

BARRIERS TO A DREAM

Issues of power and control in the
self-advocacy movement of
people with intellectual disabilities
in New Zealand

November 1994



This resource belongs
to People First.
If found wandering
far from home
please return it to us.

The People First Steering Group

~~PO Box 2017, Christchurch~~

1994

"Often service providers seem to want to empower people with disabilities to do all the things that service providers think they should do, but not those things that might offend them. Such power is never truly given; rather it is placed with the individual on a sort of conditional loan, payable on demand to those who exert real control over that individual's life."

Dick Sobsey: (1994) "Violence and Abuse in the Lives of People with Disabilities: the end to silent acceptance", Paul Brookes, United States, page 178.

"A revolution that truly empowers people with disabilities to make their own choice may or may not be in the best interests of parents, professionals, researchers and administrators."

Dick Sobsey: (1992) "Liberty, Equality, Community" in Network, Vol 2, No 1, NTRC, Kimberley, Levin, NZ

BARRIERS TO A DREAM

THE REPORT OF THE PEOPLE FIRST NATIONAL COMMITTEE SEPTEMBER 1993 - AUGUST 1994

TO: committee members, self-advocates, government, funding agencies, observers, and People First of Canada, and other supporters of independent self-advocacy for people with intellectual disability.

FROM: Derek Gosling and Ruth Gerzon,
advisers to the former People First national committee
P O Box 3017, Ohope, Eastern Bay of Plenty

DATE: 17 November 1994

Summary:

The first independent conference run by an advocacy group of people with intellectual disabilities was held in September 1993 in Rotorua. Ninety-six members chosen from 45 People First (and other self-advocacy) groups came from throughout New Zealand.

Discussions ranged over issues such as rights, labelling, community education, making decisions, workplaces and workshops, staff/client relationships, sterilisation, privacy, relationships, and the issues involved in setting up a national committee and what its role should be.

A national committee was elected with two members from each of four regions corresponding to the RHA regions. Eastern Bay of Plenty committee advisers, Derek Gosling and Ruth Gerzon, offered to advise the national committee until money was found to employ someone to do this. This offer was accepted.

Conference delegates asked the national committee:

- to look at a "union" for people with intellectual disabilities
- help new groups get started and support regional committees
- set up a constitution
- talk to government on behalf of all People First groups
- teach the community about the rights and abilities of all people with an intellectual disability

(See People First Conference Report 1993 for further details)

The Independent People First national committee established links with, and gained support and encouragement for its aims, from many government and voluntary agencies, and individuals (see acknowledgements in Appendix One for details). They made progress on many of the goals they had been asked to carry out on behalf of the people who elected them at Conference 93.

However IHC has registered the name "People First" and the IHC senior management would not permit the national committee to use the name "People First". Nor would they support any moves towards independence or any form of national co-ordination.

The committee met in August 1994 in Rotorua to discuss the implications of being unable to use the name "People First" and the lack of IHC support for national co-ordination or a national committee. They believed that without IHC support or the ability to use name "People First" they could not fulfill the aims and goals set at the People First Conference in Rotorua last year. This lack of support from the major body representing people with intellectual disabilities has resulted in the committee reluctantly deciding to disband.

While IHC remains the main service provider in the field of intellectual disability, and the national office of IHC will not let go of either the name "People First", or of their control of People First groups, independent self-advocacy would seem to be an impossible dream for the people who live their lives within IHC services.

The history of People First

Self-advocacy groups for people with an intellectual disability have been set up in many parts of New Zealand over the past nine years by IHC staff. In addition some self-advocacy groups were established independently. Each group has one or more 'advisers' - non-disabled people who support members.

Most groups called themselves "People First" after the Canadian parent organisation. Members see themselves as ordinary people, and put their abilities, rather than their disabilities, first.

Groups in many areas, however, began with a burst of enthusiasm but foundered or lapsed into becoming social clubs without a real focus on empowerment or self-advocacy for their members.

