City of Playford DDA Community Reference Group

Submission to the Australian Productivity Commission Inquiry into Long Term Disability Care and Support

For several decades now there has been much talk about people with disabilities being part of the community. As early as 1970 Wolfensberger and many others, highlighted the need for people with disabilities to have access to basic, tangible resources such as housing, education and employment. These things would help improve their lives and assist people to connect meaningfully with other people and their community (Bengt Nirjie 1982 in dircsa, 2008. Bank-Mikkelsen 1976 in dircsa, 2008. Osborn, 2006 Ramsey 2007). Certainly in 2010 we see more people with disabilities in the community than ever before. However, Ware, Hopper, Tugenberg ,Dickey, Fisher (2007) argue that people with disabilities are 'in the community, but not of the community'. Economic, social and political inequities still appear to be a primary experience for people with disabilities. To addresses some of these inequalities and for people with disabilities to fully participate as a right of all citizens, Australian Federal Government has called for the Australian Productivity Commission to undertake a public inquiry into a scheme for long term disability care and support. For the purpose of this submission the scheme will be referred to as the National Disability Insurance Scheme (NDIS). The parameters of this scheme are yet to be determined until such time as sufficient community consultation has been gathered.

Government and their organisations are the focal point for the Australian people. They must lead the way in terms of setting the political and social agenda. Government also has a responsibility to allocate resources that enable the Australian community to be inclusive and recognise the rights of all citizens. An NDIS that will be successful in improving and maintaining the lives of people with disabilities therefore must be developed within the parameters of the United Nations convention on the rights of persons with disabilities, ratified in July 2008.

Based on this premise this submission proposes the following objectives be examined and considered as fundamental to any scheme for the long term care and support of people with a disability:

1. Redefine the concept of citizenship to be innate, rights based and fully inclusive
2. Strengthen legislation and support structures for access and inclusion
3. Improve information and service provision to integrate planning for the 'whole of life'
4. Improve economic security for people with disabilities
5. Increase opportunities to education, employment and meaningful activities
6. Secure appropriate housing and supports including universal housing in new or redeveloped areas
7. Provide infrastructure that promotes and provides opportunities for independence, decision making and choice
8. Improve opportunities for community involvement and participation
9. Improve the socioeconomic position and health outcomes of unpaid carers
10. Standardise and regulate the disability sector

1. Redefine the concept of citizenship to be innate, rights based and fully inclusive

For any scheme to work the first thing that needs to happen is to redefine the concept of citizenship to be innate, rights based and fully inclusive. People with a disability must be seen as equal and valued for who they are as people.

A National media campaign educating all Australians that:

- all people regardless of ability have the right to authentic citizenship
- emphasises that people with a disability are people first and foremost and should not be defined by their disability
- emphasises valuing what 'unites us as people
- how easily what it means to be a seen as a valued 'person' can be fractured by disability whether that be congenital or acquired and can happen to anyone at anytime
- when fiscal support is directed towards people with a disability it should not be seen as going to 'someone other' rather as a proactive assurance that may be needed by anyone at anytime

Government and their organisations as the focal point for Australians must lead the way. All levels of Government must be at the 'cutting edge' in breaking down barriers – both in terms of physical accessibility through infrastructure, and also attitudinal barriers in terms of being naturally inclusive in all policies and practices. There must be genuine commitment and resourcing to ensure people with disabilities have equal access to all aspects of community life.

2. Strengthen legislation and support structures for access and inclusion

Any new policy to improve disability care and support should examine the current structure of the DDA. As complaint based legislation the onus and responsibility is placed on people with a disability who are currently among the most disempowered and vulnerable people in the community. Having to complain to gain what should be their natural right reinforces attitudes that people with a disability are the 'other' and that including them in society is difficult, costly and something extra that needs to be done. The focus should be on ensuring equal access is provided as a right.
Caveats such as 'unjustifiable hardship' severely dilute the potency of disability legislation which is intended to rectify discrimination and inequality. If we are to unreservedly welcome people with disabilities in to community life and civic participation as their inalienable right; then we can not in the very next breath say 'it is too hard to include you' 'it is too costly to consider your needs' 'you are too difficult to handle' or 'you have an adverse affect on me'. This thinking and use of 'unjustifiable hardship' gravely undermines the principles of citizenship as a fundamental right of all people.

