



THE BEGINNINGS OF A CHANGE IN DIRECTION

Good intentions, and kind impulses, do not necessarily lead to wise and truly humane measure. Nowhere is wisdom more necessary than in the guidance of charitable impulses. Meaning well is only half our duty; thinking right is the other and equally important half.

Samuel Gridley Howe quoted in Wolf Wolfensberger: Normalization p. 59

I thank you for having me here today to address you. As many of you know, I have announced that I will not seek a fourth term as its volunteer Chairman of the Board of NHIF.

The mission of the National Head Injury Foundation and, I hope, everyone associated with head injury is: *to improve the quality of life for persons with head injury and their families, and to develop and support programs to prevent head injury.* This statement seems simple enough, but it can be profound in its implications. All of us - individually and collectively - have a deep ethical, family and professional responsibility to think through its implications for our personal behaviour and for our institutional behaviour.

We must all ask the question: **What is rehabilitation? and Rehabilitation for what role in society?**

Roger L.I. Wood has written: *an unintentional shaping procedure can develop which allows a patient, whilst still in a disoriented, confused or partially conscious state, to gradually associate disruptive behaviour with attention from nursing staff (an experience which can have rewarding qualities). Slightly later in recovery, an increase of awareness allows a form of cognitive learning to strengthen the previous associations because the patient begins to realize that there is an increased chance of getting his own way by behaving in a disruptive, intimidating or even directly aggressive manner.*

Perhaps, rehabilitation is shaping other detrimental behaviours and inappropriate self-images. Perhaps it is shaping dependence. Perhaps at some level, we value the traumatic brain injured individual mainly as a consumer, as a “good dependent patient”. There is no reason to believe that solely because we have a special relationship to one or many persons who are traumatically brain injured that we are exempt from our social and cultural history and its beliefs.

Wolf Wolfensberger has written: *When we review history and literature, it becomes apparent that regardless of time or place, certain roles are particularly apt to be thrust upon deviant persons. The way in which these roles transcend time, distance, and culture is remarkable. Most of these historical role perceptions reflect fairly clear-cut prejudices which have little relationship to reality. However, as with many prejudices, the lack of objective verification is not a crucial element in the shaping of a social judgement or social policy. The major roles...include those of the deviant person as a subhuman, a menace, an object of dread, a diseased organism, an object of ridicule, an object of pity, an eternal child, and a holy innocent.*

Lest we protest too quickly: "not me.", Let us remember that only 20 years ago the Atlantic Monthly published a comment that called for "...sacrifice of mentally defective humans, or human vegetables..." to provide organ transplants and "...increase the intellectual betterment of mankind...". And in 1987 *Omni* published the following: *What we decide to do with the life in limbo that is the vegetative state remains to be seen. But it is better to begin to think about it than to ignore the increasing price we have to pay for this most unblessed death on the instalment plan.*

I think I know the "WE". It is the "THEY" I pray for. Dehumanization of the deviant starting with the so called vegetative state is a reality of our society. Witness the persistence of the medical phrase: "persistent vegetative state" - What does it mean and connote? To Whom? How easy it is to dehumanize a person who has lost "normal" cognitive ability - at birth or through an accident. This is especially easy if we are not careful in what is called the "medical Model" of rehabilitation. Where the consumer is: *the "sick patient" where after "testing" and "diagnosis" he or she is given "treatment" or "therapy" by a "therapist" and who swims in "aqua therapy" and goes to "therapeutic recreation" in an environment managed by a "doctor" in a "hospital, SNIF, nursing home, or clinic" assisted by "allied health professionals" under state "health care regulation" with "case management" and "cost containment" all leading to "restoration", "cure" or "discharge."*

All management models dictate consistent patterns of belief and behaviour from architecture to interpersonal interaction. The medical model seems to demand segregation and isolation from the community because of its convenience for staff and because the consumer is "sick." One must ask "Is this the best model for the rehabilitation of persons with head injury?" Is it driven by a control or liberation? Is it driven by convenience for doctors, administrators and staff or convenience, growth, and choice of the consumer?

Our social policy maps are dotted with large institutions that organize people so a few of them will be able to control the vast majority. And it is also dotted by individuals who consume the services provided by these institutions. What we don't need in the year 2,000 is a large leper-like colony debilitating rehabilitation system dedicated to developing dependence upon large complex professionally dominated rehabilitative service systems. John McKnight has said: It is obvious, upon the briefest reflection, that the typical social policy map is inaccurate because it excludes a major social domain - the community. By community, we mean the social place used by family, friends, neighbours, neighbourhood associations, clubs, civic groups, local enterprises, churches, ethnic associations, temples, local unions, local government, and local media.

