

Connecting the Personal with the Professional

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Disability. What did I know of it as a kid? Nothing much. What did I want to know of it? Nothing much. In fact when I did think of it at all, generally my thoughts ran along the lines of "Poor things," "It must be awful," "Oh, they're brave." Like most of the other children, I was fascinated by the family down the road - the kid with no legs, the sister and parents with no hearing or words, but hands which flew - "deaf and dumb" they were. But Mum told us, "You mustn't stare or ask questions."

Later, when one of Mum's friends had a baby, there were lots of whispers and "tut, tutting," and long faces. Again, I was to stifle my curiosity - the baby had something wrong with it; we were not to speak of it. In fact, we were to forget about it because it was a secret. The baby was sent to an institution and Mum said, "Much better for all really. Best to put it away, forget about it and have another one."

So I was 38 before I was confronted by disability. As part of my nursing education I was required to spend time in a large institution for people with severe developmental disabilities. This was *compulsory* exposure and I did not want a bar of it. I had other ideas about my nursing directions and they did not include this "disability stuff." By the end of my first day there, I was stunned into silence. I was appalled by institutional life - by its sameness, its monotony, its practices, and its dehumanising effects.

The experience was painful. I was confused and shaken, my values had been challenged; and finally, I was angry - angry about a world which seemed to treat certain of its people as less than human; angry about a society with the technology to save life, but without the will to support the living of that life; angry about the oppression, the devaluing, the marginalisation. I determined then that I would make a difference.

This paper will provide an overview of how that anger was utilised and how my experiences of disability have caused me to find my place - a place which endeavours to bridge the worlds of the disabled and the non-disabled in my capacity as an educator of nurses and as researcher of families with disabled children - and as someone whose life has recently been deeply and personally affected by the disabling consequences of my mother's stroke.

Early Nursing Experience

For some years, I practised as a registered nurse on a Developmental Disability Services community team. This brought me into contact with hundreds of families for whom developmental disability was a daily experience. I was a mother myself and that role, along with my traditional nursing education, led me to believe that these families would be under enormous pressure because of what my teachers had called the "burden of care." I knew that the families must be "living with tragedy" and were "grieving." My very experienced and committed professional colleagues had also prepared me: these parents were frequently "in denial," "did not face reality," did not accept their child as "disabled," did not "accept" their situations. This denial, I was told, led to "overprotection," "overcompensation," "neglect," "anger," "false hope," and "false optimism."

Yet, many of these parents seemed fine to me. It seemed they often became frustrated by a lack of practical assistance and adequate services, but most functioned well and were generally cheerful. Whose truth about disability was I to believe?

Research into Families with Children Who Have Developmental Disabilities

I began to question the assumptions of many professionals who base their practice on the belief that disability is an overwhelming tragedy for parents - a belief that leads to the frequent pathologising of all parental responses and behaviours. My research was designed using a participatory, interpretive approach, and it presented the voices of the parents as they spoke of the

“joy and sorrow” of their family experience. The research painted a picture which was at odds with prevalent assumptions of parental crisis and maladjustment and illustrated that much of the parents’ sorrow might be caused by the outside world, not by their children’s impairments. Whilst recognising the sadness and difficulties engendered by their situation, these parents also spoke of strength, joy, love and hope (Kearney, 1996).

In telling their stories, the parents initially presented an overwhelming picture of “no hope.” Yet it became clear that they had been inundated with messages of hopelessness from the people they were in contact with and that the professionals with whom they worked were partly responsible for the parents’ feelings of isolation, rejection, despair, and hopelessness. These feelings were compounded by negative attitudes of friends, family, and acquaintances. It seemed only reasonable to anticipate that these parents would be immobilised by a sense of despair and hopelessness, mixed with periodic pain and sorrow. Incredibly, though, they continued to struggle and fight to ensure their children’s survival and development and, at the same time, they experienced the joys of countless successes. Despite the odds then, despite the negative attitudes of others, despite the lack of ready availability of therapeutic services, and despite prognoses which indicated that their children would “do nothing,” these families were able to view their situations and their children’s futures with optimism.

