

**A REPORT TO
STANDARDS NEW ZEALAND**

**YOUTH CONSULTATION ON
HANDBOOK DZ 8165
HEALTH AND DISABILITY SECTOR STANDARD
(CHILDREN AND YOUNG PEOPLE) AUDIT
WORKBOOK**

**BY CATHY MCGACHIE
14TH MAY 2004**

TABLE OF CONTENTS

ACKNOWLEDGEMENTS	3
INTRODUCTION	4
METHODOLOGY	5
A SUMMARY OF YOUNG PEOPLE'S COMMENTS ON THE PRINCIPLES.....	9
DISCUSSION ON THE UNDERLYING THEME AND IMPLICATIONS FOR THE HEALTH AND DISABILITY SECTOR STANDARD	13
RECOMMENDED CHANGES TO DRAFT HEALTH AND DISABILITY SECTOR STANDARD ...	14
APPENDICES.....	15
APPENDIX I: QUESTIONS AND STATEMENTS USED IN THE FOCUS GROUPS	16
APPENDIX II: INVITATION TO PARTICIPATE	18

ACKNOWLEDGEMENTS

I would like to thank the young people who participated in the focus groups for their willingness to contribute their ideas to the Health and Disability Sector Standard. Many thanks also to the two young people who facilitated the focus groups with me. I am yet again reminded of the enthusiasm and abilities young people have in involving themselves in matters that affect them.

Thanks also to the key people in each organisation who helped organise the focus groups. Without them the process would not have been so easy in such a short time frame.

I am grateful to the sub-committee from Committee P 8165 for their support and openness in sharing their networks of youth organisations.

My appreciation also goes to Rochelle Bradwell for editing and formatting this report.

INTRODUCTION

The Handbook DZ 8165 Health and Disability Sector Standard (Children and Young People) Audit Workbook is aimed at assisting all people who work with children and young people in their Quality Improvement programmes. The purpose of the Handbook DZ 8165 Health and Disability Sector Standard (Children and Young People) Audit Workbook (hereafter called the Health and Disability Sector Standard) is:

- 1) To establish the degree of attainment against the Health and Disability Sector Standard.
- 2) To identify areas of compliance, and/or areas requiring additional improvement in order to reduce risk levels and provide safe services to consumers.

The care for children and young people described in the Health and Disability Sector Standard is based on fourteen widely agreed principles. The fourteen principles are:

1. Children and young people's needs are paramount
2. Holistic approach
3. Family-centred care
4. Treaty of Waitangi
5. Culturally safe practice
6. Admissions to hospital only where necessary
7. Information, participation and involvement in care and consent (children and young people)
8. Information, participation and involvement in care (family)
9. Protection from unnecessary pain and distress
10. Accommodation, facilities and equipment
11. Staff skills and training
12. Play, recreation and education
13. Continuity and co-ordination between services and within services
14. Create long-term support systems centred on the individual

The Committee overseeing the Health and Disability Sector Standard considered young people's feedback important which led to the request that young people become involved in the consultation process. A process of youth consultation was to be conducted separately to the general public comment. The information in this report presents the comments from young people on the principles of the Health and Disability Sector Standard.

METHODOLOGY

Participating Young People and Organisations

A designated sub-committee of Committee P8165 discussed the selection of organisations and designed a criteria where there was a representation of young people who were geographically diverse, urban and rurally located, Maori, disabled and Pacific Islander. The final selection of organisations was dependent on the sub-committee members' networks and the availability of young people. Where some groups did not become involved, other young people were invited to participate. The final groups of young people involved in the consultation process belonged to one of the following:

- Asia Pacific Centre for Community Health and Development Research (AKI)
- Makoura College (2 groups) (Masterton)
- CanTeen (Northern South Island)
- CCS (Christchurch)
- Tha Crib (Invercargill)
- Two independent groups of young people (Wellington)

