

PARENT TO PARENT NEW ZEALAND

MATUA KI TE MATUA **KAPOREIHANA O AOTEAROA**

MISSION STATEMENT:

Empowering parents, care-givers, and whanau who have children and family members with disabilities, health impairments, or special needs through support and provision of information

Statement of Purpose

The purpose of Parent to Parent New Zealand Incorporated is to empower parents, caregivers and whanau who have children and family members with disabilities, health impairments or special needs, through support and provision of information.

Parents will feel supported and informed as a result of their contact with Parent to Parent.

Parent to Parent will do this in a cost effective and equitable manner.

Values

The following values were developed and ratified at a meeting of the Parent to Parent National Board on 13 August 2005.

Parent to Parent New Zealand values:

- parenting
- the role of the family
- the sharing of knowledge and experience
- the dignity and worth of all people
- the role of volunteers
- diversity within our organisation

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Carla Macdonald and Robyn Smith

For your time in helping with the preparation, collating and analysing of data.

Requesting families, Support Parents, Previous Requesters, National office staff, and Regional Groups

Thank you for your frank and open comments about the services Parent to Parent provides.

*Anne Wilkinson, Chief Executive Officer
November 2005*

CONTACT DETAILS

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PARENT TO PARENT NEW ZEALAND: A PROFILE

Parent to Parent New Zealand Inc. is a national, not-for-profit organisation set up in 1983 by a small group of parents and professionals who believed in the value of parents supporting parents when faced with the challenge of parenting a child with a disability, health impairment, or special need.

Every year the organisation helps thousands of families¹ whose children have special needs by:

- Providing information, advice, and support to families
- Linking families locally, nationally and internationally with other families of children affected by the same condition, enabling a mutual support network to be established
- Training Support Parents in the skills necessary to support other parents
- Linking families with trained Support Parents who provide experienced and practical support and information
- Providing parents with information regarding local, national and international support groups for their child's disability or condition
- Supporting the specific needs of children who have brothers and sisters with disabilities
- Providing a national lending library and journal service accessible to families
- Recognising the unique and specific needs of families so that regular support is provided to avoid crises developing
- Responding to requests for information and advice about issues affecting families of children with special needs
- Providing information to the health, social care, and education professions which support children with special needs

We operate through a network of regional groups and trained volunteer Support Parents to provide information and emotional support to parents. Support Parents are parents who have children with special needs and who have completed the 18-hour Support Parent Training course, from which they have been accredited.

There are 10 regional groups through the country. Each group is affiliated to the National body and provides its own matching, support and information service. Regional groups cover the following areas:

- Northland
- Auckland
- Waikato
- Coastal Bay of Plenty
- Central Lakes District
- Manawatu
- Wellington District
- Nelson
- Greater Canterbury
- Southland

National Office

In areas where a Parent to Parent group is not active, the National office, which is based in Hamilton, provides all necessary services, including running a toll-free line, arranging Support Parent matches and providing information on any of the 3,500 different conditions

¹ To be read as - Families/whanau/caregivers

covered by the organisation. National office administers the Parent to Parent New Zealand web page at <http://www.parent2parent.org.nz>

National Office gives extra support to regional groups when required by providing national parent matches (for instance when a local family match is unavailable maybe because of the rarity of the condition) and written information accessed from international sources.

The support programme for siblings, **SibSupportN.Z.** is administered from National Office and provided throughout the country. This programme supports the specific needs of young people who have brothers and sisters with disabilities. The programme is delivered over a weekend in a camp setting with formal and informal workshops as well as fun and leisure activities. Siblings develop their own support network, through sharing and making friends with others, who understand. Workshop facilitators are young adult siblings, thus ensuring the programme is emotionally safe for the children. A vital aspect of the programme is the involvement of older sibling leaders, who relate to the children, acknowledge their issues and support them. This provides an opportunity for the development of leadership skills and ensures that the programmes are emotionally safe and suitable for the children.

The Family/Whanau Carer Support Programme is also administered by National Office. This programme is for parents of children with disabilities and has been delivered by Parent to Parent since 1999 as part of a Ministry of Health Contract. It is run as a residential weekend away where carers attend workshops on grief and support, communication, stress and information on services. The programme is designed to also provide the participants with time-out and an opportunity to develop new friendships with people who know and understand.

Regional Groups

The Regional Groups form the membership of Parent to Parent New Zealand Inc. Each group provides core services but is also able to provide additional services depending on regional requirements. For many groups this means that as well as providing matches, Support Parent training and information to requesting families, they will be involved in social activities such as morning coffee groups for parents, family weekends, information evenings, special weekends for mums or dads and promotional activities. Each group is responsible for its own funding with an affiliation fee going to the national body for the work undertaken by that body on their behalf. Regional groups are not independently incorporated, but rather, come under the umbrella of the National organisation.

In conjunction with regional groups, National Office employs coordinators who are responsible for organising family matches, information and other administration matters. An elected committee governs each regional group. These committees are required to meet monthly with all minutes and reports forwarded to the National Board and national office. Regional groups can only be established with the approval of the National Board.

National Board:

The purpose of the National Board is to ensure that the organisations purpose (Ends Policy) and CEO Limitations Policies are implemented on behalf of it's Moral Owners. The Board's governance role and model means it is not involved in management issues (these are left to the CEO, professional staff and volunteer staff) but is focused on the organisation's wider issues including setting and monitoring strategic direction, and establishing and monitoring policies.

The Board comprises five members and a President elected by the regional groups (the organisations members), at Parent to Parent's Annual General Meeting. Board members do not represent the interests of particular regions per se but represent the organisation

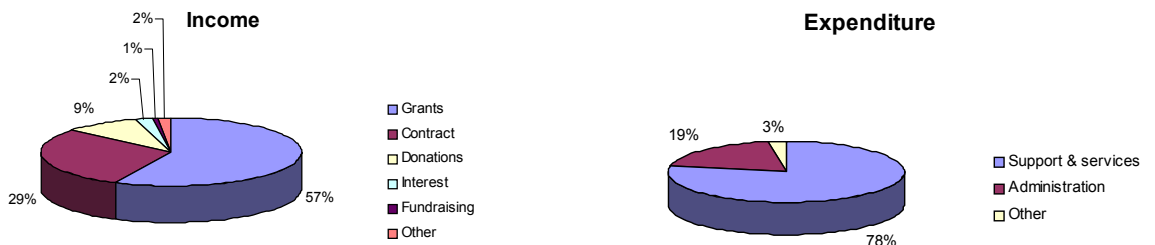
as a whole. Members are elected for a two-year term, with the Presidents term being a three year one and the Chief Executive is a non-voting member of the Board. Meetings are held five times a year over weekends.

Funding:

Approximately one half of National Office funding is from Ministry of Health contracts with the remaining coming from grants and donations.

Each group is responsible for applying for its own funding throughout the year to maintain core services and projects. Funding applications are handled by the coordinator, with grants being the major source of annual funds. Donations and funds sub-contracted from National Office make up a small percentage of their annual income.

In line with the requirements of incorporation, Parent to Parent’s end of year financial statements are consolidated. The graph shows consolidated income and expenditure for the year ended 30 June 2005.



SOCIAL OBJECTIVES

1. To find appropriate matches for requesting parents, caregivers and whanau.
Action: Coordinate one to one matching (contact) of requesting parents with a Support Parent, or should one not be available, then a Previous Requester.
2. To provide an information service to requesters which meets families' needs and reflects the most affordable and accurate information currently available.
Action: Provide current information of disability, syndrome, health impairment and support group contacts to requesting families.
3. To support and empower family members through family/whanau support programmes and sibling support workshops.
*Action: Facilitate sibling support programmes throughout New Zealand.
Facilitate Family/Whanau Carer Support Programmes.*
4. To ensure that Parent to Parent New Zealand Inc. services are available and accessible widely throughout New Zealand.
*Action: Publicise Parent to Parent services in all areas of New Zealand.
Provide toll-free telephone line for referrals.
Regional Groups providing services throughout New Zealand.*
5. To ensure that the services provided by regional Parent to Parent groups are of a high calibre, consistent with Parent to Parent New Zealand Inc. Policies, Mission Statement and Philosophy.
*Action: Support and training provided by National Office to Regional Groups.
All Regional Groups have volunteer Support Parents and administration staff.*
6. To ensure that all aspects of the organisation's activities are consistent with the principles of the Treaty of Waitangi.
*Action: Include Maori protocol in training for Support Parents and staff.
Support provided by Kaumatua and Maori providers.*
7. To ensure that Parent to Parent values diversity and creates a safe and caring environment.
Action: Values training for all staff and volunteers.
8. To be a good employer and maintain a high level of staff competence.
*Action: Employ suitably qualified skilled staff
All staff participate in annual performance appraisals and have a professional development plan.
Provide safe, accepting and family friendly working environment.*

SCOPE & METHODOLOGY

Parent to Parent's first social audit was completed in 1999. This was part of a pilot which first brought social auditing to New Zealand. A second set of social accounts was prepared in 2001. Due to the low response rate, these were not audited. Both of these social accounts did not include surveying the services provided by regional groups.

Actions from 1999 Audit and Subsequent Actions

Audit Panel Findings	
That the stakeholder consultation in the next Social Audit cycle should include health professionals	Not included in this audit, but will look to include in future audits
That Parent to Parent review its existing social book-keeping systems in order to identify other data which might usefully be reported in future as part of the social accounting	Accountability database implemented.
That consideration might be given to organising stakeholder surveys around Parent to Parent objectives	Committee's consulted
Issues Identified	
Encourage all regional groups to acknowledge the voluntary support given by Support Parents throughout the year	Achieved
Encourage regional groups to hold some of their activities in the rural areas of their region to allow for participation by rurally isolated families	Achieved
Review the roles undertaken by National Committee and National Coordinator and the supports required for each.	Achieved
Carry out an organisational review which will include the role and functions of National Office	Achieved
Encourage regional groups to provide regular professional supervision for their Support Parents, Coordinators, and members	1 group holds professional supervision for Support Parents
Develop the organisations own internet web page	Achieved www.parent2parent.org.nz
Reaffirm the role of Regional Coordinator in supporting requesting family through national match process	Achieved
Reaffirm the role of Regional Coordinator in supporting Support Parents involved in national matches	Achieved
Develop a format for Support Parents Refresher courses	Achieved
Encourage previous requesting families to train and become Support Parents	Achieved
Develop a criterion for those wishing to participate in Support Parent training	Achieved

This Social Audit includes both national and regional services of Parent to Parent New Zealand. It was undertaken over the 12 month period, 1 July 2004 to 30 June 2005. Surveys were sent to requesters to the organisation and volunteer Support Parents who supported those requesters in the months of August and November 2004 and in the months of March and June 2005. The *SibSupportN.Z.* and Family/Whanau programmes were evaluated throughout the 12 month period.

