

EDITORIAL

From Lindy Woollams



Long Bay, was the serene venue for the annual retreat

On a beautiful Sunday in May, I met with the Intractable Epilepsy Support Group, at their annual retreat at Long Bay. At this meeting, a hot topic was the shortage of funding for incontinence products, such as nappies and pads. For Wendy, the parent of a thirteen year-old boy with very high needs, the allowance of just two nappies per day is not enough. A letter from the Associate Minister of Health, Pete Hodgson, informed Wendy that the nappies are designed to hold a litre of fluid, and therefore two per day is sufficient. If a child is toileted, and the nappy or pad is damp or has been soiled, it must be reused until saturated to full capacity. The problems are obvious. The weight of the full nappy must be very uncomfortable, not to mention the smell and the inevitable rashes and burning. In order to save her son the embarrassment, loss of dignity and discomfort of sitting in a sodden nappy all day, Wendy works part-time to fund the extra nappies for her son. This extra cost to the family is \$102.00 per week.

Parents at the retreat spoke of their exhaustion in dealing with so many professionals, the needs of their disabled children and meeting expectations in their jobs and family lives. As a parent of four, Wendy commented, "I'm battle-weary, too weary to fight for every single thing I need". A fairer system surely, would be to assess the needs of each person for incontinence products, rather than a blanket amount for all.

The New Zealand Disability Strategy has a stated vision of a fully inclusive society, "... in partnership with Government, communities and support agencies, based on respect and equality". The practice of spending the day in a full nappy would do little to promote inclusion and equality for teenagers at school. We wondered how many MP's would be happy with this arrangement for themselves, or for their own children? Toileting is surely a basic human function, which cannot be limited or governed from on high.

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they can move directly from the Workforce Personnel Transition Programme into the Supported Employment Programme with the consultants who know them and their aspirations. But only ORRS funded students can access the Transition service, a situation that Barbara Woodman at Workforce Personnel would like to see changed because it "cuts out a huge group of young people wanting to use our service".

Mt Roskill Grammar, which encompasses the MacLean Centre. Lorraine Vickery has seen great benefits from the programme and is now convinced there "needs to be better inter-agency collaboration" across the sector. She describes transition as an area that is constantly changing and fraught with communication and networking difficulties. Along with others, Lorraine Vickery believes there "aren't enough choices out there", which is the result of clumsy systems together with inadequate funding.

The desirable outcome is that young people with a disability are able to make their own choices and that there are real choices on offer. "Inclusion is including choice", says Diane Willcox. Likewise, the New Zealand Disability Strategy talks of integration where "equal opportunities are assured but individual choices are available and respected". The achievement of this vision will always be clearest during the young person's first steps out of school.

"Although we might not all look alike or speak alike we all share the same emotions of love, happiness, sadness and sometimes fear — and the same desire to have a fulfilling place in society." Melinda Smith, "In A Wheelchair, So What?" 1982

EVENTS

MANY FACES OF ABUSE CONFERENCE 10 - 12 AUGUST

Advancing understanding of the presence, nature and impact of abuse in care environments, which can be experienced by disabled people, older people, children and families. More information: www.imaginebetter.co.nz

Disclaimer

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Share your news

Send us your news and views, conference / meeting dates and reports, successes and suggestions, your child's or your own artwork or poetry. Celebrate your world by sharing it with others in the PFRC Networker. Just contact us at the Centre.

PARENT & FAMILY RESOURCE CENTRE SEMINAR 6th JULY

"NAVIGATING THROUGH THE EDUCATION SYSTEM" Guest speakers include representatives from GSE, YouthLaw, IHC (Sue McKinnon) as well as parents relating their own experiences. Venue: DRC, 14 Erson Ave, Royal Oak. Sessions: 10:00am - 12:30pm & 6:30pm - 9:00pm. Contact PFRC for more information and free registration: 636-0351 or e-mail welcometo@parentandfamily.org.nz

MUSIC THERAPY RESEARCH: APPLICATIONS & INFORMATION

MUSIC THERAPY RESEARCH: Applications and Information. 15th July 9-3pm Kohia Centre, Epsom Ave. Cost \$80, \$50 students. Contact Kathryn Stevenson 579-4369 kathrynmusic@hotmail.com