I felt that their words and behaviours gave us a basis for a reinterpretation of their denial. The parents demonstrated that they frequently distinguish reality from dreams and hopes from expectations. As a group, they identify hope as akin to a belief in possibilities; and they concur that they could not function without that hope. It is the expectations and professional reality that these parents have decided to live without. Though they are conscious of the limitations of their children, these parents maintain hope and strive to keep it alive. My interpretation of their optimistic outlook is that there is no “denial of reality,” but rather a very realistic grasp of their situations, tempered by the recognition of possibilities for more hopeful futures than most professionals are prepared to imagine.

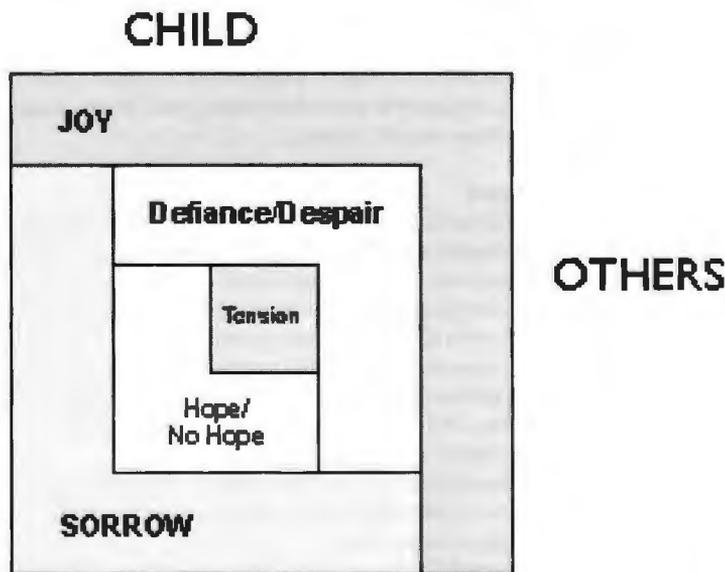


Figure 1. “Between Joy and Sorrow: Being the Parent of a Child with a Developmental Disability” (Kearney, 1996, unpublished MA thesis, University of Western Sydney, Nepean. p.124)

Cousins (1989), in writing of the hope felt by people with life-threatening illnesses, has been impressed with those who respond with a fierce determination to overcome. He says, "They didn't deny the diagnosis; they denied and defied the verdict that was supposed to go with it. The defiance took the form of a blazing determination and it was a window on the future" (83). This, for me, epitomised what was happening with the parents in my study. There was no evidence to suggest they were denying their children's diagnoses and, in fact, they all seemed to have a clear and realistic understanding of their children's conditions. They did seem, however, to be denying the verdict or defying the implications; and their "window on the future" was only made possible by that hope and optimism. These parents make a very big difference to the lives of their disabled children who, without their parents' guts, determination, and fierce advocacy, might otherwise fulfill the professionals' predictions of hopeless futures.

Implications of the Study

My research findings have been well received. Parents state that it has meaning for them and that it presents a truer version of their experiences. Many professionals also relate to the data and say that it provides a framework for evidence they have recognised in their practice, but that has been difficult to articulate or defend. Some nurses, particularly those working in acute paediatric settings, are sceptical - they "know better." Other professionals are challenged by this study and debate the interpretations, often on the grounds of methodology. This is valid criticism and I make the point here - the work makes no claims for generalisability. However, it does provide us with a different view, using parents' insights. It allows a more constructive perspective with which we might approach parents of disabled children.

As the result of conference presentations (Kearney, 1993a, b; 1994a, b, c), this research is beginning to reach a wider audience and is starting to be cited (Quinn, 1998; Petrie, In Press). This article inaugurates the publication evolution which will spread the research findings further and, hopefully, promote new studies. However, the "joy and sorrow" interpretation of disability-in-families is realising its greatest potential in the education of nurses, both at the pre-registration (undergraduate) and post-registration (postgraduate) levels. Undergraduate nurses at the Australian university where I teach are exposed to multiple perspectives regarding the impact of disability during their pre-practice education, *prior* to their socialisation by a profession which largely holds a tragic view. The postgraduates, who are experienced practitioners in disability and rehabilitation nursing, are required to consider alternative perspectives on the disability experience.

