



Alberta Disabilities Forum

"A United Voice"

Home Care and Long-term Disabilities

Issue Home Care services do not adequately address the needs of persons with long-term* disabilities.

ADF's Position The unique circumstances of persons with long-term disabilities and their families need to be recognized and addressed by the Home Care system.

Background The ADF Health Working Group's focus group raised the issue of inadequate support for individuals with long-term disabilities in the Home Care system. Currently, clients with chronic, long-term needs receive Home Care under the same auspices as clients with short-term, acute-care needs. While ADF recognizes the advantages to this system, which limits the risk of duplicating services, focus group participants cited instances in which the needs of persons with long-term disabilities had been neglected.

"People with long-term disabilities need to feel secure in knowing that support is available on a permanent basis, as it is unlikely our needs will diminish."

*Margaret McCabe,
Focus Group participant*

As members of the disabilities community, the focus group felt that having Home Care funding for both short- and long-term disabilities housed within the same system presented certain risks. In this system, the needs of clients with long-term disabilities might be sacrificed for the more immediate, acute needs of clients with short-term disabilities. Formerly, many clients with short-term disabilities were cared for in hospital settings. However, the movement toward earlier discharge from hospitals has led to an increase in the number of clients with short-term disabilities receiving Home Care. In order to address the demands created by the increase in short-term clients, some Regional Health Authorities have had to reconsider their budgets and prioritize services for clients with long-term needs. For example, in some regions home making services, such as meal preparation and light housekeeping, are only available if personal care is also needed, while maintenance support, such as bathing and getting dressed, has been greatly reduced. While we recognize the importance of short-term, acute-care needs, we also feel the health and wellness of Home Care clients with long-term needs should not be compromised.

As well, long-term disability needs differ greatly from short-term needs, and these differences have to be reflected in the care the clients receive. For example, because long-term care focuses primarily on maintenance needs (e.g. maintenance of bladder and bowel, range of motion, hygiene, and nutrition), support workers must apply their skills differently than if they were addressing short-term needs. The

Home Care provider who works with persons with long-term disabilities develops an on-going relationship with the client that needs to be holistic in its approach, constantly considering issues regarding boundaries, privacy, lifestyle and consistency. The relationship between support care workers and clients also differs in a long-term situation because the clients, unlike persons with short-term needs, have lived with their disabilities for a long time, and as a result, are often more familiar with their situations than their caregivers. The Home Care providers needs to respect this knowledge, seeing the clients as the “experts” in their situations and collaborating with them to achieve the best care possible.

Identifying and addressing the unique needs of persons with long-term disabilities promotes independence, empowering clients to achieve their fullest potential. Few options exist for persons with chronic, long-term needs whose conditions are not met by the Home Care system. As the Canadian Paraplegic Association (Alberta) states in its 1998 position paper on Home Care for people with long-term needs, when consumers do not receive the “quality and quantity of care they require, institutionalization and family burn-out” result (p. 3). Those who turn to long-term, care facilities become part of a costly alternative that does not offer the quality of life a client finds at home.

*For the purposes of this paper, long-term disabilities are those that are a year or more in duration.

Recommendations

To resolve the issues outlined in this paper, we believe the government of Alberta, through the Regional Health Authorities and in consultation with consumers and stakeholder groups, needs to:

1. Allocate adequate funding, designated specifically for Home Care services, to ensure that the needs of clients with long-term and/or short-term disabilities are met.
2. Ensure Home Care Support Worker training addresses the unique needs of clients with short- and long-term disabilities in both home-based and facility settings.
3. Consult with persons with long-term disabilities in developing policy and guidelines that acknowledge and address their distinct needs. (e.g. 24-hour continuum-of-care model, assessment criteria, preventative care, budget distribution, etc.)

4. Support the rights of individuals with long-term disabilities by assisting them in their decisions to live where they choose, whether this is in their own home, an assisted-living situation, or a long-term, care facility.
5. Develop strategies to improve the recruitment, training, and retention of Home Care Support Workers.

Work Cited

Canadian Paraplegic Association (Alberta) (1998). "Home care for people with long term care needs vs. people with short term care needs". Unpublished. Available at CPA Alberta.