NEXT ISSUE: Sexuality & Disability: Puberty to Parenthood

AUSTRALASIAN SOCIETY FOR THE STUDY OF INTELLECTUAL DISABILITY CONFERENCE 2005 10 - 13 OCTOBER

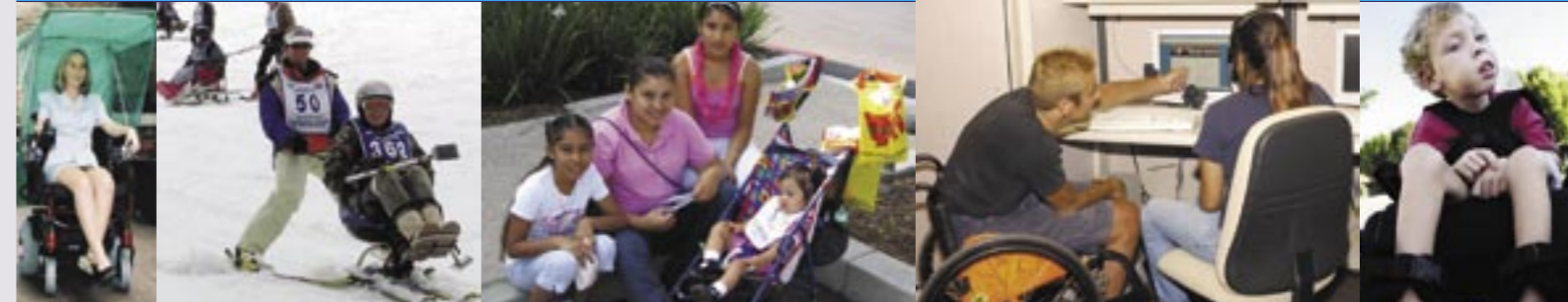
AUCKLAND. The New Zealand Branch of the Society is hosting its 40th annual conference at the Waipuna Hotel and Conference Centre in Mt Wellington, Auckland. Conference theme: "Out of the Ordinary? Creativity, co-operation, collaboration". For more information visit: <http://www.assid-conf05.org.nz>

AUTISM NEW ZEALAND CONFERENCE SUNDAY 14 AUGUST

8am - 4:45pm. Waipuna Lodge Conference Centre, 58 Waipuna Rd, Mt Wellington. For more information phone 276-8790 or e-mail autism_auck@xtra.co.nz



NETWORKER



THIS ISSUE

- ★ PFRC Online
- ★ EDITORIAL Comment
- ★ INSPIRATIONAL Interviews

★ TRANSITION What are the options after schooling?

PFRC Online

The Parent and Family Resource Centre's new website is up and running and it is bigger, brighter and better.

Our goal for our website is to provide accessible, up-to-date information for parents and families - the redesign makes it easier to navigate around the site.

Several additional features have been included:

- ★ a revamped service providers contact list which is divided into sections relating to health, education, mobility/motor skills, family support and recreation support;
- ★ a dedicated links section for children and youth which will catch their imagination while providing safe, useful information;
- ★ a new page called Research/Resources includes submissions written, relevant research (see collated results of 16+ survey), book reviews, and interesting articles;
- ★ information about entitlements; and
- ★ an extended links page.

Information about support groups and the current Networker and its past issues continue to be available online.

The next step is to introduce a forum page where you can dialogue with PFRC staff and others on any issue.

We would welcome your feedback. In the meantime, good searching.

Barbara Glenie, Centre Manager



Lindy Tammy Barbara Susan Denise

TRANSITION

What are the options after schooling? Tammy Ewing reporting

"What do you want to be when you grow up?"

Everyone has been asked this question and has asked it of someone else. Everyone has given and listened to ludicrous yet earnest answers. The parent laughs, delighting in their child's dream that is reassuringly wrapped by a myriad of possibilities. The parent of a child with a disability laughs too, but a laughter snagged by uncertainty and grief for a fragile dream.

However Barbara Woodman, Deputy Manager and Co-ordinator of Transition at Workforce Personnel (a supported employment agency), observes that these are characteristics found across society:

"Young people are more idealistic, unrealistic and often very unaware of the real world of work. The older people on our main roll have often never had a job or have really struggled so they are more realistic of what they can do; more committed to making it work; more appreciative of opportunities; less inclined to refuse an offer of work. The young people need to be gently guided through the 'growing up' process."

Alongside a young person's expectations are a parent's expectations. The age of the parent is a strong indicator of expectations.

School's Out. What now?

"The dignity to risk, the right to failure" reads a banner in the entrance foyer of the MacLean Centre at Mt Roskill Grammar. Currently there are eight pupils in the Transition Class, aged between 19 and 21 years. In their final two years at the Centre students in this class are led through a process of defining who they are, including their dreams and their fears using a visual mapping technique, such as MAP (Making Action Plans). Students will also undertake work or community experience in placements of their own choice. From this "students come away with a clearer idea of their limitations and abilities," says manager Lorraine Vickery. "They go through accepting their disability and coming to terms with it. Everyone reacts to it differently."

