



# NETWORKER

SUPPORTING PARENTS AND FAMILIES OF  
DISABLED CHILDREN AND YOUNG PEOPLE

July 2008

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## **PARENT AND FAMILY RESOURCE CENTRE (PFRC) HAS BEEN AROUND FOR CLOSE TO 18 YEARS.**

So it was surprising to hear from people who have been referred to PFRC for support recently, who said they had not known PFRC existed - and after receiving the information they wished they had learned about us much sooner. This feedback highlighted for us the need for a Marketing Plan and this work was one of the many issues addressed when the PFRC Board met for our annual strategic planning exercise held in May this year.

Until about three years ago PFRC had a very broad focus on disabled children and their families and one of our roles was to act as an umbrella group for fledgling support groups.

**A small vigorous  
community based  
resource centre for the  
families and whanau of  
disabled children and  
young people.**

Today the staff and Board at PFRC have a clear purpose and are deeply committed to our Vision - 'To create change within our society so that disabled people and their families can live the lives they desire'. We have in place a strategy that will guide us for the next three to five years.

PFRC has a Disability Information Advisory Service (DIAS) contract with the Ministry of Health and we provide advice and information in a variety of ways. In May our team responded to well over 150 communications in response to requests for information and support. Some of the work the PFRC team has been involved in includes:

- Participating in networking meetings with provider agencies and parent support groups
- Futures planning with families and development of a PATH plan
- Providing opportunities for families to consider innovative ways and means of supporting their son or daughter
- Facilitating the Support Group Coordinators' meeting, held once a term



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- Providing support for parents at meetings in the education and health sectors
- Reviewing PFRC publications and developing new publications
- Working with IHC Advocacy Service to review and develop concertina booklets about Transition and Leaving Home
- Planning and development of a number of projects relating to transition
- Distributing information on a wide range of topics to families and professionals
- Providing advice to disability providers that relate to supporting the whole family
- Coordinating a 'Visioning Weekend' for a group of families who want to explore alternatives to the current menu of services available to them when their disabled family member leaves home
- Community presentations –
  - ♦ Leaving Home (Pukekohe)
  - ♦ Transition services
  - ♦ Things to consider when planning for the future for and with a young disabled family member
- Planning for a number of seminars across the Auckland region over the next 12 months

### **Projects**

Families, education providers and government agencies are currently involved in a range of programmes,

transition services and information services for young people who are thinking about leaving school. PFRC staff have contributed to and are involved in a number of projects about transition.

Recently PFRC responded to a request for support from a parent in Franklin who is offering information to parents in the Franklin and Papakura areas who are thinking about the future for and with their young disabled family members. PFRC presented to an evening public meeting in Franklin on 18 June.

A Transition Expo is planned by the Ministry of Social Development (Work and Income). The Expo is for young people (15-21 years) and their families, teachers and other important people in their lives to have important information about contracted providers in Auckland. The Expo may help you decide which provider you might choose to work with when the student is in their last year at school. You will find details about the Transition Expo on pages 13-14.

IHC and PFRC are co-hosting an Auckland seminar in early August. We will be advertising the seminar and providing detail closer to this event. This seminar continues the IHC Rights Seminar series and will focus on mainstreaming the issues involved when young disabled people move from one environment to another when they leave school.

### **Paradigm**

Paradigm is a new service being developed by PFRC. We are currently

in the planning phase and of course seeking funding to support the programme. Paradigm is being developed as a response to the gap in the lives of young disabled people as they move from school to a life outside of school. The launch for Paradigm is planned for late 2008.

### ***Innovative Thinking and Practices***

PFRC is committed to the professional development of our team, to support staff to keep up to date with information and movements within the disability sector, both nationally and internationally.

Earlier this year a colleague and I travelled to Vancouver where we attended a conference titled "Changing the World, One Person at a Time." The key note speakers covered four key themes: 1) The good and not so good practices associated with delivering person centred services; 2) addressing people's true potential; 3) the challenge of sustaining quality and innovation over time and 4) leadership and values.

I have just returned from another Canadian experience and had the privilege of participating in a week-long residential leadership training programme hosted and presented by PLAN Institute in Vancouver. Without doubt this event was one of the most motivating and inspirational events I have had the opportunity to attend. The major theme was on the development of Social Networks for disabled people. For many disabled people the issue of social isolation and loneliness is a

common one and an issue that parents find incredibly difficult to discuss and address.

