Title: The CHOICE Pilot Project: Challenges of implementing a combined peer work and shared decision making program in an early intervention service

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Abstract

Aim

Youth participation is central to early intervention policy and quality frameworks. There is good evidence for peer support (individuals with lived experience helping other consumers) and shared decision making (involving consumers in making decisions about their own care) in adult settings. However, youth programs are rarely tested or described in detail. This report aims to fill this gap by describing a consumer focused intervention in an early intervention service.

Methods

This paper describes the development process, intervention content and implementation challenges of the Choices about Healthcare Options Informed by Client Experiences and Expectations (CHOICE) Pilot Project. This highly novel and innovative project combined both youth peer work and youth shared decision making.

Results

Eight peer workers were employed to deliver an online shared decision making tool at a youth mental health service in NSW, Australia. The intervention development involved best practice principles, including international standards and elements of co-design. The implementation of the peer workforce in the service involved a number of targeted strategies designed to support this new service model. However,
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several implementation challenges were experienced which resulted in critical learnings about how best to deliver these types of interventions.

Conclusions

Delivering peer work and shared decision making within an early intervention service is feasible, but not without challenges. Providing adequate detail about interventions and implementation strategies fills a critical gap in the literature. Understanding optimal youth involvement strategies assists others to deliver acceptable and effective services to young people who experience mental ill health.

Key words: Early Intervention, Youth Mental Health, Peer Work, Shared Decision Making, Decision Aids
Background

Following the growing body of evidence that early intervention is effective, the number of mental health services that target young people has been increasing (1, 2). In Australia, headspace, The National Youth Mental Health Foundation has established close to 100 enhanced primary care centres (3) nationally since 2006. With this relatively new service model has come the necessity to create youth friendly services that are acceptable, effective and meet the needs of young people. A central way to ensure that a service is meeting the needs of its clients is to involve them in the design and delivery of a service. Consumer involvement is a core component of many mental health policies and standards locally (e.g. (4)), nationally (e.g. (5)) and is recommended internationally (e.g. (6)). Two examples of functional consumer involvement with demonstrated effectiveness are peer work and shared decision making.

Peer work

Peer workers are individuals with lived experience of mental ill health who help others in earlier stages of recovery (7). Peer work involves sharing personal experiences; promoting holistic care and recovery; and providing true client centred care. Peer workers enter into a relationship based not on either medical or deficit model of care (i.e. focusing on symptoms), but instead on personal strengths, mutuality and anticipated benefit for both people in the relationship. Peer work represents a practical expression of recovery oriented practice and principles, and there is evidence for the multiple benefits of peer work (7-10).
There is promising evidence to suggest that peer work delivers benefits to clients (e.g. reduced hospitalization); caregivers (e.g. empowerment and knowledge); mental health systems (e.g. cost effectiveness); and peer workers themselves (e.g. mental health and wellbeing) (11). However, a Cochrane review of adult consumer-providers highlights the methodological challenges of studying such interventions and found that the overall quality of evidence was moderate to low, including risk of bias in the intervention design and reporting of outcomes (10). Regardless, policymakers have been enthusiastic about peer work, resulting in a rapidly expanding peer workforce both nationally in Australia and in many other countries. This includes youth peer workers (e.g. (12-14)) who are employed based not only on their lived experience but also based on their age. However, in comparison to the adult literature, there is a large paucity of research into youth-specific peer work.

One recent exception to this is a review of youth peer workers in the United States that demonstrated the recent growth and increasing breadth and diversity of youth peer roles (15). The review included initiatives that were ‘peer-supported’, ‘partially peer-delivered’, and ‘peer-delivered’, operating within and beyond the mental healthcare system for young people aged 9-26, with youth peer workers aged 9-25. Many of the programs were identified in the grey literature rather than the academic literature, and neglected to include sufficient information about critical factors such as core competencies, training and supervision needs. There were no studies that specifically tested the effectiveness of a youth peer support intervention, highlighting several gaps in the literature around these increasingly utilised approaches. However, the increasing popularity of youth peer work
initiatives point to the importance of peer work in the context of client-centred interventions.

Shared decision making

Alongside initiatives such as peer work are other client-centred initiatives that focus on involving each person who accesses a service in making decisions about their own care. Shared decision making is a model of decision making that incorporates evidence based practice (e.g. communicating potential harms and benefits of relevant treatment options) and client centred care (e.g. eliciting personal preferences and values about these potential outcomes and including this information, and the person themselves, in the decision making processes) (16). Rather than a linear process, shared decision making can be seen as a set of skills and behaviours that both clients and clinicians need to learn and engage in through ongoing decision-making processes (17).

