Title: Participation in developing youth mental health services

Sub-title: 'Cinderella Service' to service re-design

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Structured Abstract:

Purpose
Whilst there are pockets of excellence in the provision of Child and Adolescent Mental Health Services (CAMHS), many services fail to meet young people's needs. Considering this, the current research aimed to ascertain perceptions of CAMHS provision in a rural county of the UK to inform re-design of youth mental health services.
Design Methodology and Approach
The study comprised of two phases: phase one involved analysis of questionnaire data of youth views of CAMHS. Phase two involved analysis of the 'Have Your Say' event data which explored perceptions of CAMHS and future service re-design. Data were thematically analysed.
Findings
Knowledge of the existence and purpose of CAMHS was variable. Participants wanted accessible information about services, rights, confidentiality and for this to be provided in multiple medias. Young people wanted staff that are easy to talk to, genuine, understanding and who value their insights. Participants wanted to be offered choice about appointments, location and timing. An ideal mental health service was described as a 'one-stop-shop' of co-locality and multi-agency collaboration. Young people clearly expressed a desire to influence the design and delivery of the radical re-design and to be embedded in its development.
Practical Implications
The results highlighted multiple problems with CAMHS provision and provided a clear justification for the re-design of services.
Originality/value
This was a novel approach demonstrating the importance, utility and power of effective participatory practices for informing the re-design of services.

Keywords: *Young People, Participation, Engagement, Children and Adolescent Mental Health Services;*

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Background

1 in 10 school aged children will have a mental health problem causing significant distress and functional impairment (Green et al., 2005). Half of all people with mental health difficulties experience first symptoms prior to age 14, which often last well into adulthood (Kim-Cohen et al., 2003; Kessler et al., 2005) and have far-reaching social and economic burden (WHO, 2008; Knapp et al., 2016). Despite the prevalence and impact of mental health difficulties affecting young people in the United Kingdom (UK), services are still not sufficiently meeting their needs (Murphy and Fonagy, 2013; Lavis and Hewson, 2011; Department of Health (DoH), 2014). Whilst there are pockets of excellence in Child and Adolescent Mental Health Service (CAMHS) provision (SDO Network, 2011), this is an exception to the rule (Kennedy, 2010). Many services have confusing referral systems, extensive waiting lists, geographical variability in service investment (CAMHS Review, 2008; 11 Million, 2008a) and poorly managed transitions (Appleton and Pugh, 2011; Kennedy, 2010). Young people across the UK and Europe report difficulties accessing services, variability in type, quality and duration of interventions as well as stigma or discrimination (Gulliver et al., 2010; Lavis and Hewson, 2011; Plaistow et al., 2014; Coppens et al., 2015; DoH, 2015). These difficulties may stem from a tendency to repeatedly dismiss the views of young people (Lavis and Hewson, 2011) and as such we risk young people being discouraged from actively participating in decisions affecting their services (Worrall-Davies, 2008).

Recently, an attitudinal reform has been observed, alongside steady growth in participative practices across the UK, as seen through the establishment of national participation standards, specific mental health related participation groups (e.g., Young Minds Activists, Very Important Kids) and participation projects (e.g., Right Here Project (Mental Health Foundation & Paul Hamlyn Foundation)). Genuine participation means young people 'taking an active part in a project or process, not just as consumers but as key contributors to the direction and implementation of it. Young people are proactive in this process and have the power to help shape the process' (Street and Herts, 2005, p. 06). As such, participation should involve enabling young people to realise and act upon their rights to participate, understand and inform decisions impacting their lives. Therefore, youth mental health services should directly seek to understand how young people experience their world using participative practices.

Whilst participative methods reflect good practice, several barriers prevent such work (Worrall-Davies, 2008). These include staff attitudes, tokenism, organisational barriers and balancing young people's motivation to participate with the provision of transparent and accessible information about the processes of effecting change (Tait and Lester, 2005). Despite such barriers, when young

people can communicate their needs freely, this can result in effective change, better engagement with services and improved clinical outcomes (British Psychological Society, 2015; Street and Herts, 2005).

Participation Frameworks and Policies

Policy guidance increasingly stipulates the requirement of participatory practices across services engaging young people. For example, the United Nations Convention on the Rights of the Child outlines young people's rights to active participation.

In a recent UK Government review of health services for children, it was suggested that CAMHS, are 'Cinderella' services, in that they never get "near to the ball" (p. 2), with a proportion failing to meet the needs of young people (DoH, 2010). The review specifically called for active participative practices in commissioning and developing services (DoH, 2010); a request echoed by young people (Lavis & Hewson, 2011).