Social networks is not a “cookie cutter approach” but is absolutely unique to the individual. PFRC is looking at ways to inform families about building social networks. Families could begin by talking with pride about their disabled family member’s achievements. All too often we find ourselves describing our children in ways that will attract funding to meet a need rather than be given the opportunity to shout out with pride the great things our children do and what great people they truly are.

A theme discussed at training were the ways that the families’ voices can be heard and how their great stories can be captured. These are stories that should be heard by younger families and the wider community and PFRC is looking at ways that we can support the telling of these stories. One of the vehicles that we can use is the PFRC website. We are inviting you to share your story with us. Please email or phone us to speak to a member of the PFRC team.

### ***Annual Client Satisfaction Survey***

Every year PFRC asks our stakeholders how we are doing and how we might better meet the support and information needs of parents and families. This year our annual Client Satisfaction Survey will involve two approaches. A key question has been put on the PFRC website and a phone sample will be conducted with people

who have contacted PFRC over the past 12 months. We hope you are able to find the time to answer the on-line question ([www.parentandfamily.org.nz](http://www.parentandfamily.org.nz)) and if you are phoned, to take 10 minutes to respond to a few questions.

### ***Respite Audit and Outcomes***

A significant issue raised by parents and families this year involved an audit undertaken by HealthPac, of families who used carer support to pay for mothers’ retreat weekends. PFRC facilitated two meetings with the families involved and MoH Disability Services. Consequently, PFRC has focused on respite as the theme for this publication of the Networker.

### ***Finally***

PFRC is a small vigorous community based resource centre located in Onehunga for the families and whanau of disabled children and young people. A fundamental ethic for the organisation is that we never say no



and will always look at ways to find a solution to whatever issue you are concerned with.

You can help us to spread the word by telling one other person about the work we do.

*Bridget Snedden - Centre Director*



### **THE TEAM AT PARENT & FAMILY RESOURCE CENTRE**

#### **PFRC Board**

Colleen Brown - *Chairperson*  
Sharon King - *Secretary*  
Ann Martin  
Rod Wills  
Stacey Roche  
Mark Barratt

#### **Centre Staff**

Bridget Snedden - *Centre Director*  
Sue Robertson - *Director Planning and Development*  
Katherine Frame - *Community Advisor*  
Lavinia Manoa - *Business Support*

#### **OPENING HOURS**

Weekdays from 9am - 4pm

# Chairperson's Corner

SCHOOL'S COMMITMENT TO A YOUNG DISABLED MAN WHO WAS AN INTERNATIONAL STUDENT AT THE SCHOOL

*The school – Elim College.*

*The student – Tom Hsu from Taiwan.*

All readers will be aware of the tragedy that struck many families in Manukau City when six Elim students and their teacher perished in flood waters whilst they were at the Sir Edmond Hillary Outdoors Pursuit Centre.

Tom Hsu was one of those students. Tom was strapped to the back of teacher Tony McLean and they died together.

I went to Tom's funeral. His parents flew from Taiwan to be with their only child.

During Tom's service it became apparent that the school had taken a huge leap of faith in taking an international student with the type of needs that Tom had. However, they just did it. It seemed from the eulogies that Tom gave back far more to both the teachers and the students than he ever took. He seems to have been an inspirational young man who did his best to participate in all activities, he had an energetic personality and set goals for himself that encouraged others to aim high as well. He obviously had a great zest for life and lived it to the full.

In one moving tribute a student told the congregation how Tom had motivated him to complete an obstacle course. Tom had been slightly ahead of the other student and had cajoled him to keep going in order for the entire team to achieve the challenge.

Throughout the service it became apparent that whilst Elim College openly acknowledged their concerns and fears about having Tom in their school, they more than met the challenge. Tom was a much respected, admired and loved student.

I wish I could say the same of all schools in the Auckland region.

And this was the message that PFRC Board members and staff gave the Minister for Auckland, Judith Tizard when we met with her recently. Minister Tizard asked to meet with us to talk about parents' and children's educational experiences in the Auckland area. We all know that there are many outstanding examples of schools carrying out superb educational delivery for disabled students, however there are too many situations where parents are not getting the educational services their children require.

The forthcoming election will be a time to test central government politicians' resolve about how our children are



treated in the education system. For those of us whose children have been through the education system it is dismaying to repeatedly hear of experiences only too familiar from ten years ago.

And to the heart of this issue of the Networker. Since Travers was born 27 years ago respite care for the family has always been a contentious matter. It seems to have morphed into various forms over the years but too many parents and caregivers still have to challenge the system in order to get the service they require.

If you have any problems with any aspects of your child's life please contact the team at PFRC. They are always happy to give you information to help you make decisions about how to tackle the next step.

