

20 June 2010

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Disability Care and Support Inquiry

Productivity Commission

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Dear Inquiry Members,

I am forwarding to you through The Honourable Adrian Cook R.F.D., Q.C. submissions I wish to make to your Inquiry. I am deeply concerned and worried that there appears to be no provisions in the Issues Paper or elsewhere that the position of Norfolk Island (as an External Territory and part of Australia) will be considered by the Inquiry.

You will see from copies of letters (including my notes thereon) I have enclosed that both the Commonwealth and the Administration of Norfolk Island appear to have 'washed their hands' over the very urgent and real needs of disabled people on this Island. The Honourable Adrian Cook R.F.D., Q.C. has offered his services and advices to assist in changing this apparent failure to address a very real problem of the Island "falling between the cracks". He intends to take the opportunity in due course, to make oral (and written) submissions to the Inquiry. He has expressed his view that Australia's obligations under International Covenants and Conventions require that, at the very least, the terms of the Inquiry should be enlarged to encompass Norfolk Island's situation. He has told me that he will write to the Inquiry at the time he sends my Submissions to you.

He showed me a Press Release (a copy is enclosed) as to the new Committee on Human Rights and I have commented on this Release as an addendum to my Submissions. As my submissions to the Inquiry reveal I have had a genuine and long time experience with disabled persons on Norfolk Island. I have no professional qualifications but I am emboldened to believe that my story will provide you with a real understanding of Norfolk Island's needs for the disabled within our community.

I have also included for your information a copy of a letter from the Human Rights Commission and my reply thereto. I made an application some 12 months ago to the Commission. The delays and difficulties over the progress of my application highlight the real problems facing those who wish to help disabled persons on Norfolk Island. I will now proceed with my submission to you.

COMMENTS ON PRODUCTIVITY COMMISSION – DISABILITY CARE AND SUPPORT ISSUES PAPER

p. 2 – Widespread view that current [mainland] system is deeply flawed and will increasingly be unable to meet needs

This is a very sobering statement in an environment where disability ‘systems’ are already in place. The absence of proper systems and provision on Norfolk Island means pressures on the disabled and their carers are double-fold. Our ‘lottery’ is based on where we live (an external self-governing territory of approximately 1800 people), personal resources, and how the disability is acquired. As previously mentioned our situation is inherently tied up in intergovernmental arrangements which have failed to properly address the needs of the disabled in our community. Proper and equitable care of our disabled should not be compromised by intergovernmental arrangements.

This ‘lottery’ also depends on how vocal and resourceful carers are, how much ‘education’ is sourced on how to cope, where the resources are and what resources can be personally met or begged, borrowed or wrangled, the level of care of mainland case managers, physical access to services (eg geographical isolation) and ultimately entitlement.

p. 3 – A new national disability scheme

As an Australian citizen living on Norfolk Island without adequate provision for the person for whom I am a carer, and for those I care about, I find ‘national’ a perplexing concept. It must surely include Norfolk Island, at least in terms of the scope of ‘consideration’ of the Inquiry, if not the ultimate extension of the scheme to disabled Australians living in Norfolk Island, albeit in a different form and perhaps with provisos attached.

The paper goes on to say that the intention of the new scheme is that it ‘takes account of the desired and potential outcomes over a lifetime, with a focus on early intervention’ This is so crucially important for all disabled children, early intervention has proven to be a key in giving disabled children the best chance. My little friend Jeremiah is now three, he has been diagnosed as having high end autism spectrum disorder; he also has a cleft palate; it has been an immense personal struggle for his family to get the limited early intervention services they have managed to wrangle. In his case too little too late has denied him the best opportunities now widely recognised as being extremely beneficial to autism sufferers. The key to proper care lies in the fact that these kinds of disabilities (autism) are ‘lifetime’ afflictions both for the sufferer and their families.

p. 5 - Rural and remote areas

I think people in rural and remote areas such as ours generally accept that they cannot always achieve the same level of access to goods and services that their metropolitan counterparts can,

these are personal 'trade-offs' in choosing to live, or needing to live remotely. The reasons people live in rural and remote areas are many and varied. People should have the right to choose what is best for them and their families without feeling that they are second-class citizens. The UN Conventions on the Rights of Persons with Disabilities I am sure does say, and I may be paraphrasing it here, that a person has the right to choose where they live and that this should not prejudice their rights. There is a basic level of goods and services delivery that should form the core minimal delivery standards nationwide, including to the disabled living in rural or remote areas such as Norfolk Island. It would be grossly remiss if living in remote areas is the factor which denies equitable access to goods or services. Remote area delivery requires greater levels of creativity and a flexible approach. Consultation can mean that people with similar levels of need irrespective of where they live, as far as possible, can get similar or adequate levels of support and happily continue with their lives. It needs to be a personal question – what is it that you need to maintain a quality of life? Flexibility is the key. One of the most stressful factors in external territory living is the need to go to the mainland, often by medivac for extended periods. The costs associated with this are crippling for most families. A well considered scheme may mean giving families the option of financial support for temporary relocation to access, for example, child development services, or rehabilitation.