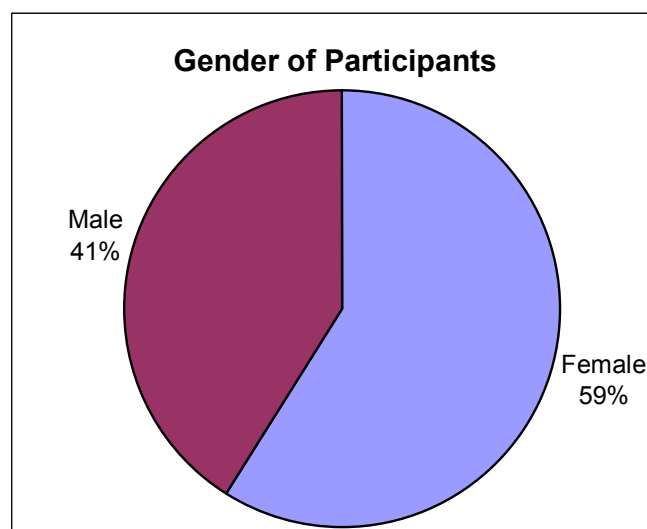
In total there were eight groups of young people involved in the consultation process, involving 51 young people in total.

A Profile of the Participating Young People

The following graphs and paragraphs explain the profile of young people involved in the consultation process. An explanation of the participants' includes gender, age, and ethnicity, whether they had been hospitalised, and whether they had a disability. The reason for asking about disabilities was to ensure young people with a disability were represented.

Graph One shows approximately sixty percent (60%) of the participants were female while approximately forty percent (40%) were male.

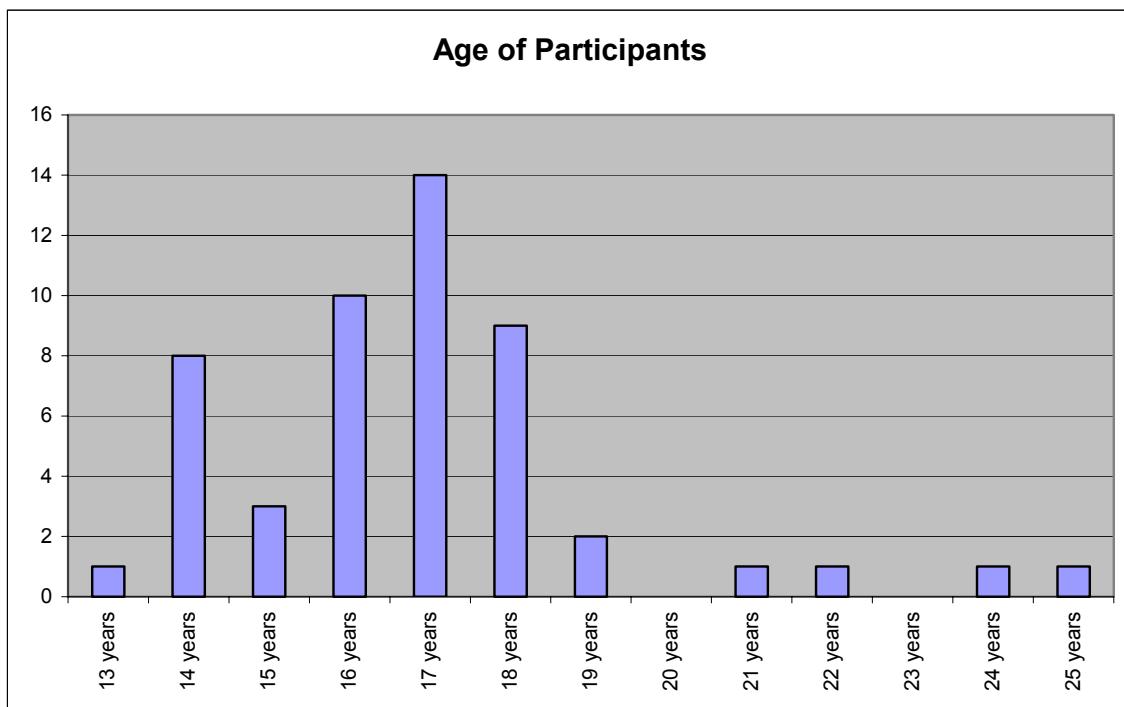
Graph One: Gender of Participants



It was important to know whether the young people were talking from experience in relation to hospitalisation. The response from young people showed that approximately sixty eight percent (68%) of the participants had been hospitalised.