*Colleen Brown - Chair PFRC*

# Respite Care Services

## *Taikura Trust is Contracted by the Ministry of Health to -*

- Provide access to disability support services in the greater Auckland area (Mercer to Wellsford).
- Any child or person with a disability under the age of 65 who meets the criteria.
- Disability support services are available to anyone with:
  - ♦ a physical,
  - ♦ intellectual and/or
  - ♦ sensory disability or
  - ♦ Autistic Spectrum Disorder (ASD).

There are two types of “respite” available to families with children who have a disability.

### **1. Carer Support**

- Funded by the Ministry of Health Disability Services Directorate.
- Allows for the essential relief of the full time unpaid carer of a disabled person.
- It is a financial contribution towards cost of an alternative carer to support the disabled person.
- The family sources this support via their informal networks.

### **2. Out of Home Respite Support**

- Funded by the Ministry of Health Disability Services Directorate.
- Allows for the essential relief of the

full time unpaid carer of a disabled person.

- A short-term break that is away from home and overnight.
- Is facility based.
- Is structured/planned.
- It is expected that the child/young person attends school/work/day programme during the day.
- During school holidays some providers offer day activities.

A dedicated person with responsibility for respite services has been appointed by Taikura Trust. Her name is Sandy Field (DD 2786314 ext 754). Sandy will be more than happy to help with any questions you may have.

## *Contracted Respite Providers – Children 0-5 years*

Name	Criteria (Age and Disability Type)	Location	Catchment Area
Spectrum Care Trust	Community based residential respite support services for families with babies and children who have high complex needs, who are technology dependant, have multiple disabilities and/or an intellectual disability and/or Autistic Spectrum Disorder	Orakau House, Papatoetoe	Regional provider
Wilson Home	Children who require a higher level of supervision due to mobility and/or challenging behaviours with multiple disabilities	Devonport	Regional provider

## ***Contracted Respite Providers – Children 5-16 years***

Please note that these providers hold a wait list and movement out of the service is dependent on:

- family moving out of area
- the child has turned 16 and needs to transition into a young persons provider
- family not wishing to access respite anymore

Name	Criteria (Age and Disability Type)	Location	Catchment Area
Wilson Home	Families who are caring for children with a physical/sensory/intellectual or multiple disabilities who have challenging behaviours and have high medical needs	Devonport	Regional provider
Spectrum Care Trust	Children with an intellectual disability and/or Autistic Spectrum Disorder with challenging behaviours	Sturges Road, Ranui	West Auckland
Spectrum Care Trust	Children with an intellectual disability and/or Autistic Spectrum Disorder with challenging behaviours	Garden Court, Mangere	South Auckland
Spectrum Care Trust	Children with an intellectual disability and/or Autistic Spectrum Disorder with challenging behaviours	Beachhaven Road, Beachhaven	North Shore
CCS	Children who have a physical/intellectual/ sensory disability or a combination of these	Longford Park, Papakura	South Auckland
Open Home Foundation 6 x beds	Children who are independently mobile, high functioning with moderate behaviours with ID and/or ASD	Oasis – 2 homes, Bucklands Beach & Howick	Eastern Corridor

## ***Contracted Respite Providers – Young Adults 16-30 years***

NZ Care homes in Hobsonville and Nicholas Gibbons are at capacity, therefore hold a wait list. Once again vacancies are dependant on:

- family or client not wishing to access respite anymore
- families moving out of area
- client moves into residential placement

Name	Criteria (Age and Disability Type)	Location	Catchment Area
NZ Care Group 16 yrs+	Young people who have an intellectual disability and/or Autistic Spectrum Disorder with challenging behaviours	Hobsonville Road, Hobsonville	North, Central and West Auckland
NZ Care Group 16 yrs+ 5 x beds	Young people who have an intellectual disability and/or Autistic Spectrum Disorder with challenging behaviours	Nicholas Gibbons Drive, Weymouth	South Auckland
NZ Care Group	Young people who have a physical disability	Andrushia Drive, Flat Bush	South Auckland
Laura Ferguson Trust 16 yrs+ 7 x beds	Young people who have a physical disability with high medical needs	Great South Road, Greenlane	Central and North Auckland

# Carer Support

## *Frequently Asked Questions*

### **1. What is Carer Support?**

Carer Support is a service funded by the Ministry of Health, Disability Services, designed to assist the unpaid full-time carer of a person with a disability to take a break from caring for a disabled person. A full time carer is someone who provides more than 4 hours a day unpaid care to a disabled person.

