Not Just Another Participation Model...

Guidelines for Enabling Effective Youth Consumer Participation in CAMH and AOD Services in New Zealand

2nd Edition

2009
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The Werry Centre for Child and Adolescent Mental Health Workforce Development
www.werrycentre.org.nz
# Guidelines for Enabling Effective Youth Consumer Participation in CAMH and AOD Services in New Zealand

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Shona Clarke
Project Leader
National Youth Consumer Advisor Project
The Werry Centre for Child and Adolescent Mental Health Workforce Development
“There is growing recognition that mental health services need to value and empower service users as genuine and respected partners in all aspects of policy and workforce development, planning, service delivery, monitoring and evaluation.”
EXECUTIVE SUMMARY

This resource is for anyone who is interested in youth consumer participation or who works with or in a CAMH or AOD service. This includes funders and planners, management and clinicians. These Guidelines will be most beneficial for those who will take the leadership and responsibility for implementing and developing effective youth consumer participation in their service.

Firstly, the many benefits and what is to be gained by youth consumer participation for both services and young people are discussed. For example, effective youth consumer participation can save your organisation money and can help boost young people’s confidence.

The key component of these Guidelines is the model of youth consumer participation – The Youth Consumer ParticipACTION Model which is implemented in three phases. The first phase ensures that management and staff are on board and supportive of the idea of youth consumer participation and are motivated to develop it. In phase two a minimum of two Youth Consumer Advisors are then recruited, ensuring retention strategies are in place. The third phase involves Youth Consumer Advisors developing, recruiting and facilitating a Youth Consultation Group who provide a youth voice with a say in service delivery and development. It is also important that Cultural Advisors, staff mentors and external supports are available to assist Youth Consumer Advisors.

There are many other strategies that could be put in place within your service that can support active youth consumer participation. This includes tips around meetings, communication with young people, staff attitudes and resourcing for youth consumer participation.

If you’re wondering “why do we need to have youth participation?” - check out Section Four which covers all the policies, strategic documents and literature highlighting the need for youth consumer participation.

Finally, ways in which to minimise the barriers that your service or young people may face in youth consumer participation are stated. It can be especially difficult for young consumers to participate in CAMH and AOD services, however there are also many ideas of how to reduce the effect these barriers might have.

Section Five includes ways in which to minimise the barriers that your service or young people may face in youth consumer participation. It can be especially difficult for young consumers to participate in CAMH and AOD services, however there are also many ideas of how to reduce the effect these barriers might have.

It is vital for Māori youth to also have a voice in the development and delivery of services to improve their access and meet their needs. Section Six describes how youth consumer participation can be implemented to ensure services are provided that are responsive to young Māori.

Finally, Section Seven describes an approach that can be used to develop youth consumer participation that ensures Pacific young people can contribute in an effective way to influence service delivery and development.

So - hocus pocus, now make youth consumer participation a focus!
INTRODUCTION

Not Just Another Youth Participation Model...

These Guidelines recommend an organisational process for implementing youth consumer participation in Child and Adolescent Mental Health (CAMH) and Alcohol and Other Drugs (AOD) services in New Zealand.

The concept of ‘youth participation’ is currently a developing initiative around New Zealand and worldwide, and the development of ‘youth consumer participation’ is just beginning to jump onto this wave.

The five sections within the Guidelines outline:

• the benefits of youth consumer participation
• an ideal model for effective youth consumer participation
• strategies to ensure active and effective youth consumer participation
• evidence for youth consumer participation
• identification and minimisation of barriers for effective youth consumer participation

These Guidelines have been developed from; the experiences of youth mental health services predominantly in New Zealand and Australia, consultation with young consumers, and a review of the relevant literature.
Youth consumer participation is mandatory for CAMH and AOD services. Documents such as the *Blueprint for mental health services in New Zealand: How things need to be* and *The National Mental Health Sector Standards* both articulate that services are required to have consumer participation, and the *Blueprint* states there should be 0.4FTE consumer roles per 100,000 people in the 15-19 years age bracket. Article 12 of the United Nations Convention on the Rights of the Child (UNCROC), which New Zealand is a signatory to, expresses that young people need to have a say in the decisions that affect them. The Treaty of Waitangi is also important in terms of the principles of partnership and participation and it’s expression through rangatahi being involved in the services they use.

So let’s be clear - CAMH and AOD services need youth consumer participation as it’s beneficial for everyone. If it’s good enough for Mr Ford and Bill Gates to consult the people that use their products/services, then it’s got to be good for mental health services. By giving young people the opportunity to contribute to the decisions services make that directly affect young people, they can contribute to service development in a positive and meaningful way. Being given the opportunity for leadership, developing assertiveness, and being listened to and respected can be very empowering for a young person, especially as many young people who have used mental health services often report feelings of isolation and oppression.

The model of youth consumer participation – The *Youth Consumer ParticipACTION Model* can be implemented in three phases. The first phase ensures that management and staff are on board and supportive of the idea of youth consumer participation and are aware of the benefits of a youth voice in services. In phase two, a minimum of two Youth Consumer Advisors are then recruited to two paid, part time permanent roles. The third phase involves the development, recruitment and facilitation of a Youth Consultation Group who act as the key conduit for providing a youth voice in service delivery and development. External support people, Cultural Advisors and staff mentors need to be available to support and advise Youth Consumer Advisors to reduce isolation, encourage retention and assist in professional development.

**Background**

**National Youth Consumer Advisor Project**

The Werry Centre for Child and Adolescent Mental Health Workforce Development commissioned Mind and Body Consultants to research consumer and family involvement in child and adolescent mental health services in 2004. The scope of the project included reviewing the workforce needs of people working in Consumer Advisory roles in the CAMH and AOD service sector.

Findings revealed a lack of Youth and Family/Whānau Consumer Advisors and a lack of processes for the recruitment and retention of these advisors in CAMH/AOD services. The report recommended the development of a resource to support the growth of this role in within these CAMH/AOD services. The current project and this document are the response to this recommendation.

The three key outcomes of the National Youth Consumer Advisor project are:

1. Establish a national support network of Youth Consumer Advisors that will share information and encourage youth consumer participation.
2. Develop guidelines for services on best practice to enable effective youth consumer participation.
3. Develop a workshop based on the guidelines to be delivered by three young people to CAMH and AOD services in New Zealand.
Consultation Process
An integral component of developing these Guidelines was the review and critique of the evidence available relating to best practice in the consumer workforce including:

1. Acknowledgement of the author’s experience as a CAMH service consumer and a Youth Consumer Advisor;
2. An extensive national and international search and review of the relevant research and literature;
3. Interviews with representatives from services who have some form of youth participation;
4. A one-day youth forum, attended by young people in consumer roles or consumer groups from around New Zealand.

This resource aims to be inclusive of different cultures, though each service will need to adjust the way youth consumer participation is undertaken to meet the needs of the diverse range of young people in their service. It is also evident that more research needs to be undertaken around consumer participation specifically for Māori and Pacific young people.

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**Case Study: Organising a youth forum – Werry Centre**

A youth forum was organised as a means of gathering lots of information and ideas from young people for the development of this document. In the style of youth participation – the forum was youth initiated and youth led, and supported by adults. In deciding on the agenda and the topics to discuss, it seemed important that we had fun, and that everyone who came along got something out of it. A venue was picked that was youth friendly i.e. not a boardroom or professional looking space. An email invitation mailout (visually appealing of course) was sent to a diverse youth consumer network and then later followed up with phone calls asking young people to suggest others that would be interested in coming. There was a lot of organising to make sure flights and taxis and any fears were sorted out for each young person – however it was very worthwhile. The day involved interactive activities and was run by a young person and a youth-friendly adult. What was ascertained was not only a really good idea of what young people thought was important and what was needed, but many of the young people felt inspired by meeting others who did a similar thing and experienced similar barriers. All the participants were keen to stay involved and meet up with each other again. All were given a voucher to show our appreciation of their input, as well as all flights/transport paid. A total of ten young people came from five different areas around the country.

“*It was great to get everyone together to know we are not alone!!*” - youth forum participant
**Key Terms**

**Young people/person or youth**
For the purposes of this document, young people are those aged 13 to 25 years. The issues relating to children participating in services are complex and need to be addressed fully elsewhere.

**Youth Consumer Advisor**
A general term for a young person who has had experience of a mental illness, used a CAMH or AOD service, and is now participating in some way in developing and improving service delivery. This term will be used in this document to cover the range of roles that currently exists. Some of the terms that have been used include; ‘Peer Representative’, ‘Youth Advocate’, ‘Youth Representative’, ‘Consumer Advisor’ (though relating to a young person). The term ‘Youth Consumer Advisor’ has been chosen as it is seen as the most accurate description of the participatory role young consumers should have in services.

**Consumer**
A person who has or is currently utilising a mental health service due to a mental health issue. They are also commonly called; ‘tangata whaiora’, ‘tangata motuhake’ or ‘service users’.

**Participation**
Taking a key part and being actively involved in a youth mental health service. There are different levels of participation in a mental health service - individual treatment, organisational level and policy levels. While having a say in individual (your own) treatment/care is essential to recovery, this document is focussed at the organisational level.

**Advisor**
Provides advice and recommendations to management and staff from an ‘expert youth consumer’ perspective.

**Advocacy**
Standing up for and being the voice for others. Advocacy in consumer participation usually means highlighting times when someone’s rights have not been respected or are overlooked. In consumer participation it can often mean liaising between staff and consumers who have grievances with the service.

**Representation**
Representing and articulating the voice of other young people with similar experiences. Since it is impossible to represent the views of all youth consumers, the term ‘advisor’ is preferable to ‘representative’.

**Youth Consultation Group**
A diverse group of young consumers who your service and your Youth Consumer Advisors can use as a reference group to obtain a fuller and more representative youth consumer perspective to ensure services are reflecting young people’s needs (see Section Two for more detail).

**CAMH Service**
Child and Adolescent Mental Health Service which includes both District Health Boards (DHBs) and Non-Government/community Organisations (NGOs).

**AOD**
Alcohol and Other Drug services.
SECTION ONE:

We’re not in Kansas Anymore - Why Youth Consumer Participation?

This section concentrates on the benefits and reasoning for why youth consumer participation is needed. It discusses what both young people and services gain from effective youth consumer participation processes.

Participation is a fundamental right for all people, whatever their age. Young people can shape their futures and our society right here and now, a fact that is evident everywhere. It is unethical to withhold this right from those who may be less assertive. As a significant number of CAMH and AOD service stakeholders are young people, the degree of their involvement indicates how willing a service is to acknowledge the specific issues and needs of their key stakeholders. Furthermore, the youth development principle of working with young people rather than for them is reflected in effective youth participation.

Benefits 4 Young People

Effective youth participation is reported to help young people build confidence and self esteem by giving them the opportunity to influence things that affect them. Young people offer a unique perspective and, through being taken seriously, will feel valued and appreciated in their role as Youth Consumer Advisor. Taking an active and independent role is often empowering for a young person and can be a significant influence in promoting recovery.

Youth-friendly services are more likely to appeal to young people, helping to gain their trust and making a positive difference in their lives. Effective participation breaks down barriers between young people and adults, promotes positive attitudes, and encourages adults to be more aware of the myriad of issues that young people face. Participation also promotes a young person to be more aware of the environmental and organisational issues that affect them, which can help them take action to maintain their wellbeing and promote that of their peers.

“We had the chance to impact hundreds of people. It was empowering and overwhelming – a privilege and a responsibility to do it well.”

Benefits 4 Services

Often decisions within mental health services are made in upper management by a small group with limited consultation with other people, specifically young people. Effective youth consumer participation ensures services and policies are more responsive to young people’s issues, needs and strengths. This means more efficient allocation of resources and a reduction in costs as services are better targeted. Additionally, youth consumer participation can assist services to attain organisational goals and maintain the standards of a quality service. Essentially – youth consumer participation can save your organisation money!

