

**Barbara asks:
Is ideology always in
sync with reality?**

The recent media hype about the future of sheltered workshops has done little to alleviate people's fears.

Parliament is currently considering the repeal of the Disabled Persons Employment Promotions Act. This Act has in the past given workshops a blanket exemption from paying the minimum wage, annual leave, holiday pay, sick pay or special leave. Many will argue that this is a breach of basic human rights.

What has not been widely published is that if the

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**RESPITE: The Stress on
Options to support Families**

The NZ Disability Strategy is underpinned by a vision of a fully inclusive society – a place where people with impairments can say they live: "A society that highly values our lives and continually enhances our full participation". However Heather Grace and Gillian Wright feel that the word "inclusion" is bandied about too easily and isn't always helpful in the day-to-day reality of looking after older children and young adults who have severe disabilities and very complex care needs.

An emerging philosophy is that seamless, quality care in the home is a better aspiration for both caregiver and the disabled person than periodic, brief experiences in a respite facility. While CCS is convinced this can work in most cases, some parents have reservations. Gillian Wright and Heather Grace are adamant they need more than carer support in the home. "Carer

Act is repealed it will not mean that everyone will be entitled to the minimum wage – but rather it will mean that people will get a fair assessment of their working capacity in view of whether they should be paid the minimum wage or not.

According to Hon Ruth Dyson, if people are not working, but are doing vocational activities or hobbies, the change in legislation will make no difference to them. If they are working but are unable to perform the full requirements of their job, they can apply for a minimum wage exemption.

On the face of it this all seems fairly reasonable. However, it will be interesting to see what effect, if any, this potential legislative change will have on: the financial viability of sheltered workshops across the board; the need for them to be more

support in the home is helpful but it cannot be considered respite or a real break from the day-to-day caring," says Gillian. "In-home respite would mean that I would have to go away to get a break, and I usually like to stay home during these times." Judi Strachan at Spectrum Care says, "going to any one model is not a good idea because not everyone wants the same – it works differently for different people".

Auckland has its own unique issues concerning respite care. There is little acknowledgement of its greater population and higher living costs, which places pressure on the family to have both parents working. The vast sprawl of Auckland also means that travel to services, such as a respite facility, is of concern to families. Currently there are people traveling from West Auckland to Creative Abilities on the North Shore!

Parents have been telling PFRC they want respite care that -

- ★ is flexible
- ★ has a range of options

commercial when tendering; the nature of the work they are prepared to undertake; the clients they are prepared to accept; their continuing willingness to run varying ability streams within the one facility, etc.

It is well known that workshops provide social interaction and structure, as well as building self-esteem for many cognitively impaired people, while also providing respite for their parents and families. For these people workshops are a valued part of their daily lives. It is to be hoped that the repeal of the Act does not disadvantage these people.

While the legislation, if passed, will not come into effect until 1 July 2007 PFRC is taking a real interest in this issue and would welcome your comments.

- ★ can be taken at short notice
- ★ and located nearby

Ministry of Health's Director of Disability Services, Geraldine Woods, has said respite care in Auckland is a top priority. "We acknowledge there is a respite problem in Auckland. We have been trying to work that through in the next Budget" (NZ Herald 19/03/05).

Who is the best voice to drive change? There is a concern from parents and respite providers alike that "able-disabled" adults are not always the best representatives for issues affecting children with disabilities. Rather there is agreement that the 'child' is the best voice, and alongside them the voice of their family. Ultimately a child's best support system is their family, which makes society's support of the family absolutely vital. As Heather Grace puts it, "If we break down, who will look after us and the kids?"

NEXT ISSUE: Transition – What are your child's options after schooling?

EVENTS

**NEW SUPPORT GROUP
BRAIN INJURY**

Informal, social and informative meetings for parents of Brain Injured children held on the last Thursday of each month at Headway House, 17 Kipling Ave, Epsom. Contact Alison: 482-3156 025-923-557 alison@brain-injury.co.nz

**DISCO FOR YOUTH WITH
DISABILITIES
Saturday 14th May**

Kelston Community Centre
For more information contact Jo-Anne Inanasi leisure Planner at Waitakere City Council Ph 836-8000 ext. 8558

**ACORN HOUSE WORKSHOPS
FOR ASD KIDS**

Acorn House is a support group for parents who want to use Photographic Learning and Communication Strategies (P.L.A.C.S.) with their ASD child.