There still is no national constitution, philosophy or policy for People First groups, and little or no training for members or advisers. Until the conference there was no clear direction or national co-ordination of groups. Without national co-ordination and support for members and advisers many groups foundered or lapsed into being social clubs without a real focus on self-advocacy and empowerment for their members.

As one adviser to a group wrote: "IHC had many years to organise People

First.....I became frustrated with the lack of organisation and communication etc, which got worse not better.....by the time the Rotorua conference was notified all the People First here had died out.....much as I wanted to keep the groups functioning I pushed against a high tide.....it was the goal of the national conference to prepare for, the inspiration of the conference to get people activated and with knowledge and further goals, and the follow up from your committee which has encouraged us to go on....."

At the Donald Beasley Institute 'Empowerment' conference in November 1991, a keynote speaker was Peter Park of the Canadian People First. He stressed the importance of People First being nationally co-ordinated and independent of any service provider.

The events of the 1993/4 year

The Eastern Bay of Plenty group, inspired by the visit of Peter Park, took up the challenge of national co-ordination and organised the first national People First conference, held at the Keswick Centre in Rotorua 26 - 29 September 1993.

They gained the funding to do this from three sources: \$14,000 came from DSW (Innovations Fund), \$6000 from Internal Affairs (Lottery Welfare grant) and \$1000 from the Roy McKenzie Trust. Two members were selected from each group to attend the conference. In some cases where IHC branches did not have People First groups, delegates were chosen by IHC staff.

On opening the conference Katherine O'Regan, Assistant Minister of Health with special responsibility for disability, spoke of the importance of the conference agenda. She said, "You want to speak with your own voices and I think that is good."

Throughout the conference it was clear that this was what the delegates at conference also wanted. So what went wrong?

Barriers begin to be raised:

Pre-conference newsletters had been sent to all groups and to IHC's national office to keep everyone in touch with the organisation and planning. A pre-conference video was sent to every group to encourage them to consider the issues to be raised in their groups before their delegates left for conference.

All known People First groups had been invited to send two delegates each to conference. However some IHC branches without People First groups insisted they be permitted to send delegates and also IHC staff to support them. This resulted in many delegates attending who had no real knowledge of People First, and a large number of IHC staff attending as their supporters.

Independent facilitators had been arranged for small group discussions and a separate programme was set up for IHC staff, advisers and volunteer support

people. However some of the IHC staff insisted on listening in to the small group discussions, even after the majority of delegates had said that they did not want them there.

A senior manager of IHC attended the conference from the second morning and attempted to persuade the conference organisers that People First should stay under the IHC umbrella. However delegates decided they wanted a national committee of their own and agreed on a voting system.

The IHC senior manager then asked the advisers to change the voting procedure, already chosen by the delegates. He asked for a change to a vote from the floor so the person IHC hoped to see elected would be more likely to be chosen as chairperson. The advisers refused on the grounds that it was not their right to make changes to decisions already made by delegates.

Despite this, the vote was taken, a national committee was chosen, and Robert Martin of Wanganui was elected chairperson at the committee's first meeting the following day.

Duplication and confusion:

Soon after the Independent People First was set up by conference delegates, IHC's national office began to more actively organise self-advocacy by:

- * setting up a national self-advocacy committee (only a few months after the national People First committee began work);
- * setting up a national self-advocacy newsletter (again a few months after the Independent People First did just this)
- * employing Robert Martin as a paid staff member (shortly after he was chosen as chairperson for the Independent People First committee)
- * arranging for Robert Martin to travel through the country, along with a senior IHC staff member, Des Corrigan, to meet with groups (before the Independent People First committee could obtain the funding necessary to provide this kind of support for groups)

These actions by IHC duplicated the work of the national committee and led to considerable confusion in the self-advocacy movement among the people who receive IHC services.

A conflict of interest:

Robert Martin was clearly put in a difficult position, with his dual roles as People First chairperson and IHC staff member responsible for promoting self-advocacy. In 1992 he had written a paper which advocated independent self-

advocacy in which he wrote that if People First remained linked to IHC, "IHC could in some way control us People First would not be a true self-advocacy body If People First disagrees with IHC it may find it very difficult to argue its case." (a full copy of this paper is in Appendix Two).