For example, Carmel Henry, Director at Renaissance, says that supported independent living is still a new thing in Auckland. "All older parents know is residential options", she says. "It's a big thing to break down." Similarly Lorraine Vickery has found that parental expectations during the transition time vary. "Some are overly protective, some have overly high expectations, some are grateful for anything. It's scary for parents at this time".

One trend that Neil Denney, Service Manager at Renaissance (a supported independent living agency), has observed is that younger people with disabilities are leaving school with higher expectations for the future. Marie Murphy, a social worker at Disabled Citizens (a sheltered workshop) agrees, saying that, "younger people are more extroverted and have had better experiences in society. Older people are quieter."

Expectations reflect and drive government strategies. Objective Four of the 2001 New Zealand Disability Strategy states: "Provide opportunities in



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inspirational interview



LOOKED UP TO AS A LEADER

Gary Sefton (43 years) enjoys helping other people, saying he "treats people as they are". He has been at Disabled Citizens, a sheltered workshop, for four years and is considered a leader by his workmates.

Gary was just 15 when he left school to begin a fragmented work-life. Gary describes a long-held job at Corbans, then says he spent two years with Workforce doing tasks such as stamping plastic lids. He then worked at another workshop for a while, before entering a period of no employment. But ever since his foster family found him the position at Disabled Citizens Gary has not looked back.

WHAT IS THE BEST PART OF YOUR JOB?
"Lovely people, lovely manager who doesn't put people down". Gary spends most mornings mowing lawns and the afternoons working in the workshop.

TELL US ABOUT THE CHALLENGING BITS
"Waking up in the morning!" Gary laughs before becoming serious. "Reading and writing. If they asked me to do it, I couldn't do it."

HOW DO YOU GET ALONG WITH YOUR COLLEAGUES?
"They call me the Trouble-maker - I like to stir things around" Gary jokes. "I like to help others out - I can get along with anyone." Gary says he is comfortable mixing with people with different disabilities.

IS THERE ANYTHING THAT WOULD IMPROVE YOUR ABILITY AND ENJOYMENT IN YOUR JOB?
"I enjoy it here. I don't want to go home - I want to keep on working." Gary has received a lot of support: "If it wasn't for Marie and Christine [staff] I wouldn't be where I am now. Money's not everything to me - I live day by day. I wouldn't work in a factory. I've been put down heaps of times."

WHAT ELSE WOULD YOU LIKE TO DO IN THE FUTURE?
Gary is currently involved in Ten Pin bowling for the Special Olympics.

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Transition: The options after schooling
employment and economic development for disabled people". This employment-focused objective is complemented with lifestyle-focused objectives. Namely, Objective Eight states: "Support quality living in the community for disabled people" and Objective Nine states: "Support lifestyle choices, recreation and culture for disabled people".

Such objectives are essentially about promoting independence and participation by disabled people. This is reinforced by the vision of the 2001 document *Pathways to Inclusion* which calls for, "a society that values the lives of people with disabilities and enhances their full participation in society" both in employment and in the community. "Community participation is only recently an acceptable outcome," explains Lorraine Vickery, saying that previously the government supported and promoted only work or training outcomes.

Pathways to Inclusion clearly delineates between its key aims of vocational services: 1) *Increase participation in the community;* and 2) *Increase participation in employment.* This has left sheltered workshops in the untenable position of being a hybrid that doesn't meet either criterion, particularly in terms of fair employment. *Pathways to Inclusion* states "the Disabled Persons Employment Promotion Act treats people with disabilities unfairly by giving sheltered workshops a blanket exemption from minimum wage and holidays legislation".

The recent repeal of this Act took place amidst a contentious consultation process and arguably scaremongering predictions of closure by some workshops. It was claimed that the repeal would effectively withdraw an option for disabled people without providing an acceptable alternative. But for Disabled Citizens the repeal meant a simple move from having blanket exemption to requiring individual exemptions. The Labour Department took six weeks to review the 70 employees. "It was done easily and nicely", says Marie Murphy. "A breeze."

Like many, Marie Murphy winces at the term "sheltered workshop", instead preferring "unique workplace". She points out that in terms of community participation a sheltered workshop is no more insular or confining than typical 9am-5pm workplaces. "Here it is just a peaceful protected environment. They love it. This is their dignity, integrity, normality."

Disabled Citizens began in 1943 to cater for psychologically and physically disabled men returning from the war. Now it provides a variety of ever-changing tasks, such as the current contract to sort and bundle 2.6 million coffee sachets. Every employee has a reviewable work-plan and is given some choice in their rostered tasks. When asked if some jobs could be considered boring or demeaning, Marie Murphy challenges the question as an able-bodied prejudice. "If it can occupy them we'll do it. Work is work for them."

