# *Down Syndrome Victoria Submission to the Productivity Commission Inquiry into the Development of a Disability Long-term Care and Support Scheme*

## Introduction

Too many Australians with a disability, their families and carers struggle to achieve a basic quality of life. Without adequate support and resources, many find themselves unable to participate meaningfully in the economic, social, cultural and political life of the nation. While Australia prides itself on being the land of the "fair go" this has not been extended to people with a disability, who frequently find themselves excluded, marginalised and forgotten. This situation is not acceptable. It is time to introduce a disability support system that meets the needs of Australians with a disability, their families and carers in the 21st century and beyond.

Australia ratified the United Nations Convention on the Rights of Persons with Disabilities in 2008. While an historic and significant moment, ratification is simply a first step on a long journey to ensure the rights enshrined in the convention are not only protected but, more importantly, able to be fully realised. Whilst it is clearly not the only factor to be considered, it is important to acknowledge that rights can remain elusive if adequate resources are not provided.

Our vision is an Australian society that ensures the full and equal social, economic, cultural and political participation of people with a disability, their families and carers. The Productivity Commission's concise summary of the goal of any new scheme is therefore a good one: "to enhance the quality of life and increase the economic and social participation of people with a disability and their families" (p9).

Resources are important but not sufficient. Any long term care and support scheme should sit within the National Disability Strategy currently being drafted by the Council of Australian Governments. The role of the strategy is to address the systemic changes that must be made so that people with a disability, their families and carers are able to enjoy the same rights as other members of the community. This includes making provision for a strong independent advocacy movement.

The Commission's detailed *Issues Paper* gives some indication of the depth and breadth of questions that must be answered before a new scheme can be developed and implemented. But just as important as dealing with the detailed questions of design and implementation is establishing the principles which should underpin the scheme. If the foundations are not adequate the scheme will ultimately fail to deliver the kinds of reforms that people with a disability, their families and the organisations that support them, such as Down Syndrome Victoria, have long been seeking. We believe the principles of equity, self-determination, efficiency and sustainability should determine the development and implementation of any new national long-term care and support scheme.

## Guiding Principles

*Commitment to the realisation of the rights enshrined in the UN Convention on the Rights of Persons with Disabilities.*

The intent of any disability support scheme should be to ensure people with a disability receive the support they require to be active, engaged, productive and participating members of the community. The scheme should be a mechanism by which people should be able to exercise the full range of their rights as outlined by the UN Convention.

*Equity in Eligibility*

The system should be fair. All people with a disability should be entitled to the support they require to be full and equal participants in the economy and the community, regardless of how they acquire their disability. People born with a disability or who acquire a disability through accident, illness or progressive medical condition should all be eligible for assistance. The scheme should also provide support to those with a psychosocial disability (mental illness). The scheme should be no fault and should provide support for people who have a permanent disability that has a significant impact on their daily life. Support should not be restricted to people with a severe or profound disability but people with a more moderate disability should also be eligible for assistance.

In other nations around the world there is a legislated entitlement to support. No such right exists in Australia. People with a disability, their families and carers should be entitled to the support they need to be active, engaged members of the community. Eligible individuals must be entitled to the support they require based on a simple and transparent assessment of their needs. This assessment process also needs to be flexible and responsive to changes. As needs and circumstances change so too should the support provided. Any assessment process therefore needs to be flexible and responsive to changes over the life course. The scheme should ensure national consistency in eligibility and access.

All individuals with Down syndrome should be eligible for assistance under the scheme. While each person with Down syndrome has their own abilities, talents, interests and strengths, and is a unique individual in their own right, all people with Down syndrome have some degree of intellectual disability. Given that Down syndrome is a genetic condition and permanent disability, eligibility for the scheme should therefore be simply and easily determined. And once eligibility has been determined it should not have to be re-established. Families of people with Down syndrome are constantly frustrated by the significant amount of time and resources expended on constantly re-establishing their family member has Down syndrome. Multiple trips to GPs to sign forms are not only a drain on the public purse but also an additional unnecessary burden on families already struggling with additional financial, emotional and physical responsibilities.