The committee's attempts to resolve the differences:

It took some time to obtain funding to hold a second national committee meeting. The Minister of Social Welfare provided the finance for a meeting to be held in Wellington in May 1994.

At this meeting the committee decided that they wanted to remain independent of IHC. The committee felt that as an IHC staff member Robert Martin may not be able to give leadership to an independent committee.

Both the advisers and Robert Martin offered to leave the meeting so the committee could openly discuss a possible conflict of interest. The committee members decided to ask Robert Martin to step down from the committee as it appeared to members he could not separate out his role as staff person from that of committee chairperson. But as they valued his advice, the committee asked him to continue to attend meetings as an IHC Liaison Officer.

During the three day national committee meeting in May members met with senior IHC management, and with the new national self-advocacy committee that IHC set up soon after the People First conference.

People First national committee members made it very clear at this meeting that it was only at national level that independence was sought. This idea was supported by members of the IHC national self-advocacy committee. There was no question of local groups not being able to continue with the valuable IHC staff support many receive. The committee said no group should be put in the situation of having to choose to be part of "IHC" run groups or receiving support from an independent People First national committee. The national committee wanted to work alongside IHC as equals. This was also made clear to all groups around the country in the third national newsletter (see Appendix Three)

Yet only a short time afterwards, at a People First meeting, Robert Martin and his IHC support person were asking groups to choose between IHC support and being part of an independent People First.

A distressed and bewildered adviser sent the national committee' advisers minutes of a People First meeting held at IHC Central Regional Office on Monday 23 May 1994 from which the following excerpt is taken:

"Branches were asked at the last meeting if they wanted to remain in partnership with IHC or to join the Independent People First group."

Throughout the existence of the People First national committee, their advisers received regular correspondence from advisers to groups around the country. It became clear that, with Robert Martin and his IHC support person visiting groups around the country, that people were increasingly confused about the national committee of People First. Extracts from this correspondence are in Appendix Four.

The name - "People First"

The name "People First" was chosen for the national committee almost unanimously by the conference delegates. Although this name originally comes from the very independent national Canadian self-advocacy organisation, IHC has registered this name and has the legal rights to it in New Zealand.

The advisers to the national committee faxed IHC's national office on 2 June, asking whether the name could be used by the People First national committee. The reply from IHC stated this was not possible. A second letter was sent to IHC on 17 July asking for clarification of IHC's position on the future of People First. Their reply of 17 August was considered at the third national committee meeting in Rotorua on 21 August (this correspondence is in Appendix Five).

The committee discussed the option of continuing as an independent national self-advocacy group without using the name "People First". However they were elected by delegates at the national conference, who made it very clear that they wished the national committee to be known as "People First" (see page 26 of the Conference Report). They had no mandate to change either the name, or the direction of the committee.

IHC's plans for the movement:

IHC senior management made it clear they would not support a national committee, writing *"...it is envisaged that over time People First groups formed locally may move to be regionally co-ordinated, but principally the IHC view is to strengthen local groups as part of an overall umbrella"*.

In their letter of 17 August IHC suggested the national committee exist just to run national (and even international) conferences for People First groups throughout the country. The committee decided not to pursue this idea.

Conference 93 was a great success and boost to self-advocacy in New Zealand. Yet the main recommendation of delegates - that there be a national committee to carry out the goals they identified for themselves - has been unable to be acted on. The advisers felt it would be pointless to hold further conferences when IHC, as the main service provider, ignored and completely overrode the decisions made by the delegates at the 1993 conference.

Equally they felt it would be irresponsible to commit scarce resources and time to hosting an international conference when there is so much work to be done in

the People First movement in this country.

An alternative was to change the name and continue the committee's work to achieve the goals set at Conference 93. However this would not solve the increasing confusion among self-advocates. To have the movement pulled one way and then another leaves people manipulated and confused. This would not further the long term interests of self-advocacy.

