

The Review

Winter - Sep 2009



The Official Magazine of the Cerebral Palsy Society of NZ Inc

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Any opinions, findings, conclusions or recommendations expressed in this publication are those of the authors and do not necessarily reflect the views of the editor or the Cerebral Palsy Society of NZ

Cover

Assoc. Professor Sue Stott and
Amy Hogan

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Our Fate in Our Hands

I attended a Medical Conference on cerebral palsy in Sydney last February. I wrote a couple of articles for the website about items I found particularly interesting.

It was not till later that I realized that this conference had deeply disturbed me and the conclusion I made was that the medical/academic world was ignoring the adult world of people with cerebral palsy. It was as if people with cerebral palsy over the age of 21 were being assigned to that black hole where they were to be left to their own devices. Even from a medical view point, scant research has been done on adult CPs. This is a world-wide phenomenon and is of great concern.

It was from this perspective that the Society decided that if something was to be done, we had to do it. Various discussions were had with the University of Auckland.

Arising from these and also discussions within our membership, a member put a project plan together with budgetary figures. This was placed before the Board in July and approved.

So what is going to happen over the next 12 months:

Amy Hogan has been employed to plan and implement a longitudinal study entitled "Cerebral Palsy through the Life Span". The goal is to gather information from birth through to death of people with cerebral palsy in New Zealand and



Assoc Prof Sue Stott, Harvey and Amy Hogan

will allow people with CP to look ahead and learn from what others have done before them. Cerebral Palsy covers a large spectrum of disability and current classification systems have been based on children. This study will entail modifying a number of these systems to cater for adults. Associate Professor Sue Stott has agreed to provide support from time to time to ensure that data gathered has the robustness required.

The hope is to have the planning phase completed by the end of December 2009, trialing of the questionnaire and logistics done by the end of April 2010 and then recruitment of the main body of participants thereafter.



It is envisaged that there will be an intensive first interview so as to back engineer people's lives. Thereafter there will be an annual questionnaire via the internet or mail. It is all quite exciting really, we are about to go where no one has gone before. The Society is in an ideal position to do this and we look to our members participating in all aspects of this study.

A study OF people with CP, BY people with CP, FOR people with CP.... Bring it on!

Harvey Brunt-GM



Assoc Prof. Sue Stott and Amy Hogan

School therapists cuts.....

The NZ Government has cancelled its decision to remove \$2.5M of therapists funding from 23 schools. This cancellation was qualified by the statement from Anne Tolley, Minister of Education, that funding would be reduced as present high needs students left school. This was of concern for future students coming through the system.

With this uncertainty in mind, the Society, via Diane Kidd (The Chair of Focus 2000 Ltd), was able to organise a meeting with the Prime Minister.

This meeting took place on the 27th August at the PM's electoral office in Huapai.

John Key was well briefed on the subject



of the proposed cuts and their *Harvey Brunt, Diane Kidd, John Key and Karl Sangster* reversal. We made him aware

that every parent desired their child to attend the school down the road, but for children with severe needs this was impractical and centers of excellence were needed (ie the 23 schools needed to maintain their staff). The need for young children to weight bear so that joints form correctly was also stressed, and severely disabled children needed assistance and therapists to ensure that this happened.

The PM was very open to this and said that the storm that occurred around this funding was significant, especially in comparison to the amount of money involved. He intimated that the likelihood of the cuts returning were minimal.

We will be writing to Anne Tolley asking when the review of the Wiley Report (published in 2001 which initially instigated this extra spending) is to occur. Harvey Brunt



Assessment standards for CP

By the time they hit double figures people with CP and their families are all too familiar with scales of function. The degree of this acquaintance tends to vary, from absorbing the numbers floating about during physiotherapy sessions to jargon filled arguments with needs assessment agencies. It has recently come to my attention that although I have been on these scales for most of my life I have a very limited grasp of what these measuring systems mean in a practical sense. It is with that in mind that I decided to investigate the most comprehensive and commonly

Implemented assessment standards for Cerebral Palsy, the 'Gross Motor Function Classification System' (GMFCS).

As its name suggests GMFCS measures the degree of Cerebral Palsy that impacts on an individual's gross motor. The system centered on how readily the person is able to achieve key age appropriate physical milestones. The aim of this classification system is to establish a present level of progress as well as track changes from birth until age 12.

