

Broken Bodies and Intact Souls

by

Don McKenzie

CNZM, OBE, B.PHYSIOTHERAPY, DIP. MANIP. THERAPY, CERT. REHABILITATION

Editorial Note

This article is based on a keynote paper presented at the 1995 New Zealand Rehabilitation Association Conference, Massey University. This keynote paper was called ' **Stop The World I Want To Get On: Reflections on Science and Soul in Rehabilitation** '

However, this original article has been re-arranged and edited, and some new material added and is now called 'Broken Bodies and Intact Souls'. The email address for correspondence or requests for copies of the original paper is: d.mckenzie@clear.net.nz

ABSTRACT

This article asks questions and poses dilemmas central to the management of disability and its amelioration. Rehabilitation is portrayed as an intensely human experience set in the broad context of a systems view of the world. The relationship between science and soul as inter-dependent creative phenomena in the healing process is discussed.

Impairment and disability are seen as natural occurrences in life. It is the way we deal with these imperfections that converts them into disadvantages.

The aim of this paper is to stimulate reflection and ongoing rational debate based on facts and human values rather than power politics.

Introduction

"Life is not a problem to be solved, but a mystery to be lived" (Watson, 1988).

If we ever hope to influence the lives of others as rehabilitationists, then we must try to understand others in terms of their needs and motives, desires and aspirations.

To do this successfully, we must understand our own needs, drives, perspectives and values, and remain open to ongoing personal growth. Thus rehabilitation is a personal journey for the rehabilitationist and rehabilitee alike. Being ready to make this journey, and to see life through the eyes of others, is the first step along the road in the company of fellow travelers.

In this article, rehabilitation and disability servicing are explored from a human perspective and in a systems context. The consumer is seen as central and, ideally, in charge of the process. The relationship between science and soul is discussed and some implications for funders, planners, and providers outlined. It is concluded that many of the improvements which remain to be made depend upon the emotional and spiritual maturity of all involved - including politicians and analysts. We need to improve the way society views so-called 'disability'.

Well researched facts on disability are hard to come by and there is a huge gap between the rhetoric and the action with regard to the social values being pursued in rehabilitation and disability management. Services are under-resourced, accident victims are favoured over accidents of biology, and both qualitative and quantitative inquiry is low on the agenda. There is a desperate need for insightful and creative research which focuses on the core quality of life issues facing people with disabilities. Data are inevitably influenced by the values involved in its collection or non-collection. This situation is compounded by the power brokers seeing disability and rehabilitation as a cost centre rather than an investment in tomorrow's pluralist society.

Coming to terms with the presence of disability in today's world is a challenge to our emotional maturity; a challenge to bring up to speed our trans-personal relationship skills, mutual understandings and tolerances so they keep pace with our reasoning and considerable technical capacities.

Prejudice or Practicality?

"Life begins on the other side of despair" (Jean Paul Sartre, Backman, 1989).

The devaluation of people with disabilities is alive and well in today's world. For example, an academic and the Director of the Institute for Bio-Ethics, Monash University (Singer, 1993), argues that, "the killing of a disabled infant is not morally equivalent to killing a person. Very often it is not wrong at all." Singer contends there can be a justification for the active killing of people who through accident, illness or old age have lost the capacity forever to make decisions for themselves.

Closer to home, a North Health maternal screening pilot programme has been set up to assess the probability of a baby having Down Syndrome or Spina Bifida. The ultimate purpose of such a test is to detect disabilities in the unborn and then terminate them (Nicol, 1995).

In the future will families who opt to keep affected babies be seen as irresponsible? Will they be denied extra assistance on the grounds that they freely chose to keep their disabled child? Will the few people with Down Syndrome who remain alive be seen as abnormal and become increasingly less tolerated by society?

When these views are taken together with hardening attitudes to the care of the elderly and chronic under resourcing of other social support systems, it is reasonable to conclude that today's competition for the world's resources is not only rationing health and disability services, but is also modifying attitudes and ethics.

