NURSING PRAXIS in New Zealand Vol. 1 No. 1 Nov. 1985 Page 25

THE CHANGING PATTERN OF CARE FOR THE SEVERELY PHYSICALLY DISABLED IN NEW ZEALAND - A NURSE'S VIEW

(A paper presented at "Rehabilitation 85," Tauranga, 1/10/85)

Charmaine Hamilton, RGON, Dip N (Sans), MA.
Principal Nurse, Pukeora Home for the Physically Disabled, Waipukurau

Accepted for publication October 1985

ABSTRACT:

Pukeora Home for the Physically Disabled was opened on the seventh of May 1957. At that time it was generally considered to be the symbol of an enlightened approach to the care of people with severe physical disabilities. Since 1957 the concept of an isolated institution providing a ´home for life´ has constantly been challenged by those people who believe that the segregation of disabled people in isolated institutions is quite unacceptable.

A major problem confronting any individual with a severe disability has always been how to combine independence of thought and action with the need for personal care and assistance. Today, almost thirty years after Pukeora was opened, a new concept, combining elements of independent community living and institutional care, is emerging. Communities for Independent Living offer viable alternatives to those individuals whose severe disability imposes restrictions on their ability to lead a ´normal life.´

Pukeora, as many of you will be aware, is a national unit providing a home for sixty-six physically disabled adults from throughout New Zealand. Administered by the Waipawa (soon to be Central Hawke´s Bay) Hospital Board, it is located some five kilometres from the main shopping centre of Waipukurau.

Commissioned originally as a tuberculosis sanatorium, and administered variously by the Army, Health Department and the Hospital Board, it is located amid outstanding scenery on a steep hill. The cynics, with twenty years hindsight, tell me that Pukeora was only created because the Government had an expensive building and no use for it. I don´t believe this to be the case at all. I feel that Pukeora was created to meet a very definite need for a small group of people in society. It is the care of this numerically small, but economically significant, group - adults with a severe physical disability - that I would like to discuss.

Pukeora was opened on seventh of May 1957. It has been open for nearly three decades. During that time a great many changes have occurred. Looking back it is possible to perceive three main themes, each corresponding roughly to a decade of Pukeora´s existence:-

> The first theme is dependence the second independence and the third interdependence.

These themes, are of course, not peculiar to Pukeora, they are reflected in many other areas of social service.

Dependence

In the late 1950´s and the early 1960´s the concept of care provided by the State for those in need was well entrenched. The provision of the physical necessities of life were guaranteed by a caring and benevolent government. Pukeora was an expression of this care and concern. It provided life long security for those who had needs which could not be met anywhere else. Pukeora was (and I believe is still), unique. The concept of a community of disabled people, living and working together was adventurous and far-sighted.

For a decade Pukeora continued to provide a home for those in its care. It also, with the best of intentions, created residents dependent on staff - not only for physical care, but for shaping their behaviour into socially acceptable patterns, or, to put it more bluntly, for training them to be good residents, living their lives within the context of others´ beliefs as to how they should live. Such a situation was, of course, not peculiar to Pukeora. Other insitutions throughout the country were doing exactly the same. Doctors and nurses dominated the care scene. They decided what was best for the patient (or resident) and any patient daring to disagree was instantly labelled a troublemaker, to be dominated and controlled. The emphasis was on physical care, fresh air, good food and cleanliness. With today´s medicine it is so easy to forget that the same emphasis, although restrictive to the individual´s personal development, did save many lives.

Independence

As the decade ended, the need for safety and security, with its inbuilt dependence on others, gave way to the search for independence. Independence, with its associated concept of normalisation, became the theme of the second decade. Isolation in institutions became unacceptable. Integration into the larger community became the new goal. Associated with this change came an appreciation of the new technology. It was felt dependence upon others could be replaced, to a great extent, by machines. Seduced by the wonder of electronics, we began the decade full of hope and enthusiasm. At last those totally dependent on others for care should achieve levels of independence inconceivable a decade earlier. It is notable that independence was still thought of in physical terms and electronics and mechanics were used to create substitutes for the physical care previously given by others. Hoists, power chairs, electric typewriters, computers, provided the tools of independence. With less people required for care, the move to normal living in the community became an achievable goal.

