Down Syndrome NSW

Submission to the Senate Community Affairs Reference Committee:

Inquiry into Planning Options and Services for People Ageing with a Disability

For Parliament of Australia

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on behalf of the Board and members of Down Syndrome NSW

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Introduction

Down Syndrome NSW is a family support organization, established in 1980. The majority of founding members were parents of very young children with Down syndrome, the first modern generation of parents to raise their children with Down syndrome in their own biological families as a matter of course.

These parents are finding that things are now harder than ever. Parents must support their child as an adult and also plan for when they will no longer be around to care for their child. We receive approximately 5000 inquiries each year, many regarding planning options and services for adults with Down syndrome. Although the lives and opportunities of people with Down syndrome have improved over the years, the future is still a big concern for all parents of a child with Down syndrome. At present, there needs to be more done to ensure a reasonable life for people with Down syndrome, once their primary carers are no longer around, is possible.

When a baby with Down syndrome is born, the family often struggles with their new circumstances. Amongst their fears are questions about their baby's future. Will he/she be dependent on us for the rest of our lives? What happens when we die or can't care for our child? Where will he/she live? Will he/she be able to work? Will my child have a good life?

Down Syndrome NSW has responded to the demands of such families with programs such as the Up, Up and Away project, the Up! Club, and seminars on financial planning and health concerns. However, Down Syndrome NSW can only do so much. Better access to the planning options and services available in the wider community is required, so that planning for the future can begin while the parents of people with Down syndrome are still around and capable of providing assistance. These services need to be funded with self-directed funding so that scarce resources are utilised as efficiently as possible.

If a National Disability Insurance Scheme as currently being proposed (www.ndis.org.au) that would guarantee life-long care and supports as is being investigated by the Productivity Commission Inquiry, was adopted and implemented effectively, many of the concerns about trying to plan for services that currently do not exist, would be largely resolved.

1.Access to planning options and services

Access to planning options and services is mixed for our members. Many are so stretched by caring for their child with Down syndrome, that they do not have the ability to seek out services. Some are unable to access information electronically and others struggle with language difficulties.

For many families, particularly those of older people with Down syndrome, services and assistance available is discovered and accessed through informal networks, established over a number of years and associations such as Down Syndrome NSW, Carer's NSW, Family Advocacy, InControl Australia, and local community organisations.

Many of our parents report that they wish they had started earlier to prepare their child for when they are no longer around. Many older parents report that as their sons and daughters age, they are more resistant to doing new things (as are many in the typically developing population).

It is often not possible for people with Down syndrome to move out of the family home as a young adult. As a result, they do not learn the independent living skills that go along with this move. As such the planning, training and preparation for a person with Down syndrome to live independently is a much longer road. This process therefore needs to start early.

The financial needs of the person with Down syndrome also need consideration. This plan is often a long term one too.

As a result of these issues the questions of exactly where their child will live, who will support them and the quality of their lives is a huge worry to most parents. To alleviate these fears, and to ensure the best outcomes for people with Down syndrome and their families, programs must be in place that allow plans to be made over the longer term.

2. Accommodation- Where will they live?

Up until recently, the only supported accommodation that was available in NSW was in group homes. In most instances this is only available in crisis situations. In the past there were not even waiting lists for such accommodation, making it impossible to plan for the future.

Things are slowly starting to change and a larger number of supported living arrangements are opening up:

- NSW's ADHC has developed *Stronger Together 2006-2016* which will provide more flexibility and wider options; and .
- The ADHC program, *My Plan, My Choice: Older Carers of People With a Disability* creates an opportunity for carers to plan for future supports.

These new programs however are limited and need to be made available to more families. Long term housing is needed.

One program which we believe will meet meets many of our members needs, is Family Advocacy's proposal to set up a Supported Living Fund. This will allow parents of people with Down syndrome to assist them with moving into their own homes, allowing this transition to occur whilst parent support is still available.   It is highly distressing for a person with Down syndrome, who has lived at home their entire life, to have to move into alternative living arrangements following the death of parents(s) with no support.

Currently however, this tragic situation is all too common due to the current lack of options available.

3. Employment/Community access

School provides the structure and programs for children with Down syndrome to thrive. Integration has meant that everyone is part of the same community and contributes each in their own way. However, when school finishes, many people with Down syndrome struggle to find how to continue to be part of their community.

People with Down syndrome want what others in the community want – a job or other meaningful ways to make a contribution, social opportunities and some control over their lives. These things can all be possible with support.