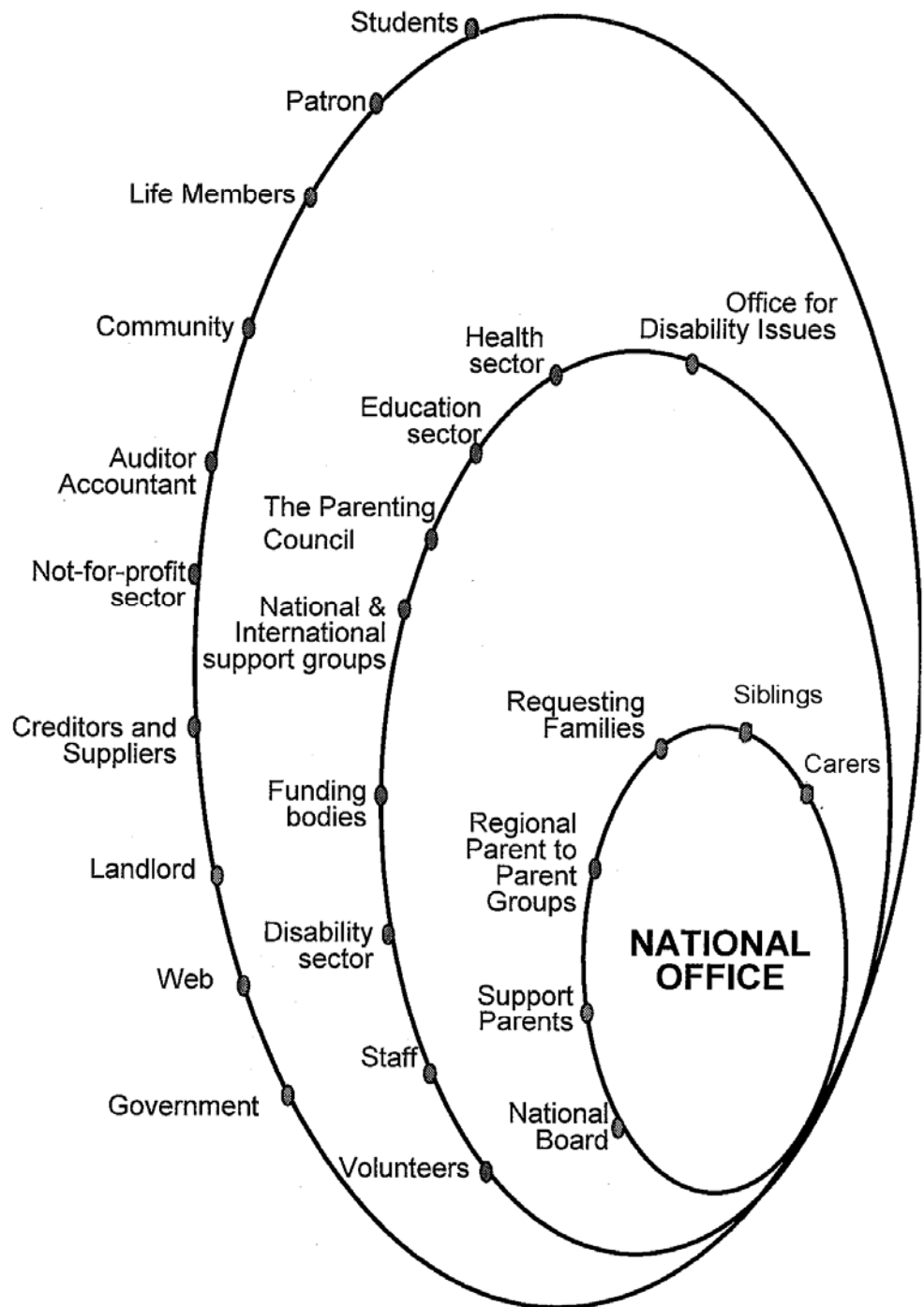
The key steps taken were to:

- Identify our social objectives
- To look at the results and recommended actions of the previous Social Audit.
- Develop our Plan for this Social Audit
- Gather the information as specified in the Plan
 - Consolidated existing information sources
 - Developed questionnaires
 - Implemented questionnaires
 - Reminders sent
 - Received and analysed results
- Prepare material for Social Audit Report
- Present initial findings to Annual General Meeting 2005
- Seek external verification of report

Questionnaires were developed using the National Office Quality Plan and Social Objectives as a starting point, and also the evaluations from the Family/Whanau Carers support and Sibling programmes which Parent to Parent New Zealand is contracted to deliver for the Ministry of Health.

In the 12 month period from 1 July 2004 to 30 June 2005, 676 parents contacted Parent to Parent requesting contact (a match) with a similar family, and 961 parents contacted the organisation for information. 209 children attended Sibling Support N.Z. programmes and 46 parents attended the Family/Whanau Carer Support programme.

STAKEHOLDERS



STAKEHOLDER INVOLVEMENT

Parent to Parent identified a large number of stakeholders but it was not feasible, due to time and resources available, to survey all parties in the audit process. The Office for Disability Issues, Health, Education and Disability Sectors, Funding Bodies and National Board were not consulted in this period but it is envisaged that this group will be consulted in future audits.

The key stakeholders that Parent to Parent New Zealand chose to consult in this period were:

Requesting families

These are families who contact Parent to Parent National office or a Parent to Parent regional group seeking information and/or contact with a family whose child has or has had the same or similar condition as their child.

- 167 questionnaires were sent out to all requesting families for the months of August, November 2004 and March, June 2005 with 37 returns, giving a response rate of 22%. Requesting parents covered both the North and South Islands of New Zealand.
- Of these, 121 (25 matches and 96 information) questionnaires were sent out from national office with 32 returned, giving a response rate of 26% and 46 were sent out from regional groups with 5 returned giving a response rate of 11%.
- For the purposes of analysis, national and regional responses were reported on together.
- National office questionnaires surveyed requesters who received information and/or a match from national office. These were posted out to requesters by national office staff.
- Regional group questionnaires surveyed requesters who received a match only. These were sent to requesters by the regional staff.
- Of the 37 questionnaires returned:
 - 13 were for a match only
 - 8 were for information only
 - 16 were for information and match

Support Parents providing support for the months surveyed

These are parents of children with special needs who have successfully completed the Parent to Parent Support Parent training course and who have been matched with a requester.

- 98 questionnaires were sent out to Support Parents used in the months August, November 04 and March, June 05 with 38 returned giving a response rate of 39%.
- National – 46 questionnaires sent, 24 received, giving a 52% response rate.
- Groups – 52 questionnaires sent, 14 received, giving a 27% response rate.

Previous Requesters providing support

These are previous requesters who have been approached to have contact with a family where there is no trained Support Parent available and the previous requester has a child with the same condition as the caller.

- 19 questionnaires were sent out, 7 received back, giving a response rate of 37%.

Siblings attending sibling support programmes

These are children whose brothers and sisters have disabilities. A total of 209 children who have brothers and sisters with disabilities attended 10 sibling support programmes which were surveyed for the social accounts.

- Evaluations were sent to all 152 parents of these siblings with 47 being returned, giving a response rate of 33%

Family/Whanau Carers attending support programmes

These are adults who care for and live with a family member who has a disability

- Evaluations were given to all 46 participants of three programmes held in the period, with 42 returned, giving a response rate of 91%

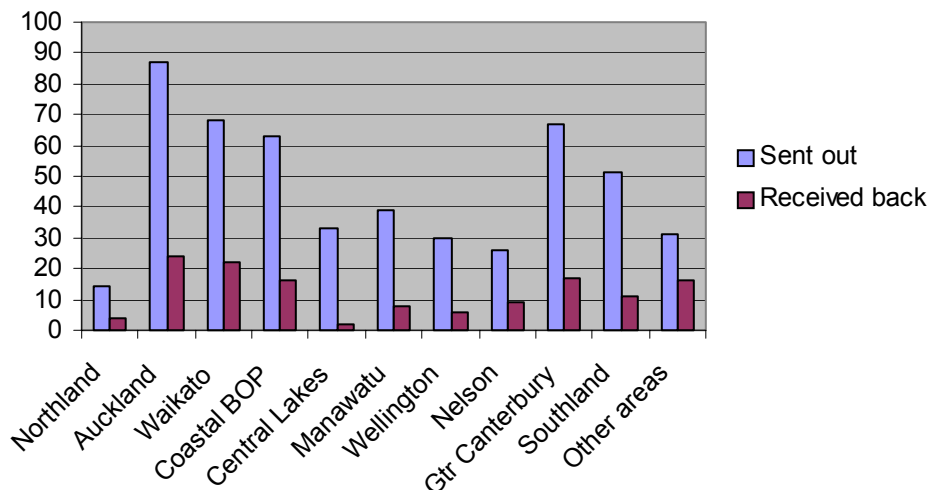
All Support Parents

These are parents of children with special needs who have successfully completed the Parent to Parent Support Parent training course, who are available to voluntarily support other parents through the matching process. All of Parent to Parent's volunteer Support Parents were surveyed.