P 7 Box 1 – Some Definitions

Both Alice (double amputee with other conditions) and Jeremiah (autistic/cleft palate) fall towards the severe end of 'activity limitations'; it is those people in particular that we should advocate justice and change for, both now and into the future. These people generally require specialist care and disability services on an ongoing basis. They require the greatest level of full and proper support.

p. 8 – Level of support needs

Jeremiah is a person with constant life-time support needs; Alice will require support for the remainder of her life. At present she has regular support needs – this may progress in time to constant support needs. There are other disabled people in our community who require varying levels of support. Are they and their families getting the support that they need; could the quality of their life be better with better more comprehensive support? In my view, using Alice as a case study, it is an unsupportive healthcare system that supports the amputation of both lower limbs but does not support the attendant home renovations or the provision of a wheelchair or pressure care equipment.

p. 11 – A 'no fault' system

NSW has no-fault system (eg no-fault acquired brain injury) other jurisdictions do not. Disability at birth, no-fault injury or progressive illnesses such as Type 2 Diabetes, etc are fault-less conditions out of the hands of the individual. A national no-fault system, which includes Norfolk Island, would provide an essential and valuable safety net for all high-end disabled Australian citizens living in 'Australia'. There are, and have been, a number of injury-related disabled individuals in our community. They are forced to move to the mainland or rely on the charity of family or the community. When you talk about disability I have also noticed how disabling degenerative or chronic illness such as cancer is in a remote community such as ours where families travel often and for extended periods to undergo expensive and protracted treatment, often over a number of years.

The cost, to say nothing of the emotional burden, is catastrophic. This is an issue particular to all remote areas within Australia.

P. 13 – UN Conventions on the Rights of Persons with Disabilities

Disabled people everywhere should have the right to choose where they live, the right to live independently and ‘the right to live in the community’ – the PADP (Provision of Aids to Disabled Persons) Scheme in NSW recognises that some types of disability require ‘enabling’ equipment and home renovations in order to assist people with the right to return to independent community living; this kind of provision is non-existent in the Norfolk context. Alice has had to rely on charity to achieve a ‘renovation’ of some kind. It was done by kind-hearted people who are not necessarily qualified builders, or specialists in disability renovations. It has been charitably funded. It does not comply with any ‘standards’ as they are non-existent. The result is substandard - an awkward, sometimes stressful and unsafe facility for which she remains very grateful.

p.16 – Eligibility and needs assessment

There are all kinds of disabilities and degrees of need. My focus is on high end needs because the high end needs people are those most in need of proper support in our community; but essentially I believe all disabled people should have access to a fair, equitable, and reasonable level of support. I recognise that we live in a context where there are limited provisions and limited resources. In my opinion Alice, for example, as a double amputee could not do without a motorised wheelchair and bathroom renovations to remain in independent living and continue to participate in society at the level she wishes to. Her case workers at the Balmain Rehabilitation Hospital agree. Need and eligibility is generally in such cases quite clear. Jeremiah simply cannot function independently and requires full-time care. It is this high end needs group that have been severely disadvantaged by the current status quo on the Island. Assessing need is in some cases a regular requirement. Alice’s needs are on a sliding scale, increasing in need and severity, the ‘need’ may change gradually or abruptly and assessment processes need to be flexible and responsive to recognise changing needs.

Other disabled people may live with a disability for the better part of a lifetime; as they age their aging may affect their general ability, which is compounded by their existing disability which they have been able to live with and cope with to date. In these cases it may be decades before needs re-assessment is required. In these cases people may not even perceive themselves to be disabled until they are no longer able to cope with everyday activities (eg a young person with a leg amputation through injury generally has good mobility and cannot foresee the difficulties of mobilising in their senior years)

p. 17 – Carer allowances

There are no specific/dedicated Carer Allowances on Norfolk. Those caring for the aged and disabled put their lives on hold to care, they accept a lower quality of life for themselves in order to care. Sacrifice and compromise is part of the ‘cost of care’ for the disabled, the carers, their families – even the family dog gets less love! I know one carer who can only work two days a week, during which time the person she cares for frets. She finds this stressful and it is difficult for her to make ends meet. He is a 90 year old Returned Services Veteran. Approaches have been made to the Department of Veterans Affairs and the Norfolk Island Government in this case for some carer relief.

I also know of another carer who does receive a kind of allowance in order that he can care for his wife. I know that he needs this support very much. In the absence of legislative frameworks I just don't see that there is a clear or fair assessment and eligibility criteria. In the case of carer allowances I do not believe that the granting of such 'allowances' in the Norfolk Island context should be 'discretionary', there should be very clear legislative frameworks and guidelines to ensure justice and equality for all concerned.

As a voluntary carer myself I feel that this is a matter for others to fully investigate, but in the case of profoundly disabled children where a parent is a full-time dedicated carer and will remain so for the remainder of their life, and in the absence of respite care services and other professional services found in metropolitan areas, a carer allowance gives very limited but necessary relief and may give enough financial flexibility to organise some personal temporary respite to attend to other personal needs, a rest, attention to and time with other siblings, something as simple as a haircut, a doctor's appointment, some sanity time. The carer should also have the right to maintain health and well-being in the midst of the care burden. Carers of disabled children especially without support mechanisms cannot generally go into paid employment. It is now well recognised in the wider Australian context that carers need to also be accorded some relief.

p. 18 – Early intervention

There is much evidence to support early intervention techniques for autism for example. Child disability carers in remote communities such as Norfolk need a clear pathway to facilitate access to early intervention programs in a *timely* manner and not be tied down in the red tape which effectively sees their children miss out on the crucial life-changing benefits of the early intervention programs; the access mechanisms to these programs need to be enabled and equitable in order that small and remote Australian communities are supported in obtaining them. Disabled children in our community continue to have extreme difficulties accessing these much needed early intervention programs (see also notes re. p. 28)

p. 19 – Natural aging/disability through aging

In my experience this is a very complex issue fraught with problems and variables. Aging is a disabling process, and you don't always know how things will pan out. I have been a carer for four significant people in my life, five if you also include my grandmother who was bedridden at home for the last eight years of her life (I am also now currently raising my two children 5 yrs and 2 ½ years).