Once eligibility has been established, the assessment process for support should focus on functional need. While all people with Down syndrome have an intellectual disability, there is considerable variation between individuals in the level of intellectual functioning and capacity for independence. The assessment process should not be dominated by medical classifications or diagnosis but focus on the assistance for daily living tasks. The assessment process should take a broad view of an individual and take account of the social, economic and environmental circumstances in which they find themselves. The assessment process must not be dominated by medial notions of functionality but be nuanced enough to capture the sometimes more subtle, less obvious supports required to establish and maintain independence. This is particularly pertinent for people with an intellectual disability who may require less assistance with daily physical care tasks but require significant support to maintain their independence within the community. It is our experience, and the experience of many families that we support, that most assessment tools and processes take a very narrow view of functionality, focus on physical care tasks and do not accurately capture the extent of support required to maintain independence.

The assessment process must also straddle the fine line between being simple and easy to use whilst ensuring a comprehensive picture of individual need and circumstance is established. We recognise that it will sometimes be difficult to balance equity with the need for responsiveness to individual circumstances. But tools exist that have been shown to be both nuanced and robust. It is essential that the tool utilised be the subject of further study before the scheme is implemented.

Although eligibility should not need to be re-established, reassessment of need should occur regularly enough to ensure responsiveness to changes over the life course. This is particularly important for adults with Down syndrome. There is a higher incidence, as well as earlier onset, of Alzheimer's disease in adults with Down syndrome. There is also increasing recognition of the particular mental health needs of adults with Down syndrome. The best outcomes are achieved when diagnosis is made early and support provided in a timely manner. Families must be able to obtain greater support when the needs of their family member with Down syndrome become more complex.

*Equity in Supports Available*

Equity also demands that there should be comparable supports available both to people who acquire their disability before the age of 65 and to those who acquire their disability later in life. In order for this to be true, there must be better linkages and coordination between all systems, but most notably between the disability and aged care system. Cooperative arrangements focused on the needs of people with a disability must be fostered across sector boundaries. This is particularly important for ensuring the needs of adults with Down syndrome are adequately met as they age, since they may develop dementia and mental health difficulties at a younger age than the rest of the population.

Down Syndrome Victoria supports initiatives that have sought to ensure young people with disabilities are not inappropriately placed in aged care facilities. Unfortunately one side effect of these initiatives is that aged care facilities and disability services are currently not working effectively together. There is increasing anecdotal evidence to suggest that once individuals are located in one system they find it difficult to access support or services from the other, resulting in significant needs not being adequately addressed. The families of adults with Down syndrome living in aged care facilities report that it is particularly difficult to access support which addresses the particular needs of their disability. Down Syndrome Victoria strongly believes there is a pressing need for better coordination and linkages between the two systems. We are therefore pleased that the Productivity Commission is conducting an inquiry into aged care at the same time as this inquiry, and expect the two reports to share much common ground.

Families and carers should also be entitled to the support they require to continue to sustain their role in supporting their family member with a disability. The families that Down Syndrome Victoria supports are actively engaged in the lives of their family member with Down syndrome. They attend our events, they browse our library, they scan our website, they spend hours on the internet, they meet and trade information with other parents - all with the goal of ensuring their family member with Down syndrome has every opportunity to reach their full potential. But there is a significant level of resentment at the exploitation of this dedication by governments unwilling to adequately fund a functioning support system. The assumption that families will continue to provide a lifetime of unpaid care with little or no formal support exhausts and angers families.

What families want most is *choice*. They want to choose what level of unpaid care they will provide and what level of support will be provided by formal services. The focus of a national long term care and support scheme should not be the replacement of informal care with formal care, but the assurance that families will be able to choose the most appropriate mix of both, to suit the particular needs and circumstances of the family as a whole.

*Equity within the Community*

The scheme should not only establish equity between all types of disability but between people with a disability and the rest of the community. In short, the scheme should recognise the additional costs of living with a disability by the provision of adequate services and support. This should always be a separate consideration to the provision of income support.