The most common way to facilitate shared decision making is with the use of decision aids. Decision aids are tools that include information critical to making a healthcare decision. They can range from complex, interactive online tools, to brief, one-page tools that summarise key information (e.g. http://optiongrid.org). Most decision aids include tailored information for a particular decision (e.g. Should I take antidepressant medication for depression?); however, a growing number of decision aids or tools are being designed that allow clinicians and clients to populate the tool with relevant information and instead use the structure of the decision aid to work through any decision (e.g. (18)). There are also key questions that clients can ask...
their clinician to try and elicit high quality, evidence-based information and engage in shared decision making behaviours (e.g. (19, 20)).

To date, trials of shared decision making interventions for mental health have only been conducted with adults, with the majority of these interventions focussed on specific disorders (e.g. depression, schizophrenia) (21-24). In youth shared decision making, a framework has been developed (25), yet few studies exist that consider/view the young person rather than parents as the decision maker. One exception to this is a decision aid that helped young people make a decision about depression treatment that was in line with guideline recommendations and their personal preferences and values (26). This decision aid focuses on a specific decision and so only assists certain young people.

Two shared decision making interventions have taken a broader approach and can be used for any decision (i.e. regardless of presenting problem) (27-30). One of these interventions, CommonGround (31, 32), also combines both peer work and shared decision making. Based in the waiting room of an adult psychiatric medication clinic, peer workers helped clients to use CommonGround to generate a report about their experiences of taking medication (e.g. side effects) and what mattered to them (“personal medicine”). This report was taken into their brief appointment with a medical practitioner and used to facilitate shared decision making.

We took the concepts of this design and translated it for a youth mental health setting where decisions are focused on which part of the service to access. Results of
the evaluation have been published (33) and demonstrate that young people felt more involved in making decisions when they received the combined peer work and shared decision making intervention. However, the evaluation results of the study only tell part of the story. Developing and implementing such a multifaceted intervention involves complex processes that are often omitted from the academic literature. In this paper we describe in detail the development process and implementation issues associated with running a combined peer work and shared decision making at an early intervention service.

Overview of The CHOICE Pilot Project

The CHOICE project was conducted between January and December 2014 at headspace Gosford, an enhanced primary care service in New South Wales, Australia. This service provides a range of early intervention services to young people aged 12 to 25 with mild to moderate mental health problems. Upon service entry, young people are assessed by the intake team, staffed by allied health professionals. Depending on the assessment outcomes, young people are referred to the headspace general practitioner, nurse or private allied health providers (social workers and psychologists) for individual counselling, other co-located partners for general support services such as housing assistance, a vocational support service and a welfare service, or external services as required. The CHOICE Project was a complementary service for young people 16 years and over accessing headspace Gosford for the first time.
The design of the intervention was informed by the existing literature in shared decision making and peer work, with input from clinical staff and the headspace Gosford Youth Alliance, a group of young people aged 16-25 years employed to provide a youth informed perspective to services at headspace Gosford (34, 35).

Eight peer workers aged 16-25 years with a lived experience of mental illness and recovery were employed part-time by headspace Gosford. Peer workers approached clients in the waiting room before their initial assessment to welcome them to the service. They offered peer work, assistance with the intake forms and introduced the online decision support tool through portable tablets (iPads) (see Figure 1). Peer workers assisted clients to complete relevant sections of the tool and invited them to take this information into the assessment session. Clinicians undertaking the assessment then used the tool to facilitate shared decision making about which part of the service and which treatment to access. When finished, clients could return to the peer worker for further assistance.

Low health literacy is a barrier to shared decision making (36) and the peer workers played a key role in checking understanding before and after clients met with the clinician. Clients could accept or decline peer work at any stage throughout their journey with headspace Gosford.

Peer work

Recruitment and employment conditions
A multi-pronged recruitment strategy was used to invite applications from as many young people as possible. This included traditional advertising approaches (e.g. advertisements in the local paper, on the hospital website and employment websites) and targeted approaches, including video advertisements created by the headspace Youth Alliance and shared on social media. The position was also advertised through a media release and the distribution of marketing collateral across schools and interagency youth services. The CHOICE Pilot Project team developed the recruitment strategy and initial support processes. Peer workers were subsequently employed to ensure their involvement in the ongoing monitoring and refining of the role and support mechanisms.