Level One: People classified as level one maintain motor skills close to or within the normal range of abilities for that age, for example they learn to crawl, stand and walk independently. The only differences are in the speed and accuracy of some of the more difficult motor functions such as running.



Level Two: People classified as level two can do most motor tasks normally but they may need to use their hands on railings or other support to balance independently. This is especially important when they are outside or on uneven surfaces.



Level Three: People classified as level three need support devices like wheelchairs or walkers to be able to achieve and maintain activities like walking and standing. They can use these aids independently, i.e. they are able to push their chairs or walkers in the classroom or round the playground.



Level Four: People classified as level four cannot independently maintain activities such as walking. They need adult supervision when attempting activities that need balance and weight bearing such as standing. Their primary mode of transport is a power chair.



Level five: People classified at level five have little or no control over their movements. Therefore they need the assistance of both people and devices to perform any motor tasks. This support includes seating harnesses and somebody to push their wheelchair.



GMFCS V

Images from the Hip Surveillance Booklet, AusACPDM

Amy Hogan

New Zealand International Boccia Team returns from Hong Kong

The Team arrived in Auckland from around the country and trained together for a day and a half prior to flying to the 3rd Asia Pacific Boccia Championships, which is one of the qualifying games for the Paralympics.



On arrival in HK, we were amazed to discover 80 docking gates for the planes. From the airport we travelled by train at 70 kms/hr for over 7 minutes to arrive at the immigration area. We travelled by mobility bus from the airport to the Hyatt. An impressive hotel with excellent service and food, especially as it had only been open for 4 months.

Our team competed over the following days until being knocked out. It was great to see the NZ team supporting each other while they played.

Towards the end of the week, we managed to do some sightseeing as well as shopping.

On the last day prior to flying home numerous teams, including NZ, went to Disneyland on sponsored tickets, which was awesome & far better than anything we had seen before.

The organisation of this event was amazing and very professional, which certainly helped foster great sportsmanship both on and off the courts.

Michael Northcott– NZ team Mgr



LOOK: A phone with a built in safety function

Two In One Plus + + +

Perfect for anyone who lives alone, the Oricom phone delivers assurance for both the user, and their family. In an emergency situation users can call for help without the need to get to their phone.

Xtra Special functions:

- ◆ Water Proof SOS Pendant with Wrist Band & red light indicator
- ◆ High Quality Speakerphone with red light indicator



Designed and engineered for people with:

- ◆ Impaired vision – Extra large buttons
- ◆ Impaired hearing – Compatible with most inductively coupled hearing aids
- ◆ limited strength & dexterity
- ◆ Arthritis

Memory difficulties – Voice prompts and recorded phone book names for easier use. (When you have an incoming call the phone will say the name of the caller if it matches your phone book directory)

This amazing phone also has a battery backup system that lasts for 12 hours, so if there is a power cut you can feel safe knowing you still have contact if there is an emergency.

WOW! THERE'S MORE SOS Emergency Pendant

Once the phone is set on the emergency function, and you require urgent attention, all you need to do is press the red button on the pendant. This will activate the speakerphone and dials your emergency numbers stored in sequence, until someone answers.

Answering the phone with your pendant

You can answer your phone by just pressing the red button on the SOS pendant. The telephone will answer the call and activate the speaker phone. Press the button again and the phone will return to standby. (You don't even have to move – Every home should have one of these phones, **might invest in one myself !!!**)

Guess what! If you are eligible for the Society's getThis&That programme it will cover the cost of the phone.

Oricom TP170WP is \$192 Inc GST and can be purchased through the Disability Resource Centres .

Janet Chapman
Members Manager



Christchurch member Sandra-Leigh Montford strongly believes that learning is a lifelong experience. Read below about the many twists and turns that led her to become a poet, a librarian and now a student of Psychology.

LEARNING IS FUN

Learning is for everyone – regardless of age! Learning is lifelong. Living with cerebral palsy is not an excuse not to learn something new.

I loved school! Those that know me will know that I am an accomplished poet. When I was first introduced to poetry in primary school I thought, "This is great! Writing poetry is easy!" At the age of ten I decided to be a poet. My peers thought I was mad. I soaked up my lessons in poetry, taking note of rhyme, alliteration and assonance. My love and skill for writing poetry has given me endless opportunities, including performing in New Zealand and Australia.