Case study – saving money

One Youth Consumer Advisor in New Zealand described how her active involvement saved their organisation money. A group of staff and the Youth Consumer Advisor decided to develop a psycho-education resource. The Youth Consumer Advisor developed the content, with lots of consultation with other young people and a number of staff. When the content was decided on, a couple of staff worked on the layout and presentation. When the Youth Consumer Advisor saw the result, she said that it wouldn’t appeal to young people, and would not get picked up. She took it away and worked on it and made it more colourful and youth appropriate, which the staff approved of. After publishing the resource there was much positive feedback and many young people picked the resource up, so many more copies needed to be printed. This is one case where the service may have otherwise organised an evaluation of the resource when they discovered it wasn’t being used and had to re work the resource, costing more money. It is evident that the Youth Consumer Advisor saved the organisation money by ensuring their resource would appeal to young people and be utilised by them, getting it right first time.

Young people are an asset to a service as they contribute enthusiasm and energy, motivating others to consider approaches and ideas ‘outside the square’. By young people being involved, services can also be appropriately challenged and organisational cultures transformed to better meet the needs of those for whom services have been set up to support - young people!

More effective ways of ascertaining client satisfaction means that services will prevent the likelihood of the ‘revolving door’. This is where young people continue to re-enter the service for whatever reason. Access to your service will also be improved, and youth consumer participation can help to build a more democratic and effective organisation.

Ensuring that young people can enhance the delivery of a service improves a service’s integrity and credibility. Services become more accountable and young people foster a stronger connection to the community, all of which are beneficial to the organisation.

“...the involvement of young people can help to highlight the necessity for introducing new services and can bring new energy and ideas to an organisation.”
To be honest, there are some roles that are better suited to young people’s skills and knowledge than adults. An ideal position is in facilitating a Youth Consultation Group to comment on service delivery from a youth perspective. Young facilitators are easier to relate to for young consumers, speak a common language and are often seen as ‘peers’. Sometimes young people can notice and suggest ideas that may have been missed by other staff members. They could also be involved in research as they have the advantage of more easily recruiting their peers for the research and disseminating the results to this group.

Youth consumer participation also highlights the potential to develop interagency relationships with other organisations that are involved in youth participation. In regions of New Zealand that have a number of youth mental health services (specifically DHB or NGO services that are already linked in with each other), it could be helpful to work together. Both young people and adults could meet on a regular basis for information, support and to work on projects that affect the whole region.

**Case study - working together**

One DHB has a number of CAMH services. The young people who advise each service meet regularly to discuss what they’ve been working on and support each other, as well as attending a meeting made up of staff and Family Consumer Advisors from each service to discuss regional issues, policies and service delivery. Collectively they decided to develop a kit for young people and their families just entering one of the services. They discussed the information that would be helpful to be included and collaboratively compiled the resource.

"Youth consumers as representatives remind us again of the multiple dimensions to the lives of those who seek agency services. In very practical ways they narrow some of the gaps in perspective that will develop between staff and service users due to the experience of mental health difficulties, and usually very significant age differences. We have benefited in our service with the Youth Reps undertaking social support groups for consumers as well as accessing the perspectives of our consumers about service adjustments which would suit them."

- Keith, staff member within a DHB
SECTION TWO:

Model (but not the supermodel type) - Youth Consumer ParticipACTION Model

This section describes a model that can best enable effective youth consumer participation in CAMH and AOD services. It has been developed based on the evidence found in the course of this New Zealand wide project.

It is able to be implemented over three key phases to ensure effective youth consumer participation. These include:

- developing a philosophy
- recruitment and retention
- supporting active participation

To guarantee that youth participation is not based on the personal commitment or whim of individuals and to ensure sustainability, a commitment to youth participation has to be clearly stated in all key documents of a service - policies, strategic plans, vision and/or mission statements and outcome measures. From there begins the process for legitimate youth consumer participation.

Different models exist which seek to enhance and ensure youth participation. An Australian organisation, Youth on Board\(^8\), has described an ideal model of participation with at least two young people involved at management level and a youth advisory council that informs and supports those young people, but also has involvement with identified projects. Both youth roles have clear responsibilities and reporting structures and this model has been successful for many organisations, particularly in Australia. The Youth Consumer ParticipACTION Model described in this document builds upon the existing knowledge (outlined in Section Four), including the Youth on Board model, and reshapes it to fit the New Zealand mental health sector and young people.

Young people have articulated their preference for a mix of both project work and providing advice as key components of youth consumer participation\(^9\). Additionally, different organisational structures allow for
flexibility in youth decision-making ensuring everyone can participate regardless of education levels and knowledge of the mental health sector. The Youth Consumer ParticipACTION Model allows for this to occur.

Currently many New Zealand mental health services are engaging in varying levels of youth consumer participation. Staff and management commitment to, and prioritising of, youth consumer participation will differ across services. The Youth Consumer ParticipACTION Model encourages effective processes to enable active youth consumer participation in your service. It can be implemented over time and begins with the development of an organisational philosophy of participation.

It is worth acknowledging that developing consumer participation will take time and fine-tuning to ensure its effectiveness. With training, retention strategies and growing familiarity with a service’s processes, Youth Consumer Advisors will develop their skills and knowledge, and become involved in more complex and ‘senior-level’ aspects of your service such as peer supervision and policy development.

Example of the recommended model in practice
A New Zealand NGO has a youth consumer participation model similar to that recommended in this resource.
Two young people are employed as paid Youth Consumer Advisors. They facilitate a youth governance group made up of young people with some form of experience of mental health issues. They advertised and recruited members through schools and other organisations, with catchy youth friendly statements on posters. The group’s aim is about improving the youth mental health system through asking the question: “what kind of services do young people want and need?” They also want to normalise the concept of mental health in society, particularly for young people. The governance group informs the two Youth Consumer Advisors about what they would like to see happen, who then go back to management to inform them on what can be improved. The young people hope that in the future they can offer their youth consumer perspectives to other organisations as well.

“It wasn’t until a couple of years into my job that I realised that only a handful of staff came to me for a youth consumer perspective and input into their projects, and the rest stayed an arm’s length away. I think that my role was largely misconstrued, and people thought I was there to catch them out or something. It wasn’t the case though, I was there to help young people have a better experience than me.”

- Mihi, Youth Consumer Advisor
Section Two: Model (but not the supermodel type) - Youth ParticipACTION Model

Youth ParticipACTION Model 2007

Developing a Philosophy

- Identify key internal supports
- Position description
- Identification/minimising barriers
- Appoint Youth Consumer Advisors

Management and Staff

Youth Consumer Advisors

Recruitment and Retention

- Projects
- Service Delivery

Youth Consultation Group

Active Participation

For example:
- Cultural Advisors
- Family Advisors

External Supports /Mentors

Youth Consumers
What the….? - Philosophy

Develop and implement a philosophy of youth consumer participation in your service

A philosophy of participation requires a service-wide shift in attitude towards Youth Consumer Advisors being seen and recognised as valuable, worthwhile, legitimate and competent team members. Development of this philosophy starts with management and youth consumer participation being visible in all discussions, policies and documents. Obviously, a person (or people) needs to take a leadership role in this process, however the development of this philosophy continues and grows with young people and their involvement.

Make sure that your organisation is sufficiently willing and ready for youth consumer participation, and that everyone is on board with the progressing of youth consumer participation. This is essential to ensure its success.

1. Ascertain where your service is in terms of understanding youth consumer participation and the role of Youth Consumer Advisors. Discuss the benefits, strengths and any concerns with all staff to ensure the environment is conducive to active youth consumer participation.
2. Identify possible barriers to effective youth consumer participation and strategies to minimise these (see Section Five).
3. Develop a job description for Youth Consumer Advisors (see Appendix A for a sample which you can adapt to your own organisation).
4. Identify one or two key staff as possible mentors for Youth Consumer Advisors (see Snooze You Looze - Supporting Active Participation, page 26).

Checklist for ensuring your service is ready for youth consumer participation:

- A culture and inherent attitude in which all staff and management positively acknowledge youth consumer participation and recognise the benefits for all.
- All staff and management believe in the competence and ability of young people.
- A budget is developed and sufficient money/resources are available and allocated.
- Initiation of a recruitment process including the development of a job description.
- Identify barriers and ways to minimise these.
- Youth consumer participation is incorporated into your service’s policies and key documents/plans.
- Sufficient staff support time is allocated.
- Strategies are in place to ensure retention.
- Seek training to address attitudes and to shift the service culture.
Acknowledge the cultural and ethnic diversity of young people - particularly Māori and Pacific

Youth Consumer Advisors currently involved in services are predominantly Pakeha and female. It is important however, to match Youth Consumer Advisors to existing youth mental health clients. Therefore, greater attention needs to be paid to recruiting males, Māori, Pacific, Asian, refugees, migrants, other ethnicities, and other minorities such as gay/lesbian/bisexual/takatāpui/fa’afafine/transgender, young people with a disability and young parents. A more diverse range of young people in Youth Consumer Advisor roles would be more representative of the young people that use services. This is particularly important in regions that have dense Māori, Pacific and Asian populations. Given that research indicates that the incidence of mental illness in the Māori population is higher than that of non-Māori\(^1\), it is particularly vital to have a Māori youth consumer voice in services.

Involving Māori rangatahi (young people) in youth mental health services is an active acknowledgment of the principles of the Treaty of Waitangi. Participation for Māori Youth Consumer Advisors needs to be culturally appropriate and developed by Māori for Māori. As yet, guidelines for Māori Youth Consumer Advisors have not been developed. As rangatahi are considered an integral part of the whānau, they need to be consulted within the context of their family/whānau, hapu and iwi. Some communities may not be supportive of young people being consulted individually, separate from the wider whānau\(^1\). Similarly, young Māori may be unwilling or unable to speak up and potentially challenge elders. On the other hand, rangatahi can be empowered to have a say in the decisions that affect their lives in a culturally appropriate way. For example, Young Māori people and services may benefit from a taumata – a group of young people that can work together, as opposed to one or two Youth Consumer Advisors having the majority of the consumer voice.

Pacific young people may also find this group method of youth participation more useful than more individual input. Pacific communities may also be reluctant for young people to be consulted independently of their family and community, and again young people may not be willing to challenge their elders.

Many cultures have a ‘collectivist’ view and see family as an integral part of wellbeing. This can be acknowledged by ensuring that young people’s views are kept confidential, so when information is reported back it is done carefully and in a manner sensitive to both the young person, the whānau and community\(^1\). The consultation environment can also affect responses, which includes the venue and who any facilitators are. For Pacific people – use a Pacific style fono. Use creative methods of participation which include food, humour and movement. Allow enough time for young people to get to know each other and the topics and issues that they are consulted on so they feel comfortable enough to have their say.

A further point which needs addressing is that Youth Consumer Advisors, as with all staff, need access to cultural advisors and supports.

Remember that young people, just as adults, come from diverse cultures and backgrounds, and so have different beliefs, skills and knowledge. One young person cannot represent all young people’s perspectives. Various methods need to be utilised to meaningfully gauge and reflect the diverse youth perspectives.
This chapter outlines how to successfully introduce the role of Youth Consumer Advisors into an organisation. This chapter also addresses the issues of recruitment and retention of Youth Consumer Advisors.

**Youth Consumer Advisors**

At least two young people who have experienced a mental illness and used a youth mental health service would be recruited to the role of Youth Consumer Advisor simultaneously (if possible). This role would be part time and shared between the Youth Consumer Advisors. Recruitment of two Youth Consumer Advisors helps to ensure young people feel supported, safe and included in an environment in which they, and their ideas and thoughts, are not the norm. This will also mean that Youth Consumer Advisors are more likely to stay. A single Consumer Advisor does not provide sufficient representation to an organisation as they are likely to feel isolated and have a hard time getting their voice heard.