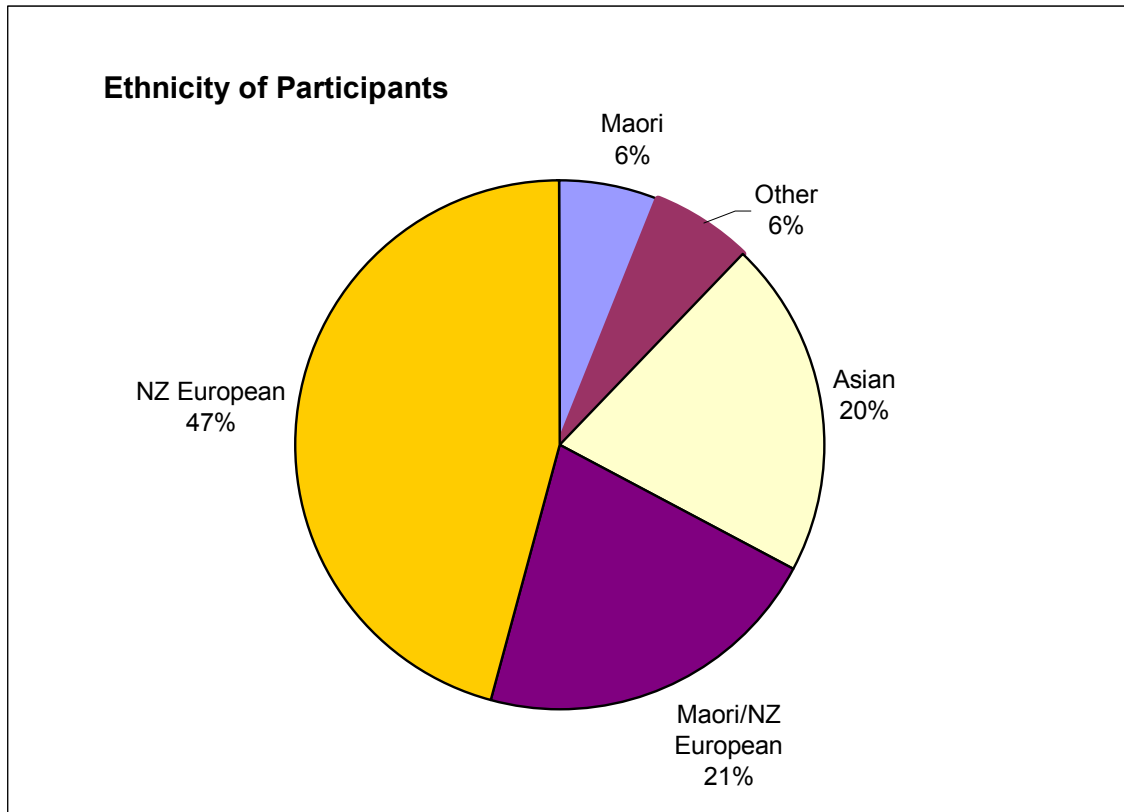
The young people ranged in ages from 13 to 25 years of age. Graph Two shows the spread of ages amongst the participants. While every effort was made to seek young people between the ages of 12 to 18 years, the groups organised for this project included those older. When this became known, it was considered more important to include the comments of the older participants than disregard them because they were not in the specified age range.

Graph Two: Age of Participants



The participants identified with a number of ethnicities. Graph Three shows the percentage of young people who identified themselves as New Zealand European, Maori, New Zealand European/Maori, Asian or British, Canadian, Pacific Islander (classified as 'other').

Graph Three: Ethnicity of Participants



The representation of young people with a disability was sought. Those with a disability constituted approximately twelve percent (12%) of the total number of participants.

Youth Consultation Process

Comments about the Health and Disability Sector Standard were collected from young people through focus groups. This face-to-face contact provided the best possible way to have a discussion about the Principles in the Health and Disability Sector Standard.

The Questions

Some of the fourteen principles could be combined together to give fewer questions for the young people to comment on. The fourteen principles were condensed into five main themes: ethnicity, family involvement, young person's involvement, staff interactions, hospital facilities and structures. These headings then formed the basis of the open questions used in the focus groups (see Appendix I). The first part of the focus group consisted of asking five open questions relating to the five core themes of the principles.

