

THE ROLE OF HEALTH PROFESSIONALS IN THE NATIONAL DISABILITY INSURANCE SCHEME.

The PANDAA conference has a long history of identifying with the vital issues of Australians living with disability and collectively you work to raise standards of support to improve the quality of life for these people who have faced many barriers in our community.

Today I want to first provide an overview of Australian disability policy over the last twenty years and in particular focus on deinstitutionalisation and the experience in Tasmania of adopting a community based model of care.

Secondly I will consider the readiness of the disability workforce to prepare for the introduction of the National Disability Insurance Scheme and the implications this has for service providers learning to balance their duty of care responsibilities with client choice and control.

Finally I will examine some of key issues affecting health professionals working in a very new national disability environment.

INTRODUCTION

I was introduced to the disability sector as a young teacher working in a Tasmanian country area school where I had a large class of 42 7 year olds some of whom had limited capacity for early learning.

In order to survive this challenge I grouped children by ability giving more advanced pupils the opportunity to work at their own level and spending more time with children who needed kindergarten and pre reading activities.

My efforts were noted by the principal who asked me to consider applying for special

education training for work with physically and intellectually disabled children in newly established special schools.

I volunteered and found myself on a two month crash course at the St Giles Home for Crippled Children in Launceston. I then spent two years as Teacher in Charge of the Devonfield Special School in Devonport and from here went to the state's mental Institution Lachlan Park in New Norfolk.

It was here I learnt about the controlling nature of institutional care...usually well meaning but devoid of responding to individual needs. Patients were treated en masse for their various mental health disorders this usually taking the form of excessive prescribed drugs to manage errant behaviour. This included children and teenagers who initially arrived at school barely conscious. My complaints to the Medical Superintendent that we did not want the children heavily medicated were met with some amazement and he assured me he would re instate the drug regime if the children were disorderly

But the children were like all others...lively and inquisitive and needing intellectual stimulation and reprieve from the drab routines of institutional life. Some had specific intellectual or physical disabilities, while others had been cast out of society by families as uncontrollable or by courts as criminal. It was a disturbing example of the people who were rejected by Australian society in the 1960s

Forty years later I returned to Tasmania as State Manager of National Disability Services, the peak disability service providers' body responsible for working with government and progressing disability policy reform

It was extraordinary to return to find so that so many attitudes and practices remained embedded in the state's system of supporting people living with disability.

The state had just closed its mental institution and embarked on a community living model for several hundred people who had spent their lives in a very controlled environment. It was a good decision by the State Minister for Health, Judy Jackson.

However her genuine reforming efforts were not matched by other areas of government. Treasury saw dollars to be saved in no longer having to maintain such a large piece of infrastructure. Staff were not offered redundancies or retraining so many were resentful or suspicious of the new policy. Central to this upheaval was the role of nursing professionals, especially mental health nursing staff who were not seen as necessarily suited to the new community based model. Indeed being somewhat suspicious of Treasury's motives in this decision I believe that it may have been an incentive to enable the employment of non professional staff as it enabled government the opportunity to devolve responsibility to the not for profit sector

As often happens with dramatic changes in government policy insufficient thought was put into the transition and there was absolutely NO coherent workforce preparation.

New non government organisations were contracted to take up the challenge of reform but had to manage their own staff development with limited resources. Some individual organisations recognised the vacuum in leadership and were innovative in balancing old and new thinking so that an appropriate mix of staff qualifications gave clients guided support in a healthy safe environment. However, the major shift in policy combined with inadequate funding, meant that many health professionals moved from the disability sector to aged care

DISABILITY POLICY DEVELOPMENT 1993- 2012

The International Year of People with Disability in 1981 stimulated a great deal of energy and vision about new models of care for people with disability. Advocacy for recognition of individual rights had developed during the 1970s and ultimately this resulted in national disability discrimination legislation in 1986.

In Canberra's Parliament House at the time a number of young people with intellectual disability were employed as messengers to distribute mail. Their very visible presence seemed to be a reminder that so much more remained to be done in extending national disability policy to employment opportunities

Further legislation in 1992 and a review of wages and conditions in sheltered workshops led to new disability employment services with stronger links to the community.

Over the past ten years there have been important disability policy initiatives in some states with Western Australia establishing an independent Disability Commission that introduced local area coordination and Victoria initiating individual support packages. New South Wales committed to a major investment in disability funding and other states and territories began to see the urgency for reform. Yet from a national perspective there was no coherent strategy with services being rationed and delivered in an ad hoc manner.. Geography often dictated the level of service and there was no certainty or consistency in planning for individuals. The medical model of disability prevailed with limited focus on individual rights and citizen entitlements

NATIONAL DISABILITY INSURANCE SCHEME.

