

Case Study: Youth participation in a local mental health service, Gosford, NSW, Australia

Key features:

This case study presents the experience of developing a prototype youth mental health service model for the state of New South Wales (NSW), Australia. It specifically presents a model for establishing youth participation in governance, planning and implementation (the Youth Alliance) and for improving the participation of families and carers in the mental health service.



Key features of the work that could potentially be adapted/adopted elsewhere include:

1. Remuneration and/ or employment of youth consultants as part of the Youth Alliance (YA) models, and or peer workers (CHOICE pilot project).
2. Processes for selection and recruitment of YA consultants/peer workers, with a focus on ensuring diversity in the representation of young people.
3. Approaches to enable youth participation and empowerment, particularly for youth from disadvantaged backgrounds. These include having a paid youth coordinator for the YA; having mentors for peer workers; offering a flexible model of participation in the YA (in 2013) and providing initial and ongoing training and development.
4. The approach to ensuring system and staff readiness for young people's participation and engagement in a Youth Mental Health service including awareness and information sessions, in-service training and formal feedback mechanisms.
5. The carer strategy (in 2010) focused on empowering families to be actively involved in the young person's care.

Introduction to the site and its practices:

In 2006, Children and Young Peoples Mental Health (CYPMH), Central Coast Local Health District (CCLHD) were chosen as the 'prototype' Youth Mental Health (YMH) service for NSW Australia. Funding from NSW Health enabled the development of an integrated YMH service platform (ycentral) in Gosford, Central Coast, NSW. This funding focused on young people with moderate to severe mental health problems. In 2007, Central Coast was chosen to be one of the first 10 *headspace* sites in Australia as part of Commonwealth Government funding. With the combined funding from NSW Health (to develop YMH for NSW) and the Commonwealth (through *headspace*), the *ycentral* site was further enhanced.

The site now includes Primary (General Practitioners) secondary (*headspace*) and Private Allied Health (Psychologists and Social Workers), and tertiary YMH services (the State funded YMH Team). Through the State YMH Project, a youth participation model was developed, termed the Youth Alliance (YA). What became *headspace* Gosford funded the implementation of this model. This model of youth participation included remuneration of young people and their involvement in actively shaping strategies and actions of the YMH services under development. Currently, the funding and organisational arrangements for *headspace* Centres across Australia is undergoing change. The case study reports on the progressive development of social participation by young people aged 12-25 years, as part of the integrated service model using both State and national resources with a focus on: the lessons from the YA model; the evolution of the CYPMH model for participation in the coming 12 months; and the next steps for *headspace* Gosford and Lake Haven.

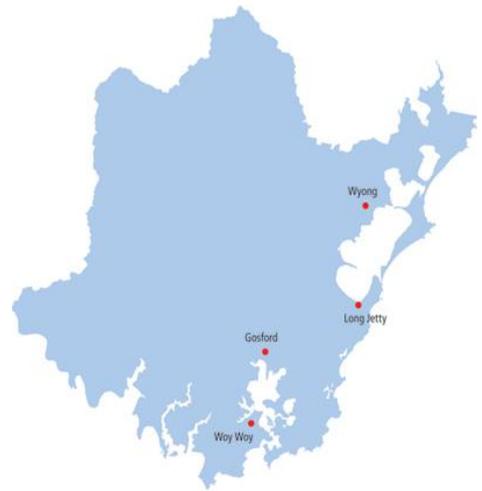
The case study report was prepared in February 2017 by Sarah Simpson, TARSC consultant and Deborah Howe, Manager CYPMH, CCLHD, case study lead and key informant. Focal points for follow up interaction are Deborah Howe, and Helen Isenhour, Manager *headspace* Gosford and Lake Haven.



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Context:

The Central Coast Local Health District (CCLHD) provides public health services to the communities of Gosford City and Wyong Shire Local Government Areas. It is located between Sydney and the Hunter Valley (see map) and had a total population of 333,119 in 2015. The region, and population served by the CCLHD, experiences a higher than average population growth particularly in the Wyong Shire. It is served by two acute hospitals - Gosford and Wyong, two sub-acute facilities and ten community health centres in addition to other community based services.