1. Chronic Schizophrenic mother – my mother was institutionalised on the mainland in middle-age due to lack of support services for her and our family on the Island, the nature of her illness did not suit the mental institutions she was placed in, she was in an out of a number of aged care nursing homes until her death, staying longest in a high-security aged facility. As a result of my mother's absence due to her disability at around the age of 9 years I also became a 'carer' for my family including my grandmother. At the time of my father's passing, I became a carer for her also, albeit from a distance. Our mother was clearly chronically mentally disabled and it was this not her aging which dictated her needs but her existing mental disability. Aged care facilities rather than mental institutions proved ultimately to be the best care option for her. She required an understanding and flexible approach to her care needs.

2. Multiple Strokes - Our father required care for the last 11 years of his life, his needs continued to increase over this time, progressing from informal home care to eventual long term nursing care at the local hospital. [My dad incidentally was a Returned Services Veteran but because we lived in an external self-governing territory so that our family could be closer to my mother's family for support Veteran's Affairs entitlements did not extend to the Island for long term formal care. As a result of lobbying formal long term care support is now available within the framework of the limited local facilities. Informal at home care support however remains absent, although extended to their mainland counterparts. Returned Services Veterans on the Island are still not receiving the full range of entitlements commensurate with their mainland counterparts. Veterans in remote areas cannot and do not access the full range of concessions and benefits accorded to their metropolitan counterparts; this must surely offset the cost of extending things such as carer allowances to veteran carers living in places like Norfolk Island. Surely it sets a precedent to extend one service (long term care) but not extend other services (like at home care support). As a child and grandchild of war veterans I find this situation particularly heart-breaking; that veterans who fought under the Australian flag are treated in this way, or seen as somehow less than their mainland counterparts because of where they live within the Commonwealth.] At the end of the home nursing period our father's needs, and my needs as a carer were at the same level and of a similar nature as that of a disabled person – bodily function/control issues, mobility, feeding, communication levels, safety issues etc. Can or would aged care services provide the right kind and level of services for age-disabled people under a new scheme? Would they be able to accommodate the changing needs of an aged person in home care? This is not a black and white issue. Dementia sufferers, for example, are generally aged and cannot live safely without carer support or specialised institutional care. Specialist facilities are now being built to care for dementia sufferers on the mainland, probably reflecting an increasing incidence rate. Our remote locality, resources and governmental arrangements would never afford us this kind of luxury. How do we care for our dementia patients safely and properly?

3. Diabetic/Aged – My godmother is 78 year old lifetime type 1 Diabetic with a congenital heart condition, neuropathy, hiatus hernia, thyroid problems and other conditions. She is now a double-amputee. I would personally classify her now as physically disabled (due to the amputations) despite her age although she remains intellectually and mentally as wonderful as ever. Assuming she were eligible (she currently is not eligible for mainland services) under a new scheme with age restrictions would she, or people like her, remain under aged services or be transferred to disability services? If she remained under aged services would she get the proper care to meet her changed circumstances and new disability?

My godmother has required increasing levels of care now for about 10 years. As a disabled person she should be classified as such and be entitled to full disability goods and services delivery rather than aged care goods and services.

If she were classified as an aged person with disability arising from 'natural ageing' the system would treat her somewhat differently. Defining 'natural aging' would in itself appear problematic.

4. My brother – short-term care as a result of an accident, with no third party compensation or insurance provisions, and little hope of recourse through the Courts, added to which there are no real support services I cancelled an overseas holiday to come back to Norfolk and care for him and get him 'back on his feet'.

5. Three of my friends (one now passed) are disabled; two of them are intellectually disabled from birth, the other was a paraplegic as the result of a 'no-fault' accident. I understand many of the issues they and their families face in our community. I pay special attention to the social needs of my two intellectually disabled friends due to their social isolation. They too will age but will live with their life-long disabilities. Some people fall within both categories. I believe family consultation and flexibility within any goods and service delivery system makes care delivery a little less painful and more relevant for everybody. The need for 'care' is always clear in these kinds of cases; and improperly considered care schemes should not put people in the midst of a seemingly insurmountable bureaucratic 'tangle' at a time when they require solid support and don't really need additional stressors.

Many people in the aged community require the same levels of home modification, equipment needs (like wheelchairs and pressure care equipment), and service delivery as would otherwise 'disabled' people. Their carers are often just as dedicated, isolated, time poor, exhausted, depressed and in need of support and respite as disability carers. High end aged care is just as complex and taxing as disability care – it is at its highest level a great deal more than being hard of hearing or having an arthritic 'dicky knee'; not wanting for a moment to detract from the difficulties associated with both of these conditions.