The reality of living with a permanent disability is not far from the persistent fear most people have of incapacity and dependency, loneliness, pain, ostracism, loss of dignity and being a burden to others. Indeed, many feel that lifelong disability may be a fate worse than death. Is society's failure to resource dignifying services for the dependent and elderly the reason for mounting political pressure for euthanasia?

The inevitability of permanent disability in our medically sophisticated society, begs civilization to answer questions about quality of life, care of others, constructive use of resources and the very right to life and death.

Market-led economics is insisting that health and disability services

become strictly rationed and targeted. In the process, moral and ethical decisions are being made by amoral accountants and administrators without reference to the ethical consequences and the values desirable for ongoing human happiness. As a result, there is a misfit between the life goals of people with disabilities and the resources available to them. It is an immoral deception to establish publicly stated policies and then not to resource policy implementation realistically.

Nothing in our political system holds planners truly accountable for the lasting affects of their decisions on society. They focus on the costs of resources rather than the long term benefits to society of rehabilitation and disability support services. The notion of 'a hand up' rather than 'a hand out' is slow to influence policy development. Present political priorities are geared to 'profit and loss' sheet numbers rather than human values. It is these attitudes which lead people to question their faith in society and a sense of duty toward it - as there is no longer any surety that, if perchance fate takes them out of production, they will remain part of the common weal. The links bonding the individual to society are strained.

Sound philosophical principles are being brought into disrepute for want of adequate resources, and a failure of planners to understand the differing needs of various disability groups. A generic attitude toward disability is detracting from the precise thinking necessary to engineer a comfortable fit between a disabled individual and their environment. Voluntary organizations are under pressure as State education and health institutions enter the fray for the charity dollar. Purchasers rather than consumers are determining which services are to be provided.

Lack of education and work opportunities is converting disability into handicap, and poverty. If you are disabled, chances are you will be poor; and if you are poor you are more likely to become more disabled. This is a poverty trap of the worst kind as no amount of personal effort will break the cycle. Lack of discretionary income is one of the most consistent factors in limiting life choices for people with disabilities. Rough estimates put the unemployment rate among people with disabilities in the USA at 69%, depending on how terms are defined (Kemp, 1995). A study by Beatson (1981), supports this unacceptably high trend among the visually impaired in New Zealand. Furthermore, financial benefits are lost when people with disabilities take up work; and yet their disability and its associated costs do not go away. In fact, they are compounded.

Tougher administration of disability allowances, asset testing of the

elderly, and asking questions about assets on invalid benefit renewal applications points to people with disabilities having to give away their assets to qualify for benefits and thus remain poor. Thus, impairment is compounded by poverty, loneliness and lack of adequate support; a situation described by Jack et al (1981), and which shows signs of worsening rather than improving.

The question has to be asked: have people with disabilities and those working in the field taken part in setting social directions, or are people with disabilities 'outside' society's accepted decision-making processes? It is easy for the State to avoid the effects of market led economics on minority groups, if the benefit to all citizens of changed policies is not measured. This is 'Alice in Wonderland' stuff which amounts to state institutionalization of ignorance.

The politics surrounding lack of disability statistics is a manifestation of this ignorance. The effects of economic belt-tightening are far more keenly felt by vulnerable groups as they are trapped by lack of life choices through no fault of their own. Moves by the State over the last decade in allocating resources for society's purposes has insisted that some sectors belt-tighten more than others. The cloak of 'affordability' turns out to be the coat of 'political priority setting'. There is money enough for tax cuts that boost the amorality of a market-led economy but which further diminish the 'caring' society.

The monetarist approach with its focus on material wealth and resource hungry growth, at the expense of the environment, social cohesion and the well-being of the soul, is the system which sees the majority of people with disabilities remaining poor, less educated, having fewer social and work opportunities and feeling less satisfied than their non-disabled counterparts (Jack et al, 1981). For market-led economics can we read law of the jungle?

Science has a job to do in staking out the progress of society by measuring the effects of change; while questions of resource allocation and the ethics thereof need still wider understanding and debate.

