

INTRODUCTION

On 17 May 2010 the Australian Government Productivity Commission released issues papers on Disability Care and Support. The Australian Catholic Bishops Conference appreciates this opportunity to contribute to this most important inquiry and thanks the Government for the opportunity to participate in the discussion.

This inquiry is an opportunity to rethink how we support people with disabilities so that they can engage with their community, get a job where possible, and live a happy and meaningful life (Sherry, Rudd, Macklin and Shorten 2009).

The following points are for the consideration on how the National Disability Insurance Scheme (NDIS) will impact on people with disability, and their families and carers in Australia.

Australia's current approach to disability services is crisis-driven and welfare-based. The proposed Scheme is intended to change that, as it is to provide funding for essential care, support, therapy, aids, equipment, home modification, access to the community, education and training. It has the potential to revolutionise the care and quality of life of persons with disability. It will abolish inequalities that currently exist for those without insurance, such as individuals who have sustained motor vehicle accidents and families who have been successful in litigations.

The Australian Catholic Bishops Conference agrees with the overall premise that the current system needs to be completely overhauled. It is also agreed that control should be with the individuals and their families through individualised funding in order to provide more choices and more accountability by service providers.

However, any new system should not only focus on people with disability under the age of 65 years. As the population ages, so do people with disability, and ongoing services and resources should be available to them. Further, this system needs to be centred on all people with disability, not just people with diagnosed profound and severe disability. People with mild and moderate disability also need support and it cannot be assumed that they will be cared for in some other way and by other means.

In the existing model, there is no sense of entitlement or "person-centeredness", costs are being minimised, and services and families are responsible, not governments.

There is a lack of formula in relation to disability funding. Individuals and their families are dependent on an *ad hoc* system from the beginning. There is little planning, coordination and consideration for funds needed to assist persons with disability throughout their life span and various transitional phases.

The issues of planning, coordination and person-centeredness are crucial and must be addressed by the Productivity Commission enquiry so that the new Scheme can incorporate them.

The new Scheme should ensure that people have sufficient funding to access the service they require, especially in areas of education, respite opportunities, community access, employment and accommodation options.

ELIGIBILITY

It has been an ongoing challenge to ensure people with disability and their families are provided with the most appropriate levels and quality of service throughout their life span. This would also include services for families supporting and caring for the person with disability. Parents and carers must be recognised and supported for the level of work and care they provide. Carers need to be recognised formally as an integral part of the person with disability. Both the person with disability and their families need consistent and good quality services. Therefore, eligibility needs to be carefully framed to ensure that every person with disability and their families are given the opportunity to participate in society. The following points need to be considered.

- Each person with disability must be considered from a *whole of life* viewpoint. Each person, with their family, needs to be assessed as an individual.
- The gifts and unique attributes of the person with disability need to be acknowledged, encouraged and nurtured, so that each person has the opportunity to reach his or her full potential.
- The process of assessment and eligibility needs to be transparent and fair, as well as providing opportunities to review the individual's situation.
- Persons with disability, who are diagnosed with a permanent or lifelong condition, should not be required to attend annual medical reviews.
- Remote and rural areas should be given special consideration. The time and cost of travel need to be addressed, especially for specialised services.
- Adequate and specialised quality services for people with dual diagnosis, that is persons with intellectual disability and mental health issues, often slip through current schemes. Therefore, a new assessment tool is required to ensure people with dual diagnosis have access to the most appropriate services and opportunities to live and work in the most appropriate setting.
- Intensive support and appropriate assistance is required for migrants, refugees, aboriginal persons and parents with an intellectual disability, to ensure all people receive the most appropriate support and services.
- Persons with mental health issues and their families need to be supported and appropriately assessed.
- Early intervention for all diagnoses and levels of ability should be addressed as a priority with opportunities for reviews for further assistance.
- The eligibility criteria that specify that the Scheme should cover disability present at birth, or acquired through an accident or health condition, but not due to natural ageing, could be replaced with, 'providing support for people of all ages, providing that the disability was acquired before the age of 65 years.'
- Eligibility for the Scheme could be described in terms of the frequency and amount of assistance needed in any of the activity and participation domains of the International Classification of Functioning, Disability and Health as defined by the World Health Organisation.

- The Scheme should be national and based on:
 - Entitlement for all eligible persons;
 - Adequate funding to address additional costs of disability;
 - Equity for all eligible persons;
 - Taking into account the impact of gender, aboriginal background, cultural diversity and remoteness of access;
 - Consistency nationally and portability across all Commonwealth States and Territories; and
 - Responsiveness to changing circumstances of individuals over their life span and respect for their needs, wants and aspirations.

DECISION MAKING / POWER

It would be advantageous to investigate models used in overseas settings and choose the best from these models that are already in existence. Best practices and application of policies of these models could then be implemented within the Australian community.

