The Review

May 2016

The Official Magazine of the Cerebral Palsy Society of NZ Inc

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Cover Photo
Kyla and Ben are two of our Steptember ambassadors
See story on page 3

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Win Sydney Steptember Prize

Register for Steptember today at www.steptember.org.nz

This year you'll have the opportunity to win lots of great prizes, including a trip for one lucky Steptember team to Sydney. To enter to win the weekend in Sydney, just register your team by the 1st of August, and you'll be automatically entered into the draw.

Thanks to House of Travel and Blackmore's Sydney running festival one lucky team will have the opportunity to complete their 10,000 steps by walking or running over the Sydney Harbour Bridge. The 9k Blackmore's Bridge Run is an achievable challenge taking in the beautiful sights of Sydney, finishing at the Royal Botanic gardens.

This great prize includes four return flights to Sydney (16 - 18 Sept 2016) plus two nights twin share accommodation. It also includes airport transfer for four people, entry into the 9km Blackmores Bridge Run and additional activities in Sydney such as daily breakfast plus a hosted dinner with Lee-Anne Wann. There will be a Steptember Pack on arrival so sign up your Steptember team by August 1st and automatically go into the draw.

It's been a busy couple of months for the Steptember team, travelling around the country promoting Steptember at the NZME Women's Lifestyle Expo's. Along with hosting corporate events to raise awareness of CP and the Steptember 10,000 steps a day challenge.

In April the Steptember Ambassador's and their parents took time out of their school holidays to join us for lunch and a photo shoot. Here are a few snaps from the day. Many thanks to Ben, Bentley, Maddy and Kyla for being such great models, and a big warm welcome to Phoenix the newest Steptember ambassador.

Once again, we are offering all members complimentary registration to take part in the challenge. All you need to do is use the code 'member' to remove the registration fee. All funds raised from the Steptember campaign go directly back into supporting programs and services run by the Cerebral Palsy Society in New Zealand.

If you would like more information about Steptember or want to know how to get your workplace involved email: shelly@cpsociety.org.nz

Thanks Shelly for this information

News From HQ

Members enjoyed day at the bay

Dear members

I hope you had a wonderful summer and are enjoying the start of cooler weather. This Review contains a number of articles I hope you find interesting.

Based on your feedback we held a number of events. Recently we attended Round the Bays followed by Cruise the Bays- which was a spectacular event run by Geneva. They had around 200 participant and about 80% of their participants have cerebral palsy. CPS was proud to support you all.

We have completed reviewing all our programmes and grants and have included our recommendations in this Review. We will continue to improve our programmes and services for you over the year and welcome any feedback you have.

We have also completed our review of what would help families with newly diagnosed children. There is information on this available for anyone interested. The main theses were improving website information with a focus on children; information packs on cerebral palsy and what CPS does for both families and the medical/ therapy community and parent welcome packs. Also there was interest in regular meetings with other families and / or mentoring. We are currently working on all of these

Thank you to those who offered to support our member focused Events. Planning for events around the country are now underway with Christchurch's excellent events planning group made up of Michael, Allison, Rach and Jude having already put together some great ideas for events for the next twelve months.

Wellington event's planning is lead by Karen and will be meeting soon as will the Auckland group.. We are also looking at members meetings around the country, if you are interested in helping- please let me know. All Events will be decided by members for members.

Young People have groups in Auckland, Wellington and Christchurch. Auckland's group is planning a movie on May 25th at Sylvia Park bean bag theatre; Wellington group has plans for a train ride; poetry session and star gazing and Christchurch's group... We will work with the groups of young people to forward what they would like and look at short term activities and longer term plans.

We have re-initiated the coffee clubs in Wellington, Kapiti Coast and Auckland (three) joining our established coffee clubs in New Plymouth and Masterton- alongside the successful

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News From HQ

The aroma of coffee attracts CP members

Christchurch one which continues to grow and Nelson that continues to be small but personable. Thanks to Karen, Trish, Debbie, Maria, Vanessa, Michael and Kathy for your support in running these- we really appreciate it.

A Member's Research Committee will review the writing of funding applications for support from the CPS members, this will be headed by Amy Hogan. She will also be holding a CP Research Seminar on August 11th in Auckland for researchers to present their work to interested members- please let us know if you would like to attend.

You will find a postcard in your Review. The postcard reads "Living My Dream".

We are asking you to write about a dream you have – something you would really like to do. Write it up and post it to us. Each quarter we will randomly select a postcard and then work with you towards how we can make your dream happen.

