Genetic Support Network of Victoria
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'Have Your Say'

Submission to

Productivity Commission Inquiry

Disability Support 2010

Background

The Genetic Support Network Victoria (GSNV) is a vibrant and active organisation which aims to maintain a thriving network committed to promoting the interests and well-being of people affected by genetic conditions. The Network is proud to be associated with a wide range of support groups throughout Victoria as well as peak professional bodies such as Genetic Health Services Victoria. The 'human, ' non clinical side of genetic diagnosis, understanding a condition, navigating a complex system for access and equity, carer and respite support and connecting with others in the same boat are common place in our day to day activity and represent the core of our enquiries. The GSNV is uniquely positioned to bring together the various types of information, service providers and support groups and work with them to feed information out to the community and provide timely responses to calls for support and advocacy.

In 2010 the GSNV identified a strong need to facilitate opportunities for our members and support groups to 'have their say and form a collective voice on all manner of topical issues such as health reform, disability services, access to therapeutics and stigma reduction. The development and circulation of position statements which are reflective of the diverse opinions of the GSNV community are very important in this election year and in response to State and Federal health reform agendas.

In June 2010, GSNV hosted a forum to gather views from its members and from professionals/experts in a range of disability related areas to inform this submission to the Productivity Commission's Inquiry into a National Disability Care and Support Program. The forum was held in the spirit of creating a vision for disability support. The inspiration for the spirit of this forum was taken from a report called 'Early Childhood Intervention: A Vision for Victoria' authored by the Victorian Women's Trust, Gateways Support Services & Kids Plus Foundation facilitated and authored by Mary Crooks (see http://www.vwt.org.au/store/files/1254542309.pdf).

Participants were as follows:

- Moira Rayner, Moira Rayner and Associates, GSNV President
- Christine Williams, Advocate/Support Group Rep, Porphyria Association/GSNV Committee
- Louisa Di Pietro, Team Leader, GSNV
- Penny Dodds, Project Administrator, GSNV
- Alice Ames, PhD Student, University of Melbourne, Genetic Health Education
- Anne Murphy, Victorian Representative, Australians Mad as Hell
- Carly Findlay, GSNV Member
- Dinah Reddihough, Director, Developmental Medicine RCH

- George Vassilou, Advocate, Parent/Carer
- Helen Adams, Executive Officer, Disability Connections Victoria
- Kate Willoughyby, Snr Physiotherapist, RCH/MCRI Gait Clinic
- Liat Harrower, Advocate – Lobbyist, Australian Perseverance Alliance
- Sarah Foley, Program Manager and Snr Physiotherapist, Kids Plus Foundation
- Sarah Olliff, Executive Officer, Kids Plus Foundation
- Stephanie Gotlib, Executive Officer Children with Disability Australia
- Jacinta Cannon, Pierre Robin Support Group

The forum and the forum agenda was simple and practical, centered on addressing the key questions of the Productivity Commission's issues papers with the aim of identifying key elements of a new disability care and support system that will transform the lives of people living with a disability in Australia.

The consensus from participants at the forum and others who provided their views is that there is a desperate and urgent need for a new funding model that will allow for a care and support system for everyone affected by disability.

The Submission

Part 1:

Our response to some of the key questions from the issues papers published by the Productivity Commission taken from the experiences, ideas and views of the forum participants.

Part 2:

Our vision of how a National Disability Insurance System could transform the lives of people with a disability in Australia so that they can engage with their community, get a job, and live a happy, productive and meaningful life.

PART 1

Issues Questions

1. Design elements of a new scheme?

The key design elements of any new scheme are that it should be a national scheme that addresses both the social and economic needs of people with disabilities and/or their families in Australia.

A single nationally administered scheme should ensure that eligibility and entitlements are the same wherever you live. It should be simple and remove the need for endless form filling, red tape and the wasted time of renegotiating the system when you move to another suburb or another State. It should include a national database designed to hold information at a local level, allowing people to access information about services or equipment providers in their local area. It should be interactive and allow for feedback or information/data collection or sharing that can be used for research to further improve the system.