Consideration needs to be given to whether Youth Consumer Advisors need to be past clients as opposed to currently using your service. For the latter, boundary issues may arise, and both young people and staff may have difficulty with the constantly changing nature of their relationship. Young people have commented that it is easier to be a past rather than a current client. However, current service users may be included in the youth consultation group.

Rule of thumb – if decisions you make are going to impact on the lives of the young people in your service – ask for their input and feedback!

Youth Consumer Advisors should expect that their pay band is comparable to that of Adult Consumer Advisors in similar roles, taking into account education and job experience.

**What Youth Consumer Advisors can do:**

- Create, develop and provide consultation on pamphlets and psycho-education resources.
- Be on selection panels for new staff.
- Facilitate focus groups.
- Obtain feedback from other clients.
- Look at templates of service forms, surveys and questionnaires.
- Suggest ideas about how to improve service delivery and/or make it more youth-friendly.
- Develop and work on other youth initiated projects.
- Network with other Youth Consumer Advisors to check out what youth consumers are doing in other services and regions.
- Meet with new staff and clinical trainees to help them understand the importance of youth consumer participation and how they can integrate this into their work.
- Give input in to the development of policies.

The role of Youth Consumer Advisor can evolve as the young person gains more knowledge and skills. This means they will be involved with more complex and higher-level aspects of your service.
Buddy system
More experienced youth consumers can act as mentors or buddies to newer and/or younger Consumer Advisors. This can be helpful in terms of ensuring support and encouragement to articulate ideas and opinions. Mentors or buddies can provide support in a number of ways, such as debriefing, briefing, history of issues and your organisation, translating (jargon), and advocacy. Additionally, Adult Consumer Advisors can provide encouragement, back up, information, advocacy and corroboration.

Recruitment strategies
- Involve young people in the recruitment process, from the wording and placement of advertisements through to short listing and interviewing.
- Ensure all recruitment information is youth-friendly, including posters, pamphlets, and correspondence. Give interested young people all the info about the job – such as pay, meeting obligations, what to wear, the job description, and who will be interviewing them.
- Recruiting through your service may not always be the best method as many young people do not identify as having a mental illness. While you want to recruit (and retain) young people who have experienced a ‘mental illness’, try advertising through schools, universities, primary care organisations, and other youth networks.
- If you’re really having difficulty recruiting young people, particularly for the Youth Consultation Group, consider widening the specifics to young people who have had a sibling or a parent with a mental illness.
- Ask staff to identify one of their clients or ex-clients who may be interested in either the Youth Consumer Advisor or Youth Consultation Group roles. Ask a staff member to contact the young person to ascertain their interest, but make sure their confidentiality rights are not breached. Young consumers who are already involved may also know other young people who would be keen to get into youth consumer participation.
- Ask the national workforce development organisations, The Werry Centre, Te Pou, Te Rau Matatini, Matua Rakī and Regional Mental Health Workforce Development Co-ordinators to advertise through their consumer networks.

Retention strategies
Ensure your Youth Consumer Advisors feel valued and worthwhile by utilising the strategies outlined.

- The number one way to acknowledge the value of Youth Consumer Advisors is appropriate pay. Other good employment conditions include consistent hours and access to leave.
- Ensure that your service understands the purpose and nature of the youth consumer role. Develop a job description and role specification and communicate the relevant information to your staff.
- Reinforce the idea that young people are a resource and that young people want to work collaboratively with staff.
- Include Youth Consumer Advisors in all events and forums that occur for other staff that take place within your service.

“You do it because you want to make a difference and if you don’t see any worthwhile changes, you lose your enthusiasm pretty quickly.”
A comprehensive orientation introduces the Youth Consumer Advisors to the organisation and its structures, and introduces your service to the Youth Consumer Advisors and their expertise. Create good processes around beginning and leaving, welcomes and farewells.

- Have formal mechanisms in place for addressing conflict.

- Promote an infrastructure of support for Youth Consumer Advisors. This includes support from mentors, other Consumer Advisors and staff. Ensure your Youth Consumer Advisors meet regularly with their key mentors. Consider external supervision for Youth Consumer Advisors as it allows them to be more open without fear that what they say will get back to management.

- For Māori and Pacific young people, it is especially important they have access to cultural and/or peer supervision.

- Don’t forget to include Youth Consumer Advisors in team building and planning days.

- Provide the resources to enable the Youth Consumer Advisors to network with other Youth Consumer Advisors.

- Avoid TOKENISM!
  Young people will usually not stay involved if they feel that your organisation is not committed to youth participation and they are only consulted on small things. Being able to see the results of energies put in and being acknowledged for that is powerful. Inform young people of the outcomes of their ideas and projects and give them the feedback that other staff and consumers have given.

- “It was really good, so much information, sharing of ideas – has encouraged me and taught me a lot. Motivation increase[d] SIGNIFICANTLY.”
  –regarding the Werry Centre youth consumer forum

- Young people in Consumer Advisor roles have to publicly admit experiencing a mental illness which can be a really big deal. Let Youth Consumer Advisors know they don’t have to talk about their experiences if they don’t want, and support them if they do.

- Be understanding and flexible in terms of offering part time positions, flexible hours and extra time for completion of projects if required.

- Ensure the Youth Consumer Advisor role is fun, and have interesting things for Youth Consumer Advisors to do as well as the necessary mundane stuff. Maintain motivation by implementing some of the young peoples ideas as quickly as possible to show that your organisation is serious and committed to youth participation.

- Employ a person who is sufficiently skilled for the role, or who will be able to develop the necessary skills with appropriate support.

- Provide annual reviews (for pay and performance) and regular feedback.
Training and education
Consult young people on their personal development and training needs.

Typical training requests include:

- meeting procedures and process
- chairing meetings
- public speaking
- presentation/facilitation skills
- decision making skills
- boundary setting
- assertiveness and communication skills
- interviewing techniques
- cultural perspectives
- understanding of the Treaty of Waitangi
- introduction to Te Reo Māori
- historical understanding of ‘consumer movement’
- structure of mental health services and how they work; nationally, regionally and locally
- key mental health documents e.g. Mental Health Sector Standards, Blueprint
- key information about mental health services in New Zealand and relevant international publications
- IT (Information Technology)
- time management skills
- documentation and report writing
- group and team dynamics
- handling the media
- peer supervision
- legal information

This training may be undertaken by senior staff or externally. Develop a training plan with the Youth Consumer Advisor as part of their orientation.

Educating colleagues about the Youth Consumer Advisor role is also important so that they have the skills to communicate effectively and positively with young people.

“Clearly, there is no magic formula for an effective youth participation project and no guarantee for its success, but youth participation models invented, developed, and co-steered by young people themselves may have the best chance of survival.”
Not Just Another Participation Model...

Snooze You Looze – Supporting Active Participation

This final part of implementing effective youth consumer participation involves the Youth Consumer Advisors developing, recruiting and facilitating a Youth Consultation Group made up of consumers who are past or current users of the service.

This section also includes ensuring that there is:

- adequate staff support
- external supports to assist Youth Consumer Advisors in their role
- active youth consumer participation which is integrated across your service

Youth Consultation Group

A Youth Consultation Group is a reference group for the Youth Consumer Advisors. Advisors can consult the group about issues that arise in their role and obtain a wider perspective. The Youth Consultation Group would meet on a regular basis, for example once a month, or more frequently, and discuss issues or anything that the Youth Consumer Advisors are involved in. The Youth Consumer Advisors can then obtain the perspective of a number of young people that can be utilised to feedback to the service.

This group needs to be as multi-ethnic as possible, especially considering that participating via groups may be more effective for Māori and Pacific young people. Young people could be recruited to the Youth Consultation Group via youth friendly posters and pamphlets. Recruit a diverse group of young people and provide some time for young people to get to know each other before they start working together.

Group members may also have the opportunity to be involved in various projects. Working parties could be set up to work on particular tasks/projects. In this instance, it is appropriate that the group members involved receive financial remuneration for their contribution. Also consider offering food, training, fun, opportunities for socialising and more formal acknowledgements such as references.

Members of this group could also become Youth Consumer Advisors for your service later on which could address recruitment and succession issues.

Case Study

One mental health organisation for young people (15-25 years) has the ‘consultation group’ idea down pat. The organisation employs a part time Youth Participation Worker who organises and coordinates youth participation within the service. The worker is responsible for making sure young people are treated with respect and supported within the organisation. The young people at the service decided that the best model for youth participation was a group to increase the range and diversity of ideas and perspectives. The consultation group members were recruited through staff and via pamphlets in the waiting room. The group aims to improve the mental health system for young people and be a voice for young people who have felt powerless. This group also developed a peer support model for young people in the inpatient unit which has been successful in showing young people that others have ‘come out the other side’. Two young people coordinate peer support and are working towards having a drop-in centre as well.
Utilisation of multiple participation and consultation strategies will increase the amount of information gathered from young people (see Section Three for ideas). Remember to have flexibility about the time of day, attendance and consider transport costs for Youth Consultation Group meetings.

**Staff Mentors**

At least two staff mentors should be engaged to act as the Youth Consumer Advisors’ key contacts. They need to be available to talk through issues so the Youth Consumer Advisors can keep up with what’s going on and how to most usefully proceed. The staff mentors can also act as advocates for young people in meetings and where Youth Consumer Advisors cannot be present to articulate their views.

Staff mentors must not take the lead, but instead offer assistance when problems arise or act as a sounding board. The responsibility and input into youth consumer participation should not fall to one staff mentor/role as this creates vulnerability. In this situation, youth consumer participation could be prone to becoming low priority and could disappear from your service.

Staff mentors should be approachable adults who are committed to, and understand youth participation. They will need to have time to provide support and constructive feedback.

Some staff members within a DHB describe the concept of youth consumer participation as being parallel to therapy in terms of empowerment. Participation does not need to be exclusive but rather, part of a normal progression along the ‘treatment’ journey. Participation can contribute towards a young person’s self-development within a safe environment. This can include the development of skills such as the ability to critique, articulate and self-advocate.

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**Case Study**

One New Zealand service used a number of different methods and types of youth consumer participation for one project. The idea was adult initiated – the staff wanted to develop a youth-friendly brochure about the service for their clients. The two Youth Consumer Advisors were given ownership of this project. They asked other staff members what information they thought was important to be included. They then held an hour and a half long focus group with a small group of young consumers, brainstorming what they thought was important in the brochure and what it should look like. The Youth Consumer Advisors took everyone’s ideas back and developed a brochure, which then went back to staff and the young people originally consulted to make sure they were on track. One staff mentor offered to help find quotes for the cost of publishing the brochure. Since this project was youth led and had youth consultation it meant the brochure was overtly for young people by young people. The resource was frequently utilised and therefore, a success.
Section Three: Weather Forecast: Grey Skies Are Clearing Up
- Other relevant stuff

This section is about conditions that need to be in place to make sure Youth Consumer Advisors can actively participate in service development and delivery.

Resource Me

- Show young people that their work is valued. Provide a budget and sufficient resources such as training/education, a work space, access to the internet and photocopier, and administrative support.

- Provide young people in the consultation group with supports that they deem appropriate, such as transport costs, appropriate remuneration and training/professional development.

- Provide resources for Youth Consumer Advisors to network and participate in external forums with young people in similar roles.

- Support youth consumer participation in ‘wider’ projects, for example national forums, international conferences and research.

Meetings

- Meetings need to be at times that suit Youth Consumer Advisors. Remember, some young people may be studying and therefore have assignments/exams, and they may also be involved in extra-curricular activities.

- Ensure the venue isn’t too formal and provide young people with all the necessary information.