The second part of the focus groups asked for comment on a number of statements (see Appendix I). Twelve statements were then formulated from the fourteen principles and the young people were asked for their agreeance, disagreeance, or indifference, on the twelve statements. Some of the formulated statements were either negatively stated or positively stated. For example, 'Young people should receive their healthcare as close to or in their own home and community'; 'Young people should receive their healthcare away from their home and community'. Each focus group included two or three negatively worded statements. These statements were different for each group.

The inclusion of negatively worded statements gave validity to the information gathered.

After the young people gave their responses to the statements they were asked for their reasons for the responses given. This was conducted as a group discussion and not as an interrogation of individuals as to why they gave their response.

Procedure

An invitation to participate was sent to key people in known youth organisations. An example of the invitation to participate is in Appendix II. A follow-up phone call was made to each of the key people to ascertain their level of support for the consultation process. Five organisations were involved in the final consultation process. In addition, two independent groups were also organised.

The contractor was present at all focus groups and conducted the focus groups in the same way. Two focus groups also had one or two young people co-facilitating with the contractor. These young people met with the contractor before the focus group started. The purpose of this meeting was to let them know the process to be undertaken in the focus groups and to give them an opportunity to choose the parts they wanted to facilitate.

Analysis and Reporting

The responses given from the young people were analysed for patterns and themes. The emerging themes had implications for the fourteen principles. A summary of the themes and patterns are recorded in the next section. The information from the summary was then put into the format required in the public comment document. The recommended changes to the draft Health and Disability Sector Standards are attached.

Ethical Considerations

A number of ethical considerations were addressed throughout the consultation process. Firstly, all participants were informed of the main objective of the consultation, the process of the focus groups, and what the information would be used for. Secondly, participation was voluntary. Young people were invited to participate, not told. Participants were informed they could withdraw their involvement at any time during the focus group. Thirdly, confidentiality of participants was maintained. Individual names and personal details were not gathered at any point in the process.

A SUMMARY OF YOUNG PEOPLE'S COMMENTS ON THE PRINCIPLES

Young people did not comment directly on the Health and Disability Sector Standard document. Instead, comments were sought from young people through the reformulation of the principles as explained in the methodology.

The summary of comments is grouped by themes that correspond to the fourteen principles. These are presented below in conjunction with quotes from the young people.

Young People's Needs are Paramount (relating to Principle Number 1)

- A young person's needs being met should be a priority

"Because we have rights and we are the patient."

Holistic Approach (relating to Principle Number 2)

- Teens agreed that it would be good to take a holistic view of young people offering assistance where necessary. A holistic approach allows staff to get to know the patient better and therefore they can address health needs more accurately.
- Taking into account all aspects of a young person *"is important as they understand you physically and psychologically"*.

Family Involvement and Family-centred Care (relating to Principles' Numbers 3 and 8)

- Staff should not automatically assume the involvement of parents and family.
- A staff member needs to ask the adolescent patient if they want parents or family involved in any matters relating to them.

"It depends on the individual if they want parents involved or not, so just ask"

"If a young person doesn't want family there, then they should respect that"

- Adolescents would probably like to have their parents/family involved however they want to make that decision for themselves.
- Young adolescents are more likely to have parents involved in everything about their care than older adolescents.

"Family shouldn't be told anything without the young person"

"I was insulted when I was diagnosed because my family were spoken to and not me. I was 14 years old and told to stay outside while in the next room they had a meeting about me. I was really angry."

- Most young people want their parents to stay with them whenever possible or necessary

"I would want my parents to stay because I would not be so scared"

Treaty of Waitangi and Cultural Consideration (relating to Principles' Numbers 4 and 5)

- The majority of teenagers believed that culture should be taken into account when dealing with patients.

"Respect each person's background"

"The aim is to help you to get better, so if that helps then yeah"

"Some cultures have different beliefs that need to be respected"

"They should be treated in the same way they are treated in their culture"

*"Treat all patients individually (with own needs)
then you will treat them according to their culture"*

Locality of Healthcare (relating to Principle Number 6)

- Young people want treatment as close to their home or community. For those with long-term healthcare, then some would prefer to be treated at home.

