Research Paper

Enablement and Community Integration of People with Acquired Brain Injury from a Social Work Perspective

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ABSTRACT : *Community integration for people with brain injury refers to returning to the mainstream of family and community life. Independence and enablement are closely linked to the experience of empowerment for people with brain injury. Community integration following brain injury includes satisfaction, emotional and behavioural difficulties and adjustments and cognitive problems. Community-based approaches to brain injury will have to be flexible to meet the individuals' needs. Health and social care professionals must be aware of issues affecting the individuals with brain injury to adapt to the changes in their lives.*

KEYWORDS *Community integration, brain Injury, disability, empowerment, adaptation and adjustment to disability*

I. INTRODUCTION

Since the early 1980s, the social and political imperative to close institutions has resulted in a focus on community integration and participation. Despite considerable attention to community integration and related topics such as social adjustment, community participation and quality of life, health and social care professionals needed to understand what community integration meant [1]. While much of the early research in this area involves people with mental illness, learning disabilities and developmental disabilities [2], community integration is an issue for all people with disabilities including people with brain injury.

In the context of community integration for people with brain injury, it all refers to returning to the mainstream of family and community life following an acquired brain injury. Other terms and phrases for the same phenomenon include and related to independent living, normalisation, deinstitionalisation, mainstreaming, social model of disability and empowerment [3] These are defined as

- activities, including daily living activities (ADLs),
- hobbies and productive activity in work,
- educational activity,
- relationships with partners, family, friends, work, wider community and social roles in relationship between the individuals and others,
- physical independence, community mobility and economic independence.

There are two frameworks that have led to the development of instruments for measuring community integration. The first model is the WHO classification system International Classification of Functioning and Disability -ICIDH [4] The second was developed to conceptualize the experience of individuals with brain injury in relation to community integration. Some researchers discussed community integration literature based on the structure of outcome measures [5]. Others stated that community integration could be classified based on perspectives with differing issues for individuals, families and professionals [6]. In addition, others developed conceptual models consistent with the perspective of individuals with brain injury to describe the main constructs of community integration [1]. In addition, much of the original research on brain injury examined issues like location of lesion, amount of amnesia and intracranial pressure. These are all associated with body structures and functions. At the activity level, issues like mobility, bathing, getting dressed and undressing, eating and drinking are included in the ICIDH system. One of the most often reported outcomes is the Functional Independence Measure (FIM) that focuses on basic activity of daily living. The question can be raised, how do these ICIDH areas relate to or fit with community integration? Equally, where does community

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integration fit within the ICIDH framework? The answer is that community integration is a participation indicator that includes body functions and activities. Moreover, community integration is the bridge between body structure, function, activities and external and internal factors of the environment as well as dealing with the social barriers that disabled people are faced with. For example the issues surrounding social support and general conformity to societal norms are both linked to the contextual factors of ICIDH and conceptual definition of community integration. A revision of this terminology took place in the mid-1990s with the new classification reflecting a change of emphasis to more neutral descriptions of body structure and function (impairment), activity (disability) and participation (handicap). The most recent terminology, WHO in the International Classification of Functioning and Disability (ICIDH-2) classified level of functioning for the whole person as an activity. [7] identified this as a positive change in terminology from disability to activity that removed the negative connotations of the term disability and placed functional status under the dimension of activity. Since an individual's functioning and disability occurs in a context, measuring how the individual with brain injury integrates into the community should include a list of social factors. Community integration has been conceptualized as the opposite of handicap, where handicap has been defined as the social disadvantage resulting from disability or impairment [4]. Therefore, community integration should be the ultimate goal of rehabilitation and return to productive activity following a brain injury [8]. Recent revision of the concept of handicap has led to the more universal notion of participation as a possibility of community integration. Participation underlines several dimensions such as personal maintenance, mobility, exchange of information, social relationships, home life and assistance to civic life [9]. However, WHO's definition does not include the engagement and abilities of the individual's in social settings and equal access to community resources, and social and economic opportunities that are accorded to other members of society. The researcher defines community integration as parity between individuals with brain injury and their non-disabled neighbors as equal members of society. Furthermore, an integrated community is envisaged as an inclusive and accepting community characterized by the non-discriminatory treatment of individuals with brain injury and others marginalized populations.