When I was in high school I had an appointment with the career guidance counsellor. At the age of 16 (1970's) I knew exactly what I wanted to be. So, when I was asked what career path I would follow I answered, "I want to be a psychiatrist!" I was very quickly informed that I could not be a psychiatrist because disabled people cannot be doctors. "Ok, I'll be a psychologist," I immediately replied. She shook her head. "Can I be a social worker?" I sensed my choices were wearing thin. "Perhaps," was the career counsellors' response.

Well, I ended up as a librarian. I graduated in 1991 with the New Zealand Library Studies Certificate. I have had a 17 year career as a librarian. Currently, I am a volunteer creating a



Sandra-Leigh Montford (right) with friend Judy Charlton.
Photograph courtesy of Allison Franklin.

library for a medical centre in Christchurch.

In 2003 I completed a Diploma in Journalism. This was something I was always going to get around to! I have written many articles over the years for various organisations.

But wait – there's more. This year I embarked on a Degree in Psychology with the Open Polytechnic of New Zealand...no, I'm not mad - as some people have suggested. I'm following my lifelong dream! So, in 7- 8 years I will be a Clinical Psychologist with the aim of counselling disabled people.

If you have a dream – go for it. Take small steps if you need to. If there's a subject you want to learn about, start by borrowing books on it from the library. I challenge you all to learn something new!

Leigh Montford



ATANZ Biennial Conference

The Adaptive Technology Association of New Zealand held its biennial conference at Canterbury University with guest speakers from as far away as the USA. Also present were trade displays from a number of the leading adaptive technology companies in NZ and Australia. Members, users and parents travelled from all over the country to share experiences, ideas and learning new or improved ways to enhance people's lives using adaptive technology.

The adaptive hardware varies from low tech, like a card with letters and numbers or pictures that a person can point at to get their ideas across to someone else, to high tech cameras that track eye movement to operate computers & software.

Adaptive software varies depending on the purpose and age range it is targeted at. Software aimed at young children often included game play to make it more interesting. Some software is also used by businesses to improve productivity, an example being Dragon Naturally Speaking. Software pricing can vary from free to \$50k plus.

The keynote speaker was Dr Sarah Blackstone from the USA who has a great deal of experience in research and training people to use Social Networks and Augmentative Alternative Communication (AAC).

One of our members, Thane Pullan, presented his experiences with the Erica Eyegaze system. He said that the system was very good for him, but did have flaws, an example of this being that it would not work with internet explorer 7 or 8. This creates vulnerability with things like internet banking. His picture



featured in the Christchurch newspaper.

Another of our members, Sonja Carpenter, who is a master's student gave an interesting talk on functional telecommunications, barriers, and facilitators.

There was a lively discussion with representatives from Ministry of Health (MOH), Ministry of Education (MOE), Ministry of Social Development (MSD), and ACC. The interesting thing I discovered was that they all meet at a higher level and are looking at a person's needs in a holistic manner. The result is that the cost is apportioned to the relevant departments. The extra bonus is that the information from the assessments will be interchangeable so people should have less repetition in questions.

In addition, to improved advocacy for our members around adaptive technology and extend the influence of the CP Society, I have become a trustee of ATANZ. This should help the needs of our members, as well as the wider community.

More information is available from www.atanz.org.nz.

By Michael Northcott



2009 ANNUAL GENERAL MEETING

Notice is hereby given that the Annual General Meeting of the Cerebral Palsy Society of New Zealand Inc will be held on Sunday the 18th October 2009, beginning at 2pm. at Yarnton House at 14 Erson Avenue, Royal Oak, Auckland.

Resolutions for consideration, and **Nominations** for the Executive Board must be sent to: Cerebral Palsy Society, PO Box 24759, Royal Oak, Auckland 1345 to be received no later than 4pm on 18th Sep 09.

The agenda, financial report, etc. will be sent to each member prior to the 4th Oct 08.

Remember, to vote at the AGM you must be a current financial member

Playback Theatre is Back Playing!

As promised, the Playback Theatre troupe has been re-commissioned for another brilliant night of theatre.

Last year's performance at Coyle St was one of the funniest evenings I have been to. Members of the audience are invited to relay a story from their lives. It can be any incident, funny, serious, whatever. Then the troupe acts out the story again, hence the playback theatre name.



Last year the audience provided some stories that had us all in stitches with tears streaming down our faces. Our members certainly have some cracker stories to tell !

