

KEEPING
IN
TOUCH



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Cornelia de Lange Syndrome Association (Australasia) Inc.

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International: www.cdlsworld.org

Online support groups: OZ/NZ online discussion group:
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International Online Support Group:
www.cdls-support.org

DISCLAIMER

This newsletter is not intended for diagnostic purposes or self treatment. The Cornelia de Lange Syndrome Association and its committee do not necessarily endorse or recommend any products, services, methods or literature mentioned within. Any questions about treatments should be discussed with your child's doctor.

Defining moments for a movement whose time has come

Opinion

Simon McKeon ABC Disability 25 May 2011



Over 1000 people at the National Disability and Carer Congress declared that every Australian counts.

Credit: ozgurdonmaz (iStockphoto)

Recently, I was honoured to address the National Disability and Carers Congress in Melbourne, an event that attracted over 1000 people from right across the nation, all united in their determination to get a better deal for people with a disability.

About a week later, the Treasurer Wayne Swan delivered a Federal Budget focussed on driving workforce participation - with the Treasurer warning the nation that 'we don't have an Australian to waste' when it comes to not only addressing skills shortages but positioning Australia for projected growth in an environment where the national unemployment rate is headed towards 4%.

For me, these two events signify that the time has come for major reform in the way services to Australians with disabilities are funded and delivered; not only to enhance the basic human rights of people with disabilities but to greatly enhance the level of participation in the economy by people with disabilities, their families and carers.

I spoke on the second day of the Congress and by then the mindset of delegates was firmly focussed on the prospect of the National Disability Insurance Scheme (NDIS) and how an NDIS might transform not only their lives, but future generations of Australians with a disability.

And while the NDIS is still at this point in time just a draft policy proposal under examination by the Productivity Commission, expectations are running high right across the disability sector that the NDIS must happen soon.

Sadly, for many thousands of Australians with a disability, their families and carers, the NDIS - no matter how promising - will come too late. They have already endured more than their fair share of difficulty.

But for hundreds of thousands of vulnerable Australians, the NDIS represents a flicker of hope that they in their lifetimes, will finally get the support they need to live the relatively normal lives most Australians take for granted.

So with the recent release of the Productivity Commission's draft report recommending the establishment of the NDIS, we are entering a phase in Australia where some big decisions and policy for the future will be shaped for people with a disability and their families in Australia

It is absolutely imperative that these decisions are made - one way or the other - rather than subjecting people with disabilities to another round of enquiry, consultation and review - or death by a thousand (paper) cuts.

Let's not mince words - there is a national crisis confronting disability in Australia. It is nothing new - sadly crisis is a permanent setting.

But this time the crisis has had a very powerful spotlight shone on it by the Productivity Commission, which up-front diagnosed the system as: "inequitable, underfunded, fragmented and inefficient and gives people with a disability little choice."

This observation is of no surprise to people with disabilities, their families and carers, who have been trying to tell the nation of this situation for decades.

However, such a sombre assessment from the Productivity Commission must be a wakeup call to most who would naturally assume that in Australia - as a modern, prosperous, nation - some of our most vulnerable citizens, i.e. people with disabilities, get the support and care they need.

It is obvious that there must be root and branch reform to the way disability services are funded and delivered across Australia, and the NDIS is at the heart of this reform as its vehicle.

Over recent years, there have been persuasive arguments made from many quarters for comprehensive reform but for whatever reason, those calls have gone largely unheeded; mainly, in my view, because disability has never been considered a mainstream political issue.

But now in 2011 after years of fighting, pleading, knocking on doors and telling stories, a convergence of factors means that the sector may actually be on the cusp of something significant.

Before I addressed the Congress, the organisers had asked me to choreograph a modest stunt for the benefit of the Every Australian Counts campaign - the simple act of conference attendees holding up a placard which read 'I Count'.

It was a dignified, stoic silence - nothing of the din and bells and whistles that characterise political events. The overwhelming sense in the room was one of resignation - people know that if the NDIS doesn't materialise in the near future it may pass by and it won't be revisited any time soon.

Most present are well versed in the many economic, social and humanitarian arguments for reform, having practised them on politicians and policy makers over the years. They were heartened by the earlier reminder from Bill Shorten that the door remains ajar for reform.

The NDIS has the potential to deliver massive benefits - not only to individuals with a disability but to the nation - and represents a neat fusion of economic and social policy; a landmark, legacy-making reform on the scale of Medicare, enshrining the Treasurer's call that 'we don't have an Australian to waste'.

Simon McKeon is Australian of the Year 2011.

What can you do to help the campaign for disability service funding?

Go to the Every Australian Counts web site and register your support. Ask your friends and family to do the same.