Geographic area of CCLHD.
Source NSW government, undated

The population served by the CCLHD also experiences a relative disadvantage compared to other parts of NSW. This is particularly acute in Wyong area (NSW Health, CCLHD 2013). While the population in Central Coast is growing for all age groups, the greatest proportional increase will be in people over 70 years. The CCLHD population has higher lifestyle risk factors in relation to education, physical activity, diet, obesity, smoking, alcohol/drug use and psychological distress than NSW, and higher average death rates than NSW from all causes, from cancers, respiratory disease and from stroke. The Central Coast has relatively poor access to general practitioners and hospital specialists and limited support services for the ageing community (CCLHD 2015). Addressing the gap in primary care and aged care support services is therefore a key focus of the 2012-2014 Clinical services plan (NSW Health, CCLHD 2013).

Aboriginal people experience higher levels of mortality and morbidity from mental illness and from related injury and suicide than the non-Aboriginal population (Yerin Aboriginal Health Services Inc et al., 2013). Aboriginal people in 2011 represented 2.9% of the Central Coast population, with about 40% living in the Gosford Local Government Area. Socioeconomic indicators such as educational attendance show the Aboriginal population to be disadvantaged (shown in Table 1 in Yerin Aboriginal Health Services Inc. et al., 2013). There has been a steady increase in the number of referrals to the Aboriginal mental health services provided by both Eleanor Duncan Aboriginal Health Service and the CCLHD, with both usually working closely with other services such as Drug and Alcohol and Chronic Care (Yerin Aboriginal Health Services Inc et al., 2013).

Current CCLHD plans and policy approaches emphasise population health and expansion of community based services. The programmes target high-risk behaviours to improve health, reduce the incidence of chronic diseases, and manage demand for hospital services. However, slower growth in resources, particularly in workforce and physical space, mean that many community services operate from accommodation which is no longer adequate for the service provided and / or services are not always located in the areas where population growth and demand is occurring (NSW Health, CCLHD 2013).

Community participation is explicitly included in Australian health accreditation standards and there is policy support for patient, public or community participation in health services (Nathan et al. 2014). In NSW, each Local Health District has a board of 6-13 members appointed by the Minister. The selection criteria for board members aim to ensure an appropriate mix of skills and expertise to oversee and provide guidance to large, complex organisations. These include: expertise and experience in matters such as health, financial or business management; expertise and experience in the provision of clinical and other health services; representatives of universities, clinical schools or research centres; knowledge and understanding of the community and other background, skill, expertise, knowledge or expertise appropriate to the organisation. At least one member must have expertise, knowledge or experience relating to Aboriginal health. Medical, nursing and midwifery and allied health staff can nominate short lists of interested clinicians for the Minister to consider when making appointments to the board, providing for local clinical input on the Board. Board members do not, however, represent the group or interest that nominated them, but carry out their role and functions in the interest of the Local Health District and its community (NSW MoH 2012).

The Local Health District Board responsibilities include: seeking the views of providers and consumers of health services and of other members of the community it serves about district policies, plans and initiatives; discussing with the chief executive of the Local Health District how to support, encourage and facilitate community and clinician involvement in the planning of district services; and advising health service providers and consumers and other community members about the district's policies, plans and initiatives for health services (NSW MoH 2012).

Stakeholder engagement is a standard in the NSW Health corporate governance framework and considered to be fundamental to improving individual and community health outcomes. Local Health Districts must ensure that appropriate consultative and communication strategies are in place to involve consumers of health services, other members of the community and staff and that they have a Local Partnership Agreement with Aboriginal Community Controlled Health Services and Aboriginal community services. They have a duty to undertake at least annual performance reporting to the public by publishing an Annual Report and to make appropriate information on key policies, plans and initiatives available to the public. The opportunities for community participation and or public consultation include:

- The development and implementation of a Community Participation Framework;
- The development, implementation and review of health service plans, operations and programmes;
- The development of Local Health District strategic priorities and plans;
- Activity based funding programmes and services;
- Dialogue on how to reduce social disadvantage and meet community health needs;
- Specific consultation with the Aboriginal community;
- The provision of public health information, such as on emerging health issues and public health trends;
- Disseminating the outcomes of research and technological innovations and developments; and
- Participation in specialist technical, clinical and consumer forums.

Consumer, carer and/or community participation are also included, through both formal and informal mechanisms in finance or budget planning and in the allocation of funds. A Community Consultation Advisory group, established within the Local Health District, reports to the Board, and is involved in specific service reviews and setting of service standards; and there are project working groups; quality and accreditation processes; advisory processes and other district committees (NSW Ministry of Health 2012). CCLHD specifically have a Consumer, Community and Engagement Committee, that helps to facilitate and oversee the involvement of consumers and local community members in developing the Local Health District's plans, policies, care design and initiatives relating to health service provision. The committee provides advice to the Chief Executive and Board for improvement of health in the local community.