### **2. How do I Get Carer Support?**

The unpaid carer may self refer or be referred to Needs Assessment Service Coordination Service (NASC) Agency. Assessment of the carer's need for support will be considered in conjunction with the needs assessment of the disabled person they support.

There is no entitlement to a specific number of carer support days that can be allocated to the full-time carer.

There is an annual allowance that if exceeded, can only be allocated with the written approval of the DSD Service Manager for the area. Carer Support allocation is reviewed annually.

Carer Support days must be used within the 12 month period for which they were allocated. The allocated days cannot be carried over from one year to the next.

### **3. How Can I use Carer Support?**

Use of carer support days is subject to Carer Support Guidelines.

It is the full-time carer's right to choose and co-ordinate their relief support.

Carer Support can be used in half day, daily, weekly and/or a bulk block or any combination of these as long as the person does not exceed their annual allocation. A half day is defined as over 4 hours and up to 8 hours. A full day is 8 hours up to 24 hours.

Informal Carers provide relief care in an informal setting e.g. a family home. People who provide care are typically friends, neighbours, other people or some family members such as grandparent, grandchild, daughter, son, extended family members.

Formal Providers provide support in a formal/commercial setting and/or via an organisation. These providers include organisations such as rest homes, private and public hospitals, professional home workers, voluntary organisations, day care centres etc.

### **4. What is the Carer Support Subsidy Payment?**

Carer Support is a subsidy payment intended as a reimbursement towards the costs of providing relief support. Carer Support is not expected to cover the full costs associated with taking a break. Carer Support is not a salary, nor is it a wage.

*From November 2007 the rates are:*  
Informal Carers \$76 per day (GST exclusive) for a 24 hour period

Formal Providers \$85.50 per day (GST inclusive) for a 24 hour period

### **5. When Can Carer Support Not be Used?**

Relief must be provided to the full-time carer. It is not usually expected that relief is achieved where the full time carer remains in the presence of the disabled person while the relief takes place. However, the full-time carer may wish to stay in their home doing other things while the relief support is being provided.

#### ***Carer Support can not be used:***

- When the full time carer is at work
- If the support carer lives at the same address as the full-time carer
- If the support carer lives at the same address as the disabled person
- By the spouse, partners, parents and other full time carers, even if they do not live at the same address as the disabled person.
- To convalesce after discharge from hospital
- For any disabled person living full-time in MoH funded residential care services
- As part payment to attend parent retreat weekends
- By people who are entitled to payment covered by ACC
- Personal Health and Mental Health clients

### **6. Where Can I Get More Information about Carer Support?**

- [www.moh.govt.nz/disability](http://www.moh.govt.nz/disability)
- [www.taikura.org.nz](http://www.taikura.org.nz)
- HealthPAC freephone 0800 281 222

# Carer Support Subsidy

## *What is It and How Can We Use It?*

### ***History of the Carer Support Subsidy***

The Carer Support Subsidy was previously known as Aid to Families and then Alternative Care and was legislated into Parliament in 1976. Back then it was only available for families who had a disabled child under the age of 16 years. In 1993 there were significant changes made and if you were caring for a disabled person over the age of 16 years you could now access the Carer Support Subsidy. This was at a time when there was an entitlement to Carer Support regardless of actual need. It is now needs based. As would be expected the criteria to access Carer Support Subsidy has changed over the past 30 years.

Many parents are not aware that there is a policy relating to the use of the Carer Support Subsidy. This article is to ensure that all families have the same information.

Families need to know that Carer Support is a subsidy and this means that it is only a contribution to the full cost of care.

Although not stated specifically, the Guidelines are a Ministry of Health (MoH) policy document and HealthPac is responsible for the administration for Carer Support payments. Carers must adhere to government policy.

Families have been informed that as

of March 2008, the policy contained in the Carer Support Guidelines will be enforced by MOH HealthPac.

### ***Carer Support Subsidy Guidelines Inclusions***

Carer Support is available for the full-time unpaid carers of disabled people who have been assessed as eligible for the service by a Needs Assessment Service Co-ordination Service (NASC) Agency contracted by the Ministry of Health, Disability Services Directorate.

A person with a disability is someone who has been identified as having a physical, intellectual or sensory disability (or a combination of these) which is likely to continue for a minimum of six months and result in a reduction of independent function to the extent that ongoing support is required.

### ***Definition for a full-time carer (8.1)***

“The full-time carer must provide full-time unpaid support to the disabled person in the person’s own and/or family home. This excludes carers receiving payment from residential care services and disabled people who are receiving services from an alternative paid carer.”