An aging population and lack of nursing care facilities will force more at-home care on the Island as it will in the wider Australian population; those affected and their carers should be empowered and supported in this as it actually realises considerable cost-savings in more formal long term care arrangements. Lack of facilities or finance can often make at home care an enforced 'choice' – lack of proper support takes away people's right to choose how they manage this care. In the more modern progressive context we do appear to expect to have a choice (which we must pay for to the best of our ability). Care always comes at a cost whether it is personal or financial or both. Health and wellbeing schemes associated with both disability and natural aging should contain core guidelines with a fair degree of flexibility (carers, like those cared for, come in all shapes, sizes and ages, and differing backgrounds, some have a lot of time, some have little time, some have resources, others not, some are aged themselves and may need more respite than younger carers, some are family and friends, or simply caring neighbours helping out). Carer support needs to be able to assess in a flexible manner the 'carer community' surrounding a disabled person to deliver a good outcome for all concerned.

Whilst these options do need to be properly considered the issue in my view is not whether a system of delivery is narrow or wide; but whether amongst it all there is some discretionary power or flexibility given to those co-ordinating care and goods and service delivery to meet the true needs of clearly disabled people as they present, and particularly introduce a safeguard for those who fall through safety nets and cracks in current policies, guidelines, and legislation. These are the people the system currently truly fails. Disabled needs are exactly that 'needs' they are not wants and they are often immediate. The 'disabling' event, especially when unforeseen, throws people's lives into crisis mode, entire families and sometimes communities are affected. I believe in fairly strict guidelines and assessment mechanisms, home/life assessment 'audits', good appeal and review processes for the disabled community, and some discretionary powers at management level would alleviate 'inflationary' practices and more properly and honestly match care needs and services. The reality is that you cannot hide true 'dis-ability' – people simply cannot do a set task. Educating disability workers, the disabled and carers in what is available, and where and how it can be accessed is a crucial part of the process. For example, there is an absolutely wonderful facility in New South Wales 'The Independent Living Centre', it provides an incredible service to disabled people (or aged or otherwise afflicted people wanting to get back to or maintain independent living) but I only found out about it by sheer accident. When talking to an aged carer I met a few days later they said they had also never heard of it. When I went there I thought to myself how different much of my father's life could have been had we known about this (if in fact it may not have been there at the time). The products this centre offers could make such a difference to so many disabled and aged people and their carers, brochures should be in all the rehabilitation and general hospitals, all aged care facilities, all places where the aged congregate, respite facilities, advertisements in carer support literature, magazines for the disabled and older population, etc. Little things such as these 'life-facilitators' often do make a very large and meaningful difference to the disabled and aged people and their carers, there are incredible, often inexpensive products which 'enable' people in wonderful ways.

p. 21 – Short and long term disability/assessment criteria

Long-term needs are clear for the permanently disabled, in terms of disability through accidents and the like, many people and their families in reality cannot do without proper support beyond a couple of months, life comes to a screaming halt, particularly for rural people who have to give up jobs, leave children in the care of family or friends, etc to move to the metropolitan centres for extended periods (or permanently) for rehabilitation or medical care and to access services with little or no cash reserves – this puts enormous pressure on them personally and financially – bills, mortgages, school fees, still have to be paid, away-from home accommodation needs to be found and paid for, travel and food costs mount up. It can in fact be catastrophic on many levels. The problems of short term disability are just as real and immediate as long term disability.

In terms of regularity of assessment in my experience it really depends on the condition or disability – sometimes a situation may accelerate exponentially and change or decline is rapid. At other times or in other situations it remains static or slow. Disabled people and their families should be assigned one case worker to whom they can stay in contact with on a regular basis if required – it is distressing to be dragged from pillar to post and not be able to form professional 'care' relationships. Some people may only require standard six monthly checks or assessments but others require more frequent or increasingly frequent contact. A one-on-one situation means you

have a case worker who understands your needs, your history, and the projected need for ongoing assessment – you do not get lost in the system. Being able to say ‘can you please come out and look at my/our situation again, we’re not coping with very well with what’s in place right now’ is a system that supports the truly disabled very well. In essence if you are putting down guidelines for assessment, it is prudent to put inbuilt flexibility into it; some kind of discretionary power perhaps for case management teams.

Page 21 – Income and assets

Means testing is fair; but it is important that people are not forced into abject poverty or lose their homes in order to pay for high-end care needs; many of our disabled are disabled through no fault of their own; by birth, progressive illnesses, etc and they often can no longer work; they may rely on accumulated assets to continue to live for the rest of their lives, or they may need to receive benefits or family support. They need to be able to afford basic services like telephone, gas, electricity and food. Remote communities pay more for basic service delivery as transport costs, added to which business monopolies and the like have an inflationary affect on prices; they are also less likely to have access to a full range of disabled services and therefore need to meet more of these service costs personally. Income and assets testing would need to be very generous, the cost of proper disability care, particularly lifetime care, is prohibitive for most people and well out of the reach of the average citizen, especially when the ability to work is non-existent, curbed or removed for both the disabled individual and the carers.