There has been a policy commitment to inclusion of consumers and carers at all levels of decision making in mental health in Australia since 1997 (Goodwin and Happell 2006). The NSW Mental Health Commission established in 2012 is headed by a Commissioner, with provision for appointment of six Deputy Commissioners (5 part-time and 1 full-time), one of whom must be a person who has or has had a mental illness (NSW MoH 2012; Mental Health Co-ordinating Council 2015). The NSW Mental Health Commission has also developed a peer workforce framework that supports the development of a peer workforce in mental health services across NSW. A peer workforce refers to people with lived experience of mental illness who are employed in peer worker roles to support others. Such a workforce is seen to bring a tremendous range of benefits (Mental Health Commission of NSW, 2017), as shown in the video on the power of the peer workforce and the peer work hub site. In March 2015 the Commission hosted a Peer Work Forum which explored opportunities for strengthening the peer workforce as a central pillar of mental health reform in NSW. A series of videos from the forum are available online.

The CCLHD is one of 15 health services (8 metropolitan and 7 rural or regional) in NSW, established as individual statutory corporations under the NSW Health Services Act 1997. The Local Health Districts are responsible for managing public hospitals and health institutions and for providing health services to defined geographical areas of NSW. Their primary purposes are to provide relief to ill and injured people through the provision of care and treatment; and to promote, protect and maintain the health of the community. The NSW Minister for Health approves funds from the annual budget to the Local Health Districts on the basis of meeting local needs and within agreed activity targets. This is done through activity based funding and funding of services such as population health as a total programme or 'block'

funding (NSW Ministry of Health 2012). The 2016-17 NSW Government budget allocated AUD\$1.8 million (USD\$1.35 million) to mental health funding to continue mental health reforms, an increase of AUD\$106 million from the previous year. This included AUD\$11 million for a statewide rollout of a *CAMHS GOT IT!* Teams programme providing early mental health intervention to young people in schools (NSW Government 2016).

The *NSW State Health Plan: Towards 2021* brings together NSW Health's existing plans, programmes and policies and sets priorities across the system for the delivery of 'the right care, in the right place, at the right time'. A key direction is 'keeping people healthy' – to be achieved through orientation of the system towards prevention and population health. The CCHLD Clinical Services Plan 2012-2021 emphasises the reorientation of service provision to community and population based services. *Caring for the Coast* is a CCLHD strategy applied to all their programmes with the mission to promote and enhance the health and wellbeing of the Central Coast community.

Living Well: A Strategic Plan for Mental Health in NSW 2014-2024 is the strategic plan for mental health care in NSW developed by the Mental Health Commission and adopted by the NSW Government in 2014. The plan emphasises the importance of people-to-people support and self-agency. It is the whole of government response to *Living Well*, including a commitment of AUD\$115 million (USD\$86.4 million) to commence the first stage of reform (NSW Health 2014). Key reforms include: strengthening prevention and early intervention; shifting the focus to community-based care; developing a more responsive system; working together to deliver person-centred care; and building a better system. The reforms seek to shift the balance of care from specialist clinical services to community-based support and provide a foundation for people with mental illness to live and be supported in the community. They involve a wide range of stakeholders, including other government sectors such as justice (corrective services and the courts), education, community services and housing (NSW MoH 2015; NSW Health 2014). There is also a shift from a person being seen as a patient, to a consumer, to a person with mental health issues (as shown in [Figure 1](#) in a NSW MoH factsheet (2015)).

In CCLHD, the approach to mental health services provision is also one of person-centred care. The management of people with mental health issues increasingly takes place in the community, facilitated by a range of community based treatment and support programmes that focus on prevention and early intervention. This model relies on service integration within Mental Health Services ('One Service'), as well as across divisions within CCLHD. It also relies on the inclusion and involvement of other service providers such as general practitioners, the Aboriginal Community Controlled Health Service, non-government organisations, community and consumer groups and other government agencies including education, family and community services, and housing (NSW Health, CCLHD 2013).

Within CCLHD, CYPMH, the state funded YMH Service is an example of a specialist multidisciplinary youth specific service for young people aged 12-24 years who present with moderate to severe mental health issues. The YMH team is co-located with *headspace* Gosford- at the 'ycentral' site at the Gateway Building in Gosford. The YMH team is a mobile service and provides support to young people at locations in the community that suit them, including schools, emergency departments, community health centres and in the home. A Consultation and Assessment Team within CYPMH provides all the triage functions for the YMH team.

