The importance and benefits of youth participation in mental health settings from the perspective of the headspace Gosford Youth Alliance in Australia

Abstract

Objectives: Young people's participation in decision making that affects them is increasingly recognised and valued as a right. Youth participation in mental health settings is fundamental to service design and delivery, and is beneficial for the young people as well as the organisation. Headspace recognises the many benefits of youth participation with its national and local youth participation initiatives. In 2013, headspace Gosford in Australia established its current youth participation model, called the Youth Alliance (YA), consisting of 12 young people. These young people contribute ideas and opinions around service design and delivery, and participate in a range of activities.

Method: This paper presents the findings of a focus group conducted with the YA immediately following recruitment. All 12 young people participated in a two hour focus group which sought to identify the key reasons these young people joined the YA, and what they hope to achieve in their capacity of YA consultants.

Results: The two main reasons participants joined the YA are to help 'overcome barriers to help seeking and ensure young people get the support they need' and 'to build confidence, social skills and make new friends'. The barriers to help seeking identified by the participants are consistent with those outlined in the literature.

Conclusion: Youth participation in youth mental health settings is beneficial to young people as well as organisations and the community, and it is crucial that strategies are put in place to increase youth participation. The ways in which these young people perceive their participation as beneficial to themselves as well as the organisation and the community is the focus of this paper.

Young people's participation in decision making that affects them has become widely valued and respected as a right. Increasingly, youth participation in mental health settings is recognised as fundamental to service design and delivery (Monson & Thurley, 2011; Muir, Powell, & McDermott, 2012; Wong, Zimmerman, & Parker, 2010).

The aim of youth participation is to empower and engage young people around issues that are relevant to them. Participation may take on a variety of forms, but includes the contribution of ideas, opinions and feedback to an organisation, and participation in a range of activities. Effective youth participation ensures that young people are included as active valued members of a team and not just engaged in a passive capacity or given token roles (Checkoway, 2011).

Youth participation is beneficial for both the individual and the organisation. Youth participation is beneficial for the young person as it facilitates the development of social skills and self-esteem (Checkoway, 2011; Head, 2011), and has been found to be pivotal to recovery from mental health issues (Laws, 1998). Youth participation allows for young people to gain skills and a sense of empowerment and make healthy connections with positive role models (Mokwena, 2006; Revans, 2009). Young people who engage in meaningful youth participation often have an enhanced sense of belonging and feelings of being valued, which can contribute to positive mental health (Oliver, Collin, Burns, & Nicholas, 2006). Specific to mental health settings, youth participation enhances mental health literacy, which in turn protects against the further development or onset of mental health issues (Edwards, Wood, Davies, & Edwards, 2012). Youth participation is also beneficial to organisations as young people are creative and can draw on their personal experiences to make

valuable contributions (Gray, 2002). They can help make services more responsive and accessible to young people and challenge existing presumptions about what young people need, and in turn increase service credibility (Mokwena, 2006; Revans, 2009).

Headspace recognises youth participation as fundamental to the delivery of quality services for young people with its national and local youth participation initiatives. Headspace is Australia's National youth mental health foundation. Headspace offers services to young people aged 12-25 years who may be experiencing mental health and/or drug and alcohol issues. Headspace provides young people with meaningful opportunities to directly participate and collaborate with its services and encourages the development of new and innovative models of youth participation within headspace platforms.

In 2013 headspace Gosford on the Central Coast in New South Wales (NSW), Australia, re-established its youth participation model, called the Youth Alliance (YA), which had ceased in 2009 (for an overview of the previous model see Howe, Batchelor, and Bochynska (2011)). headspace Gosford is under the governance of Children and Young People's Mental Health (CYPMH) which is a service of Central Coast Local Health District (CCLHD). Headspace Gosford re-developed its youth participation model, informed by both the lessons learned from the previous YA (2007-2009) (Howe et al., 2011) and an in-depth review of the literature (Checkoway, 2011; Hart, 1992; James, 2007; Muir et al., 2009; Oliver et al., 2006; Shier, 2001; Treseder, 1997). The current model of participation has a variety of levels of participation, so that the degree to which young people participate can vary depending on the projects and the availability or interest level of the young people.