- 439 questionnaires were sent out with a response rate of 31% (135)

- Responses were received from:

Northland:	4/10
Auckland:	24/81
Waikato:	22/57
Coastal Bay of Plenty	16/53
Central Lakes	2/29
Manawatu	8/37
Wellington	6/25
Nelson	9/26
Greater Canterbury	17/53
Southland	11/40
Other areas	16/42



Regional Parent to Parent groups

At the time of the audit there were 10 groups affiliated to the national body of Parent to Parent New Zealand but the Auckland group was in recess as there was no committee. A committee was formed in October 2005

- 9 questionnaires were sent out to Parent to Parent regional groups with a response rate of 100%


Staff

At the time of this audit Parent to Parent had 17 staff (1 male and 16 female), employed throughout the country. 6 staff work in National Office and 11 regionally. Of these 17 staff only 2 have been with the organisation for more than 3 years and 6 had commenced within the last twelve months.

All Parent to Parent staff were surveyed

- 6 National Office and 11 regional staff with 16 returned, giving a response rate of 94%

SOCIAL OBJECTIVE RESULTS

Results and responses proceeded with  form part of the recommendations, which will be priorities in the coming year's Action Plan.

OBJECTIVE 1: To find appropriate matches for parents, caregivers and whanau who request them.

Indicators from Parent to Parent's Quality Plan:

- *Callers feel valued and supported*
- *Maori families/whanau indicate that they feel valued and respected*
- *Parents indicate that the service met their needs*
- *Parents indicate that they were well supported through the matching process*
- *Requesting parents are satisfied with the length of time taken to process their request.*

What we did:

Questionnaires were sent to the 121 parents² who were matched with a Support Parent or previous requester in the months of August, November 2004 and March, June 2005. Responses were received from 29 requesting parents, 38 Support Parents and 7 previous requesters.

What our stakeholders told us:

Requesters:

29 surveys were received from parents requesting a match

Satisfaction

28 people indicated that they were satisfied with the way in which their personal details were handled – 96%

1 person did not respond either way.

 17 people indicated that the match met their needs – 59%

8 people indicated that the match did not meet their needs – 28%

4 people did not indicate either way.

(graph following)

Some comments requesters made regarding their match:

- *I felt my contact with my national match was very helpful and am grateful for having been able to talk with someone in a similar situation.*
- *It was good to receive an international contact at a later date, which I had not expected.*
- *I think you provide a valuable and confidential service to us parents, sometimes grappling for answers. Talking and contacting others in similar circumstances can be most helpful. Thanks for all your hard work.*

² Within this document this is to be read as parents/caregivers/whanau

Reasons given why the match did not meet the requesters needs:

- *I have not contacted the Support Parent offered yet but they are not a direct match*
- *Her child had other conditions that meant the results of surgery etc were different due to other medical conditions of the child*
- *Parent to Parent were not to know that we were at different stages*
- *We kept missing each other by phone – as I am always out at the hospital and so we never ended up speaking*
- *Given contacts of other families with similar conditions (still waiting)*
- *One did the other didn't. But it was ok to talk. Even though I know there were other people with autistic kids, it did seem like I was the only one*
- *Haven't been in contact yet - been in hospital*
- *In process*

📌 **Action:**

- Inform each caller that matches are provided on similarities – Parent to Parent unable to match on exact condition.***
- Ensure that follow up accountability calls to the requester are actioned within two weeks so that if necessary further action can be made.***
- Offer to reimburse requesting parents calls to previous requesters.***

Number of Support Parent contacts

10 people responded they had one contact with the person they were matched with – 34%
6 people responded they had 2 - 4 contacts with the person they were matched with – 21%

2 people responded they had 5+ contacts with the person they were matched with – 7%

3 people responded they had no contact with the person they were matched with – 10%

8 people did not answer this question

📌 Length of time to process request:

1 person responded that the length of time taken to complete their match was less than 48 hours – 3%

8 people responded that the length of time taken to complete their match was 2 – 4 days – 28%

3 people responded that the length of time taken to complete their match was 5 – 7 days – 10%

4 people responded that the length of time taken to complete their match was 8 – 14 days – 14%

6 people responded that the length of time taken to complete their match was more than 14 days – 21%

7 people did not answer this question

This question was misunderstood, as national office records show that the time taken from the initial request from a family until a match contact was arranged, was greater than indicated.

22 people responded that they were satisfied with the length of time taken to process their request - 76%

3 people responded that they were not satisfied with the length of time taken to process their request – 10%

4 people did not answer this question

(graph following)

■ **Action:**

- a) **Introduce regular staff “outstanding requests” meetings to brainstorm with the wider staff group, possible actions for outstanding and difficult requests.**
- b) **Ensure that matches are complete or other action taken within three weeks of initial request.**
- c) **Regional Groups to forward match requests to National Office daily.**
- d) **When requesters are unable to be contacted for follow up accountability calls, they will be contacted by letter**

Support Parents:

38 surveys were received from Support Parents involved in matches over the four months.

Satisfaction

31 Support Parents responded that they felt the match was appropriate – 82%
6 Support Parents responded that they felt the match was not appropriate–16%
1 person did not answer this question

24 Support Parents indicated that they were able to meet the requester’s needs for support satisfactorily - 63%
8 Support Parents indicated that they were able to meet the requesters needs for support very much so – 21%
3 Support Parents indicated that they were not able to meet the requesters needs for support – 8%
3 people did not answer this question

Some Comments:

- *only to the extent the child had the same condition however the age component was some 10 years difference.*
- *I found it an honour to ‘serve’ on the Parent to Parent line. It reminds me I’m not alone and every time I do a match I feel I get more than I give. Thanks for trusting me in this.*

Number of Support Parent contacts

24 Support Parents indicated that they had one contact only with the requester – 63%
12 Support Parents indicated that they had 2 – 4 contacts with the requester – 32%
No one indicated that they had more than 5 contacts with the requester
2 people did not answer this question

12 Support Parents indicated that they expect to have ongoing contact with the requester – 32%
21 Support Parents indicated that they do not expect to have ongoing contact with the requester – 55%
5 people did not answer this question

■ Time taken for Support Parent to make contact:

7 Support Parents made the call within 24 hours from being given the requesters details – 18%
8 Support Parents made the call the next day from being given the requesters details – 21%
10 Support Parents made the call 2 – 4 days after being given the requesters details – 27%
6 Support Parents made the call 5 – 7 days after being given the requesters details – 16%
5 indicated that it took more than 7 days – 14%
2 people did not answer this question

Note – some Support Parents indicated that it was difficult to make contact with the requester being unavailable –not home.

(graph following)

➤ **Action: Staff taking initial phone call to ascertain appropriate time for Support Parent to make contact.**

Previous Requesters:

19 Surveys were sent to Previous Requesters involved in matches over the 4 months and 7 were received back.

Satisfaction

4 Previous Requesters indicated that they felt the match was appropriate – 57%

Note – 2 Previous Requesters commented that they are still waiting for the requester to contact them. 1 Previous Requester had contact only through email.

2 Previous Requesters indicated that they felt they were able to meet the requesters' needs for support satisfactorily – 29%

2 Previous Requesters indicated that they felt they were able to meet the requesters' needs for support very much so. – 29%

3 people did not answer this question

Contact with requester

3 Previous Requesters had one contact only with the requester – 43%

2 Previous Requesters had 2 – 4 contacts with the requester – 29%

2 people did not answer this question

1 Previous Requester indicated that they expect to have ongoing contact with the requester (14%) and 1 may have ongoing contact (14%)

2 Previous Requesters indicated that they would not have ongoing contact with the requester – 29%

4 people did not answer this question

1 Previous Requester indicated that the requester contacted them within 24 hours of being notified of the request – 14%

2 Previous Requesters indicated that the requester contacted them the next day from being notified of the request – 29%

1 Previous Requester indicated that the requester contacted them 2 – 4 days after being notified of the request – 14%

1 Previous Requester indicated that the requester contacted them 5 – 7 days after being notified of the request – 14%

2 people did not answer this question

Regional Groups:

9 of the 9 regional groups surveyed responded to the questionnaire.

Contact with requester

3 Regional Coordinators indicated that they have weekly contact with the requester while their request is being completed by National Office – 33%

3 Regional Coordinators indicated that they have fortnightly contact with the requester while their request is being completed by National Office – 33%

2 Regional coordinators made contact but made a judgement call re frequency based on the needs of the requester

1 Regional coordinator did not respond to the question.

Regional groups were asked what cultural activities they offer to families and results are included under Objective 6.

Commentary

The aim of this objective was to ensure that appropriate matches were found for parents, caregivers and whanau who request them. The 1999 social audit results showed that 69% of requesting families felt that their needs had been satisfactorily met, this increased to 87% in 2001. This year's social accounts show that 59% of respondents were satisfied that their needs had been met. Although our stakeholders, requesters and Support Parents indicated that generally they found the match was appropriate and met the requester's needs, there has been a decrease in requesters satisfaction.

From the feedback we have received from families we can conclude that in many cases Parent to Parent was unable to access a similar family due to the uniqueness of the child's condition. This requires Parent to Parent to provide requesting families with a realistic expectation from the outset as to the likelihood of obtaining an exact match. We also have a role of ensuring that parents understand that contact with a parent whose child's condition is not exactly the same can provide meaningful and effective support for them.

Other feedback received showed that while requesting families valued very highly the contact they had with another parent, the length of time taken for the process to be completed affected the usefulness of the match. As a result national office have instigated a variety of procedures to ensure that matches are completed in a timely fashion.

In some cases, where requesters were matched with a previous requester the contact did not occur. This could be due to the cost of the telephone call which Parent to Parent have now taken responsibility to cover where this is a barrier.

"From the first phone call I received from my Support Parent, B, a true bond was formed which has lasted for nearly a decade. She has become a valued friend whom I have called on time and time again and who has been able to lean on me when her life has had setbacks. Our families have become close as well and this has been very beneficial to all of us, including our non-disabled children.