A more positive and proactive course of action is for **all** organisations whether public or private to be required to have Actions Plans. These Action Plans must be highly visible and have their processes and outcomes clearly stipulated and resourced so that they can be measured and independently reviewed (Bigby 2006a). Currently many 'Action Plans where they exist at all' have a serious lack of design regarding the implementation of processes and measuring of outcomes (Bigby;2006a,10). Timelines for executing raised actions are undetectable and do not have to be adhered to. Issues can be put down as 'ongoing' and postponed should other more favourable or seemingly 'important' issues arise. They can also be the first things to be eliminated when budgets are constrained. If organizations do not develop Action Plans, adhere to timelines and also devote adequate resources to the inclusion of people with disabilities, then they will remain in a devalued position within our community.

3. Improve information and service provision to integrate planning for the 'whole of life'

People with disabilities like all people have varying and changing levels of need, interests and desires to be fulfilled in order to live happy, healthy and productive lives. One mode of intervention, model of service delivery or response doesn't fit all. Services need to be designed and delivered to meet the needs of the people rather than the other way round and need to consider the whole person and take a whole of life approach.

To achieve this there needs to be:

- Single point of data collection, information and assessment that:

    - Travels with the person for their life span rather than stays with a compartmentalised service
    - Can be added to and accessed as appropriate
    - Avoids duplication of systems such as medical, administration, ageing and disability
    - Reduces administration costs.
- Portability of funding and services. Current service models restrict people by geographical boundaries and funding criteria restrictions. People should be able to move location or change services without losing services or continuity of service delivery. The quality and quantity of service delivery should not depend on where a person lives or whether they are fortunate enough to get the 'good' teacher or doctor who understands disability.
- National system of funding and service models and standards
- There needs to be an agency that proactively provides information and advocacy for families when they have a child with a disability. Many families don't know the information and services that are available to them, what to look for or ask for, what their rights are etc. Access to appropriate and timely information is vital particularly at developmental life stages and key transition points. Information about services, eligibility and anything relevant to a person's disability should be provided and promoted so that people/families are not floundering and are aware of what is available and how to access it.
- All educators, medical and allied health professionals to have disability awareness training as a mandatory component of their professional education/training
- Service systems need to be more integrated to manage a whole of life and holistic approach. Under the current division of service sectors i.e disability, ageing, mental health there is confusion and wasting of time and resources differentiating whose portfolio or 'problem' the person is. For the person experiencing Dual Diagnosis or multiple needs, this uncertainty often prolongs stays in hospital, hinders recovery and significantly affects families and service organisations.

4. Improve economic security for people with disabilities

People with disabilities, just the same as any Australian have needs that require addressing in many areas of everyday living. However, Saunders (2006) articulates 'disability represents a substantial percentage of disposable income, and thus poverty rates are much higher where there is a disability present'. People with Disabilities, have needs that are complex, comprehensive and interconnected; education affects employment which affects income which affects life choices, which affects health and wellbeing and so on. Just as needs are interconnected, so too are the responses of government to those needs, however there are some key areas vital to wellbeing that are at the fore of the responses in 2010 and including education, employment, housing and wellbeing. Much of marginalisation of people with disability is directly linked to their poor socio-economic status.

One step towards improving the socio economic status of people with a disability is connecting them to their community and empowering them to pursue their own lifestyle choices. This could be achieved in part by the introduction of Self Directed Services (SDS)

This practice has popularity in the UK and some parts of Europe. Research from these countries highlights the benefits of changing from a system of welfare and dependency to a self directed support (SDS) where individuals with disabilities are the person at the centre of planning (PCP) what they need for a fulfilling life.

    - The dignity that comes from controlling your own life and the support you need to live it
    - The chance to tailor support more closely to your needs and aspirations
    - The opportunity to find creative and flexible alternative forms of support (In control, 2008)

The benefits for people with disabilities would be:

- ability to make choices about their own life and lifestyle and develop genuine goals and aspirations for the future, just the same as other Australians
- opportunity to develop skills in planning and managing resources
- dismantling of the existing power structure, giving bona fide consumer choice and power to people with disabilities
- increased self esteem, reduced social isolation and overall improvement in health and well being

Important considerations for the successful implementation of a system of SDS are:

- People with a disability could be offered SDS in whole, or in part. Alternatively, people could choose to remain with the existing funding arrangements. The option to change to different funding arrangements could be reviewed, as SDS grows in popularity or when the person receiving funds see its success and/or as skills develop and they becomes more confident.