While the implementation of the YA is still in its early stages, thus far these young people have attended a number of YA meetings and have been involved in a number of community awareness and fundraising events. As the YA becomes fully implemented, YA consultants are expected to attend monthly meetings, participate in community awareness events, be available for consultation by the service as required, be involved in focus groups and consultations that direct local services, and develop and/or participate in projects.

In August 2013, the new headspace Gosford YA was formed, consisting of 12 YA consultants. This followed a recruitment process which included advertising, information sessions and written applications. Young people aged 16-25 who live on the Central Coast, NSW, and are passionate about youth mental health were invited to complete an application form outlining their reasons for wanting to become a YA consultant. The recruitment focussed on ensuring young people from diverse backgrounds including those from minority and marginalised populations were recruited. Thirty eight applications were received of which 21 young people were identified as from minority groups, CYMPH and headspace users and those who self-identify as having personal experience with mental health issues and invited to a "meet & greet". The remaining applicants were predominantly psychology students wishing to gain work experience in mental health; providing they did not report personal experience with mental health they were excluded. The "meet and greet" served as an exercise to measure motivation and allowed for initial attrition. Eighteen applicants attended, all of which were invited to be part of the YA in a voluntary capacity and given vouchers for their participation. Thirteen accepted the invitation, of which 12 have continued to form the current YA. Efforts were made to gain

feedback from those young people who were invited to participate but declined participation or failed to show up. The majority of these young people were hard to contact and failed to return follow up calls; the few young people that were contacted commented that they had "*decided to do something else instead*".

Of these 12 young people, 7 are female and 5 males, ages range from 15 to 23 (mean age of 18.9), ten live with their parents and two live in a refuge. Nine young people are at school, TAFE or University, two are employed and one is looking for employment. Eight have a current mental health problem and four have had mental health issues in the past. One person has no current or previous personal experience with mental illness, but is a carer of a parent with a mental illness. Diagnoses include anxiety, depression, post-traumatic stress disorder, eating disorder, and borderline personality disorder (some participants had multiple diagnoses). Nine have a family member with mental health problems. Seven YA consultants currently, or have previously, accessed mental health services. The objective of engaging a diverse group of young people who have personal experience with mental illness was met.

This paper presents the findings of a focus group conducted with the YA immediately following recruitment which sought to identify the key reasons these young people joined the YA and what they hope to achieve in their capacity of YA consultants.

Methodology

All 12 young people participated in a 2 hour focus group in September 2013, shortly after commencement of the project. The focus group was conducted onsite by the research officer at CYPMH who was previously unknown to the participants. The focus group was part of the ongoing evaluation of this project.

Questions focussed on the young people's expectation of the YA, why they had joined and what they would like to achieve. Even though the researcher had prepared a list of topics, the majority of the questions were answered naturally throughout the 'focus group conversation'. The focus group was carried out in a manner that allows the young people to freely express their opinions without pressure (Lambarth, 2002).

The focus group was recorded and transcribed verbatim. The transcript was coded with 'NVivo' to identify key themes.

Approval for this study was received by the Hunter New England Human Research Ethics Committee of Hunter New England Local Health District. All participants were provided with an information statement and consent form. Participants were assured of their anonymity and that participation or their decision not to participate will not in any way impact on their involvement with the YA or headspace. Each participant was given a $40 voucher for their participation.

Findings

Analysis identified a number of reasons the young people joined the YA, and ways in which they perceive their participation as beneficial to themselves as well as headspace and the community.