Towards a More Positive Paradigm

"The only true standard of greatness of any civilization is our sense of social and moral responsibility in translating material wealth into human values and achieving our full potential as a caring society" (Rt Hon Norman Kirk, in Watson, 1988).

Inspired by Nobel prize-winner Levi-Montalcini (1988), I put it to you that we are not born to live as brutes. We all know the sad, deep harm one human can inflict on others, but from that despairing recognition can we rise to create new ways of thinking and believing in the quality and sanctity of life. Levi-Montalcini's plea is to "keep alive the fire of hope and strive for harmony between our higher cognitive abilities, our spiritual selves and our emotional beings. Therein is our humanness, our evolution". Scientific and technical advances are outstripping our emotional capacity to deal with the profound questions raised by progress in modern health care. Hence the call to: "Stop The World" while we work on our emotional and spiritual maturity.

Habilitation, rehabilitation and disability management should be seen in the general context of social development, much of which is influenced by science and its methods. It is worth taking stock of how well these methods are working in today's economic and political climate.

Science as practiced by today's health researchers, appears to have limitations when describing the experience of living with a disability. So much published work focuses on trivial amounts of variation or on remote characteristics, all in pursuit of scientific respectability, when creative and insightful 'quality of life' studies, which analyze subjective data, would be of more practical use.

What is more, French (1994), indicates much evidence suggests that health and social science workers are no better at managing people with disabilities than the average citizen, and that their attitudes may become more negative as professional education proceeds. If disability is to be treated as one of the inevitable but natural consequences of modern life, then new ways of exploring and understanding the complex phenomena that constitute the reality of disability have to be found.

Designing a more inclusive society cannot proceed without more reliable information about the quality of life of people with disabilities compared with the rest of the community. Even the term 'quality of life' is open to interpretation. To some, it means

liberation from constraint, to others it is an index to assist in the allocation of resources for the preservation of one life over another (Parmenter, 1993). Given such ideological confusion, it is easy for researchers and analysts to be trapped by political dogma.

The knowledge-base driving the development of disability services must take account of the subjective 'experience' of living with a disability and the inter-personal and societal relationships that accrue from it. There is a need for research which reflects a 'user view' and which focuses on social and environmental barriers rather than personal impairment.

Sorting out the confounding variables involved in measuring individual rehabilitation and support needs in a community setting is a tall order for the reductionist approach to scientific inquiry. It is suggested by Richardson (1995), that rich data is available via the use of qualitative methods that give a wealth of information germane to quality service and effective delivery. Methods of inquiry are required which fully explore and look deeply at the meaning disabled individuals make of their particular life contexts.

In addition, the health and social sciences have an ethical obligation to resist being manipulated by economic and political ideologies, and to remain open to the collective interests of the wider community.

An Intuitive View of Rehabilitation

"We have to find ways to unlearn those things which screen us from the perception of profound truth" (Moore, 1994).

An intuitive view of rehabilitation is based on an ecological conception of the world. An understanding of nature, not only as structure, but also as dynamic process. From this standpoint, good health is seen as both a scientific and spiritual process. The strongest expression of well-being is when the physical, psychological, social and spiritual components of health are in harmony.

Many of the world's indigenous cultures, reflect an understanding of this transcendent reality. Indeed, Maori perspectives on pain and rehabilitation emphasize unity between mind and body and close ties between individuals and whanau. In addressing Maori needs in rehabilitation, Durie (1990), proposes three principles: partnership, participation and cultural affirmation. Durie points out that irrespective of the nature of an impairment, disability or handicap, there is a disturbed sense of well-being and consequent

distress which ought to be recognized and accepted before all else.

Good healers use intuition and subjective knowledge in their practice but this is not acknowledged in the professional literature or schools. These practitioners use more wisdom, talent, intuition and artistry; attributes which are not easily quantified and taught. Indeed traditional research distances itself from understanding such attributes.

In an attempt to make sense of these realities, the word 'soul' is coined here not for its religious or anti-science connotations, but rather to put some creativity back into science as a counter-balance to the reductionism that dominates today's health literature.