"If I can have treatment at home that's awesome"

*"Having treatment near home is important because of family.
It is less traumatic for everyone"*

The Participation of Young People (relating to Principle Number 7)

- Young people want to have the opportunity to be involved in everything that affects them (and everything affects them).

*"Young people have rights and it is our health they are talking about
so we need to have involvement"*

"Our life, our bodies"

- Priority should be given to young people's needs – ahead of the involvement of family.

"Young people should know everything the family knows"

- Teenagers want clinicians to use words they understand. This means limiting the medical jargon and talking to them 'straight'. Relating to young people as though they are adults would promote equality and would influence the way the medical profession present information to the patient (i.e. not talk down to them).

*"They need to explain things plainly and what it means
so we know what is happening"*

"Don't talk down to us"

“We should be talked to with as much respect as an adult, but not using those fancy words. Otherwise, we come out knowing the same as what we went in knowing - nothing”

- A young person should be given the opportunity to give consent to treatment, no matter what age.

“We should co-sign with parents any consent forms that we are too young to sign by ourselves”

“Young people should be informed on all things that happen to them”

- Young people are different to children.

“Teenagers and children are different on all levels”

“Teens know more about their own thoughts, we use different language, we’re able to rationalise, we have different priorities, and don’t need our Mums and Dads around as much”

Least Painful and Distressing Situation (relating to Principle Number 9)

- Teenagers agree with the least invasive treatment as possible, although they do ask to be informed of all options of treatment.

“We want the easier treatment and we should be informed on all treatment available”

Facilities (relating to Principle Number 10)

- Young people wanted hospitals and other medical centres to provide facilities that were interesting and comfortable for their age group. They talked about a facility where they can relax such as TV, computer, music, games, etc. The aesthetics, such as coloured walls and couches, would also help.
- Teens suggested a teen facility where people their age are all together. They thought being in an adult ward or a children’s ward was not the best option.

“Let’s have things that make it more homely such as a TV that we can choose the channel”

Staff training (relating to Principle Number 11)

- Young people think it is necessary for staff to complete training on how to relate to their age group. In particular, teens want staff to understand their psychological needs as well as their medical needs. They also want staff who can talk in their language, know how to talk with them, are friendly, understanding and happy to be working with them.

“Qualifications don’t mean everything. Staff need to relate to young people”

“Staff need training on how to work with young people”

- Staff may be better equipped for being aware of young people's needs if they are educated on the development of young people.

"Staff should be open and caring and be knowledgeable on all things that young people have going on in their lives, including their emotions"

"Take us seriously"

"Treat young people equally to an adult, be more caring and aware of young people's needs"

Recreation (relating to Principle Number 12)

- Young people want a youth-friendly environment. This would help them feel comfortable and contribute more positively to the experience. Boredom was the main cause of any long-term healthcare plan. To prevent boredom they wanted games and activities and things to do during their time.

"I need something to play or do if I am going to be in hospital for a long time"

Working Together and Long-term Support Systems (relating to Principles' Numbers 13 and 14)

- Organisations and healthcare workers should work together to provide the best care for the patient. Certain aspects of a young person should not be shared.

"They can share ideas and give the best care for the person"

- A case manager such as a youth liaison officer should be appointed to a patient. This would ensure quality of care.

"If they had a youth liaison officer or youth manager that deals with all our needs then that would help"

DISCUSSION ON THE UNDERLYING THEME AND IMPLICATIONS FOR THE HEALTH AND DISABILITY SECTOR STANDARD

In all the information gathered during the consultation process, there is an underlying notion that warrants further explanation.

Many topics that recognise the typical development of a young person were discussed. The fact that young people were keen to be recognised more like adults than children, were adamant of the right to be involved in all matters pertaining to themselves, wanted to be the gatekeeper to family involvement, want staff to be well educated and knowledgeable on youth culture and able to relate to young people, reflected the typical development of young people. These ideas were interwoven into all themes, yet more strongly within the principles relating to the participation of young people, the training of staff, the involvement of family, and the accommodation and facilities provided.