I do not think direct annual funding entitlements are useful unless the utilisation of these entitlements is firmly restricted or linked to a number of goods and services delivery areas directly related to the disability, and the individualised funding arrangement allows people to tailor-make their care needs. Direct annual funding, especially lump-sum funding encourages rorting and would require fairly strict auditing measures. In some cases carers have too much control over disabled individuals and the disabled do not receive the care or funding intended for them. The disabled and the age-disabled are a very vulnerable group of people in our society. One disabled person on the Island says of her family ‘They treat me like a dog.’ This sums up in a worst case scenario how disabled people without good choices available to them can sometimes be made to live.

Lump sum payments also work on the premise that people can wisely manage their finances. This is a misconception; a great proportion of society in general does not manage their finances efficiently. Case workers should be assigned to ensure quality delivery of goods and services needs. If lump sum payment were to be considered perhaps it could be held in ‘trust’ and case workers help to identify needs, match up goods and services delivery, and manage the ‘fund’ in consultation with the disabled individual or carer. I still feel however that even this would leave disabled people in a vulnerable position. The power of choice should always rest with the disabled person if they are able to express their views. I feel mainstream funding with proper budgetary considerations, lines of accountability and auditing might better alleviate the potential to misappropriate funds and rort the system.

Carers should not be penalised for choosing, or being forced, to care. They should not have to forfeit their own resources set aside for raising children, personal retirement income and their own aged care security whilst simultaneously putting their life on hold to take on caring roles. Into the

future given our aging population many more people will have to factor caring roles into their everyday lives. People should be encouraged to care.

Page 24 – Individualised funding and remote area delivery

I do not believe that people should be able to treat funding as ordinary income and do what they like with it. This defeats the purpose completely of isolating public moneys and channelling them into disability needs. Disability funding recognises a real ‘extra-ordinary’ need for goods and services delivery – this is where the spending should be directed. I do not believe that primary carers or other family members should be able to pay themselves directly for providing care, this should be under the direction of a caring and empathetic case worker working within clearly set guidelines, the disabled person and the families need to identify a primary carer and the cost or burden to that person of providing that care before assigning allowances delivery. Carers cannot generally work full time, if at all, they often to varying degrees also subsidise the lives of the people they are caring for.

Individualised funding would be extremely effective in remote areas because different areas are able to provide different services – individualised funding allows service and goods delivery ‘gaps’ to be filled creatively within the framework of available resources thereby providing the best level of care in the limited circumstances.

Properly trained ‘case workers’ should be responsible for monitoring individualised funding. They should know or be able to find out what is available where, they should be familiar with the particular challenges of the disabilities presented and assess the person’s living conditions, ie alone or with family, the physical environment of the home, how services such as meals and personal care are delivered, etc.

Service providers who profit from service delivery should never be permitted to influence or sway the choice of a disabled person or a carer to access or choose their provider services. The need should be independently matched to the service.

Individualised funding is the best way to empower people, you will never find identical conditions or situations, tailor-making goods and services delivery is by far the ‘best practice’ approach. People are much happier when they are enabled and empowered, given reasonable choice and the tools to continue to live with dignity the best life they are able.

p. 25 – The nature of services/co-payment

Only the disabled and their carers can identify on an individualised basis which services would best form the foundation of their care needs priorities. In the area of disability surely service provision must be consumer-driven and providers should be required to adapt accordingly to the needs of the disabled rather than vice versa. Make people matter! Gross profiteering from other people’s misfortunes is distasteful and is to be discouraged at all cost.

Living in an environment like Norfolk Island where there is little to no service provision the needs hierarchy becomes very clear immediately. Without the requisite home modification and aids and appliances my Godmother could not go back to independent living. Limited personal care services make her increasingly reliant on a team of voluntary carers. We face constant transport issues getting her to and from and between hospitals, on to planes and into vehicles. There is no

wheelchair taxi on the Island. There are many places in the community she just can't go to even if she were well enough and wished to go. There is no respite care for disability carers. Meals for her are provided under a mixed arrangement. Meals on wheels is available but out the question as they fail to meet her strict dietary requirements and need to be collected by someone and delivered. Due to her complex medical conditions and the cost of medication, etc she cannot not afford this service in any event. Until recently she has managed her personal care at home generally unassisted, except for a few little hand-ups now and again. As a double lower-limb amputee, especially if she becomes ill, this will now almost certainly change. The district nurse provides a 'fee for service' visit three times a week. In some areas, without clear service guidelines, I question the effectiveness and value of this service for disabled people (not so much for our aged who are more physically independent than my godmother). Clear guidelines need to be established regarding the disabled persons requirements and the district nurses duties with regard to the identified needs. In an ideal world, the District nursing service probably needs to be extended to better accommodate our more complex disability needs. This service should be reviewed in confidence, and impartially, with the disabled individual on a regular basis.

Co-payment must be affordable to the disabled person. It is not unreasonable to expect co-payment, but it is unfair and inequitable if that co-payment arrangement is so inflexible that it might render the disabled person destitute and unable to meet the cost of basic needs such as essential medication, food, gas, electricity and telephone. My godmother takes something like 15 different medications, some covered, many not. A person should not have to choose between buying bread of life-maintaining medication. Perhaps it should be somehow tied to whether the disabled person is able to engage in remunerative work, and also income and assets tested.