Well, it's time to get a new set of stories together because there will be another evening of Playback Theatre on Saturday the 12th September, beginning with drinks and nibbles from 5pm, with the Theatre beginning around 6pm. This year, the event will be at the new CCS Building, 14 Erson Avenue, Auckland. The application form for tickets (\$10 per person) can be downloaded from our website or we can mail one out, just call 0800 503-603. Cheers Harvey Brunt



Nomination Form

Nominations for the Executive Board of the
Cerebral Palsy Society of New Zealand Inc
for 2009/2010

Please tick a role

- President
- Vice President
- Secretary/Treasurer
- Board Member



Name of Candidate: _____

Signature: _____

Name of Nominator: _____

Signature: _____

Name of Seconder : _____

Signature: _____

Nominations and resolutions must be received by 4pm on the 18th Sep 09. The candidate, nominator and seconder must be current financial members as of the 18th Sep 09.

Please return nominations and resolutions to:
CP Society, PO Box 24759, Royal Oak, Auckland 1345



Ruapehu beckons CE kids

On Wednesday 12 August 14 families, with children attending Conductive Education at the Coyle Street Centre, and two Conductors departed for Ohakune - a ski town only 20mins from the Turoa ski field on the southern slopes of Ruapehu. The families rendezvoused at The Peaks Motor Inn before heading to the famous Powderhorn Chateau for a sumptuous meal and kids' disco. It was a fantastic way to kick off our alpine sojourn, with the children dancing their little socks off well into the evening.

Thursday morning dawned fine and clear, so off up the mountain we headed for a day of tobogganing, building snowmen, snowball throwing (albeit mostly among the parents) and high-altitude fun. For some children it was their first experience in the snow. They enjoyed exploring a new environment. The day was indeed a gift with lots of big smiles all round.

Dinner on Thursday was a more casual affair at Margaritas Mexican



restaurant where we ate our meals by the roaring log fire. It was a relaxing end to an exciting day in the snow.

Friday morning we all said our good-byes and headed home to Auckland. Some families visited Lake Taupo on their way back and a couple of the families, along with the Conductors, visited the beautiful King Country's Waitomo Caves. The caves were a magic experience, especially the boat trip deep underground with thousands of glow-worms alight on the cave roof above our heads.

The three-day trip was an unequivocal success and will be remembered fondly by all involved.

Thank you to all the people who helped with organising and fundraising to make this trip happen. Thank you to Gyongyi and Zsofia for the fun activities they provided and the support they always give to the children and families. Thanks also to The Cerebral Palsy Society for their generous support.

Kristin Taylor



Friends help plan your future

As told on the home page of the Cerebral Palsy website, in June, a concept called “circles of support” has been launched. The aim of a “Circle” is to gather a group of friends around a person with a disability to help him or her think about their life and pursue a great future. This idea was developed through the “Belonging Initiative,” established by Parent and Family Resource Centre.



Co-ordinator Ainslie Gee explains “A life brimming with engaging and rewarding relationships is often portrayed to us as normal and typical. We could be led to believe that this life filled with friendships is one that most people (out there) have everyday. Yet more and more studies seem to be exposing that this ‘life’ isn’t, in fact, so common place. Many people experience loneliness and social isolation as an everyday occurrence. Finding friends can be a hard graft, and maintaining those relationships can be even harder. Relationship building takes energy, time, practice, and can benefit from a common ground and a developing shared history.

For people with disabilities, the experience of a life enriched with deeply satisfying (unpaid) relationships can be a somewhat elusive one. Regular friendships although desired, can be difficult to find and maintain and for some rather evasive. Compounding this, at times isolating experience, can be the reality that the folk (outside families) involved in disabled peoples lives are often paid staff. These people, despite doing often well intentioned and commendable work,

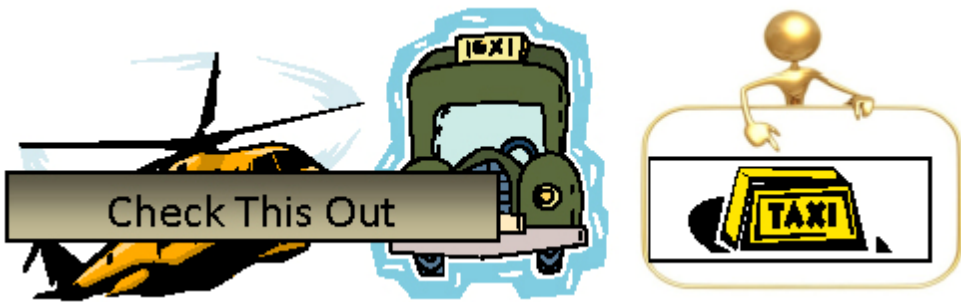
are in the end paid to be there which can create atypical relationships.