- The importance of introducing and maintaining training support mechanisms to assist people with disabilities and their carers to successfully navigate the system enabling them to get the best out of it. Many people with disability and their families have become accustomed to other people, often professionals, making choices about their lives. They may be completely overwhelmed by key principles of choice, rights and responsibilities or fiscal accountability. It is here professionals and people with disabilities could develop partnerships to identify goals, locate resources, develop skills and build independence. The most promising component of the SDS model is the potential for true community involvement and civic participation.

- The benefits of adapting SDS into an Australian model, is that is has been in practice now for several years and some strengths, limitations and safeguards have been established. Building on the success and safeguards of the UK model would allay the fears of detractors of SDS who question the practicality, and those people who have legitimate concerns over potential exploitation of the system.

- The most promising component of the SDS model, after an improved social economic position, is the potential for true community involvement and civic participation, the inherent foundation of citizenship.

- If people with disabilities are actively seeking and engaging in activities of their choice, it is more likely that they will feel fulfilled, therefore reducing isolation and increasing general wellbeing.

The introduction of SDS for people with disabilities could see a dismantling of the existing power structure, giving bona fide consumer choice and power to people with disabilities. If people with disabilities are actively seeking and engaging in activities of their choice, it is more likely that they will feel fulfilled, therefore reducing isolation and increasing general wellbeing. To ensure the success of a NDIS including individualised funding political leaders must ensure that they spend time communicating the key principles of self-directed support, reassuring and educating the wider public, and ensuring that the pathway to the new system is clear and that many of the present interest groups can identify new roles for themselves within the new system (Duffy 2005; 10).

An NDIS must have adequate funding to ensure people with a disability have sufficient fiscal support for each individual to pursue a meaningful and active lifestyle and should consider:

- Income support separate from funding for equipment and services
- If through income tax, similar to a Medicare scheme a public education campaign as to the genuine and potential assurance for all Australians must be promoted widely to avoid a dichotomy between ‘employed people’ and ‘people in receipt of disability support’
- Cautionary note an investment scheme like the superannuation scheme could see a people with disabilities with reduced finances, if the market crashes as in 2008. It is unlikely that most people with a disability could remedy a substantial cost of income, like self funded retirees who can seek to improve their hardship by undertaking casual work or top up from other sources.

5. Increase opportunities to education and employment and meaningful activities

Access to appropriate education, employment and meaningful activities are essential to people’s physical and mental health, personal wellbeing, sense of identity and economic security. Unemployment, underemployment and a lack of genuine choices in education and employment are issues that significantly affect people with disabilities.

People with disability are still at the lowest end of the socio-economic scale even when they are in full employment. Coupled with low levels of income when employed, is the reduction or loss of benefits when participating in the workforce despite an increase in cost to participate such as additional transportation and finding suitable training (HEREOC). The major issues that need to be addressed are:

- Need to provide improved access to transport or an allocation of access cab vouchers specifically to enable people that need them to participate in employment, work experience, education etc. People with a disability shouldn't be prevented from working because of a lack of access to transport
- People should not be prevented from accessing education and employment due to lack of access to personal care. Current education standards don't include access to personal care services. People with a disability who are capable of undertaking tertiary education studies should have equal rights and opportunities to access education on campus.
- Current individual allocations of paid carer hours are insufficient to cover access to education, employment, meetings etc. The system is set up to cover some limited personal care but doesn't allow choice and is insufficient to meet need.
- Improve access to transport for hospital appointments etc similar to Home assist provided for older people or a system in the UK of volunteers using their own cars who are reimbursed to provide a hospital/ medical transport service.
- People shouldn't have to wait long periods of time (sometimes years) for vital equipment such as wheelchairs etc.
- People with a disability in employment have access to equipment through the workplace modification scheme which is great. The same level of service should apply to other people with a disability who require it. Having timely and early access to appropriate equipment can assist in people being more independent and work ready as well as in reducing the onus on employers to make the workplace adjustments thus reducing some of the current barriers to employment.
- Workplaces and their agents need better training to support people with disabilities, particularly in the initial phases of commencing employment. Training for adequate workplace support may include increasing awareness of the many skills of people with disabilities, greater flexibility, reducing barriers to access and introduction of inclusive equipment.