According to Taylor (1994), the notion of 'soul' is not analytic nor materialistic. It is oriented toward the intuitive, the visionary, the archetypal and the transcendent. Its ethic is not power over others but is preservative of relationships, cultures and the self. It uses science as a tool to understand the mystery of experience rather than a supreme rational goal for living. It is profoundly optimistic. It emphasizes multiple realities and expanded human potential.

Thus, the true locus of healing in the rehabilitation context may not always be clinical and technical intervention but rather the spiritual relationship between patient and healer; a relationship based on balancing the rational with the intuitive; an awareness of the power of healing that takes place in the context of positive affiliative and intimate relationships (James and Kirkland, 1993).

Psychotherapist Thomas Moore (1994), holds that `soul` has to do with self-transcendence, creativity, genuineness and depth. It is who we are and how we exercise the `craft of life`. He says care of the soul is not about curing, fixing or changing - nor is it about some ideal of perfection. Rather, it deals with life day by day in the present; the here and now. It gives the power back to each of us encouraging us to take responsibility for our own well-being.

Many of today's complaints are characterized by a sense of emptiness, disillusionment about relationships, depression, loss of values, yearning for personal fulfillment and a hunger for spirituality. In short we lack soulfulness and seek solace in materialism and instant fixes. Moore suggests that care of the soul is not primarily a method of problem solving; its goal is not to make life problem free, but to give ordinary life depth and value. Only we ourselves, each of us, can organize our lives to give expression to who we are.

Most of us find in dealing with life's major challenges, that there is a point beyond which secular experience does not take us. In denying a problem we forfeit the chance to grow. Thus, a major question for contemporary healers is: can we consciously alter our behavior by changing our values and attitudes to regain the humility, spirituality and ecological awareness we have lost?

Some Implications for Rehabilitation

"The fault, dear Brutus, is not in our stars but in ourselves, that we are underlings" (William Shakespeare, Julius Caesar).

Rehabilitation is littered with messy confusing problems that defy technical solution. These are challenges affecting a growing proportion of the New Zealand population, but which do not attract well endowed PhD students, academic prestige or research money.

Schon (1987) writing on preparing professionals for the demands of practice, points out that, compared with the rigors of science, professional issues are messy, indeterminate human situations. They are situations not entirely resolvable by rational and technical approaches. The presenting problems and solutions are often multifactorial and defy our existing segmented search for solutions. Further, academic disciplines are also political territories and inter-disciplinary projects can quickly become victims of professional rivalry. Professional conflict is avoided by separating disciplines to the detriment and confusion of the end user. What is more, solutions to problems are often financial, environmental, attitudinal, and political in nature. A holistic perspective, rather than reductionist analysis, is called for. The case is not in the book.

There is a conflict of values as society rations health and rehabilitation services

How does one respond to the conflicting requirements of efficiency, equity, quality of care and quality of life?

It is suggested here that rehabilitationists have a moral obligation to integrate traditional scientific thinking with a deep understanding of the philosophy, knowledge and practice of human caring (Watson, 1988).

Professional development should value wisdom, spirituality and ethics, as well as intellectual and technical skills. In practice, institutionalized inertia continues to block useful concepts such as community living, quality of life for people with disabilities, and respect for the psychological and spiritual dimensions of health.

Regrettably, today's healing relationships are being modified by fashions in treatment, reimbursement regimes and the threat of complaint.

How Is It For The End User?

No new paradigm will emerge until we systematically 'tap in' to how contemporary life really is for a person with a significant, permanent disability.

A dilemma many of us with disabilities face is that we have to make our own lives, a process that calls for independence and assertion, which does not endear us to the power brokers. We must become aware of, and accept our new and unique natures and status, and lay claim to our intimate relationship with all life. We have to move to a new personal centre, shedding normal compulsions and impossible expectations and responsibilities, to find a new way of participating in life's stream. Our focus is on what we can do, not what we cannot do.

We have to find ways of coming to know and accept our new selves in such a manner that allows our personalities to remain whole. "I am who I am". But, is that not the challenge of life for us all? Of course it is. Thus, accepting and coming to understand impairment in our uniquely modern time as part of the normal course of events/chance occurrences, is part of coming to terms with the demons in human nature. It is about 'conquering the shadow' (Fordham 1954).

