

Principles of youth participation in mental health services

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Participation of consumers in mental health services has developed rapidly in Australia, and by the late 1990s most adult mental health services had a formal mechanism to involve consumers in planning, policy making and service delivery. After evaluations which identified consumers' concerns about restricted access to services, poor continuity of care, and lack of support for all age groups, the *National Mental Health Plan 2003–2008* outlined a commitment of Australian state and territory governments to facilitate the genuine participation of consumers in decision making at all levels. In addition, the Plan supports the empowerment of consumers, as well as their families and carers, stating that they should be able to participate fully and meaningfully at all levels, and that participation and partnership are the hallmarks of a quality mental health system.¹

Although consumers had described improved opportunities for participation in policy and planning, particularly at a national level, participation across the spectrum of service delivery, from prevention through to recovery, had not yet been achieved, especially for young people and children. The Plan recognises that different approaches to participation will be required for each group of consumers, including children and adolescents; however, to date, few models of youth participation in mental health have been implemented.¹

Participation of young people — why is it different?

Young people's experience of mental illness and their subsequent treatment needs are often different from those of adults. For young people, the experience of mental illness is often episodic rather than chronic and, as such, they view their time as a consumer of mental health care to be short term rather than longer term. Consequently, they often do not relate or identify with the term "consumer". Even young people with serious mental illnesses often reject the term "consumer", preferring to be identified as a "young person" or "youth".

Although the onset of mental illness is highest in adolescence and early adulthood, young people experience substantial barriers in promptly accessing health care services. Most young people have little previous experience of the health system — particularly the mental health system — and how it is structured. They might not have a general practitioner of their own, or may not think their problems are related to their health or that they could benefit from treatment.^{2–4} Many are concerned about confidentiality, particularly when they are in a transitional stage of reducing their dependence on their parents. Some find the symptoms of mental illness disturbing, embarrassing or shameful. In addition, the illness itself can interfere with their capacity to seek appropriate care.

In the face of these numerous barriers, it is essential that mental health services are "youth friendly". Young people have been described as being very discerning about when, where and from whom they seek assistance.⁵ Mental health services need to provide accessible and non-threatening environments, where health professionals understand the special needs of people who are not only young and "inexperienced" as health consumers, but also in the early stages of illness. Young people are best positioned

ABSTRACT

- Young people with mental illness face many barriers in accessing care and often have different needs to those of adult consumers. Young people's participation in mental health services is one way of addressing quality and access issues, through receiving feedback and implementing youth-driven and youth-friendly strategies.
- *headspace*, the National Youth Mental Health Foundation, established in July 2006, highlights the mental health care sector's commitment to young people. Existing youth participation programs provide examples of what can be achieved at national and local levels and with varying levels of financial and other support. These include:
 - Ybblue, the youth program of *beyondblue*;
 - Reach Out!, a web-based service;
 - Headroom, providing health promotion and a website; and
 - Platform Team (ORYGEN Youth Health), comprising current and past clients who advise the service and provide peer support.
- Current practice in youth participation in mental health services involves a variety of methods, such as ensuring information and education is appropriate for a youth audience, and participating in peer-support programs and staff selection panels.
- Challenges in the future development of youth participation in mental health services include avoiding tokenism, acknowledging that young people are not a uniform group, translating national strategies into local improvements in services, and gaining the support and cooperation of health care workers in genuine participation.

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to judge what is youth-friendly and what is not, whether they feel welcomed by a particular system of care, whether the style and content of education and information works for them, and whether their opinions and wishes are respected.

In return for their contribution to improving services, young people feel valued and listened to, develop confidence and new skills, and feel they have "put something back" into the system that helped them.

Models of participation by young people

The advent of *headspace*, the National Youth Mental Health Foundation, in July 2006 has highlighted the commitment of the mental health care sector to adolescents and young adults, and the need to seek their continuing participation as services improve and expand (see McGorry et al, *page S68*). The resources of *headspace* include a Youth Services Development Fund to help support the development of more accessible, effective and integrated approaches to service delivery in local communities. The participa-

1 The mental health system through our eyes

By Vittoria Tonin, Platform Team, ORYGEN Youth Health

Many young people battle life with a mental illness, and many remain undiagnosed until their condition becomes acute. In these situations young people are not the only victims, as their friends and families suffer too.

For 10 years I battled depression alone, suffering and confused. Despite unsafe practices like eating disorders and suppressing my emotions, my mental illness went unnoticed. One day it became too much and my life was in jeopardy. Before my first overdose I had told my medical team of my plans to kill myself, but it was the police intervention that led to me being admitted to a child psychiatric ward.

Life as a teenager is very confronting and hard enough to cope with by itself, let alone while carrying the extra burden of mental illness. Often teenagers are unaware of their condition, don't know where to seek help, don't want to be treated differently to their peers, or are ashamed of their illness.