- Don’t overload them with information and piles of paper that aren’t so helpful – summarise and explain. People often do not tend to read pre-readings for meetings, so don’t expect young people to read huge amounts either.
Ensure they have access to transport.

As with anyone who starts a new job, Youth Consumer Advisors need to be provided with support for as long as they need. Have staff mentors available to young people to debrief, answer questions and look at the agenda before and after meetings. Ensure young people on the Youth Consultation Group are reminded a week or the day before a meeting via txt, email or phone – whichever is best for them.

Keep Youth Consumer Advisors informed of changes and issues as they arise so they are as prepared as everyone else.

Make meetings interesting, interactive and include creative methods such as break out groups, warm ups and brainstorming as these are good for keeping everyone engaged, not just young people.

“I want to have the feeling that I’m supported and I want to be involved and taken seriously.”
- Brian, youth consumer, 2006

If a group of young people are involved in a meeting together, it is beneficial for them to meet each other before hand, get to know each other a little, and plan any contribution to the meeting.

Allow young people to present during meetings as other staff have the opportunity to do. Ensure staff or other mentors support and facilitate this if the young person requires.

If young people are not actively contributing in a meeting, ask them what they think – especially if they look like they want to contribute but may not feel assertive enough to do so.

Some young consumers find it emotionally tough working in the organisation they received mental health services from. Ensure supports are in place, including some encouraging words about their work being important as well as support to articulate their feelings.

Sometimes information, background info, and meeting information can be tedious and confusing, so take the time to explain this so that young people better understand the more complicated information.

I can see clearly now the communication is there

Be open and honest about the limits and boundaries to Youth Consumer Advisor roles. Communicate these limits and boundaries clearly in a job description and in person. Be clear about how much say young people are actually going to get and explain this to them.

In order for youth consumer participation to be effective, there needs to be open, clear communication between all. This means that young people’s words should not be reworded and put into ‘adult language’ – they are how they are.

In projects or tasks, be specific about the expectations and the role Youth Consumer Advisors will have. The less ambiguous you are, the more information you are likely to obtain.

Identified staff mentors/supports are a huge help in terms of reducing the feeling of ‘us and them’.
Be nice people!

- Treat young people as people – not an illness. When referring to a young person – let them self title, and say their name rather than ‘consumer’ or ‘kids’.

- Listen to young people – they are more likely to value professionals who listen and take their views seriously.

- Avoid patronising or condescending language and speak to each other as equals. Remember that Youth Consumer Advisors are colleagues.

- Young people may also need to change their own attitudes and preconceptions towards others. This is facilitated when young people experience positive, respectful relationships with adults who take them seriously and acknowledge their competence.

Things to keep in mind

- Regularly review and evaluate participation with Youth Consumer Advisors and their staff mentors. Ensure participation isn’t tokenistic and is working well. Evaluation provides for the opportunity to review how the barriers to youth participation have been challenged, and gives young people the opportunity to voice their views on youth consumer participation within the service.

“**I found a lot of mental health professionals thought they had some sort of monopoly on insight and knowledge. That’s a kind of discrimination and it used to really annoy me**”

- The evidence highlights that it is also good practice to give young people constructive feedback as it lets them know their views and ideas have been taken seriously. Don’t forget to update young people on the progress and changes made due to the projects they’ve been involved in. Seeing the concrete impact of the effort they’ve put in is beneficial in keeping them interested in their role in developing your service.

- Relinquish power and control! Address the imbalances of power. It is empowering for young people to know they are trusted by those in charge, and are given the responsibility to do things their way and learn from the process. Involve young people in the planning and visioning parts of projects so they have ownership of the process and understand what to expect. They also need to have a say in what is to be discussed – active participation, not just answering the questions the organisation decides to ask.

- If young people are still receiving support/treatment from your service, they may be unwilling to freely express their mind in case there are repercussions for their care. Some Youth Consumer Advisors have articulated how difficult it was to be in a Youth Consumer Advisor role and still be receiving services. They also felt that staff respected them more after they had been discharged. Consider employing clients who have been discharged.
Consider having a discussion with new Youth Consumer Advisors about what they’d like to occur if they became unwell. Usually young people want something similar to other staff members who are going through a difficult time.

Young people who’ve had difficult life experiences may also find it more difficult to voice their opinion, especially if their views haven’t been taken into account in the past. Supportive opportunities for active participation will build confidence.

Develop the concept of a consumer ‘team’. Hold regular meetings between Adult Consumer Advisors, Family/Whānau Consumer Advisors, and Youth Consumer Advisors. This will promote supportive relationships and ensure a consumer voice is heard and valued within services.

Other ways of participation

Different methods of participation will suit different projects or different aspects of a project. Young people may also prefer some methods over others. For example, young people tend to prefer face to face participation methods rather than more passive ones such as surveys. This includes small groups, hui, fono, focus groups, youth panels and workshops, and could include interactive activities such as art and drama.

Youth Consumer Advisors could sit on recruitment panels to help assess the suitability of prospective staff members, or orientate new staff to youth consumer issues.

Cyber-participation such as message boards, discussion forums, internet sites and email groups can be utilised for young people who may not be able to attend meetings, or as a means of communicating with other Youth Consumer Advisors in other regions.

While not strictly participation, Mitchell discussed the idea of consumers as educators. Young people can develop psycho-education resources or give presentations for other consumers, family/whānau and for staff as young consumers can often have the experiences and knowledge to better inform staff and families/whānau about the real issues.

Example:

A resourceful part time Youth Consumer Advisor within one DHB was involved in a number of projects over the past couple of years including; making newsletters for the young people in the waiting room, developing a youth friendly website, consultation on groups run for the young consumers, consultation and involvement in the development of psycho-education material and information pamphlets, and trying to improve the look of the waiting room area.
Section Three: Weather Forecast: Grey Skies Are Clearing Up - Other relevant stuff
This section focuses on a discussion of the evidence used in the development of these guidelines. Evidence includes literature on strategies for enabling adult and youth consumer participation, strategic documents, policies, personal and anecdotal experiences, and a youth consultation process.

While the idea of a youth consumer workforce is becoming increasingly valued by the New Zealand government and services alike, there is minimal literature available which describes the key components of a quality youth consumer workforce. In fact, there are numerous contrasting interpretations and definitions of what youth consumer participation actually is. What is clear, however, is that the value of consumer involvement in mental health services in New Zealand has become increasingly accepted in recent years. Nevertheless, there is still significant work to be done in increasing the capacity and capability of the consumer workforce, and measuring quality outcomes for services who actively value and enable consumer input.

*Whakamārama te Huarahi - To Light the Pathways (A Strategic Framework for Child and Adolescent Mental Health Workforce Development 2006-2016)*18 draws attention to the lack of literature around youth consumer participation in CAMH and AOD services in New Zealand and the issues that act as barriers to effective youth consumer participation, many of which are discussed in detail in this resource. *Whakamārama te Huarahi*18 also highlights the lack of training and other resources for Youth Consumer Advisor roles in New Zealand.

The adult consumer workforce and adult mental health services are far more established in consumer participation than the youth consumer workforce. Given this, evidence relating to the adult consumer workforce may provide some insight into the philosophy and processes of developing such a workforce for youth services. Adult
consumers have worked hard to build an effective consumer participation workforce, and have succeeded somewhat in consumer representation being seen as an integral part of a quality mental health service. The influence of a history of paternalistic mental health services where mental health consumers were powerless and vulnerable to the services that dictated decisions supposedly in their ‘best interests’, needs to be acknowledged. De-institutionalisation, the rise of the consumer movement, and the development of seminal reports and consequent policies (e.g. Blueprint and National Mental Health Sector Standards) means that services have improved somewhat in their approach to consumer inclusion and their acknowledgement that consumers need to have a say in the services they receive.

Aspects of stigma around mental illness are also somewhat compounded by ageism. Our society does not readily integrate and accept young people and their perspectives, making it even harder for young people with mental health issues to have an active and meaningful part in the world.

The Mental Health Sector Standards provide guidelines for service providers, consumers and their families/whānau about what can be expected from mental health services in New Zealand. Services have obligations under the Code of Health and Disability Services Consumers’ Rights. If services comply with the Mental Health Standards, then they are likely to meet their obligations under the Code.

There are eighteen standards in the Mental Health Sector Standards and Standard 9 states: “Consumers are involved in the planning, implementation and evaluation at every level of the mental health service to ensure services are responsive to the needs of individuals.”

Standard 9 has six criteria:
- consumer involvement in policies and procedures
- decision-making
- training and support
- payment for time and expenses
- clear job descriptions or terms of reference
- feedback

Under Standard 9 of the Mental Health Sector Standards, all services are required to have access to a Consumer Advisor. However, many CAMH or AOD services purport to meeting this standard as they access Adult Consumer Advisors or, in some cases, Family/Whānau Consumer Advisors. Standard 9 does not specify who the consumer representative should be. Adult Consumer Advisors cannot represent the views of young people as it is widely acknowledged that adults’ views, opinions and decisions can differ from those of young people.

Te Tāhuhu also articulates the necessity for consumer participation, stating there needs to be an emphasis on; “…fostering a culture among providers that promotes service user participation and leadership.”

Although little has been actually published on youth consumer participation specific to CAMH and AOD services in New Zealand, some strategies relating to adult consumer participation are applicable to youth consumer participation. These include processes around meetings, evaluation of participation, valuing consumer participation and recognising power and paternalism.
In addition, as services and decision makers have begun to acknowledge that young people have the right to be heard in service delivery, there is increasing literature available which outlines positive experiences of youth participation in decision making, on boards, in communities, and in sectors other than mental health.

“I used to be really shy and anxious about talking with groups of people. After a while of being involved in meetings and different groups with supportive people, I continually felt more confident because I was proving to myself that I could assert myself and what I had to say was worthwhile.”

– Hayley, youth consumer

Key Principles of Youth Consumer Participation

While there is evidence supporting the idea that young people know what they need and can articulate this if given the appropriate support, in lots of ways it’s easier to talk about what youth consumer participation isn’t.

- Youth consumer participation is not passive methods of participation, such as telephone interviews and client satisfaction surveys. Surveys tend to ask for responses on a narrow set of questions and do not always allow respondents to articulate their own thoughts.

- Active participation is not recording or listening to young people describing their experiences in mental health services, but is about enabling young people to have a more active role in improving service delivery.

The above methods are often considered ‘youth participation’ by services, but the reality is that these methods do not allow young people to make any real changes within a service.

Street and Herts talk about how ‘involvement’ and ‘consultation’ are not true forms of participation. The concept of ‘involvement’ doesn’t define how much power or influence a young person has. ‘Consultation’ is just as vague, implying that young people are asked their opinion on projects that are adult-led and driven. Both these approaches are potentially just ‘lip service’ and do not constitute active consumer participation.

If your service does use some of these methods to obtain youth consumer perspectives – that’s ok - now’s the time to build upon this and develop more effective youth consumer participation. Good participation is a process, and should not exist in isolated events or ad hoc activities.

Often services/staff align with family/whānau rather than the young person which means the people that are most affected (young people) do not have much of a say, or an autonomous voice. This is not the case as much in adult mental health services.

Young people in consumer roles can find that their personal recovery and other young people’s are enhanced through their role modelling and influence in service improvement.
The Ministry of Health’s publication *Moving Forward*\(^4\) states that consumers should be involved in all aspects of the sector, including planning and policy. Resource guidelines to meet the goals suggested in *Moving Forward*\(^4\) are estimated in the *Blueprint*. The *Blueprint*\(^2\) suggests that there should be a 0.4 FTE consumer role per 100,000 people in the 15-19 year age bracket. There are no recommendations available for youth consumer representation in the under 15 years age group, and people over 20 years old are included in the adult age bracket. The *Blueprint*\(^2\) talks about how individually, consumers should take an active role in the decisions about their treatment, and, as a collective, should be involved in evaluation, decisions and all other aspects of services.