330 Days: the work accomplished by the national People First committee and advisers:

The committee has been able to do the following things asked for at conference:

1. **Start a newsletter** - four issues were circulated and groups had begun to write in with their ideas on issues presented and news to share. The illustrated newsletter contained stories of self-advocates who had made changes in their lives, of issues of human rights, of funding sources, questions for groups to consider (such as the request from government for suggestions for an alternative name for the Invalid's benefit)
2. **Lobby with government for equal rights.** Several letters were written to government to place before it the feelings people voiced at conference. Over 130 copies of the conference report were printed and circulated to government, individuals and libraries in tertiary institutions, around the country and overseas.
3. **Support members and advisers.** Many letters from members and advisers were received and answered them with advice and help. Copies of the Canadian People First books for members and advisers were obtained and distributed to groups.
4. **Educate the community** The committee began to edit the video of the conference. They asked Eastern Bay of Plenty People First to complete this work. This will be an excellent resource for educating the community and staff of service providers. In addition, committee members have given talks to groups who want to know more about People First.
5. **Help new groups set up.** Some new groups wrote to the committee and were given information they needed to get going. The committee had planned to use the money offered by government to travel to support new groups if they had been able to continue.
6. **Established positive links with government and other advocacy agencies** with similar aims. Paul Curry and Julia Tinga of the Ministry of Health were supportive throughout, and advisers had begun to establish links with other disability advocacy organisations.

7. Obtain funding The committee were supported by a Lottery Welfare grant to help cover administration costs, and a grant from the Minister of Social Welfare enabled the committee to have its first national meeting. Two RHAs set aside money that could have been used to set up the organisation more formally if it had been able to continue, and negotiations had begun with the other two RHAs.

Where to now?

It is difficult to see where People First goes from here, but clearly there will be no further moves towards independence or national co-ordination while the senior management of IHC continue to hold their present views. It is hoped that this report engenders some debate among individuals, government and voluntary agencies that support independent self-advocacy. From this may come a way ahead that will enable people with intellectual disabilities to achieve human rights and freedom of speech.

This setback also does not negate the excellent work by groups in some areas where staff and volunteer support for independent self-advocacy remains strong.

Two Eastern Bay of Plenty People First members are continuing the work of editing the 1993 Conference video. Some extracts have already been used with People First groups and in training staff of disability organisations. It has proved to give a powerful message and will be a valuable tool for self-advocates and staff training.

Members and observers who attended Conference 93 know that the people are ready to speak up. Their voice cannot be silenced forever. One day their story will be told, in their words. One day the dream of truly independent self-advocacy for people with an intellectual disability in Aotearoa/New Zealand will be a reality.

Note from the advisers:

We did our utmost to help the delegates to the conference achieve their dream. Even with the support this movement received from many directions, the barriers were too high. We can do no more.

Our hope is, that with the present funding changes in the disability scene, self-advocates rather than service providers might be able to make more of their own decisions about the direction of their self-advocacy groups.

However we would welcome feedback from self-advocates, advisers, other voluntary advocacy agencies, government agencies, funding agencies, and all others on this report, and ideas for a way ahead. We will collate these for any future group that may wish to try again to make the dreams of the people a reality in the years to come.

Appendix One **Acknowledgements:**

We wish to acknowledge the financial support and encouragement of the following agencies and individuals:

- * The Minister of Social Welfare, who provided funding for the first national committee meeting in Wellington
- * Dr Keith Ballard (editor) and the authors of "Family, Whanau, Disability and Society", who donated the proceeds of their book sales in the first year to the national People First.
- * Lottery Welfare, who provided funding for administration
- * The RHAs, and especially Midland and Central RHA for their staunch support, patience, and advice.
- * The Ministry of Health for unfailing support and advice
- * Other staff and members of disability organisations throughout New Zealand and overseas.
- * People First of Canada, who wrote to support the national committee, enclosing a paper detailing similar barriers put in their way of their movement 20 years ago.
- * Volunteer advisers convinced of the importance of independent self-advocacy, who encouraged the national committee advisers and kept them in touch with what was happening around the country. Their help has been and will continue to be will be invaluable in the movement.
- * The many IHC staff at the grassroots and branch level who encourage independent self-advocacy, and who supported the advisers throughout a difficult year. Some spoke to us of their grief and bewilderment at the barriers that prevented the movement from continuing.