The theoretical model of community integration provides a means of understanding and organizing significant issues identified in the literature on community integration following brain injury. In an attempt to articulate an inclusive understanding of community integration, researchers have identified services users' and carers perspectives in defining the term [1] [10]. A theoretical model has been developed by [11] that includes the areas of general integration, support, occupation, and independent living. General integration refers to an individual's acceptance, conformity and orientations to their community. Support is defined as both the close and diffuse relationships that make up their social system. Occupation refers to someone's productive work and leisure activities. Lastly independent living means the individual's personal independence and satisfaction with their living arrangements. This means providing support to help people stay in their own homes to prevent any unnecessary hospital or residential care admissions, adapting their homes to make life easier and giving people power of choice and control over their own lives. The degree of independence permitted by one's living arrangement seems to be an important indicator of community integration. [2] studied integration among former mental health service users and discovered that those living in smaller residential facilities coped better than those who live in larger ones. However, community living alternatives such as residential and nursing homes can offer environments that are just as restricting as institutions. These institutions may reduce or diminish the capacity of the residents to be more autonomous and self-directed.

II.   DEFINITION OF COMMUNITY INTEGRATION

Community integration is an indication of an individual's adaptive capabilities and is a multi-dimensional construct that captures a person's individualized life experience [6] Community integration is an issue for all people with disabilities including adults with brain injury and it has been identified as the ultimate goal of rehabilitation and recovery [11] [12] [13]. However, the literature of the past few decades offers little in the way of a consensual definition of community integration. Most of the definitions have some elements in common that integration involves relationships with others, independence in one's living situation and activities to fill one's life. The social model of disability implies social inclusion for people with disabilities. This includes community integration and participation in valued social roles. Many researchers recognised that community based rehabilitation for brain injury is essential and will secure positive outcomes [14] [15].

[16] explored cognitive problems after brain injury impinged on everyday activities following a discharge from hospital or rehabilitation units. Brewin and Lewis's study found that brain injury caused respondent to become fatigued at work because of the effort of concentrating which led to adjustment difficulties to carry on with their jobs. Communication was also affected as respondents experienced difficulties in understanding, remembering and concentrating on language that inhibited them from engaging in social activities as well as restricting their abilities to make decisions.

[14] pointed out that community-based approaches to brain injury will have to be flexible and based on local needs and geographical aspects. [8] acknowledged this and developed a 'Whatever it takes' model for community-based services. This model concentrates on empowering the individual through maximising self-determination. Ten core principles are described that include: recognising the need for organising services around the individual, teaching skills in the environment in which they are applied, manipulating the environment to assist with community integration, focusing upon life roles, facilitating continuous support networks, working to prevent the individual from becoming fragmentised by service provision, promoting informed choice, respect and rights for the individuals with brain injury.