Rehabilitation then is not always the restoration of loss. Rehabilitation can mean to begin afresh; to re-equip oneself for a new life and to develop adapted skills, strategies and attitudes which preserve self-respect, validity and worth. It can mean to creatively build another life, sometimes from the very beginning. To live anew.

If people are to turn their lives around, they need to be understood on their own terms in the first instance. They need to be helped by a positive and encouraging environment. They need to be supported by societal attitudes where marginalization is replaced with validity. Where there is hope for a decent quality of life. Where alienation is replaced by genuine heart-felt concern. Where the 'least restrictive environment' is replaced by the 'most conducive setting'. Where institutionalized ignorance is supplanted by actualized potential. Where economically based thinking is overcome by carefully observing and valuing what people with disabilities are teaching society.

The systems way of looking at maintaining health, in its broadest sense, implies the need for flexibility and co-operation, and the preservation of a large number of options for the individual to interact with their environment. It implies creating conditions in which the individual can explore their own inner responses, feel supported, and be encouraged to regain a place in the real world of genuine human intercourse.

There is a preservation and enhancement of another's personal integrity and unique humanity, through a process of mutual understanding resulting from empathy, genuineness and sincerity. The emphasis here is to balance the rational with the intuitive, and give due weight to the subjective experience and harmony within an individual's inner self, or, within the critical spheres which constitute their personhood. Healing the split between the self as experienced and the self as perceived.

Ultimately, People Rehabilitate Themselves, Sometimes with Professional Help.

Changing The Way We See And Do Things

French (1994), reports two factors as being important in breaking down the prejudice towards people with disabilities: non-competitive contact where people are of equal status; and the pursuit of common goals which are obtainable through co-operation.

Two other elements call for a unique mind-set when administering disability as compared with health services: first, disability services are concerned with satisfying the many needs of the few, while health focuses on the few needs of the many. Second, authentic experience changes perspectives. To have a disability is to know. To hear about disability is to be in doubt (Spiro, 1995).

In building a more inclusive society, rehabilitationists and analysts will become more relevant the more they listen to and develop genuine alliances with consumers. Consumer groups are a reservoir of learning rather than a nuisance to be humoured.

Professionals, analysts and managers will continue to miss the mark if they do not engage in educational forums that highlight both consumer and professional viewpoints, involve consumers in the development of policy and educational material, and become intimately involved in consumer and support organizations (Kemp, 1995).

Likewise, planners, funders and providers need to be more accountable for the long term outcomes of their decisions, as distinct from implementing political fashion.

It is time to see the management of disability as an issue central to the future well-being of our society and to build an index of national well-being which accounts for social as well as economic factors, and includes the status of people with disabilities. As stakeholders, we have an obligation to begin clarifying the issues surrounding disability via rational debate; and how better to do so than through the pages of this article.

The approach to rehabilitation sought here incorporates a respect for genuine science and ethically based research, with a deep philosophy of reverence for the dignity of humankind, a sense of aesthetics and metaphysics.

In summary, rehabilitation is seen both as a science and an art with all the creativity and sensitivity these terms imply. The term recognizes that mutually respectful, caring inter-personal relationships can unleash human potential. It is the quality of the relationship between rehabilitationist and subject that may tap that human potential.

Inherent in the concept is a moral ideal that is preservative of the harmony between mind, body and soul, and which enhances human dignity and integrity. The values involved are those of respect for the wonders and mysteries of life, celebration of uniqueness, a non-paternalistic style, high regard for the individual's subjective and spiritual centre, the patient as the agent of change, a striving for more self knowledge, self determination and self healing regardless of the presenting condition.

The intervention is one of mutual discovery and full participation by all parties, with the subject at the centre. An enabling rather than de-valuing process (Watson 1988). Self help, sense of control, feelings of dignified worth, personal responsibility and a positive milieu are powerful tools for healing whose potential may be unrealized in our institutional approach to rehabilitation and healing.