### ***Things to keep in mind when using the Carer Support Subsidy***

Carer Support is needs based and accessed through a Needs Assessment.

Therefore depending on your assessed needs, the number of days allocated will vary for each person and could be any number of days. There is a limit to the days that the NASC can authorize. After this limit of days the allocation requires authorization from the MOH. You will need to discuss this with your service co-ordinator.

You cannot use your Carer Support Subsidy while you are at work to pay for the care of your disabled child, regardless of age.

If you are not at work i.e. you don’t work at all or you don’t work in the school holidays or you finish at 3pm, then you can use your Carer Support Subsidy to pay for the care of your son/daughter to attend camps and holiday programmes etc.



## *Carer Support Guidelines April 2005*

The following has been reprinted directly from the Carer Support Guidelines April 2005. It is reprinted here so that families have a clear understanding of what is contained in the Guidelines and so that they can ensure proper use of the Carer Support Subsidy.

### ***Ways in Which Carer Support Can be Used***

There are a variety of ways to utilise the days of Carer Support. These will vary according to the full-time carer and disabled person's needs and wishes. The full-time carer and disabled person are able to choose how they use their support days. It is the individuals' right to choose



and, in most instances, co-ordinate their relief support.

The service co-ordinator may assist with information and/or with coordination if required. She/he may have the flexibility to put together an appropriate package in a variety of combinations up to the number of days allocated (and taking into account other community support services the disabled person may be receiving). It needs to be remembered that the programme is designed for disabled people and carers to be supported to choose, arrange and monitor their own carer support over the year.

The carers of disabled people are able to access up to their maximum day allocation in a combination that suits their needs. Carer Support may be used in half day, daily, weekly and/or a bulk block, or any combination of these as long as the person does not exceed their annual allocation. (A half-day is defined as over 4 hours and up to 8 hours, and a full day is 8 hours to 24 hours).

Carer Support is a form of relief support and must therefore be provided in such a way that relief is actually given to the full-time carer. For example, it is not usually expected that relief would be achieved if the full-time carer remains in the presence of the disabled person while the relief takes place, however, the full-time carer may wish to stay in their home and engage in other activities while relief support is being provided.

Relief support should be delivered in appropriate environments if provided in formal settings (see 8.3 for definition of Formal Providers), where all possible

precautions have been taken to ensure the environment is safe. For example, disabled children should receive formal relief support in developmentally appropriate environments.

### ***Options May Include Respite Care***

Where the disabled person goes to another setting to receive the necessary support (e.g. a respite bed in a residential facility), or where a friend, or extended family member who is not a professional home worker provides the respite services in the disabled person's or relief carer's home.

Respite care may also include day activities, either half days or full days of activities, which will comprise a range of recreational and other activities. (While these provide relief to the carer they will also be stimulating for the disabled person). Regular ongoing access to day programmes should be separately accessed and not funded from Carer Support.

### ***School Camps, Holiday camps, etc.***

Only where the purpose is to provide respite for the carer and only if the full-time carer does not also attend the camp. Carer Support may contribute to the cost of the disabled person's support person, to camp fees or other expenses.

### ***Day Care Fees***

Carer Support may be used to place a disabled child in day care to allow the full-time carer some daytime relief, as long as the full-time carer is not engaged in paid work whilst the child receives day care.

*Bridget Snedden*

# Parents' Views of Respite

The theme of Respite is always a topical issue for families, as a break from our children is something that we all want and need at one time or another. An observation though is that we don't use words like respite when we are talking about our child who is not disabled.

All our children need to spend time with other children or extended family members. Sleepovers are one way that children begin to learn how to be away from mum and dad and the familiar surrounds of home. Many parents talk about how their disabled child has so few friends, if any, that sleepovers don't get a chance to happen. Parents tell me how they have never been away from their child overnight, because they can't find anyone to look after their child. They talk about people's willingness to have their non-disabled sibling but not their child who is seen as "different." This is hard stuff to take in when you are a parent of a disabled child who you love dearly and would walk on hot coals for.

I absolutely appreciate why many families make the decision to seek and receive formal respite services. All too often it is the respite that keeps the family functioning on a daily basis and keeps many marriages and relationships together. We need to remember that respite comes in many forms and families need to decide for themselves what that looks like for them. For some that could be a few hours with a baby sitter a week or participating in a community activity on a regular basis.