Gilli Sinclair CEO

Programme Recommendations

Members find programmes beneficial

We had an amazing response to our survey with strong relevance of programmes for those using them. However many members were unaware of the programmes and their availability

- National coverage was identified as an issue however this was not demonstrated in all programmes. There is a presence issue across the country which is currently being addressed. The best served area is identified as Auckland with Counties as the least served area.
- The most commonly identified groups that could do with more service are families of newly diagnosed children and young people. This has been started.
- There is a strong interest in CPS leading a variety of advocacy issues.
- Cost benefit analysis of swipe card concept for all programmes has been reviewed- the reconsideration that we use a swipe card for getOutThere is being trialed shortly.
- We are working to improve the on line forms facility and simplify all forms- reducing the information required.
- We are identifying innovative ways of increasing membership's understanding of the range and opportunities for programmes

Recommendations for Individual programmes include for the getOutThere programme, the undertaking of taxi company education and promotion of taxi stickers and the consideration of putting information on the back of swipe card. For the getThis&That programme we are looking at innovative ways to increase awareness within membership –read article on page 16 and we are currently looking to increase suppliers- including paediatrics; online; left handed; ranges that promote for disability (eg Nike). For the getPhysical programme we have increased time frames for members who have demonstrated utilisation and we are reviewing activities with the view to expansion of providers and activities

Website

Remember to visit our website regularly to keep up with the latest News & Notices

www.cerebralpalsy.org.nz

What CPS can do to improve situation for families with newly diagnosed children.

We invited people from Auckland, Wellington and Christchurch to participate in face to face or phone interviews covering what had worked well for them when their child was diagnosed; what would have worked better and what could CPS do to improve their situation. This is the result of forty interviews of people (all mothers) with a child diagnosed with cerebral palsy.

There were five main themes:

1. **Improved website** for more information about CP and what is available. For example information on Conductive Education, Carlson and other specialist schools, a greater understanding on what you qualify for and therapies and alternative therapies options all need to be discussed on the website. Great example of this is mychildwithoutlimits- excellent parenting info and explanations.

2. **Information packs for paediatricians** and NICU re CPS on what is available including a direct referral form to CPS (with parental opt off permission)

3. **Regular meetings with other families** with children with cerebral palsy for parents and siblings- e.g. Mum's support group OR list of parental contacts for mentoring individuals. (This may require some training as well) (contact list not to be publically available)

4. **Parental welcome pack** e.g. Deaf association; Cerebral Palsy USA- opportunity to personalise packs and provide information that is easy to read and easy for a family to utilise and find out what CPS can offer them.

5. **Consideration for families with children with severe Cerebral Palsy.**

This will require:

- Website improvements with focus on newly diagnosed; treatments etc. in one section.
- Consultation with paediatricians and child development teams to discuss options.
- Direct referral opt off programme
- Establish and trial regular meetings and mentorship programmes
- Review potential for a number of parents to support newly diagnosed children.
- Systemic review- anticipate 100 children per annum- 2 per week.
- Review parent packs offered by others
- Discussing with the board about affiliate membership covering people with "suspected CP"

Oyster Accessible Travel NZ

Written by Kimberly Graham (Mother of Finlay)


The Oyster Team - Kim, Jill and Maddy celebrating the launch of the website on 1st March 2016

A 'one-stop' shop accessible travel resource was inspired by my son Finlay a long-term wheelchair user. He has Athetoid CP and finds it difficult to maintain weight bearing. Our young family thrives on travelling and exploring new places. I could see clearly that this was going to become harder as Finlay grows. I knew it wouldn't be long before we would need more adaptive equipment, the convenience of a roll-in shower and wheelchair transport.

The planning that goes into organizing a 'barrier-free' breakaway can be hard work. I would find it frustrating that I couldn't just book the room with a roll-in shower and see photos of it. I thought "wouldn't it be great if I could just have the equipment we needed dropped off at our booked accommodation!"

All these thoughts started to formulate as I trolled the Internet trying to organize our 'out of the box' family holidays. The thought of leaving our adapted home with its specialized equipment was daunting. Our Finlay also has sensory anxiety that can result in bringing on seizures. This adds to the necessity of having everything planned well to avoid any surprises.

A year ago I was introduced (by my cousin Jill) to a highly motivated lady by the name of Maddy Widdowson. Maddy quickly became passionate about my 'one-stop' shop idea for accessible travel. All three of us decided quickly to put in our own funds to find a web designer to do the job. Before long Oyster Accessible Travel NZ started to take form and was launched 1st March 2016.