Write to your federal MP explaining how important it is to support the findings of the productivity commission.

Write to newspapers.

Helpful web sites:

<http://www.abc.net.au/rampup> ABC Disability Portal

<http://www.d4d.com.au> South Australian disability services campaign

<http://everyaustraliancounts.com.au> Campaign for the NDIS

Association News

NEW FAMILIES

A warm welcome to our new families from South Australia

MEMBERSHIP FEES PAID

Sandilands WA

DONATIONS

General: S. Sandilands, D. Humphrey, A. McGee, M. Nuttall, Annette Fordham.

Web hosting for 3 years: David Humphrey

Regular Deduction: S Kinchella

Special:

In honour of the Rollo Family, and in celebration of Keith Urban: Julie Gonella (USA).

Celebrating 18th Birthdays:

In honour of **Kyah Wicks**: Jenny Rollo

In honour of **Faith Hernandez**: Eric Bellon, Nivin Thanabalan, Roberto Regozo, Chris Fronda, Lucilyn Olivar, Gilbert Marquez, Jun Gunay, Carlos Mamucod, Denise Cereno, Baby Delos Reyes, Charito Hernandez, Eliseo Hernandez, Cliff O'Regan, Linda O'Regan, Dela Cruz Family, Mr & Mrs Baby Mora, Mr & Mrs Mar Aguila, Jaramillo Family, Mr & Mrs Benjie Hernandez, Paraiso Family, Mr & Mrs Ian Fernandez, Mr & Mrs Jhun Baron, Iluminado Porillo, Anne Bennett, Raylee Singleton, Kate Jackson, Mr & Mrs Lito Ressoreccion, Sue Cornish, Rachel Jeffries, Kath Collins.



Faith's extended family and friends celebrated her 18th birthday with a "pink" party!

Thanks to all for your generous donations.

PayPal is now available on our website for membership and donations.

Management Committee

The **CdLSA Management Committee** welcomes our newest ordinary member – Lil Routley, our SA coordinator, and mum to Ella. Thank you for volunteering and we look forward to working with you! This brings our numbers to eleven.

CdLS Clinic Days

Dr Jane Law held a Sydney clinic day in April, when two new patients were given thorough health checks, and three others had follow-up appointments. Families appreciated the chance to have a full health evaluation which is especially important as people move from child into adult health services.

Clinic days also offer a rare opportunity for families to meet, compare notes and stories, and enjoy a little social time together.

The places for the clinic day on 29th June are now filled. If you would like to have an appointment with Dr Law at any time please contact Jenny Rollo.

The Sydney Clinic Day



Kyah and Brodie



David with Sandra, Shirley and Kyah

Challenging Behaviour DVD

The **Understanding and Changing Challenging Behaviour in Cornelia de Lange Syndrome** interactive DVD is now available to Australian and New Zealand families and professionals.

The DVD was written to help guide parents and carers to understand and help change challenging behaviours shown by children and adults with CdLS.

Produced by Prof. Chris Oliver (UK) and his team, this DVD reflects over 25 years of research into behaviours of people with CdLS.

To order your copy:

In New Zealand please contact Liz Molloy.

In Australia Email through the "Contact Us" page of the web site, making it clear that you are ordering the DVD, and include full postal address. Free to financial members. Non financial members need to then pay for your order through clicking on the "DONATIONS" link on the web site. Cost is \$5 which covers packaging and postage within Australia. Postage cost to our friends outside Australia will depend on destination. Ask during the initial email request. Not on email? Contact Jen.

Collis Curve Toothbrushes are also available for \$5 each.

Facebook

Do you have a facebook account? Would you like to join in the CdLS Discussion group? There are presently 269 members (increasing daily!) of this general group representing families and professionals from many countries around the world. This is the fastest way to receive parental advice for your tricky questions. It's a great place to swap stories of celebration as well as seek solace for the sad times...and make friends.

There are also discussion groups limited to specific countries (Australia, Canada and New Zealand) for those pesky regional questions about local services, etc.

How to join: open a facebook account. Search for friends. Ask them to invite you to join the discussion group. New to CdLS? Send an email through "Contact Us" on the web site. One of the Facebook veterans will contact you with a friend request. It's that simple. See you online!

NSW Government Approves RASAIID

Jenny Rollo



The RASAIID Executive L to R: Mike Crook (Treasurer), Estelle Shields, Lyn Allen (Vice President), Jenny Rollo OAM (President), Disability Minister Andrew Constance, Ryde MP Minister Victor Dominello, Marilyn Jones (Secretary) and Megan Poole.