I can recall that when my son was about 15 months old (he is now 20 years), a disability service provider was offering Shared Care as part of their menu of services. At the time I was heavily pregnant with our third child and a break sounded like heaven. As I believed at the time that "they knew best" I decided to go along with the idea and met a family that had put their name forward to do the Shared Care. They sounded and looked like good people and we left our wee boy with them for an afternoon to try it out. When I returned to collect him I remember vividly thinking that there was no way in the world I would have done this if he was not disabled and decided then and there that it would never happen again. This decision then forced me to find other ways of getting a break. Over time I developed good friendships with other local women with young children and we all found ways to share the care of our children.

As families I believe that we need to explore lots of different ways to meet our needs. There will never be enough government resources to meet all of our family's needs or that of our sons or daughters. Respite is only a part of the list of funded and unfunded services available to families. PFRC can help you think about what else is possible.

In March of this year a colleague and I had the opportunity to travel to Canada to attend a conference in Vancouver "Changing the World One Person at a Time." While there we were invited to a Families Conference in Edmonton. Both

of the conferences really showed to me that there is a strong desire of families around the globe to start to take greater control and governance over how they live their lives and how they would like services to take a back seat and to have a less dominant presence. One of the lessons we brought home was that we need to keep discussing and exploring ways that this can happen.

*Bridget Snedden*

***“Respite” is defined as “an interval of rest or relief”***

All carers need a break from caregiving in order to try and live an "ordinary life"

For our family, respite comes in two forms. We use Ministry of Health (MoH)-funded facility-based, overnight, out-of-home respite once per month. Carer Support days allocated by the MoH are the second option and they allow us to have short flexible breaks. We can use these allocated days to partly pay for holiday programmes, exercise classes and other short breaks of a few hours.

These regular, planned breaks enable us to continue to function as a family.

*Gillian Wright, mother of Andrew (19) and Jamie (16)*

## *Respite Experiences Over Two Decades*

Our family had our first respite experience in the 1980's. We took our first break from our girl, who was primary school age at the time, when she went to a holiday programme run by our local support group.

Until then, we had extra-ordinary limitations placed on the way our family was able to access and enjoy our community. Beaches and playgrounds had to be carefully chosen for their safety, proximity to roads and how popular they were. The holiday programme allowed me to set aside time on a daily basis to do something typical with my other two children, like going to the movies and watching the entire film without feeling anxious or having to leave. We were able to relax in each other's company.

An agency spent two years for a family trying to find a suitable place for their son so his family could have a 'short- break'. The boy's mother said that she fought very hard for the arrangements that they currently have in place and she feels for parents who are less able to be as proactive as she has been.

Different 'pots' of funding are used by the family for different things. They use their Individualized Funding for 'after school' care. They use their CCS contract funding for weekend support (every second weekend) and also carer support days for the other weekends.

The holiday programme experience introduced us to the notion that our girl could enjoy having space from us and have fun at the same time. The programme introduced us to people who were willing to come to our home at weekends. Respite worked for all of us.

Not all our attempts at respite were successful. I recall when 'the shit hit the fan' and our girl was breaking up to three windows a week, when we were all dealing with behaviours that really challenged our family and the professionals we were working with. Despite being referred to 'a respite service' and attending an interview, we were declined respite services. My husband and I found the interview process demeaning; it was a low point that left our family feeling very exposed. We had been where we didn't want to go in the first place and wondered how much more humiliation we needed to go through before help was provided.

The family has just been informed that they will not be allocated extra carer support days. This contradicts earlier verbal conversations. Once again the family will have to go into 'battle' to renegotiate funding.

The mother identified many barriers that impact on finding respite care. She thinks this is often about not having been given the right information or knowing where to go to access support. This is a constant stress on the family and becomes very exhausting.

*Mother, 7 year old son*

We'd like to think that nowadays, respite services have clear rules for access and friendly processes for accessing supports and services.

The Ultimate Respite Experience came from family and friends when we left our girl (then 11 years of age) with people we totally trusted. We went overseas for three weeks and this holiday proved to be a turning point in our lives. When we returned, life was never as bad again. We have reflected on why this might be. We think the tension valve had been released for all of us. We needed the physical break from constantly responding to relentless crises. As a family unit and as individuals, we all needed the opportunity to completely switch off from our roles and responsibilities.

In later years we have experienced consistent worry about our daughter's epilepsy and the need to be vigilant about seizure activity. Natural breaks mean we can enjoy each other's company in varying groupings with family members. These periodic natural breaks are arranged for appropriate times and events and feel right for us as a family. We choose carefully when our girl goes with us and when respite is "right." For example, we will go to Cirque du Soleil as a family and we will arrange respite when we go to the Opera. Our young adult children enjoy natural breaks from their sister so that they can just "be."