Currently, the funding and organisational arrangements for *headspace* Centres across Australia is undergoing change, including a change in the role and function of the *headspace* National office and a transfer of funds from National Office to local Primary Health Networks in each region.

The participatory practices:

Late adolescence and early adulthood is the peak period for onset of mental illness. Mental health systems in Australia tend to provide either paediatric or adult services, however, so that young people aged 18-24 years usually receive services in adult mental health settings. In 2007, the federal government established the National Youth Mental Health Foundation called *headspace* which "aims to deliver improvements in the mental health, social well-being and economic participation of young Australians aged 12–25 years." Sites were established in each state and territory across Australia, providing an entry point for young people to access a broad range of services operating in their local community (Howe et al. 2013).

In 2006, the NSW State Government committed AUD\$18.6 million to a reform agenda to reconfigure and integrate mental health care for young people. Due to their long history of successfully reconfiguring local mental health service delivery for young people, CYPMH was chosen to develop and evaluate the 'prototype YMH service' for NSW. The funding focused on establishing: a YMH Clinical model for the Central Coast region; a co-located 'one stop shop' (the ycentral physical site); a YMH specific website (ycentral.com.au); primary care level YMH initiatives (a general practitioner on site and a range of other initiatives); a YMH consumer participation model (the YA); training and workforce development and social recovery. Another major outcome was the development of the key principles for YMH for NSW. After the first-year, funds were allocated across NSW to support the reorientation of mental health services and enhance their capacity to work with young people requiring specialist mental health support. In 2008, a local Central Coast Consortium (lead by the Central Coast Division of General Practice) gained one of the first 10 federal (national) grants to establish *headspace* Central Coast (now called *headspace* Gosford).

These two (state and federal) funding streams contributed jointly to the development of the *ycentral* physical site, where both CYPMH and *headspace* (Gosford) are co-located, as an integrated service platform incorporating primary, secondary and tertiary mental health care for young people in one accessible site (Howe et al. 2013).

As a first step for the State mental health funding, a set of key principles were developed based on a literature review and feedback from young people through the YA. The feedback was representative of the diversity of young people in the Central Coast, including Aboriginal, homeless, and Lesbian Gay Bisexual Transgender Intersex and Queer (LGBTIQI) young people and relevant stakeholders, such as those involved in CCLHD Adult Mental Health, Youth Health and Drug and Alcohol Services. Other NSW Youth and Mental Health services in rural and remote areas were simultaneously undertaking the same exercise. Both sets of principles were discussed at a NSW YMH Forum in 2007 and a common set of nine key principles for YMH services were endorsed by the *NSW Mental Health Program Council* in 2008. The Council incorporated the key principles within a reporting pro-forma. NSW YMH services were required to report their activities annually against each principle and demonstrate how each principle is addressed within their service (see *Box 1*). Principles seven and eight focus on improved participation (Howe et al. 2013).

Box 1: Nine key principles for youth and mental health services

1. Commitment to a promotion and prevention framework for mental health
2. Improving early access
3. Sustainable clinical governance of youth mental health and quality control
4. Promoting 'best practice' youth mental health clinical services
5. Developing effective strategic partnerships
6. Focus on recovery and hope
7. Establishing youth participation in governance, planning and implementation
8. Improving participation of families and carers in mental health services
9. Developing a youth mental health workforce (Howe et al. 2013)



ycentral website screenshot © D Howe 2017

In partnership with *headspace* Gosford, from 2007-2009, CYPMH established the Youth Alliance (YA) model for participation, consistent with principle seven. Under this model 16 young people aged 15–24 years were employed on a casual basis, supported by a full-time paid coordinator, and involved in the ongoing development and implementation of the NSW YMH Service Model. The YA were actively involved in the development of youth mental health services. They participated in training, consultations, working parties and community awareness activities. These young people were instrumental in ensuring *ycentral* developed as a youth-friendly site. The participated in developing a virtual tour of *headspace* Gosford, in the site design, the selection and placement of the furniture and reception desk and in numerous working parties guiding the development of services at *ycentral* and the ycentral website.