The key reason these young people joined the YA is because they are passionate about youth mental health. They believe that young people continue to experience significant barriers to help seeking, barriers which they are hoping to help overcome in their capacity of YA consultants. This suggestion that young people experience barriers to help seeking and do not receive the support they need is supported by the literature (Reavley, Cvetkovski, Jorm, & Lubman, 2010). Research shows that up to 71% of adolescents with a diagnosable mental disorder do not receive professional help, and even when adolescents' parents report that they believe treatment is required, nearly half do not receive help (Sawyer et al., 2000).

From the perspective of the YA consultants the most significant barriers to help seeking for young people is the stigma associated with mental health problems; poor mental health literacy in schools and at home; insufficient visibility and acceptability of youth mental health services; fear of disappointing parents; and the strong desire in young people to be perceived as 'normal' and to 'fit in'. Analysis of the focus group identified key ways in which the YA consultants hope to help overcome these barriers.

While these young people are committed to making a difference for other young people, they recognise that participation also holds personal benefits. The most common 'personal' reasons for joining the YA were the opportunity to make like-

minded friends, build social skills and networks in a safe way and learn to better support their peers. In addition, a number of young people commented that being part of the YA is "*a good way to build new skills and work experience, and it looks great on a resume*", but this is considered more of an 'added benefit' than a reason for joining.

"I want to fight stigma so young people with mental illness don't have to hide their illness and get the help they need"

The young people identify stigma as the most significant barrier to help seeking that they would like to combat in their position as YA consultants. They explain that mental health stigma is everywhere, at home, at school, and in the community. They explain that young people go through great lengths to maintain perceptions of 'normality' out of fear of being ostracised. Comments such as "*I want to help normalise mental illness so people don't feel like they're the only one anymore*" and "*I would like to make it ok for people to talk about mental health*" were common.

This is explained by some of the participants as follows:

> *Stigma is a big problem… It's taboo to talk about mental health problems. If you're like going through it you're either going to refuse to acknowledge that you've got a mental health problem or once you do you're going to feel like the class freak… People think having a mental health problem makes you a crazy person… While we're probably ahead of other generations, and our*

generation is probably the most accepting of mental health problems, we have a very long way to go.

When I was going through it, it would have really helped me to know I wasn't the only one going through this… But we don't talk about this stuff and I thought I was the only one, that I was the only one crazy enough to have depression.

Mental health stigma is a well-recognised barrier to help seeking (Kranke, Floersch, Townsend, & Munson, 2010; Plaistow et al., 2014). Young people are particularly susceptible to stigma and less willing to access mental health services than adults as they are concerned with social interaction and peer acceptance while at school (Kranke et al., 2010). The desire to be 'normal' and to 'fit in' is a common feature of adolescence. It is well established that part of young people's reluctance to seek help is fuelled by their fear of appearing to be 'different' at an age where fitting in is very important (Medlow, Kelk, Cohen, & Hickie, 2010).

One participant argues that this is particularly true for males as from a young age they are told to "*toughen up*" and "*suck it up*", and reaching out for help is "*entirely unacceptable".* This idea is supported by evidence that help seeking is inhibited by embarrassment and a fear of being perceived as weak (Moskos, Olson, Halbern, & Gray, 2007), and that boys are less likely to access services than girls (Chandra & Minkovitz, 2007).

The stigmatisation that surrounds mental illness is increasingly recognised as a central issue, if not the central issue, for the entire mental health field (Hinshaw, 2005; Plaistow et al., 2014). Consistent with the current findings, a number of studies have found that young people report stigma as the largest barrier to accessing mental health services (Bowers, Manion, Papdopoulos, & Gauvreau, 2013; Chandra & Minkovitz, 2007).