- An NDIS could see could see people with disabilities purchasing tangible resources such as skill development or training and workplace supports to enable them to achieve meaningful and concrete employment opportunities.

- Diversity in the Public Sector should increase and the Government seen as 'raising the benchmark' with regard to employing people with disabilities. True diversity will see people from all strata's of the hierarchy of disability presented the opportunity of being retained in the public sector. In essence this means employing not only people experiencing physical disabilities, but people with intellectual disabilities or mental health issues also. It is all too easy to use people with physical disabilities, such as people who use wheelchairs, as the only example of including people with disabilities.

6. Secure appropriate accommodation, housing and supports including universal housing in new or redeveloped areas

People with a disability should have equal opportunity to choose where they live and with whom. They should have access to a range of support services necessary to support independent living and community inclusion, and to prevent social isolation.

Ensuring people with a disability have access to secure and accessible low cost accommodation of their choice and support to live independently will ultimately reduce the cost of providing remedial services and addressing the myriad of social issues arising from isolation and mental stress.

An NDIS scheme must enable people with a disability to have choice to purchase accommodation services to meet their needs and to live as independently as possible with whom they choose both through the allocation of any funding and improving the availability of housing/accommodation options.

- New public housing stock should include a percentage built to Universal design standards
- Local Government should be supported to work with developers to offer greater accessibility in all new housing developments including houses built to Universal design standards
- Urban regeneration projects for older housing stocks to include a percentage upgraded to Universal design standards
- Focus on providing early intervention and support for people to learn skills to live as independently as possible and reduce reliance on support services
- People living in supported accommodation should have sufficient funding and rights to choose their care and support and who they live with, and to have access to meaningful activities and community interaction
- People living in supported accommodation should receive an acceptable level of care and support with suitably trained staff and a transparent and responsive review and complaints process

7. Provide infrastructure that promotes and provides opportunities for independence, decision making and choice

The provision of infrastructure that promotes independence, decision making and choice will reduce the level of dependence on support services and the resources required to support them. Barriers to access to buildings, streetscapes, transport and facilities prevent people with a disability from living independently and participating fully in everyday life. To be a 'morally or socially just society' requires that we move beyond minimum DDA (1992) standards and circular rhetoric towards a strengthened, live and participatory community (Bitmeade2004;8).

Local Government authorities have a significant role to play and should be supported in ensuring built environments are accessible for all through development and planning mechanisms for streetscapes, neighbourhoods, housing, parks and public buildings.

Builders and developers must be made accountable for ensuring access is provided to meet the needs of people with a disability to all buildings and developments.

Lack of access to transport infrastructure is also a significant impediment to independence for people with a disability. Affordable, accessible and flexible transport options are crucial to people's independence and wellbeing in facilitating access to vital services and the community. Improving access to public transport and better coordination and use of community transport will reduce reliance on higher cost services.

8. Improve opportunities for community involvement and genuine civic participation

The introduction of an NDIS that would support people with disabilities for the whole of life could see a dismantling of the existing power structure, giving bona fide consumer choice and power to people with disabilities particularly in areas of community involvement and active civic participation. This can be done in a number of ways;

- Genuine, timely and ongoing consultation with people with a disability, their families and people working within the sector seeking their input particularly around important issues such as; level and type of need, policy development and implementation, funding, power structure and the design of services. These inquiries must be conducted on a regular basis to strengthen people with disabilities involvement and to secure the tenets of changing needs

- Partnerships and collaboration from people with disabilities should be an integral component of policy development at a government level not a top down approach which presently occurs. When decisions are implemented from a top-down approach with little or no collaboration, this affects those people at the coal face with a reduction in their autonomy. It can be legitimately argued that this top down approach provides structure and accountability; however it also sets the agenda and has the power. Also professionals, even those with the best intent and good will, may have their own agenda which could be counterproductive for individuals, or even recruit them into their own ideologies. 'Not all alliances between socially valued and devalued people are moral, fruitful and advantageous' (Kendrick,2004)

- People with disabilities often have a limited social and economic status, thus a correspondingly lower political profile. Improving their social and economic status, with some of the abovementioned strategies should inherently advance their political standing. For many years human services linguistically bought into the market ideology of 'consumer' and 'customer'. Theoretically this terminology promoted notions of empowerment, choice and inclusion, however does nothing to address the power inequities or disadvantage that people with a disability were experiencing. Rather than service models of provider and consumer we should be working together in partnership to identify goals, locate resources, develop skills and build independence.