Services could request the YA to participate in consultations or to conduct consultations within the broader youth population on the Central Coast. The YA toolbox contained a 'Request for Consultation' form and a document outlining the process. The form was electronically circulated to staff and the *headspace* group. Many consultation requests stipulated that participants have an interest or experience in the area to be investigated. The YA conducted 63 consultations with numerous services across the Central Coast which provided opportunities to influence the design and development of youth mental health services.



ycentral site waiting room © D Howe 2017

The YA reached over 4000 young people including with a range of services within CCLHD such as for sexual health, Central Coast CYPMH, Central Coast Youth Health Service, Violence Abuse and Neglect Services as well as Gosford City Council and *headspace* Central Coast (Howe et al. 2010; 2011). Several YA Consultants participated in a focus group facilitated by the Central Coast Youth Health Service to plan for a chronic illness peer support programme for 12-25 year olds living with chronic illness. This programme provides support for young people dealing with the emotional impact of chronic illness, including the feelings of isolation, anger and fear they sometimes experience. Eleven members of the YA were consulted in the development stage of a proposal for a nutritional study to be undertaken by Central Coast CYPMH. YA Consultants were involved in the pre-testing of the questionnaire and information sheet, and were asked to comment on the layout, language and presentation of the questionnaire. In July 2009, the YA participated in the focus group hosted by NSW Consumer Advisory Group, the statewide body that represents mental health consumers at all levels of the NSW Government and that ensures that the views of mental health service users are heard by State and Commonwealth decision makers, services and the broader community. YA Consultants had an opportunity to express what works and what could be improved for young people in the mental health system (Howe et al. 2010).

In August 2013, *headspace* Gosford re-established its YA model. It offered various levels of participation, according to the projects and the availability and interest of young people (Coates and Howe 2016). The development and implementation of the YA in 2013 was informed by lessons from the previous YA model (in 2007–2009) and a review of the literature (Howe et al. 2010; 2011; Coates and Howe 2016). The current model for participation for *headspace* is the Youth Reference Group, described below.

This integrated service approach to mental health services for young people was developed over 4-5 years beginning in 2007 (Howe et al. 2013). In 2014-15, *headspace* at national level funded service innovation projects across Australia. *headspace* Gosford received funds to develop a CHOICE project to explore the role of peer workers and to develop a tool for shared decision-making in youth mental health services.

In terms of **youth participation** for *headspace*, the YA model using paid youth volunteers is transitioning to the Youth Reference Group model that includes young people on a voluntary basis. *headspace* Gosford and Lake Haven have recently recruited volunteers for 2017. Young people must be aged between 16-25 years, have knowledge of youth mental health issues and a passion for advocating for a youth perspective within a mental health service. The Youth Reference Group aims to bring a youth perspective to service management and decision-making processes. It is a group of young people that *headspace* centres can consult with on topics such as a quality of care, service delivery, community engagement and health promotion. The responsibilities and time commitment of youth reference group members include: participation in a monthly 2 hour meeting; travel to and from meetings that alternate between the two *headspace* centres; attending initial training of 1-2 days about *headspace* and a range of topics; maintaining regular and at least fortnightly contact with the group; supporting local *headspace* activities; involvement in community education activities; and completing a wellness plan.

CYPMH is currently reviewing the model of participation to be used across the service, including the use of a peer-work model. Findings from this work are not yet publicly available.

Consistent with the principle of **improving the participation of families and carers**, CYPMH developed a carer strategy (2010) that focused on empowering families to be actively involved in the young person's care. Clinicians were trained to work with carers and families, a carer's library was set up, a number of carers' forums, involving carers in service feedback and the development of the 'minds, myths and me' booklet for young carers (Howe et al. 2013). The *ycentral* website has a dedicated area for families and carers which includes specifically tailored information and resources for parents, family members, friends or carers of a young person aged between 12 – 25 years, who is going through a tough time or who are worried that they may be developing a mental health problem.

Between 2007-2009, CYPMH and *headspace* Gosford, implemented a training and education strategy across the Central Coast Sector including employing a Training and Education Project Officer, development of training material specific to best practice in YMH, and development and delivery of workshops and seminars specifically targeting workers within the YMH sector across three tiers including specialist YMH workers, vocational workers and 'point of first contact' workers (e.g. school staff and youth workers) (Howe et al. 2013). The *ycentral* website has an area for workers/schools including useful articles, links and resources for anyone working with youth or in a health-related field, including opportunities for training and online training. In May 2015, the CYPMH and *headspace* Gosford organised the 2015 "Believe, Share and Connect" Forum with the participation of the education sector. This was the first Student Mental Health Forum held on the Central Coast of NSW and offered secondary students, from grades 8 and 9, the opportunity to learn more about mental health issues, express their ideas on ways to increase mental health awareness at school and open up a dialogue about emotional wellbeing. A video provides a short overview of the day.