Individuals and community groups gave willingly of their money and their energies to buy the materials needed for independent living. The welfare system, balancing the cost of care of paid staff against the cost of care by relative and machine, supported the initiative. Nursing, with its increased awareness that caring involves so much more than the provision of good physical care, not only supported but actively promoted the concept. Community living was to be the new norm. Sadly, the reality did not match the dream. The new technology, while solving some problems created new ones.

To illustrate, perhaps we could just consider power chairs. Power chairs provide mobility at the touch of a button. They enable their owners to come and go at will. Users have the choice of seeking assistance or avoiding it, as they wish. They often provide the means whereby others can express their need to give in concrete terms. The advantages are tremendous, but as with any technology, there are problems. The very machine that enables independent mobility can create isolation and dependence. Isolation comes about for two main reasons. Those who have given feel they have done their bit and withdraw. Personal assistance is not required and a man in a moving chair is conceived of as going somewhere. He is a busy man, with no time for idle chatter. Personal interaction can actually become less. The physical dependence on others to push the chair is replaced by dependence on a skilled technician to repair the chair when it breaks down. When this happens reversion to a manual chair causes problems because the programme no longer allows for someone to push. Power chairs require very little physical effort to control. Exercise, as a consequence, is very minimal, leading to increased dependence on others for physiotherapy. Power chairs do not create independence, rather they change the pattern of dependence. Unskilled staff, regularly required, are replaced by skilled staff, irregularly required. What is true for power chairs is equally true for many other machines and electronics.

Slowly over the years it became evident that technology was not going to provide the promised freedom; rather, it created the new group of disadvantaged - the care givers.

The hoist, the computer, the power chair, all aids to care, made it possible for a devoted relative to provide care in their own home for an individual with a severe disability. But, after the initial fanfare and flurry of activity had ceased, the care giver was often left to cope. Devotion and dedication could sustain the care giver during trying times, but year in and year out it was not enough to overcome the exhaustion and burnout that was almost an inevitable consequence of too many demands with too few resources. For those individuals whose relationships were already strained, the caring twenty-four hours a day, seven days a week, often became too great and they opted out of the relationship. Gradually, the Health Service was left to absorb those disabled who had nowhere else to go.

Probably the group who benefitted most in the move to normalisation in community living were the children. Supported by a very extensive support network, small enough to need only limited physical effort by usually young parents, they lived and grew up in a relatively normal environment, but as families split up and parents grew older, the need for institutional care again became evident. As the concept of normalisation, living in a house in the community, became a reality for a few, it became increasingly obvious that for many this was not a realistic long term goal. The main reason for this I feel, was the overwhelming emphasis on physical care and the neglect of the mental and spiritual aspects of personal development. Replacing lost physical abilities is not, in itself, independence.

Independence is the freedom to survey all available alternatives and make choices. It is not an end state. It cannot be dispensed by others. It is the result of tuition and experience. Once this is recognised, the need to provide facilities which cater for the whole person becomes increasingly evident. It is relatively easy to teach unskilled people to provide basic physical care for disabled individuals, but the development of mental, social and spiritual aspects of an individual's life require skilled intervention. The scarcity of qualified personnel, and the economics of care, mean that this can best be achieved in a small community setting. Hospital Boards have resurrected their plans for small local units; voluntary groups have become involved; and Pukeora has, with some surprise I think, realised it is uniquely situated to provide a much needed link between institutional care and community units. As a consequence of this realisation, part of the nurses' hostel at Pukeora has been converted to flats where selected residents can be prepared for independent living.