"Oyster is a website showcasing New Zealand where both the domestic and international visitor with extra mobility needs can source information specific to their requirements"

It covers everything! - Accessible accommodation, 'things to do', transport, equipment-hire and accessible walks. It also has plenty of 'links' to downloadable brochures and maps that relate to accessibility in the towns and regions around New Zealand. There is an interactive blog and review system to provide user feedback. Also photographs to back up specific accessibility descriptions.

We will continue to develop Oyster Accessible Travel adding to it daily. We also have an interactive FaceBook page that we would love you to 'like' and a Newsletter that you can subscribe to for all our seasonal updates.

Come on board and visit us at www.oysternz.co.nz

Consumer Consortium Report

6–8 April 2016 Report

This was my second Consumer consortium conference and having an idea of the process I felt more able to contribute than I had the first time round and it was great to meet the new C.P Society parent rep, Andrea. A lot of interesting speakers presented a variety of information some of which I have summerised below.

DSS work programme update.

This was an outline and update of the DSS activities and there up and coming programme. One of the subjects was around whether there is a need for disabled persons to have photo identification cards. These cards would have details of their disability on it, to help the police and emergence services if the need ever arises where there is no one around to speak on the disabled persons behalf in emergancy situations.

DSS Demographic Report.

This presentation showed a breakdown of the number disabled using the DSS services, it showed the number of clients using services by age ,ethnicity,disability. One of the interesting breakdown was the number of providers and the number of clients and the number of clients per providers.

- Approx. 80% of clients are served by 20% of providers:
- 51 Home and Community Support Services providers for 7256 clients = 1:142
- 97 Community Residential Services providers for 6012 clients = 1:62
- 28 Support Living Services providers for 2,910 = 1:104 clients

Prioritisation tool

Tony surrounded by his family

This was a presentation around the use of the the tool and process in the useage of it. and then the three goals of the tool.

The three goals of the Tool are :

1. A fairer and more transparent process for prioritising access to ministry funding for complex equipemant or modifications.
2. That disabled people and or their families have a 'voice'in the prioritisation process,by completing an Impact on life questionnaire.
3. That disabled people who have the greatest need and ability to benefit from the equipment or modification will be the ones who receive access to funding.

We discussed why the Tool was developed and the processes in applying it.

Here is further explanation of the Prioritisation Tool from the Ministry of Health website. "To assist with fair and transparent allocation of resources, the Equipment and

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Consumer Consortium Report

Modification Services (EMS) Prioritisation Tool has been designed to determine which disabled people get access to funding, based on current need and the person's ability to benefit from the equipment or modifications , Service allocation can be evaluated against the following principles.

1. They make an effective contribution towards helping disabled people to live, as far as possible, as others do in their own home and communities.
2. They represent value for money both now and in the future.
3. They are allocated fairly through a consistent, principled and equitable approach.
4. They reflect a lifetime perspective by recognising that the services that are most appropriate for a person may change over time." Editor

DSS Engagement Guidelines

This has been published on the Ministry of Health's website: www.health.govt.nz. This guide was developed in close consultation with Disabled People's Organisations and provides practical tips to anyone wishing to engage with people with disabilities. The purpose of the guide is to break down some of the barriers disabled people face, so that we can all benefit from disabled people's full participation in New Zealand society.

Health of Older People

This presentation around the Health of Older People Strategy from 2002 and the main objectives:of the Strategy are:

- Healthy ageing
- Living well with long term health conditions and disability
- Excellent acute care, rehabilitation, and recovery from injury and short term illness
- Well-coordinated support for people with high and complex needs
- Respectful end of life

Other areas that where discussed, were New Model update LAC Hutt ,Enabling Good Lives Waikato Demonstration Update ,and the Purchasing Guidelines

By Tony Voss (Consumer Rep)

Opt In

Many disabled people and people with health conditions work, and enjoy the rewards it provides.

Opt In enables people who get Supported Living Payment and are interested in getting a job to work closely with an experienced Work and Income case manager.

Joining Opt In is voluntary and people can stop at any time. Their Supported Living Payment is not affected by joining (or leaving) Opt In. When people find work their case manager will talk about how this income may affect their benefit payments.

Opt In is available in most Work and Income service centres from 9 May 2016

SPELD NZ; a Credible Option

Roughly one-quarter of people with cerebral palsy experience some degree of learning difficulties. The more severe the brain damage, the greater the risk of cognitive impairments. Problems might include difficulty with executive functions — the skills needed to solve problems, make decisions, pursue goals and exercise self-control.