The Young People's Alliance is a core element of the NSW Youth Mental Health Service Model. The involvement of young people as partners in the development and evaluation of Central Coast Children and Young People's Mental Health (CC CYPMH) allows for the improvement and validation of service provision, to reflect the needs of the community that it was established to serve. (CC CYPMH 2007:5)

The YA recruitment process (2007-2009) directly engaged those young people currently or previously using mental health services in consultation on and co-design of services as previously described, including in contributing to youth friendly aspects of the *ycentral* physical site design and fittings, brochures, community awareness campaigns, website development and design. It engaged young people from diverse backgrounds as 'consultants', including indigenous young people, those from different cultures and languages and from low socioeconomic groups. Once funding for the YA coordinator ceased however, the level of youth participation declined, raising the need to adequately resource such processes (Howe et al. 2010; 2011).

The approach used for the YA in 2013 built on the prior work. Recruitment focused on ensuring young people from diverse backgrounds, including those from minority and marginalised populations, and those with experience of mental health issues, rather than psychology students wishing to gain work experience. Of the 12 consultants recruited, eleven had current or previous personal experience with mental illness. The remaining consultant was a carer of a parent with a mental illness. While YA consultants expressed a desire to make a difference, their participation was also motivated by personal benefits such as building new skills and getting work experience (Coates and Howe 2016). In 2017, there are seven new Youth Reference Group members for *headspace* from diverse backgrounds and experiences, all with a lived experience of mental health problems. Details of the recent recruitment and application process are outlined on the Youth Reference Group page on the *ycentral* website.

The higher levels of mortality and morbidity from mental illness and related injury and suicide among the Aboriginal and Torres Strait Islander population underlines the specific need for their participation and the development of tailored resources. The *ycentral* website includes links to national *headspace* resources such as *yarnsafe* which is a campaign to increase awareness of *headspace*, as a place for Aboriginal and Torres Strait Islander young people to seek information, help and support.

The national *headspace* website also includes a range of real stories about diverse young people's experiences of mental health problems, including in relation to getting help and or their participation in YMH services (ranging from information, consultation, advocacy and co-design).

Factors and inputs affecting the participatory practices:

Policy and funding commitments creating opportunities for improved participatory practices in the development and improvement of YMH services have resulted from shared values and commitments, at national, state and local levels, to more integrated YMH services that emphasise mental health, prevention and early intervention, and to youth participation in the development of such services,

Changes to the YMH component of CYPMH since its establishment have included changes to access and triage, entry criteria, changes from specialist positions (such as drug and alcohol workers and YMH family workers) to generalist YMH positions, a greater focus on intensive case management and a reduced emphasis on a group programme approach. The changes were informed by ongoing service evaluation, including client data and feedback from clients, carers and clinicians (Howe et al. 2013).

Responsibility for commissioning local/regional *headspace* services has moved from *headspace* National Office (Melbourne) to Primary Health Networks, who sub-contract to other organisations for delivery, including *headspace* Gosford and Lake Haven. Changes to the YA model since its development in 2007-2009 were described earlier, and *headspace* Gosford and Lake Haven is currently transitioning to a different model.

Based on the CYPMH and YA experience to date, a range of factors and inputs affect youth participation in YMH services. A key issue is around human and financial resources. From a State perspective, no specific budget has been allocated to fund participation or peer work models in youth mental health. Funding has, therefore, been found from within existing budget and or new project allocations. However, the YA experience and evaluation underlined the importance of having a paid co-ordinator to supervise, provide support to participants and facilitate their empowerment. The YA project, for example, included a strategy for YA consultants to facilitate consultations with young people on the Central Coast. YA consultants gained experience consulting with various organisations but required support to do this. The *headspace* YA Coordinator and the Training and Education Officer developed a training package, including an accompanying booklet on formal methods of consultation. The training provided a broad range of skills and experiences including for public speaking, working as a group, facilitating meetings, proposal writing, event organization, recruiting public participation, conducting formal consultation, evaluating data, report writing and hoped to improve general self-confidence (Howe et al. 2010). The earlier note that the level of youth participation declined with reduced funding points to the need for sustainable funding. Appropriately remunerate young people for their time (as cash or vouchers) and engaging YA consultants as employees may assist with uptake and integration of participatory practices, and probably contributed to the YA consultants in the 2007-2009 process reporting that they were valued and empowered by their participation (Howe et al. 2010; 2011).