B's daughter was much older than mine but this didn't detract from the match at all. I was able to ask her how she had coped over the years and if she had still had joy and laughter in her life because, initially, I couldn't see any of that ahead of me. She was able to reassure me that while, at first, things might seem bleak, my life would have meaning and purpose and happiness, and that it would not be hard to love my daughter even though the road ahead was not as I had originally hoped for".

Feedback from a parent who was matched

OBJECTIVE 2: To provide an information service to requesting families which meets families' needs and reflects the most affordable and accurate information currently available.

Indicators from Parent to Parent's Quality Plan:

- *Callers feel valued and supported*
- *Maori families/whanau indicate that they feel valued and respected*
- *Parents indicate that the service met their needs*
- *Requesting parents indicate the information met their needs*
- *Requesting parents are satisfied with the length of time taken to process their request.*

What we did

Questionnaires were sent to all 96 parents who requested information from National Office on their child's condition in the months of August, November 2004 and March, June 2005. Responses were received from 24 requesting parents giving a 25% response rate.

What our stakeholders told us

Requesters:

24 surveys were returned from requesting parents

Satisfaction

22 people indicated that they were satisfied with the way in which their personal details were handled – 92%

2 people did not complete this question

22 Requesters indicated that the information met their needs – 92%

2 Requesters indicated that the information did not meet their needs – 8%

Some Comments:

- *I am very impressed with the quality and quantity of the information sent out.*
- *Information was mainly on idiopathic XXX; my son has congenital XXX, they are very different.*
- *The information was very, very, very educational and informative. The whole process of dealing with Parent to Parent has been very helpful. Thank you; I have passed your contact details on to several families*

Length of time to process information request

3 Requesters indicated that they received the information the next day – 12%

6 Requesters indicated that they received the information 2 – 4 days after they requested it – 25%

6 Requesters indicated that they received the information 5 – 7 days after they requested it – 25%

9 Requesters indicated "other" for length of time (more than 7 days) - 37%
(graph following)

Some Comments:

- *After waiting quite some time I was about to make contact again when the information arrived. Could have been quicker or explained due to circumstances the information was on its way*
- *Received above and beyond what I expected.*
- *While it took longer than I was told it was excellently researched and worth the wait*

20 Requesters indicated that they were satisfied with the length of time - 84%

2 Requesters indicated that they were not satisfied with the length of time – 8%

2 did not tick the box but responded that they did not mind the wait – 8%

(graph following)

■ **Action: Review request and follow up accountability process to ensure that all requests are dealt with within 14 days.**

Commentary

The aim of this objective was to ensure that the provision of the information service meets families needs and reflects the most affordable and accurate information currently available. As with the previous social audits, feedback shows that requesting families found the quality of the information to be excellent and that the vast majority of them were happy with it. One aspect of the process that could be improved, as was found with objective one, is the length of time taken to supply the information to families.

Procedures are being developed so that the workload and length of time taken to respond to information requests is monitored and time delays do not occur.

"I contacted Parent to Parent for the latest information on Jessica's condition. This arrived within 2 weeks, with a friendly wee note from the sender. We don't own a computer, so this was an extra bonus, receiving this information, via snail mail".

Feedback from a parent who requested information

OBJECTIVE 3: To support and empower family carers through family/whanau support programmes and sibling support workshops.

Indicators from Parent to Parent's Quality Plan:

- Carers will indicate strengthening of personal coping strategies
- Carers will indicate knowledge of how to access health & disability support services
- Carers personal development will enable them to effectively and safely manage their responsibility of caring.
- Carers will indicate that the programme was sensitive and culturally safe

What we did

Throughout the country, 209 children who have brothers and sisters with disabilities attended 10 sibling support workshops (SibSupportN.Z.), which were surveyed for the social accounts. Evaluations were distributed to camp participants to pass on to their parents. The total number of parents surveyed was 152. 47 evaluations were returned, giving a response rate of 31%.

Evaluations were passed out to all 46 participants who attended the Family/Whanau Carer Support programmes nationally and 42 were returned, giving a response rate of 91%.

What our stakeholders told us

Sibling support workshops:

47 evaluations returned

Satisfaction:

On the scale 1 – 5 (5 = very helpful & 1 = not helpful) parents were asked if the programme had been helpful to their child/ren.

30 rated it 5 – 64%

14 rated it 4 - 30%

2 rated it 3 – 4%

1 rated it 2 – 2%

Therefore, 94% of parents rated the SibSupportN.Z. programme as helpful and very helpful, and 6% as not so helpful

(graph following)

41 parents indicated that the programme had some positive effects on their child/ren – 87%. 6 people did not write a response.

Comments:

- *Understands more about what's happening now and is more understanding toward her brother. She got a lot from making friends with others that had the same problems.*
- *Yes. My child looks forward to spending time with other siblings who are dealing with problems with relating to their brothers and sisters, and who know what he is going through.*
- *My child has gained so much over the years and has developed lots of good coping strategies. Thank you.*
- *Has built up good network of friends who are in similar circumstances to her. More tolerant to brother.*

- *Friendships with others from the programme made the weekend worthwhile. Getting away from the stress of home life and learning and really having fun.*

42 parents indicated that the programme had no negative effects on their children – 89%. 4 parents indicated that it did 8% and 1 person did not answer this question.

Some Comments:

- *The disabled sibling thinks he should get to go away on camp too.*
- *One person was causing trouble for my son, getting others to gang up and not include him.*
- *My daughter went with two other friends and I think their friendships are strengthened because they all have something in common.*
- *I do not recommend any changes to this programme. My daughter enjoyed every minute of the programme. It met all her needs and was really great for her*

Cultural sensitivity:

42 parents (89%), indicated that the programme was sensitive and culturally safe for their child/ren. 5 parents did not indicate either way.

Recommended changes:

- *longer period at camp*
- *different locations*
- *buddy system for when they first arrive at camp*
- *workshops for siblings who have lost a brother/sister.*

Other comments:

- *Just, please keep my son on the mailing list, he really enjoys getting mail for him that deals with 'issues' pertaining to his situation. Thanks again*
- *A well run programme. Well done and keep it up. Thank you*
- *Thank you for providing an opportunity for these kids to just have fun and feel a little special themselves*
- *My daughter has not stopped talking about the fantastic weekend she had and can't wait to attend next year. For her, being with children her own age and them understanding her situation has been great*
- *We thank you for the time and effort that went into this weekend considering Auckland doesn't even fall into the Waikato area!! I think the good response to the weekend shows there is a need for sibling camps etc and I would encourage all at Parent to Parent to keep up the great work.*
- *My child has found it very hard to fit in at school, and to feel comfortable in new situations, yet at the Sib Support workshop and camp she must have felt very safe as she joined in and enjoyed herself. She's never been away from home before and it was a very safe first experience of that*
- *I think it would be good to have some sort of feedback from you on how the camp went, subjects covered, what the children did etc. I have no idea what the camp was like, it would be good to know! Thanks for all your efforts and time put into this camp*
- *Retaining the same course presenters has enabled children to build an excellent rapport with them and the content of the programme. Well done Parent to Parent! These camps are very successful in many ways.*

📌 **Action: Feedback from facilitators to parents at the completion of the programme. This will be in the form of a newsletter.**

Family/whanau carer support programmes:

46 Evaluations were passed out to all participants who attended the programmes and 42 were returned.

Registration/venue/time

34 (81%) participants indicated that they found the registration process very good. 4 (9%) found it satisfactory and 1 (2%) found it difficult.

3 did not comment either way.

When asked if they would prefer any changes to the venue, time or location of the programme, participants commented that the venue was fine. Some people indicated that the timing was difficult for them as farmers.

Satisfaction

On a scale of 1 – 4 (4 = very helpful & 1 = not helpful) participants were asked if the programme had been helpful to them in their role as a family/whanau carer:

31 rated it 4 - 74%

6 rated it 3 - 14%

3 rated it 2 - 7%

2 did not answer this question

Therefore, 88% rated the programme as helpful or very helpful in their role as family/whanau carers

On a scale of 1 – 4 (4 = very helpful & 1 = not helpful) participants were asked if they found the manual helpful:

18 rated it 4 – 43%

21 rated it 3 – 50%

1 rated it 2 – 2%

2 did not answer this question

Therefore, 93% rated the material covered as very helpful.

On a scale of 1 – 4 (4 = very worthwhile & 1 = not worthwhile) participants were asked if the programme was worthwhile:

35 rated it 4 – 83%

6 rated it 3 – 14%

1 rated it 2 - 2%

Therefore, 97% rated the programme as worthwhile and very worthwhile.

(graph following)

96% of the participants indicated that they enjoyed the programme.

Comments:

- *Very supportive, caring non-threatening environment. Good for networking and ongoing support. Perhaps shorten some of the personal sharing time in the group discussion time*
- *What a wonderful place to meet so tranquil and isolated. Thank you.*
- *Great to have GSE and Support Net come along Trainers great, Both very skilled and knowledgeable and great presenters. Having presenters with true empathy was wonderful. Great venue - relaxing, Meals wonderful not to have to do it and well catered. Thank you Thank you Thank you.*
- *Not feeling intimidated within the group was awesome. That we all had the special needs aspect of our lives was very positive. Liked the availability of fruit. The goodies on the pillows. Continued supply of drinks. Bonus of the spa pool. Tutors being one of us*
- *I found this programme to be fantastic. It far exceeded my expectations. Awesome sharing of experiences, strategies, great friendships made. My confidence has increased hugely.*

- *The whole package was awesome – people, programme, food and accommodation was really enjoyable.*
- *I have never been to anything like this before so I was really surprised to walk away with confidence and knowledge*
- *The programme was more than worthwhile. It was compulsory for me to attend to see the light and recharge.*
- *Everything was very worthwhile. Covered a lot of topics, not too much depth or too intense.*

The following questions were asked at 2 of the 3 programmes:

28 evaluations were passed out with 26 returned

Presentation

On a scale of 1 – 4 (4 = excellent & 1 = poor) participants were asked how they found the presentation:

19 rated it 4 – 73%

6 rated it 3 – 23%

1 person did not answer this question

Therefore, 100% rated the presentation excellent or very good.