Module 2

Introductory Workshop 1: 7 July 9:30--:30
Introductory Workshop 2: 28 July 9:30--1:30
Fencible Lounge, Uxbridge Rd Howick
Contact Bronwyn Julian 273-7221
www.acornhouse.org.nz

**TURNER SYNDROME SEMINAR
One day seminar**

Saturday 21st May, Hamilton
Speakers include an endocrinologist, a gynaecologist, paediatric endocrinologist and audiologist. For more information contact: Lee or Emma 07 846 4862 leandemma@paradise.net.nz

SENSATIONAL SIBLINGS

This is a support group for 8 -13 year olds who have a sibling with a disability which meets on the second Friday of each month in Takapuna 6 -8pm. Free, fun and varied activities, such as **Siblings Idol, drama night and obstacle races.**

Contact Julie at DINS 488-0210 or e-mail dis_help@xtra.co.nz

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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.



NETWORKER



THIS ISSUE RESPIRE

★ The stress on options to support families
★ EDITORIAL: PFRC's Position on the Disabled Persons Employment Promotions Act

IT'S ELECTION YEAR

It's election year and the team at PFRC have been very busy mobilising your issues through political forums, submissions and engagement with the community.

Barbara, Centre Manager, attended the recent Caring for the Carers Summit in Wellington, which was attended by approximately 300 carers covering a wide spectrum of situations. The Hon. Ruth Dyson and the Hon. Pete Hodgson in opening the conference, acknowledged the number of carers in New Zealand and the important contribution they make to the national economy. They spoke of:

- ★ the Government's goal to have a fully inclusive society and its achievements to date
- ★ the need to do more to fulfill Objective 15

of the Disability Strategy
★ the importance of the recently formed National Carers Alliance as a vehicle for providing a unified voice for carers, as well as networking and training

The summit provided a valuable networking opportunity and a chance to share some very real life experiences. We look forward to a future Summit harnessing the energy to plan for the future.

PFRC recently prepared a submission relating to the discussion document: Ageing New Zealand and Health and Disability Services: Demand Projections and Workforce Implications 2001 – 2021. Key points made were that:

- ★ the Discussion document makes no distinction between individuals with a life-long disability or those with later-onset or age-related disability

- ★ there are existing difficulties accessing support services, particularly for personal care support, carer support, or respite care
- ★ depression can be a common occurrence for disabled persons and also for their carers which is not well recognized or understood by the community

Currently we are beginning talks with political parties about issues concerning families with children with a disability or special needs. Please contact us if you have specific issues or questions that you would like us to communicate in our discussions.



RESPITE The Stress on Options to Support Families

"I was asked why I wanted respite care for my son!" exclaims Heather Grace.

"Why!" She shakes her head looking like she doesn't know whether to laugh or be outraged, incensed that this question was asked by a NASC agency. Heather's son Brendon (22) faces going into a rest home because of the lack of appropriate respite options in Auckland. For Heather, real respite means out-of-home, overnight care for Brendon.

"Improve the support and choices for those who support disabled people," states Objective 15.2 of the 2001 New Zealand Disability Strategy. This objective was followed by a blank space in the 2004 Progress Report for the NZ Disability Strategy. The neglect of this area is astonishing considering that it was as

far back as 2000 that New Zealand's report to the United Nations on the Rights of the Child stated that family caregivers of disabled people lacked information about available government services and had difficulties accessing services. Furthermore the Hon. Ruth Dyson, Minister for Disability Issues, has been speaking for at least five years about the appalling gaps in services for people with disabilities and maintaining that respite is one of her highest priorities.

The Needs Assessment process through NASC agencies may well produce the documentation for a reassuring package of support but frequently keels over in the implementation of service provision. The 2001 Disability

Survey found that nearly one fifth of parents or caregivers of disabled children reported needing respite care or carer support in the previous 12 months, with nearly half reporting that they had been unable to access this care. Little had changed in the unmet need for respite care since the 1996 survey.

More recently the 2004 Service User Survey of Disability Support Services by the Ministry of Health found that many users felt that the amount of respite was inadequate, it was difficult to get information on entitlements and there was an inconsistency of allocation. Users of disability services recommended "client-centred and flexible services". *Continued on page 2*

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RESPIRE: The Stress on Options to support Families

The same song is sung by respite providers. Judi Strachan, Service Manager: Child, Youth and Respite at Spectrum Care, says that parents would prefer more flexibility. Likewise Caroline Campbell, Team Leader: Children and Families at CCS, would like the government to "break down restrictive and inflexible funding streams".

