogers (in Corey, 2001, p170) supports that people ‘are capable of self-directed growth if they are involved in a specific kind of therapeutic relationship’ such as what occurs in Augmentative and Alternative programs. Rogers also emphasized the attitudes and personal characteristics of the therapist (social educator/carer) and the quality of the client/therapist relationship as the prime determinants of the outcome of therapeutic process. The writer believes that social educators and caregivers not only need to address the issues of aging, but also address their own attitudes, values, beliefs and personal characteristics towards the person who has developmental disabilities, otherwise social educators and caregivers are not addressing quality of life and meeting their responsibility to duty of care. The author agrees with Overeynder’s (2004, p2) statement that people with developmental disabilities who are also aging ‘…have the same rights and responsibilities as all citizens while still needing supportive services.’

Health Concerns for those who are aging with developmental disabilities

Studies show that people with developmental disabilities die from causes similar to those found in the general population. Overeynder (2004) states that studies have shown that cardiovascular disease, respiratory disease and cancer are contributing factors to dying. She also states that people who have mobility impairments, mental health conditions, the original disability, and the implications of medications, which have been started in early childhood, might have serious adverse effects after prolonged use. She states that people who have developmental disabilities are more prone to greater risks of developing chronic diseases.

Suggested ideas

Different client groups such as those who have developmental disabilities and who are aging will have different cultural factors which influence their values, attitudes, beliefs and the way in which they communicate their physical and spiritual needs. These factors contribute to their coping mechanisms, meaning and development of life in their communities. It is important for the social educator and caregiver to see what this minority group has experienced in relationship to that of the dominant culture.

What interaction has happened to encourage quality of life between these two social groups? Vanier (1999, p.3) encourages a sense of community remains between these two social groups as part of L’Arche ethos ‘communities where people with intellectual disabilities and those without a disability come together to share their lives. These communities are places where each person's particular gifts can be revealed and honoured….' The author believes that through Augmentative and Alterative Communication that emotional, intellectual and spiritual quality of life can be addressed more clearly and people who have developmental disabilities will have the opportunities to communicate their needs. These needs are met through different forms of literacy and being literate helps a person to move more freely and be more successful in their emotional, intellectual and spiritual life.

Social educators and Caregivers need to become familiar with the experiences of those who have developmental disabilities; by learning their language. It is about bringing their experiences, understandings, knowledge and skills into a context where they can be understood and experience their intellectual, emotional, and spiritual life forces, rather than just their external physical needs. This will enhance quality of life outcomes.

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