Cultural Sensitivity

On a scale of 1 – 4 (4 = very well & 1 = not well) participants were asked if their cultural needs were met:

17 rated it 4 - 65%

5 rated it 3 - 19%

1 rated it 2 – 4%

3 did not respond

Therefore, 84% indicated that their cultural needs were met.

Satisfaction

On a scale of 1 – 4 (4 = excellent & 1 = poor) participants were asked how they rated the programme overall

20 rated it 4 - 77%

5 rated it 3 - 19%

1 did not indicate

96% rated the family/whanau carer support programme as excellent or very good.

Sexuality Workshops

28 evaluations were passed out with 20 returned

On a scale of 1 – 4 (4 = very helpful & 1 = not helpful) participants were asked if the material covered was helpful in their role as carer

7 rated it 4 - 35%

11 rated it 3 - 55%

2 rated it 2 - 10%

Therefore, 90% found the material covered as helpful in their role as carers.

Positive Parenting Workshop

18 evaluations were passed out with 16 returned

13 participants indicated that they found the session useful – 181%, while 2 did not find it useful -12%, and 1 did not comment.

Commentary

This objective was to support and empower family members through family/whanau support programmes and sibling programme. Previous social audits did not include this objective as the programme had only been going for a short time at that stage.

The feedback received for both sibling support and family/whanau programmes was extremely positive. Participants reported increased confidence, knowledge and support for their situation.

Parent to Parent will aim to further develop its capacity to be able to offer more of these programmes.

“My son has been attending your sibling camps now for the last nine years. I remember the first camp he attended was so scary for him and for me, not knowing what to expect and having to face others who were in similar situations to us. We had unspoken fears of people coping better than us, or not coping at all, or the fact we would be exposed in some way that would make us not accepted for lots of reasons.

The Camp Mother and lots of kids running around and saying goodbye to families with their siblings welcomed us. Leaders introducing themselves and reassuring us Mums and our kids of what was what and making us feel as though we had always been a part of their group. S was so emotional as I was leaving and begged me not to leave him. The camp mother stayed with him as I left crying and drove away wondering whether or not I would receive a phone call and fetch him that night.

Now its been nine years of amazing life changing camps and activities provided by Parent to Parent. S has not only come to accept his sibling with more understanding and insight, he has come to respect others in all walks of life. S’s confidence began to take flight as he gained acceptance and courage from the people he rubbed shoulders with at Parent to Parent. The leaders were all in the same boat as well as the other kids that attended and this was of great importance to him. S would always say how much the leaders helped him understand the feelings he had and the deep issues that would never have had the opportunities to surface unless he was in this particular group, who not only had knowledge but lived the life he also lives. The workshops are invaluable so much so S has been training as a leader, to help others in the same way he has been helped.

What a privilege its been given to see my son grasp hold of so much and gain all this confidence through Parent to Parent. How unique this organisation is and what they have to offer, its more than just a break away from their challenged family lives, it’s the most powerful tool I have every experienced in seeing a young man grow through so many challenges and become a young guy who is quite humble, kind and sensitive to others, confident in who he is and not embarrassed of his brother (well most of the time!). I am deeply grateful for all the opportunities Parent to Parent offers S and our family – you have changed our lives and lightened the load so many times.

*By the way, that first camp I left S crying, the day I arrived back for him and we drove toward home, I looked to see him crying and I said what’s wrong “... oh mum I don’t want to leave, everyone there was just like me and they were real cool.”
Our heartfelt thanks to Parent to Parent for all you are for all that you do.*

*Feedback from a parent whose child attend a SibSupportN.Z. programme
“Hi, I am 17 years old and I have been with Parent to Parent for 9 years.*

Parent to Parent has provided me with friends, support and enjoyment, and lots of fun times and memories at their camps. The camps have given me time away from my brother and has given us time as a team to strategise and talk about problems we have being a brother or sister of a special needs sibling.

I gained confidence in myself as I was really shy and had no friends and now I respect others more.

The camps are really fun and we do heaps of exciting activities with friends in our team building games. We all form friends with team leaders and they feel like best friends and not just leaders.

I don't know what I would've done without Parent to Parent, now I really want to carry on as a team leader and create opportunities for others the same ways I have been given".

Feedback from a sibling

"I found the Parent to Parent Family/Whanau programme to be very worthwhile.

It was a unique opportunity to meet others who faced similar life challenges. This helped lessen my sense of isolation.

The programme content was excellent. Everything covered was relevant, no matter whether your child had been recently diagnosed, or you had been living with a disability for a number of years. It certainly helped that the programme was delivered in a relaxing environment. Because I felt more at ease, I was more receptive to what I was hearing.

It was useful to learn new coping strategies, not only from the programme facilitators, but from other parents as well.

The knowledge I gained from the programme enabled me to feel more confident, motivated and enthusiastic about my role as a parent of a child with special needs. Thank you for giving me the opportunity to attend".

Feedback from a parent who attended a family/whanau weekend

OBJECTIVE 4: To ensure that Parent to Parent New Zealand Inc., services are available widely throughout New Zealand.

Indicators from Parent to Parent's Quality Plan:

- *Calls received from parents living in regions not covered by a regional group*
- *Increase in number of parents accessing services*
- *Parents accessing service directly from regional groups*

What we did

167 families requested information and/or a match in the months of August, November 2004 and March, June 2005. Responses were received from 37 requesting parents. 9 Regional Groups were surveyed with 9 responses received and 439 questionnaires were sent to all Parent to Parent's volunteer Support Parents with 135 returned.

Requesters for both matches and information for the 4 months surveyed were from the following regions:

Northland	4	Manawatu	6
Auckland	26	Wairarapa	2
Sth Auckland	4	Kapiti	5
Waikato	24	Wellington	25
Bay of Plenty	14	Nelson/Marlborough	3
Central Lakes	9	Canterbury	19
Hawkes Bay	4	Sth Canterbury	3
Taranaki	2	Otago	1
Wanganui	5	Southland	11

(graph following)

📌 Action:

- National Office to focus on PR in areas that are not covered by a regional group.**
- Provide additional training and support to those regional groups, which had a low request rate.**

What our Stakeholders told us

Requesters:

37 questionnaires received

Access

32 requesters indicated that they experienced no barriers in contacting Parent to Parent – 86%

4 Requesters indicated that they experienced barriers in contacting Parent to Parent – 11%

1 person did not answer this question.

Comments on the barriers people experienced:

- *My match was in North Island. I have Toll Bar on Phone. So have not been able to contact them*

- *Was given an out of town phone number for a previous requester*

55% of regional groups provide toll free access to their group.

9 Requesters found out about Parent to Parent through the hospital – 24%
 5 Requesters found out about Parent to Parent by a brochure – 13%
 5 Requesters found out about Parent to Parent through other support groups – 13%
 8 Requesters found out about Parent to Parent through their Teacher/School – 22%
 1 Requesters found out about Parent to Parent through Plunket – 3%
 2 Requesters found out about Parent to Parent from a friend - 5%
 2 Requesters found out about Parent to Parent through community networks – 5%
 1 Requester found out about Parent to Parent through the phone book – 3%
 4 people did not answer this question.
 (graph following)

■ Requesters aware of Parent to Parent Services (Respondents could mark more than one service):

Website –	30 yes	7 no
Library and Journal -	23 yes	14 no
National Newsletter -	23 yes	14 no
Email access -	27 yes	10 no
National toll free line	29 yes	8 no
Support Parent training -	25 yes	12 no
International matching	15 yes	22 no
Contact details – Support groups	31 yes	6 no
National matching with other families	34 yes	3 no
Information relating to special need	31 yes	6 no
Information on websites	30 yes	7 no
Family/Whanau Programmes	26 yes	11 no
Sibling Support Programmes	24 yes	13 no

■ **Action:**

- a) **Send the latest newsletter and service information sheet to people requesting a match only, and to those attending sibling support and family/whanau programmes.**

Regional Groups:

9 questionnaires received

Networking:

Regional Groups listed over 49 separate organisations that they network with. These fell into the following categories (respondents could mark more than one organisation).

Health	10
Education	8
Social Services -	28

Paid hours per week:

15 hours	2
18 hours	2
20 – 25 hours	1
25 hours	1
32 hours	1
35 hours	2

44% of coordinators work 15 to 18 hours with 23% working 20 to 25 hours and 33% working 32 to 35 hours a week.

Services that regional groups provide:

	Yes	No		Yes	No
Matching	9		Information	9	
Family camps	6	3	Siblings Support	8	1
1 parent 1 sibling	3	6	Hospital packs	5	4
Coffee mornings	8	1	Newsletter	9	
Support Parent training	9		Refresher courses	6	3
Workshops	6	3	Seminars	6	3
Tollfree line	5	4	Email contact	9	
Support to parent during matching	9		Social activities	9	
Telephone support	9		Recreational activities	3	6
			Toy library	1	8

All Support Parents:

135 questionnaires received

Matches arranged through the regional groups in the last 12 months:

77 Support Parents have not been involved in a match through their regional group, 24 have been involved in 1 match, 20 in 2, 3 in 3, 2 in 4 and 4 Support Parents indicated that they have been involved in 5 matches over the year.

5 people did not answer this question.

Commentary:

The aim of this objective was to ensure that Parent to Parent New Zealand services are available and accessible widely throughout New Zealand. Since the previous audit the number of regional groups providing a toll free line has increased from 22% to 55%. While other comparisons show no significant movement in the results, it is noted that the number of organisations that the regional groups network with has reduced slightly. Over the last two years 50% of regional groups have had new staff appointed. It takes time for regional coordinators to establish relationships with other organisations and this may account for the reduction.

While general information about Parent to Parent is reaching a wide area, knowledge of our specific services is more limited. This will be addressed in the action points regarding PR and regional group training.

"My initiation to Parent to Parent began 5 ½ years ago, when I bravely contacted the Regional Coordinator.

I needed to know about the education and health services available for our special needs daughter, as we were moving from a region where we had lived for the past 17 years.