Many staff of IHC and other service providers, and volunteer advisers all over the country genuinely support people with intellectual disabilities having the freedom to determine their movement, their future and their lives. With their efforts, with government support and with the increasing numbers of people with an intellectual disability willing and able to stand up for their rights, we believe the goal of an independent self-advocacy movement will one day be reached in spite of the present set-back.

Appendix Two

A report written by Robert Martin in 1992

If People First is to be an effective voice for people with an intellectual handicap then the following needs to be discussed and put into action:

1 People First as a national organisation

To achieve this we will need:

"a written constitution to give us rules to work by."

"to know how we are going to organise ourselves."

This could be done in two ways:

We can try and make the present way we organise ourselves work by:

Each branch committee accepting responsibility of supporting a local People First branch which would include all people with an intellectual handicap. The Branch Committee could help us find suitable support people, not staff, and help us with the funding, as most of us have little funding of our own after paying out board fees. The Branch Committee could help us set up a committee so we can hold a meeting each month. At these meetings we could talk about the things that are important to us.

Each People First would then elect a member to the Regional People First Committee. The Committee should meet at least four times a year. It should help those branches that don't have a People First to get started. It should also talk about the things that are important to us.

Each Region could then be represented by say two people on a National Committee that could meet say two or three times a year. One of these meetings could be held at the same time as the IHC conference, which would allow more people to attend.

The advantages of organising ourselves like this are:

We remain part of IHC. It won't cost a lot of money. Branch committees can help their People First committee.

The disadvantages are:

We are not independent and IHC could in some way control us. People First would not be a true self-advocacy body. If People First

disagrees with IHC it may find it very difficult to argue its case.

or we could try a different way to organise ourselves by:

Asking DSW for money for a separate self-advocacy body. Many groups like Citizen Advocacy receive money to advocate for us so why can't we do it ourselves.

People First could use this money to set up a self advocacy group. This would be a small group of people who would be the national body and they would have to help us start groups throughout the country.

All people with an intellectual handicap could belong to this group.

We could call the national group say the **People First Self Advocacy Trust** or some other name we choose.

The Trust could help pay the costs of branches being set up

We could decide if regional committees were required or not.

The advantages of organising ourselves this way are:

We are independent.

We would be able to speak for all people with an intellectual handicap.

We could join with other advocacy groups that help other people with disabilities, for example, Disabled Persons Assembly.

The disadvantages are:

We would not necessarily have the support of Branch Committees.

We would have to find our own support and pay our own expenses from the money we may be able to get from DSW.

2 People First and IHC

People First should be represented on the Branch Committee with its own seat. This would mean that People First would elect their own representative. It would require a change to IHC's constitution.

People First should be represented on Evaluation and Monitoring Teams as self advocatess and to help people speak for themselves. This should be a requirement of all PREM evaluations.

People First should be represented as of right at all levels in IHC. This would mean that they would attend Conference and the AGM, either as delegates on in partnership as a separate group but joined

to IHC.

3. Funding of People First

Most members of People First have little money left over after paying their board fee.

People First could be funded either by:

- i) Separate funding by IHC. This could be part of fundraising or say a part of the money we pay to IHC for services could be made available to us.
- ii) Separate funding applied for through DSW similar to SAMS to pay for the costs of self advocacy.

It is very important that People First have its own funding so that it is independent.

4. People First in Action

To be effective People First must:

Have training to be effective self-advocates. Such training should be done by advocacy groups such as DPA rather than IHC.

The support of People First should come either from Branch Committee members, people in the community or other agencies such as DPA or Citizens Advocacy and not IHC staff.

People First must learn to speak for all people with an intellectual handicap.

People First should be part of DPA or Citizen Advocacy groups so they can share common problems and support each other.

People First must be supported to be able to become a self advocacy body. To do this a constitution is required and a structure or organisation must be set up.