Among people who have cerebral palsy, those with spastic quadriplegia have the highest likelihood — about a 50-percent chance — of mental retardation. It's also possible, however, for cerebral palsy to affect a person's entire body, yet have no impact on intelligence.

Maree teaching Keira the enjoyment of reading

SPELD NZ the not-for-profit organisation, with more than 40 years experience, may be an option for CP people with specific learning disabilities, especially if the difficulties indicate conditions such as dyslexia.

Each year SPELD NZ assists nearly 2,000 children and adults throughout New Zealand with assessment, tuition and support. SPELD NZ teachers are all primary and secondary trained, with classroom experience and in addition undertake highly specialised training. They work on a one-to-one basis, tuition is tailored to each student's particular needs.

Once you are a member of SPELD NZ you will be referred to one of the trained assessors who will complete a Diagnostic Assessment of Cognitive and Educational Abilities and write a full report including recommendations for future learning.

The assessment covers cognitive assessment and educational achievement testing. It will indicate intellectual and educational strengths and weaknesses and give a broad view of your child's mode of learning. The assessment evaluates the skills involved in effective learning such as language and auditory skills, visual skills and spatial awareness, speed of processing, short and long term memory, reading, spelling and basic mathematics, and attention, concentration and academic fluency.

The report is written for both parents and professionals so includes some technical language. However a clear summary is included and the assessor is happy to answer any questions.

If the assessor's report recommends one-on-one tuition all you need to do is contact your regional SPELD office and they will connect you with local specialised teacher.

For more information ring 0800 773 536 or go the website www.speld.org.nz

In The Year 2015

WE SUPPORTED BOCCIA
throughout New Zealand

WE PROVIDED 76 GRANTS to
our members for various things

WE HELPED OUR MEMBERS to
**accomplish 60 million steps
with STEPTEMBER**

Cerebral
Palsy
Society

WE ASSISTED 486 MEMBERS with ***gTT*** to purchase items that aid them with everyday living. ***getThis&That*** helps members to purchase items such as crutches, wheelchairs, walking frames, etc

WE FUNDED 21,600 ***getPhysical*** sessions. ***getPhysical*** assists members to maintain their physical ability, and fitness. It includes private physiotheraphy, gym memberships, etc

In The Year 2015

WE FUNDED 27,880 TAXI journeys with the ***gOT*** programme. ***getOutThere*** helps our members to gain a greater access to the community by using taxi vouchers to fund the fare, also discounted rates

WE FUNDED 16 MEMBERS through the ***getStructured*** programme. ***getStructured*** helps to financially assist members set up a legal framework. It includes wills, power of attorney, trusts, etc.

WE PROVIDED 65 TRIKES through our ***GOYT*** programme. ***getOnYourTrike*** is designed for young people aged 3–18 who have CP

WE SENT OUT 7,200 COPIES of ***The Review***

The Review

March 2016

Stockholm Conference Beckons Amy

In June this year I am traveling to attend 5th International Conference of Cerebral Palsy (ICPC) in Stockholm Sweden. Several other conferences will be held concurrently related to childhood disabilities. This 4 day meeting (1st – 4th June) will bring together some of the top research scholars from around the world representing many different fields including but not limited to Neurology, Pediatrics, Neurology, Orthopedics and Psychology.


CP conference moves to Stockholm

The central theme for this conference is "Challenging The Boundaries." Broadly speaking there will be several main focuses While I am there I will summerise each theme and report back when I return home. It will be excellent to have the chance to review the European and American work especially in the areas of Selective Dorsal Rhizotomy (SDR) and Stem Cells, which is of great interest to our members.

Below are examples of the lectures I will be attending.

"Latest Advancements in CP Interventions:" This session will focus on how best to manage CP and its symptoms at all levels. Especially around the types of interventions that are most effective and helping with the invisible aspects of the disability that can have a huge impact on function and quality of life such as pain management.

"An overview/update of evaluation & management of pain in people with Cerebral Palsy."

"Global Research": The best ways to foster communication amongst CP Researchers and Clinicians worldwide in terms of developing hip surveillance and developing best practices in areas such as spasticity and promoting comfortable mobility long term.

Classifications of Function in 21st Century: What are they good for?

"Quality of Life": How best to help young people and adults manage their own conditions and be able to avoid long term complications in later life such as problematic joints or difficulty staying well in the workforce or living away from primary caregivers.