It was a scary proposition and we were stepping into the unknown, but through the phone call to Parent to Parent, I began to feel positive and supported about the move".

Feedback from a parent who has accessed services

OBJECTIVE 5: To ensure that the services provided by regional Parent to Parent groups are of a high calibre consistent with Parent to Parent New Zealand Inc policies, mission and philosophy.

Indicators from Parent to Parent's Quality Plan:

- *Complaints dealt with in accordance with documented process in Complaints procedure manual*
- *Satisfaction from parents with the way their privacy was handled*
- *Support Parents indicate that they feel valued and respected*
- *No workplace accidents*
- *Staff feel valued and supported*
- *Coordinators have undertaken training and personal development.*

What we did

Questionnaires were sent to 167 parents who requested a match and/or information in the months of August, November 2004 and March, June 2005. Questionnaires were also sent to 98 Support Parents and 19 Previous Requesters who supported the requesting families. Responses were received from 37 requesting parents (29 for match and 24 for information), 38 Support Parents and 7 previous requesters.

9 Regional Groups were surveyed with 9 responses received and 439 questionnaires were sent to all Parent to Parent's volunteer Support Parents with 135 returned.

What our stakeholders told us

Requesters:

37 questionnaires received

Satisfaction

34 people indicated that they were satisfied with the way in which their personal details were handled – 91%

3 people did not answer this question

Of the 29 questionnaires returned from people who requested a match:

17 indicated that the match meet their needs – 59%

8 people indicated that the match did not meet their needs – 28%

4 people did not answer this question

Of the 24 questionnaires returned from people who requested information:

22 indicated that the information met their needs - 92%

2 Requesters indicated that the information did not meet their needs – 8%

Support Parents used for matches August / November / March / June

98 questionnaires were sent out to Support Parents with 38 returned.

Privacy Act Compliance

32 Support Parents indicated that they were aware of the Privacy Act Compliance Procedure – 84%

5 were not aware of the procedure – 13%

1 person did not answer this question

(graph following)

Valued and Supported

35 Support Parents indicated that they felt valued and supported by Parent to Parent staff – 92%

2 Support Parents indicated that they did not feel valued and supported by Parent to Parent staff - 5%

1 person did not answer this question

Comments:

- *Only during the matching process. The other times (most of the time) I do not hear from Parent to Parent*
- *Thankyou for the thankyou cards*
- *You certainly keep us up to date with everything thanks.*
- *I feel more valued and supported by this region. We have been in a better "frame of mind" since moving here.*

29 Support Parents indicated that they found contact from the regional coordinator during the matching process as helpful – 76%

7 Support Parents indicated that the coordinator did not contact them – 18%

2 people did not answer this question

32 Support Parents understood the reimbursement of toll charges –84%

5 Support Parents did not understand reimbursement of toll charges – 13%

1 person did not answer this question

35 Support Parents understand the accountability forms – 92%

2 Support Parents did not understand the accountability forms – 5%

1 person did not answer this question

32 Support Parents were aware that supervision and support available to them – 84%

6 Support Parents were not aware that supervision and support available to them – 16%

Support Parent involvement

Support Parents listed 18 activities they take part in. These were:

Matches with requesting families – 28

Family Camps – 7

Sibling Activities – 7

Speaking Engagements – 4

Fathers activities – 1

Workshops – 5

Training – 8

Social Gatherings – 8

Committee Meetings – 6

Mothers Activities – 5

Coffee mornings – 1

Support Parent Supervision - 3

Respondents could mark more than one activity

Training

36 Support Parents indicated that they found the training received to become a Support Parent appropriate for supporting the requester they had been matched with – 95%
2 Support Parents did not find the training appropriate – 5%

24 Support Parents have not attended further training sessions – 63%

14 Support Parents have attended further training sessions – 37%

Training covered: Behavioural, Governance and Management, Dyspraxia Conference, Committee Training, Refresher Training, Conference 2004.

Action: All regional groups will provide at least one refresher training course for Support Parents per year.

Previous Requesters:

19 questioners were sent out with 7 received.

Valued and supported

5 previous requesters responded that they felt valued and supported by Parent to Parent National Office matching staff – 71%

2 people did not answer this question

Awareness of services

4 previous requesters responded that they were aware of a Parent to Parent group in their area - 57%

1 did not know and 2 did not respond

From this 3 previous requesters have had contact with their regional group in the past – 43%

5 previous requesters were aware of the training to become a Support Parent – 71%, and 2 did not respond

All Support Parents

439 Support Parent surveyed, with 135 responding.

Number of years they have been a Support Parent:

1 year 13

2 years 10

3 years 11

4 years 11

5 years 13

more than 5 years 70

7 people did not answer this question

(graph following)

Involvement with regional groups

Activities organised by regional groups, which Support Parents attended:

Supervision	3	Training Session	19
Family Camp	10	Social Events	32
Sibcamp	3	Committee Meetings	7
Collection Day	1	Fathers Weekend	1
Conference	1	Fundraising	1
None	79		

Respondents could mark more than one activity
(graph following)

Note –some reasons for not attending:

- *Timing of events*
- *Transport*
- *Work*
- *Age of children – did not cater for older children*
- *Not appropriate*
- *Rural*
- *Don't need the support initially offered*
- *Lack of babysitters*
- *Unaware of activities*
- *Busy*

Action: Regional groups to ensure that the activities are appropriate for families whose children are teenagers and young adults

Valued and Supported

100 Support Parents indicated that they felt valued and supported – 74%

19 Support Parents indicated that they did not feel valued and supported – 14%

16 people did not answer this question

📌 Support Parents were asked about what would they like their regional group to provide, to support them in their role as Support Parents

- *That the training cover loss of a child*
- *Phone contact regardless if needed for match – other ways to be involved*
- *Refresher course*
- *Childfree catchups / nonfood related outings / training reunions – refreshers*
- *Feedback as to how individual matches went and ways to improve*
- *Newsletter / phone call annually*
- *Supervision*
- *Informal get togethers*
- *Social events for partners / guest speakers on topics related to special needs / family days / pampering days for stressed mothers*

📌 **Action:**

- Contact and feedback to Support Parent after requester match accountability has been made.**
- Further action required to better support and involve Support Parents.**

Training

47 Support Parents indicated that they attended further training – 35%

86 Support Parents indicated that they had not attended further training – 64%

2 people did not answer this question.

Regional Groups

9 questionnaires returned

Services

Regional Groups were asked if the services national office provides meets the needs of the group

	Yes	No	N/A	Did not answer
National Matching	8	1		
Disability/Health Info	9	0		
SibSupport Programme	8	1		
Telephone support and advice	7	0		2
Tollfree line	7	2		
Mailing labels	0	3	5	1
International matching	4	1	1	3
Insurance cover for assets	4	2	2	1
Organisational manual updates	9			
Support parent manual	9	0		
Support parent certificates	6	3		
Committee training	8	1		
Coordinator training	8	1		
Employment support	9			
Police vetting	8		1	
Journal lending	5		4	
Posters / pamphlets / bus cards	5	3	1	
Library books	8		1	
Badges	5	4		
Financial support	8	1		
Conference organisation	9			
Contract signing	8	1		
Funding application support	8	1		
Support for coordinator	8	1		
Display boards	9			
National newsletters	6	3		
Parent to Parent merchandise	4	2	2	1

Communication:

Asked how is the information shared with regional group members

Newsletter	4
Email	4
Committee meetings	6
Phone	2
Memos	2
Social Activities	1

Strengths:

Groups perceive their strengths as:

- Excellent Coordinator - knowledge and strong committee. Support for families through camps etc (other than core services), wide network of contacts
- Retention of committee members & support parents, secure, safe, permanent office space, opportunities for participation in social activities for families.
- Committee, Community support to families, Activities, Hospital packs, Newsletter
- Toy Library, Networking / Community
- Tenacity / strengthening group structure after no group or coordinator for over a month

- Strong, Supportive committee, Range of activities, Regular newsletters, Good communication, Toll free number, Physical location - central and helpful for networking, Excellent coordinator
- Regional Coordinator, committee, Support Parents, Volunteers, Fundraising supporters and donors, Growth within region. Range of referrals, Number of quality Support Parents. Family "in-kind" donations - support of committee's partners, Growing reputation. Diversity of activities tried. Diversity of experiences within the committee and group as a whole. Education for families and community through our Information evenings. More sound financial base
- Good at unrecognized support, Supportive activities, Good communication between committee and families, Have a motivated committee, Experience from long-term committee members, Many families enjoy coming to the outings that are offered
- Fantastic Activities, Camps, Resourceful in coming up with new ideas, Good at supporting each other, Very knowledgeable, Spreading resources within the community and networking, Increasing our profile, Social interaction, Friendships made over the past 12 years, History, New Committee - able to learn, woman's weekends, support groups.

Weaknesses:

Groups perceive their weaknesses as:

- Small committee, people's family/work commitments can make it difficult to get them together, very big geographical area, ability to stimulate Support Parents to attend events
- Refresher training - have been unable (to date) to implement this adequately over the past 2-3 years. Inconsistency of funding
- More committed volunteers, Planned structure in activities
- Lack of funding
- Funds - this being worked on.
- Apathy toward attending support group by families, Difficulty attracting new Support Parents, not acknowledging Support Parents.
- Lack of funding, Small amount of "untagged" funds for initiatives, advertising etc., Number of funding applications needed to be filed, lack of patronage to group events, low support for some fundraising events, Lack of representation on committee, some committee members reluctant to accept changes.
- President feeling unable to provide adequate support to Coordinator because of personal time constraints, Unable to attend all activities, Finding a service i.e. coffee mornings etc that can better service the needs of younger families
- Weakness in attracting committee members - newer families or families with younger children,.