UK mental health policy and guidance recommends meaningful, active participation when planning, developing and transforming services (CAMHS Review, 2008; DoH, 2011a; DoH, 2014; DoH, 2015; Mental Health Taskforce, 2016). The Future in Mind report (DoH, 2015), set out specific recommendations of the Children and Young People's Mental Health and Wellbeing Taskforce, which included the requirement of involving young people in shaping services and setting key priorities.

Rationale

Nationally and internationally, young people are not receiving the best deal in terms of mental health services (Coppens et al., 2015; DoH, 2015). Across the UK access difficulties have been observed and many appointments are cancelled or not attended by young people (Children's Commissioner, 2016). In addition, the highest rates of referrals were recorded for 16 -18 year olds in to CAMHS, with the least amount of service contacts. Such discrepancies and high levels of disengagement with services suggested problems of accessibility, engagement and service provision for children and young people. Considering national recommendations, clinicians, commissioners and service providers in a rural county of the UK set out to involve young people to help inform the development and improvement of services. This paper reports on youth participation research undertaken in 2011, which identified service barriers and informed the redesign of youth mental health services.

Research Methodology and Sampling

Participants and Ethics

A service evaluation survey and participation event were undertaken to inform service re-design. All respondents were young people who volunteered. Demographic information was not gathered, to preserve anonymity and maximise the likelihood of response. Young people were informed that their data would be used anonymously as part of routinely collected service data. The study protocol and ethical considerations were reviewed by the Norfolk & Suffolk NHS Foundation Trust research department (approval number: 2011MH01-SE).

Phase 1: Identification of Barriers

A service evaluation questionnaire was administered to obtain the views of young people with or without experience of CAMHS services. The questionnaire included a combination of quantitative and qualitative responses. Participants with prior engagement with CAMHS (referred to throughout as the CAMHS sample) were requested to answer questions based on their experiences and those without such engagement were asked to respond to questions in terms of what they would like from a service if concerned about their own or a friend's mental health. The questionnaire examined participant's awareness and purpose of CAMHS, positive and negative experiences, staff attributes, appointments, and sources of help for understanding mental health difficulties. The questionnaire was administered at a Well-being event and distributed to City Locality CAMHS, using convenience sampling. Details from non-responders were not recorded for pragmatic reasons and to ensure voluntary participation. A total of 44 young people from the Well-being day (YP) and 54 CAMHS young people (CAMHS sample) completed the survey.

Phase 2: Verification of Barriers and Developing the Service Re-Design

A Stakeholder Event: 'Have Your Say' was organised by the Mental Health Trust. This event provided a platform for young people to express their views regarding CAMHS and the development of an ideal youth mental health service. A total of 77 people attended the event of which 17 (22%) were young people (with and without CAMHS user experience) and 60 (77.9%) were multi-agency professionals and commissioners from both statutory services and the voluntary sector. Participants were recruited using posters and emails to practitioners working with young people in statutory and voluntary organisations.

The event was structured around five embedded key workshops, exploring the quality criteria outlined within the 'You're Welcome' Standards Framework (DoH, 2011b). Workshop 1 explored what constitutes emotional well-being. Workshop 2 explored pathways through mental health services including publicity, accessibility, confidentiality, consent and rights, joined up working and

health issues. Workshop 3 considered service location and accessibility. Workshop 4 explored practitioner perceptions and attributes. Workshop 5 focused on implementation. The findings from each workshop were transcribed and analysed using a thematic analysis approach (Green and Thorogood, 2004). Two co-facilitators independently and inductively derived themes from the transcribed data, and then met to review themes to ensure consensus. The primary author checked the themes to ensure fit with the raw data. Finally, the primary author presented the derived themes to other co-facilitators for verification. This paper reports combined results of the survey and qualitative data collected.

Results

Quotations presented below reflect those best fitting the derived themes. The quotes also represent the variety of responses from participants engaging in the research.

Feeling Good and Keeping Well – Perceptions of Mental Health

Good mental health was associated with feeling *'hopeful', 'confident', 'motivated', 'self-aware', 'emotionally stable' and 'resourced'.* Conversely poor mental health was described as having a *'lack of hope'* and feeling *'isolated'*, *'confused', 'fearful', unloved', 'sad', 'undervalued'* and *'out of control'*. The range of responses clearly indicated that perceptions of good and poor mental health are multi-dimensional and highly individualised.

