

Launch of DVD

A Place to Call Home -talking about devolution

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Thank you Allen Madden for your warm Welcome to Country.

On behalf of Greystanes Disability Services and the WSIDSG I would like to welcome you all to a very special and important occasion this morning.

Welcome Minister and thank you for agreeing to launch A Place to Call Home: talking about devolution. We really appreciate you being available at such short notice -your first official occasion on this your first full week as Minister for Disability Services.

I was recalling on the weekend that it was back in the mid 80s that you and I both worked in the Department of Community Services. In those days I think you were working in the policy area in head office and also had operational roles in both head office and regionally. I was involved in closing the Department's three large residential institutions for state wards who had an intellectual disability, and developing the services to support them in the community. Those large residences were Clairvaux at Katoomba; Werrington Park near Penrith which is now the site of the University of Western Sydney Werrington campus; and Brush Farm at Eastwood which is now an educational facility for staff of Corrective Services. So how remarkable that our first major contact after so many years should be for you as Minister for Disability Services to be celebrating with us the successful closure of another institution, and to be launching a DVD about devolution.

In my years of working in the public sector I was required to prepare many briefings for many new Ministers over that time. In most respects this event today is pretty much another of those briefings. It will identify some of the key issues, it will highlight some key things that have been achieved, highlight some pressing issues and matters that haven't been achieved, and identify some priorities that need to be addressed. As a result I hope you will be further informed, that you will be moved by the courageous journeys of the families and individuals in the DVD, and be inspired to address the pressing issues around devolution.

The Greystanes Children's Home at Leura accommodated about 40 children and young adults with intellectual disabilities, having been established by the late Elizabeth McDonald in the early 1950s. Greystanes operated on a traditional medical model, where most of its staff were Registered Nurses or Enrolled Nurses, where residents shared bedrooms and lots of equipment, and where access to the community was largely via group excursions.

About 12 years ago the then Board of Directors proposed, and the then Minister approved, a redevelopment plan for Greystanes. That plan included the building of two large 12 bed so called group homes, on the same grounds at Leura. Clearly it was a plan that didn't comply with the NSW Disability Services Act 1993, its Principles, and Applications of the Principles in a number of ways including:

- it would not be in the community;
- it would not be in ordinary housing;
- it would not promote maximum physical and social integration in the community;
- it would not enhance the image of people with disabilities; and
- it would still be clustering large numbers of people with disabilities together.

Appropriately, very strong concerns were expressed about the plan at the time.

Understandably, it was a time of great anxiety for parents and for staff, who worried about the future, and about how appropriate support could be provided in the community if Greystanes was to close. Most of the residents had been in Greystanes since they were young children. Many parents were generally satisfied with their child being there, and many of the staff had not worked in community based disability support services and had worked at Greystanes many years.

But nevertheless and thankfully the proposal was legally challenged. And as they say the rest is history. But a very positive and a very important history.

Instead of developing its 12 bed group homes, Greystanes was required to provide a service that did comply with the DSA. The old Board resigned and a new Board embraced a new plan, a plan that complied with the DSA. Parents, guardians and advocates were actively engaged along with the Department, to ensure proper implementation of the plan.

As a result these young adults with intellectual disability progressively moved into ordinary housing, in ordinary neighbourhoods, in ordinary streets and alongside ordinary neighbours. Not into a centre, not into a complex, not into a facility nor into a cluster. Where they live has no special name, just a house number, in an ordinary house, in an ordinary street and alongside ordinary neighbours -just like you and me. This was as a result of the great work of the residents and families of Greystanes; of staff of Greystanes past and present including Jo Ridley, Bob Weaver and Sue Lennon; of the commitment of the Greystanes Board of Directors and of the Metropolitan North Region of Ageing, Disability, and Home Care Department of Human Services NSW.

The devolved service supports people with severe intellectual disability who have complex health care needs. Many have complicated health conditions and significant physical

disabilities as well. A number receive their meals through a tube in the stomach on account of the high risk of aspiration. Many have epilepsy, cerebral palsy and sensory impairment, and for many the flu virus is a life threatening prospect.

The new service doesn't operate on a medical model, and its frontline support staff are not primarily nurses. They are support workers who have completed or are undertaking Certificate 3 or 4 in Disability Studies. All of the people supported enjoy meaningful social and educational day programs away from where they live. Good health care is provided on the basis of individualised Health Care Plans involving the person, their parent or guardian, the Greystanes' Health Care Team, support staff and the person's own personal General Practitioner. Our Health Care Team includes a Clinical Nurse Consultant, Physiotherapist, Speech Pathologist, Registered and Enrolled Nurses, and a soon to be recruited Dietician.

I followed some of the Greystanes devolution news in the local Blue Mountains Gazette and in the broader media, including on ABC Stateline, when it featured. I was working in the Attorney Generals Department at the time as the Director of the Office of the Public Guardian and then later as Director of Victim Services.

When I was appointed as the CEO in April 2008, Greystanes had been fully devolved for at least two years. So I asked parents of those people now living in the new Community Living Program how they felt back when they were originally told that Greystanes had to close. Overwhelmingly they said they were alarmed, fearful and angry. Many said they were happy with Greystanes at the time, and the prospect of moving their son or daughter into the community raised major concerns for them, concerns about safety, health care, community acceptance, and ongoing security of tenure.