Using a model similar to Medicare, but focussed on disability support, would be more practical than using a medical model for disability services. The following points should be considered in the provision of services under this *Disability Support* model.

- **The significance and importance of early intervention is vital at birth and when a disability occurs.** For example: immediate support for first diagnosis of mental health issues; rehabilitation after accident or medical condition; early intervention for children diagnosed with developmental delay.
- **Individual packages to support the specific needs of people**, and their families and carers. These individual packages also must include the Deaf and Hard of Hearing. That is, Deaf and Hard of Hearing Australians should have access to adequate support including real time captioning for meetings and events, audio induction loops, Auslan interpreters, captions for television programmes, volume controlled telephones and visual warning fire and smoke alarms.
- **Funding that is flexible according to the supports required** by the person with disability to support their full participation in society.
- **People with disability, and their families and carers, must have portability of services in their support.** That is, they are able to transfer their funding to a new location.
- **Purchasing power of services** for individuals with disability and their carers remain with them.
- **Freedom to choose services** particular to the need of the person. This must include choice in respite support for the families and carers providing primary care.

- **People living in remote and rural areas** should be given special consideration regarding travel time and availability of services.
- **Migrants and refugees with disability** should be assessed and supported in a timely manner consistent with the needs of the individual.
- **Support workers should be recognised and encouraged in their work role** with appropriate remuneration. There needs to be a strong career path and incentives to attract support workers to the disability sector.

FUNDING

The level of funding and the source of income for past schemes have been inconsistent. There is an urgent need to provide transparency and accountability, especially to the client receiving funding and services. The following points need to be considered.

- Funding to individuals must be transparent and sufficient to cover the needs of the individual and their families.
- Opportunities and incentives for private health insurers should provide ongoing or extended cover for essential therapies.
- There need to be opportunities, incentives and encouragement for those on lower incomes to join private health insurers.
- A provision should be created in Medicare to provide a more comprehensive and extensive cover for the basic therapies, such as speech, and occupational and physiotherapy, especially for those individuals and families on a low income.
- Bulk billing should be extended to all medical specialists for people with disability.
- The gap payment for hospital fees and charges should be waived for people with disability.
- The taxi voucher subsidy should be increased in rural and remote areas, especially for services that are utilised on a regular or recurring basis, such as medical or therapy services.
- A fuel allowance for families, carers and service providers transporting a person with disability to services, especially those living in remote and rural communities, should be considered.
- Funding for individualised disability support should support full participation in all areas of life - spiritual, political, civil, cultural and economic – as set out in the various articles of the United Nations' Convention on the Rights of Persons with Disabilities.

FURTHER COMMENTS

The needs of people with an intellectual disability or mental illness need particular attention in assessment, treatment and accommodation. Families must be provided with appropriate respite and support during the initial assessment period and ongoing.

People with disability and their families in remote and rural areas, older parents caring for children with disability, people with a dual diagnosis, young carers, aboriginal people, and migrants and refugees experience increased disadvantage and often miss out on appropriate assessment and services. There is an urgent need to ensure that all people with disability receive the support necessary to ensure their full participation in the life of our society.

An assessment tool for those with intellectual disability and who are ageing needs to be urgently addressed. The current Aged Care Assessment Team tools are not appropriate for ageing people with intellectual disability.

The issue of older parents who are carers of persons with disability must also be addressed within the Scheme.

Access to early intervention strategies, rehabilitation services and treatment for those who are eligible should be aligned to individual needs, emphasising self-determination, choice and flexibility.

The Scheme should provide for a national framework, which is economically sustainable, seamless, accessible and fair for all. Further, the Scheme should promote and enhance access to education, vocational training and employment of people with disability.

The Disability Discrimination Act (1992) and the United Nations' Convention on the Rights of Persons with Disabilities must be acknowledged and included.

CONCLUSION

One of the hoped outcomes of the proposed National Disability Insurance Scheme will be to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms for all people with disability, and to promote respect for their inherent dignity.

It is important that the Scheme is simple, easily accessible, with input in its design and evaluation by users of the service.

Governments need to ensure that the rights of persons with disability are upheld by clarifying and acting upon policies that directly relate to the historic discrimination and exclusion of persons with disability. This will ensure that all persons with disability in Australian society will enjoy all human rights and fundamental freedoms. Hence, people with disability, and their families and carers, will, in fact, *"engage with their community, get a job where possible, and live a happy and meaningful life"* (Sherry, Rudd, Macklin and Shorten 2009).

The Australian Catholic Bishops Conference is involved in a wide range of activities across a considerable network of Catholic health and welfare services. The expertise available across this network is considerable. The Conference and its affiliates would be happy to work with the Government in addressing and redressing the many difficulties that people with disability experience on a daily basis. The Conference can be contacted through the:

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We wish the Government well in its consideration of this very important topic.