The development of young people requires those working with them to treat them with as much respect as they would give an adult. Some examples are:

- being asked for their opinion
- being regarded as an equal
- being spoken to honestly and openly
- to have use of youth appropriate facilities
- being regarded as someone who has knowledge, feelings and opinions
- being consulted on all matters concerning them
- not restricting what they can be involved in
- ensuring they are included in the decision-making process
- to be supported by staff who understand how to relate to them

All these examples are typical developmental needs of a young person. There are many differences between children and young people and this must be made evident in the Health and Disability Sector Standard.

The ability to involve youth in the ways described above is not simply about ticking off an objective to meet certain criteria. Aotearoa/New Zealand has a requirement under the United Nations Convention on the Rights of the Child [UNCROC] to ensure children's and young people's rights are upheld. Particular to the topic of discussion are Articles 12 and 13, which state:

Article 12

States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.

Article 13

The child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice.

United Nations Convention on the Rights of the Child

The rights described above must be reflected in the Health and Disability Sector Standard. Every effort has been made to do this in the recommended changes to the Draft Health and Disability Sector Standard.

RECOMMENDED CHANGES TO DRAFT HEALTH AND DISABILITY SECTOR STANDARD

The comments obtained from young people related to the principles outlined in the Health and Disability Sector Standard. There are a number of suggested changes that reflect the thoughts and desires of the participants. These changes are worded so that it gives more emphasis on teenage development and the application of youth development.

To reflect youth development wider than the principles there are a number of suggested changes to the overall document. These mainly reside in the introduction, although some suggestions are also given in the sector solutions.

The attached document or attached electronic file titled 'SNZ suggested changes' gives the recommended changes to the Health and Disability Sector Standard in the format given for public comment.

APPENDICES

APPENDIX I: Questions and statements used in the focus groups

APPENDIX II: Invitation to participate

APPENDIX I: Questions and statements used in the focus groups

Part One: Questions used in the first part of the focus group

If you have to go to hospital and have some health problems attended to then:

- 1. How should you, as a young person, be treated (other than medically)?*
- 2. What is important for a young person when they go into hospital?*
- 3. How should a hospital be set up to make it more welcoming and appropriate for young people?*
- 4. Should the staff take a person's ethnicity into account when dealing with them?*
Why? Why not?
- 5. What about family? What involvement should family have with your treatment, being informed etc?*

Part Two: Statements asking for participant responses used in the second part of the focus group

(Please note: These statements have all been worded positively. Some of the statements used in the focus groups were re-worded to give a negative statement)

Options: Agree, Disagree, neither agree nor disagree

Staff need special training, knowledge and skills to work with young people

Young people's needs come first, not anyone else's (e.g. nurses, doctors etc.)

Staff should take into account all aspects of a young person (e.g. physical, emotional, psychological, spiritual, cultural and developmental)

All organisations that work with the young person should work together

Staff should take the opportunity to give advice and care on all sorts of health care as well as what the young person has come for

Young people want families to be involved in everything about their hospitalization and to stay with them whenever possible

A young person's ethnicity should be taken into account when receiving some sort of healthcare

When there is a choice, young people should be given the least distressing treatment possible

Young people should receive their healthcare as close to or in their own home or community

When in hospital, the equipment, facilities etc. should be appropriate to young people

Information should be given in a youth appropriate way

Young people should automatically be involved in giving consent, participate in decisions, be entitled to privacy of their care and treatment given

APPENDIX II: Invitation to participate

GAINING YOUNG PEOPLE'S PERSPECTIVE ON THE HEALTH AND DISABILITY SECTOR STANDARDS (CHILDREN AND YOUNG PEOPLE) AUDIT WORKBOOK

Standards New Zealand wants to ensure the quality of health services to children and young people. They are presently conducting consultation on a health document titled DZ 8165 Health and Disability Sector Standards (Children and Young People) Audit Workbook. This document will assist all people who work with children and young people in their Quality Improvement programmes. It will also be particularly useful for providers and designated Audit Agencies during the certification process associated with the Health and Disability Services (Safety) Act 2001.