The UNCROC is a treaty that contains 54 articles on a range of rights for children and young people up to 18 years of age, and recognises the young person as a holder of rights and freedoms. In particular, Article 12 is about young people having a say in the decisions that affect them and Article 42 states that young people have the right to know their rights. New Zealand signed this convention in 1993 and has since implemented a variety of strategies to improve the rights of young people\(^1\).

The Treaty of Waitangi is also relevant to youth participation. Māori see the participation of rangatahi as an expression of the partnership between Māori and the crown\(^11\). More specifically, youth participation is about protecting the rights of young people, and building the partnership between young people and the people that are involved in their lives, while ensuring young people have a say about the decisions that affect them.

New Zealand is a pluralistic society and the sector needs to reflect this diversity. However, the Youth Consumer Advisor workforce is dominated by Pakeha women, which means that it fails to represent the diversity of society. It seems that Māori, Pacific and other cultures experience even more barriers to having a say about the services they use. The Treaty of Waitangi provides the mandate for Māori to have the right to be involved in services in order to help these services meet their needs. However, so far appropriate ways of doing this have yet to be established. Also, one needs to take into account the fact that ‘participation’ has different meanings for different cultures and communities and therefore, needs to be meaningfully explored with young people of these cultures when establishing youth consumer participation.

One of the six principles of the *Youth Development Strategy Aotearoa*\(^25\) is that “[positive] youth development is triggered when young people fully participate”. This principle recognises that it is beneficial for young people to have more control over issues and decisions that affect them, and to be involved in evaluating those decisions. It also acknowledges that young people can contribute to community change just as adults do, and bring unique perspectives, innovation and ideas. Young people who have experienced mental health issues and used services, and have access to appropriate supports and representation, are more likely to make a positive contribution to society, have supportive and caring connections with others, and make choices that influence their own life, than those who don’t participate\(^25\). The principle therefore, suggests that effective participation will ultimately result in a country where young people with mental health issues are more optimistic and positive.

Other New Zealand documents, such as *A Guide to Effective Consumer Participation in Mental Health Services*\(^22\) and *The Code of Health and Disability Services Consumers’ Rights*\(^20\), state the importance of consumers participating in decisions that affect them in a way that is transparent. Another is the *Service User Workforce Development Strategy for the Mental Health Sector 2005-2010*\(^17\) which identifies the goal; “By 2010 people with experience of mental illness will be a skilled, powerful, pervasive and openly identified part of the mental health workforce in New Zealand”.

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**Effective participation leads to ownership of outcomes and builds individual capacity while ensuring that services and policies reflect young people’s needs.**

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One of the most commonly used models for thinking about youth participation is Hart’s Ladder of Participation. Hart’s ladder describes eight rungs – the top five being the differing degrees or levels of participation. The bottom three rungs describe youth involvement which is not true participation, rather, tokenism, decoration and manipulation. There is some debate, however, whether participation should be categorised hierarchically like this. In Hart’s ladder, the highest form of participation is ‘youth-initiated, but with shared decision-making with adults’. This is considered higher than both ‘adult-initiated’ and ‘youth consulted’ participation.

Active youth consumer participation ensures that services meet the needs of their youth stakeholders.

A horizontal version of Hart’s Ladder is Westhorp’s Continuum of Youth Involvement. In Westhorp’s continuum, decision-making can occur at any point along the continuum, though young people have more direct input towards the right end of the continuum. Regarding Westhorp’s continuum, Wierenga et. al. states that workshops and forums come under structured consultation as often young people’s views are reinterpreted by adults, which can be disillusioning for young people and cause misinterpretations.

While these two models are somewhat widely known, they do not emphasise the necessity of young people having an active say, and condone participation in which adults have significantly more power and control in the process than young people.

The Realities of Youth Consumer Participation

In reality, youth consumer participation isn’t so easy – for young people or services. While Section Five of this document focuses on strategies for identifying and minimising barriers, services need to be proactive in fostering a philosophy and environment that supports youth consumer participation. Three of the primary considerations for services are; service attitude/culture, stigma and value. Stigma (negative and harmful attitudes to people with a mental health issue) can be a problem as young people who are discharged from a service will often want to get away from services as fast as possible. Also, some clinicians have been reported as having negative perceptions about young people’s competence in affecting changes in service delivery. This attitude can prevent staff from being able to work as colleagues with young people. However, effective and supportive participation can challenge misconceptions about young consumers’ competence.

“\textit{When you get to a certain age, you start to think that young people don’t know, at least you forget that they do know.}”

Young people who are working in Youth Consumer Advisor roles report feeling undervalued in the work that they do. Youth Consumer Advisors speak candidly about experiences of feeling isolated, ‘battling’ with organisations and fellow staff members to be valued and taken seriously, and tolerating inadequate pay. There are young people who, despite their own difficult experiences, are willing to stand up and support the rights of others – but currently there is a lack of incentive and motivation for them to do so. Adult Consumer Advisors have long talked about feeling unappreciated in services as often their pay is lower than other jobs that require similar skills, qualifications and levels of responsibility.

If the capacity and capability of Youth Consumer Advisors is increased and improved, mental health services will be enhanced and more responsive to their clients’ needs.
If necessary, organisational hierarchies need to be ‘constructed’ so that young people’s voices are heard and reach the top.

Other skills required of Youth Consumer Advisors include; good communication, assertiveness and motivation. Training needs to be offered to ensure that young people have the skills and knowledge to participate effectively. Existing staff within services need education in how to communicate with young people as colleagues, and what the Youth Consumer Advisor role is. It’s not just about giving young people a say – it’s about listening to a young person’s views, respecting the young person, and actively implementing ideas in practice – active participation.

Example:

A New Zealand NGO youth organisation for a specific minority group of young people is run almost completely by young people. There is an adult that coordinates the organisation, though to spend more than $50, they have to obtain sign off from the board made up of young people. There are adult supporters but they have a back seat role, and only provide support when needed. Lots of young people are very passionate about improving the lives of other young people from the same minority, and tend to enjoy meeting others and socialising with them. The organisation is proud to state that they are for youth, by youth. Young people bring creativity and energy to the organisation and keep the service grounded – letting the coordinator know when stuff is irrelevant to them. The coordinator asserted that it was exceptionally important to value young people and the resource they provide, whether that was by focussing on people’s strengths and/or offering movie vouchers and praise.
This section focuses on the key barriers that Youth Consumer Advisors, staff and services face in implementing effective youth consumer participation. Each barrier is followed by a strategy to minimise its effect.

Barriers for Youth Consumer Advisors

1. Feeling intimidated

Many young consumers struggle with a lack of self esteem and confidence and most have never been in a position of influence. Young people can feel intimidated, especially if adults have the attitude that the Youth Consumer Advisors are ‘tag-ons’ to a service/team and can’t really help. Young people are especially likely to feel like this if they have not felt heard in the past. Meetings and management can be daunting for anyone! This experience can be exacerbated if the young person comes from a different cultural background.

✓ Ensure all staff are on board with participation by educating staff and management as to why it is a necessity and the benefits of youth consumer participation.

✓ Ensure more than one Youth Consumer Advisor is employed.

2. Stigma and discrimination

Young people in Youth Consumer Advisor roles often complain of discrimination from staff and management in terms of unequal rights.

✓ Don’t make decisions that affect young people or your Youth Consumer Advisors without them – listen to, and respect what they say.

“Being the sole representative of a disempowered group in a powerful organisation can be a lonely and disempowering experience.”

22.
3. Environment

Formal environments that focus on procedure and bureaucracy can deter young people from being actively involved in service development.

- Promote youth friendly meetings and environments through use of comfortable and informal rooms.
- Promote and sustain an environment where questions are welcome and encouraged from everyone.

4. Language

Language that is incomprehensible and alienating can prevent young people (and others) from actively engaging in discussions.

- Avoid or explain business and legal jargon, or medical and psychological terminology.
- Expand acronyms.
- Develop a glossary.

5. Resources

Limited resources for youth consumer participation can be very discouraging and disempowering for young people. All staff feel more valued when they have their own physical space, desk and access to a computer in an organisation. Suitable remuneration and reimbursement also signals your service’s appreciation.

- Ensure consumer participation is well resourced and young people have the same working conditions and physical resources as other staff.

“Mental health organisations can help keep youth consumer reps involved by paying them an appropriate amount for the work they do!”

– Werry Centre youth forum participant

6. Imposition of adult ideas

When adults impose ideas on young people, or expect young people to be motivated about adult led or initiated projects, it is not surprising when young people are not inspired. Young people have their own views of what’s important.

- Let young people come up with the ideas about what they will work on.
- Get young people to brainstorm about topics that staff bring up or want support with.
- Think about the difference between contributing to decisions versus endorsing decisions.
- Encourage adults to step back and support youth consumer participation rather than drive it.
7. Confidentiality
Some professionals express concern about confidentiality and therefore, limit information flow to Youth Consumer Advisors, perpetuating feelings Youth Consumer Advisors may have of being ‘less valuable’ team members.

✔ Reach agreements about confidentiality.
✔ Ask Youth Consumer Advisors to sign confidentiality agreements.

8. Feeling ineffective
It can be disillusioning for young people if they make suggestions, or put time and energy into a project, but nothing changes or they never hear anything about it again.

✔ Keep young people updated and don’t let their work get lost – keep it on the agenda of meetings.
✔ Ensure there are regular updates on youth initiated projects to make sure Youth Consumer Advisors’ work does not get lost.
✔ Work creatively at implementing young people’s ideas.

Example:
One DHB employs a part time Youth Consumer Advisor. Aside from attending some staff meetings, their involvement in the service was predominantly dependant on staff coming to them to ask their input, or using their own initiative to come up with projects or ideas to improve the service. There was no formal structure for youth consumer participation which meant that the Youth Consumer Advisor did not have an active voice within the service, and their skills and knowledge were under-utilised.

9. Feeling safe
When asked for their thoughts, young people who are clients in a service can feel pressured to give particular feedback or responses, for fear of repercussions to their own treatment. This may partly be due to internalised stigma. Similarly, the legitimate phenomenon of young people wanting to move on from their experiences means that it can be hard to recruit ex-clients to youth consumer roles.

✔ Ensure current clients feel safe to express themselves without fears of repercussions.

10. Tokenism/window dressing
A number of issues can lead to tokenism or window dressing, that is, attempting to include young people but doing it in a way that isn’t active participation. Young people can be left with ‘decision-less decisions’ – decisions about things that don’t matter, or decisions where nothing happens. Many services have good intentions for giving young people the opportunity to have a say about the services they receive, but don’t know the best way to go about it. Some people in services find it hard to relinquish their control.
Within some services, if the ideas of young people don’t fit with that of management, their ideas may well be rejected.

✔ Follow these guidelines!
✔ If you’re going to do it, do it right! Put time, effort and money into youth consumer participation – or don’t do it at all!

Don’t give up when the barriers test your commitment to participation!
Barriers for Services

1. Money money money
The number one barrier to youth consumer participation is money. However, appropriate consumer participation is mandatory.

- Ensure money allocated for ‘consumer participation’ is used for youth consumer participation.
- Creatively budget for youth consumer participation.
- Talk to other services who have youth consumer participation about how they found the money to pay for it.

2. Attitude and service culture
Negative attitudes can exist which perpetuate negative stereotypes about young people, such as ‘they don’t care’ or ‘they don’t want to be involved’. This is sometimes termed ‘adultism’ and is basically the belief that because someone is young, they’re not that intelligent, able, or credible, which can leave young people feeling worthless and alienated.

The culture in a service should be about equality, although this is difficult if the culture of the service is also about dividing people. Young people will not thrive and participate in this environment.