"I want to educate parents so they stop putting so much pressure on us, and get us the help we need, when we need it"

The YA consultants also highlighted fear of parental disappointment as a barrier to helping seeking. Comments such as "*I found it really hard to seek help because I didn't want to disappoint my parents*" were common. The YA consultants suggest that parents measure their success as parents by their children's resilience and positive mental health. They explain that admitting to struggling with mental health issues is not only admitting personal failure to be resilient but also elicits a sense of failure in parents. This idea is explained in by two participants as follows:

> *Some parents have the idea that it can't happen to my child because I'm a good parent, you know... My father refused to believe I was suicidal until I was on suicide watch.*

> *There's also social stigma for parents… They often feel they can't mention this to the rest of the family or their friends because that may mean they failed as parents. Parents see their children's success as a reflection of their own*

success as parents. That's the hardest stigma to change. Parents often push

kids so hard and refuse to accept things about them because it's not what

they value; it's not what makes them feel like they've succeeded.

Following on from this, a number of participants stressed that "*parents also need to be educated about mental health*" and *"we should have a marketing campaign targeting parents".* One participant elaborates on this suggestion as follows:

We also need to change the stigma that parents have... You know, parents

need to be educated... There's the stereotype of the mopey teenagers and

parents expect that to pass. I remember telling my mum that I was having

really bad thoughts and I was suicidal, I was depressed and I was having

serious problems, like real serious. I told my mum this one morning and she

said 'ok, tomorrow I'll take you to headspace and we'll get you the help you

need'. She never mentioned it ever again.

Consistent with this, participants in a study by Chandra and Minkovitz (2007) identified the belief that their parents would deny the issue and reject the idea of accessing mental health services as a barrier to help seeking for young people. Similarly, a study by Leavey, Rothi, and Rini (2011) found that young people may not seek help because they are concerned about confidentiality and do not want their parents to be informed.

"I want to educate people about mental illness and treatment options so they can recognise when they need help and know how to get help"

All the participants expressed a strong commitment to increasing mental health literacy. They argued strongly that young people do not know what mental illness means and are not able to recognise mental health problems in themselves or in others. Comments such as "*people don't understand what having a mental health problem means*" and they "*don't recognise when they need help*" were common.

One participant describes this as follows:

> *Most people don't even know if they have mental health problems. They don't know that they have anxiety issues and that that's why they won't go out and do things or speak to people… because of anxiety or depression. They don't recognise it and don't know how to deal with it. I was probably in denial about being really really depressed for a really long time. Once I realised that's what I was I took the steps to get out of it. If I had had someone come in and explain it to me maybe that could have happened a bit earlier.*

Furthermore , a number of participants explain that even when young people recognise that they are struggling with a mental health problem, misconceptions of what counselling means and a lack of understanding of treatment options further inhibits help-seeking. This is explained by one of the participants as follows:

> *Young people don't understand what counselling means and it's intimidating. A lot of people don't know what they're getting into, what sort of help, they don't know that counselling is more than 'how do you feel about that?" That*

it's an actual discussion… Young people think counsellors are people who think they have the answers and tell you what to do with your life… I would like to explain to young people what counselling means, and how it can help… People need to be told what a counselling session looks like. I'd do a mock counselling session that can be shown to young people. I'd do it in front of a crowd at schools so people know it's not just about 'how do you feel' 'yup, you're nuts'…. It's important to show the process… The most natural thing in humans is fear of the unknown. That's what it's all about, fear of the unknown. Our imagination is always worse than the reality.

Furthermore, the YA consultants want to help empower young people to take charge of their own recovery, and make sure they get the support they need, as opposed to being passive recipients of a service. As noted by one of the participants:

I know so many people who have been through the mental health service … and they say it didn't work. They don't know that when they're not getting along with their counsellor they can say 'I don't think this is working' can you refer me on. They don't understand that they can be honest with the counsellor. A lot of people will lie because they think they're going to be judged. And that's what I think we need to be telling people: 'Use your voice and if it's not working out and you're not getting along with your counsellor you need to say that … It is important that we teach people how to negotiate their relationship with their counsellor.

This observation is consistent with a study by Rickwood, Deane, Wilson, and Ciarrochi (2005) which identified negative attitudes and beliefs related to seeking professional help as a significant barrier to help seeking for young people. They found that beliefs such as the belief that professional help is not useful, or previous negative experiences with help seeking, inhibit young people getting the support they need.