It was after working some years as a community nurse, and the attainment of further qualifications, that I took up a university appointment as a lecturer in nursing. I recognised that the education of students new to the nursing profession would be a powerful venue for disability awareness to take root. Here my goals and aspirations of making a difference have taken shape and been put into practice as I have taught and developed courses in which our students' understandings of people with disabilities have been challenged. In Australia, many nursing programmes do not include disability topics at all. In New South Wales, the curriculum has been steadily eroded and marginalised due to an environment of competing values and priorities for scarce time in an expanding curriculum which increasingly emphasises technological competence. At the University of Western Sydney (UWS) Nepean though, we are building understandings about disability from the undergraduate curriculum (despite these constraints) all the way through to the innovative Masters of Nursing (Disability) and (Rehabilitation).

Teaching Undergraduates (Pre-registration): Bachelor of Nursing

Although nursing education is provided within a paradigm of holism and attention to people as biopsychosocial beings, its focus is on the individual's response to illness. A logical extension of this education and practice is the conceptualisation of disability as a problem to which individuals must respond and adapt - leading a number of nursing theorists to see adaptation, the

promotion of independence, and self-care as primary objectives (Orem, 1991; Roper, Logan & Tierney, 1996; Roy, 1984; Roy & Andrews, 1991).

At UWS Nepean we address the concept of disability differently and we both utilise and challenge the World Health Organisation's (1980) international classification of impairment, disability, and handicap (ICIDH and, more recently, ICIDH-2). In our courses, we emphasise the contextual and interactive nature of the constructs of impairment, disability, and handicap. This enables us to conceptualise disability as a function of impairment in context, as a state which alters according to factors in the environment, be it the physical, psychological, social, cultural, political, or total environment. Such a model not only enables us to consider the impact of impairment, but also acknowledges the centrality of factors outside the individual in the production of disablement. This framework is compatible with nursing's core paradigms and is useful in enabling undergraduate students to develop some beginning understandings of disability as a concept that has social influences, constructions, and meanings.

Since 1997 and the implementation of a new curriculum, an elective course, Nursing and People with Disabilities, has been offered, not to prepare students for speciality practice, but rather to raise consciousness regarding people with disabilities - people with whom they will come into contact, in whatever area of nursing they choose to practise. To date, about 50 percent of our students have elected the course which is offered over eight weeks and takes the form of three-hour workshops. Students are required to read around the topic for the week prior to class. These readings, along with personal and professional experiences, are workshopped in class using scenarios and trigger questions to guide the discussion. This occurs in an environment of shared storytelling and learning with the emphasis being exploration of ideas such as:

- * Societal values and attitudes (including transcultural), ethical issues, rights, and discrimination.
- * Models and paradigms of disability and the impact of various conceptualisations for people with disabilities.
- * The experience of disability, with an emphasis on the family.
- * Evaluation of supports - includes policy and legislation, access issues, education, services, work, recreation, technology.
- * Implications for nursing.

As part of their assessment, students negotiate a relevant topic of interest to research and explore in detail for their semester paper. Some topics chosen by students in 1998 include: "Helping people with intellectual disabilities to grieve" (written by a student working in an institution for people with intellectual disabilities); "The impact of health professionals' attitudes on care for people with developmental disabilities"; "Heart failure: A hidden disability" (written by a student working in cardiac rehabilitation); "Quality of life: Institutions vs. Home" (by a student working in a large institution); "Living with a disabled child at home" (by a Chinese student whose younger brother has cerebral palsy and who wished to examine cultural differences); "Epilepsy: 'Disability' because of its effects or because of stigma?"; "Inside a Deaf world" (by a student with a hearing impairment); and, from the local perspective, "How is the Aboriginal community handicapped in the Australian society?"

The words of one of these students, reflecting her struggles with written English, manage to capture some of the purpose of this education:

Nurses are not only known to be a carer of the sick but as well, an advocate for the rights of the people they care for. Being that disabled people are still part of the society who would have its own especial rights, this therefore makes it a responsibility to caring nurses to know these rights to help ensure they will not be violated or ignored. ("Reaching towards equality for people with disability," 1998 undergrad paper)

Feedback from other students, and evaluations of the course, have been consistently positive with the majority of students stating that the course should be compulsory, i.e., part of the core curriculum.