- Ensure your service has a positive attitude towards young people having an active role within the organisation and the resources available for Youth Consumer Advisors to show all staff that they are capable, contributing members of the team.
- Before employing Youth Consumer Advisors, ensure that your organisation is ready and willing for the experience.

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“One of the hardest parts of youth representation was starting up peer representation where there was none – creating the role, while feeling unsupported. There were times when I felt undervalued and that my ideas and initiatives were not being backed and supported as they should be. The most important thing I did was to keep going even though I felt discouraged. It is important to believe in yourself, believe in your work, and see the value in it, [and] the difference that your input can make to provide young people with a voice.”

- Carlee, a past Youth Consumer Advisor
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3. Understanding the Youth Consumer Advisor role
Some professionals and services have a limited or incorrect understanding of the Youth Consumer Advisor role. A culture can be inadvertently built where it appears that the Youth Consumer Advisors are against adult staff. Staff should view this role as a valuable resource. Youth Consumer Advisors want to work with staff not against them - they are working towards the common goal of better outcomes for young people.

- Young people could facilitate a workshop for all staff about their role.

Attitude is important – all the structures and policies in the world won’t make participation effective if there are unspoken negative attitudes. Similarly, young people must have a positive attitude. They can’t fall into the trap of thinking they have nothing to say and nothing to contribute or that adults won’t listen to them.
4. Communication skills
Clinicians may not be used to conversing with young consumers as colleagues, and some adults may feel uncomfortable in the company of young consumers outside of their clinician/client role. Clinicians may try to maintain their professional distance or have a condescending manner, neither of which creates a conducive environment for effective communication.

✓ Have young people (as experts) present a workshop for staff about how to communicate with youth consumers as peers.
✓ Resource young people to develop assertiveness in communication.

5. Lack of staff mentor time allocated to resource youth consumer participation
Without appropriate support from key staff mentors, there may be a lack of goals or direction and Youth Consumer Advisors will be left to ‘use their initiative’ while not having a lot of say in actual service delivery.

✓ Allocate staff time and resource to ensure that youth consumer participation is recognised as a priority for the organisation.
✓ Ensure mentors have dedicated time available to support this important aspect of your service – reduce their caseloads.
✓ Allocate key staff mentors.
✓ Ensure mentors also have access to any training they may require for this role.

6. Hiring the right person
Some services are so keen to get young people involved in their service that they hire a young person that isn’t right for the job. Services may have a hard time recruiting and retaining young people. Despite working with young people in a clinical capacity, some adults may be unsure how to interact with young people on a professional level.

✓ Develop a job description and Youth Consumer Advisor specifications. Check out Appendix A.
✓ Informally interview candidates with a panel and decide together on the best person for the job.
✓ Include at least one young person on this panel.
✓ Develop Youth Consumer Advisor orientation packs which provide information on the service, the mental health sector, and training opportunities available.
✓ Consider an informal familiarisation with your service for potential Youth Consumer Advisors to ensure they are keen to undertake the role and are clear on the job description and expectations.

Case Study
- Ineffective Youth Consumer Participation
One New Zealand service has attempted youth consumer participation, though they have had a number of barriers that has meant effective participation has been hard to achieve.

A group of young consumers meet together on a regular basis, facilitated by a small group of staff members. The young people talk about their experiences and are planning to develop a resource that documents their journey. While staff state they have a youth participation group, the young people have no autonomy and no power in terms of decision making or making any real changes within the organisation. Unfortunately this means that this group is more tokenism, decoration and peer support than active, effective youth consumer participation.
7. Utilising Adult Consumer Advisors
Having access to an Adult Consumer Advisor doesn’t fulfil your responsibility for consumer participation in a CAMH or AOD service, as young people are the primary clients of your service!

✓ Ensure that young people have an active voice.
✓ Utilise the suggestions outlined throughout these Guidelines.

8. ‘Retirement’
Once a young person has been working for a service for a while and has a good grasp of consumer participation and the skills to be effective, they eventually become too old to fulfil a ‘youth’ role.

✓ Challenge the notion of being ‘too old’ for this role at 20. Most Youth Consumer Advisors currently in New Zealand are in their early 20’s.
✓ Encourage young people to stay on as ‘senior Youth Consumer Advisors’ and mentor younger Consumer Advisors.
✓ Provide sufficient incentives for good Youth Consumer Advisors to stay.
✓ Promote succession planning.
Not Just Another Participation Model...
Creating and implementing innovative and culturally appropriate responses to tackle the obstacles facing CAMH and AOD services in delivering to the indigenous Māori population takes courage and commitment. Māori youth consumer participation is a proactive step in this direction. It can flourish in an environment where the overgrowth (obstacles) have been cleared so that new ideas and input from our rangatahi (youth) can generate more productive ways of working with our Māori taitamariki, rangatahi and their whānau.

There is overwhelming evidence documenting the over-representation of Māori youth in negative mental health statistics including difficulties accessing healthcare, more alcohol and drug use, and high rates of emotional and mental distress. The Māori rate of access to mental health services in 2003 was recorded at 1.35% compared with 1.86% for the rest of the population. Between the ages of 15 and 19 Māori youth admission to CAMHS is disproportionately high. Some concerning health disparities between Māori youth compared to Pākehā/NZ European youth were also identified in the second national survey of the health and wellbeing of secondary school students in New Zealand entitled Youth ’07. The survey (which included 2059 students who reported they were of Māori ethnicity) found that taitamariki Māori are more likely to report mental health concerns and substance use, and are less likely than Pākehā/NZ European students to report being able to access health services when needed.

Cultivating processes that have the potential to yield much new growth and improve services for Māori are therefore a priority. “The inclusion of whānau and tangata whaiora as part of your service will add an element of accountability that will strengthen the central purpose of a mental health and addiction service provider, i.e. to improve outcomes for tangata whaiora”.

Parapara waerea a ururua, kia tupu whakaritorito te tupu o te harakeke
(Clear away the overgrowth, so that the flax will put forth many young shoots)
Māori youth consumer participation is integral to ensuring services are provided that are appropriate, proactive and responsive to Māori. As is already highlighted, youth consumer participation is mandatory for CAMH and AOD services. It is therefore vital for Māori youth to also have a voice in the development and delivery of services to improve their access and meet their needs. Te Tiriti o Waitangi embodies the principles of kāwanatanga (partnership), rangatiratanga (protection) and ōritetanga (participation) which when applied to the health sector provides a further guide to Māori inclusion.

Kāwanatanga (partnership) – involves active partnership with Māori in service delivery with a guaranteed share in power for Māori in decision making

Rangatiratanga (protection) – protection and improvement of the Māori health status

Ōritetanga (participation) – participation at all levels of the health sector by Māori will lead to equality of outcomes.

The New Zealand Health and Disabilities Services (Safety) Act 2001

Rangatahi Consultation Process
To make sure these Guidelines include the voice of rangatahi, we have endeavoured to have a wide consultation with Māori youth and to find out what was really important to them so:

- We held three youth hui in the North Island for Māori rangatahi under 25 years of age who had used either a CAMH, AOD service or one stop shop. One hui was open to rangatahi from anywhere in the country, another involved a service in Hamilton (Whai Marama) that has a Youth Advisory Group, and the third was with some of the young people who access He Kaakano, the Māori Team at Whirinaki CAMHS, Counties Manukau DHB.

- A questionnaire was sent to T N T, a Rangatahi Advisory Roopu which is part of the Te Puna Hauora Kaupapa Māori Tamariki/Rangatahi mental health services based at Tauranga Hospital, Bay of Plenty DHB. The name T N T is representative of an explosion of new thoughts and ideas and the breaking of new ground.

- We reviewed the literature including policy documents relevant to Māori, Māori youth, youth participation, Māori mental health and Māori youth mental health.

Embracing traditional Māori values, the key areas that rangatahi were asked to comment on included whānau, whānaungatanga, manaakitanga, kaitiakitanga, and taha wairua, taha tinana, and taha hinengaro.

Limitations of the Consultation
We sought to provide safe and supportive forums to encourage rangatahi to share their concerns and ideas. Identifying these rangatahi who were willing to participate in the forums did not prove to be an easy task and so we acknowledge that the number of young people we were able to consult with was relatively small. We acknowledge that we consulted with young Māori people exclusive of their whānau, hapū, iwi.

We do, however, see this consultation process as a starting point for future discussion, development and research. We acknowledge that regional and individual differences exists e.g. “knowledge of Te Ao Māori” including knowledge of iwi, participation in Māori community and Te Ao Māori that also need to be taken into account. We anticipate that further research in this area will provide further insights into the specific requirements for Māori Youth Consumer Participation.
What did we find out?

Despite these challenges, the forums were invaluable for us in terms of determining how rangatahi thought they could participate in service delivery and development. They were also very useful in outlining what worked and what didn’t work, around encouraging young Māori to attend the forums.

It was evident that rangatahi, whilst not entirely clear what was possible for them in terms of service delivery, were very vocal about what didn’t work.

The consultation process that rangatahi preferred was for them to be consulted as a group, and have their whānau and iwi connections acknowledged.

In light of these comments it is clear that good support is needed to nurture *Nga Mahi Whaiora Rangatahi* (Youth Consumer Participation) and can be best explained by the Flax or Harakeke Model. The Harakeke (Flax Root) model when demonstrated is a useful and effective method of supporting *Nga Mahi Whaiora Rangatahi*. It involves creating an “environment that stimulates growth”.

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**The Harakeke (Flax) Model**

Using the Harakeke or Flax model thus provides an understanding of the relationships and elements needed to nurture young people’s development.

*Rangatahi at the Centre*

The flax at the centre firstly represents our Whaiora Rangatahi. They are surrounded by a host of other influences that provide vital tautoko for them, namely, whānau, hapu, iwi, community

*Tautoko for Rangatahi*

While Whaiora Rangatahi may need guidance and direction individually at times, essentially they want to be consulted collectively in a group, where they get to agree on the type of environment they consider works for them. Included in the circle of influence and reference would be the important entities such as whānau, hapu, iwi, and community. These groups provide reference points to add support, advocacy and ongoing development in accordance to Whaiora Rangatahi roopu aims and aspirations.

*Nourishment*

In order for the young flax ‘rau’ (leaves) to maintain their vitality and richness, they would have to be nourished, nurtured and be gifted with certain elements from the environment. It provides the pia (succulence and nutrition) from papatuanuku through paiaka (roots) to the harakeke (flax plant).

**Metaphor for the Harakeke Model**

The environmental elements represent tikanga, wariu, (principles/values) that should nourish the productivity and growth of the harakeke.

The paiaka (roots) are our maatua tupuna who have long established, ‘nga taonga tuku iho’ from times past to the present. These taonga establish a stable history of life experience that have continued to guide the whānau, hapu and iwi through the centuries.

The pia (sap) represents the specific food required to feed certain parts of the harakeke, the rangatahi, whānau, hapu, iwi, and community, each needing certain nuturitional components to function at capacity.

Te Rito (new shoots), represents the Whaiora Rangatahi developing, surrounded by all the necessary supports to achieve their aspirations and goals for greater wellbeing.
Rangatahi Consultation Process
Rangatahi prefer to consult as a group

Components needed to enable Rangatahi Roopu to flourish

Manaaki
Wairua
Pūkanga
Whakawaia
Ūkaipō
Kotahitanga
Kaitiakitanga
Rangatiratanga
Whanaungatanga
Where to from here?

Comments from rangatahi are summarised in the table below. These comments and a number of practical recommendations have been combined and grouped according to relevant core values specific to employing young Māori as part of a Youth Consumer Advisory Group (Rangatahi Roopu) for mainstream and kaupapa Māori CAMH and AOD services.