When talking about innovation in service provision in our community there are qualified carers living in our community at present, but they remain underemployed in their area of qualification or are employed in other areas because many cannot afford to have paid care and rely on family and friends to provide a care network. Were there any funding for disability care on the Island individuals could creatively use the services of these people to meet in part or in full their most pressing support needs. A bonus is that a person is constructively employed in an area for which they are suitably qualified.

Community participation programs and day care facilities, particularly for our younger disabled would be wonderful, and are at present totally absent. When basic services are absent it seems very 'pie in the sky' and idealist to dream that one day these kinds of things might happen in our community but it would be wonderful to think one day they can happen.

It would also perhaps not be unreasonable to expect co-payment from the Norfolk Island Government for access to delivery of mainstream mainland disabled goods and services under the current intergovernmental arrangements ie *Norfolk Island Act 1979* (Cth), or that the Norfolk Island Government be compelled to implement new funding mechanisms to finance the unmet needs of disabled people in our community.

p.28 – Assessment tools

In our community in the absence of assessment tools, outcomes for the disabled are very much dependant on the advocacy skills of the carer. It seems to come down to who you ask, how you ask,

who's doing the asking, and how much you 'kick up'. You basically don't stop asking the question until you get the answer that you need or want; a 'no' from one person can be a 'yes' from another. It is a very inequitable, ad hoc and confusing way to administer disability services. It certainly does not protect the 'rights' of all afflicted individuals.

On Norfolk not only is there no legislative or policy framework for disability care, there are no real avenues of appeal, and apparently no political will to change the status quo in the near future. In my opinion there are too many other conflicting or higher priority community-based issues at present to even begin to expect the Norfolk Island Government to address disability issues.

Through experience, particularly in my carer roles with Dad and Alice I have come to the realisation that disability services and assessment is a very specialised field, mainland assessors who have worked for a long period of time in the field are unfailingly professional, compassionate, empathetic and they understand immediately the real logistical difficulties of working in an environment where there is little or no formal disability support. They do everything they can, within the guidelines they have been given, to find the resources needed to make the best of a bad situation. Professionalism from assessors makes disabled people and their carers feel supported and cared for in their journey. In my personal opinion, many people who have even the remotest of professional public responsibility in this area on the Island remain apathetic and unsympathetic to the very real needs of the disabled. Last year I overheard a disabled person say to a healthcare worker 'I feel as if I should write a letter to the local paper apologising for living.' This is not how it should be. Healthcare professionals have a duty of care which should not be conveniently overlooked. In their defence however healthcare professionals in small communities are under considerable pressure, are forced to multi-task, and also to some degree feel compelled to protect their jobs as well.

p.28 – Service coordination and linkages with mainstream services

The statement that an 'unmet demand' in health care may result in excess and costly demand for disability services a cash strapped health service facing many competing demands may give lower priority to an early intervention...' is very relevant in the Norfolk Island context also. Recent studies in America have confirmed the increased demand for specialist childhood early intervention programs for children suffering from Aspergers, Autism and ADHD, etc. Our community is a cross-section of the wider Australian community and the increasing demand for specialist early childhood intervention services in this area cannot be met by our cash strapped health service. Community fundraising and charity goes some way to meeting this need but it is ad hoc, falls well below standards met elsewhere, and some of our children fall through the cracks or 'miss the boat' so to speak. Current arrangements do not allow our disabled children or their carers (who are Australian citizens) to access mainstream services. In my view, children in particular should have the right to the best care and greatest opportunity, irrespective of where they live in Australia. Children disabled from birth should not fall victim to intergovernmental arrangements, lack of legislation, political will or oversight – or their personal inability to pay income tax now or in the future. A disabled child who grow into a disabled adult should never be asked to pay tax, or be penalised for not being able to do so, or living in a unique environment where his or her parents and the general community are not at present required to do so. Disabled children should be outside and above all of these considerations. The primary consideration should be that these children get a 'fair go'.

Disability and proper aged care support and forecasted unmet demand in these areas will always remain 'unmet demands' until someone recognises the demand and takes responsibility for making the attendant changes required. In terms of the mechanism for this in the Norfolk Island context it can be as simple as rescinding the powers under Schedule 2 of the *Norfolk Island Act* and the Commonwealth taking back responsibility for healthcare and social welfare and linking in service co-ordination and mainstream services; or alternatively compelling the Norfolk Island Government to make the necessary changes; or a middle-road approach which sees a co-operative resolution.

p. 29 – State and territory funding of aids and appliances

It is absolutely erroneous to say that 'all states and territories provide subsidies for the purchase of aid and appliances' – Norfolk Island does not. At page 37 it is again stated that 'currently all levels of government provide some funding for disability services', whilst the Norfolk Island Government does govern across the three tiers of government (local, state and federal responsibilities) and some sketchy provision is made in the Healthcare and Social Services legislation, I am not sure that it can be said that this statement applies equitably in the Norfolk Island context.

p. 30 – Catastrophic injury

Some comment needs to be made on this as well; it is an area which seems to scream of the need for a consistent national policy as people living in different parts of the country are treated so differently. My friend became a paraplegic as a result of a catastrophic injury. Unable to work, and without any support services on-Island he moved to the mainland away from his family and friends (his support network). His disability was severe and permanent – he remained heartbroken and homesick 'in exile' and his final wish was to come back home. There are other 'luckier' people who can continue to live (and work) in our community with accident related disabilities. Their needs will change over time. Severe accidents in our community require a medivac to the mainland often for extended periods. These life-saving medivacs place a considerable cost burden on our small community.