The social work profession is interested in facilitating the best fit between the changes from hospital to the individuals environment with the assistance of other professionals i.e. Occupational Therapists, Psychotherapists, Speech and language Therapists, Care Support Workers, District Nurses. All these professionals work within the framework of assisting the individuals with brain injury to adapt to the changes in their lives. It is import for the health and social care professionals to use an assessment tool to measure. There is no agreed and widely used assessment to measure the level of integration. The Community Integration Questions (CIQ) is the most widely used assessment of Community Integration in the United States of America. This was designed by [17] to assess the social role limitations and community integration of people with brain injury. Since its development, the CIQ has become one of the most popular and widely used measures of community integration for people with brain injury in USA and Canada. The CIQ is a 15 item instrument divided into three aspects of community integration: home, social and productivity. The Community Integration Questionnaire has been conceptualized as the converse of handicap in the WHO (1999), which is impairment, disability, and handicap. Higher scores indicate greater integration into community. The questionnaire about community integration has been utilized to assess individuals in the model system for brain injury. Scores are based on the type of activity, how often the activity occurs and whether the activity is performed alone. Community Integration with the CIQ was viewed as the opposite to handicap [5] [6]. Individual issues related to community integration following brain injury include satisfaction, emotional and behavioral difficulties and cognitive problems. The term 'satisfaction with brain injury literature' is mentioned in many forms which presents a difficulty when defining the construct. Some of the most common terms in the brain injury literature refer to general health status and quality of life [18] [19]. General health status refers to the combination of physical, social and emotional status. Quality of life denotes the perceived adequacy of the environment and positive feelings towards situations, some of the terms are 'life satisfaction', 'morale', 'happiness' and 'well-being' [20]. Regardless of many definitions, quality of life is often described as an individual's appraisal between his/her current situation and a perceived standard. Researchers agree that quality of life has a cognitive and emotional component [21]. The term quality of life links with the concepts of life satisfaction while the emotional component is referred to as positive or negative effects. With quality of life and life satisfaction, the individual is deemed to evaluate his/her surroundings from an internal and external focus [20]. During this assessment the person compares his/her situation to external standards and internal aspiration. It can be assumed that both quality of life and life satisfaction are viewed as personal and reflective.

III.   COMMUNITY INTEGRATION AND EMPOWERMENT

Independence and enablement are closely linked to the experience of empowerment. Feelings of independence and successful recovery have been found to promote empowerment in people with physical disabilities [22]. Empowerment is central to the process of community integration and inclusion [23]. Within the community integration literature, the concept of empowerment has received considerable attention. A variety of empowerment theories exist, each conceptualizing empowerment in slightly different ways. For example, a number of empowerment theories suggest that gaining power over social and political resources is an important aspect of empowerment [24][25]. According to [25], empowerment "conveys both a psychological sense of

personal control or influence and a concern with actual social influence, political power and legal rights" (p. 121). As well, [26] view citizen participation as a key contributor to empowerment, whereby individuals who exhibit a greater amount of citizen participation also experience greater levels of empowerment. Other empowerment theories have less of a political emphasis and focus on the concepts of choice and control, viewing empowerment on more of a personal level. Empowerment has been defined as "opportunities for, and conditions that, promote choice and control, community integration, as well as valued resources" [27p. 127]. [28] describe empowerment as a process in which individuals move from being dependent and powerless to having control over their own affairs. Key elements in the empowerment process are the notions of choice and control, as well as the importance of individuals' perceptions of the distribution of power in their communities. For adults with brain injury who participated in this study, empowerment had little relation to political influence or citizen participation. Empowerment means having control over decisions that affected service user's daily lives. Most likely, these service users equated empowerment with being healthy and independent and with the ability to maintain what they perceived as an acceptable quality of life. This notion fell more in line with [29] definition of empowerment as a process whereby "individuals achieve increasing control of various aspects of their lives and participate in community life with dignity" (p. 7). Being independent is associated with feeling in control and exercising choice, even when service users relied on their families or carers for support. Needing support from others does not mean that they were dependent or less empowered. Empowerment is a process which can have a powerful impact on individuals with brain injury and the challenge of community integration. Empowerment has been associated with increased self-confidence and self-esteem, enhanced formal and informal supports, as well as stronger feelings of control and independence [27]. Empowerment is directly relevant to staying healthy and being independent in the community that has strong links to integration and participation. The concept of inclusion plays a central role in community integration for all service users. Social inclusion involves not only the achievement of rights and power within the community, but more importantly the full participation in families, communities, and society. Individuals with brain injury must have control over their decisions related to community involvement as well as the care and support that they receive in the community. The statutory bodies must ensure that they are not simply promoting institutionalization within the community by providing services over which these individuals have little control or decision-making ability. Inclusion relies strongly on the principle of empowerment and community [23], whereby individuals gain control and become empowered to participate fully in their communities.