2. Who should be eligible?

The terms of reference for this inquiry refer to a tax-payer funded National Disability Insurance Scheme (NDIS) with regards to providing "long-term essential care and support for eligible people with severe or profound disability" only. Whilst we recognize that people with long-term severe or profound disabilities should be a priority for support through an NDIS there are still many people with long-term mild to moderate disabilities who need, and should also have the right, to access the support and services that they require in order to function to their full potential in their communities. Too many of these people already fall through the cracks in the current system and establishing a system that has the potential to limit access to support even further for these groups of people is unlikely to be supported in the community.

Our position on eligibility into the new scheme is that **all** persons with a long-term physical, mental, intellectual or sensory disability that impairs their ability to fully and effectively participate in all aspects of life, on an equal basis with others, and who require additional assistance, care or support to do so should be eligible. This includes people who have disabilities that are long term and episodic (e.g. related to chronic conditions, co-morbidities of a chronic condition or mental illness) or long-term but not necessarily lifelong (e.g. recovery from a stroke or accident). It also would include children with learning disabilities or behavioral/social concerns who currently cannot access the support they need at school. As in other countries we believe that this should be a legislated right in Australia and one that is supported by the United Nations Convention of Rights of Persons with Disabilities.

Eligibility criteria for a new scheme may include a medical or psychological assessment of disability. Entitlements should be based on need that takes into account other reference factors associated with the disability including social and environmental factors. Families and carers should also be entitled to support under this system, in order to carry out their caring roles. People should be informed adequately on how the scheme works and what their options and entitlements are. Together with co-coordinated service provision this will ensure that people with similar levels of need get similar levels of support no matter where they live in Australia.

3. Who gets the power?

To whatever extent possible people with a disability or their family/carer should have the power to make decisions on how they or their family member/dependant is best supported and what services they need. Families should have the power to make decisions for their children until such time as those children are eligible by age, or able to make those decisions for themselves. Under this system it will also be necessary to provide people with disabilities or their families/carers access to information. Everyone needs to understand how a new scheme works and what choices they have and what they are entitled to. They also need to be encouraged to take control of defining their own or their dependants individual care plan. Appropriate training should be made available for people with a disability or family/carer who require extra assistance with navigating a new system. If required, an advocate or case manager should be provided to inform and offer choices.

In cases of conflict it is important that any decision is made with the best interest, and the rights of the person with a disability (child or adult) in mind. Any disputes should be resolved quickly and informally in line with the guiding principals of the International convention of the rights of people with disability.

Anyone eligible for support under the new scheme should be assessed based on need against nationally determined criteria and both a short and long-term care plan developed. This should be reviewed annually and funding entitlement for each year determined. The person with a disability or their family/carer should then design a package of care that is most appropriate to their own or their dependant’s needs. Assistance with designing or implementing a personal budget based on the assessed level of need should be provided if required. This will allow recipients the opportunity to select providers themselves, pay providers directly or through an intermediary if they choose to do so. With annual reviews of funding, any misuse will become apparent and accountability assured.

The benefits of this type of model are enormous. By giving people with disabilities or their families/carers the power to administer their own funds they become consumers, clients and potentially employers and they ultimately have more control over their own lives. This type of model also bypasses the “middle man” of the current system, where administration costs in government departments and service provider organizations can consume up to 70% of funds that are allocated to assist a person with a disability.

4. What services are needed and how should they be delivered?

Service that are needed and should be provided under an NDIS are:

Early Intervention Services – This is a key service that is relevant across all types of disability and has the potential to reduce on-going support needs and produce better long-term outcomes.

- These services should be one-stop shops that provide access to health professionals, therapies, counseling etc related to the disability. A working example of this type of service would be the Headspace model that is currently being rolled out in the mental health sector.

Therapies/treatments – These can be provided either on referral or by purchase through self-directed funding with a new scheme and people with a disability or their family/carer can select which therapy best suits their needs.

Personal Assistance-Where required this can be provided through an agency or service provider or sourced individually.

Respite Services-These service can be provided in the form of in-home care or out-of home programs for the person with a disability to allow their families/carers to have a break from their caring roles. Families should have the ability to choose what type of respite best suits their needs and how it is delivered.

Supported accommodation- This gives people with disabilities the opportunity to be supported to live as independently as possible in their own homes, in their family homes or in group homes or villages. They or their families should be able to choose which option suits them best.

Education support- Children or adults assessed as requiring extra support in an educational setting should be provided with access to that support including therapists/aides, programs or equipment. Wherever possible therapies etc should be provided within the educational setting itself. This will require co-ordination between the scheme and the Education Department.