### Rangatahi prefer to consult as a group

<table>
<thead>
<tr>
<th>Core Elements</th>
<th>Description</th>
<th>Quotes from Rangatahi</th>
<th>Summary of Feedback</th>
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<tbody>
<tr>
<td>Manaaki</td>
<td>(Caring for, showing respect and hospitality for others)</td>
<td>“Willingness from staff to understand the young person.”</td>
<td>• Providing kai at meetings is a way to appreciate and nurture the Rangatahi and manuhiri (visitors).</td>
</tr>
<tr>
<td>Whakawaia</td>
<td>(Orientation – the process of becoming accustomed to new situations and surroundings)</td>
<td>“Having another young person [currently working at the service] to assist and help the new person when they’re starting out”.</td>
<td>• Powhiri or whakatau will appropriately welcome the Rangatahi Roopu or new members to your organisation.</td>
</tr>
<tr>
<td>Wairua</td>
<td>(Ensuring the spiritual environment is ever present)</td>
<td>“Being respected by the other staff is important to me.” “Karakia is important in my culture and is important to me.”</td>
<td>• Having karakia and waiata at meetings and promoting the use of Te Reo and Māoritanga in the workplace. • Reciprocity – ‘ako’ (learning both ways) where all young people feel they are being listened to.</td>
</tr>
<tr>
<td>Pūkenga</td>
<td>(Rangatahi being supported to develop skills to deal with challenges)</td>
<td>“Having a group [is best] because everyone has different experiences and backgrounds.”</td>
<td>• Rangatahi Roopu to be made up of equal numbers of young women and young men (and in mainstream services – a range of ethnicities) to acknowledge diversity. • Service is to assist in identifying further training opportunities for rangatahi to participate in, including support to undertake internal and/or external cultural competency training in such things as Te Reo and Māori Mental Health.</td>
</tr>
<tr>
<td>Ūkaipō</td>
<td>(Holistic nurturing that provides for tinana, wairua, hinengaro and whānaunga needs)</td>
<td>“An environment that is relaxing, linking together mind and body.”</td>
<td>• Environment to be set up for rangatahi to use – relaxing, confidential, non-judgemental, youth-friendly colours, couches, chill-out space, access to food and drink.</td>
</tr>
<tr>
<td>Framework</td>
<td>Model</td>
<td>Description</td>
<td>Mentor role to include:</td>
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</tbody>
</table>
| **Kaitiakitanga** | (Providing guardianship and protection) | “Working in a safe environment.” | • Liaison with CAMHS/AoD service staff  
• Advocacy for youth voice on issues  
• Work with Rangatahi Roopu on group projects, activities etc.  
• Arrange appropriate compensation for Rangatahi’s time and expertise by way of transport to/from hui, petrol vouchers, food, vouchers, money etc. |
| **Kotahitanga** | (Cultivating unity) | “[working with people who] would go with you to the end” | • Rangatahi Roopu meet regularly (fortnight and/or when appropriate) in a group of 4 or more, with a youth friendly adult. Ideally this role would eventually become a position for experienced Youth Consumer Advisors to assist in the running of the meeting and advocate for the young people as and when the Rangatahi Roopu requires. |
| **Rangatiratanga** | (Being able to determine your own future) | “To have a say about how we want to be treated.” | • Assist in accessing financial support (e.g. Te Rau Matatini, Ministry of Health, Te Pou scholarships etc that will encourage further study in mental health)  
• Rangatahi Roopu may meet with larger groups of rangatahi of diverse backgrounds when wider consultation is needed such as with other Youth Consumer Advisors.  
• Rangatahi Roopu will develop peer support as experienced members mentor new Rangatahi Roopu members, creating a more whānau centred approach for advice seeking. |
| **Whānaungatanga** | (Providing opportunities to promote whānau support and build and maintain rangatahi relationships) | “Having a friendly environment – staff that help young people to feel they ‘fit’, a sense of belonging.” | • Whānau and personal support – rangatahi need to be consulted within the context of their whānau, hapū and iwi, and with support from kaumatua and kuia (Te Rau Matatini, 2008) |

*Framework adapted for Māori youth consumer participation context.*"
Conclusion

Māori youth consumer participation is essential to ensuring services are appropriate and responsive to young Māori. The Māori youth voice therefore needs to be considered and heard in the development and delivery of services. Te Tiriti o Waitangi’s principles of kāwanatanga (partnership), rangatiratanga (protection) and ōritetanga (participation) can be applied to ensure effective te urunga whaiora rangatahi Māori.

The Harakeke model provides CAMH and AOD Services with a framework to explore new and innovative ways to improve services for Māori. Included in this is the cultural values, principles and supports for improved outcomes for Whaiora Rangatahi Māori.

**Suggested highlights from the survey, that can be addressed are:**

1. Māori youth consumer participation can guide services about how to ensure they are Māori youth consumer friendly.
2. Māori rangatahi can be a part of a larger consumer group, a rangatahi roopu, who meet regularly and provide advice from a young Māori whaiora perspective.
3. Māori rangatahi consumers should not work in isolation, hence services need to consider making available the types of support networks they may need for rangatahi, i.e. Kaumatua, kuia, community rangatahi groups etc.

Finally, Child and Adolescent Mental Health Services for rangatahi Māori are charged with the responsibility to better understand the needs of this diverse group. This may mean adjusting some of the current priorities of services to enable the ‘voice of rangatahi’ to be heard.
SECTION SEVEN:

Pacific Youth Consumer Participation

A Health Profile of Pacific Youth, 2008

“I am not an individual,
I am an integral part of the cosmos,
I share divinity with my ancestors, the land, the seas and the skies.
I am not an individual because
I share a tofi with my family, my village, my nation.
I belong to my family and my family belongs to me.
I belong to my village and my village belongs to me.
I belong to my nation and my nation belongs to me.
This is the essence of my sense of belonging”

Tui Atua Tupua Tamasese

Pacific young people’s voices have largely been missing from CAMH and AoD services. To address this, there needs to be a concerted effort to ensure Pacific young people have an active say in the mental health and AoD services they receive. The approach used to develop and implement youth consumer participation should be tailored to ensure ethnicities such as Pacific young people can contribute in an effective way to influence service delivery and development.

Pacific people’s view of “mental illness” is different to the dominant Western view that mental health services have in New Zealand. “Pacific people often view mental disorder as ‘spiritual possession’ that is usually caused through the breach of a sacred covenant between peoples or between peoples and their gods.” Therefore different and more traditional approaches to healing need to be acknowledged. Pacific approaches are likely to be wellness focussed (as opposed to deficit based) and make use of individuals’ and families’ personal strengths all within a holistic context. These concepts have implications for how services implement and develop youth consumer participation.
Why specifically Pacific?

Pacific youth and their mental health

New Zealand’s population is steadily becoming more diverse, especially among young people (0-19 year olds) who make up 28% of the total population\(^3\). Pacific young people make up 9% of New Zealand’s 0-10 population\(^3\) and nearly half of New Zealand’s Pacific population is under 20 years of age, and is increasing\(^4\).

There are a number of statistics that highlight the importance of addressing Pacific young people’s mental health needs. Pacific youth are more likely to experience both general and serious mental health disorders than older Pacific people\(^3\). In addition, the Youth 2000 survey found 18% of all Pacific students reported suffering from depressive symptoms\(^4\). Of concern is that this rate is higher than the proportions for Maori (16.2%) and NZ European (11.7%)\(^2\).

The Pacific rate of access to mental health services in 2008 was 5% of all mental health clients aged 0-19 years at a time when Pacific people made up 9% of the total under 20 New Zealand population\(^4\). Therefore it seems that New Zealand is faced with a huge challenge to make sure there is policy that ensures good processes and enough resources for services that meet Pacific youth mental health needs.

Using Pacific values based models in addressing the above Pacific youth needs is essential. Developing Pacific youth consumer participation is one way to better meet the needs of Pacific youth.

What else needs to be considered?

Barriers

As well as the other barriers outlined in this document, there are some additional barriers to take into account. As identified in the 2005 CAMHS Stocktake\(^2\) a number of cultural barriers such as language and communication impact Pacific peoples accessing child and adolescent mental health services including insufficient culturally appropriate services, specialists and resources.

There is also a fear of cultural shame which causes stigma around mental illness in Pacific Island cultures\(^4\). This can make Pacific youth consumer participation especially difficult to implement and maintain.

Pacific born versus NZ born

The Pacific Peoples and Mental Health report\(^4\) notes a higher rate of mental health needs amongst New Zealand born Pacific people when compared with those born in the Islands who experienced some traditional upbringing. For those that are born in the Islands, there tends to be a strong commitment to traditional values which includes respect for one’s elders and the importance of social status. A communal life-style, physical environment and language play an important part in Pacific Island culture and coping with mental illness in the New Zealand environment can be difficult because of the difference in culture and values.

Pacific for Pacific by Pacific is based on an Island-born adult model which excludes New Zealand born Pacific young people\(^3\). One service worker stated that the Pacific family is a communal unit and its influence on service delivery “excludes the involvement or experiences of youth, particularly New Zealand-born youth consumers, from being included in definitions of what may help them to get well.”

Arguably there is an invisibility of needs of NZ born Pacific youth within Pacific mental health care\(^3\). For NZ born Pacific young people, English is usually their first language and they may not necessarily have a good understanding of Pacific Island culture which can be a barrier to Pacific youth participation in ethnic specific services. NZ born Pacific young people can feel alienated and have a sense of not belonging to either culture and feel as though they
Section Seven: Pacific Youth Consumer Participation

do not fit in anywhere\textsuperscript{43}. The differing needs of Island born and New Zealand born Pacific youth are evident in the literature\textsuperscript{40}, therefore services need to be understanding and responsive to these differences.

**Family**

Family values are a core part of Pacific culture and religious beliefs. Pacific values and beliefs are very much tied into traditional cultural religious beliefs as well as Christianity\textsuperscript{38}. Family and individuals are often described as inseparable and a wider understanding of family needs to be applied. Therefore elders, grandparents, aunts, uncles and siblings etc. may be more influential in a young person’s life. Since extended family is so important, families have such a huge impact on recovery\textsuperscript{44} and will consequently play a part in Pacific youth consumer participation.

**Pacific young people**

To work with young people there is a need to move beyond ethnicity and consider youth culture and how that affects young people in New Zealand. Agnew et. al. cite one Pacific leader as stating, “think carefully about how our practices and understandings of Pacific culture can sometimes exclude those who are key to its very survival in the future.”\textsuperscript{38}

**Consultation Process:**

In the development of these guidelines the Youth team with the support of our Pacific Cultural Advisor met with young Pacific people who had used a CAMH/AOD services. A fono was held in Auckland after sending invitations to CAMH and AOD services nation-wide as well as identified young Pacific consumers. Along with our Cultural Advisors we facilitated a focus group which included six Pacific young people between the ages of 15-24.

Questionnaires were also sent to CAMH services with high Pacific populations, to be completed by young Pacific people (with assistance from Pacific workers from their service). Questionnaires were completed one on one and in focus group situations. A total of eight questionnaires were collected and were instrumental in developing and identifying considerations unique to Pacific youth consumer participation.