The experience of fulfilling relationships in people’s lives has been linked to greater wellbeing, increased life satisfaction and an increased safeguarding against the vulnerability of isolation and loneliness. Put simply, having friends, although not always straightforward and easy, creates an increased possibility for joy in many people’s lives.

Circles of Support offer one way to deliberately swell the amount of people in a person’s life. A circle of support is a group of people who are intentionally invited to come together in friendship and support of a person with a disability. Circles of Support can provide people an opportunity to be in a genuine relationship with the person at the centre, a mechanism for developing that relationship, and a role to play in that person’s life. Circles can also provide a person with a disability a way to identify and pursue the good life with friends who want to share it with them.”

For further information on Circles of Support please contact Ainslie Gee (09) 6360351 ainslie@pfrc.org.nz





Freedom & Choice

“The benefits of joining the getOutThere programme”

Great: For all those members, who are currently on the total Mobility Scheme with your Regional Council, or are not but may be eligible.

Exciting: Opportunity for you to pick up the phone, and give the friendly staff at the Cerebral Palsy Society a call for more information about this fantastic programme

Tailor-made: For current financial members with Cerebral palsy

Outings: To increase access into your community

Unprecedented: Voucher system, that subsidises your taxi transport

Teamwork: Spirit & Dedication

Taxis: To getOutThere! - Into the community/ Social interaction

Hailed: Easy – Relax – Call your friendly Taxi Service

Estimated: 270 members are accessing the getOutThere programme – Increasing weekly

Route: By way of Phone OR Computer to our website www.cpsociety.org.nz

Endorsed: “To enhance the lives of people with Cerebral Palsy”

It is rewarding when the CP team pick up the phone and hear:

- ◆ The getOutThere programme has changed my life
- ◆ I save my 6mthly taxi vouchers and go to concerts out of town. I could not afford the fare before, and I love listening to the music.
- ◆ I have become so much more independent.
- ◆ It's great to be able to go to the CP events now – I can use my taxi vouchers to pick me up and drop me back home.
- ◆ The vouchers have reduced family pressure of having to take my son everywhere.
- ◆ It means we can have a relaxed family outing and not have to battle the traffic & parking problems with the van.

It's That Easy – Janet Chapman Members Manager



Clarifying Immigration

The Society touched base with the Minister of Immigration the Hon. Dr Jonathan Coleman who explained policies regarding migrants with disabilities. He stated that the “needs of New Zealanders with disabilities must come first, and immigration policy is framed with this principle in mind.

However all applicants who apply for residence in NZ, or who apply to be in NZ on a temporary basis for twelve months or more, are required to have an acceptable standard of health. This is determined by completing an immigration medical. This assessment covers any needs immigrants may have to access both medical and special education services. And the costs that such needs would impose. People who are determined to be likely to impose significant costs are not considered to be of an acceptable standard of health.

In terms of significant costs to NZ’s health service, a sum of NZ\$25,000 has been set as a benchmark figure. For acute medical conditions, if there is a relatively high probability that the condition or group of conditions, will require health services costing in excess of NZ\$25,000 within a period of 4 years, the person would fail to meet the health requirement. The situation is the same for chronic recurring medical conditions.

In the case of applicants who may impose significant costs on NZ special education services, an applicant who has a condition or group of conditions , which would give them a relatively high



Hon. Dr Jonathan Coleman
Minister of Immigration

probability of requiring Ministry of Education “Ongoing and Reviewing Resourcing Schemes (ORRS) funding would not meet the health requirements.

Where an immigration officer is not satisfied that an applicant is of an acceptable standard of health, the applicant’s medical certificate and associated tests are referred to a medical Assessor or the Ministry of Education, for further examination

.There is a provision in the Refugee Quota programme for up to 75 refugees to be accepted each year for residence in NZ under the Medical/Disabled sub-quota for people with significant medical conditions or disabilities. It is important to note that the partners and children of these people are included within the sub-quota.”



Qualify at your workplace

A nationwide, work based, disability information qualification is now available in New Zealand. The qualification consists of on the job training, so there is no need to go to University or Polytechnic.



