

In the six decades of the history of The Spastic Centre, it has always been a challenge to secure sufficient resources and then to utilise them in a way that best addresses all the differing and growing needs of clients and families.

For the parents of a young child, this means access to timely and supportive allied health services. For a teenager it may mean help in accessing sporting or leisure activities and opportunities to connect with peers. For the parent of an adult son or daughter, the need for respite care and concerns about future accommodation arrangements may become paramount.

For far too long the disability sector has had to bundle up all the family stories of distress and anguish over waiting times and service gaps and call it 'unmet need'. Giving the issues a collective label may package them neatly. However, I am ever mindful that this unmet need in fact represents the collective heartache of so many individuals and families. Over the years, hundreds of families have shared their stories with me, and I have come to understand only too well the complexities and additional stresses that are created by gaps in our service system.

There are different perspectives to this problem. On the one hand, it is true that the disability sector has never been better resourced than it is today. The *Stronger Together* initiative of the NSW State Government has brought new programs and additional services to many. On the other hand, there are still significant service gaps. Permanent accommodation places for adults are still sadly lacking.

Considering our own services, for instance, approximately 300 clients are part of our Community Access Services and our supported employment services, now called Packforce. Of these, almost one third are living at home with their parents. For many of these people and their families, the long-term planning of accommodation options brings challenges and uncertainty.

On the issue of the need for equipment, there has been some recent success. Following lobbying by a number of disability organisations and individuals, including The Spastic Centre and families, NSW Health has injected the PADP scheme with an additional \$5 million of recurrent funding. While this is welcome and will reduce the number of clients on the existing waiting list, we estimate an additional \$7 million of recurrent funding is still required to adequately address ongoing need. Since March 2007, The Spastic Centre has invested \$850,000

from our own fundraising activities directly into purchase of equipment for children to assist families who are experiencing a long wait for essential equipment.

For the parents of a newly diagnosed child, there can still be no guarantee of ready access to all the services they need. I am well aware that in some areas there are still significant waiting times for allied health services.

We need multiple strategies, both short and long term, to address these issues.

Improving Services Today

Looking at our own Spastic Centre services, we are in a process of constant evolution and change. We have in place procedures for regular and detailed monitoring of our service responsiveness, both in terms of timeliness and quality. Of the array of measures used for this purpose, probably the most significant are statistical record keeping in relation to client volumes and waiting times and monthly reporting mechanisms to The Centre's Board of Directors.



Moira & Glenn Turnbull - take the chance to have a break with The Spastic Centre's Flexible Respite Program

Currently 4,000 children and adults and their families come to us annually for services. Whilst the need is great, we are confident that our service efficiency and effectiveness is optimising the resources that are available to us.

The range and scope of our services also continue to expand. We are increasing the opportunities available in sports, leisure and the arts, and our respite initiatives are flexible and responsive to the differing needs of families. The web is also bringing us a new world of possibilities for breaking down the social isolation felt by so many of our teenagers and adults.

We are indeed fortunate, that in these troubled economic times, our staffing levels have been maintained as we head into our next budget year. There has been no need for a reduction in services despite the challenge of fundraising when funds for many donors are tight.

The Spastic Centre is currently exploring new fundraising activities that will assist us to engage new audiences and increase our revenue to improve our services. Later this year we will be piloting a program where highly trained advocates recruit younger donors, via stalls in shopping malls and on the street, on a monthly direct debit basis. This has proved very successful for other organisations and I believe could bring significant additional revenue to enable us to serve you better into the future.

Securing New Funding

The NSW State Government, primarily through the

Department of Ageing, Disability, and Home Care (DADHC) provides nearly 60 per cent of the funding for The Spastic Centre. This funding is tied to specific programs and is appropriately acquitted against those activities.

Negotiations have recently taken place with DADHC regarding the allocation of non-recurrent funds. Over the next three years there will be an additional injection of funds to address waiting lists for children and adults in need of therapy in some areas of the state, including rural and metropolitan regions.