The concept of a national insurance scheme to provide a safety net for citizens was first raised by Gough Whitlam in the 1970s. He envisaged an Australian scheme including features of the United Kingdom's National Social Security Scheme. While Medibank and subsequently Medicare offered universal health insurance, there was no specific recognition of the additional costs associated with the provision of disability services. For over thirty years the disability sector lobbied for recognition of their entitlement to specific disability support. State and Federal Governments responded with a range of different programs all with ever changing guidelines, funding agreements and limited resources.

It was not until the Vision 2020 Summit in 2008 that the idea of a national disability insurance scheme with strong advocacy from University of Tasmania's Professor Christopher Newell, author of 'The Changing Face of Disability in Australia' and Melbourne businessman Bruce Bonyhady, now Chair of the National Disability Insurance Scheme Board.

It was an idea floated at a significant national event but it required a champion within the Federal Government. to take it to the next stage of serious decision making. Newly elected Bill Shorten became Parliamentary Secretary for Disability in 2008 and worked hard to understand the portfolio...He saw disability as a form of apartheid and spoke extensively around the country for a new way of ensuring people with disabilities accessed their rights as citizens.

In 2010 the Federal Government referred the concept was to the Productivity

Commission which conducted hearings around the country and in their final report concluded the existing system to be “underfunded, unfair and fragmented”

It recommended a national insurance scheme with clear eligibility guidelines and lifetime support for those requiring it.

With this unequivocal demand for reform it was up to first the government and then the parliament to act to introduce what became known as the National Disability Insurance Scheme...later known as Disability Care

Few policies attract support from all sides of politics but there was cross party support for a scheme whose time had not only come but was in fact overdue.

The scheme has now been agreed in all States and Territories and four launch sites ...

Tasmania, South Australia, the Hunter in NSW and Barwon in Victoria

commenced on July 1 this year. Western Australia, Australian Capital

Territory and Northern Territory will join the roll out of initial services in July 2014.

Queensland will join the scheme in 2016

In Victoria and New South Wales the launch sites are focussed on people living in particular regions, while South Australia is working with children and Tasmania with young people 15-24 years.

Therefore Disability Care is trialling new ways to approach disability support across a wide age range and in selected regional areas.

This will enable comprehensive evaluation of experiences and enable adjustments to the scheme as it expands around the country

The Disability Care Website is

www.disabilitycareaustralia.gov.au

It includes a range of information and publications for individuals and service providers
The key difference in Disability Care is that it puts the person with disability at the centre of planning and decision making. For many years now specialist disability services have been obliged to try to fit the person into the most accessible and economic model that government will subsidise. This has resulted in services that do not necessarily provide the kind of support an individual needs. People have been required to fit in to what is available rather than services consider what best suits the individual

Central to the design of Disability Care is placing the individual at the centre of decision making to exercise choice and control. .This is a major challenge for services but it is also a challenge for families and individuals.

It is also a challenge for professional nursing staff who have maintained their commitment to the disability sector despite the uncertainty associated with policy shift and chronic underfunding. of the past

On the positive side the new scheme has recognised the role of nursing staff by highlighting the desirability of their skills in attracting staff to work within Disability Care.

.Nevertheless there is considerable uncertainty among employers about how the new model of support will impact on the business models of some service providers who will no longer be eligible for block funding that guarantee specific services.

The principles of Disability Care are welcome and long overdue but the mechanisms of best practice will take time and patience to resolve that balance between client choice and control and the delivery of quality standards of support and care. Early intervention is

a special characteristic of the scheme and this is obviously a significant area of expertise among nursing professionals.

Some of you will also have experience of comparable reform in the aged care sector and will bring important insights to how that experience may be used to inform the introduction of Disability Care.

Certainly there has already been criticism that Disability Care has eligibility criteria birth to 65. Those who enter the scheme before 65 are guaranteed on going support and over time this will guarantee lifetime care.

However there are those currently over 65 who see aged care as inadequate and therefore view this age designated criteria as discriminatory.

It is not an easy argument to win with older citizens except to point out the existing aged care service regime and improvements for the future.

As an organisation PANDDA is ideally placed to both monitor standards of care and advocate models of best practice. In the early years of the scheme there will be a need for strong voices to speak up about how the new scheme can be refined to ensure the best possible level of support for some Australia's most vulnerable citizens

Despite Australia initiating this major overhaul of disability policy there remains much to be done in changing attitudes and practices.

The United Nations Committee responsible for monitoring how well Australia is maintaining its commitment to the Convention on the Rights of Persons with Disability signed in 2008

brought down its report last week. Issues of major concern include

- Continuing use of restraints, shackles and seclusion of people with psychosocial disabilities in hospitals
- Sterilisation of women and girls without informed consent
- Provision of disability services in indigenous communities
- Access to Justice
- Employment

Clearly despite the justifiable celebration of Australia's introduction of a national disability insurance scheme there is still a long way to go in guaranteeing that people with disability the kind of citizen entitlements we all take for granted. I know that you and your organisation are committed to working through these challenges to raise standards of care and support throughout the country

Presented by Margaret Reynolds

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