In addition to the barriers outlined above, another significant barrier to help-seeking identified by the participants is limited service visibility and a lack of knowledge around service availability. One of the participants comments that: *"A lot of teenagers don't know about stuff like headspace. They don't know what services they could use. I didn't know when I had depression".* The participants argued that increasing service visibility should be a priority focus.

The argument that mental health services are not visible enough (Moskos et al., 2007; Plaistow et al., 2014), and that many young people do not know about services such as headspace is supported by the literature. Based on a national sample of 3021 young Australians who participated in a telephone interview Yap, Reavley, and Jorm (2012) found that few young people spontaneously mention headspace as a mental health service where they would seek help or refer a friend. This study found that young people who have the greatest need for mental health services were not more aware of these services than those who did not.

The young people in the current study explain that while there are headspace pamphlets at school, no one looks at them because it is neither socially acceptable

to do so, nor an appropriate communication tool for young people today. Comments such as "*you're communicating in print media with the technology generation*" and "*the problem is that you're not from our technology generation so you don't quite understand*" were common. These comments are consistent with a study by Burns, Davenport, Durkin, Luscombe, and Hickie (2010) which concluded that technology is important in the lives of young people and that online mental health services that encompass promotion and prevention activities are important in engaging young people.

The need for greater mental health literacy in young people is supported by the literature (Ross, Hart, Jorm, Kelly, & Kitchener, 2012; Yap et al., 2012). Research shows that there continues to be deficiencies in the public's knowledge in how to prevent mental disorders, recognition of when a disorder is developing, knowledge of help-seeking options and available treatment, knowledge of effective self-help strategies for milder problems, and first aid skills to support others affected by mental health problems (Jorm, 2011). There is, however, evidence that interventions can improve mental health literacy and have a positive impact on mental health outcomes for young people (Jorm, 2011; Kelly, Jorm, & Wright, 2007).

"I want to help make mental health education as important as physical health"

The YA consultants also argued that bringing mental health education into schools should be a key priority. They say that education around mental illness is not part of the curriculum and "*teachers never talk about mental illness or give you any information*".

As argued by one of the participants:

Mental health promotion should be targeting the entire lifecycle. By the time you're in kindy you know to wear sunscreen and a hat and not smoke. Mental health needs to be addressed in the same way. I can't remember once talking about mental health at school.

While they recognise that young people can access school counsellors, they describe this as "*social suicide*". They explain that mental illness is stigmatised to the point where accessing the school counsellor is very likely to lead to being teased and even bullied. As explained by some of the participants:

As a teenager you will absolutely feel like you have the neon sign above your head saying 'freak' when you walk into the counsellor's. There is a phrase we use at my school to refer to someone who goes to the counsellor, 'social suicide'. You don't do that if you want a life.

At high school you worry about being at the bottom of the food chain and things like this push you down and give people even more reason to push you down… This is the stuff we need to change through education.

This suggestion that mental health resources at schools are scarce (Bowers et al., 2013; Chandra & Minkovitz, 2007) and that stronger partnerships between mental health and education sectors is needed is not new (Plaistow et al., 2014). In 1999

the NSW School-Link initiative was implemented across New South Wales, Australia, to systematically formalise partnerships between schools, Technical and Further Education (TAFE) and mental health services to work together to improve mental health outcomes for children and adolescents (Maloney, Jones, Walter, & Davenport, 2008). Increasingly, evidence shows that interventions promoting the mental health of young people can be implemented effectively in schools and community settings and have positive outcomes (Barry, Clarke, Jenkins, & Patel, 2013; Berridge, Hall, Dillon, Hildes, & Lubman, 2011).