Down Syndrome NSW has run a pilot program, Up, Up and Away, to help adults with Down syndrome find ways to meet their goals for life. Many have found suitable jobs, greater independence, leisure interests and greater community participation through this program. More programs like these are needed.

In addition wider community education is needed regarding the benefits of employing people with disabilities. Our member families indicate they frequently use job support services which are generally good, but there are just too few jobs available.

Community members who have employed people with disabilities, in particular, those with Down Syndrome, report the benefits to not only the person with Down syndrome but their business/organisation. These businesses report that people with Down syndrome are valuable, loyal, competent workers.

The advantages of employment to people with Down syndrome are many. Even just a few hours in a job can provide well-being for the individual and take stress off of the family.

Alternatives to employment such as Community Access programs also provide security. However, if the person with Down syndrome has health or capacity issues, these programs are often a poor or unsuitable alternative.

Access to social activities can be just as important as employment. Down Syndrome NSW runs a peer support group in Sydney, called the Up! Club. This program, and others like it run by other community groups, provide a number of advantages to people with Down syndrome including:

- They assist people with Down syndrome in participating in the community;
- They promote the development of social skills and independence;
- They highlight and teach the importance of peer support;
- They provide guidance in how to establish and keep friends / promotion of a social networks; and
- The skills learned assist with and promote employment goals and skills needed for employment.

In addition, such social groups increase awareness in the community.

Unfortunately many of the available social groups tend to cater for adults in the 18-25 age group. The differing needs of adults with Down syndrome in the older age groups i.e. 30-40 are not as well met. As the first generation of people with Down syndrome raised at home as a matter of course ages, services for this older age group are in ever greater demand. The now older carers of this group have pioneered many of today's opportunities but they are now tired and unable to continue trailblazing.

4. Health concerns

Many Association members are concerned about their adult children's health and fitness.

People with Down syndrome are affected by aging differently to many others in the community. People with Down syndrome age earlier, so aged services need to be made available earlier, and earlier retirement, at age 55 for example, would better meet their needs.

There is also a greater incidence of early-onset dementia in people with Down syndrome. More general mental health issues can also arise with age.

In relation to broader mental health issues, these can arise for people with Down syndrome as a result of isolation, due to no job or meaningful activity and a lack of control over their lives. We have a growing number of calls to the Association surrounding these issues.

The health of ageing carers of people with Down syndrome is also a concern. As adults with Down syndrome age, so do their parents. In this circumstance the needs of both carers and the people they care for become simultaneously greater. Due to better health care and family support, people with Down Syndrome are now living much longer than in the past.

Respite seems to be widely available for older carers. However, strict rules surround the use of such respite services. For example, in most instances respite carers cannot be of the family's choosing, so strangers from an agency, which likely change on each occasion, fulfil this role which is not ideal.

These services are also relatively expensive. One of our members relates that she utilised a respite carer to go walking with her daughter. This cost more than a personal trainer would have cost (which would likely have been more beneficial to the person with Down syndrome) and hence a better use of these funds.

5. Self-Directed funding

As seen above in the respite example; our members feel strongly that decisions about how to use funding should rest with the carers and the individual with Down syndrome. Being given control over who provides services and how those services are given is important in that it not only shows respect to the person with Down syndrome, but it will also improve services and the quality of care for all. Individuals and their families are more than capable of managing these funds. As a member put it,

> *"we have spent all our children's lives working to find the best supports, programs and ways to help them live their lives. We are assertive, caring and know how to find things. We would be very skilled at managing direct funding. It would relieve a lot of stress."*

6. Conclusion

Although the availability and awareness of services has increased in recent times, greater access to planning options is sorely needed. In addition, more real options for housing, jobs and supported living is required.

Access to all of this must be made available much earlier, to ensure that people with Down syndrome can complete establishment of their lives post their carers demise and the transition to this life, whilst their support networks are still in place to help.

We believe that the best way to achieve these goals is through a move to self directed funding, so that the scarce resources are utilised in the most efficient manner possible, achieving the best outcomes for people with Down syndrome and their families.

Resources

Stronger Together 2006-2016, NSW ADHC
http://www.dadhc.nsw.gov.au/dadhc/Publications+and+policies/stronger_together.htm

Supported Living Fund for NSW, Family Advocacy, http://www.family-advocacy.com/docs/Supported_Living_Fund_website.pdf

My Plan, My Choice: Older Carers of People With a Disability, NSW ADHC
http://www.dadhc.nsw.gov.au/NR/rdonlyres/A8B4C308-232A-45A6-9969-9FB7B576B436/4383/revisedspec1.pdf