The role description and selection criteria were based on the most relevant existing peer work roles and adapted for the current study. The selection criteria balanced the need for specific skills and the need to employ young people with a past or current experience as a consumer of mental health services. Approval was required for the applicant's age to be a genuine occupational qualification authorised under the NSW Anti-Discrimination Act 1977 and for the position to be designated for young people with a past or current experience as/or with a consumer of mental health services. The positions were purposively designated as hospital employees rather than as reimbursed volunteers to emphasise the professional nature of the role. One of the main goals of recruitment was diversity, so eight positions offering approximately two four-hour shifts per week were advertised.
Shortlisted applicants were offered an interview. The interview panel consisted of project staff members and a young person from the headspace Youth Alliance. The interviews were designed to maximise the chances of applicants having a positive experience in order to recruit the most appropriate candidates. Given that experiencing mental ill health as a young person (a prerequisite) increases the chances of also experiencing disruption to education and employment, we did not want the application or interview process to act as a further barrier for applicants. Some examples of how this was done include establishing links to an employment agency to support young people with the application process and having informal interview processes in a relaxed and youth friendly environment. The applicants who were not successful in obtaining a peer work role were given an honest and sensitive explanation on the decisions to not appoint them to the role. Alternative opportunities such as the Youth Alliance were also explored.

Training and ongoing professional development

Initial training was a five-day package, which covered the following topics: introduction to peer work; recovery orientated practice; using lived experience in peer work; and self-care. All peer work training was developed and delivered in partnership with an experienced peer worker working in a peer-led service. An additional full day of training was provided on shared decision making by an investigator and expert in shared decision making (MS). The peer workers also completed all mandatory training required by the governing employer (NSW Health). As they began establishing their roles and interacting with clients, peer workers themselves identified further training needs. Subsequently, peer workers received

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additional professional development on the following topics: domestic violence; understanding intellectual disability; cultural competency; and working with family and friends to support recovery. Each of these sessions lasted for half a day. All training and professional development was delivered in a face-to-face format.

Support

Peer workers received support through line management, reflective practice, supervision and mentoring (see Figure 2). On a day-to-day basis the peer workers were primarily supported by their line manager who provided guidance, oversight, motivation and support. Daily support included coaching, debriefing and facilitating whole of life conversations to foster wellbeing and self-care. Peer workers and the project manager met monthly to discuss the ongoing running of the project, review practice against the position description and make decisions about the day-to-day operations of the role and project. Peer workers were encouraged and supported to use a monthly journal. They also attended monthly group supervision led by an external consultant with expertise in peer work.

Additionally, peer workers were each allocated a mentor who provided ad hoc support throughout the project. Mentors were purposively selected on the basis that they were strong advocates for peer work and readily available (i.e. working in the same organisation) but were not part of the project. This allowed peer workers to talk freely about their experiences of working on the project with the mentor having some distance from the operation of the project. Mentoring sessions tended to
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focus on the peer workers’ experiences of the role, maintaining work life balance and workforce capability development in a mental health context.

**Decision support tool**

*Shared decision making and decision aids*

To facilitate the promotion of shared decision making by peer workers within the service, a decision support tool was developed. The International Patient Decision Aid Standards (IPDAS) (37) provide guidance on all aspects of developing a decision aid, which usually involves support for a specific treatment or health related question (e.g. ‘Should I take antidepressant medication?’ or ‘Should I undertake a screening test for prostate cancer?’). Standard decision aids provide detailed information about the possible treatment options, including the translation of the highest quality evidence available into readily understood graphs describing the potential benefits and harms of each option.

Other ways in which shared decision making can be facilitated include the use of prompts for clients to use in clinical encounters to elicit the type of evidence-based information normally provided in a decision aid. Shepherd and colleagues (19) tested three key questions and demonstrated that they were effective at increasing the degree to which clinicians shared evidence-based information. These questions are: 1) ‘What are my options?’; 2) ‘What are the possible benefits and harms of these options?’; and 3) ‘How likely are each of those benefits and harms to happen to me?’.
Rationale and development phases for decision support tool

For the purposes of this project, we wanted to promote shared decision making across the service at the point at which clients had their first appointment. We aimed to set a collaborative tone for treatment decision making, communicating to clients that their involvement critical to ensure that effective, personalised decisions were made. For this reason, a decision aid that supported a specific decision was not appropriate. Rather than develop a traditional decision aid, we sought to develop what we refer to as an online ‘decision support tool’ (DST), which engaged clients in a conversation about what mattered to them, what their options were at the service, and how these options might work for them in their personal circumstances.