A "glorious wish-list" is how Marie Murphy describes *Pathways to Inclusion* and is convinced there will always

be a need for sheltered workshops. "How do you put some people into the community?" she demands, giving examples of people who have returned to Disabled Citizens after disastrous experiences in regular employment, including verbal abuse, ostracization and theft of wages. However she does acknowledge that, "disability is evolving" and credits current government strategies that "keep us moving forward".

Independence in terms of choice in employment and community participation is what most people take for granted. This is the premise behind the 2003 report *To Have an Ordinary Life*. "Ordinary" is used in the sense of being reflective of the aspirations of adults with an intellectual disability to access the everyday things that others take for granted, such as "being given opportunities to grow, learn and develop throughout life, and being valued by others for what they have to offer". Its priorities for action include moving away from historical models and current policies that are "custodial and constrictive" and actively moving toward community membership and long-term support centred on the individual.

The services of Renaissance are reflective of their embrace of these government reports and strategies, which Carmel Henry describes as realistic and key guiding documents. "Everything we do is measured against the New Zealand Disability Strategy, particularly in terms of promoting choice." Promotional information from Renaissance asserts a vision "to promote equity for choice, independence and participation with disabled people" and a core philosophy of empowerment and inclusiveness.

Renaissance is funded to assist people with low to medium disabilities into supported independent living, "as long as that person makes that choice" qualifies Neil Denney. When a referral is received from a NASC agency a Renaissance coordinator will meet with the person in their home and formulate an Independent Living Plan that takes into account the holistic needs of the person. With NASC approval and funding, the coordinator and a community support worker will support the ongoing goals of the person, through means such as providing budget coaching, transport training and assistance to find employment and accommodation.

"Independent supported living is still a new thing to Auckland. But it's the way of the future", says Carmel Henry, adding that it has been difficult breaking down an entrenched mindset. Renaissance has just celebrated its fourth birthday and was the first organisation in Auckland to receive a contract to provide this service.

With funding Renaissance would be eager to assist a wider range of disabled people, even those with high needs. "We say there's no one who can't live independently with appropriate support," says Neil Denney. To the suggestion that at some point supports might undermine independence, Carmel Henry is quick to interject: "Supports are there to support the independence", she clarifies. "Independence is about choice, for example the who, when, where... how you spend your money etc."



It follows that the independence of the person with the disability impacts on the independence of their parents. A child's impending adulthood is ideally viewed as a time of change, a time when the parent can become less of a 'carer' and indulge in more self-care. But for some parents nothing changes.

Diane Wilcox, owner of Ashley Cottage, (a small semi-rural respite facility for 16-65 year-olds), meets lots of parents whose lives have changed little since their children left school. Respite days continue as before, becoming even more necessary as parents age. It is not uncommon for parents aged in their 70's and 80's to still be primary caregivers while battling their own age-related illnesses and disabilities. These parents want their children to "have a normal life and have safe experiences", says Diane Wilcox. At the same time she is critical of policies that seemingly imply that everyone is capable of holding down a job, adding that parents say they want "honesty, not flowery words and empty promises".

The lack of government-funded options for young people with high or very high needs, suggest that the government is either naively optimistic about the capabilities of some disabled people or has an economic interest in mainstreaming. Lorraine Vickery struggles to think of the scant options available to young people with very high needs: Creative Abilities, Ranfurly Care, Care Homes Trust and Focus 2000.

Disillusioned from seeing so many young people leave their school with few options, Somerville Special School has just opened the Maurice Paykel Centre to provide a programme for school leavers. Joy Bates, Secretary of the Somerville School Board of Trustees explains the situation simply: "We had students at Somerville having nowhere to go", with little else to do but sit at home with no stimulation and the parents unable to keep going to work.

Joy Bates acknowledges they "have been lucky with

money from private trusts", which has enabled this venture. The purpose-built centre is located in the school grounds on land rented under a 10 year lease. The Maurice Paykel Centre only caters to those with ORRS funding for Very High needs. Even so, the ORRS funding is not enough to cover the costs of the programme, particularly with the need for a high staff:young person ratio.

Currently there are just six young people in the programme (which runs from 8:30-3:30, 48 weeks of the year) but there is room for 15. There is no age limit - "they can be there forever", says Joy Bates. Under this funding stream from the Ministry of Social Development programmes have to be life-skills based and will include cooking, socialising and bringing the community to the Maurice Paykel Centre when it is not practical to make excursions. In terms of achieving the community participation aims of government strategies, "all you can really do is have enough staff to take people out", says Joy Bates.