Our health system needs to take the next step forward in removing the barriers between health professionals and young people. It needs to start listening to what we are saying and what we are asking for. To know what works best for us, the system has to become youth-friendly and youth-oriented.

Even when youth-specific services are available, many young people don't know they exist, don't know how to access them, or fear the repercussions of using them. For us to pick up the phone, to see a professional, and to acknowledge and discuss our problems takes immense courage. Fear of the unknown and the stigma of mental illness stands in the way. Fear of rejection can be enough to prevent young people from asking for help.

Some people think that treatment will cost too much, so they or their families will not be able to afford it. Some live in regional or remote areas far removed from services. No young person should be stripped of their right to access treatment, but financial and geographical inequalities make this happen every day.

For society to develop youth-friendly mental health services, it must learn to listen to young people, do so willingly and frequently, and take notice of what it hears. A company designing a new mobile phone would ask their market what they would like, and then design the product. Mental health care is no different — the more the authorities and the experts listen to young people, the more successful our health care system will be.

Young people deserve to feel safe and comfortable when accessing all types of medical services. We need to be kept informed throughout our treatment, and told about our rights, roles and responsibilities. This will increase the level of control we feel over our own situation and give us the power to participate in our treatment.

Young people are not always willing to comply with recommendations about their treatment, but this happens in all age groups. Look below the surface to find out why. For many young people, treatment can be a frustrating process in which they feel separated, powerless, pressured and left outside "the loop". Instead, including us in our recovery, for example by carefully discussing the choice of a new medication, will make it more successful and sustainable.

Youth mental health services must understand that they need the opinions and input of their young clients as well as the advice of clinicians, academics and scholars. Neither being young, nor having a mental illness, means our opinions don't matter, or that our input will not help improve the service and provide better outcomes. People accessing health services should not be disadvantaged by geography, or by their financial status or their socioeconomic rank. Neither should they be disadvantaged by their young age, or their type of illness.

As young people, we are often told we are "the future". If the health care system thinks the same way, then we will all benefit. ♦

tion of young people, including those who have not been consumers of mental health services, will be central in refining the activities of *headspace*.

Existing youth participation programs provide an insight into what can be achieved, at both national and local levels. The examples of youth participation given below are leading the way in terms of best practice for involving young people in mental health care services. They demonstrate the range of circumstances in which participation can occur, varying in scope from national to local, and differing markedly in the level of financial support.

Ybblue

Ybblue, the youth program of *beyondblue*, promotes the central message that "it's okay to talk about depression" and encourages young people, their families and friends to seek help when it is needed.

Communicating the message depends on meaningful participation by young people, achieved partly through the Ybblue Crew. The Crew, a group of 33 young people aged from 16 to 25 years and living across Australia, works to provide advice on how to recognise depression, how to talk about it, and how to get help. Specific aims include:

- increasing awareness of depression, anxiety and related issues and their impact on young people, their families, friends and the community;
- helping people gain a clearer understanding of what depression is and what it is like to experience depression;
- working with and promoting awareness of support services to encourage an effective community response; and
- ensuring that information about depression is relevant and accessible to young people.

The Crew advise on the content and presentation of the Ybblue website (<http://www.ybblue.com.au>), are active in public speaking and media appearances, write and edit a newsletter (*YBInformed*), and develop and edit Ybblue materials, such as fact sheets and postcards. Two Ybblue Crew members are on the management committee of *blueVoices*, the consumer and carer arm of *beyondblue*.

Ybblue allows young people to make decisions and positive contributions about mental health services, drawing on their unique "lived experience" of mental illness.

Reach Out!

Reach Out! (<http://www.reachout.com.au>) is a web-based service in an appealing format that aims to inspire young people to help themselves through tough times. It provides information, guidance about where to find help, and the opportunity for discussion. The program is supported by corporate and other sponsors, and health professionals contribute their expertise (see Burns et al, *page S31*).

A "career structure" is available for Reach Out! participants. They can initially join an advisory board and then progress to Youth Ambassador status as they develop their commitment, level of knowledge and skills. Ambassadors, of whom there are now about 80 around Australia, can move on to become Reach Out! Youth Leaders and assume extra responsibilities. Reach Out! members "mentor" the content of the online forum, ensuring it remains positive and removing potentially damaging material from public access.