Attempts have been made to understand the terms adaptation, adjustment, acceptance and coping that are often used to address the concept of adjustment to disability [30] [31]. This has resulted in theories, models and approaches being applied to psychosocial treatments and interventions to assist the individual and family in managing the change process following a sudden alteration in health status [32]. [33] addressed this in terms of reflecting on the interaction between a person's value system, level of emotional maturity and acceptance of self and his/her health status. Furthermore, there are factors determining the theory of adjustment to disability i.e. how the individual interacts with others, group identification influencing the liking of others, the reaction to loss and premorbid personality. This multifaceted perspective includes a range of psychological and sociological aspects that has theoretical similarities in emotional reaction to death and dying [34]. This means disability being viewed as a form of loss for which a grieving response process occurred [35]. The response to illness, injury or loss includes outcry, denial, intrusion, working through and completion or getting on with life. [36] reformulated the concept of adjustment and [37] suggested the use of different types of coping skills. This means more active social roles for the individual as opposed to the passive emotional response in the stage models of adjustment. These models are often related to as stage models or mental health models. The empirical basis for such models has been questioned by [30]. [38] developed a coping process model in relation to brain injury and quality of life outcomes. This model acknowledges the interaction between cognitive deficits and cognitive beliefs and individual and family life-cycle factors. As the severity of the damage increases, it is thought that the capacity for self-awareness decreases [39]. Other factors influencing the adjustment process are education, social network, cultural, financial and vocational factors, stigma, barriers and resources. Coping style and individual's cognitive belief system and control to the coping models which influence the individual's behavior in response to the illness and determine the extent to which the individual adapts. In contrast to these social and psychological perspectives [30] referred the adjustment of disability to a social model of disability.

This theory suggested that definitions of disability are relative rather than absolute and the concept of disability can be viewed as a social construction. This perspective suggests that the role of ideology is seen as an important factor in shaping individual and social meanings. This contrasts with the medical model of disability where disability is equated with illness, personal tragedy, with specialist health intervention as provided in dedicated settings. It is described that the able body attitudes, policies, practices and procedures dominant in health, social and educational services create more barriers. As [40] describes this able bodied prejudices as the service user falls victim to premorbid value system. This leads to emotional reaction of anger and sadness, loss of confidence and anxiety as being increased by social factors including environmental barriers and the emotional reactions to others [31 p295]. In addition to these feelings, dependency, unemployment, segregation and relative poverty can be identified. [41] states that disabled people may suffer from the product of being discriminated against and being made to feel inadequate, disillusioned and unable to do anything about it.

IV. SOCIAL BARRIERS TO COMMUNITY INTEGRATION

Gender, race/ethnicity, culture, religion, income, employment status, housing, transport, disability prior to brain injury may influence and determine the level of community integration. There is not much literature to make a strong link between these variables and the level of community integration. There are also misconceptions about the individuals with brain injury. People with brain injury may have no physical disabilities and they were often referred to as the "walking wounded". This raises concerns for the "walking wounded" who are at a disadvantage in comparison to a person with brain injury with a physical disability, because their problems are not visible and do not show any external signs to indicate their injury. There is also a potential pressure on the individual to perform to standards that they cannot realistically achieve. Others frequently misidentify the appearance or behavior of individuals with brain injury as being indicative of a mental health problem or a learning disability. However, misidentification of the condition is understandable for a number of reasons; firstly it is difficult to determine the cause of a person's disabilities in the absence of background knowledge of the person and their circumstances. In addition, their behaviour may bear similarities to that of a mentally ill person or somebody with learning disabilities. Secondly, a member of the general public may interpret the actions of a brain injured person as indicating the presence of a disability which is more salient to them then brain injury. Therefore, brain injury may continue to be wrongly identified until it is as salient in the public mind as are issues of learning disability and mental health. Finally this is not to say that there are not misconceptions in the mind of the general public about the latter conditions also.