Currently the Centre is mindful of ensuring new applicants to the Centre will fit in with the existing group and that there is a balance of different of disabilities. "Parents are pretty enthusiastic", says a buoyant Joy Bates. She has had enquiries about the Centre from other schools and is happy to share resources in the hope that other schools will be able to establish a similar scheme.

For people with a low-medium disability at the other end of the continuum, there are far more choices in terms of employment and community participation. Tertiary training is one such option for school leavers, with a 2002 survey finding that 4.5% of tertiary students had a disability.

Financial assistance can be obtained through Work and Income NZ (WINZ). Here students on an Invalid's Benefit

can apply for a Training Incentive Allowance, a maximum of \$3,420 to put towards course fees and associated costs.

These days it would be difficult to find a tertiary institution that did not have a Disability Office and courses tailored to people with a disability. At Unitec a student with a disability can access support services including note-takers, sign language interpreters and textbook taping. Wendy Russell, Disability Manager, acknowledges that most students with a disability have come from a mainstreaming school situation. However Unitec also has courses targeted to students with an intellectual disability, such as the Certificate in Employment and Community Skills.

Tertiary institutions can use their own discretion to admit students who may not otherwise meet the criteria. Wendy Russell gives the example of a man with cerebral palsy who has been attending Unitec for 11 years doing one paper a semester: "He will never be able to use it but it's a means for him to get out and meet people. He doesn't want to go into a sheltered workshop; he wants to be with able-bodied people".

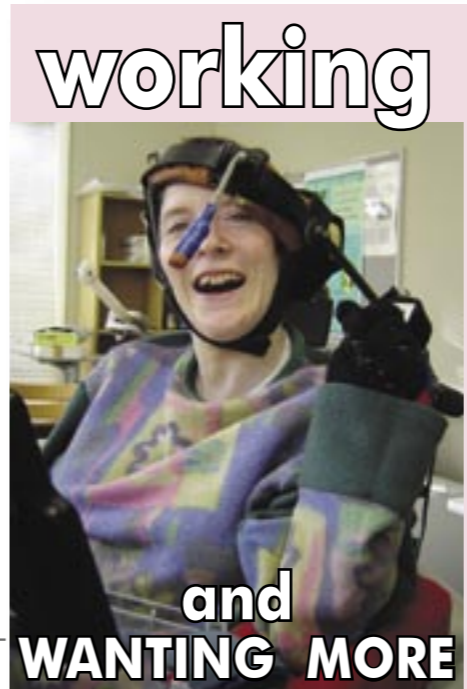
Assistance for school leavers with a disability extends beyond education into employment. Supported employment agencies, such as Workforce Personnel, provide a free service, which includes career planning, job search, an on-site job coach and regular support visits if necessary. As an incentive for employers there is the possibility of a WINZ Job Plus subsidy, which subsidizes the employee's wages for a specified time to mitigate any extra costs incurred, such as extra training.

Currently Workforce Personnel is engaging in a pilot project of a Transition from School Programme that they first ran nine years ago. They are working with ten schools across Auckland. Referrals for the Transition Programme come from the students via the school. An advantage for the young person is that

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"Independent supported living is the way of the future."



inspirational interview

Before I meet with Mandy Slade (24 years) I have heard all about her. "Everyone knows Mandy", people say. She is described as a computer whiz and held up as a success story for what can be achieved despite having severe cerebral palsy.

Mandy was 21 when she finished her schooling at the MacLean Centre. Since then she has tried her hand at a course at Unitec, worked at Carlson School and for the last two years has been working at Talklink as a Speech Therapist Assistant and creating communication books.

WHAT IS THE BEST PART OF YOUR JOB?
"Communication days, once a term". On these days clients of Talklink get together to discuss their communication needs and equipment.

WHAT IS CHALLENGING IN YOUR JOB?
"Nothing"

HOW DO YOU GET ALONG WITH THE

OTHERS AT YOUR WORK?
"Well". Mandy agrees that she is viewed as a role model.

IS THERE ANYTHING THAT WOULD IMPROVE YOUR ABILITY AND ENJOYMENT IN YOUR JOB?
"More money and more hours." Mandy's hours have recently been reduced due to her wage subsidy from WINZ being discontinued.

WHAT ELSE WOULD YOU LIKE TO DO IN THE FUTURE?
"Play Boccia" which Mandy has just started. She would also like to do more study, not with computers, but instead English or Maths. Currently Mandy lives at home and, because there are no other options, goes into respite care in a rest home. She would like to live independently in a flatting situation but has reservations about the quality and reliability of home help she would receive.