Bronwen Foxx, Vice President of the New Zealand Federation of Disability Information Centres, explains

The National Certificate in Community Support Services (Disability Information Provision) (Level 4) is designed for people already working in the health and disability sector as Disability Information Consultants or equivalent, and/or those wishing to pursue a career within the sector.

The role of the Disability Information Consultant is to provide a comprehensive, efficient and friendly information and advocacy service for people with all types of disabilities, their families, care givers, support agencies, health professionals, government and the wider community.

Graduates will either be existing Disability Information Consultants or people who work in the health and disability sector, who provide any form of information to people with disabilities. It would be great for Field Officers as well. People awarded this qualification are able to provide information on disability legislation, specific conditions, transport, education, finance, employment, social and recreational activities; and advice and support that empowers individuals and promotes choice.

Basically there are workbooks that people complete and have assessed. These workbooks are based on the work that they do daily. The assessment activities include knowledge-based tasks and workplace verification tasks. Together these tasks confirm a trainee's competency in practical tasks, underpinning knowledge, understanding of policies and procedures, and application of learning to the job.

Work places are required to provide their trainees with copies of some of their policies and procedures to make the learning specific to the organisation. The New Zealand Federation of Disability Information Centres NZFDIC will assist workplaces to identify the required policies and procedures. The NZFDIC is supporting the learning through its regional meetings, and is providing training opportunities nationally. Courses have already started, but people can enrol any time they like.

For further information contact

Bronwen Foxx
Disabilities Resource Centre Trust
PO Box 528
WHAKATANE
Telephone: 07 3071447
Email: bronwenn@drct.co.nz



Sallyjane Cranfield
Disability Information
Service (Otago)
Community House
283 Moray Place
Dunedin
Telephone: 03 471 6152
Email: Sj.dis.dn@xtra.co.nz



Sporty options in Christchurch



ParaFed Canterbury is a sport and recreation organization supporting individuals with a physical disability in the wider Canterbury region since 1967.

ParaFed offers a wide variety of sport and recreation opportunities including:

- ◆ Accessible Gymnasium
- ◆ Sports Training Groups – athletics, boccia, shooting, swimming & table tennis
- ◆ Junior Sports Club After School Program
- ◆ Regional and National Competitions
- ◆ Sports Equipment for loan
- ◆ Recreational Swimming sessions at Hydrotherapy pool
- ◆ Taxi Vouchers
- ◆ Arts Programme
- ◆ Sports Development Clinics & Open Days
- ◆ Wheelchair Rugby & Wheelchair Basketball



We have members with a huge variety of disabilities including members with cerebral palsy, spina bifida, spinal cord injuries, head injuries, amputees, visual impairments, just to name a few.

Of particular interest to readers of the CP Society Review may be:

Junior Sports Club

An after school program run on a Wednesday afternoon for children aged 5 – 16 years with disabilities. This is an opportunity to try out a variety of sports and recreation opportunities in a safe and supported environment. Approximately 65% of the children who attend have cerebral palsy.

Athletics Training Group

ParaFed runs an athletics group on a Tuesday afternoon from 5 – 6pm. Members attend this running group attend for a variety of reasons from fitness, social to those whose goals are more competitive. This group is coached by another ParaFed member who has a disability and is also a competitive runner. As a side note all of our runners in this group have cerebral palsy.

ParaFed Boccia Club

ParaFed Canterbury runs the only boccia club in Canterbury. We have a wide variety of members ranging from Paralympians, Kerri Bonner, Jeremy Morris & Greig Jackson, through to novice children. We train at the Burwood Hospital Gym on Saturday mornings.

Recreational Swimming

ParaFed runs two sessions at the Burwood Hydrotherapy pool each week – Sunday 1.00 – 2.30pm and Wednesday 4.30 – 6.30pm. The Hydrotherapy Pool is heated to 35°C and is fully accessible with entry ramp, wet chairs and a pool hoist.

For further information: Phone 03-3854449 or Email - info@parafedcanterbury.co.nz



Leadership Defined



"It doesn't appear so, as we are still forcing people to live together in groups of 4 - 5 in community houses," lamented Marguerite

Ava stated that his needs, connected to his blindness, can be met by serving the community. He hopes his presence in South Auckland, persuades the youth of his community to stop thinking "it's too difficult" and start believing that they can improve their own situation.