Until now supported accommodation has only been allocated on a crisis basis in NSW. This resulted in parents having to relinquish their children to the state to get the accommodation services they need; elderly women – even in their 80s and 90s - still caring for their sons and daughters with dependent disability; parent carers struggling to continue caring and others lobbying and agitating to change the system. All of us worried about what would happen to our loved-ones after the primary carer died.

In October 2004 a group of 20 parents from the Ryde area of Sydney joined forces to change the system for their own sons and daughters. Along the way we became a very active part of the parent-led movement across the country to change the system for all Australians.

The RASAIID parents have individual histories of agitating for change going back 20 years or more, but it wasn't until we joined forces for this specific goal, and then connected with others across the country, that we started to see some political results. We are a cohesive group boasting long-term friendships between the parents and the children, some for as long as 30 years.

We support each other, our children look out for each other, and we can now see a bright future where these friendships can continue to blossom.



Some of the RASAIID families gather to celebrate our political win – a secure future for our children.

On 1st of June 2011 the newly elected Minister for Disabilities, Andrew Constance announced his government's approval of the building of RASAIID. The NSW government has promised us \$3 million towards the infrastructure, and guaranteed recurrent funding for the care of our sons and daughters. This recurrent funding will also enable us to apply for federal funding for capital works that was designed by Bill Shorten for groups like RASAIID. Once a site is identified we will have all the elements for building homes for our loved ones.

In the nearly 7 years we have been lobbying there was always one or another element that was elusive to us, and, despite verbal support, encouragement, and direction from previous ministers, we never had a written guarantee of support until Andrew Constance made good on the promise he made at our RASAIID Rally in November 2009, as Shadow Minister for Disabilities. We sincerely thank Minister Constance for his integrity and humanity. This time has been a rollercoaster of hope and despair.

The RASAIID model will have a high level of family governance in supporting our sons and daughters who are unable to speak for themselves due to their intellectual disability. This will guarantee service provision remains at the highest level. The residents of RASAIID will be able to pool their funds so that their individual needs are met within the structure of their preferred living arrangements. Staffing will be at higher levels for all residents than are presently available in the “group homes in the community” where often only drop-in support is the norm.

Of equal importance, the residents of RASAIID will be amongst the first in NSW to be offered individual funding packages to meet their care needs. The implications of this are far-reaching and life-changing for all people with disabilities in NSW. Now the power will be where it belongs – with the people who use the services. This is another advantage of individual funding that may not have been previously recognised. Until now people with disabilities have had to accept services which were decided by the providers - whether they were good, bad or indifferent. Individual funding will allow service users to shop around for the provider which will meet their requirements. People with disabilities will no longer feel they are the recipients of charity. Service providers will have to toe the line and improve their service provision if they hope to survive in this brave new world.

For this group of ageing parent-carers there is a bright light at the end of our tunnel. The siblings are delighted to be able to continue supporting their brothers and sisters in their new living environment. Although hanging on by our fingernails, we can now continue our loving care for the couple of years we anticipate it will take until RASAIID is built. We are elated that our children (aged between 27 and 52 years!) will have the home they need and the future they deserve, shared with their friends in the Ryde community where they have lived their whole lives.

We encourage other groups of like-minded families to get together to start planning for their own children’s future.

www.rasaid.org.au



RASAIID presented with the Macquarie Park Rotary Community Service Award 2010



Don't give up on Obsessional Behaviour!

Madeleine Witham

Over the last two years we have been really having a battle over Ella's obsession over her hands and fingers. If she had even a tiny little piece of dry or peeling skin on her hands she would pick it until it was a massive sore and bleeding, she just couldn't control it at all. So I started bandaging the offending fingers because she refused to wear a band-aid and would just rip it straight off if I put one on. The bandaging then became an obsession of its own and she would get anxious over the edges being in exactly the same place. I couldn't wash her hands, and changing the bandages became a massive problem we all dreaded. So I came up with the idea of using gloves so she could take them off for a bath and for eating etc. Well you all can guess what happened...I spent two years sewing up holes, having a massive screaming fit trying to wash them every week or two (you can imagine what they looked and smelt like) and then she started wearing two woollen gloves on each hand in the middle of the Sydney summer. The skin underneath started to die and shrivel. I can hear you asking "Why didn't you just remove them?" but there will also be those of you who know their own little mite with CdLS and you can probably understand why it wasn't so easily solved.

I was at the point of giving up. She wouldn't even let me leave her because I was the only one who could sew up the holes of the stupid things! I had unwittingly made a problem much bigger and uglier. I had made a rod for my own back!

We met with Chris Oliver in Brisbane last year and he recommended doing it very slowly but he also admitted that it was going to be a big problem for us because even trying to wash them would cause Ella to have a massive panic attack and take a few days to get over it.