- People with disabilities should be able to choose which activities are most meaningful to them in regards to their lifestyle or to their life goals

- Encourage the development of advocate groups who will be regularly sought out by Government to determine where the NDIS is tracking in terms of meeting its vision or goal.

- Promote and adequately support and resource innovative Asset Based Community Development models of practice which encourage people to strengthen their own resources and networks with projects such
    - 'community visitors program'
    - volunteering with community
    - mentoring programs for specific needs based groups. Autism, metal health, disadvantaged groups such juvenile offenders with learning disabilities
    - community education and support groups delivered by people with experience of disability such as mental health issues,

9. Improve the socio- economic position and health outcomes of unpaid carers

Parents and carers need pro active advice and support as soon as they become aware their child is not developing as expected. They need access to timely, regular and appropriate respite and support services to reduce carer stress and enable them to continue as 'normal' a life as possible to reduce the economic and social 'burden' on families and the community in general.

Social capital exists in many families and friends of people with disabilities. Kendrick (2007) acknowledges the significance of families in community participation. He clearly sites the primacy and importance of their role in supporting people with disabilities with unpaid care, love and responsibility. Families 'often will seek the very best outcomes for their family member experiencing disability' (Kendrick in BPB 2007:144). Government has utilized carers and their skills as a means of vastly reducing expenditure on the welfare system. Now is the time to legitimately support families, friends and unpaid carers in their often unique and sustaining role of caring for individuals with disabilities.

- The current carers support payments do little to ameliorate the hardship experienced by carers and would need to be reviewed and lifted in line with Australian basic wage, especially where the responsibility of caring of a person with a disability reduces opportunities for employment.

- Self directed funds; many carers and families could benefit from SDS by helping an individual with disabilities to achieve their goals, build skills, capacities and networks while valuing their status as a person. SDS allows for

people with disabilities to purchase their own resources for 'breathing space' for themselves and their carer for holidays, recreational and leisure pursuits, in home supports or community involvement (DHS 2006).
- Need to reduce carer stress, increase respite opportunities, more support for carers

There are many advantages of a NDIS but if the system is mismanaged or sufficient resources are not made available, it could be at risk of putting added pressure, subtly or otherwise, onto families, obliging them to take more responsibility for family members with disabilities. At no stage must it be assumed that responsibility for people with disabilities can be relinquished by the State, under the guise of SDS or developing social capital, and put back into the lap of families. To avoid this an independent source must seek information and evaluations from people with disabilities, families members, service providers, advocate groups.

Standardise and regulate the disability sector

Funding for disability related services comes from both Commonwealth and State Sources (Bidmeade 2004). As such this is confusing and cumbersome, and often scarce resources are wasted in administration. Part of a NDIS success would see the Federal Government unifying both legislation and funding to the Federal Portfolio.

- National system of standards, funding and service models

- Organisations and service delivery agencies to be regularly reviewed by an independent source to evaluate the things such as transparency, accountability and best practice standards, not current minimum standards.

- Lift the value and profile of people with disabilities and Disability Services in general, particularly around people with intellectual disabilities and mental illness. Bigby (2006b;8), emphasizes that 'the value accorded to people with an intellectual disability in the community is low and reflected by the wages and status of the direct care workers'.

- Stop seeing Human Services primarily as a market enterprise. Agencies often have competitively tendered for funds to deliver services to people with disabilities. These agencies seek to employ the cheapest means of labour, which usually means employing unskilled and untrained workers to support people with disabilities. Often people without training are supporting some of our most vulnerable members of society, particularly those people with dual diagnosis or multiple and complex needs. The fault does not lay with the untrained employee, or arguably with organisations who seek to compete against each other for financial viability. The fault lays with a system that has turned human beings in to a market enterprise

- Organisations to be mandated to will need to ensure that staff are trained in current and emerging trends and needs, so human service workers can support, and assist if necessary, people with a disability to make decisions that are in the long term goal of independence and citizenship.
- Current waiting lists for services such as Speech Therapy, OT, Autism SA are too long can be as much as 2 years. Some of the reasons relate to high staff turnover delaying referrals and assessments. Requirement for referrals to be signed by a 'professional' such as an OT when often it is the day to day worker who knows more about the person's needs.

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