Upgrading Our Facilities

The Spastic Centre now has over 70 sites throughout NSW and in the ACT. We have an established schedule of regular upgrading and refurbishment. Earlier this year we completed our Lifestyle Apartments at Granville, providing an accommodation upgrade for 12 adult residents. These apartments have been widely praised and have raised the bar for the quality of future residential facilities.

Venee Burges Hostel, home to 32 residents, has also been refurbished with reroofing and bathroom upgrades. Painting and refurbishing work will shortly commence on our Ashfield House, home to a number of our adult clients.

In the Upper Hunter Region, the heritage-listed East Maitland Post Office has been purchased to become the base for our therapy services in the district. A new site at Tuggerah replaces previous rental premises at East



Lifestyle Apartments, Granville

Gosford and Berkeley Vale.

A new service site was established at Ballina to replace the original Coffs Harbour site and will serve the growing population in the area.

In the Central West, our rental site in Orange has been purchased and is being upgraded to accommodate our service expansion. Both purchases have been made possible through a generous donation from the Sargents Foundation.

A Long-Term Vision

Taking a longer view, many of you would be aware of our efforts to support the development of a National Disability Insurance Scheme. This is a bold vision of a no fault universal scheme. It would be funded by a compulsory levy, that would secure funding for anyone in need of services or support due to significant disability, whether present at birth or acquired. The adoption of such a scheme would address the uncertainty and inequity that currently exists for individuals and families. Please visit the website.

www.ndis.com.au

Our Global Responsibility

In my last update I brought you news of the outcomes of our International Cerebral Palsy Conference. This important event galvanised the collective resolve of the most influential cerebral palsy researchers in the world today.

In parallel with the service activities of The Spastic Centre, the Cerebral Palsy Institute and the Cerebral Palsy Foundation are committed to finding the answers to cerebral palsy for the generations of children to come. Finding prevention strategies is of course the ultimate answer to unmet need.

It is understandable that some parents would prefer that our sole focus were on the provision of services for children and adults today. As the oldest organisation of its type in the world, we feel that we have a responsibility to balance immediate needs with a long-term vision of the future. Not to do so would be remiss. I am confident that this dual focus is the best strategy for our organisation. It will continue to serve us well and assist us to attract funding for both purposes.

As always, I welcome you to contact me directly with questions or feedback.

Sincerely,



Rob White
Chief Executive Officer



Sargents Kids Quarters, Orange

National Disability Insurance Scheme

The Spastic Centre is a strong supporter of a bold new idea, first raised at the 20/20 Summit in Canberra, which has the potential to transform the lives of people with a disability and their families.

A National Disability Insurance Scheme (NDIS) would be a no-fault insurance scheme for anyone who has, or acquires a significant disability.

Funded through general revenue or a Medicare type levy on all Australians, NDIS would provide lifelong funding for essential care, support, therapy, aids, equipment, home modifications and access to the community, education and training.

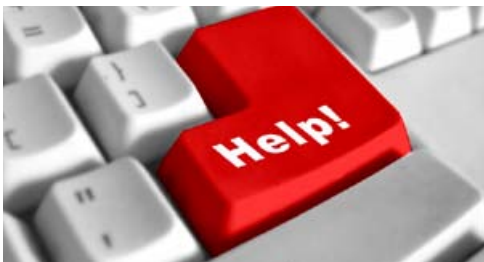
The scheme would provide peace of mind for ALL Australians - knowing that a safety net was in place should they or a family member be affected by disability, either from birth, or as the result of accident or illness.

The NDIS campaign is gaining bi-partisan support across Australia, but we need your help.

A new website has been launched at www.ndis.org.au. I urge you to please visit the site and take action in one (or more) of four ways:

TAKE ACTION

www.ndis.org.au



EMAIL YOUR MP

An online tool makes this very easy.



SIGN THE PETITION

Circulate it amongst friends and family.



VISIT YOUR MP

Tell your MP the difference NDIS could make to your life.



SPREAD THE WORD

Through Facebook, email, Twitter or by talking to your local paper.

As we know, anyone can be touched by disability, so making NDIS a reality is everyone's responsibility. It will not be introduced without broad community support, so we also need you to engage other people with a disability, family, friends, other carers and colleagues to join the growing band of supporters for NDIS.