Support Parents: *Respondents were able to mark multiple answers.*

New Support Parents are recruited by:

Local Paper	4
Local Support Groups	6
Previous Requesters	8
Personal contact	8
Family/whanau programme	3
Newsletter	9
Other	2
(graph following)	

Groups acknowledge Support Parents by: *Respondents were able to mark multiple answers.*

Invitation to events	3
Newsletter	3
Thank you cards	4
Appreciation evenings	2
Phone calls	2
Gift	1

(graph following)

Supervision provided to Support Parents by:

Coordinator	6
Facilitators	2

1 group did not answer this question

Toll/calls reimbursed

Yes	5
No	1

3 groups did not answer this question

In 2003 there were 22 new Support Parents

In 2004 there were 40 new Support Parents

Training:

Ongoing training offered to Support Parents

- Refresher training
- Ask Support Parents to notify coordinators of any pertinent training they have undertaken specific to their child's disability
- Invited to attend Coming of Age Conference
- Information evenings
- First aid training

☛ Privacy Act Training offered:

	Yes	No	Did not answer
Coordinator	1	6	2
Support Parent	2	6	1
Committee Members	2	6	1

☛ Action:

- Training for coordinators, Support Parents and committee on Privacy Compliance.**
- Introduce Privacy to Support Parent training course.**

Commentary

The aim of this objective was to ensure that the services provided by regional Parent to Parent groups are of a high calibre and consistent with the organisations policies, mission and philosophy.

Issues identified from the results involve the recruitment, support and ongoing training and development of volunteer Support Parents. Regional Groups have identified funding and attracting new committee members as concerns. Training for regional coordinators and committees will have a focus on these issues over the next 12 months.

Response from the questionnaire sent to All Support Parents was particularly high from those who have been a Support Parent for more than 5 years. While these people value their role within the organisation, they have not attended many of the regional group activities, as they have not considered them to be suitable for their stage in life.

Regional groups stated that 84% of services provided by National office meets their needs. This is an improvement on the last social audit.

"I really enjoyed the Support Parent Training course weekend, as I'm passionate about "giving back" to other parents in similar situations. My favourite though, was the Family/Whanau Carers Support weekend.

I have now recently become a Committee member. For me, this is an amazing step, as I had always been comfortable as a homebody. My husband, always takes on this role".

"Through the camps and Parent to Parent training and seminars I have attended, I have gained the knowledge, encouragement and desire to become a Support Parent myself which in turn benefits others.

Parent to Parent are invaluable in providing information packs on specific conditions to families and make superb efforts to match families of similar age and conditions so they can support each other. Their newsletters are full of helpful information, photos and stories of families who have triumphed and beaten the odds in spite of the serious setbacks they endure. Many of these families can identify with the saying "one step forward, two steps back".

Parent to Parent has certainly helped and supported our family in that we have grown in knowledge that in turn helps us to cope with life and all its trials. Knowledge is power, understanding and inner strength".

Feedback from Support Parents

OBJECTIVE 6: To ensure that all aspects of the organisations activities are consistent with the principles of the Treaty of Waitangi.

Indicators from Parent to Parent's Quality Plan:

- *Parents identifying as Maori indicate they feel valued and respected*

2001 Census showed that 1 in 7 people were of Maori ethnicity which equates to 14% of the total population.

What we did

167 parents requested matches and information in the months August, November 2004 and March, June 2005. Responses were received from 37 requesting parents.

98 Support Parents used in the 4 months were surveyed with 38 Support Parents responding and 7 previous requesters who have been involved in a match.

209 children who have brothers and sisters with disabilities attended 10 sibling support programmes which were surveyed for the social accounts. Evaluations were sent to the 152 parents of these siblings with 47 being returned.

Evaluations were passed out to all 46 participants who attended the Family/Whanau Carer Support programmes and 42 were returned.

9 Regional Groups were surveyed with 9 questionnaires returned.

What our stakeholders told us

Requesters:

37 questionnaires returned

From the 37 requesters that contacted Parent to Parent during the months of August, November, March and June: 25 (68%) people identified as NZ European, 6 (16%) as Maori, 2 (5%) as NZ European/Maori, 1 (3%) as Asian and 1 (3%) as Middle Eastern. 2 people did not answer this question.

17 (46%) people indicated that their cultural needs were satisfactorily met and 17 (46%) very much so.

3 people did not answer this question.

100% of Maori indicated that their cultural needs were met and that they felt valued and supported.

Support Parents used in the 4 months

Of the 98 questionnaires sent 38 were returned

■ From the Support Parents used in the months August, November, March and June 34 (89%) identified as NZ European, 2 (5%) as Maori and 1 (3%) as Indian/European. 1 person did not answer this question.

6 (16%) Support Parents undertook cultural training to support them in their role whereas 20 (54%) indicated they had no cultural training. Only one Support Parent indicated that this was provided by their regional group. 12 people did not answer this question.

■ **Action: Recruit more Maori parents as Support Parents.**

SibSupport N.Z.

152 evaluations sent out with 47 returned

From the 47 evaluations returned, 42 parents (89%) of siblings indicated that the SibSupport programme was sensitive and culturally safe for their child/ren and 5 parents did not respond (11%).

Family/Whanau Carer Support Programmes

28 Evaluations handed out with 26 returned

From the 42 evaluations returned, 84% of participants at Family/whanau programmes indicated that their cultural needs were met. 4% indicated that they were not met and 12% did not respond.

Regional Groups

9 questionnaires returned – 100%

Regional Groups were asked:

What cultural activities is available to families

Human Rights	1
Treaty of Waitangi	1
Respect for individual needs	1
None	4

2 groups did not answer this question

What cultural training for Support Parents

Treaty of Waitangi	2
Human Rights	1
Cross Cultural Awareness	1
None	4

1 group did not answer this question

Cultural Training for Committee Members

Committee Training	1
Cross – Culture Awareness	1
Human Rights	1
Treaty of Waitangi	1
None	3

2 groups did not answer this question

Cultural Training for Coordinator

Treaty of Waitangi	2
Human Rights	1
National Training	1
None	4

1 group did not answer this question

■ Only 1 group (11%) provided cultural training for coordinator, committee and Support Parents.

■ **Action: Cultural training for all staff and volunteers.**

Commentary

The aim of this objective was to ensure that all aspects of the organisations activities are consistent with the principles of the Treaty of Waitangi. All Maori service users indicated that the service they received was culturally safe and sensitive to their needs. The number of Maori families using Parent to Parent's service is slightly higher (16%) than the percentage of Maori in the population according to the 2001 Census.

Cultural training has been delivered at National Conference over the last 5 years and as a result of the previous social audit, a Maori cultural component was developed for the Support Parent training course and has been in use for about 4 years. However, cultural development of staff and volunteers at a regional level is required.

"Our family has been involved in various ways with Parent to Parent for several years and have accessed their advice and services on many occasions to our benefit. We certainly recommend to other families in need of help and advice that Parent to Parent can help, they are a vital source of information when needed and it is a great comfort to know they are there.

In the past our daughter has attended sibling camps, which have helped her to a great degree in learning to cope with her brothers' disability, life in general and in knowing there are other siblings who face these difficulties. They learn together that they are not alone and are given strategies in how to deal with problems that are 'huge' to them.

Our family has had the privilege of attending weekend camps where we meet other families with a common bond. These camps are invaluable to us, we gain and give support and can have fun in a non-judgemental environment".

Feedback from a Maori parent

OBJECTIVE 7: To ensure that Parent to Parent values diversity and creates a safe and caring environment.

Indicators from Parent to Parent's Quality Plan:

- *Parents indicate that they feel valued and respected in their contact with staff*

What we did

167 parents requested matches and information in the months of August, November 2004 and March, June 2005. Responses were received from 37 requesting parents.

What our stakeholders told us

Requesters:

From the 37 questionnaires 25 (81%) requesters felt valued and supported by the contact with national Office Staff throughout the matching process.

12 people did not answer this question.

■ From the requesters that contacted Parent to Parent during the months of August, November, March and June 25 (68%) people identified as NZ European, 6 (16%) as Maori, 2 (5%) as NZ European/Maori, 1 (3%) as Asian and 1 (3%) as Middle Eastern.

2 people did not answer this question.

17 (46%) people indicated that their cultural needs were satisfactorily met and 17 (46%) very much so.

3 people did not answer this question.

■ **Action: Recruit Support Parents from more diverse ethnic groups.**

Commentary

The aim of this objective was to ensure that Parent to Parent values diversity and creates a safe and caring environment. A high proportion of requesters (92%) felt valued and supported by their contact with Parent to Parent staff. The number of people from a variety of different ethnic groups who have accessed our services has increased. With the recent changes in demographics within New Zealand, it is important that Parent to Parent establishes relationships with different ethnic communities.

“Over the years, I became more and more involved. I always felt comfortable, valued and understood as a person when being amongst people from Parent to Parent. They also made me really laugh and giggle again. I believe in what Parent to Parent was trying to achieved”.

Feedback from a parent

OBJECTIVE 8: To be a good employer and maintain a high level of staff competence.

Indicators from Parent to Parent's Quality Plan:

- *No workplace accidents*
- *Staff feel valued and supported*
- *Management policies and procedures are implemented and their effectiveness monitored*
- *Parents indicate that they feel valued and respected in their contact with staff*

What we did

- 167 parents requested matches and information in the months of August, November 2004 and March, June 2005. Responses were received from 37 requesting parents.
- 17 Parent to Parent staff members were surveyed with 16 returned
- 439 Support Parents were surveyed with 135 responses received
- 9 Regional Groups surveyed with 9 questionnaires returned.

What our stakeholders told us

Requesters:

37 questionnaires returned

Valued and Supported

25 (81%) of requesters felt valued and supported by the contact with national Office Staff throughout the matching process.

12 people did not answer this question.

All Support Parents:

135 questionnaires received

100 Support Parents (74%) indicated that they felt valued and supported by Parent to Parent staff, 19 Support Parents (14%) indicated that they did not feel valued and supported.

16 people did not answer this question.

Regional Groups

9 questionnaires returned

Staff supervision

■ Regional Groups were asked to identify what supervision is undertaken by the Coordinator

- Informal peer supervision
- Bimonthly with trained supervisor
- Use own networks of professionals for support
- Private supervision with a counsellor on a 1:1 basis
- Use President and committee members also national office staff

■ **Action: Develop supervision procedure and access at varying levels for staff.**

Staff

From the 17 questionnaires 16 were returned, (5 from National Office and 11 from staff in the regions).