Knowledge about CAMHS

Of the 'Have your Say' day sample, 81% had never heard of 'CAMHS' and 63% did not have any knowledge of the purpose of the service. 53% of the CAMHS sample knew what the purpose of the service was. They described CAMHS as a place to receive 'help' for a multitude of mental health difficulties. These samples stated that the service:

> *'helps young people and teens with various mental health problems'* (YP 12)

> *'helps (young people) overcome' and 'understand (their) problems'* (YP 42)

Although the CAMHS sample were relatively well informed, the results show that young people from the general population were largely unaware of the existence or purpose of CAMHS.

Helpful and unhelpful aspects of CAMHS

The most helpful aspect of mental health services was having a place to seek support and talk about worries. Young people said:

Having 'someone to talk to about hard things and when stressed' (CAMHS 14)

Having access to *'Early Intervention Service… to learn to cope with psychosis' (YP 12)*

Having someone *'who understands' and is there 'when needed' (CAMHS 3)*

Several barriers and concerns were outlined including lack of treatment choice and feeling 'done to' rather than actively involved in care. Young people described:

'As a teenager (14+) I was misdiagnosed a lot and forced on meds (medications)'. (YP 17)

Feeling *'ganged up on and threatened' (by CAMHS services)* (CAMHS 3)

Young people were asked which elements of CAMHS were most important to them. The first choice was 'confidentiality' (40.9%; 26.2% respectively). The general population sample that attended the well-being day felt that the second important element was a 'friendly and welcoming environment' (20.5%) whereas the CAMHS sample valued 'staff who understand the needs of young people' (16.7%). These responses indicate that young people have a multitude of expectations regarding what constitutes positive care. They indicate that the difference between a positive and negative experience revolves around being a participant who is valued and offered choice vs. being an observer who is 'done to'.

Location of services

Participants stated they would most like appointments to be at an NHS CAMHS building (20.5%; 45.2% respectively) or at home (29.5%). Young people would also like appointments to be:

'Anywhere that isn't at home, college etc. and where can get to alone' (CAMHS 38)

'When (they) need to be seen' (CAMHS 01)

It was clear that young people want *choice* in relation to timely and accessible appointments which may positively influence engagement with CAMHS.

Accessibility and Location

Participants stated that an ideal service should be '*physically accessible*', '*close to transport links*' and a '*reasonable distance*' to travel. Additionally, services should balance ease of access with proximity to places where young people go, yet not be *'located near to where friends and family go'*. Poor locations involved any place where a young person doesn't want to be, such as:

'Mental Health buildings', 'GP surgery', 'Police Stations', 'Hospitals'.

Overall participants want to be able to get to services independently, without taking up too much time and to maintain their privacy attending a location away from their peers/family.

Co-locality of Services

Participants wanted integrated services, built around a 'one stop shop' model of co-locality. Participants suggested that this way of working would reduce the difficulties associated with service *'transitions', 'repetition of personal histories'* and *'stigma'* associated with attending a designated *'Mental Health Service'* building. A *'one stop shop'* model could link NHS services with charitable organisations and run using a *'drop in/walk in'* service. The participants wanted the service to be located within a *'generic young person space'* which could *'reduce stigma and make (it feel more) anonymous'.* This model of working was the most desirable option emerging as a description of an ideal mental health service.

Mental health workers

The perceptions of mental health staff greatly varied across participants. Some focused on staff values such as being *'honest', 'trustworthy'* and *'caring and empathic'* whereas others were concerned with practitioner knowledge such as being *'experienced'* or *'understand(ing) confidentiality'*. The CAMHS sample wanted staff to be easy to talk to (83.3%), understanding (73.8%) and supportive (69%). Young people also said they wanted staff that were:

> *'Friendly casual people...younger and not so Doctorish'* (YP 19)
>
> *'A laugh and know what you're on about'* (YP 36)
>
> *'Experienced'* (YP 40)

Young people prioritise personality attributes over knowledge and skills. Participants were also interested in workers being *'creative', 'adaptive and versatile'* and adopting an *'individualised'* way of working. Generally, participants wanted to be seen by staff who are respectful, have a multitude of skills and knowledge and know when to '*seek further assistance'* as required. Overall, young people want staff to value and respect them.