We currently have no contact with the NASC because their services are not needed.

*Mother of 21 year old*

# Transition Expo

Thursday 11th September 2008

Onehunga Community Center. 83 Church Street, Onehunga

11am – 4:30pm (closed) 6pm – 8:30pm

## Purpose of this Expo

Ministry of Social Development (MSD) have funded Transition providers to work with ORRS funded Students in their final year of school to support them to move from School to work and community participation.

MSD will provide an overview Transition Services and explain how the Transition process works. Transition providers will also present their service and highlight points of difference. (Refer to schedule on page two).

Transition providers will also have a stall where you can gather written material, talk to staff and ask questions.

## Who should attend?

All students who are 15-21 years and who are ORRS funded (Ongoing Reviewable Resourcing Scheme)

Parents families and caregivers

Teachers

NASC

Work & Income staff and the Health & Disability Team

Group Special Education

Office of Disability Issues

Members of Parliament

# Transition Expo

## Schedule for Presentations

11:00 – 11:15	Ministry of Social Development, Work and Income
11:15 – 11:30	Laura Fergusson Trust
11:30 – 11:45	Spectrum Care Trust Board
11:45 – 12:00	Workforce Auckland (Elevator)
12:00 – 12:15	Hohepa Homes Trust Board
12:15 – 12:30	IDEA Services
LUNCH	
1:30 – 1:45	Ministry of Social Development, Work and Income
1:45 – 2:00	Poly-Emp Employment & Advisory Service
2:00 – 2:15	Pasifika Consulting Limited
2:15 – 2:30	Te Roopu Taurima O Manukau Trust
2:30 – 2:45	Framework Trust
7:00 – 7:15	M.S.D
7:15 – 7:30	Edge Employment (AMHS)
7:30 – 7:45	Maranga House Trust
7:45 – 8:00	C.C.S Disability Action
8:00 – 8:15	Royal NZ Foundation for the Blind
8:15 – 8:30	The Deaf Association of NZ Inc

### ***Parking and Access***

Onehunga Community Centre – front faces Church St. Free car park, lift and ramps behind the Onehunga Community Centre (Lower Municipal Place) Selwyn St. Disabled parking drop-off and ramp also on library side of building.

For further information about the Transition Expo, go to [www.parentandfamily.org.nz](http://www.parentandfamily.org.nz) or phone Parent and Family Resource Centre (09) 636 0351.

# "ICE"

## *In Case of Emergency*

ICE – Store the names of people to be contacted in an emergency, under the name "ICE"

For more than one contact name simply enter ICE1, ICE2 and ICE3 etc.

We all carry our mobile phones with names and numbers stored in its memory but if we were to be involved in an accident or were taken ill, the people attending us would have our mobile phone but wouldn't know who to call. Yes, there are hundreds of numbers stored but which one is the contact person in case of an emergency? Hence this "ICE" (In Case of Emergency) Campaign.

The concept of "ICE" is catching on quickly. It is a method of contact during emergency situations. As cell phones are carried by the majority of the population, all you need to do is store the number of a contact person or persons who should be contacted during emergency under the name "ICE" (In Case Of Emergency). For more than one contact name simply enter ICE1, ICE2 and ICE3 etc.

The idea was thought up by a paramedic who found that when he went to the scenes of accidents, there were always mobile phones with patients, but they didn't know which number to call. He therefore thought that it would be a good idea if there was a nationally recognized name for this purpose. In an emergency situation, Emergency Service personnel and hospital Staff would be able to quickly contact the right person by simply dialing the number you have stored as "ICE"



## Organisations Based at the Parent & Family Resource Centre

### AUCKLAND DISABILITY PROVIDERS NETWORK (ADPN)

ADPN aims to bring together service providers in the disability field to collectively work on initiatives and issues that affect them all.

### AUCKLAND DOWN SYNDROME ASSOCIATION (ADSA)

ADSA is a run by parents for parents of people with Down syndrome. They support, inform and educate parents and the wider community on all aspects of Down syndrome.

### RECREATE AUCKLAND TRUST

Recreate is a Charitable Trust established to provide holistic recreational opportunities that enhance the social, emotional and physical development of young people with disabilities while also providing support and respite for their parents and families.

### TAMAKI NGATI KAPO

Tamaki Ngati Kapo Provides information and support to Maori visually impaired and their whanau.