To ensure the DST was appropriate and useful for clients, we worked together with several groups of young people and clinicians using principles of co-design (38) and co-creation (39). A prototype DST was drafted in advance of the peer workers commencing work in conjunction with two similar services (headspace Glenroy and headspace Craigieburn). This tool became ‘My Pathway’, which suggested a journey through headspace in which young people could choose the most relevant parts. This was a web-based platform that was delivered via iPads in the waiting room and then in consultation with the intake worker. The final version of the DST contained five main sections, including: 1) an engaging landing or ‘home’ page; 2) ‘What Matters to Me’ (presenting problems and preference elicitation); 3) ‘Some Options’ (key details of each section of the service); 4) ‘My Decision’ (theory-driven decisional support designed to reduce decisional conflict); and 5) ‘More Info’ (fact sheets, videos, podcasts and online applications).
Implementation issues

The level of support required to integrate eight peer workers into the role, service and workplace was significant, layered and complex. During the implementation phase, a range of strategies were applied to address several barriers. From this, key findings and recommendations were generated as outlined below.

Role ambiguity and uncertainty experienced by peer workers

Peer workers were not required to have previous work experience therefore additional training and support was required to develop general workplace practices (e.g. completing timecards) and to instil confidence in peer workers to feel comfortable in the workplace. Although initial training was provided to educate peer workers, this was insufficient regarding instilling role clarity and direction. At times throughout the project, peer workers experienced some role confusion, being uncertain of their role, responsibilities and how to approach their work. This was exacerbated as the role was purposely designed to be flexible in order for peer workers to shape the nature of their work. Moreover, some peer workers also felt that they were of ‘lesser value’ than clinical staff.

In response to these concerns the project team worked together to map out the differences between peer work, non-clinical work and clinical work, and emphasised the unique and positive aspects of peer work.

Number of peer workers employed
Eight peer workers were employed to work four-hour shifts, which ended up occurring either two or three times a week depending on their availability. This number of peer workers was chosen to provide a diverse range of peer workers (e.g. age, gender, lived experience) for clients to engage with. However, having this many peer workers commence at once added additional, unanticipated complexity to the implementation process. Firstly, it was difficult for existing staff to get to know each peer worker as there were a number of peer workers starting at the same time and the shifts may not have coincided with other staff members’ shifts. Clients who wanted to see the same peer worker more than once in the week may also have found it difficult to achieve that consistency. Secondly, it took longer for peer workers to engage in peer work and develop the skills required to feel competent in their role. Thirdly, coordinating events (e.g. supervision, training) for all peer workers to attend was made difficult by the large number of peer workers. Lastly, the number of peer workers employed was approximately the same number of staff members employed in the intake team. While this helped in terms of minimising imbalances between the size of each team, it meant that the number of staff members seeing clients doubled in size when the project commenced.

Culture change

The introduction of a relatively large number of peer workers at an existing service required efforts to manage the culture change at the service. A confidential staff survey was used before and after the implementation of peer workers to identify any critical barriers that needed addressing. Three major concerns were raised through this process that we sought to address. Firstly, similar to the peer workers,
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non-peer staff members were unsure about what peer work entailed or the benefits of this approach above what the service was already providing. Secondly, staff members were concerned about confidentiality. This covered concerns about working with past clients; peer workers having access to client records and seeing friends or peers in the service; and also concerns about whether non-peer staff would be able to continue to use ‘black humour’ to cope with the stress of the job. Lastly, as not all staff members had been involved in devising the CHOICE Pilot Project and attending consultation meetings, there was uncertainty about how it would be integrated into the service.

In response to these initial and ongoing concerns, the following strategies were employed: 1) the mentors that were included in the support structure for peer workers were also asked to become ‘champions’ for the project across the whole of the service; 2) we ran training opportunities for all staff members that provided additional information about peer work, detailed the professional nature of the role including details about confidentiality procedures, highlighted key differences between clinical and peer roles, emphasized similarities in the professional behaviours peer workers adhere to, and discussed the value that peer work could add to the service system; and 3) additional support was provided for any staff members identifying concerns about the role.