"Family and Social Support": How best to introduce fun and engagement into the rehabilitation process and not just simply relying on clinical measures such as the work of Cole Galloway and the GoBabyGo Cars. What do parents need most from clinicians at the different points of the diagnosis journey.

Amy Hogan

Two Day Think Tank Planned

Recently I participated in a Disability Research Hui hosted to AUT. The two-day event had the expressed purpose of bringing together researchers who have specialised interest in disabilities studies. Aside from being a great networking opportunity the overall agenda stimulated discussion on how individuals with disabilities could be become actively involved in setting research priorities rather than simply being recruited as participants after study topics and aims have already been decided.

At the Hui it was agreed that New Zealanders with disabilities do not enjoy the same level of health as others in our communities. This disparity is evident in shorter lifespans, lower rates of breast screening, and higher incidence and earlier onset of chronic illness. While disability organisations and researchers have worked to close the gap, there is no agreement on which issues have priority. Collaborations between organisations and researchers exist, but greater cooperation is needed to make the most of limited funding.

Believing that collaborations are supported by strong relationships and a shared agenda, we are convening a Think Tank that draws together the passion and wisdom of disability activists/advocates and researchers. The aim of this 2-day event is to bring leaders in the field together, with a view to distilling the salient health issues in Aotearoa New Zealand and charting a path towards addressing them"

The Think Tank will comprise large and small group discussions, with breakout groups addressing specific issues and questions.

The four main topics under discussion will be

1. The need for disability research. Speaker- Paul Gibson
2. The social model and health. Speaker- Martin Sullivan
3. Maori concepts re disability & health. Speaker- Huhana Hickey
4. The ICF model and social determinants of health. Speaker- Clare Hocking

The highlights of the discussion at the Hui were establishing links with people throughout the country and laying a foundation for collaborative work in the areas of Politics and Identity (wider advocacy and political representation), Physical Access (making research accessible) and Abuse (challenging definitions). Outcomes from the event will be circulated later in the year which I will summerise on our website. If you would like any further information please feel to email me.

Amy Hogan

Time To getThis&That

Long time CP member Michael Bull has benefitted greatly over the years from the getThis&That programme provided by the Cerebral Palsy Society This voucher based programme allows members with Cerebral Palsy to purchase small items that are needed to manage the affects of their Cerebral Palsy. Our aim is to eventually satisfy 90% of what is needed to help manage the affects of living with CP. We feel the programme is being underused and Michael is a good example of how beneficial getThis&That can be

Michael Bull leads by example

He is a man about town who is often seen in many parts of Auckland. He has a good eye for a bargan, has our Michael and loves an occasional shopping spree. Since the programme has started in 2008 he has bought many items including big handle cutlery, shower chairs, toilet seats, key turners, urinal bottles, poncho for protection from the rain and a walker which he uses at home.

Other members should follow Michaels example and fully utilize whats on offer

Cerebral Palsy Society members can apply to be on the getThis&That programme and successful applicants will be sent $200 in vouchers. The personalized vouchers will be valid for one financial year (1 July – 30 June). Only one allotment of vouchers will be made in one financial year (Jul-Jun). Members who wish to participate in the programme in the following year can re-apply.

Members can use their vouchers at pre-authorized suppliers ONLY. If the item costs more than the value of your vouchers the member must pay the difference.

Pre-authorized suppliers are many and varied. If you go to the CP website www.cerebralpalsy.org.nz and click on the programmes link you will be surprised at the quality of suppliers that have signed up. Orthotic Centres throughout the country from Auckland to Invercargill have come on board. Brolly Sheets (big solutions for wee problems) has signed and so have two new Auckland supplers SK Clothing (For bandanas, feeders and wheelchair capes etc) and SlipOn NZ Ltd Specialising in swimwear, incontinence briefs & aquatic aide. Going down the country Up2date - Equipment & Hire showroom Whakatane – Eastern Bay areas, LIFE Unlimited store Gisborne, DTSL (Assistive Technology Division) Palmerston North, Disability Information & Equipment Centre Kapiti, Access Mobility Blenheim (Mobile Service), Aspire Canterbury Christchurch, Queenstown Disability Resource Centre and Southland Disability Resource Centre have all signed up. JUST TO NAME A FEW!!!

So if you are a member you have $200 with your name on it. Go and apply now.