Parallel with this change in emphasis has come the development of the Ryder Cheshire Home in Palmerston North. This home, situated in the grounds of the old Caccia Birch homestead, is a completely new, purpose built complex catering for twenty-four individuals with varying degrees of physical disability. It is designed to provide independent living in a small community setting. A pilot scheme for homes in other centres, it was expected to require minimal staff input. It has, however, been found necessary to provide for some residents considerably more physical, emotional and educational support than was originally intended.

The reason for this is, I think, a recognition by people with a severe disability that they can live and grow in such a setting.

Small community units such as the Ryder Cheshire and Laura Fergusson Homes, form part of the continuum of care ranging from individual care by relatives in the home to care in the larger institutions by paid staff. For the first time it is now possible for adults with a severe disability to select a service appropriate to their particular needs. I should like to see this continuum of care further expanded to provide for care in an institutional type setting, but one rather different from those currently in existence. Called Independent Living Centres in some places, this is not an appropriate terminology in New Zealand where Independent Living Centres already exist in another form. Possibly a more appropriate title for the unit I am about to describe would be Communities for Independent Living.

I foresee groups of severely disabled individuals working together, with able-bodied paid employees, creating their own communities, each designed to meet the quite specific needs of the individuals living in that community. (I must stress at this point again that I am only talking about a small group of adults with severe physical disability.) I believe that these communities should be run by the residents for themselves. They should be able to manage the enterprise, providing for their own needs within the financial constraints presently imposed upon such institutions.

The community could then develop, at its own pace, a pattern of life geared to the needs of its individual members. Ideally such a community would be purpose built, in pleasant surroundings, separated slightly from the larger community but with easy access to that community. Provision would be made for the young and old, for couples - either or both disabled, the single, for friends and for family visitors. There would be easy access to medical, dental and optical care, to the bank, the shops, the church, the TAB, the restaurants; the need to visit determined by the resident and arranged for his convenience. In such a setting, the residents determine their own needs and act to meet those needs as they are able. When assistance is required, they determine what assistance is needed, who will provide that assistance, and when it will be required. Such a community is, of course, far from the concept of normal living, but normal living, with its inherent problems, its lack of security, the increasing isolation of individuals, and the rising incidence of crimes of violence, is not, for many individuals with a severe disability, a practical goal. I see it as only in a community such as I have briefly described that some individuals will be able to develop their full potential. For such a centre to succeed in its objective of enabling disabled people, even with a severe disability, to order their lives, its residents have to be equipped with the skills necessary for effective decision-making. Children currently being cared for in a normal family situation should in the future be well prepared to live in such units. But for those who have grown up in the system which emphasised dependent physical care, the move to such a degree of independence, with its implicit responsibilities, is only possible with a long and intensive period of preparation.

Interdependence

As we reach the end of our third decade at Pukeora and have begun a programme specifically designed to prepare people with a severe disability for independent living, we have realised that there is a third dimension to human relationships which must be added to the dimensions of dependence and independence. This is the dimension of interdependence. We are all involved in mutually dependent relationships. We are all defined in terms of others; mother, father; brother, sister; employer, employee; friend, foe; client, nurse; doctor, patient. I can call myself a nurse but, without clients, it is no more than a name. It is only when we realise that each individual - disabled or able-bodied - is part of the series or complex interrelationships that make up our life experience, that the potential contribution of even severely disabled people can be realised. Dependence and independence have, in the past, been treated as if each has a separate existence of its own. They do not. They are not alternatives, they complement each other, and, in doing so, create interdependence. Interdependence is a byproduct of the move to independent living. Today the focus is no longer on what a person cannot do but on what they may be able to do. The emphasis is no longer on physical disability but on potential ability. The orientation is no longer on what has occurred in the past but on what may be achieved in the future. Caregivers are moving from being the dominant partners in the care scene to becoming equal partners. We are finally beginning to work together for our mutual benefit. At last we have realised it is possible for individuals, even with severe physical disability, to achieve their full potential as contributing members of society.