All IHC branches must be required to support People First as an organisation until it is strong enough to support itself.

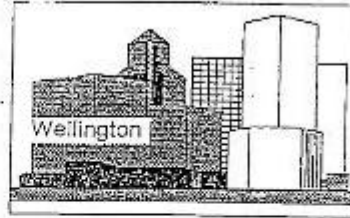
5. People First and DPA

The Disabled Persons Assembly could help us as they are mostly people with a disability and they should understand our problems. We need to join with other groups but many of the others like Citizens Advocacy provide advocates rather than help us to be self advocates. We do need this other help but also need to learn to speak for ourselves.

Appendix Three

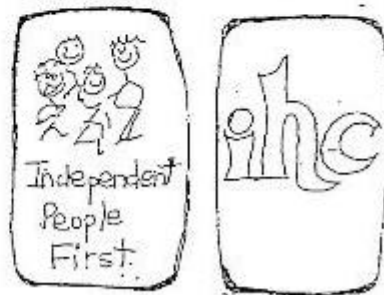
INDEPENDENT PEOPLE FIRST NEWSLETTER THREE - JUNE 1994

Your national committee met in Wellington in May.



Here are some things they decided:

1. That the national committee needs to remain independent
 - The national committee of People First wants to work alongside IHC and other groups that support people with intellectual disabilities as equals, not to work for them.
 - The committee will support all people with an intellectual disability (not just people who get IHC services)
 - the committee will get their own money directly from government and decide themselves how to spend it to support self-advocacy.
 - this does not mean any changes for your group. Some groups work closely with IHC and have good support from IHC staff. That is fine. It is just at the national level that the committee decided to be independent.



This meant the chairperson, Robert Martin, could not stay on the committee, because he now works for IHC, so he resigned. The committee thanked him for all his work for People First. They want to keep working closely with Robert, so he offered to continue to support their work as their IHC liaison person.

2. IHC now has their own Self-Advocacy Committee. The Independent People First committee met them in Wellington. The two groups talked of how they can work together to support People First and all self-advocates.



Your group can get help from both Independent People First and the Self-Advocacy Committee now.

Appendix Four

Extracts from letters to the national committee advisers from advisers to groups around NZ

The recent refusal by IHC's national office to let the People First national committee use their name was a major setback, but the more subtle and far-reaching barriers to the national committee achieving the goals set at Conference 93, has been the spread of misinformation. Evidence of how widespread this was is in the following excerpts of letters received from advisers. The names and places referred to have been removed or changed to protect the identity of the writers.

February 94:

"Much of the meeting was devoted to 'explaining' Independent People First in a much briefer and unrecognisable form. It was said that Independent People First worked from the top down with the national committee making all the decisions instead of the individuals in each little group deciding!.....They didnt make Independent People First sound bad but less self-advocating, when some of what was done at the meeting was fully IHC directed and not self-advocating, but probably not discerned by most self-advocates."

We were broken up into little groups.. John(an IHC staff member) was roving listening to each group. Melissa (an adviser) wanted to speak up about Independent People First - that it was not like what had been said, but wasn't sure what to do.....another person who had been at the national conference asked some questions but didn't feel able to speak out..."

March 94:

"It seems as if Richard (a self-advocate) cannot go anywhere without staff. John (IHC staff) came and spoke - things were said about the 'breakaway Independent group' and also anti the newsletter..... but the feeling here is that independence is still strongly sought."

Early July 94:

"We attended several meetings but were rather disillusioned by the major input of John (an IHC staff member) on behalf of Richard (a self-advocate) supposedly. We all felt it was very much an IHC point of view."

Mid July 94:

*"If the day had*been reported it would have looked like a perfect consultancy process...the organisers frequently stated that the people should choose support workers. Of course they chose IHC staff, who else did they know? I felt they had been manipulated without them suspecting a thing. It left me shocked and shaken...."*

Appendix Five

Copies of correspondence between the national People First committee
and IHC's national office



THE NEW ZEALAND SOCIETY FOR THE INTELLECTUALLY HANDICAPPED (INC.)