Ross Flood

Cole's Vision Transports Kids

In May the CP Society office had the privilege of a visit from Dr Galloway neuroscientist, physical therapist and founder of GoBabyGo. He very generously spent some time with us explaining his philosophy and answering questions. The following article is inspired by his visit.

"The same joy and excitement experienced by every dancer or musician, astronaut or athlete can be seen in newly mobile children." — Cole Galloway.

Cole sends Brendan on his way

When asked to expand on this quote James "Cole" Galloway said "The transition from a largely immobile and passive person to a person with greater mobility resulting in greater independence is a transformation - even if that mobility is deemed 'non functional' by mobile adults. For example, a child hitting a switch to make a racecar go around in circles is fun for most young children. For those who were largely immobile until the second they hit the switch, it can be a powerful jump start to their exploratory drive and adventure-seeking self. Driving in circles might be non functional in many folks eyes, but to that immobile child, it is not only 'fun' and 'stimulating' but potentially transformative -- especially if they can get the opportunity to move each day. Thus, the dancer exploring a jump, the musician completing a difficult passage, the astronaut experiencing a new view of earth, the athlete's emotional release at achieving a personal best -- you can literally see these emotions in the wide eyed, open mouthed smile and joyful laugh of a child's first moments after hitting that switch and being whisked away in their racecar."

With these thoughts in mind Dr Galloway insists mobility is a human right. For those who remain dubious about that statement he challenges them to think about how movement and mobility influences their life (not just their ability to get around, but what that 'getting around' means to their thinking, planning, happiness and friendships)

Dr. Galloway set out to provide the very young with a means to motor around on their own.

His initial motivation to get involved was "my frustration with the current level of technology, the lack of innovation, the cost and my own lack of understanding (and respect for) what individuals with significant mobility challenges face in terms of daily life. Later my motivation switched to helping kids and adults with mobility challenges take ownership of the tech and training available to them. This is where I am currently -- a place between hope and frustration -- and continuing to encourage others in science, education, medical and the industry to work together to solve the key issues with current assistive and rehabilitative tech for mobility."

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Cole's Vision Transports Kids

He began with high-tech robotic chairs, but soon realized that such devices were too expensive and produced in low volume for the demand. After some tinkering, he hit upon a simple, cheap and effective substitute: mass-market battery-power cars available at toy stores — a Barbie Jeep or Thomas the Tank Engine, for example — that could be individually adapted to the child's needs. Dr. Galloway discovered that for $200 he could purchase a $100-ride-on car from Toys "R" Us and $100 of Home Depot supplies to create an easily operable vehicle for children with physical impairments. He realized he had found an alternative to the power wheelchair,

However he insist that those we propose to help actually help us!

"That is the core of 'user centered' design -- where users of technology have a deep and meaningful role in the concept to commercialization of the technology that they use," he said.

As Dr. Galloway puts it, "The drive for exploration through movement and mobility is a deep part of being fully human.

Coles vision has created branches of GoBabyGo in many parts of the world including NZ. Go to our local branch website for more information www.gobabygo.org.nz

Ross Flood

Living My Dream

Several months ago, at the Wellington conference a young woman in a wheel chair said she wishes that she had had a chance to be a ballerina. At the same time, there were Youtube videos on some young women in wheel chairs dancing with Australian ballet companies and the New York ballet company.

Several days after a young boy also in a wheelchair said he would love to take the ball onto a big rugby game.

Cerebral Palsy Society started talking about what we could do to make your dreams happen. Your dream is your cherished aspiration, ambition or ideal.

We are asking you to write about a dream you have – something you would really like to do. Write it up and post it to us. We will randomly select a postcard and work with you on that dream. We can work with you to give you a fantastic opportunity to make your dream happen. You will find a postcard in your Review. We will randomly select a card every quarter and work with you in your dream. The postcard reads **"Living Your Dream".**

"Living My Dream" is open to anyone (any age) with Cerebral Palsy who is a member of CPS. Someone can fill your card out with you- but the dream needs to be the dream of the person with CP. We can't promise we can do everything, but we are committed to trying. This is part of our philosophy of "freedom and choice".

Proactive ADL Gets Results

Auckland Disability Law manager Sue Plowman very generously answered some questions from the CP REVIEW about the purpose and progress of the law centre.

She responded by saying “Auckland Disability Law (ADL) is a small Community Law Centre with five staff. We have two solicitors, a community worker, an administrator and a manager. It is very important to us that we are connected and working proactively within the disability community. This means we do a variety of work including legal case work, legal education delivery and community engagement. As Martine Abel, Chair of the ADL Steering Group, says ‘ADL is proud to have stated in our constitution that the majority of our Steering Group (governance group) must be disabled persons so as to ensure that our legal service is focused on “nothing about us, without us.”