Workplace Support- People with disabilities should be given every opportunity possible to hold down employment. Those who require services or equipment at work to enable them to perform their jobs at an equal capacity to their co-workers, should be provided with those supports. Workplaces should be required to provide adequate facilities and should be funded or given tax incentives to enable them to support this provision.

Aids and Equipment (including vehicle and home modification)–The timely provision of aids and equipment that suit the needs of individuals with a disability and provides them with the means to reach their full potential and to interact with and be valued members of their communities, should be a priority in any new scheme. Information on where to get professional advice or where to purchase or source aids and equipment should be made available through a national database.

Often in the current system the provision of services is highly inadequate. For example in the Early Childhood Intervention sector there are just not enough therapist/specialists (both government funded or private) to cope with the numbers of children requiring assistance. This situation is worse in rural areas. The long waiting times for access, and the limited service offered in most cases, is not acceptable and defeats the purpose of early intervention. Waiting lists negate early intervention in the truest sense. We need to start investing in training more early intervention therapists/specialists now to cope with demand and to be able to offer children the services they need, when they need them.

It is also important to ensure that the industry can attract and retain therapists and disability workers and as such they need to be paid **competitive** salaries and given additional incentives to work in rural areas. In doing this the industry will be able to attract quality workers who will have better job satisfaction, and retention of workers within the industry will rise considerably.

5. Funding

It is our opinion that the whole Australian community should share the cost of a disability care and support scheme. Hence the most appropriate way to finance it should be a tax-payer funded scheme similar to, or an extension of, the current Medicare levy for health care support. Whilst this may be perceived by the Australian public as being an additional tax it will be very important to raise awareness in the community about why this fund is needed and how it will benefit all Australians.

All Australians need to be made aware that disability can happen to anyone at any time. They also need to be made aware that they already fund the current wasteful and dysfunctional disability support system through their taxes, and through their support of raffles and fundraisers that charity organizations currently arrange to raise money for essential equipment and services for people with disabilities that they sadly cannot access through the current system. Raising this awareness in the community should make it very apparent that establishing a socially funded scheme that is sustainable and cost-efficient will benefit all Australians.

We recognize that a scheme that provides infrastructure and support for all people with a disability may at first glance appear financially unfeasible. However we believe that over time and with early intervention for all types of disabilities that ongoing support needs will be reduced for many eligible people and this will ultimately reduce ongoing costs. In addition, there may be a number of ways that a scheme can be structured to ensure that everyone that is eligible can access support. For example, people with severe disabilities or those with the highest care and support needs depending on circumstance could be funded through an NDIS funding scheme while people with lower support needs could be allowed non means tested 100% tax deductions on the cost of services or equipment.

In summary, a well-designed and cost-efficient tax-payer funded system will be sustainable and will benefit all Australians with disabilities who need support.

6. Organising and implementing a new disability policy

The current system is dysfunctional and unsustainable and too many people are already struggling and not having their needs met. It is our opinion that a complete reshaping of the current system is required and we should not be deterred from aspiring to create the best possible system just because it may be perceived to be too complex to achieve.

Any new national scheme should sit within the National Disability Strategy that is currently being drawn up with the aim of breaking down the disabling barriers that people with disabilities face in their everyday lives and promoting the principal of social inclusion. A new scheme will also have to rely on seamless integration between all government departments and service providers so that there is continuity of care and support across all sectors. For example the education system needs to use the same criteria for eligibility for support as an NDIS so that children continue to get the support they require at school.

Service providers may also need to restructure the way they work, as the system becomes more and more consumer driven. There will be more competition, more accountability and consequently better choices and better services for the people who require them.

Health care and other professionals will need to be trained to identify and diagnose disabilities early and direct their clients in the right direction for early intervention. Teachers will need to be trained on how to include children with disabilities in their classrooms and be given support to do so. More therapists and specialists will need to be trained and will be required for both city and rural areas. Information systems will need to be developed and appropriately trained workers for administering and supporting the system will be required.

It is likely that it will take many years to completely reshape the current system. However, with the current system failing so many people it will not be viable to continue with the current system until a new one is up and running. There are a number of things that can **immediately** start being implemented, that will benefit people who need support now but also inform and shape the new system. For example, we should immediately move towards offering more and more eligible people Individual Care Packages that allow them to self direct their funding. Many States already have working models in place for these packages but there are very limited in number. If more funding is put into these packages, and increasingly more people have control over their own funding, then this will give government departments, service providers and other organizations the opportunity to gradually restructure so that they are NDIS ready when the new scheme is implemented.