The additional costs of living with Down syndrome are not always apparent. When compared to the capital costs of a wheelchair or home modifications, the lesser costs associated with the multiple health needs and intellectual disability of people with Down syndrome, may seem insignificant. However, the sum of these costs has a significant impact on the family budget. Children with Down syndrome, for example, follow the normal pattern of development, usually achieving the same developmental milestones as other children. They do however take longer to achieve each milestone, and stay in each developmental period for longer. Children with Down syndrome therefore spend a longer period in nappies, and take longer to achieve toilet training. This may appear a trivial example but the cost of a further two years of nappies beyond an average child certainly has an impact on the family budget.

In order to achieve equity between people with Down syndrome and their families and the rest of the community, these often hidden costs must be taken into consideration in determining what supports and services can be purchased through the scheme.

The provision of better support and services should not reduce the onus on communities and government to become more accessible and inclusive. No-one with a disability should need to use their entitlements to address issues of inaccessibility and exclusion – the onus should be on systems, programs and policies to better meet the needs of a diverse community, including people with a disability, their families and carers.

Down Syndrome Victoria is very concerned that the provision of individualised packages of support may lead to pressure being placed on individuals and families to use that support to facilitate inclusion. The most obvious example is education. Inadequate resources and support, and lack of teacher training and professional development mean that the education system is currently failing to meet the needs of many children and young adults with Down syndrome. This is true of both the specialist and mainstream school systems, but is most striking when children with Down syndrome attend mainstream schools. Families should not be expected to use their support package to address these failings. While the package may be used to provide additional speech or occupational therapy, for example, it should not replace a basic entitlement to appropriate educational support. It is the responsibility of the broader education system to ensure teachers are adequately prepared to meet the educational and learning needs of all children in their classroom and that both schools and teachers are provided with the resources and support they require to meet the additional needs of children with a disability in their schools and classrooms. It should not be the responsibility of the National Disability Insurance Scheme to make up for the failings of the broader educational system.

*Equity in Scheme Funding*

Finally the principle of equity should extend to the funding of the scheme. The cost of supporting people with a disability should be borne by the broader community. As the Commission rightly points out in its issues paper, social insurance is the most appropriate approach, as private insurance would function neither “efficiently or equitably”.

*Self Determination*

The scheme should institutionalise mechanisms to ensure people with a disability, their families and carers are able to exercise choice and control. The scheme should be person centred and individualised, based on the choices of the person with a disability, their family and carers. The services and supports purchased through such a scheme should be broad and diverse, determined by the individual needs and circumstances of those assessed as eligible. This includes purchasing supports and services from mainstream providers, rather than disability specialists only. The scheme should create and support a marketplace for services and supports that will drive innovation and efficiency, improving value for money.

There is strong evidence from around the world, including Australia, which demonstrates the positive impact of self-determination and control on health and wellbeing. The scheme must create a culture of independence rather than foster continuing dependence.

The scheme should also recognise that the introduction of choice and control requires an investment in information, resources and advocacy to ensure people with a disability, their families and carers are provided with the tools they need to make informed choices. The scheme should recognise that some individuals will require greater support to plan and exercise choice than others. This is particularly true for people with an intellectual disability who will require greater time and support for decision making. The additional cost in supporting people to make choices should not detract from the amount of support to be made available – it should be regarded as a separate cost to be borne by the scheme itself.

The scheme should provide a range of choices to individuals – from complete self-management to a brokerage system in which individuals would be responsible for planning but not direct purchasing. The emphasis should be on flexibility and choice. One of the strongest criticisms of the current system is its one-size-fits-all approach – the emphasis in the new system should be the development of a range of models that allow individuals and families to chose the planning and purchasing model which bests suits them and their circumstances.