So in January I thought that was just it. I was going to deal with this issue and our whole family knew it was going to be long, loud and ugly. I bought her a whole little tea set from Ikea, a table and chairs, and supplied food like flour, sugar and coconut to make "mixtures" because she loves doing this but doesn't want to get her gloves wet! So we started taking one off for ten minutes and cajoling, rewarding and working hard to do this every day. It took at whole three months but she is now completely glove and bandage free! If she gets a sore then I told her (and she understands) that she has to "manage" it herself and I give her a tube of cream to put on it so she can't pick it.

It was not an easy process but I just want to encourage you with this little story, that with the will and some imagination we can effect some change with our children.

Don't give up!

The following two articles are provided by Rose Humphrey, our QLD Co-ordinator.

WHAT DO WE MEAN WHEN WE TALK ABOUT SUPPORT CIRCLES?

Pave the Way has been assisting families throughout Queensland to develop support circles for over 7 years now. Forming a support circle is not something every family chooses to do but many of those who have say that the circle is an important part of their family member's life.

Circles usually involve a small number of trusted people who come together regularly to provide support to the person with disability and their family in their decision making and planning. Some families refer to their support circle as their team, their think tank or brains trust. Support Circles can have a number of purposes which are expressed well by such terms and may include:

- Assistance with planning and with decision making
- Bringing new and different perspectives to discussions
- Bringing energy, imagination and commitment
- Encouraging and supporting the person to dream
- Ensuring the person is loved, safe and supported

For families, inviting others to be a part of their support circle is just one way to involve them in their family member's life both now and into the future. The decision to involve others in this intentional way is based on a belief that while it may be important to have some support through funding and services and to have legal and financial mechanisms in place, at the end of the day, it is *people who love and care for us who keep us safe.*

For circle members, being involved in a support circle is not necessarily about taking on any particular roles but rather for them to bring their 'ordinary antenna' to the gatherings by sharing what they know from their own personal experience. It is also an opportunity to deepen their relationship with the person at the centre of the circle. Over time some circle members become more involved in practical support for the person but this is usually a result of getting to know the person better and the relationship that evolves between them rather than out of some expectation or sense of obligation.

Many families have said that one of the benefits of establishing a support circle is that they often feel better supported as the circle gatherings enable time in the busyness of life for regular conversations about their vision and their plans. For others, the strength of a circle lies in the growing confidence of their family member who feels supported by the ongoing commitment and encouragement of a group of trusted people.

This article first appeared in the June 2011 Pave the Way Newsletter. If you would like to discuss these ideas further, please feel free to contact Pave the Way on 07 3291 5800.

“Statutory Wills” – Wills approved by the Supreme Court

Any individual who is aged 18 or over can make a will, so long as they have the capacity, or legal understanding, to do so. People with disability who have capacity can make a will.

If someone dies without a will, whether because they have no capacity to make one, or whether they simply fail to make arrangements to do so, the Rules of Intestacy apply. These rules set out who is to receive the individual's estate in the absence of a will and are summarised on page 27 of Pave the Way's booklet, *Planning for Now, Tomorrow and the Future*. Copies are available on Pave the Way's website or from the Pave the Way office.

If a family member with disability cannot make a will, the first thing to do is to obtain advice from a solicitor about the affect of the Rules of Intestacy in their situation. Pave the Way has a list of solicitors with experience in this area. If the Rules of Intestacy produce an undesirable result (eg, part or all of an individual's estate will pass to an estranged brother or sister), and if the individual's estate is of considerable size, it might be worth seeking advice about a “statutory will”.

A “statutory will” is a will approved by the Supreme Court for someone who does not have the capacity to make (or change) a will. The Queensland *Succession Act* gives the Supreme Court the power to authorise a will to be made, altered or revoked for anyone without testamentary capacity, where the Court is satisfied that:

- the person is still alive;
- the person lacks the capacity to make a will;
- the will is one the person would have made, altered or revoked if they had the capacity to do so; and
- the order the Court is asked to make is “appropriate”.

In the few cases heard by the Supreme Court, it appears that the Court is prepared to glean from all the circumstances whether the will is one the individual with impaired capacity “would have made”, even though it might be difficult to determine their actual wishes. In the case of *Deecke v. Deecke & Anor* [2009] QSC 65 (1 April 2009) the presiding Judge, referring to the individual with impaired capacity as “the first respondent”, stated:

“I am satisfied that the proposed will should be authorised to be made on behalf of the first respondent, having regard to the first respondent's present circumstances and existing relationships and to the very limited extent that her wishes can be understood”.

These applications to the Supreme Court are expensive and the Court can order the legal costs to be paid from the person's assets.

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