**Summary of Pacific youth consumers’ views**

- Young people considered ‘having their say’ as critical to their and their peers’ improved access of CAMHS services.
- They preferred a combination of being consulted as a group, and working on a one to one basis, depending on the issue or task.
- Having family members, friends and church elders as an important part of their support systems. This includes support coming from the community – church in particular (prayer and mentorship).
- Having the choice around their welcome and prayer procedure.
- Payment or acknowledgement for the ‘job’ would depend on the task at hand and overall workload. Ideas ranged from koha, vouchers or salary.
- There is a wide range of people/roles/community resources they would draw on for support in this role including key workers, ministers, elders, friends and designated support staff.
- It would be important to provide a youth friendly space for this work to be carried out.
- Have good links with other Pacific services.
- They felt it would be important to:
  - consult with current Pacific youth consumers to gather feedback
  - develop a non-judgmental approach
  - utilize consumers
  - be trained appropriately
  - be informed of and offered opportunities for professional development
Fonofale Model and youth consumer participation

Because of the needs outlined, services may need an altered approach to ensure Pacific young people can impact service change. One way to do this is to consider Pacific youth consumer participation in the context of the Fonofale Model which was developed by Fuimaono Karl Pulotu-Endemann in the mid 1980’s. Like Te Whare Tapa Whā, the Fonofale model uses the metaphor of a house /whare / fale. It sets a foundation and can provide guiding principles for Pacific youth consumer participation.

The roof represents the cultural beliefs, customs and values that are the shelter for life. They are constantly changing to meet the needs of new environments and therefore include both traditional and western methods of healing. Just as with Maori services, from mainstream to kaupapa Māori, respect for a continuum of cultural orientation, from traditional through to more adapted palagi cultural orientation would be beneficial.

Next is the foundation which is represented by family (both nuclear and extended) and is the fundamental base of social organisation in Pacific communities and the way cultural values and beliefs are displayed.

Four pou (supporting posts) connect the culture and the family and provide the means for ongoing interaction between both. Each pou represents a dimension. They are: Spiritual, Physical, Mental and Other. These are explained in the following table.

Surrounding the fale are three dimensions: environment, time and context. Environment is the relationship between Pacific people and their physical setting. Time relates to the specific time in history and context is the set of circumstances present.
### Section Seven: Pacific Youth Consumer Participation

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Explanation</th>
<th>Youth Consumer Participation in practice</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Culture</strong></td>
<td>Culture is the source of beliefs, customs, language, sense of belonging and values. Culture is constantly changing to meet the challenges of new environments.</td>
<td>Just as with Māori services, from mainstream to kaupapa Māori, respect for a continuum of cultural orientation from traditional through to more adapted palagi cultural orientation. Support from Cultural Advisors and whoever is culturally important to young people and could include church elders, key workers and family. Services need to be responsive to the range of differences within the Pacific youth community e.g. NZ born compared with Island born. Address issues of cultural identity and connection when developing youth consumer participation.</td>
</tr>
<tr>
<td><strong>Family</strong></td>
<td>Family is the foundation and the basic unit of social organisation in Pacific communities through which values and beliefs are displayed. Families provide a sense of security, connection and belonging. A role within a family gives life purpose. These things need to be reflected in youth consumer participation.</td>
<td>First talk to the person whose status is recognised within the family. Talk to the most appropriate person first. Consulting with and informing families regarding aspects of youth consumer participation and possible roles and tasks involved. Since family is the foundation, when developing Pacific youth consumer participation, establish a sense of belonging so that youth consumer participation reflects family values. Ensure family members are priority members of support systems, whilst also drawing on a wide range of people / roles / community resources for support eg, key workers, ministers, elders, friends, designated support staff, mentors.</td>
</tr>
</tbody>
</table>
**Spiritual**

Spirituality is one’s belief system that may have Christian or traditional influences and incorporates all or some of the natural world, history, language and beliefs.  

Role of the church can be both a unifying force and a pressure for young people. Lore (traditions and customs) important in considering mental and physical health and illness.  

| Give young people the choice around their welcome and prayer procedure and ensure that this is facilitated by the appropriate people.  
Be respectful of the varying spiritual influences. |

**Mental**

Mental is the psychological domain relating to the mind. It includes emotions, thoughts and beliefs. 

| Appropriate training to be offered to further young people’s knowledge and skills. Training and study scholarships may be one way to do this.  
Payment or acknowledgement for the ‘job’ would depend on the task at hand and overall workload, including koha, vouchers, or salary. This signifies respect for a young person’s story, experiences and expertise. |

**Physical**

Physical is one’s biological or physical wellbeing and the relationship between the body and elements from the environment including food, water and air. 

| Food is important during fono and is one way to unite people and show respect.  
A comfortable and youth friendly space in which to work is helpful to encourage young people to actively participate. |

**Other**

Other includes other variables that may influence health and wellbeing. This includes age, sexuality, status and gender, all important factors when considering a diverse range of people who participate. 

| Educate elders to allow young people to be advisors when appropriate. Be respectful of the fine balance required between elders leading and young people respectfully having a say.  
Be mindful of the differing ways to viewing status. In the Islands, people are assigned status that reflects age, cultural achievements and genealogical connection. In the Islands, there is also a status of serving, young people participating in services may be looked up to as they are leaders using their knowledge to help others. |
Time, context and environment are the three overlapping dimensions surrounding the fale, which may directly or indirectly influence any or all of the above. Pacific youth consumer participation must be flexible and take into account differing contexts i.e. – in different situations, different approaches to youth consumer participation may be necessary. Therefore good networks with other Pacific services should be pursued.

Some Pacific young people responded to our questionnaire stating that it was “Best to mix cultures and work together”.

Ultimately young Pacific consumers ‘having their say’ is critical to their and their peers’ improved access of CAMHS services and their right to have input into the decisions that affect their lives.

Conclusion

It is evident that Pacific young people want to contribute to mental health service delivery and design and we therefore need to begin utilising the recommendations outlined to facilitate this.

When implementing Pacific youth consumer participation, needs of New Zealand born versus Island born Pacific youth need to be taken into account. This chapter is designed to be a base for starting to think about and put into practice effective Pacific youth consumer participation. We recommend that future investigation in this area will provide further insights into creative ways to ensure Pacific young people have an active say in the CAMH and AoD services they receive.

Finally we acknowledge the limitations of this consultation process in that we have only consulted with Pacific youth exclusive of their families, particularly given the feedback from youth indicating that family and family members would have an integral role to play in development and ongoing support of Pacific youth consumer participation.
CONCLUSION

Hocus Pocus - Make it a Focus!

Young people are capable of really contributing to the positive development of CAMH and AOD services in New Zealand, provided they are given the opportunities and appropriate support. There are young people out there that will be excellent Youth Consumer Advisors, and are willing to make a difference. It’s now up to services to allocate time and resources into developing this beneficial and essential aspect of service development and delivery.

These Guidelines advocate active youth consumer participation through the identification and minimisation of barriers, first ensuring a philosophy of youth consumer participation, followed by developing specific strategies for recruitment and retention of Youth Consumer Advisors and providing ongoing support. Your service now needs to take on the responsibility of enabling effective youth consumer participation with the assistance of young consumers.

This document also covers the other things you need to know about youth consumer participation to ensure it is effective, successful and not tokenistic. This includes looking at; the benefits for both services and young people, the evidence around why it is necessary, and how to minimise some of the barriers your service may face. Many strategies for ensuring active participation were also discussed.

Developing a more diverse youth consumer workforce is important and there needs to be discussion with groups such as Māori, Pacific and young men about what would help them to participate. It can be difficult to effectively engage with young consumers from different ethnicities. This is an area that needs more research in order to ascertain how services can help these groups to participate more effectively.

Finally, it is worth reiterating that youth consumer participation should be a priority in youth mental health services. If youth consumer participation is given sufficient time, energy and resources, your service will be able to better support the needs of young people.

“participate to the max!”

- youth consumer forum participant
## USEFUL WEBSITES

### New Zealand

<table>
<thead>
<tr>
<th>Organization</th>
<th>Website</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental Health Commission</td>
<td><a href="http://www.mhc.govt.nz">www.mhc.govt.nz</a></td>
</tr>
<tr>
<td>Mental Health Foundation</td>
<td><a href="http://www.mentalhealth.org.nz">www.mentalhealth.org.nz</a></td>
</tr>
<tr>
<td>Ministry of Youth Development</td>
<td><a href="http://www.myd.govt.nz">www.myd.govt.nz</a></td>
</tr>
<tr>
<td>New Zealand Mental Health &amp; Addictions Workforce Development Programmes</td>
<td><a href="http://www.mhwork.org.nz">www.mhwork.org.nz</a></td>
</tr>
<tr>
<td>Office of the Children’s Commissioner</td>
<td><a href="http://www.occ.org.nz">www.occ.org.nz</a></td>
</tr>
<tr>
<td>The Werry Centre for Child and Adolescent Mental Health Workforce Development</td>
<td><a href="http://www.werrycentre.org.nz">www.werrycentre.org.nz</a></td>
</tr>
</tbody>
</table>

### International

<table>
<thead>
<tr>
<th>Organization</th>
<th>Website</th>
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</thead>
<tbody>
<tr>
<td>NSW Commission for Children &amp; Young People</td>
<td><a href="http://www.kids.nsw.gov.au">www.kids.nsw.gov.au</a></td>
</tr>
<tr>
<td>Save the Children</td>
<td><a href="http://www.savethechildren.net/alliance/resources/publications.html">www.savethechildren.net/alliance/resources/publications.html</a></td>
</tr>
<tr>
<td>Young Minds</td>
<td><a href="http://www.youngminds.org.uk">www.youngminds.org.uk</a></td>
</tr>
<tr>
<td>Youth on Board</td>
<td><a href="http://www.youthonboard.org">www.youthonboard.org</a></td>
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</tbody>
</table>

### Websites about Youth Organisations

<table>
<thead>
<tr>
<th>Organization</th>
<th>Website</th>
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<tbody>
<tr>
<td>Rainbow Youth</td>
<td><a href="http://www.rainbowyouth.org.nz">www.rainbowyouth.org.nz</a></td>
</tr>
<tr>
<td>Youthline</td>
<td><a href="http://www.youthline.co.nz">www.youthline.co.nz</a></td>
</tr>
</tbody>
</table>
REFERENCES


## Position: Youth Consumer Advisor

### Location: ‘ABC Service’

### Reports to: Manager

### Functional relationships:
Youth Consultation Group, adolescent clients, key staff mentors, and all other clinicians and service management.

### Primary objectives of job:
To provide a youth consumer perspective and voice on all aspects of service delivery of ‘ABC Service’. This occurs by actively participating in meetings, commenting on all aspects of the service and having a say in decisions that will impact on the children, young people and the families/whānau using this service.

### Key tasks:
- Provide a youth consumer perspective and actively participate in all aspects of service delivery.
- Promote and role model a recovery or resiliency perspective to other staff and young people.
- Ensure a Youth Consultation Group is developed, recruited and facilitated.
- Undertake youth-initiated projects that aim to add to the effectiveness of the service.
- Act as a liaison for feedback between clients of the service, staff and management.
- Attend appropriate ‘ABC Service’ meetings and provide a youth consumer perspective.
### Person Specification:

<table>
<thead>
<tr>
<th>Person criteria</th>
<th>Minimum</th>
<th>Desirable</th>
</tr>
</thead>
</table>
| Person criteria | • Has personal experience of a mental health issue and is a current or past user of a CAMH or AOD service.  
• Can apply own experience to this role.  
• Can articulate when support is needed or if mental ill health is an issue. | |
| Knowledge | • Has some computer literacy.  
• Can apply own experience to this role.  
• Understands the applicability of the Treaty of Waitangi to this work.  
• Understands some of the issues for children, adolescents and their families regarding mental health and illness.  
• Has motivation to undertake further training to fulfil the requirements of this role. | • Is able to use Microsoft Word, Outlook, and Powerpoint.  
• Has knowledge of the mental health sector/system.  
• Has an awareness and understanding of various documents such as the Mental Health Standards, and concepts such as recovery, resiliency etc. |
| Attributes | • Has good communication skills.  
• Is empathic and understanding.  
• Can work in a team environment.  
• Is respectful of cultural and other differences.  
• Is open minded.  
• Is assertive when necessary.  
• Has the ability to work with people in various positions within the service. | • Is enthusiastic.  
• Displays initiative.  
• Can be diplomatic. |