The success of this document is reliant on feedback from those who work with young people and the young people themselves. The committee overseeing the development of the document has requested that young people be part of the consultation process and have the opportunity to have their voice heard through a separate consultation process.

I have been contracted by Standards New Zealand to undertake the consultation process with young people. I have both worked for several years in the youth sector, and have experience in youth development through community organisations and educational institutions. I am also Director of a youth participation consultancy business called Youth Works Ltd. I am committed to having young people's opinions heard and respected and I am pleased to undertake this work with Standards New Zealand.

The information gained from the consultation groups is primarily to advise the committee on young people's views on the draft document. It is intended that this information will influence the content of the final document. Feedback will be given to the participants of the focus groups as to the influence their comments have had on the final document.

I am seeking a group of young people to join in a focus group in your region. The focus group will be aimed at gaining young people's opinions and suggestions on the health service delivery for their age group. This will be guided by the content of the draft document, Health and Disability Sector Standard (Children and Young People) Audit Workbook.

What is required?

- To help co-ordinate a group of young people (6 - 10 people) who want to take part in a focus group (see below for an example on how to invite and inform young people).
- To find a suitable day and time for the young people to meet. Please liaise directly with me (see contact details below). It is hoped that the focus group will be conducted before 5th May 2004. It is intended that the young people be between the ages of 12 – 18 years inclusive.
- If possible, to organise the use of a room where the focus group can be held without interruptions.

The emphasis for this project is gain youth consultation on the document named Health and Disability Sector Standards (Children and Young People) Audit Workbook. I am asking for your assistance in co-ordinating a group of young people in your area who could be willing to participate in a fun and interactive session.

The following is an example of inviting young people to participate. This can be given to them or discussed verbally.

“You are invited to give your comment and opinions on how to work with young people in a health setting (such as in hospital, day surgeries, those receiving home care for a long time, etc.) Since you are a young person, your opinions are valuable as your comments will benefit all young people who use any health service. We need to get your side of the story and give you the opportunity to have your say on what you want and what would work for you if ever you were in hospital (or receiving any other short or long-term health care). Your opinions are important. Your opinions and suggestions will help guide staff on how to work with young people and how to provide for them. The information given from your session will be collected with other young people’s comments around the country. It will then be reported to a committee overseeing the final workbook that guides staff on how best to work with young people.”

What you may need to know and do:

- *the session is designed to be fun and interactive*
- *the session will be no more than 1.5 hrs long*
- *there is free food and drinks*

- *the facilitator will reimbursement bus fares or other transport costs related to and from the meeting (just ask the facilitator)*
- *participation is voluntary*
- *you will remain anonymous. Any comment cannot be traced back to you. No names will be used. However, quotes (comments word for word) may be used in the final report.*
- *all information given in the session will be recorded (in writing)*
- *you are invited to co-facilitate the group with Cathy (the person in charge of this project). She would meet with you for about 40 minutes before the focus groups to talk through the process. This may be on the day and just prior to the focus group. You can conduct as many of the activities and discussions planned as you like or you can just be back up for the facilitator. This is an opportunity to learn new skills in leadership within a group and gain a certificate for your C.V. acknowledging the support you gave in the project.*

What we need to do is:

- *arrange a day and time to suit you and the group (sometime within the next three weeks if possible)*

Where to from here?

Contact me when, and if, you have (can get) a group of young people together. Then fill in the form on the last page and e-mail back to me. It would be appreciated if you could give me at least one week's notice of the date.

Thank you for your support on the project. I look forward to meeting you. If you have any questions please do not hesitate to call me (details below).

Kindest regards,

Cathy McGachie

Telephone: 021 238 8403

Email: youthworks@xtra.co.nz

Please complete and send back to me – youthworks@xtra.co.nz

Your Name:

Where are you from? (org., school, community group, etc.):

Contact Phone Number:

E-mail Address:

Intended date for the session:

Times allocated:

Where the session will be held:

Number of young people willing to participate in the session:

Name of anyone willing to co-facilitate with Cathy:

Please place a tick in the brackets if the following statement applies to you:

The young people have been informed of the project in the way similar to the example above. []

Thank you.

Kindest regards

Cathy McGachie