There is very little support for temporary (or permanent) disability as a result of catastrophic injury in our community. People rely on reserves to live on, or upon the charity of family and friends, or community charity. Fundraisers for such events are a regular part of the Island way of in-part dealing with, supporting and caring for those affected.

The issues and anomalies raised in respect of catastrophic injury victims raised in the paper are present in our community, but magnified manifold due to the absence of proper mechanisms to deal with them and to achieve a fair outcome.

p. 36 Sources of funding

This is an area for which I am hopelessly unqualified to make comment but it is one of the major issues which would probably prevent resolution– the fact that due to the unique intergovernmental arrangements people residing in Norfolk do not contribute to the Commonwealth taxation scheme; nor is there a locally based income tax. Island residents cannot 'choose' to pay Federal income tax; they can however, for example, choose to vote in mainland elections. Whilst the taxation issues and the anomalies that living in Norfolk Island constantly present continues to be debated the needs of

disabled people cannot be met without some concessions being made or agreement on a way forward is reached by both governments. Disabled people are caught hopelessly in the cross-fire.

At present Norfolk Island is not a welfare state, there is no unemployment benefits; but there are many people who are struggling to make ends meet. In other remote areas of Australia there are entire communities relying on social welfare who do not contribute to government coffers, yet they are afforded far more rights than wage-earning Australian citizens living in Norfolk Island caught up in the politics of living here.

Close examination needs to be made in relation to the Norfolk Island Government's ability to pay for any attendant changes if they were made. If anecdotal evidence is to be believed our economic prospects and budgetary decline does not put our community in a very fiscally optimistic position. Although I believe it may not really be feasible to do so, the Norfolk Island Government could increase the locally based Healthcare Levy to meet this need, the income from which would need to be clearly earmarked and protected from misappropriation. This perhaps could also factor in a 'futures fund' approach to meet the needs of an aging population. I am not so naive as to think that we can initiate change without funding; I am simply asking my elected representative how this disability goods and services deficit and funding might possibly be achieved.

In terms of voluntary contributions by the community, in kind or financial the level of volunteerism is already uncommonly high in our community. It is an Island heavily reliant on volunteerism. Fundraising for people suffering hardship, especially as the result of medical evacuation, long term medical care on the mainland, sustained or chronic illness, catastrophic injury, etc, occurs regularly and is very generously supported by private individuals and the business community. It was recently put to me that 'we cannot continue to run a government healthcare system on charity'. Whilst this is not necessarily my view, there is a long tradition of fundraising on the Island, especially for catastrophic events. The only thing I would say is that this does not provide a fair and equitable distribution of funds as not everybody who has a misfortune is lucky enough to be a beneficiary to these fundraisers. It is part of the 'Island-way' however at times fundraising is selective as it is initiated privately. Irrespective of whether funds for this kind of care are governmentally provided or provided by charitable means it still is a major community burden on such a small population, particularly in the current climate.

p. 40 Governance and infrastructure

The issues paper recognises 'different levels of government would have to agree about their functions in the new system and the way funding might move between them'. This statement would infer some consideration be given to the Norfolk Island government and Norfolk Island community's ability to pay for and deliver services to disabled people within the Norfolk Island community. It also infers that the Federal Government might possibly have a role to play in the deliberations in the Norfolk Island context if this Inquiry were truly a 'national' inquiry.

p. 42 Implementation issues

If Norfolk is not considered in a 'national disability plan' it is not truly national. Does Australia comply with the international covenants on disability and the rights of a child if Norfolk is excluded at the very least from consideration, if not the final implementation strategies. As the issues paper

so rightly pointed out the Australian, state and territory governments have quite different roles and systems in each jurisdiction and it is an immense challenge to propose a move to a nationally administered system.

In the Norfolk Island context what are the options, particularly if the Norfolk Island Government is unable to make adequate contribution, or is unwilling or unable to cooperate on key issues to achieve a fairer outcome for the disabled people in our community?

p. 44 Costs and risks

It is clear that there is an unmet need in our community. How it is quantified is very much dependant on what guidelines might be put in place which defines what is a 'reasonable or appropriate level of goods and services provision' in Norfolk Island, even if it were to fall below the national standard, or be less than mainstream services in metropolitan areas.

Future prevalence rates are certainly relevant when talking about disabilities in Norfolk and in the wider Australian community. Conditions such as Aspergers, Autism, and diabetes related disabilities are generally recognised as being on the increase.

I also feel that in the Norfolk Island context with an aging population the lower cost of informal care does alleviate considerably the cost burden to the Government of formal long term nursing care in the public facility at the local hospital. Informal at home care represents a significant cost saving to the Norfolk Island Government and is probably a situation which is beneficial to encourage. The downside of this is that changing social pressures make it difficult for the traditional carers, primarily women, to commit fully to the carer role as their predecessors did. There are significant pressures for women today to remain fully-employed in the workforce. Providing incentives for informal care arrangements (ie within the family) would certainly alleviate some of the costs of the public care burden.