We do a lot of legal case work around discrimination that disabled people experience. Commonly we provide specialist legal services to disabled clients in relation to employment, housing, accessing services (health, education, disability and mental health support services) which are associated with disability. Annually, we handle over 200 individual cases. Below are some recent examples of the types of cases we handle:

- Employment cases, in which employers attempt to fire disabled employees due to medical incapacity, or are not providing reasonable accommodations, or are discriminating against their workers in other ways because of their disability.
- Education cases, where disabled students encounter issues accessing tertiary education, or disabled teenagers and children having problems accessing disability support services in the secondary, primary and Early Childhood Education settings.
- Housing is another area of concern, particularly finding appropriate housing for families with high-needs disabled children such as autistic children or those with physical accessibility needs.

ADL is primarily an Auckland focused service in terms of our legal case work and our legal education mainly because of our funding limits. But we do have Disabled people contact us about legal issues, or other community law centres contact us to seek advice for their Disabled clients, associated with disability law. We try to find them local lawyers, disability organisations or provide guidance to local community law centres to assist. ADL does have aspirations to become a national specialist disability law service.

We do a lot of legal education particularly within the disability community often in partnership with disability organisations or providers but are now starting to run public education series. Legal education is about raising Disabled people’s awareness about their legal rights so if they encounter legal problems they are in a better position to seek assistance and start sorting their situation.

Since July 2015, we have had nearly 500 people participate in our legal education sessions.

For further information

Phone: 09 257 5140
Fax: 09 257 4693
Text ADL: 027 457 5140 (TEXT ONLY)

info@adl.org.nz

Freedom Of Choice VS. Safety

The hui was a great success

Successful supported decision making empowers disabled people to make their own decisions and have control over their lives, on an equal basis with others, and is consistent with Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

This statement was the basis of the Conversation discussed at the Supported Decision Making Hui, hosted by Auckland Disability Law, held at the Waipuna Hotel and Conference Centre, on Wednesday 20 April and Thursday 21 April 2016.

The hui, which was attended by 137 people over the two days, discussed this positive Conversation which is one part of a much bigger journey in relation to supported decision making. It was agreed everyone needs support when making decisions. Some people need a more targeted circle of support and tools to assist them to make decisions about their own lives. Supported decision making from this perspective is about nothing about us, without us.

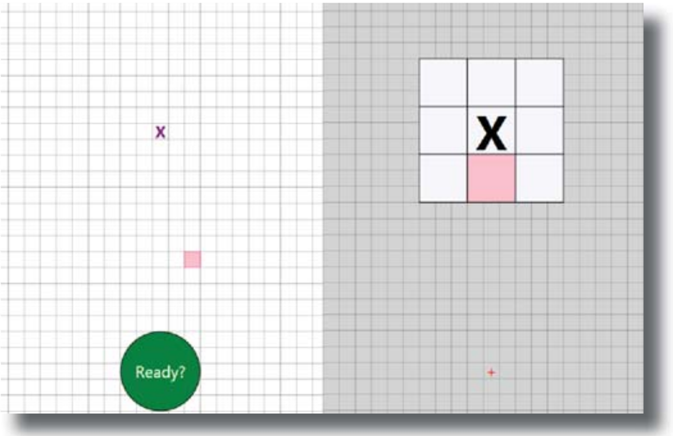
It was very noticeable that a common theme threaded its way through each conversation which was the balance between freedom of choice vs. safety. One poignant moment brought home to me how important both these aspects were when a mother revealed how her daughter was treated at school. Apparently a teacher shoved her daughter in a cupboard and locked the door after her behaviour became uncontrollable. Surely a more civilised, safer, supported decision making solution could be found involving all concerned.

There were many more poignant moments as groups and panels discussed What does supported decision making look like in New Zealand today? What are the realities for those at the centre of the decision making process? Insights into ways to communicate effectively with cognitively impaired, non-verbal adult family members. A session was organised from a manager's perspective when setting up a new service, which covered how plans can be put in place to include opportunities to use supported decision making, overcoming road blocks in the process, and recruiting and training staff and the Minister Nicky Wagner, Minister for Disability Issues, gave a short presentation on the importance of supported decision making in enabling disabled people to have more choice and control over their lives with particular reference to the Enabling Good Lives demonstrations.