In literature, women's experience of brain injury is often ignored because of the greater numbers of males with brain injury. If the male to female ratio is 2:1 and 1 million are affected per annum [42] then 330.000 women are affected per annum and this is not reflected in the literature. Furthermore, [43, p141] has reviewed the literature and the authors could not find a single subjective account from a female perspective. By using a qualitative research method, [43]'s study focused on six women with TBI who were interviewed about their experience and supports the idea that there is a series of phases to adaptation following brain injury. The study highlighted the importance of focusing on positives, looking to the future, social engagements and the ways of assisting the individuals with brain injury in the construction of a new self.

The income of disabled people is, on average, less than half that of non-disabled people, even after direct taxes and benefit payments have been accounted for. Disabled people still earn 30% less than non-disabled people [44]. At the same time, the experience of impairment and disabling barriers can mean that disabled people have increased costs compared with their non-disabled peers. Disabled people are more likely to live in poverty; 27% of individuals in households with one or more disabled adults of working age have incomes below 60% of median income, compared with 20% of individuals in households with no disabled [44]. Among workless households with children the majority have at least one disabled parent. Children are more likely to experience poverty if there are disabled adults in their family and levels of economic inactivity among disabled people vary depending on the severity of impairment [44].

For individuals with brain injury impairment in the areas of cognition, behavioral, interpersonal skills and physical abilities are the significant factors in successful return to employment. Most studies have revealed that cognitive and behavioral impairments have restricted successful return to work. However, there are studies that have focused on physical deficits which can also be significant barriers to employment [45]. With regard to behavior, interpersonal skills, impairments such as memory and executive function, impulsivity, disinhibiting

behavior and poor self-monitoring have been identified as significant barriers for successful return to work [46]. In addition, as contributory factors such as lack of motivation, initiation, decision making, perseverance, interest, flexibility and patience have been identified as the most common factors between those who return to work and those who do not [47]. Therefore it is possible to state that the more severe the brain injury the more unlikely that the individual will successfully return to work and remain employed.

V. CONCLUSION

Professionals need to have good interpersonal skills and clear and concise communication which requires flexibility in their application when meeting the wide and varied needs and presenting behaviours of brain injury survivors. Many brain injury survivors lack insight and awareness and will subsequently understate their needs, and there is a real requirement for knowledge and tenacity in gaining detailed information about eligible need to formulate an in-depth assessment.

Professionals need to be equipped with skills in managing difficult behaviour including understanding its origins, responding appropriately and being assertive and clear regarding boundaries with survivors who can exhibit disinhibited, impulsive behaviour. This also includes de-escalation some of the compulsive and difficult reactions often might be displayed by the survivors. Brain injury survivors will often have many agencies working alongside, including health, social care, housing, substance misuse and police, and the brain injury social worker needs to be able to co-ordinate these services in establishing a robust support network.

There needs to be recognition that working with brain injury survivors can be intense and time consuming, particularly working with those who are isolated, vulnerable and have co-morbidity issues, such as mental health, substance misuse, or a history of violence or risk taking. Lack of insight increases vulnerability levels as brain injury survivors will put themselves repeatedly at risk. The social worker is often the only support available and will need to be proactive to facilitate in accessing the appropriate services. Navigating and supporting brain injury survivors through the welfare rights system is challenging work as their disability can be largely hidden. Many brain injury survivors have difficulty in articulating the effects of their disability; they fail the employment and support allowance medical assessment and consequently get pushed back into the job market prematurely or inappropriately, causing anxiety, depression and anger. Without the support of a social worker many misrepresent or deny they have a disability due to poor awareness and insight problems. Others have reduced tolerance and refuse to fully co-operate, leading to benefit realignment or withdrawal. Returning to work can be challenging for brain injury survivors. Often the issue is not to do with physical disability as work environments can usually be adapted, but more to do with adjustments that will satisfy the effects of cognitive impairment and psychological need. Employers need to be supported in recognising the need for a structured and organised day, alternative training methods, consistent work space, need for memory prompts and clear boundaries regarding appropriate office behaviour.

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