He distinguishes control systems from associations that are created by consent; that can respond rapidly and to individual need, without disabling bureaucratic red tape. I suggest, rehabilitation must be achieved by consent not control.

In head injury rehabilitation, it may be that:

- To be small is to be truly beautiful
- The community resources should become the fundamental support structure wherever possible; and,

- Constant support for families and friends, not supplanting them is the way to go.

I think NHIF should do whatever is necessary to empower persons with head injury to govern and speak for themselves. We must call to a close the days of parents speaking of the needs of their adult children - spouses speaking for spouses and public sector federal and state officials telling all of us what is best for professionals, facilities, families and persons with head injury alike. Our single most important role is to liberate persons with head injury. We are not using wisdom if the effect of our interventions is greater dependence and isolation from the larger community. We must seek the consent of the persons with head injury. We must demand that the community supply resources. In large measure "outcomes" will be dictated by their opportunity to model their behaviour to the standards of the larger community. The learning cannot take place in therapeutic social and economic isolation. In large measure outcomes are how we perceive and relate to persons who have experienced head injury. One does not seek control over another who is valued. One does not relate to a valued colleague as superior/subordinate.

In the coming years we at NHIF desperately need your involvement! We have a staggering agenda of raising public consciousness and making statutory change in order to improve quality of life. Change can be achieved only with the full participation of all. We must start now, before we build a bow wave of impatience, frustration and despair.

We need maximum possible community support and integration for our loved ones - Patrick Bush and every other person with head injury. We learn by careful observation, queuing and copying those who do things well. Are we, in our rush to rehabilitate, systematically denying many of those we profess to help to help from this valuable learning experience by segregation?

We need not take a decade to relearn the lessons of the developmentally disabled. They learn better in regular classrooms without specially trained teachers than they do in a segregated special education environment. We need small, personalized facilities without locks, without walls, integrated in every way possible into the larger surrounding community. We need help to integrate those who are isolated at home.

The Foundation's public awareness programs must take a new tack. We must at the local support group level and at the national media level flatly resist the "aren't you suffering parents and spouses wonderful for your courage, sacrifice and commitment" approach. We must not allow the "miraculous recovery" syndrome to become the norm. We must this year identify a cadre of persons who have experienced head injury to articulate their commitment to life and learning and concern for a chance to contribute and to be valued.

To the extent that the Foundation can enable and liberate those persons it will be successful and the community will respond.

If we believe this, the Foundation has and will continue to take certain very specific steps.

It has or will:

- Work with accreditation bodies to stress community resource utilization as superior to in-house provision of services when and wherever possible.
- Make certain that providers relook at relationships within their facilities; with their environments, including families; and relook at their labelling, locking and management models to conform to the principles of valorization.
- Implement the persons with head injury council immediately and amend its bylaws in April to structure this part of NHIF on equal footing in every way with the professional and provider's and State Association community.

- Instruct its State Associations to review committee structure to assure representation of persons with head injury.
- The NHIF Executive Committee has appropriated \$5,000 to begin the process of transferring the role of advocate spokesperson and governance to persons with head injury.
- In April the persons with head injury council should be prepared to assume their rightful place on the Board of Directors and their elected leader will automatically become a member of the Executive Committee
- In 1988 or 1989 NHIF should have a national symposium for persons with head injury, organized and managed by them.

Lest we think we are at the end of the road, let me quote from a recent letter to NHIF: *We have been supporting NHIF since we discovered it several years after our daughter, Meg, was injured in a car accident in September of 1978 in which a head injury left her brain damaged. Your newsletter often details success stories about such cases, but I am sure you are also interested in those in which the outcome is otherwise and so I want to tell you about Meg's history. Although the neurosurgeon who cared for her expressed "guarded optimism" because of her age - she was only twenty years old and working at her first real job when she was injured - she descended into an underworld from which she never emerged, and on August 7 of this year she took her own life with a gunshot that ended the nine terrible years that followed the accident.*

Ladies and Gentlemen: As the German Journal Together put it:

He, too, who cannot count, counts for something;

He, too, who cannot speak, has much to say....

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