2 Issues in expanding youth participation in mental health services

- Avoid tokenism — seek genuine contribution and respect its value
- Set realistic expectations, so goals are neither trivial nor unachievable
- Acknowledge that young people are not a uniform group. They can vary markedly in age, developmental stage, experience with mental illness, knowledge and skills. A single individual will rarely represent the whole group
- Recognise a duty of care, for example in transport, accommodation and chaperoning, especially for participants younger than 18 years
- Note that national initiatives for youth participation may need a very different approach to local initiatives, but that national initiatives are effective only if they ultimately improve community-based care
- Take care that participation does not entrench young people as “professional advocates”. Mental health care aims for recovery. Similarly, young people have many other interests and needs that should be respected
- Expect that participation requires a degree of commitment, but it should also allow the flexibility to accommodate demands, such as study or the fluctuating effects of illness
- Encourage health care workers to accept, appreciate and encourage the benefits of youth participation, even though it may challenge traditional perceptions of professional roles
- Ensure that youth participation is adequately resourced, to maximise its contribution and avoid disappointment from insufficient support

Headroom

Headroom (<http://www.headroom.net.au>), developed within the Children, Youth and Women's Health Service of the Government of South Australia, provides a partnership model of participation for young people aged under 18 years. The project started with two full-time equivalent positions in 1997, although funding has declined since then. Headroom reflects the commitment of the service to working with young people, providing mechanisms to support their participation in mental health care. Involvement of Headroom's members is facilitated by an Internet chat room, as well as more traditional methods, such as face-to-face meetings and email.

Health promotion and a website are now the focus of Headroom's activity. Members of the group assist in identifying issues of most concern to young people, develop written information and DVD presentations, provide focus testing, and advise about the look and “feel” of the site. The group also plans and conducts promotional activities, including presentations to funding and health bodies.

Feedback from young people has been very positive:

I liked the friendly way of explaining things and the way it's presented.

I like ... the thought of knowing other people are going through the same stuff you are, and knowing that you are not alone and there is someone who can help.

I really feel that this has answered a lot of questions I have had for a very long time. Especially things like self-esteem, friends, trauma and independence.

I also really like this web site because it contains professional information so no one can point you in the wrong direction, even mums [and] dads don't have a lot of the answers. Chances are they have problems with a lot of the issues discussed here too.

Platform Team, ORYGEN Youth Health

The philosophy of ORYGEN Youth Health acknowledges that their clients learn much about what has helped and what has not, and that this knowledge can improve the service and help others. The Platform Team is a group of current and past clients who meet regularly, initiating issues for discussion themselves, as well as responding to issues raised by staff and others. There are usually about 10 members of the Platform Team, with varied experiences and backgrounds. The Team operates as a group, in contrast to the individual consumer consultation model often used in adult services, and has considerable autonomy and responsibility in determining its activities.

Other elements of youth participation at ORYGEN include:

- peer support by past clients, who visit the ORYGEN inpatient unit and also staff a drop-in centre in the outpatient unit. Peer-support workers receive training and mentoring, and are paid for their time;
- the *Jargon Filter*, a newsletter produced by ORYGEN clients, which provides information about the service, personal experiences of illness, and the scope for recovery;
- contribution to community education about mental health issues; for example, by speaking at schools, talking to youth workers, and presenting to the media; and
- membership of selection panels for staff applying to work at ORYGEN Youth Health, providing, among other benefits, a clear symbolic message that young clients' views are valued. Panel members receive training and payment for their participation.

A personal account of the experiences of one Platform Team member is given in Box 1.

Challenges

Enthusiasm about youth participation in mental health services must be matched by adequate resources, a clear understanding of the rights and responsibilities of those who become involved, and a genuine appreciation of the benefits that can flow from seeking input from young consumers. Some of the issues to be considered in expanding the role of youth participation are listed in Box 2.

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References

- 1 Australian Health Ministers. National Mental Health Plan 2003–2008. Canberra: Australian Government, 2003. <http://www.health.gov.au/internet/wcms/Publishing.nsf/Content/mental-pubs-n-plan03> (accessed Jul 2007).
- 2 Booth M, Bernard D, Quine S, et al. Access to health care among NSW adolescents. Sydney: NSW Centre for Advancement of Adolescent Health, The Children's Hospital at Westmead, 2002.
- 3 Sawyer MG, Arney FM, Baghurst PA, et al. The mental health of young people in Australia. Child and adolescent component of the National Survey of Mental Health and Well-being. Canberra: Mental Health and Special Programs Branch, Australian Department of Health and Aged Care, 2000. [http://www.health.gov.au/internet/wcms/publishing.nsf/content/70DA14F816CC7A8FCA25728800104564/\\$File/young.pdf](http://www.health.gov.au/internet/wcms/publishing.nsf/content/70DA14F816CC7A8FCA25728800104564/$File/young.pdf) (accessed Aug 2007).
- 4 Youth Affairs Council of South Australia. Getting through: responding to young people's mental health issues in the youth sector. Adelaide: YACSA, 2006.
- 5 Deane FP, Wilson CJ, Ciarrochi J, Rickwood D. Mental health seeking in young people. Report for the National Health and Medical Research Council of Australia. Grant YS060. Wollongong, NSW: University of Wollongong, Illawarra Institute for Mental Health, 2002.

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