I then asked how they felt about the new Community Living Service and what it provides for their son or daughter, now that Greystanes had closed. Overwhelmingly parents expressed very strong and very positive opinions about how so much better things were, compared to when their son or daughter was in Greystanes.

Their comments included things like the right to live in the community and be fully included, better health care, community access, the dignity of living alongside ordinary neighbours, individualised attention, and privacy and space.

Most significantly, a number of parents said to me: if only I had known back then how much better things could be for my child. If only I had known, it would have saved me so much anguish, and I wouldn't have had to waste so much energy in trying to fight it.

All of this was so important, and it is the reason I decided to produce the DVD A Place to Call Home –talking about devolution. I thought if I could capture this it would help a lot of parents who currently have their adult sons and daughters in residential institutions. There were important and powerful stories here that needed to be told. I thought it might also

help other people who have involvement in large residences, such as front line staff, service providers and of course funding agencies and government.

I thank David Coyne, the then Acting Regional Director of Metropolitan North Region of ADHC, for providing funding towards the cost of producing the DVD. David along with a number of other senior staff of the Metro North Region, including Serge Perrine, were closely involved in the Greystanes devolution, and I would like to put it on record that much of what has been achieved is a tribute to their support and commitment as well.

I confess I have absolutely no skills in producing visual media. All I wanted was the stories these wonderful people had to tell. But as you would imagine turning this into reality is not a simple business. We were so lucky to be referred to Lesley Seebold and Rod Freedman of Change Focus Media. The DVD is a testament to their professionalism, skill, and the very respectful way they worked with the families and individuals concerned.

In the Facilitators Guide on the DVD there is a web link to an important resource provided by Family Advocacy called, "Presenting the Evidence: Deinstitutionalisation, A Review of Literature". You see, the research tells us that when deinstitutionalisation is done properly, parents will almost always be satisfied with their sons and daughters move into the community, after it occurs. We see this in the DVD.

Devolution is a pressing issue. Thousands of people with intellectual disability still live in large residential institutions throughout Australia. In NSW alone there are more than 1500 people with intellectual disability living in approximately 30 large residential facilities. Nine of these, and certainly the largest, are operated by Ageing, Disability and Home Care, and accommodate well over 1000 people.

Time is fast running out for many of these people to have their chance of a decent life, living in the community. And in October this year, it will be 12 years since the Government's announcement of its 12 Year Plan to close all of these facilities and provide appropriate support for these people in the community.

Minister, we ask you to champion these important matters in your new portfolio. So few people have moved out of institutions over those 12 years.

It is very distressing that rather than closing these institutions some are in fact currently being rebuilt or have already been rebuilt. Rebuilt in ways that are contrary to the DSA, contrary to the spirit and intention of the DSA, and contrary to the United Nations Convention on the rights of disabled persons, a convention to which Australia is a signatory.

And what message is this for people with intellectual disability that these institutions are being rebuilt? What message is this for their families? What message is this to those families who are understandably nervous about devolution, that is those families I talked about

earlier? Those who would ultimately embrace devolution, if it was to happen and was done with genuine consultation, with the appropriate resources and with committed leadership.

And in the modern and enlightened year of 2010 what message is this for the community of NSW? Do we really want to promote a message that people with intellectual disabilities are different to everyone else? That they don't belong along side ordinary neighbours, in ordinary housing, in ordinary streets? Or is it that because of their particular needs, we in 2010 still only know how to provide services in special accommodation facilities such as centres and clusters and residences and complexes? In environments that segregate them from the community.

No one got it wrong when Greystanes was made to devolve. The necessary resolve was there, so too was the willingness, including that of Ageing, Disability and Home Care, to properly plan, provide the information, genuinely engage with parents and guardians, and allocate the necessary resources.

There is a significant number of people with intellectual disability who have complex care needs, currently living in large residential facilities in NSW including in government run facilities. It is still often contended, when discussing how best to support people with intellectual disability who have complex care needs, that they can't be adequately supported in the community. This argument is usually put when justifying or defending the role of large residential facilities. This was the argument used when the non-conforming Greystanes devolution plan was first proposed. But it is clearly untrue and you will hear more about this in the DVD.

We have an obligation to provide people currently in large residential facilities and their families and guardians, with all the information and assistance they need. We must do this so that they can fully explore and consider alternatives, and to ultimately be empowered to fully participate in the planning and implementation of a devolution strategy. That is a devolution that is necessary to ensure the person with a disability enjoys their right to a life in the community. We hope this DVD can be one of the resources to assist in doing this.

Obviously the DVD would not have been possible without some very generous, courageous and remarkable people agreeing to tell their stories. Stories about their journeys through a devolution process; about their concerns and aspirations for their son and daughter in relation to a future devolution; and about life now, having previously lived in an institution for more than 30 years. We are privileged to have a number of these people here this morning and to be able to hear a little more of their important stories.

Thank you.

John Le Breton

24 May 2010