Help Seeking Behaviours

Young people described what would encourage or discourage help-seeking if they had concerns about their own or another's emotional well-being. They described that support from specific people determined help seeking behaviours with support from their 'friends,' 'parents' and 'family' acting as a motivator for help seeking. For example, one young person described:

'Talking to my parents and (getting) reassurance that mental support isn't the same as in the Victorian era'. (YP 12)

A further motivator for help-seeking included the response of the service. Young people identified that services respecting, listening to and believing their specific needs is important. Young people said they wanted to be:

Taken seriously - *'I wasn't just attention seeking, it was a life-threatening illness'* (CAMHS 34)

Understood and believed - *'helped by being understood'* (YP 39) and *'believe(d)'.* (YP 09)

Given space to use *'my own knowledge (as) I know when something is wrong'.* (CAMHS YP) and their *'own desire to get better*' (CAMHS 23)

Additionally, participants identified several barriers to engaging with CAMHS. *'Stigma'* acted as one of the biggest barriers to help-seeking. They expressed:

Worries that staff *'would be judgemental and not understand'* (YP 33)

Fear of being discredited by *'being classed under just being a teenager'*. (CAMHS 03)

Sources of Information

The way in which information is delivered and received has evolved over recent decades due to technological advances which mean that young people use multiple media for sourcing information regarding the issues affecting their lives. When questioned about the types of information sources used, the most common included the 'internet, friends and sometimes parents.' Participants described wanting information in an 'accessible format', provided in a variety of medias including '*television', 'internet*', and through *'school training'*. The information should clearly explain *'what services are available', 'what to expect', 'who can attend appointments'* and *'staffing'* prior to the initial appointment. Overall participants required access to more detailed information, prior to engagement with services and for this to be presented using multiple technologies and formats.

Confidentiality and Rights

Participants expressed that CAMHS were not providing accurate or accessible information about confidentiality, consent and rights. Young people did not understand '*when or why information is shared'* or what rights they have regarding treatment options. Participants wanted services to better explain the boundaries of confidentiality, information sharing and to explain more clearly about rights regarding treatment options, consent and refusal. Participants wanted information to be

provided in multiple formats including '*YouTube, Facebook, paper leaflets*' and supplemented with '*face to face discussion*'. Young people did not fully understand confidentiality and rights despite having a clear sense that they wanted to know this information.

Service change implementation

Participants described that the future service design should focus on improving multi-agency integration. Additionally, participants wanted access to *'specialist services offering choice'* that *'accept referrals from various agencies'* and offer better cross-agency *'communication'.*

Summary of Results:

Results indicate that mental health is highly individual and that this should be reflected in the package of care provided by services. A proportion of young people demonstrated that they did not know of CAMHS, what help they were entitled to, or how to go about help-seeking. Barriers to using CAMHS services included lack of appropriate information about services or treatment options, poor knowledge about rights or confidentiality, inflexibility regarding appointments and feeling undermined or discredited due to age, developmental stage or lack of knowledge. Participants want improved service publicity and accessibility, understandable explanations about treatment options, and clear information about confidentiality and rights provided in multiple formats. Participants also want choices about where, how often, and by whom they are seen within services. Additionally, participants want to influence their care, not feel like it is being done to them, but to be valued for the insight they bring to the practitioner. Participants felt that future service re-design would be best provided using a 'one-stop-shop' model of co-locality which could reduce stigmatisation and poorly managed transitions as well as increase inter-agency collaboration, access to timely, dedicated, personalised and appropriate interventions

Discussion

The themes identified suggested that major changes were required in order to improve child and youth mental health services. Contrary to Ford et al, (2005) who suggests that young people fail to access care because they can't or won't seek help, participants in the present study suggest that help-seeking is limited due to a general unawareness and lack of knowledge of services. Such knowledge would aid young people in making informed decisions regarding care and shared decision making regarding treatment options.

Raising awareness of available services is likely to improve young people's clinical outcomes (Raby and Edwards, 2011). Young people also valued practitioners taking time to discuss treatment options

in an open, transparent and clear manner. Such practice can be achieved through continued participative and collaborative practice, which values both the practitioner's knowledge or skills and the young person's insights.

Furthermore, the results showed that young people want future services to reduce existing barriers such as inflexible appointment systems and stigmatic or judgemental practices. Young people want services to consider help seeking requests as credible, value the subjective experiences of patients, and work flexibly to meet patient's individual needs in a collaborative manner. In order to meet these requests, innovative service re-design is required so as to introduce practices that can work responsively to such needs (e.g. Kennedy, 2010; DoH, 2011a; DoH, 2015).

The results clearly demonstrated that there is no single 'good mental health' and that services are complex and multi-faceted. Services must be simplified and designed so that interventions can be informed by patient insight, practitioner skills and the current evidence base. This echoes the Kennedy report (2010) whereby service providers are encouraged to engage young people to agree a 'common vision for healthcare, health and well-being of children and young people' (p.8). Although this report relates to the service level, the same notion applies to the design of each patient's care whereby active involvement and shared decision making should be encouraged at every level.