Teaching Postgraduates: M.a. Nursing (Disability) and M.a. Nursing (Rehabilitation)

Our Masters program in Nursing was first offered in 1997 and is the only one of its kind in Australia. It is also unique in that uses disability as its unifying theme. This was a difficult concept to sell during the development of the course, as I discovered, for to rehabilitation nurses, disability is a dirty word. They told me that they did not want to know about disability as this is what they were fighting against. They said that the people they worked with were not disabled, and that the nurses' job was "to ensure they did not become disabled." These views were held by nurses working with people with brain injury, with spinal cord injury, with neurological insult, and with degeneration, etc. It was clear that, for many of these nurses, disability meant "people who were *born* like that."

I was rather startled by the realisation that the rehabilitation nurses had no understanding of disability as concept, as theory, as an area of debate and study, or even of its relationship to policy and legislation. Most, in fact, saw any discussion of disability as something to be avoided or to be approached in a theoretical sense, as something involving the management of grief. For a time it seemed that many would not support a course which included disability in its conceptualisation, which in fact *emphasised* disability, which outed it for candid discussion.

Nevertheless, our MA program now features an introduction to Disability Studies, via the course "Studies in Disability: Contexts and Meanings." This course aims to help students do four things: 1) understand concepts of disability from historic, cultural and social perspectives; 2) critically analyse paradigms of disability; 3) evaluate services for people with disabilities within a context of current social policy and legislation; and 4) explore the experience of disability from multiple perspectives.

Students attend three-hour workshops for fourteen weeks in which the history, paradigms and models of disability are addressed; along with discussion of the philosophical, social, political and legal frameworks; a critique of services for people with disabilities; and exploration of ethics, meanings of disability, and human responses to disability. In recognition of the diverse nursing practice experiences of the students there is a fair degree of flexibility in the subject. The first few sessions focus on the core underpinnings and are facilitated by myself or by a guest expert, whilst the remaining sessions are facilitated by the students who negotiate a topic of interest for in-depth exploration. Generally, they link their workshop topic with their major written paper and use the class session to "nut out" some issues. Examples of topics addressed in 1998 include:

* "The segregation of leisure and fitness activities for people with disabilities: 'Activity as therapy.'"

* "Language as oppression: Nurses' talk about people with disabilities."

* "The impact of disability legislation on services."

* "Guardianship legislation: What does it mean for nursing practice?"

* "The impact of acquired disability: Implications for rehabilitation."

* "Sexuality and disability: A hidden dimension."

Many of these MA students are highly experienced practitioners and a number hold senior positions in the profession. They all report being challenged (particularly by the social model proponents), being caused to think and speak of changing their practice. Frequently, "being challenged" is a painful process, and includes "feeling insulted" and "wondering why I've spent all these years doing my best to care for these people." By the end of semester, however, the students believe they are developing new understandings, and have commented that "All nurses in rehabilitation should know about Disability Studies."

This is a quantum leap from the thinking that was predominant during the course development. Remember the nurses who thought disability was a dirty word? They are now some of the staunchest supporters of the approach, and believe that their understandings and practice are enriched by the perspectives of other disciplines. Students, too, are examining the broader issues and are being proactive at an institutional level. They are, in French's (1994) words, "widen[ing]

and deepen[ing] their knowledge of disability and join[ing] disabled people in their fight for justice" (58).

Implications for the Pediatric Ward

Revisiting my "joy and sorrow" research and the ongoing contact I have kept with families and professionals, I am now involved in study of the difficulties encountered by disabled children and their families when they go to hospital. There is much anecdotal evidence and some research (Robinson, Oxnam, Kelly, Broadbent & Dillon, 1993) which indicates that children with disabilities have a more difficult time in hospital than others. Robinson et. al. describe the nursing experience of caring for children with disabilities on an orthopaedic unit and suggest that "at best the care provided by nurses, to families of children with disabilities, is of an inconsistent quality" (25). The authors contend that supporting a child with disabilities involves a high level of complexity and that difficulties arise due to the focus of nursing being on medical and technical issues rather than on "the child's disability and the maintenance and restoration of pre-existing abilities following surgery" (25). The nurses in this study recognized that their inability to verbally communicate with many children with disabilities resulted in conflict between nurses and parents and acknowledged some situations where children are effectively silenced in terms of representing their own interests or needs, in their ability to participate in decisions, and in their increasing dependence on carers. Such silencing of children with disabilities may be understood in terms of nurses' predisposition to view people with disabilities as tragic alongside a general underestimation of such peoples' capacities, abilities and human qualities (Gething 1992).