P. 45 Benefits

Socially responsible policy making and the implementation of equitable welfare arrangements benefit everybody. A national scheme is a misnomer if it does not address the needs of a nation *in toto*. International human rights conventions recognise the particular vulnerabilities of disabled people, and especially children, in our community and their rights to inclusion and protection. Failing to properly recognise or consider the needs of disabled people living in the external territories, including Norfolk Island, may have 'unintended consequences'.

p. 51 – 54 Terms of Reference (TOR)

In my limited experience, Norfolk Island is generally excluded from such considerations unless it is specifically expressed to be 'included'. The Terms of Reference do however state that "The Commonwealth, along with the States and Territories, has a major investment in disability specific support. However, there remains a significant level of unmet demand for disability services which impacts upon the lives of people with disability, their families and carers'. Under the "Scope of the

Review” the Commission is to consider ‘eligibility criteria for the scheme’. Many people living in Norfolk Island are Australian Citizens currently excluded from mainland arrangements due to the unique intergovernmental arrangements. The TOR also asks the Inquiry to ‘consider implications for Commonwealth and State and Territory responsibilities’, as well as the ‘contributions of Commonwealth and State and Territory governments’ and implementation issued including ‘state and territory transitions’. In its closing lines the TOR states that the Commission is to seek public submissions and to consult as necessary with the Independent Panel, State and Territory governments, government agencies, the disability sector and other relevant experts and stakeholders.

All of this really does beg the question as to whether ‘Norfolk Island’ is, or should be, a part of the scope of this Inquiry and included as part of the ‘Territory governments’ mentioned in the terms of reference in the consultation process.

Conclusion

Hopefully what has been outlined above, in tandem with the complaint now lodged with the Australian Human Rights Commission, would be compelling enough for the Inquiry to acknowledge that despite Norfolk Island’s apparent exclusion within the scope of the Inquiry and its unique external self-governing territory arrangements it would now be seen as prudent and in the ‘national interest’ to ensure that as part of a review of ‘national’ disability systems that Norfolk Island, as part of the Commonwealth of Australia, is included in the Inquiry and that the Inquiry is satisfied that the Norfolk Island Government is delivering the goods and services that it should. This in turn ensures that Australia is in full compliance with the international covenants to which it is a signatory and is fulfilling its duty of care to Australian citizens living on Norfolk Island. At the end of the day in any governmental processes the disabled should not be the ‘sacrificial lambs’ and often, unless you or your family are personally affected, disability remains a very low priority on most people’s agendas. In this light, I ask for some clarity as to who has ultimate and final responsibility for disability issues on Norfolk Island and is goods and services delivery in this area considered adequate, and equitable.

Yours sincerely,

Rachel M. Nebauer-Borg

Copy:

Administrator of Norfolk Island

Minister for Home Affairs

Human Rights Commission

ADDENDUM: COMMENTS ON PRESS RELEASE (Attached)

NEW RIGHTS COMMITTEE RIGHT FOR THE JOB

Page 1 – The new Bill will appoint the President of the HRC as ex officio on the Admin. Review Council to ensure that the ‘business’ of government regards how legislation impacts on the rights of individuals. This is highly relevant in the current Norfolk Island context.

Norfolk Island seems to not figure in much of the checks and balances and independent inquiries that are so important for good transparent governance. Does the Administrative Review Council have any function in Norfolk Island?

At present the Norfolk Island situation in regards to the disabled seems to be caught up in the midst of intergovernmental ‘business’ under the umbrella of the *Norfolk Island Act 1979* (Cth). Given the responses we have received from the Federal and Norfolk Island Governments it would appear that the Commonwealth’s transfer of ‘powers’ (which contains matters of a local, state, and federal government nature) under Schedule 2 of the Act is the crux of the matter and it has directly affected the will or ability to consider the equitable delivery of goods and services to disabled individuals by leaving it in the hands of the NIG without any proper Federal Government auditing or assessment mechanisms (that I am aware of). There has been some acknowledgement in number of reports brought down by Standing and Select Committees on the inadequacy of delivery of health and social services on Norfolk Island; but no subsequent action to my knowledge.

Australian citizens living in Norfolk Island suffering disability are ineligible for goods and services delivered to tax-payers on the mainland. This I understand, but there is no comprehensive replacement scheme on the Island.

Having now read this, and the Issues paper I do not think that Australian citizens living in Norfolk Island are even being considered within the scope of this Inquiry. Page 26 of the Issues Paper mentions delivering expanded services in remote and rural Australia including specific communities, such as Indigenous Australians. It makes no mention of the external territories – we appear to be completely outside of the system (other than in the context of general references to ‘territories – which begs the question ‘does this include Norfolk Island?’). If Norfolk is excluded, it must be considered a significant oversight. I believe all of the issues the Inquiry is addressing are just as relevant to Norfolk Island as they are to the rest of Australia, even more so given the lack of existing proper provision for disabled people in our community.

Disability needs are often (particularly of the profoundly disabled such as that of an autistic child like Jeremiah) life-long needs both for the individual, and also their family and carers. Surely the care and well-being of disabled people throughout the world should be at the forefront of welfare considerations given their high level of vulnerability.

How a scheme for Norfolk would operate and be funded is clearly a matter for the NIG and Commonwealth governments. I feel there is some immediacy in this issue as an almost total *absence* of full and proper provision for these people in a modern democratic society is, in my view abhorrent, negligent and unacceptable.