At present Spectrum Care, Creative Abilities and the Wilson Centre report that they are full, but not at capacity. What meaning can be drawn from this is unclear because PFRC still hears from parents struggling to access their respite allocation. It is likely that problems lie with the location of respite providers, the ages they accommodate and whether they are appropriate for those with high and complex needs.

A current government initiative seeks to improve the accessibility, seamlessness and equitability of support services. Led by the Office for Disability Issues and in consultation with the disability sector, a cross-sectorial review of long-term disability services is underway. In addition the Disability Services Directorate (DSD) sponsored the Quality and Safety Project to provide advice on improving community and residential disability support services. This was only recently completed and the Government is currently considering the findings and

recommendations.

Respite providers recognise the need for quality support for families with disabled children. "Support families from the start," says Caroline Campbell at CCS. The alternative is clear. 85% of families with a child with a disability are single-parent families, almost always with the mother as primary caregiver. In many other situations a mother will be unable to return to work because of the complications of raising a child with a disability. Lyndsay Rendall, Operations Manager at the Wilson Centre, agrees that the primary responsibility for the care of a disabled child usually falls to the mother.

At the recent Carers Summit in Wellington the Office for Disability Issues stated that a Government objective was to "ensure that family caregivers of disabled people are protected from economic hardship and insecurity arising from their caregiving role" (NZ Herald 21/03/05). One strategy, the high-profile Working for Families package, targets mainstream families in an attempt to lift the rate of participation of women in the workforce. But little has been done specifically to support women with a disabled or special needs child. Two ways of achieving this are: provide flexible, short-notice respite and carer support so that women can ensure they

can work regularly; or recognise that caring for a disabled family member is valued work and pay accordingly.

Heather Grace may have been asked "Why?" but respite providers appear to agree on the purpose of respite. It's a break for both parent and child say CCS, Creative Abilities, Wilson Centre and Spectrum Care. Using respite facilities becomes necessary when family and social networks are not willing or able to ease the stress experienced by a family with a child with a disability. Although

85% of families with a child with a disability are single-parent families, almost always with the mother as primary caregiver

Judi Strachan at Spectrum Care has concerns that a service dependency may develop, she believes parents need to give themselves permission to take a break.

Giving yourself this permission can be more difficult in Pacific and Maori cultures. The Pacific Island Advocacy and Support Service (PIASS), says that for most families respite is viewed as something that is absorbed within the immediate and extended family. In the Pacific culture there is a stigma attached to putting one's children



An artist's impression of respite or relief

into respite care. Although nobody may actively point the finger, parents are likely to feel the pressure of being the focus of gossip and judgement.

For CCS it is important to give a family intensive support in the first few years of a child's life. "For many families access to early and intensive support in the first five years would greatly reduce the burn out and high stress which results in high use of services later," says Caroline Campbell. "Residential respite is a valid choice for some families and there are respite providers who have great expertise in this area but CCS focuses on working with families on developing a range of sustainable community options." Currently CCS is working with the Ministry of Social Development to develop a national strategic project with the aim of providing a more intensive early intervention support delivery model for children with disabilities and their families.

Respite providers have varying views on what the respite experience should be like for the person with the disability. For the disabled people it's about having a holiday; "a space for themselves," says Liz Soper. CCS instead emphasizes the need for a family focus with typical family activities. However all agree on the importance of ensuring that a child does not feel that he/she has done anything wrong and is being sent away.

The value a child takes from the respite experience depends on the quality of the care and the approach taken. Stanaway Hideaway was originally set up in 2002 to fill a need for respite for people with physical impairments. "Now because of parents' crises we have ended up doing what we don't agree with," says Liz Soper, which is mixing people with physical and intellectual disabilities together. Rather,

"needs need to be met individually" says Liz, who has been vigorously campaigning with this message. She is thrilled that they have been successful at last - Creative Abilities has just received a new respite house through the North Shore Housing Trust that will focus on high and complex needs for all ages.

Similarly Gillian Wright and Heather Grace express concern about the mixing of people with different abilities. But instead they view disability along a continuum from the severely disabled to the able-disabled. In a respite situation they don't think their children should necessarily mix with their able-bodied peers.

"For many families access to early and intensive support in the first five years would greatly reduce the burn out and high stress which results in high use of services later"

"It's not realistic," says Gillian. "They have a right to be with people like themselves. Don't force an artificial situation." Similarly Liz Soper talks of the importance of being with "people who understand them".