Conclusion

"While with an eye made quiet by the power of harmony, and the deep power of joy, we see into the life of things" (William Wordsworth, Tintern Abbey).

Never has it been more important to recognize the imbalance that is seeping into health-care practice depriving us of a sense of meaning because the emphasis is becoming too one-sided and has concentrated on the development of the intellect and economy to the detriment of the spirit.

There are more dimensions to rehabilitation than the purely physical. As rehabilitationists we are called upon to work on the relationship between the uses of science and moral values. We have an obligation to battle against bigotry and insufferable ignorance and prejudice which are still leading to unspeakable degradation of the human spirit because of chance intervention of impairment which we turn into handicap. We are all diminished by failing to challenge the destructive powers of the dark side of the human psyche.

Perhaps rehabilitation, as a discipline, is not popular because it makes ultimate demands upon rehabilitationists to blend the natural sciences with a deep understanding of self-transcendence, the soul and the meaning of creation. Most often the broken bodies we deal with have intact souls and they cannot 'stop the world' and choose to hop on or off.

As practitioners we are required to know and accept ourselves to a degree that enables us to connect with other human beings as they quest for wholeness.

Acknowledgements

I am extremely grateful to Elizabeth Palmer, Bryan Paynter and my wife Rosemary McKenzie for their editorial advice and guidance in preparing the original paper upon which this article is based. I am also indebted to my secretary Tracey Black who has patiently sourced and tape recorded references and prepared this manuscript.

Sources

Backman M., (1989), "The Psychology of the Physically Ill Patient: a Clinician's Guide": Plenum Press, New York.

Beatson P., (1981), "The Blind at Work: A Report on Employment of the Blind in New Zealand": Palmerston North, Department of Sociology, Massey University.

Durie M., (1990), "Rehabilitation Disability and Maori Development", Proceedings, Pain and Rehabilitation Conference, Auckland NZ. New Zealand Rehabilitation Association, 28/29 March, pp 22.

Fordham F., (1954), "Introduction To Jung's psychology": Harmondsworth: Penguin Books.

French S., (1994), "Attitudes of Health Professionals Towards Disabled People: A Discussion and Review of the Literature", Physiotherapy, October, pp687.

Jack A, et al., (1981), "Physical Disability, Results of a Survey in the Wellington Hospital Board Area": Department of Health Report 59.

James L, Kirkland J., (1993), "Beyond Empathy: Seasons of Affiliation, Intimacy and Power in Therapeutic Relationships": A.N.Z.J. Family Therapy, Vol.14, No.4, pp177-180.

Kemp J., (1995), "Keynote speaker Stresses Importance of Consumers": Archives of Physical Medicine and Rehabilitation, Vol.76, March, P295.

Levi-Montalcini R., (1988), "In Praise of Imperfection: My Life and Work": Basic Books, New York.

Moore T., (1994), "Care of the Soul": Harper Perennial, division of Harper Collins, New York.

Nicol R., (1995), "Downs Out, Anxiety Up": New Zealand Listener, 1 July, New Zealand Magazines Limited.

Parmenter T., (1993), "Quality of Life: Can it be Measured?": The Proceedings of the Second National Rehabilitation Conference of the Commonwealth Rehabilitation Service, Sydney NSW, pp552-571.

Richardson B., (1995), "Qualitative Approaches to Evaluating Quality of Service", *Physiotherapy*, September, pp541.

Schon D., (1987), "Educating the Reflective Practitioner": Jossey-Bass Inc., San Francisco, USA.

Singer P., (1993), "Practical Ethics": second edition, Cambridge University Press, p191.

Spiro H., (1995), "Science in Practice": in *Scientific American, Science in Medicine*, Jan-Feb., Scientific American Inc., New York. p6.

Taylor E., (1994), "Desperately Seeking Spirituality": *Psychology Today*, Sussex Publishers Inc, November/December, pp56-68.

Watson J., (1988), "Nursing: Human Science, Human Caring: a Theory of Nursing", National League of Nursing, New York, Centre for Human Caring, University of Colorado Health Sciences Centre, Denver, Colorado.