

## **Executive Summary – Housing and Attendant Services: Cornerstones of Community Reintegration after SCI**

Individuals go through a demanding functional rehabilitation process following a spinal cord injury (SCI). Having a SCI involves taking into account important issues (e.g., financial support, insurance, technological devices or equipment, etc.) when planning for discharge home. Appropriate housing and attendant care are cornerstones of successful community reintegration. In cases where individuals are more vulnerable, the quality of these resources, especially in terms of functionality and availability, can make the difference between whether an individual can live independently or not. This is particularly true for people with spinal cord injury who tend to use more services (particularly related to housing) than people with other disabilities such as TBI or Stroke.<sup>1</sup>

### **Housing after SCI**

Housing is a fundamental need for all people. Finding appropriate living arrangements within the community can be difficult for many people with SCI after they are discharged from rehabilitation.

Multiple studies have researched barriers to securing appropriate housing for people with SCI. Two systematic reviews<sup>2,3</sup> identified inaccessibility of housing, transportation and of other natural and built environments as impeding participation and community reintegration in people with SCI.

The choice of residence is limited by many factors and the limitations are magnified as the severity of disability increases. A low FIM score appears to increase the risk to move to a nursing home amongst people with SCI after rehabilitation discharge.<sup>4</sup> The number of functional limitations was significantly associated with autonomy indoors and outdoors. This implies that the greater number of functional limitations, the greater the restriction in autonomy indoors and outdoors.<sup>5</sup>

Barriers for community reintegration also include lack of social support from family and friends, inaccessibility of housing and transportation, feelings of isolation or decreased sense of belonging, not being psychologically prepared for returning home, and lack of personal control over the environment.<sup>3</sup> Anzai et al.<sup>6</sup> found through multivariate analysis 4 factors that were significantly related to location of discharge (i.e., to an extended care unit or to a house/apartment): insurance; private funding for equipment; age; pre injury living situation.<sup>6</sup>

The research also looked at facilitators to positive housing outcomes in people with SCI. In a systematic review, Dwyer and Mulligan<sup>3</sup> found that the accessibility of the environment (i.e., housing, community, transport, health professionals, and assistive devices), re-establishing self, support and connections were strong facilitators for community reintegration. In another systematic review, authors found amongst facilitators having adequate personal care assistance, having appropriate social support, having adequate specialized equipment and appropriate occupational therapy input.<sup>2</sup>

Freedom of choice related to selecting where people with SCI will live is a feature of life satisfaction for many. Those discharged home tended to have a significant improvement in their FIM score from the onset of rehabilitation to discharge.<sup>4</sup> Boschen (1988)<sup>7</sup> found that having one's own apartment was preferred by people with SCI and their choice was determined by the quality of the environment, particularly in terms of accessibility. Living in an environment considered to be minimally restrictive which enables active participation in daily decisions

according to the principles of independent living is more likely to contribute to improved quality of life.<sup>8</sup>

### **Attendant Care Services after SCI**

Attendant care services are a set of resources designed to provide a person with SCI with support so they can engage in the important activities of daily living. This support is usually put into place after discharge from rehabilitation when the individual returns to his/her community. Several important decisions are required when considering attendant care services, such as who will provide the support, how it will work, and who will pay for it. At the same time, the relationship between rehabilitation services and community resources must also be considered in the context of the built environment to ensure the best opportunities for independent living among people with SCI. For example, the quality of housing adaptations can influence how the attendant care services will be provided in terms of the intensity and frequency of care.

We found intervention research testing the effects of attendant care - participants received either 8 in-home visits with an occupational therapist or 8 social visitors over a 6-month period.<sup>9</sup> The client-centred visits by an OT increase the number of life roles performed and improve life satisfaction, but there were no significant difference between groups in FIM or CHART scores.

Other research (one prospective controlled trial, and two pre-post studies) found that skills training can improve knowledge in people with SCI and their attendants up to six months post-training<sup>10</sup> and that common but damaging health conditions like Urinary tract infections can be reduced or prevented by a simple educational intervention delivered by a clinical nurse.<sup>11</sup>

In observational studies, we found that generally people with SCI are satisfied with informal attendant services, though there were substantial unmet needs, including support for activities of daily living and housekeeping.<sup>12,13</sup> Personal attendant turnover is associated with people with higher injury levels and increased need for assistance in exercise and transfers.<sup>14</sup> The most significant predictors of personal care assistance use are motor function, days spent in rehabilitation, and length of stay in a nursing home.<sup>15</sup> When caregivers are informal (i.e., non-professional) they tend to be female spouses of men with SCI, and that the caregiver burden can be overwhelming, particularly as number of hours per day and age of caregiver increase.<sup>16,17,18,19</sup>

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