Strong, positive views and lively debate vibrated off the walls and into the thoughts of people attending the second session of the Disability Leadership forum series, entitled "Stepping Up," held at Auckland's Western Springs Garden Community Hall, on August 11th

A panel of four started off proceedings with the task of exploring the theme; what does leadership mean to us? The quartet were Huhana Hickey from Auckland Disability Law, Philip Patston from Diversity Works, Ava Fa'amoe, Chairperson of the Otara Community board and Marguerite Vanderkolk from IHC.

Huhana spoke at length on how hard it was to obtain employment and the need for voices who are not afraid to step forward. Philip spoke of the need to dream positively about what the future could look like.

Marguerite asked the question why are we so tolerant of the status quo. Has the revolution started yet?

All four panellists were adamant that we all have the ability to lead. A superb example was given of American Rosa Parks who, in the year 1955, refused to give up her seat to make room for a white passenger and thus became an important symbol of the modern Civil Rights Movement. Rosa led by her defiant act, a simplistic act that changed the course of history.

As stated on the Cerebral Palsy website, after the three part, stage 1 forums in Auckland, participants will nominate up to 25 people from the wider group to represent their interests. Those nominated will go forward to contribute to the development of a strategy and plan that provides a guide for ongoing leadership development. The outcome will be a plan that guides the actions of those who are committed to work together, to make effective leadership a reality.

Ross Flood



Tribute to Erzsi – Parents and CE

Erzsi came to New Zealand in 1993 with her husband and two daughters. She was one of the first Conductors to arrive and dedicate her life to building up the Focus Conductive Education Centre to what it is today.

Her never ending belief, passion and love for the children and families was outstanding. She described CE as being “the essence of my being” and for those of us who were lucky enough to know her, know that this is true. She always had such a positive energy and belief that our children could achieve anything with creativity, motivation and support. “Ask them to reach for the moon and they will hit the stars. They are amazing,” Erzsi said.

Erzsi was a huge role model for the CE team and she had the ability and vision to turn any situation into a positive learning opportunity. She believed that almost anything was possible. Erzsi was not just a great colleague, she was a caring friend and to some of us she was our family in New Zealand.

We are all so thankful for those years that we knew Erzsi and the great knowledge and wisdom that she shared with us. Although we have had to say goodbye she will be with us and will be living in our hearts forever.

Erzsi's funeral was held on Friday 14th August 2009. It was a touching service that brought together family, close friends, colleagues and parents – everyone who had been touched by Erzsi and the special person that she was. It is hoped that a memorial tree or plaque



can be arranged to celebrate Erzsi's life and her dedication to the children and families at CE.

By Renata Gyimesi (close friend and Senior Conductor) and Tracy Wadsworth (parent)

New Zealand Boccia 13th National Championships

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...a detailed online directory highlighting accessible accommodation in New Zealand including luxury hotels, motor inns, boutique homestays, holiday parks and back-packers.



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Accommodation website a hit

"Well done, Lianne and Peter Kalivati, for getting the accomobility.co.nz website together. I've been in a wheelchair for 18½ years and travel regularly in NZ and overseas. I'll let you know of any other places I come across that can accommodate people in wheelchairs."

Above is one of the many complimentary emails received by the "Accomobility Team" after the launch of their website, which is a comprehensive guide to accessible accommodation in New Zealand.

The website, expertly designed by Richard Laing and Lynda Beckham, is proving to be increasingly popular, registering 1051 visits in June.

The main feature is the "Search NZ" section where nineteen regions throughout the country are put to the accessibility test. Each accommodation site is well documented detailing such things as parking for the disabled, the accessibility of the shower area and whether or not travellers can check in early and check out late by arrangement. The bathroom/shower coverage is particularly impressive, as it includes valuable information, like is there space for a commode chair on both sides of the cistern and whether or not there is a lip or step into the shower.

The "Accomobility" site grew out of holiday frustrations after Peter Kalivati was diagnosed with motor neuron disease, in November 2006.

"We came across many obstacles when we wanted to take a break away from home," said Lianne Kalivati, who is a learning and behavioural resource teacher by profession.

On one occasion Peter was booked into a motel in Palmerston North which was advertised as being accessible, she said. "Peter was not able to take his wheelchair inside the motel unit because it was too small. On another occasion we visited a motel in Hamilton which had a portable ramp. This was dragged to the front door of the unit, but the gradient was so steep, and the front door so narrow, Peter was not able to bring his chair inside the unit.

The "Accomobility Team" are endeavouring to assign these, all too familiar examples to yesteryear. Judging by the website's popularity they are winning the battle.

Go on, check it out www.accomobility.co.nz

