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> Catastrophic Injuries and Quality of Life

WHEN WORKING WITH INDIVIDUALS who have sustained catastrophic injuries such as spinal cord injuries, severe traumatic brain injuries and multiple amputations, vocational rehabilitation efforts are often directed at Quality of Life (QOL). How though does one define quality of life? To what extent are (public and private) funding agencies responsible for funding quality of life expenditures? This paper will examine quality of life from both a vocational rehabilitation perspective, as well as raise issues from a public policy and funding agency perspective.

The World Health Organization (WHO) defines QOL as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment."

(WHOQOL, 1999)

In the field of vocational rehabilitation, the concept of QOL is a central tenet. George Nelson Wright in his definitive textbook on rehabilitation *Total Rehabilitation* wrote: "Rehabilitation is a facilitative process enabling a person with a handicap to attain

The concept of QOL is also embedded in public policy. Typically though, policy and regulations of public institutions do not refer directly to QOL. However, QOL is acknowledged in concepts such as promoting independence or overcoming effects of disability. For example, section 16 of the Worker's Compensation Act (of British Columbia) defines the purpose of vocational rehabilitation: "To aid in getting injured workers back to work or to assist in lessening or removing a resulting handicap..." Published regulations of the Insurance Corporation of British Columbia (ICBC) state that vocational rehabilitation expenditures can be made in order to: "...improve the post injury earning capacity and level of independence by the insured."

> The Need for Sense of Purpose

When working with workers with serious injuries or medical conditions, the primary goal of vocational rehabilitation is return to (paid) work. However, this goal is not always attainable due to the nature of the disability. In these cases, our responsibility does not end there though. Clients with severe injuries who are unable to work have a very large void in their lives to fill. A basic human need is to have a sense of purpose in life. Without a sense of purpose, workers can become depressed, develop feelings of low self-worth, or develop secondary psychosocial problems such as substance abuse, family breakdown, and social isolation.

"Love and work are the cornerstones of our humanness." SIGMUND FREUD

usefulness and satisfaction in life." He added: "Any kind of rewarding activity considered useful or satisfying - not merely paid employment - is the goal of rehabilitation." (Wright 1980, p. 3)

In some cases, helping the worker to pursue volunteer work or avocational pursuits is an appropriate form of vocational rehabilitation intervention. Depending on the extent of deficits, helping to obtain and maintain volunteer placements can

easily be as demanding as assisting one to obtain paid employment. Extensive efforts have to be made to ensure compatibility between the needs of the volunteer setting and the worker's abilities. As an example, a popular volunteer setting is delivering low cost meals to seniors (*i.e.* Meals On Wheels). This volunteer activity requires a volunteer who is capable of driving, locating homes on a map, is pleasant, and who is dependable and reliable. If a volunteer is unable to drive, gets confused or lost easily, is irritable, or unreliable, this would not be a suitable match. Often times, workers with brain injuries may require job coaching to teach the appropriate volunteer work skills. In some cases, they will require on-going monitoring and assistance in order to maintain the volunteer activities in the long term.

Volunteer placements need not be restricted to charitable and public institutions. Volunteer work placements can also be arranged in private business or industrial settings as well. Although some workers may not be competitively employable, they may still be productive in the workplace, and add value in a variety of work settings, provided that there are on-site supports. Supervision can often be provided by supervisory staff, co-workers, or in some cases by job coaches.

Not all injured workers with catastrophic injuries are suitable or interested in volunteer work activities. In these cases, vocational rehabilitation efforts should be directed at ensuring that their lives have purpose, structure, and meaningful activities. The services of occupational therapists, lifeskills workers, or recreation therapists are often useful in these cases.

> Promoting Independence

In many cases, not only are some severely injured clients unable to work, they are also have difficulty with self-care activities. Many are unable to independently participate in leisure and recreational activities that they used to enjoy. Some clients require ongoing rehabilitation services to maintain their lifestyle, and in some cases keep them out of institutional settings.

“Everyone has his own specific vocation or mission in life; everyone must carry out a concrete assignment that demands fulfillment.”

VIKTOR E. FRANKL

One of the issues facing funding bodies is determining the extent to which they are willing to fund QOL expenditures. It is now common practice for funding agencies to fund

home and vehicle modifications for wheelchair dependent clients. These QOL expenditures promote independence, and allow clients to live in their own homes and communities.

However, many sports and recreation activities are now catering to the needs of people with disabilities. Is it incumbent upon funding agencies to provide recreational equipment such as disabled skiing equipment and ski passes, racing wheelchairs, exercise equipment, accessible recreational vehicles, and home workshops, (just to name a few) to enable injured clients to maintain their pre-injury activities, as well as to develop and maintain avocational or replacement activities?

If so, to what extent, and for how long?

> Rehab Maintenance Programs

Following a severe injury, rehab services such as occupational therapy, speech therapy, and physiotherapy are often provided as treatment in the acute stages of the injury. Once all of the treatment goals have been met or at least endeavored, many individuals still require some form of maintenance program to maintain the daily living skill gains made to date, as well as their living situation. Sometimes, this intervention is necessary to keep the client out of institutional care.

As an example, a brain injured client with severe cognitive impairments who is unable to

initiate activities of daily living independently, and problem solve complex tasks, might require skilled assistance to assist in planning his weekly schedule, budgeting assistance, paying bills on time, meal planning, shopping, medication compliance, parenting, and other daily living occurrences that one normally takes for granted. This form of assistance though is really not treatment, nor is it home nursing care. Funding agencies are often reluctant to pay for services that do not fit well established evidence-based treatment criteria with well articulated goals, anticipated outcomes, and time frames.

If the alternative to such a maintenance program though is costly institutional care, the funding agency is more likely to take the pragmatic route and accept the need for such a service. However, in some cases, the cost of maintaining clients in their own home and community is far higher than institutional care. This type of example raises many issues, including ethical considerations. Should funding agencies pay to maintain clients in their own homes, when care can be provided in a facility for less expense? Should funding decisions be driven mainly by cost? Where do the client or family members enter into the picture as far as choices of the living situation? What if the client is a young adult or even an adolescent, and the available facilities are geared to geriatric populations? If so, where is the quality of life for the client? These types of cases force us to ask the question: What is the value that we place on quality of life?

In tort claims, the concept of "full compensation" is a well established principle that enables the injured party to be placed in a position where he or she would have been had the injury not occurred, regardless of cost. However, when rehabilitation and care funds are provided by agencies under Workers' Compensation legislation, government funded programs, or private insurance plans, full compensation is not the benchmark. Rather, entitlement decisions are made based on a set of policy criterion including cost considerations. However, many policies concerning QOL are not clearly defined, leaving interpretation of policy in the discretionary hands of decision makers.

> Conclusions

Quality of Life is a central, but often overlooked tenet in vocational rehabilitation. As such, the aim of vocational rehabilitation is not simply to assist with return to work, but also to help our clients achieve useful, satisfying, and productive lives. Nowhere does this apply more than working with clients who have sustained catastrophic injuries where oftentimes a return to paid employment is not possible. Efforts to assist with quality of life interventions can be time consuming and very costly. Although funding agencies and insurance schemes do acknowledge QOL in terms of catastrophic injuries, most funding agencies are grappling with the issue of the degree of coverage of QOL expenditures. The funding for QOL raises a number of troubling ethical issues that have no easy answers. <

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