### CYSTIC FIBROSIS ASSOCIATION AUCKLAND

The CF Association provides support and information to families of people who have Cystic Fibrosis.



## What We Do

**PFRC IS A KEY SOURCE OF INFORMATION AND ADVICE IN AUCKLAND FOR PARENTS, FAMILIES AND WHANAU OF DISABLED CHILDREN AND YOUNG PEOPLE AND PROVIDES A STRONG VOICE FOR CONCERNS OF PARENTS AND FAMILIES.**

PFRC maintains a high public profile to enhance the role of families and whanau in the disability sector and provides a strong voice for concerns of parents and families.

PFRC provides leadership to ensure the voices of families and whanau of disabled children and young people are heard locally, nationally and internationally.

PFRC supports families and whanau in ways that respect, promote and safeguard their disabled children and young people.

PFRC builds and maintains alliances with community groups, disability organisations, government agencies and service providers and support families to work effectively with these organisations.

## Who We Are

**PARENT AND FAMILY RESOURCE CENTRE (PFRC) IS A DISABILITY INFORMATION ADVISORY SERVICE (DIAS) CONTRACTED PROVIDER FOR DISABILITY INFORMATION SERVICES.**

PFRC was founded in 1990 and has evolved into a dynamic organisation providing information and advice to the families and whanau of disabled children and young people in the Auckland region.

## Upcoming Events

### CALENDAR OF EVENTS FOR JUNE - NOVEMBER 2008

- |                 |   |
|-----------------|---|
| 23 June 6pm     | PFRC Annual General Meeting<br>at 92 Princes St, Onehunga   |
| 24 June 7:30pm  | Auckland Dyspraxia Support Group Meeting,<br>St Johns School Hall North Shore.<br>Guest speakers                |
| 30 July 10:30am | Support Group Coordinators' Meeting at PFRC   |
| 4 September     | Young People's Rights Seminar Series -<br>IHC and PFRC  |
| 11 September    | Transition Expo 11am-4:30pm and 6-8:30pm<br>Parent & Family Resource Centre &<br>Ministry of Social Development |
| 30 October      | Trusting Partnerships Conference<br>(Standards Plus & Parent to Parent)   |
| 26 November     | Support Group Coordinators' Meeting at PFRC   |

## Funding Acknowledgements

The Parent and Family Resource Centre appreciate the support from:

- Lottery Ministers Discretionary Fund
- COGS
- Auckland City Council Training Partnerships
- JR McKenzie Trust
- ASB Community Trust
- NZ Lotteries Grants Board

This Edition of the Networker has been generously funded by the Anonymous Trust.

### *Vision*

To create and lead change within our society so that disabled people and their families can live the lives they desire.

### *Mission*

The Parent & Family Resource Centre will create and lead change through the provision of current, accurate, information, knowledge and guidance.

### *Values*

#### **Respectful**

PFRC is respectful of everyone we connect with.

#### **Deeply Committed**

We are deeply committed to our Vision.

#### **Principled**

Through principled actions we build relationships by being open, honest and fair and by keeping promises.

#### **Innovative**

We respond creatively.

## DIAS Provider

The Parent and Family Resource Centre (PFRC) is a Disability Information and Advisory Service, otherwise known as a DIAS Provider. We are contracted by the Ministry of Health to provide a service to families and whanau of disabled children and young people in the Auckland Region.

## Purpose of PFRC

PFRC provides information and advice for parents and families that is relevant and current. Information is provided in a range of media.

PFRC provides leadership to ensure the voices of families and whanau of disabled children and young people are heard locally, nationally and internationally.

PFRC maintains a high public profile to enhance the role of families and whanau in the disability sector and provides a strong voice for the concerns of parents and families.

PFRC supports families and whanau in ways that respect, promote and safeguard their disabled children and young people.

PFRC develops and maintains alliances with community groups, disability organisations, government agencies and service providers. PFRC supports families to work effectively with these organisations.



The Parent & Family Resource Centre Inc - CC21603 - is a registered charitable entity in terms of the Charities Act 2005. For more information about the Parent & Family Resource Centre Inc, visit the Charities Register at [www.charities.govt.nz](http://www.charities.govt.nz)

PARENT AND FAMILY RESOURCE CENTRE INC. is a Disability Information and Advisory Service (DIAS) and is open weekdays 9 - 4, Cnr. Spring & Princes St. Onehunga. Post to PFRC, P O Box 13 385, Onehunga, Auckland.

For more information on PFRC visit [www.parentandfamily.org.nz](http://www.parentandfamily.org.nz) or phone (09) 636 0351