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IHC NATIONAL OFFICE
P.O. Box 4155
Wellington

Our Ref AD/OG/03

8 June 1994

Derek Gosling
~~Ch. Waikato Polytechnic~~
WHAKATANE

RE PEOPLE FIRST

Thank you for your fax of 2 June. The National Executive Committee of IHC met on Tuesday and discussed People First and the confusion arising out of the second organisation being established with a similar name.

It was agreed that the name People First remain the responsibility of IHC on behalf of self advocates and that we advise the Registrar of Companies at the Department of Justice that we do not approve of Independent People First being registered as a separate name because of the confusion caused and would cause.

People First is active in many parts of New Zealand and a quick check around the country shows over-whelming support for its continuation under the auspices of IHC with the butterfly as the logo.

There are other self advocacy groups in New Zealand such as Action on Self Advocacy and I would respectfully suggest that the group you are advising find another name.

I would like to repeat my suggestion at the meeting we had last month that there is a potential for an organising group to plan and run a national hui or conference for the various groups of self advocates from People First, Action on Self Advocacy and others and maybe you should concentrate on that aspect of supporting people with an intellectual handicap.

A copy of my letter to the Registrar of Companies is attached for your information.


J B Munro
CHIEF EXECUTIVE

Independent People First
Box 3017, Ohope
Eastern Bay of Plenty

17 July 1994

Chief Executive
IHC
Box 4155, Wellington

Dear Mr Munro,

Thank you for your letter of 8 June 1994 about the use of the People First name. Your decision has certainly created an interesting situation for our committee.

At the conference in Rotorua last year most delegates were very clear that they wanted People First to be independent of IHC. Consequently I am somewhat surprised by your assertion that there is "overwhelming support" throughout the country for People First continuing under the auspices of IHC.

I am equally surprised that you found it necessary to carry out such a survey after the national People First committee, which was democratically elected by representatives of all People First groups throughout the country, told you that they wished to be independent of IHC.

However, you have made it very clear that you will not permit this committee to use the name Independent People First although this name was decided by an overwhelming majority vote at the conference in Rotorua (see 1993 Conference Report page 26).

I have always felt that the encouragement and support of IHC is vital to the success of People First. It is now very clear that an Independent People First would not have IHC support at present.

A meeting of the committee has been convened to discuss the contents of your letter. It would be helpful for the committee, in their deliberations, if you were to provide them with an IHC perspective of where you see People First going in the future.

Presumably you support a national committee? If so, what is the role of such a committee and what is its relationship to IHC's self-advocacy committee?

The IHC publication, *Setting Up a Self-Advocacy Committee* (by Trisha Fitzgerald, 1986) states "it is important that the facilitator (for self-advocacy committees) is not a staff member and is independent of the facility" (Section

4:i). Does IHC still support independent facilitators/advisers for People First groups?

At the national committee meeting in Wellington, Robert Martin said that IHC did support independence for People First, but not for two or three years yet. Could you advise if this is still IHC's position? If so, what do you feel needs to happen before People First is ready for independence?

I believe that the people at the 1993 conference made it clear that they wanted independence, and feel an obligation to support them in reaching their goals. Equally I have no wish to see People First divided or becoming less effective through dissension or division.

Ruth and I have said, on a number of occasions, that we have no desire to continue long term, as advisers for the national People First committee. Personally we would be prepared to stand aside if we were assured that the movement was ultimately to become independent. We recognise that IHC support is vital for the success of People First and if that support is conditional upon the movement remaining, at least for the moment, under the auspices of IHC, then it may well be that this is what should happen.

Although I know you are extremely busy, I would appreciate a reply before our committee meeting, in the week beginning 15 August 1994.

Yours sincerely,



Derek Gosling
Adviser, People First National Committee



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IHC NATIONAL OFFICE
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File Ref: AD/0G/03

17 August 1994

Derek Gosling
Advisor, People First
PO Box 3017
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EASTERN BAY OF PLENTY

Dear Derek

Thank you for your letter of 17 July, and my apologies for tardiness in reply. I trust that your meeting this coming weekend will find my letter helpful.