In contrast Caroline Campbell at CCS, believes that disabled children should experience respite in a family situation, in preference to mixing with a narrow definition of 'peers'. "They're children," agrees Lyndsay Rendall, at the same time acknowledging that there are difficulties in coordinating a respite experience that meets the wide range of needs.

Engaging with 'like' people has benefits, but how alike should a peer group be in a respite situation? More importantly, does it support the notion of inclusion that permeates national strategies?

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A Mother's Day....

For mothers who have a child with a disability, social contacts usually gradually withdraw, their children don't go to play at friends' houses and siblings suffer the effects as well. Heather Grace and Gillian Wright describe the lives of their families as "restricted by the most disabled member of the family". While acknowledging parenting will always have its difficulties, for these mothers it is the constancy of care and the fact that it will continue through adulthood that is most wearisome.

This is a day walked in their shoes:

★ Gillian has Andrew (16) who has severe intellectual disability and ASD (and is strong and nearly 6 ft tall); and Jamie (13) who has epilepsy and an intellectual disability.

★ Heather has Jacci (7) and Brendon (22) who has cerebral palsy, poor vision, epilepsy and is tube-fed.

5 - 6 am Heather's son Brendon wakes after a night of tube-feeding and constant waking with colic. Heather prepares Brendon's feeds and medicines: Brendon will need bolus feeds every two hours until 8pm. A baby monitor is on at all times as Brendon has little airway protection.

6 am Gillian gets boys up and help them shower and dress. Andrew's bed will be wet and sheets

need washing.

8 am Gillian's children go to school (get mobility transport). Heather takes Jacci to school when Brendon's caregiver arrives.

During the morning it's 1 - 2 loads of washing for both mums, housework, meetings, medical appointments, sorting out issues with school, respite, prescriptions etc. Both mums have to be on call all day for their children.

2:30 pm Heather leaves to pick up Jacci from school and be home by 3pm when the caregiver finishes. Takes Jacci to any after-school activities if she can find care for Brendon. Then its activities with Brendon, such as music, talking books or playing with his sister.

3 pm Gillian at home ready for when boys come home from school. They have afternoon tea, then go for a walk or attend after school activities.

5 pm Gillian serves dinner. Family eats outside because the boys are so messy and lets the birds clean up. Supervises baths and entertains "kids who can't entertain themselves".

5:30 pm Heather serves dinner; then homework and fun activities with the kids.



7 - 8 pm Caregiver arrives to help Heather with Brendon - positioning him for the night, administering all the medicines and connecting food pump. Jacci is showered, story time, game time.

8 pm Gillian puts the boys to bed. Then makes school lunches, tidies up and goes to bed herself.

8:30 pm Heather puts the kids to bed, then has time for herself before bed.

Heather and Gillian are part of the 16+ Respite lobby group calling for the government to provide appropriate respite facilities for those aged 16 and over. Their aim is to secure five more respite houses across the Auckland region, specifically catering for those with high and complex needs.

HOW do I get RESPIRE?

Contact the Needs Assessment Agency (NASC) in your area and ask for an assessment (or a re-assessment if you have previously had one).

NASCs in Auckland

★ **Taikura Trust - Ph: (09) 278-6314**

Intellectual disability (0-15 yrs), physical all ages), sensory (all ages), neurological (all ages), age-related (under 50 years).

★ **Access Ability - Ph: (09) 262-5370**

Intellectual disability (over 16 yrs)

Once the NASC Agency has the referral you will be contacted to make a time that is convenient to you for a Needs Assessor to visit you at home. The Needs Assessor will participate with the family to take a comprehensive look at the disabled individual's personal and development needs, social and family networks, respite, carer support, education, training, vocational and employment needs. In consultation with the family this will then be written up as a formal document.

The Needs Assessor will forward the information from the assessment to a Service Coordinator who is then responsible for planning and organising any service provision and supports for the family. It is up to the family to find a carer to provide Carer Support.

The allocation of Respite days and Carer Support days varies greatly depending on individual needs and circumstances. In addition to Respite days, Carer Support days can also be used for out-of-home, overnight respite care. Respite is provided, and most costs covered, by a respite provider contracted by the Ministry of Health.

If at any stage more respite care is needed, the family needs to contact the NASC Agency for a re-assessment.

RESPIRE FACILITIES in Auckland

Creative Abilities
(09) 444 0608

Wilson Centre
(09) 488 4688

Spectrum Care
(09) 634 3790

Masada Learning and Recreation Centre
(09) 576 5229

Parklands Jocelyn Enterprises
(09) 233 4304

*For more respite facilities contact your NASC agency