Discussion and Conclusion

This project implemented a combined peer work and shared decision making intervention in a youth mental health setting. Peer work and shared decision making
are both gaining momentum within health care settings, with peer work aligning strongly with the future of mental health services and its focus on recovery oriented practice (40-43). The CHOICE Project is innovative and pioneering in bringing these two components together in a youth focused **headspace** service. This work was inspired by the principles of CommonGround(31), the first program to integrate peer and decision support in adult mental health. Since this study was designed and carried out, further work on the implementation of electronic decision aids has been undertaken and can be used to guide future work in this area (44).

While this project demonstrated that delivering peer work and shared decision making within an early intervention service is feasible and leads to young people feeling more involved in making decisions about their own care (45), it also highlighted a number of implementation challenges, in particular around the integration of a youth peer workforce into youth mental health service delivery. Although there is now guidance for how to set up peer work programs in general (46), there is little to guide the development and implementation of youth specific peer work programs. What is known from a recent scoping review of this area (15) demonstrates that there is a need to better describe and evaluate critical factors such as core competencies, training and supervision needs to better define the diverse roles that youth peer workers may play in a range of settings. Despite the use of targeted strategies to integrate the peer workforce in the service, peer workers experienced role confusion and remained uncertain of their role, responsibilities and how to approach their work. This observation is consistent with the literature; the experience of role ambiguity and uncertainty is a well-established
implementation challenge in peer work (35, 47-50), in particular for younger peer workers (51).

The peer work implementation literature highlights that the readiness of a peer worker to take on a role within a mental health service is crucial to the success of peer work as well as the wellbeing of the peer worker (47, 52-54). Given the age and level of work experience of these young peer workers, their ‘readiness’ to fully embrace their role was limited, and they required more training, support and guidance than was anticipated or available. As described above, the core training and ongoing professional development provided to youth peer workers in this initiative covered a range of topics, only some of which were anticipated. The model was purposefully designed to be flexible so that peer workers could shape the nature of their work; however, this caused confusion for peer workers who needed direction and clarity around the scope of their role.

From these experiences, we recommend that younger peer workers are provided with a clear framework around the scope of peer work, and clarity around what is expected of them on a day to day basis. By involving more experienced peer workers in the development of roles and position descriptions, this would afford new peer workers more clarity whilst ensuring input from peer experts. Another recommendation is to employ fewer peer workers with longer and more frequent shifts. This affords greater opportunities for peer workers to gain support, familiarity and training with staff. It also allows peer workers to develop skills and confidence more quickly. The limited hours and length of time between shifts was a barrier to
developing role confidence experienced by this project. Employing fewer peer workers for longer shifts or using a staggered recruitment approach would support and enhance greater integration of peer work into a service for the first time.

These challenges and recommendations highlight the need to further explore how best to implement youth peer workers in mental health settings. There is an urgent need for more research into this area as the youth peer workforce is expanding rapidly. Firstly, randomised trials investigating the effectiveness of youth peer work by comparing youth peer workers and peer workers of any age would contribute to knowledge about the necessity of age restrictions on peer work roles (e.g. only employing young peer workers in youth mental health). Secondly, qualitative research that seeks to explore the experiences of youth peer workers would help to understand how becoming a peer work impacts the identity and career pathways for individuals who are already vulnerable due to their lived experience of mental ill health, but also potentially vulnerable as they are young and potentially inexperienced. Lastly, a more rigorous and systematic examination of the implementation challenges associated with implementing peer work in youth mental health settings would strengthen recommendations and inform a more detailed framework for policy and practice in this area.

The CHOICE Pilot Project fostered a collaborative approach to mental health treatment for young people. The outcomes of the project have seen a transferrable, combined peer work and shared decision making model that utilises principles of evidence based practice, technology-friendly clinical encounters, and both client-
centred and recovery-oriented care. It is essential for future research to build on this pioneering work and address some of the critical issues relating to youth specific peer workers in mental health settings. Developing an evidence base for this area will ensure that early intervention services are supported to develop and implement effective peer work interventions to reach young people at the time when they need it most.
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Figure 1. Overview of The CHOICE Pilot Project procedure

Step 1: Welcoming clients
- Peer worker greets client in waiting room
- Provides initial peer work session, offers assistance
- Helps client to complete ‘what matters to me right now’ section of decision tool

Step 2: Assessment with clinician
- Client takes report from tool into session
- Clinician conducts usual assessment
- Clinician uses ‘service type’ section of tool to discuss options and ‘my decision’ to make decision with client

Step 3: Follow up assistance
- Peer worker greets client after assessment
- Offers any follow up assistance, aims to reduce decisional conflict
- May refer to ‘information’ section of decision tool
Figure 2. Types of support provided to youth peer workers
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