Down Syndrome Victoria looks forward to the widespread implementation of individualised funding as a means of ensuring people with a disability are able to access the kinds of support necessary to help them achieve their own goals. But as individualised funding becomes more prevalent the importance of advocacy groups increases. Overseas experience has shown that the most effective individualised systems include a significant role for advocacy organisations to ensure people with a disability have a collective voice on issues of shared concern. The danger of individualised funding is that it has the potential to prevent collectivism and advocacy. People with an intellectual disability may be particularly vulnerable and isolated. Advocacy organisations also play an important role in ensuring people understand their rights and have the ability to exercise them in a meaningful way. This is again of particular importance to people with an intellectual disability who may be vulnerable to exploitation and abuse.

The role of peer supporting building resilience in people with Down syndrome and their families must also be acknowledged. Current research on resilience suggests that despite the very real demands of life with a child with a disability, most families can and do make the adjustment and incorporate the additional needs of their child with Down syndrome into their daily lives. Research shows that the divorce rate of parents of a child with Down syndrome is lower than that of parents of children with other disabilities, and lower than that of the general population.

International research also highlights the important role peer support plays in this adjustment process. This confirms our own anecdotal evidence, which suggests that the opportunity to share the load with others on the same journey contributes to the health and wellbeing of families, helping them to not only make the adjustment but also ensure continued successful functioning within universal services.

*Efficiency and Effectiveness*

The scheme should redirect attention from short-term costs to long-term outcomes, identifying and developing those services and supports which maximise independence, productivity and participation. In this way services and supports are reframed as investments rather than charitable handouts. In this way too the interests of the individual and the interests of the scheme will become aligned - both have the goal of ensuring every individual has every opportunity to reach their full potential. While such a scheme would obviously be interested in reducing long-term costs, individuals are most interested in identifying and using those services and supports which maximise their independence and participation. This is most obviously seen in investment in early intervention and education.

The importance of early intervention for children with Down syndrome cannot be overstated. Because Down syndrome is diagnosed at or before birth, the opportunity for intervention can begin at day one. Under current arrangements many children with Down syndrome stay on waiting lists for months and then do not receive adequate early intervention to ensure they develop the skills to reach their full potential. Most children with Down syndrome receive only a few hours of therapy a week. With such limited availability, the burden falls on parents to source and pay for other kinds of support or carry out the work themselves. Some parents report to Down Syndrome Victoria that early intervention consists only of observation of children and identifying areas of need. These are brought to the attention of parents who are then responsible for sourcing and paying for specialised assistance or trying to marshall what limited resources are available to meet the additional needs of children themselves.

While parents should be, and expect to be, active participants in meeting the needs of their children, there is considerable stress, resentment and anger at the perceived transfer of responsibility of early intervention to parents. Yet the evidence suggests that when adequate and appropriate early intervention is provided, there are multiple benefits to the child and to the family.

It is also important to note that there is now increasing evidence to demonstrate that individuals with Down syndrome continue learning well into adulthood and with appropriate support can continue to master new skills and achieve greater independence. It is therefore important to ensure that while early intervention should be a particular focus, the scheme should also recognise the ability of people with Down syndrome to continue to learn throughout their life and provide them with opportunities and support to do so. Once again this is an area where the interests of the individual and the interests of the scheme are aligned – ensuring adults with Down syndrome are provided with opportunities and support to continue to learn, grow and develop will ultimately promote greater independence, reduce costs to the scheme and ensure people with Down syndrome have a better quality of life.

In maximising efficiency and effectiveness, the scheme should also establish national standards and ensure portability across jurisdictions. The scheme should also provide an entitlement to services over time rather than a lump sum payment from which the individual should pay for the services they require (although larger sums may sometimes be necessary for the purchase of equipment). In this way the scheme would automatically balance the possibility that some people will live longer than expected and others shorter, and that some will have more severe disabilities than expected, while for others the impact of their disability may be less than anticipated.

Another important aspect of an efficient system is data collection, research, identification of best practice, support for innovation and benchmarking. These are not currently in evidence and should be features of the new system.