Even when technical nursing/medical care/intervention is excellent, many families report feeling devalued, isolated and marginalised. Their expertise is being dismissed, frequently with adverse effects for their children, e.g., inadequate pain control. Their children are treated as objects and, not uncommonly, are accused by staff of "not belonging here" and "taking up too much time." Parents who have, in the past, not been believed regarding their children's often subtle symptoms, will hesitate and delay before going to hospital again - sometimes with dire consequences. These parents, like those in my "joy and sorrow" study, speak of everything being "a fight" - they say they have to constantly battle and advocate just to get what is right and just for their children. One mother, herself a doctor, says that she now understands the look which she now shares with other parents of disabled children - it comes from previous combat experience and the anticipation of negativity or rejection.

In an environment which is attempting to integrate services for people with disabilities, it is imperative that all health professionals, and in particular nurses, provide an appropriate and sensitive service to people with disabilities whom they meet in hospital. We need to educate paediatric nurses regarding disability because it is these nurses who have the highest level of contact with disabled children when they require treatment for their medical conditions. Further research in the hospital experience will provide more knowledge about intervention and will help us improve the encounters within acute paediatric services for disabled children and their families.

Suddenly a Child of a Disabled Parent: Another Adventure

All my childhood, nursing education, and subsequent scholarly activities - teaching, research, supervision, consultancy, curriculum review and development, writing, conferences, membership in community and professional organisations, keeping current in the disability literature - have had a very important influence on my development in recent years. My recent honorary appointment at The Royal Alexandra Hospital for Children puts me in a position to advocate, consult, educate and research in the clinical setting which will provide broader opportunities for the inclusion of the disability perspective. Yet, all of this has been undertaken from the observer's point of view, looking through the disability lens and, while I have developed a strong sense of advocacy for the academic inclusion of issues related to people with disabilities, nothing

had touched me personally or prepared me completely for my mother's severely disabling stroke three years ago.

It was hard to make sense of the fact that one day Mum was an independent woman whose life revolved around meeting with friends, animated and opinionated conversation, reading, going to the theatre, being a Red Cross telephone support person for isolated people, driving for Meals on Wheels, and keeping tabs on her children via the phone. And the next day, she was close to death, unable to move or speak. Two days after the stroke she communicated to me through mime, drawing an invisible noose around her neck and then tightening it, expressing an unspeakable desire.

The trouble began when the medical staff were keen to admit her to a nursing home while I was keen to get her into a rehabilitation program. "Not worth it. . .," the medicos indicated, ". . . she's too old, too frail, too sick - she'll never make it."

"But you don't know her," I insisted; "she's stubborn, determined, and high-spirited." Suddenly, I was the family member fighting for my loved one's rights, that daughter who's demanding aggressive rehabilitation for her sick mother. But I was just trying to get them to understand that life is not just survival; life is about living.

Suffice to say that what followed was a very distressing and prolonged period of fighting the system, denying the verdict, and advocating for Mum, who has defied all odds and is still with us. My own situation, however, is now very similar to all those families with whom I had worked and researched for years. When my partner resigned her academic job to become my mother's carer, I recognized first-hand the total disruption and restructuring of lives that disability had meant for my clients in the past. It meant moving house (for Mum, that included moving away from her familiar neighbourhood). It meant organising children's schedules, a sharp drop in earnings - all the things associated with caring for disabled relatives. It means that we now have the combat fatigue that others speak of, and that my partner's and my lives are now largely defined by my mother's needs. We are living the disability experience, but even though we are subject to its vicissitudes, we are Mum's allies and have ensured that her impairments have not made her dependent. Independence is about having control in one's life, and this is indeed possible, when carers are allies and hope is maintained.

I use this personal experience in my nursing classes daily, along with the works of the disability scholars. My students respond well even as their most basic assumptions are being challenged regarding disability. They enjoy the highly contextualised nature of the teaching. I feel that these accounts of the disability experience are vital to the education of nurses and that they contribute to the development of further research and understanding. I am determined that all the students will be imbued with a sense of the dignity of all human beings and that, by connecting multiple experiences and by collaborating in research and education, these new professionals will go far in bridging the worlds of the disabled and the non-disabled.

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