A further concern arising from the results pertains to the provision of information about confidentiality and rights. It was apparent that participants felt services inadequately communicated or explained this. Locally and nationally, young people are experiencing care as something that is done to them and about which they have no say or rights ((e.g. 'Pushed into the Shadows') Children's Commissioner, 2007; Lavis and Hewson, 2011). Transparency is important for improving ethical engagement and collaborative informed approaches to care. Clear information relating to this should be provided in a variety of formats in advance and explained fully to all young people along with information regarding treatment options and what to expect from accessing services.

Young people want services to be set up using a 'one stop shop' model whereby a variety of youth services would come together in a welcoming, friendly and non-stigmatising venue. These findings mirror many of the national trends (Lavis and Hewson, 2011; 11 Million, 2008b; YoungMinds, 2009). Furthermore, such a model could potentially reduce the stigma currently associated with attending a designated Mental Health Service, lessen the potential for poorly managed transitions within or across services as observed nationally (Appleton and Pugh, 2011; Kennedy, 2010) and promote multi-agency collaboration (Kennedy, 2010; Lavis and Hewson, 2011). When designing such

suggested models, practical limitations require careful consideration, such as the sharing of data between agencies; organisational, systemic and cultural differences; and financial / contractual complexities. Although these potential challenges exist they need to be addressed without impacting on the quality of services experienced by young people and solutions generated in conjunction with young people themselves.

In order to meet the multi-faceted needs of service users, it is a fundamental requirement that services now and in the future continue to involve young people, for example in recruitment of staff (Laws, 1998). Additionally, future services will need to proactively engage young people, to design and develop appropriate processes of working, such as appointment procedures, early and crisis intervention (Lavis and Hewson, 2011). These participatory practices would improve the likelihood that services adequately meet the practical and personal needs of the young people it is intending to engage. With appropriate involvement and active decision making, it is likely that future services could considerably positively alter patient's experiences of mental health care (Street and Herts, 2005; HASCAS, 2008).

Implementation and progress

Considering the research results, participatory work has been influential in transforming services. Firstly, three youth mental health pilot project teams were established as part of the children, family and young people (CFYP) service re-design. Secondly, a dedicated Youth Council was convened which involves young people with lived experience of accessing mental health services. This council provides a platform for young people to consider the current problems within mental health services and work proactively to inform service provision. Thirdly, further research and evaluation was planned in conjunction with the youth participant lead to improve access and reduce barriers. Furthermore, such active and ongoing participation processes have more recently led to the development of an integrated CFYP mental health service for 0 -25 year olds, incorporating: a youth wellbeing service at a non-NHS youth venue; integrated working with non-statutory organisations; schools work and mental health promotion; and involvement of young people in staff recruitment. Further service transformation, incorporating participation principles, is planned in line with the results of the current study and recent policy and national guidance (Lavis and Hewson, 2011; DoH, 2015). To achieve effective change and successful participation it is planned that the CFYP services continue to *actively* seek out young people's views throughout the process, so as to avoid tokenistic practice or isolated consultation.

Study Limitations

This study was undertaken in a rural county of the UK, and thus findings are locally situated. However, we suggest that the core implications are generalisable to services across the UK and are in line with current Government policy. It was not possible to determine whether there were any systematic differences between responders and non-responders completing the CAMHS questionnaires. Similarly, it is evident that the current study lacks participant's demographic details in both phases of the research. Although this ensured anonymity and voluntary participation, it was not possible to determine if there was any bias in the sampling. The Have Your Say event was over-represented by practitioners as compared to young people. Although this was inevitable due to opportunity sampling, this is an important caveat to the interpretation of the responses provided and highlights the need for further targeted research.

Conclusion

The views of young people are critical in informing service design. Information provided by young people at a local level mirrors that observed nationally and internationally, indicating the ongoing need for reform in CFYP mental health service provision. It also shows that young people are motivated to be involved in the development of services (Vasilliou-Theodore & Penketh, 2008), and want to improve the standard of care for themselves and future generations. The results of the reported participation have directly informed the ongoing redesign of local services but have the potential to shape the learning of youth mental health services nationally and internationally in conjunction with large scale cross-country research (e.g. Coppens et al., 2015). It is important to ensure young people are given further choice, opportunities and power to continue effecting change. The service re-development is built upon a culture of active participation, that values and listens to the very same young people it is assisting. Although active and genuine participation can be challenging, this should never be a justification for failing to involve young people.

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