Auckland Disability Law is in the process of asking presenters to agree to publish their seminar notes on the ADL website www.aucklanddisabilitylaw.org.nz

Ross Flood

Computer Mouse Project



My experiment task. Participants had to click the square with the X in it. Left, before zooming. Right, the same square after zooming.

I am a PhD student at the University of Auckland and I am working on some 'assistive technology' to help with using a computer. More specifically, I'm interested in making very small buttons easier to click with a mouse.

I find 'assistive technology' to be a strange name. Isn't all technology supposed to be assistive? To me, 'assistive' indicates helping people be 'normal', rather than helping them perform a task. So, I don't think it's a great name. I think it is dividing people into groups of those who need assistance, and those who don't. I think design should try to avoid segregating users into separate groups like that.

So, when it comes to clicking small buttons, I have designed a tool for this specific context, rather than for a specific user group. The idea is that anyone could use this tool when they find a button to be annoyingly small. But what constitutes 'annoyingly small' may vary from person to person.

My solution is very simple, it is basically a zoom lens. It is activated by holding down the mouse button for an extended period of time. This generally makes selecting a small button easier, but it takes longer to do. It also means the user isn't forced to use the zoom lens when they don't want to (i.e. for bigger buttons).

With the help of the CP Society, I have been running a study to test this. I have found that both people with and without CP use the zoom function, albeit for slightly different button sizes. Using the zoom helped with accuracy too. However, this design still needs more work. For example, it is not very useful for people who use track balls.

Aside from my work, there are already options available to help with using a mouse. In Windows, Magnifier can help with visibility. Also, adjusting the pointer speed of the mouse can improve mouse movements. A less commonly known tool is the Bubble Cursor which makes buttons easier to select when using the internet. It can only be used with Google Chrome and is available from bubblecursor.com.

By Alex Payne

Great Day Out At Mt Smart

Leah Martin is a mum of one our young members. She is completing a Personal Training course and organised the donation of 48 tickets to the Warriors match against the St George Dragons, plus lunch. Leah's family has been associated with Warriors boss Eric Watson for a number of years. Below she describes the great day out

Alicia Mcphee and Kristen Williams get the thumbs up from Peter Leitch

"I am currently working on my business which focuses on the health, fitness and wellbeing of people who have a disablity. Enabling, Empowering, and Enlightening those with disabilities, helping them physically and mentally realize their capabilities, worth, then help guide and support them to be active members of society.

With the help of Eric Watson and the Warriors, I organised a day out at Mount Smart Stadium, for 48 disabled friends and myself to watch the Warriors play the Dragons. Many of these people had never been to watch a game live like this before and it was an amazing day. Not only did we have front row seats, but food and beverages were supplied and brought to our seats. We also had the privilege and pleasure and were absolutely thrilled to have Sir Peter Leitch, and the Minister of Health Jonathan Coleman visiting us. Then during the second half Eric Watson, the owner of the Warriors, came to see us with Jim Doyle, the CEO of the Warriors. Then finally Simon Mannering came bearing gifts for everyone, bringing us all Vodafone Warriors Hats. It was a perfect day, everyone was smiling, we all felt special, as we watched the Warriors slay the Dragons.

Alicia Mcphee and Kristen Williams get the thumbs up from Peter Leitch

Once again thank you to Eric Watson and the Warriors for your generosity and making our day possible. Thank you Sir Peter Leitch and Jonathan Coleman for lifting our spirits, and coming to see us, your presence alone had such a positive effect on our day. Also thank you to my 50 friends for coming with me. You were all so great and I had a wonderful day with you all. Finally, a huge thank you to everyone thats understands, appreciates, and supports people with disabilities. We all need to do our part to ensure a brighter future for the next generation of people with disabilities."

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Auckland

• Research Meeting	August 11th
• CP Day	October 5th
• Auckland Events	TBA

Hamilton

• Hamilton Mid winter event	July 16th

Wellington

• Wellington Coffee club and Events catch up	July 9th

Christchurch

• Christchurch Casino Lunch	August 28th
• First of Christchurch plays	October 3rd
• Christchurch Christmas	December 4th

Young people in Auckland

- May 27th - Movie night
- July 21st - Fairy, and Pirates party

Young people in Wellington

- May 28th - Train trip to Kapiti Coast
- June 6th - Celebrate Matariki
- July 7th - Spoken Word at Meow

Young people in Christchurch

- Go to www.cerebralpalsy.org.nz to see the full list of events