"I want to see peer networks established in schools so young people can support each other"

The YA consultants suggest that an effective way to increase mental health literacy in schools may be through a 'peer support network' connected to headspace but implemented in schools. They explain:

> *Youth talking to youth is more effective in getting young people to get the help they need than adults trying to convince them…. I'd love to share my experiences with others, and when I needed help I would have loved the opportunity to talk to someone my own age.*

> *Getting over my depression for me was a conscious thing. I started opening up to friends but didn't want to see a counsellor. I don't want to talk to someone I don't know. I'd rather talk to my friends. It's harder to open up to people you know than a counsellor but I think it's important for young people*

to help each other and for young people to have the skills they need to help their friends.

Young people are an important first port of call for peers with mental health difficulties (Leavey et al., 2011; Yap, Wright, & Jorm, 2011). Many young people with mental disorders do not receive professional help due to their preference to rely on themselves or share their problems with friends or family, as opposed to seeking formal sources of help (Leavey et al., 2011; Rickwood, Deane, & Wilson, 2007; Ross et al., 2012).

Through their participation in the YA these young people hope to increase their own mental health literacy so they can better support their peers. Comments such as "*I joined the YA because I want to learn how to be a better friend and better support my peers*" were common. This sentiment if reflected in the following comments:

I want to learn the skills that if someone came up to me with an issue I'd be able to help them. Instead of telling them to go speak to headspace I want to give them something so they walk away from me more informed and better prepared.

I often talk to friends who are feeling down but I have no idea what to do. I'm really afraid to give bad advice but just listening can be good. I want to learn how to help people get better.

I like to see what I can do to help other people on a personal level as well. I know a lot of people who are in a bad situation and don't know what to do … I don't know what more I could do.

I want to be able to help other people going through the same things as what I went through and give them the skills so they can just get past that. Looking back I really regret how I dealt with those situations and I just want to be able to help other people better so they don't have to experience the same things I did.

The importance of equipping young people with the necessary skills and knowledge to support their peers through mental health problems is not new (Gulliver, Griffiths, & Christensen, 2010; Ross et al., 2012), and this need is currently being addressed through the development of basic mental health first aid training for adolescents (Ross et al., 2012).

"I want to make some friends, build personal confidence and social skills"

There was a general consensus that being part of a YA offers an opportunity to make new friends and build social skills in "*a safe way*" where they will be "*accepted regardless for who they are*". This motivation is reflected in the following comments:

For me, my disorder makes it really difficult to socialise with people, just because I'm very volatile in social situations. I tend to get offended by things really easily. So it's a lot easier for me to be in this situation where people

have their own issues and understand what it's like to be misunderstood, or have people have perceptions about them that are completely wrong. For me it's a lot easier to be here and practice how to improve my social skills than do it anywhere else.

That's the same with me... I'm not good at socialising...You know …. I'd say something and I wouldn't realise it's the wrong thing and then I'd alienate people and all of a sudden I'm on my own, again. This is an opportunity to build social skills, but that makes me sound a bit like a dork.

In this group here, I don't feel like I'm going to be judged because we all have our own things. This is a safer place than like school.

I'm a really shy person but at the events I've attended as part of this group I actually talked to some people. That was good for me. It's pushing my boundaries in a good way. … I want to gain confidence.

These comments further support the suggestion that developing peer networks should be an area of focus.

Conclusion

The findings show that the two main reasons participants joined the YA are to *"help overcome barriers to help seeking to ensure young people get the support they need"* as well as *" to build confidence, social skills and make new friends".*

Despite obvious benefits to youth participation for both the young people as well as organisations and the community, barriers to participation continue to exist (Muir et al., 2012). Although in recent years youth participation programs have been implemented at national and local levels, the National Youth Participation Strategy (NYPS) in Mental Health (2008) identifies that youth participation in mental health in Australia remains limited. A key challenge to successfully implementing a youth participation model experienced by headspace Gosford, both currently as well as with the previous YA (2007-2009) (Howe et al., 2011), regards the successful integration of this model into an existing structure. Consumer participation models cannot simply be 'fit' into existing structures (Monson & Thurley, 2011), and a lot of work needs to be done to gradually integrate a model into the organisation.

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