General practitioners waiting room ycentral site © D Howe 2017

Having a flexible participation model that can adapt to the strengths, abilities and capacities of young people also facilitates participation. This might include having a continuum of opportunities for participation, where young people can participate to the degree that they wish, from being informed to being actively engaged in co-design of services. For example, as part of the development of the 2013 YA model it was proposed to have a three-tier model with: five young people employed as casual employees for a minimum of three hours per week; 10 young people whose participation is flexible dependent on their personal circumstances and remunerated with vouchers; and a pool of young people who could be engaged on an ad-hoc basis (Coates and Howe 2016).

Challenges identified in the 2007-2009 YA process included the reliability and availability of the YA consultants; getting a balance between support and allowing autonomy and control; and the availability and project-based nature of funding. Those from more disadvantaged backgrounds were more difficult to contact and often required greater support to complete allocated tasks (Howe et al. 2010; 2011). This is where having an identified youth participation co-ordinator is of great value to enabling participation:

“... when the young people from more disadvantaged backgrounds could attend meetings of the YA, their contribution was of incredible value” (KI interview).

Staff do not always hold positive attitudes and beliefs about the benefits of youth/peer participation for both the young person and the organization, including in relation to how empowering the young person assists in their recovery or protects against the development of mental health issues. Meetings were held by the YA coordinator in 2013 with the different teams within CYPMH to discuss the YA in more detail. This identified the staff concerns about youth participants' capacity to maintain confidentiality; about their own mental health (as shown in the video described in the section on context about the power of peer workforce); and about their potential to misinterpret conversations about clients that they may overhear. These issues were addressed through different mechanisms, such as careful supervision and appropriate training for YA consultants on confidentiality and by ensuring YA consultants had a completed 'wellness plan' before starting their role. Furthermore, existing staff should be actively engaged in this process, with consultation commencing before young people are recruited. CYPMH staff were consulted throughout the process of developing the model (Coates and Howe 2016). Experience has shown that greater investment needs to be made in ensuring system and staff readiness for change: “.. we need to do this early and we need more than one-day of in-service training” (KI interview).

Finally, it is seen to be important to build capacity into the model of participation for evolution or adaptation over time as the confidence levels of both the youth consultants and service providers increases (Howe et al. 2010; 2013; Coates and Howe 2016). This points to the issues raised in the literature of the role of peer workers and community health workers and their 'professionalization' over time, whether they are formally part of the system or not (Simpson and Loewenson 2016).

Perceived or measured outcomes:

A range of process, social and health outcomes have been identified over the years. Some of these outcomes have been documented in earlier sections of the case study, such as in relation to the ongoing changes to the YMH component of CYPMH being informed by the service evaluations and in the development of the youth-friendly website for ycentral.

The YA 'consultants' from the 2007-2009 process indicated that they had gained numerous skills including teamwork, communication, presentation and consultancy skills, and skills in public speaking and time management. They reported that they were valued and empowered by their participation in the project. A homeless YA consultant in the 2007-2009 process obtained stable accommodation through the course of the project and young people acquired a range of new skills and confidence that enabled them to access stable accommodation and keep it. Furthermore the young people were key to ensuring that in the design and fit out of ycentral as a youth friendly site (Howe et al. 2010; 2011).

The evaluation of the YA model from 2013 found that the consultants considered being part of the YA offered the opportunity to make new friends and build social skills in a safe way. The two main reasons for becoming a consultant were “to help overcome barriers in help seeking to ensure young people get the support they need” and “to build confidence, social skills and make new friends” (Coates and Howe 2016:298). Similarly, Rapper Philly took part in the development of the Indigenous Hip Hop Project, Gilimbaa and *headspace* video 'Got a lot going on'. This featured young people in remote Northern Territory communities and was described earlier (yarnsafe). In a *headspace* national [video](#) he talks about the benefits from participating in developing the video.

Areas for shared learning:

The Central Coast experience with youth participation at the ycentral site within *headspace* Gosford and CYPMH, and specifically the YA model offers a range of insights and learning on social power and participation for young people in a mental health service, particularly regarding learning's from implementation of such initiatives. In addition, while not possible to cover in detail in this case study, the learning from the CHOICE pilot project which included peer workers aged 16-25 years who were employed part-time at *headspace*, provide important insights to and build on the experience of the YA.