Who We Are

At the time of this survey Parent to Parent had 17 staff (1 male and 16 female), employed throughout the country. 6 staff work in National Office and 11 regionally. Of these 17 staff only 2 have been with the organisation for more than 3 years and 6 had commenced within the last twelve months.

Qualifications that some staff have are:

LLB, BSocSci

Papers towards BBS, BA, Sci Psy

Graduate Diploma in Not-for-Profit Management, Dip Tching

Papers towards Grad Dip in Not-for-Profit Management

Cert in facilitation in Community Groups, Nat Cert in Computing, Kiwi Host

Training:

All staff attend national training 2 to 3 times a year. Training is held over weekends and is delivered both internally and by trainers outside the organisation.

■ Training undertaken by staff since 1 July 2003

No Sweat Parenting	1
Committee Training	3
1 st Aid course	3
Treaty of Waitangi	1
Coming of Age Conference	5
President/Coordinator Training	7
Computer	2
Human Rights	1
Unitec	2
Personal Studies	1
Privacy Act	1
Disability Specific	5
Financials	2

■ **Action: Introduce 3 to 6 monthly, one to one training and support for all regional staff from National Office.**

Management policies and procedures are monitored and regularly reviewed.

There have been no work place accidents in the period.

Commentary:

The aim of this objective was to be a responsible employer and maintain a high level of staff competence. Actions developed from the 1999 social audit included carrying out an organisational review and looking at the roles and supports required for the National Board and CEO. This resulted in increased staffing levels at National office and in the regional groups. The National Board adopted a strict governance model of functioning, which resulted in a significant change in the role, and responsibilities of the CEO.

Results from these accounts show that in all areas of Parent to Parent's work service users feel valued and supported, indicating a high level of staff competence in their contacts with families. Apart from training delivered by National Office, the training undertaken by regional staff has not always been relevant to their key tasks. While

supervision has been undertaken the results have indicated the need for an organisational process for supervision /job coaching.

ECONOMIC IMPACT

Cost to provide Parent to Parent service:

Parent to Parent provided a service to 4546 people over the twelve month period from 1 July 2004 to 30 June 2005. A breakdown of the services provided is:

Matching and Information requests	1637
Support Parent Training	106
Training and Information Seminars	360
Family activities	1959
Sibling support	439
Family/whanau programmes	45
Total	4546 people

Expenditure for the year \$839,478

Cost to provide service per person: \$185

Volunteer Contribution

Matching with another family:

1003 Support Parents voluntarily supported families through our matching service over the year. The average time spent supporting a family has been calculated at a conservative estimate of one hour and the hourly rate calculated at \$16.00.

This gives a volunteer contribution of: \$16,048.

Sibling Support Programme:

44 volunteer leaders worked at the 10 sibling (8 weekend and 2 one day) programmes over the year.

5 volunteers per weekend programme of 25 hours, at an hourly rate of \$16.00 per hour, equates to \$2,000 per weekend programme.

2 volunteers per one day programme of 5 hours, at an hourly rate of \$16.00 per hour, equates to \$80.00 per one day programme.

This gives a volunteer contribution of: \$16,160.

Parent to Parent volunteers have contributed to other areas of our service but because we do not have the data we are unable to quantify this in economic terms.

ENVIRONMENTAL IMPACT

Parent to Parent is conscious of their environmental responsibilities within the various offices. Paper, envelopes and plastics are recycled, save power mode is used on photocopiers and computers, where appropriate double sided printing is done, and conservative use of air conditioning is encouraged.

Parent to Parent car pool for events, activities and training that families, volunteers and staff attend.

SOCIAL AUDIT STATEMENT 2005

Parent to Parent New Zealand Inc

The Social Audit Panel has examined the draft Social Accounts submitted to us and discussed them in detail with John Pearce of the Social Audit Network (UK), Carolynn Hull of Just Dollars Trust, Piet Vink of the Christchurch Small Business Enterprise Centre (CSBEC) and Lindsay Jeffs of Social Audit New Zealand at the Social Audit Panel meeting held on Wednesday 2 November 2005. I have examined the revised Social Accounts which were prepared following the Social Audit Panel meeting and which have taken into account various points identified in the notes of the Social Audit Panel Meeting.³ We also examined a sample of the data and the sources of information on which the Social Accounts have been based.

We believe that the process outlined above has given us sufficient information on which to base our opinion.

We are satisfied that, given the scope of the social accounting explained in the revised draft and given the limitations of time available to us, the Social Accounts are free from material mis-statement and present a fair and balanced view of the performance and impact of Parent to Parent New Zealand Inc as measured against its stated social and economic objectives and the views of the stakeholders who were consulted.

In the notes of the Social Audit Panel meeting we identified a number of important issues to be taken into consideration during the next social audit cycle. In particular we would refer to the following:

- i. The social objectives be re-examined, and if necessary updated to more closely reflect the services provided by the organisation.
- ii. A wider range of stakeholders be consulted about the organisation's performance as measured against its mission statement, statement of purpose and social objectives.
- iii. The impact P2P has on its clients be assessed and reported on.
- iv. Additional staff performance indicators be included.
- v. Consideration be given to using LM3 as a tool for assessing the financial impact of P2P.
- vi. Environmental policies and suitable indicators be developed.

The members of the Social Audit Panel⁴ were:

Lindsay Jeffs, Social Audit NZ (Chair)
Carolynn Hull, Just Dollars Trust
John Pearce, Social Audit Network (UK)
Piet Vink, Christchurch Small Business Enterprise Centre

Reviewed by Lindsay Jeffs:
Chair of the Social Audit Panel

Dated: 9 August 2006

³ The notes of the Social Audit Panel meeting form part of the Social Accounting and Auditing process and may, by arrangement, be inspected along with the full social accounts at the offices of Parent to Parent New Zealand Inc National Office, P O Box 234, Waikato Mail Centre, New Zealand.

⁴ Members of the Social Audit Panel have acted in an individual capacity.



ACTION PLAN

Parent to Parent New Zealand is indebted to our stakeholders for their honest and frank responses to the questionnaires sent to them. We value your comments and have identified a number of matters that need to be addressed and propose to pursue the following initiatives as priorities in the coming year:

- Inform each caller that matches are provided on similarities – Parent to Parent unable to match on exact condition.
- Ensure that follow up accountability calls to the requester are actioned within two weeks so that if necessary further action can be made.
- Offer to reimburse requesting parents calls to previous requesters.
- Introduce regular staff “outstanding requests” meetings to brainstorm with the wider staff group, possible actions for outstanding and difficult requests
- Ensure that matches are complete or other action taken within three weeks of initial request.
- Regional Groups to forward match requests to National Office daily.
- When requesters are unable to be contacted for follow up accountability calls, they will be contacted by letter
- Staff taking initial phone call to ascertain appropriate time for Support Parent to make contact.
- Feedback from facilitators to parents at the completion of the programme. This will be in the form of a newsletter.
- National Office to focus on PR in areas that are not covered by a regional group.
- Provide additional training and support to those regional groups, which had a low request rate.
- Send the latest newsletter and service information sheet to people requesting a match only, and to those attending sibling support and family/whanau programmes.
- All regional groups will provide at least one refresher training course for Support Parents per year.
- Regional groups to ensure that the activities are appropriate for families whose children are teenagers and young adults
- Further action required to better support and involve Support Parents.
- Training for coordinators, Support Parents and committee on Privacy Compliance.
- Introduce Privacy to Support Parent training course
- Recruit more Maori parents as Support Parents.
- Cultural training for all staff and volunteers.
- Recruit Support Parents from more diverse ethnic groups.
- Develop supervision procedure and access at varying levels for staff.
- Introduce 3 to 6 monthly, one to one training and support for all regional staff from National Office.



ACTIONS ALREADY IMPLEMENTED

- Contact with Support Parent after match accountability to “report back”, on how match went.
- Review request and follow up accountability process to ensure that all requests are dealt with within 14 days.

WHERE TO NEXT

Parent to Parent New Zealand wishes to raise stakeholder awareness of our Social Accounts and will post the report on the Parent to Parent Web page. The report will also be formally presented to staff and committee and summarised in our next National Newsletter.

Social Auditing is an ongoing process and the organisation will look at continuing the process over the next year using existing evaluations and requester feedback.

Social Auditing will allow Parent to Parent New Zealand to review our social objectives where necessary.

GLOSSARY

The following terms when used within the organisation have the following meaning:

Coordinator	Person responsible for the regional coordination of services to requesting families
Employees	Paid staff
International Match	Requesting parent is matched by National Office with a similar parent overseas
Regional Group	Groups affiliated to the National body of Parent to Parent New Zealand
Regional Match	Requesting parent is matched by local Coordinator with a Support Parent from the same region taking into account the child's age, ethnicity, gender, and type of support request.
Matching	See Regional Match and National Match
National Match	Requesting parent is matched by National Office with either a Support Parent or another parent nationally
National Office	The national office provides information, national matching, and support services to regional groups and geographic areas where there are no local groups
Previous Requesting Parent	Parent who has contacted Parent to Parent in the past seeking information and/or support
Requesting Families:	Parent, care-giver, or whanau who has contacted Parent to Parent seeking information and/or support
Social Audit	Process whereby an organisation can account for its social performance, report on, and improve that performance. It assesses the social impact and ethical behaviour of the organisation in relation to its own aims and those of its stakeholders.
Stakeholder	People or groups who are either affected by or who can affect the activities of the organisation
Support Group	Group existing to support person and/or families of those affected by a particular condition
Support Parent	Parent who has successfully completed the Parent to Parent Support Parent training course.
Support Parent Training:	18 hour training course covering skills essential for supporting parents of children with special needs
Volunteers	Committee members, parents, Support Parents, and others giving of their time or expertise freely.
Whanau	Family