It should also be noted that whilst it is inevitable that some jobs will be lost during the restructuring process that the new system will more than compensate and actually create more job and training opportunities for Australians. It will provide a system that will create job satisfaction and be able to attract and retain workers. It will also provide opportunities for carers to re-enter the workforce if they choose or be supported in their caring role.

7. Other Ideas

The Australian government could raise awareness of this issue in the same way as they have raised awareness of national health priorities such as heart disease, stroke, diabetes etc. Targeted advertising campaigns have significantly raised health literacy and health awareness of the Australian health consumer and contributed toward attitudinal changes. Disability should be treated in exactly this way, it is a national priority, a national concern and could affect anyone at any time. Lets put disability on the National health agenda and raise public perception that this too is a ‘quality of life’ issue.

Continued consultation with the Australian Public (particularly people with disabilities and/or their families/carers) is essential throughout the design and implementation process of any new disability and care support scheme that follows on from the Productivity Commission Inquiry.

This is Australia’s chance to completely reform the current system and to implement a scheme that represents an internationally recognized, best practice Disability Support System based on ensuring equality for those affected by disability in our society. We should take this opportunity to draw on the experience of a number of international models in order to design, without any compromise in quality, one that will best serve all Australians.

PART 2

Our Vision……

Imagine an Australia where people with disabilities are included and accepted and given every opportunity to fully participate in all social, cultural and economic aspects of our society, on equal terms with everyone else. Where they are just ordinary people living ordinary lives.

This change has come about through significant political, social and economic reform. A new National Disability Strategy incorporating policy and legislation that address the many disabling barriers that Australians with a disability face in their daily lives has been put in place. Within that framework, a no-fault National Disability Insurance Scheme now provides people with disability and their families/carers an entitlement to the support, assistance and care that they need to participate fully in society. This has given them access to the same opportunities as everyone else. It has given them a new visibility as equal participants within their communities and has helped shape and change social attitudes. They are now accepted, respected and included in Australian society.

In this new Australia:

- Short and long-term individual care plans have provided people with disabilities and their families/carers with a reassurance that there will be continuity of care. They can be confident that they will be fully supported at school, in higher education or training and in the workplace or in whatever they choose to do. They can aspire to be the best they can be. They are now able to plan for their futures.

- People with disabilities and their families/carers are now in complete charge of their own lives. This is a very significant change that has been brought about through the provision of individual support packages that allows them to self-direct their disability support funding. They now have choices and are able to select services, equipment and housing that best suit their own needs. The national structure of a new support scheme also allows them to choose wherever they want to live without the fear of losing or compromising their support funding.

- There is now timely access to early intervention services, equipment and aids regardless of the type of disability. The new one-stop shops that have been created offer people with disabilities and their families/carers easy access to health professionals, therapists, counselors, equipment and all the information and support they need. These facilities are offered as part of, or integrated with mainstream services wherever possible, in order to promote and enhance social inclusion. Through adequate early intervention programs more people have overcome their disabilities or now have significantly improved long term outcomes with fewer ongoing care and support needs and costs.

- People with disabilities now have significantly more freedom to move around in and access their communities and are no longer isolated or restrained because of physical and environmental barrier. Everywhere in the community shops, businesses and all public venues have or are installing appropriate facilities that provide access for all abilities. All new housing, workplaces or building projects are required to comply with national accessibility standards giving people with mobility issues more choices and freedom within the community. All means of public transport now cater for all abilities.

- People with disabilities and their families/carers no longer feel excluded, isolated, pitied or seen as a burden because they now get the support and care they need when they need it, which allows them to participate freely within or outside their own communities to whatever extent they can. This has led to a significant decline in the diagnosis of mental health related problems amongst people with a disability and their family members and fewer marriage break-ups amongst those in a caring role.

We are realistic and we know that this change will not happen overnight. However, step-by step over time we can begin to make the changes that we believe will make this vision a reality. The implementation of a new National Disability Insurance Scheme now will be a vital component on this journey as it will help shape the future, change perceptions and drive us closer to our vision.