*Sustainability*

Sustainability should be achieved on four levels:

1. Individuals should be sustained over the life course. They require certainty in order to plan meaningfully for the future. They need certainty that should their needs and circumstances change, the system will respond appropriately.
2. Families and carers should be sustained and nurtured in their caring role, equipped with the tools and resources they require to appropriately support their family member with a disability.
3. A sustainable system must also address such issues as capacity, workforce development, infrastructure, research and innovation etc. It must ensure supports and services are available through a diverse range of organisations, which must be viable and sustainable.
4. Finally the entire system itself should be sustainable. Any new scheme must be affordable over the economic cycle and take account of demographic and social trends. The number of people with a disability is increasing and the number of people willing and able to provide unpaid care is decreasing.

It is a little understood fact that the population of people with Down syndrome continues to increase due to the combined influences of an unchanged birth rate and significantly increased life expectancy. The development and introduction of routine cardiac surgery over the past twenty years has significantly improved the health of people with Down syndrome and resulted in a life expectancy, which is slowly approaching that of the rest of the population. The challenges facing the first generation of people with Down syndrome who will outlive their parents are only now beginning to emerge.

Any new scheme must therefore must take account of these social and demographic trends and ensure the needs of all are able to be met both now and in the future. The scheme must account for both the social and economic needs of the nation and ensure they can be met in a fiscally responsible manner.

**Conclusion – The Importance of Insurance**

The existing system is fundamentally flawed and far beyond minor reform. Simply tinkering with it will not deliver these outcomes. It may be possible to design a system that delivers some of these principles. But we believe all of these principles are best achieved by a social insurance approach. That is why Down Syndrome Victoria supports a National Disability Insurance Scheme.

The scheme is within the nation's capacity to deliver. While there may be additional funding required in the short term, in the long run we believe the scheme will not only deliver better outcomes but also significant savings. In working to ensure people with Down syndrome and their families receive the support they require to be productive, participating members of the community, the interests of individuals, the interests of the scheme and the interests of the nation are all aligned.

People with a Down syndrome and their families have waited many years for change. And there have been reforms introduced which have made a difference to their lives. But their effectiveness has been constrained by a fundamentally flawed system. The time for piecemeal reform is over. The time for a transformational change in the form of a National Disability Insurance Scheme has come.

Appendix One

## About Down Syndrome Victoria

Down Syndrome Victoria is the state-wide peak organisation representing individuals with Down syndrome and their families. We represent more than 4000 families across Victoria.

Down Syndrome Victoria is a membership based organisation. Our members primarily consist of people with Down syndrome and their families, who play an important role in maintaining the volunteer state-wide peer support network, contributing to our strategic and advocacy directions, and acting as information distributors to other families. Our combined experience makes us leaders in the area of intellectual disability.

Down Syndrome Victoria is a member of the Down Syndrome Australia network of state associations. Established by parents in 1978, it is a non-profit association which relies on public and private sector support to fulfill its mission with and on behalf of individuals with Down syndrome and their families.

## About Down syndrome

Down syndrome is the world's most common chromosome disorder and cause of intellectual disability – it is not an illness or disease. It occurs at conception in one of every 700 to 900 births worldwide and affects people of all ethnic and social backgrounds. In Victoria, forty-five to sixty babies are born with Down syndrome each year.

The human body is made up of millions of cells, and in each cell there are 23 pairs of chromosomes – or 46 chromosomes in every cell. Down syndrome is caused by the occurrence of an extra chromosome, chromosome 21, hence the name Trisomy 21. Therefore, people with Down syndrome have 47 chromosomes in their cells instead of 46. This results in a range of physical characteristics, health and development indications and some level of intellectual disability. Down syndrome is usually recognisable at birth and confirmed by a blood test.

Down syndrome affects, but does not determine development. People with Down syndrome are each as unique as any other person, with their own talents, abilities, thoughts and interests. Everyone with Down syndrome experiences some delay in areas of their development, and some degree of learning disability. However, this will vary significantly from one individual to another, and what happens after birth will be far more important in shaping the outlook for any individual with Down syndrome than the occurrence of an extra chromosome at conception.

With appropriate health and education services and with the support and opportunities available today, people with Down syndrome can look forward to long and fulfilling lives as valued members of their families and the broader community.