IHC is The New Zealand Society for People With an Intellectual Handicap who are often called Self Advocates. The organisational name People First was registered by IHC to protect the name and to be developed as the framework for Self Advocates, irrespective of service provider, to meet at the local level to do those things Self Advocates wish to do, particularly in regards to rights, responsibilities and being heard.

IHC is an umbrella organisation with various strands, including service provision through four regional structures, 52 branches who carry out tasks of advocacy, promotion, self advocacy, funding and monitoring of services and in addition we have a number of interest groups such as Parent to Parent, Downs Association, Autistic Association to name but a few who are supported under the IHC umbrella.

There are clear lines of responsibility and communication and it is envisaged that over time People First groups formed locally may move to be regionally co-ordinated, but principally the IHC view is to strengthen the local groups as part of the overall umbrella.

We have appointed a fulltime National Co-ordinator of Self Advocacy, and part of Robert Martin's job is to promote and encourage People First groups for Self Advocates interested in being part of such groups. Our experience over the years suggests that groups rise and fall according to personalities and issues.

As indicated to you earlier, we see the need for a committee or task force to take responsibility for organising a national hui or conference of Self Advocates and their selected support people to bring together nationally, say every two years, Self Advocates from People First groups and similar groups from all over New Zealand to share information and have the chance through forums to endeavour to influence the decision makers. This periodic get-together does not require the setting up of a separate organisation that could lead to confusion and misunderstandings and conflicts of loyalties, but rather the acceptance by a core group of people willing to organise such get-togethers on a national basis. The current national committee of "Independent People First" and their advisors could well be that task force.

IHC is committed to support Self Advocates irrespective of where they live, work, recreate and spend their day through the ongoing support to Self Advocates and the development of People First groups. We do not employ staff already employed as residential or vocational workers to be People First organisers, advisors or support people, but we encourage staff, parents, friends as volunteers to take an interest in encouraging People First groups. Ideally there needs to be a separation of roles. However it is not always that easy to differentiate, but we must be constantly educating people to understand the need for the separation of roles.

Self Advocates must be free to choose their own support person, who should not be disqualified because they have as their support person a caregiver, teacher, parent or tutor who may also be working with them. Most people are mature and genuine enough to avoid any suggestion of conflict of interest.

In the area of monitoring services, I believe that Self Advocates should be members of key points and evaluation and monitoring teams and this is strongly encouraged by IHC with existing monitoring structures including training of self advocates to be part of evaluation teams.


I understand Robert Martin is joining you in Rotorua this weekend and he can speak for himself in regard to where he sees the future of People First. For me, we are all learning as we go along and the important thing is for Self Advocates to develop at their own speed and for the next few years the resources and enthusiasm should be put in at the local level, rather than topped down to develop People First groups.

My suggestion is that Independent People First does not set up as a separate or independent organisation, but the nucleus group, that you both played a key role, undertakes to provide a task force role to coordinate a national hui or conference in 1995 or 1996 and if successful could lead on to perhaps New Zealand hosting an international conference in the years ahead.

The support already indicated to you by CFA and RHA's would presumably continue to be available, and naturally IHC would assist. I have recently received a fax from People First Canada outlining their wish for bids to be made to host an international conference in 1996 and I attach that information for your information.

Kind regards,

Yours sincerely



J B Munro
CHIEF EXECUTIVE

Note from Ruth Gerzon, August 2024

Sadly, this attests to the reluctance of some disability agencies to give up their control of people with a disability willingly.

It was 10 years later that a change of personnel and policy led IHC to let go of their control of People First. They contracted me to support people with a learning disability to set up their national organisation, an organisation that still stands strong and celebrates its 20th year of independence this October.

I am re-publishing this paper to remind People First members of their history. Freedom and independence does not always come easily, and there is still a need for People First members and other advocates to support people with a learning disability to be heard when they speak up about their rights to choose how to live their lives.

Kia kaha, kia maia, kia manawanui

Be strong, be brave, be committed