The first insight is that reimbursement and recognition of the contribution that young people and their carers make is critical for effective and sustained engagement. Truly valuing participation means putting participants (carers and consumers/young people) on an equal footing with health professionals and

others in the health system. This requires ongoing resources for both a youth participation coordinator and enabling reimbursement as paid staff and or participants. As indicated, no funding has been allocated for participation or peer work in the system and the approaches covered in this case study have been funded through existing budget allocations and or new project funding. This is a challenge because it potentially means a trade-off i.e. to stop funding something else within YMH. The CCHLD experience however can provide insights into how to be opportunistic in using funding for advancing participation.

Another area of learning is about paying attention to how to get the balance right between professionalising young people who participate and empowering them, particularly when for most young people, it is their first experience of the workplace. They are potentially more vulnerable due to their age and or having experience of mental ill-health. Linked to this, it is important to have a flexible model that allows young people to participate at a level and or to a degree that suits them, such as in the three-tier model for the YA in 2013.

The Central Coast approach has focused on ensuring diversity of representation of young people who have experience of service contact and mental illness. This was done both by active inclusion of participants from diverse backgrounds and, for example, by screening out applicants for the 2013 YA who were predominantly psychology students wishing to gain work experience in mental health, and who did not report personal experience with mental health (Coates and Howe 2014). Enabling the participation of young people from diverse backgrounds, however, demands support in the form of a youth participation coordinator. Such a person is needed to undertake follow up visits with a youth representative, who does not attend some meetings or events, to better understand and help to address any barriers to their participation, including transport and hours of events. This means resourcing participation appropriately.

Finally, it is important to ensure that the system and staff are ready for change and implementation of participatory approaches. Implementation of the YA model was accompanied by regular email updates and presentations at a staff forum, the YA coordinator attended the business meetings of the different teams within the CYPMH to describe the YA and provide an opportunity for questions about the YA consultants once they were recruited, and management formally asked for feedback about the YA. Consultations with staff identified underlying concerns particularly among clinical staff, not previously highlighted, about the participation of young people and particularly former clients, described earlier. The KI indicated that on reflection improving system and staff readiness for implementation and change could have been improved.

Key features for adoption or adaptation in other settings include the use of paid YA consultants and or peer workers (as per the CHOICE pilot project), and processes/approaches used in:

- the selection and recruitment of YA consultants/peer workers;
- supporting and enabling youth participation, including having a paid youth coordinator and or mentor,
- supporting a flexible model of participation for the YA, and for initial and ongoing training and development; and
- ensuring system and staff readiness for young people's participation and engagement in YMH.

In terms of application elsewhere, in 2006 CCHLD was chosen as the 'prototype' Youth Mental Health (YMH) service for NSW with funding from NSW Health for the development of an integrated YMH service platform (ycentral) in Gosford. The following year, funds were then allocated across NSW to support the reorientation of mental health services and enhance mental health services' capacity to work with young people who require specialist mental health support. In addition, the common set of nine key principles for YMH services developed as part of the prototype were endorsed by the NSW Mental Health Program Council and incorporated, at that time within a reporting pro forma which NSW YMH services were required to report against and demonstrate how each principle is addressed within their service.

The outcomes of the youth participation model that was developed and implemented across the ycentral site have been presented at both State (NSW) and National YMH Conferences. The Manager of CYPMH was invited to present the overall ycentral model at an International YMH Summit held in Killarney, Ireland in 2010. The outcomes of this Summit included an International Declaration on Youth

Mental Health (2013). This declaration sets out a shared vision, principles and an action plan for mental health service provision for young people aged 12-25 years with the vision of a world where:

Young people feel empowered to exercise their right to participate in decisions that affect them.... and where..80% of youth mental health services will be able to demonstrate evidence of engaging young people and families in the development of services. (ACAMH, 2013)

There are significant benefits perceived for the CCLHD in being involved in the Shaping Health project. Areas of particular interest for the exchange include:

- gaining a better understanding of community participation and decision making models that are working elsewhere in the world;
- working through how these could fit within the Population Health model that exists within Central Coast Mental Health Service and Local Health District;
- gaining insights into the barriers in implementing these models and the possible solutions to these; and
- broadening the network of researchers or practitioners available to CCLHD, for the focal person to bring information back to the health service for local dissemination and action.

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